

The Relationship between Compassion Fatigue and Psycho-somatic Manifestations among Informal Caregivers of Elderly Patients Receiving Chemotherapy

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Abstract

Caring for elderly cancer patients receiving chemotherapy is a complex process requiring empathy and compassion. Informal caregivers will certainly become exhausted as a result of their intense interaction with their diseased elders. Caregivers' physical and mental health will improve by resolving compassion fatigue and its accompanying psychosomatic symptoms, which will reflect on the quality of care provided as well as patient outcomes. **Objective:** To explore the relationship between compassion fatigue and psycho-somatic manifestations among informal caregivers of elderly cancer patients receiving chemotherapy. **Setting:** Four chemotherapy clinics affiliated to the Damanhur Oncology Center in El- Behera, Egypt. **Subjects:** A convenient sample of 440 subjects signifies the subject of the present research, which were divided into two equal groups; group A: 220 informal caregivers who accompanying their elderly cancer patients during the chemotherapy sessions, and group B: 220 elderly cancer patients who undergo the recommended chemotherapy sessions. **Tools:** Three tools were used for data collection: 1) Socio-demographic and Clinical Data of informal caregivers and their elderly patients receiving chemotherapy Structured Interview Schedule, 2) Compassion Fatigue Scale (GFS), and 3) Psycho-somatic symptoms scale. **Results:** the total compassion fatigue percent score of the studied informal caregivers of elderly patients receiving chemotherapy was 80.8 ± 12.7 , indicating a high level of compassion fatigue. The majority of them (90%) were found to possess high psycho-somatic manifestations, with a total percent score of 80.4 ± 12.4 . Furthermore, a statistically significant positive correlation between informal caregivers' total compassion fatigue and their total psycho-somatic manifestations ($r=0.864$ $p=0.000$) was found. **Conclusion:** Informal caregivers of elderly cancer patients receiving chemotherapy have a significant level of compassion fatigue that is more evident among female caregivers and also among daughters and sons of the diseased elderly. Compassion fatigue has a considerable positive link with psycho-somatic manifestations that are manifested among informal caregivers and are directly linked to their caring process. **Recommendations:** Ongoing assessment must be done for informal caregivers of elderly cancer patients receiving chemotherapy to monitor their level of compassion fatigue and any manifested psychosomatic complains. This will help in the implementation of suitable interventions to alleviate and prevent future complaints and suffering.

Keywords: Compassion fatigue, Psycho-somatic manifestations, Informal caregivers, Elderly cancer patients, Chemotherapy.

Introduction

Cancer is the world's second leading cause of death, estimated 9.6 million deaths (WHO, 2018) while in Egypt, it is considered the third cause of death following cardiovascular disorders and diabetes mellitus (WHO, 2019). It is one of the most common diseases experienced by people of all ages, but it is more prevalent among elderly persons (Cancer research UK, 2016). Approximately 60% of cancer cases and 70% of the cancer-deaths occur in individuals with 65 years of age and older (Eliopoulos, 2018; WHO, 2018). According to statistics of The National

Oncology Medical Institute in Damanhur, Egypt, Elderly patients suffering from cancer represent 45% of the total number of cancer cases admitted to outpatient oncology clinics for chemotherapy treatment (Statistical record of The National Oncology Medical Institute, Damanhur, Egypt, 2021).

In older adults, the increased prevalence of cancer is mostly attributed to age-related changes in molecular, cellular, and physiological processes, such as less efficient and less active DNA repair, inactivation of suppressor genes and activation of less efficient cellular repair mechanisms, altered drug catabolism, and decreased immunity

(VanderWalde et al., 2016; Komseli et al., 2021). In addition, long-term exposure to carcinogens and stressors may make older adults more susceptible to cancer (Cinar & Tas, 2015).

Although various tactics of management for cancer are available today, each one comes with its own set of drawbacks (Afrasiabi et al., 2020). Chemotherapy is one of the main cancer lines of treatment; it works by targeting rapidly the dividing cells, particularly cancer cells. (Smith et al., 2019; American Cancer Society, 2019). Chemotherapy may result in various side effects, such as nausea and vomiting, diarrhea or constipation, anorexia, hair loss, anemia, and chronic infection. Many of these side effects go away slowly, but some could last for months or even years to recover. Unfortunately, some side effects can last permanently, such as long-term damage to the lungs, kidneys and reproductive organs (American Cancer Society, 2020). Chemotherapy is therefore known to be the most frightening treatment documented by elderly cancer patients and their caregivers (Estape, 2018).

Globally, the burden of cancer is rising, putting immense physical, emotional and financial pressure on not only the patients but also on all those who care for them (WHO, 218). In this respect, the majority of elderly cancer patients are cared for by informal caregivers, most of whom are family members (Cai, 2021). Therefore, they are closely attached to and often overwhelmed by the patients and are profoundly affected by their pain and suffering. The primary responsibility of informal caregiver as helpers is first and foremost to meet the psychological, emotional, physical needs of the patients as well as managing their own life (Decadt et al., 2021). Those caregivers may get fatigued and exhausted as they are encountered daily not only by the increased demands of their own responsibility, but also by their emotional involvement with the suffering of elderly cancer patients who need empathy as well as extensive care (Johnson, 2015). This exhaustion that is due to caring for others in emotional and physical pain is referred to as "Compassion Fatigue" (Melissa, 2016).

Compassion fatigue (CF) is defined as "a state of emotional, mental, and physical exhaustion that can occur in individuals who regularly care for others who are experiencing trauma, suffering, or emotional distress" (Baqeas et al., 2021). It is also referred to as "the emotional cost of caring" (Sarra & Feuz, 2017). CF is a sort of burnout that occurs gradually over time as a result of stress buildup and exposure to the trauma and suffering of others (Alharbi et al., 2019). Therefore, caregivers of elderly cancer patients who frequently afford care in a difficult and emotionally intense atmosphere are liable to develop compassion fatigue. CF that could be manifested by informal caregivers is multifactorial; they may be exposed to traumatic experiences such as physical or emotional abuse, neglect, and end-of-life care, all of which can be extremely distressing and raise the risk of compassion fatigue (Kolthoff's et al., 2016).

Caregivers of elderly patients are not assigned only to this caring role; they may also be loaded with other heavy workloads and responsibilities, which can trigger physical and mental stress. Furthermore, they may feel isolated from their contacts because of the caring duties, and this may exacerbate feelings of tension and exhaustion (Sarra & Feuz, 2017). Other factors could add to the caregivers overload as having other unpleasant life events or trauma situations and subsequently may increase their liability to experience compassion fatigue. In addition, certain personality features, such as having a strong sense of duty and high empathy may raise the risk of suffering from compassion fatigue (Cross, 2019).

It is also remarkable that caregivers of the elderly patients suffering from cancer and receiving chemotherapy may overlook their own self-care needs, such as exercise, rest, and social support, resulting in physical and mental exhaustion and therefore may also contribute to other health problems either physical or psychological that may be psychosomatic in nature (Cocker & Joss, 2016; Kolthoff's et al., 2016). The term "psycho-somatic" is derived from the Greek words; "psyche", which means "mind," and "soma," which refers to

"body". Psycho-somatic manifestations are Physical symptoms or complaints caused or influenced by psychological factors such as stress, worries, emotional pain or burnouts (Willacy, 2020). Circulatory and respiratory problems, gastrointestinal symptoms, and aches that have no medical explanation or laboratory support are all examples of psycho-somatic manifestations that may attack those who are under severe psychological pressure as informal caregivers of elderly cancer patients receiving chemotherapy (WHO, 2000; Stock et al., 2008).

In relation to psychological symptoms, informal caregivers of elderly cancer patients may experience depressive mood, tension and worry, mood fluctuations, difficulty concentrating, fear and phobia, nightmares, weight gain or loss, lack of appetite, and sleeplessness. All of these health indicators can be attributed to the physical and mental strains of the caregiving process and responsibilities, as well as the caregivers concerns and anxiety about their beloved ones' health (Stock et al., 2008; Willacy, 2020).

Compassion fatigue and psychosomatic symptoms experienced by informal caregivers of cancer elderly patients who are receiving chemotherapy can have a significant impact on the quality of care offered to elderly patients. Caregivers may feel emotionally drained and may unfortunately find it difficult to give care or even to empathize with their patients, resulting in a reduction in their well-being and health outcomes (Cocker & Joss, 2016). Moreover these variables may have a huge impact on caregivers' personal lives, in the form of interpersonal problems and conflicts, social isolation, and difficulty managing personal lives, all of which can contribute to compromised performance and burnout (Irani, 2021).

Nurses should be aware of the negative effect of compassion fatigue and psychosomatic manifestations on the care provided by informal caregivers for elderly cancer patients receiving chemotherapy. In this context, nurses from different specialties could have a cohesive role to play in understanding the causative factors leading to compassion fatigue and psychosomatic complaints.

Subsequently, they can take initiative to alleviate these phenomena in order to prevent their negative impacts on the general health of caregivers as well as on the overall caring process provided for the elderly patients receiving chemotherapy (Adimando, 2018). These nursing objectives could be accomplished by encouraging informal caregivers to take proactive measures to control their stress and maintain their health. This may be enhanced by obtaining as much as possible assistance, engaging more in self-care activities, taking frequent breaks, obtaining respite care, or seeking professional counseling and/or therapy if needed. (Papadakos, 2021).

Aim of the study:

The present study aimed to explore the relationship between compassion fatigue and psycho-somatic manifestations among informal caregivers of elderly patients receiving chemotherapy.

Research Question:

Is there a relationship between compassion fatigue and psycho-somatic manifestations among informal caregivers of elderly patients receiving chemotherapy?

Research design

A descriptive correlational research design was followed in this research.

Study setting:

The research was conducted at Damanhur Oncology Center in El- Behera Governorate, Egypt. The center is affiliated to the Ministry of Health and Population (MOHP), and serves three governorates namely; Alexandria, El Behera and Matrouh. It provides medical, surgical, intensive and emergency medical services for patients of all ages, from both urban and rural areas.

The center is made up of two main buildings (the inpatient and outpatient buildings), that have 124 beds. The inpatient building consists of 5 floors; the underground floor includes a radiotherapy unit, an admission department, and diagnostic department which has X-ray and CT-scan units. The first floor has an intensive care unit of 9 beds capacity. The other two floors contains inpatient units with a total

capacity of 86 beds divided into 46 beds for medical division (20 beds for females and 26 beds for males) and 40 beds for surgical division (20 for females and 20 beds for males). In addition, the last floor contains 4 operating rooms.

The outpatient building has 4 floors; the surgical dressing, medical, and urology clinics on the ground level. The oncology clinics are on the first floor, while the other two floors include 4 chemotherapy clinics. This research was conducted in the chemotherapy clinics, which contain 25 beds for chemotherapy patients; they are open from 8 a.m. to 8 p.m. every day except Friday.

Study subjects:

The Epi info V 7.0 program was used to calculate sample size for the present research based on the following statistical parameters:

- Population size=500 elderly cancer patients (in three months).
- Expected frequency is 50%.
- Tolerance for error = 5%
- 95% confidence level

The program revealed that the sample size must be at least 218 informal caregivers and their elderly cancer patients. Accordingly, a convenient sample of 440 subjects signifies the subject of the present research, which were divided into two equal groups:

Group A: Two hundred and twenty (220) informal caregivers who accompanying their elderly patients with cancer during the chemotherapy sessions, and fulfilling the following criteria:

- 1- Aged 18 years and above.
- 2- They look after the patients at least five days a week (to be considered caregivers).
- 3- Willing to participate in the research.

Group B: Two hundred and twenty (220) elderly cancer patients who visited the chemotherapy clinics to undergo the recommended chemotherapy sessions and were discharged thereafter, and meeting the following criteria:

- 1- Aged 60 years and above.

- 2- Have had at least three chemotherapy sessions at the time of data collection.

- 3- Agree to take part in the research.

Tools of data collection:

In this research, three tools were used for data collection as follows;

Tool I: Socio-demographic and Clinical Data Structured Interview Schedule of informal caregivers and their elderly patients receiving chemotherapy

This tool was developed by the researchers based on a detailed review of relevant references to elicit information about the elderly and their informal caregivers. This tool is divided into two parts:

Part 1: Data about informal caregivers of elderly cancer patients which include:

A. Socio-demographic data: such as age, sex, level of education, marital status, number and age of children, occupation, and monthly income. Additionally, relationship to the elderly patient, number of hours spent with the elderly patient per day, responsibilities either inside or outside the home and type of care provided.

B. Social, recreational, and spiritual activities: such as frequency of visiting relatives and acquaintances, practicing hobbies and interests, and participating in recreational and religious events.

C. Clinical data: presence of chronic diseases as hypertension, cardiovascular diseases, diabetes mellitus and/or others.

Part II: Data about the elderly cancer patients receiving chemotherapy which include:

A. Socio-demographic data: such as age, sex, marital status, level of education, place of residence, occupation prior to retirement, and income.

B. Clinical data: such as the onset, type and duration of cancer, the number of chemotherapy sessions received the presence of side effects from the treatment, the presence of physical problems, and the use of assisting devices.

C. Functional status: such as activities of daily living and instrumental activities of daily living.

D. Cognitive and mental problems: such as the presence of memory impairment, confusion, poor concentration, difficulty getting attention, sluggish responses, difficulty solving problems, and disorientation.

Tool II: Compassion Fatigue Scale (GFS)

The compassion fatigue scale is a 30-item self-assessment questionnaire based on the Professional Quality of Life Scale, version 5 (ProQOL-5; by **Stamm, 2009** and Portuguese version by **Carvalho, 2011**). It is consisted of 3 subscales namely; Compassion Satisfaction (10 items), Burnout (10 items), and Compassion Fatigue (10 items). In the current research, only compassion fatigue subscale was used. The informal caregivers are asked to rate how often each item occurred in the previous 30 days, on a 5-point Likert scale from 1-5 (1=Never to 5=Very often). Scoring is done by summing up the item responses for the 10-item of the subscale and higher scores suggest higher levels of compassion fatigue. A percentage score of 60% or greater was regarded high, while less than 60% was considered low.

Tool III: Psycho-somatic symptoms scale

This scale was adopted from **WHO (2000)** and **Stock et al, (2008)**. It is made up of 22 items that evaluate a range of self-reported symptoms or health complaints, including **psychological symptoms** (9 items), **circulatory/breathing symptoms** (5 items), **gastrointestinal symptoms** (4 items), and **pain \ aches** (4 items). The informal caregivers are instructed to rate the frequency of incidence of such symptoms in the previous 30 days, on a four-point scale ranging from 1= never to 4= very often. The scale's ratings are added up, and a higher score suggests further psycho-somatic symptoms. For categorical presentation, a percent score of 60% or higher was considered high, while a score of less than 60% was considered low.

Method

1- Preparation of the study

- **Tool I (Socio-demographic and Clinical Data Structured Interview Schedule of informal caregivers and their elderly patients receiving chemotherapy)** was developed by the researchers after a thorough review of related literature.
- **Tool II (Compassion Fatigue Scale (GFS) and tool III (Psycho-somatic Symptoms Scale)** were translated into the Arabic language by the researchers and reviewed by a jury of 5 experts from related fields for content validity, and the required modifications were done.
- **Tool II (Compassion Fatigue Scale (GFS) and tool III (Psycho-somatic Symptoms Scale)** were tested for reliability using the Cronbach alpha test. They were proved to be reliable ($r = 0.93$ and 0.95 respectively).

2- Approval

- Before imparking to the present research, an approval was obtained from the Research Ethics Committee (REC) of the Faculty of Nursing, Alexandria University.
- Permission to conduct the research was obtained from the responsible authorities at the Faculty of Nursing, Alexandria and forwarded to the director of Damanhur Oncology Center in the El Behera Governorate in Egypt to obtain the necessary approval to carry out the research in the chemotherapy clinics after being informed about the purpose of the study, the date and the time frame of data collection.

3- A pilot study

- A pilot study was conducted on 22 elderly patients receiving chemotherapy and their informal caregivers (22) to assess the applicability, clarity, and feasibility of the research tools. They were not among the research subjects; the necessary modifications were done accordingly.

4- Collection of data

- The researchers used to visit the study setting twice a week, from 8 a.m. to 4 p.m. Each elderly patient and his or her informal

caregiver who met the inclusion criteria were interviewed individually in the chemotherapy clinics.

- Elderly patients were interviewed in the chemotherapy rooms before the beginning of the treatment session to ensure that the patients are comfortable and not exhausted from the session, while their informal caregivers were interviewed in the waiting area to collect the necessary data afterward.
- In order to get the informed consent from respondents, the researchers began the interview by explaining the purpose of the study to both elderly patients and their caregivers.
- The interview time for each elderly patient ranged from 20 to 30 minutes, and the interview time for each caregiver ranged from 30 to 45 minutes, depending on their level of comprehension.
- Data collection covered a period of 5 months from the mid of March 2021 to the end of August 2021.

5- Ethical Considerations

- After explaining the purpose of the study, each participant provided informed written consent or witness consent.
- The anonymity of the participants was taken into account.
- The confidentiality of the participants' data was assured.
- Each participant was informed that participation in the research is entirely voluntary and that he or she could opt-out at any time.

Statistical analysis procedure:

Following data gathering, the data was coded and transferred into especially designed format to be suitable for computer feeding. Data was entered into an International Business Machine Statistical Package for Social Sciences (IBM-SPSS version 25). After data entry, data was reviewed and amended using frequency analysis, cross tabulation, and manual revision to identify any errors. Descriptive statistics were used to assess the variables, which comprised percentages,

frequencies, arithmetic mean, and standard deviation (SD). It was used to calculate central tendency and dispersion for normally distributed quantitative data.

The one-way ANOVA test was used to compare the means of more than two samples. The Pearson correlation coefficient (Pearson's r) is a metric for determining the linear correlation between two sets of data, which interpreted as the following; $r < 0.2$ (No correlation), $r 0.2-0.4$ (Weak correlation), $r 0.4-0.6$ (Moderate correlation), $r 0.6-0.8$ (Strong correlation), and $r > 0.8$. (Perfect correlation). For this research, the level of significance was set at $p \leq 0.05$. For graphical presentation, Microsoft Excel was used to create bar graphs for data visualization.

Results

Table (1) illustrates the socio-demographic characteristics of informal caregivers of elderly patients receiving chemotherapy. It can be seen that 63.2% of them were females, 57.7% of the studied caregivers were aged 40 years and more, and secondary education was prevailing among (35.0%) of them. It was also observed that more than one half of the studied caregivers were married (57.3%), while 27.7% of them were single. A percent of 58.2 of the studied subjects have children, employees constituted 57.7% for the studied caregivers and 67.7% of all subjects reported that their monthly income was insufficient. The table also shows that 47.3% of the studied caregivers were sons or daughters of elderly patients, and the majority of caregivers (85.0%) shared a home with elderly patients. The mean of duration of elderly caregiving was 40.6 ± 29.7 month. A percent of 57.3 of the studied caregivers reported caring for elderly patients all day. All caregivers in the study reported providing care and having patients' self-care responsibilities and responsibilities towards the other family members (100.0%). Astonishingly, 59.5% of caregivers reported no psychological support from others. The same table also reflects that most of the informal caregivers 87.2% reported that their recreational activities had been reduced or even discontinued as a result of their caring duties and a remarkable result that

caregivers' spiritual activities tended to be increased (56.8%).

Regarding health profile of the informal caregivers, the table represents that nearly three-quarters of them (74.5%) had various health problems such as osteoarthritis (57.0%), hypertension (40.2%), and diabetes mellitus (37.8%), among other health issues.

Table 2 represents the socio-demographic characteristics of the elderly cancer patients receiving chemotherapy. It was observed that 64.1% of them were females and more than one half of the elderly patients (55.5%) were in the age group of 60 to less than 75 years old. It was also noted that 57.7% were married. Around two-thirds of the elderly patients (64.5%) were illiterate. Furthermore, 51.4% of the elderly patients were housewives and 73.3% of them reported that their income was insufficient for subsistence. Furthermore, the majority of the elderly patients receiving chemotherapy (94.1%) had other health issues such as, diabetes mellitus (44.0%) and hypertension (39.6%). More than three-quarters of them (87.7%) had physical limitations, either mobility (84.5%) or vision (15.5%). The same table also shows that the majority of the studied elderly patients (91.4%) had memory disturbances, 85.9% had difficulty concentrating, and an equal percentage were distractible or had delayed responses (68.6 % and 68.2 %, respectively). Almost three-quarters of the studied elderly patients were found to be confused.

Table (3) reported that the total compassion fatigue percent score of the studied informal caregivers of elderly patients receiving chemotherapy was 80.8 ± 12.7 , indicating a high level of compassion fatigue.

Table (4) illustrates that the majority (90%) of the studied informal caregivers were found to possess high psycho-somatic symptoms in general, with a total percent score of 80.4 ± 12.4 . According to the table, the studied informal caregivers had a high level of diverse pains/aches (95.5%), with a total percent score of 87.0 ± 12.1 in the form of back pain (78.6%), headaches (77.2%), and neck & shoulder pain (76.4%). This is followed by GIT symptoms (94.5%), with a total percent score of 79.8 ± 12.0 , such as, abdominal problems (65.0%), stomach troubles (64.5%), and

constipation (40.5%). They also showed a high degree of psychological symptoms (90.5%), with a total percent score of 82.9 ± 13.6 , such as depressive mood (85.9%), mood swings (85.5%), nervousness & anxiety (78.2%), and sleep disorders (69.5%).

Table (5) clarifies a statistically significant positive relationship between female sex of informal care givers of elderly patients receiving chemotherapy and the degree of compassion fatigue ($F = 74.290$ $P < 0.001$). There were also significant relationships between widows caregivers, housewives, daughters and sons of elderly patients, and compassion fatigue ($F = 3.034$ $P = 0.030$, $F = 7.692$ $P < 0.001$, $F = 4.959$ $P = 0.001$), respectively. Living in the same residence as the elderly patients was also found to be positively correlated with the level of compassion fatigue reported by informal caregivers ($F = 8.354$ $P = 0.004$). Furthermore, the same table shows that there were statistically significant correlation between the duration of elderly patients' caregiving and the duration of care delivered throughout the day, and caregivers' compassion fatigue ($F = 6.979$ $P < 0.001$, $F = 43.280$ $P < 0.001$).

Table (6) shows a statistically significant positive correlation between elderly patients aged 85 years and more and the degree of compassion fatigue reported by their caregivers ($F = 7.963$ $P < 0.001$). The level of compassion fatigue in caregivers was also found to be strongly related to married elderly patients ($F = 8.713$ $P = 0.001$). This table also illustrates that physical disabilities manifested by the elderly patients were positively correlated with compassion fatigue in their informal caregivers ($F = 5.596$ $P < 0.001$).

Table (7) shows a statistically significant positive correlation between caregivers' total compassion fatigue and their total psycho-somatic manifestations ($r = 0.864$ $p = 0.000$); including psychological symptoms ($r = 0.785$ $p = 0.000$), circulatory/breathing symptoms ($r = 0.783$ $p = 0.000$), gastrointestinal symptoms ($r = 0.717$ $p = 0.000$), and Pain/ aches ($r = 0.762$ $p = 0.000$). For illustration, the greater the compassion fatigue experienced by informal caregivers of elderly cancer patients receiving chemotherapy, the greater the psycho-somatic manifestations.

Table (1): Socio-demographic characteristics and health profile of informal caregivers of elderly patients receiving chemotherapy

Caregivers' socio-demographic characteristics and health profile	No. N= 220	%
Sex		
Female	139	63.2
Male	81	36.8
Age		
18 to less than 20	6	2.7
20 to less than 30	34	15.5
30 to less than 40	53	24.1
40 and more	127	57.7
Education		
Illiterate	51	23.2
Basic	27	12.3
Secondary	77	35.0
Above average	39	17.7
University	26	11.8
Marital status		
Married	126	57.3
Single	61	27.7
Widow	14	6.4
Divorced	19	8.6
Having children		
Yes	128	58.2
1-2	79	61.7
3-4	46	35.9
5 and more	3	2.4
No	92	41.8
Working condition		
Not working	123	56.0
Working	97	44.0
Employee	56	57.7
Skilled works	30	31.0
Free work	11	11.3
Income		
Not enough	149	67.7
Enough	71	32.3
Relation to the elderly		
Husband/wife	36	16.4
Son/daughter	104	47.3
Brother/sister	19	8.6
Other degree relative	61	27.7
Living with elderly		
Yes	187	85.0
No	33	15.0
Duration of elderly patients caregiving		
Less than 1 year	24	10.9
One year to less than two years	38	17.3
Two year to less than three years	36	16.4
Three years and more	122	55.4
Mean ± SD (Months)	40.6±29.7 month	
Min-Max	1-180 month	
Duration of caring for the elderly patients all over the day		
All the day	126	57.3
Part of the day	94	42.7
Care provided /responsibilities		
Patients' self-care responsibilities #		
- Helping with feeding and drinking	154	70.0

Caregivers' socio-demographic characteristics and health profile	No. N= 220	%
- Helping with dressing and grooming	162	73.6
- Helping with bathing and toileting	175	79.5
- Helping with moving inside the house	196	89.1
Responsibilities towards the other family members#		
- Providing basic needs for other family members (cooking, cleaning, etc.)	168	76.4
- Caring for other diseased family member	160	72.7
- Helping children in school home works	78	35.6
Presence of psychological support for informal caregivers		
No	131	59.5
Yes	89	40.5
Effect of caregiving responsibilities on the caregivers' recreational activities		
- Not affected	28	12.8
- Decreased	96	43.6
- Stopped	96	43.6
effect of caregiving responsibilities on the caregivers' spiritual activities		
- Increased	125	56.8
- Decreased	28	12.8
- Not affected	67	30.4
Health profile of the informal caregivers		
Have diseases #	164	74.5
- Osteoarthritis	92	57.0
- Hypertension	66	40.2
- Diabetes mellitus	62	37.8
- Heart diseases	27	16.5
- Psychological disorders	24	14.6
- Respiratory diseases	22	13.4
- Urinary diseases	21	21.8
- Neurological disorders	11	6.7
Have no diseases	56	25.5

Multiple response

Table (2): Socio-demographic Characteristics and health profile of elderly patients receiving chemotherapy

Elderly patients' socio-demographic characteristics and health profile	No. N= 220	%
Sex		
Female	141	64.1
Male	79	35.9
Age		
60 to less than 75	122	55.5
75 to less than 80	83	37.7
80 and more	15	6.8
Education		
Illiterate	142	64.5
Basic	36	16.4
Secondary	28	12.7
Above average	4	1.8
University	10	4.6
Marital status		
Married	127	57.7
Single	5	2.3
Widow	83	37.7
Divorced	5	2.3
Working condition		
House wife	113	51.4
Skilled works	56	25.5
Employee	30	13.6
Free work	21	9.5
Income		
Not enough	161	73.2
Enough	59	26.8
Health profile of elderly patients receiving chemotherapy		
- Health problems other than cancer (comorbidities)		
Yes		
- Diabetes mellitus	91	44.0
- Hypertension	82	39.6
- Osteoarthritis	25	12.1
- Renal problems	9	4.3
No		
	13	5.9
- Physical disabilities		
Yes		
- mobility problems	163	84.5
- Visual problems	30	15.5
No		
	27	12.3
- Memory disturbances#		
- Memory disturbance	201	91.4
- Lack of concentration	189	85.9
- Confusion	162	73.6
- Distractibility	151	68.6
- Delayed responses	150	68.2
- Difficulty with problem solving	76	34.5
- Difficulty with orientation to time, place, and persons	20	9.1

Multiple response

Table (3): Total score and percent score of compassion fatigue among caregivers of the elderly patients receiving chemotherapy

Compassion fatigue	Never		Less time		Somewhat		Often		More time	
	No.	%	No.	%	No.	%	No.	%	No.	%
Feeling depressed because of the elder painful experiences	0	0.0	3	1.4	27	12.3	127	57.7	63	28.6
Being affected by the painful experiences of the elder	0	0.0	0	0.0	6	2.7	67	30.5	147	66.8
Feeling on the edge because of caregiving process	18	8.2	46	20.9	51	23.2	50	22.7	55	25.0
Having fearful thoughts and obsessions because of the care giving process	2	0.9	5	2.3	38	17.3	72	32.7	103	46.8
Avoiding activities or situations reminding with the elder painful experiences	1	0.5	15	6.8	44	20.0	92	41.8	68	30.9
Having difficulty separating personal life from that of a caregiver	3	1.4	17	7.7	17	7.7	79	35.9	104	47.3
Being surprised by unexpected thoughts since the beginning of caregiving	0	0.0	6	2.7	51	23.2	98	44.6	65	29.5
Being preoccupied by more than one person to take care of	37	16.8	9	4.1	40	18.2	80	36.4	54	24.5
Inability to remember important experiences during caregiving	0	0.0	16	7.3	41	18.6	134	60.9	29	13.2
Having the same pain as the elder I care for	0	0.0	5	2.3	10	4.6	43	19.5	162	73.6
Total Compassion Fatigue Score (Maximum allowed score is 50)										
Mean ± SD	40.4±6.3									
Min-Max	19-50									
Total Compassion Fatigue Percent Score										
Mean ± SD	80.8±12.7									
Min-Max	38-100									

Table (4): Total percent score and level of psycho-somatic symptoms among caregivers of the elderly patients receiving chemotherapy

Psycho-somatic symptoms scale	Never		Rarely		Sometime		Very often	
	No.	%	No.	%	No.	%	No.	%
A) Psychological symptoms								
1- Depressive mood	1	0.5	6	2.7	24	10.9	189	85.9
2- Nervousness/Anxiety	0	0.0	6	2.7	42	19.1	172	78.2
3- Mood swings	0	0.0	6	2.7	26	11.8	188	85.5
4- Difficulties to concentrate	20	9.1	73	33.2	88	40.0	39	17.7
5- Fear/Phobia	3	1.4	18	8.2	101	45.9	98	44.5
6- Nightmares	7	3.2	22	10.0	85	38.6	106	48.2
7- Weight gain/Weight loss	46	20.9	25	11.4	87	39.5	62	28.2
8- Lack of appetite	33	15.0	36	16.4	94	42.7	57	25.9
9- Sleep disorder/Insomnia	1	0.5	19	8.6	47	21.4	153	69.5
Total Psychological symptoms percent score								
Mean±SD	82.9±13.6							
Min-Max	38-100							
Psychological symptoms classification								
High	199 (90.5%)							
Low	21 (9.5%)							
B) Circulatory/Breathing symptoms								
10- Trembling hands	34	15.4	25	11.4	111	50.5	50	22.7
11- Trembling	38	17.3	37	16.8	107	48.6	38	17.3
12- Speech impediment	45	20.5	36	16.4	86	39.1	53	24.0
13- Rapid heartbeats, circulatory problems, dizziness	4	1.8	22	10.0	121	55.0	73	33.2
14- Breathing difficulties	20	9.1	38	17.3	122	55.4	40	18.2
Total Circulatory/Breathing symptoms percent score								
Mean±SD	70.7±17.4							
Min-Max	25-100							
Circulatory/Breathing symptoms classification								
High	182 (82.7%)							
Low	38 (17.3%)							
C) Gastrointestinal symptoms								
15- Diarrhea	63	28.6	60	27.3	83	37.7	14	6.4
16- Constipation	0	0.0	9	4.1	122	55.4	89	40.5
17- Stomach trouble/Heartburn	2	0.9	9	4.1	67	30.5	142	64.5
18- Abdominal problems	1	0.5	9	4.1	67	30.5	143	65.0
Total Gastrointestinal symptoms percent score								
Mean±SD	79.8±12.0							
Min-Max	31.3-100							
Gastrointestinal (GIT) symptoms classification								
High	208 (94.5)							
Low	12 (5.5%)							
D) Pain /aches								
19- Back pain	0	0.0	3	1.4	44	20.0	173	78.6
20- Neck and shoulder pain	0	0.0	4	1.8	48	21.8	168	76.4
21- Fatigue	19	8.6	52	23.6	119	54.1	30	13.6
22- Headaches	3	1.4	14	6.4	33	15.0	170	77.2
Total Pain /aches percent score								
Mean±SD	87.0±12.1							
Min-Max	37.5-100							
Pain /aches classification								
High	210 (95.5%)							
Low	10 (4.5%)							
Total Psycho-somatic symptoms percent score								
Mean±SD	80.4±12.4							
Min-Max	38.6-100							
Total Psychosomatic symptoms scale classification								
High psycho-somatic symptoms (60% and more)	198 (90.0%)							
Low psycho-somatic symptoms (Less than 60%)	22 (10.0%)							

Table (5): Correlation between caregivers' socio-demographic characteristics and their total compassion fatigue percent score

Caregivers' socio-demographic characteristics	Total Compassion Fatigue Percent Score	
	Mean±SD	Test of significance
Sex		
Female	84.9±10.0	F:74.290
Male	73.9±13.8	P:<0.001*
Age		
18 to less than 20	78.6±12.7	F:2.040
20 to less than 30	83.2±13.7	P:0.109
30 to less than 40	77.3±14.1	
40 and more	81.8±11.5	
Education		
Illiterate	82.7±12.6	F:1.350
Basic	82.2±9.4	P: 0.253
Secondary	79.4±13.9	
Above average	82.7±11.4	
University	77.3±13.3	
Marital status		
Married	79.6±11.6	F:3.034
Single	80.2±16.1	P:0.030*
Widow	88.4±7.6	
Divorced	85.5±5.3	
Having children		
1-2	81.7±10.8	F:719
3-4	78.8±13.5	P:0.542
5 and more	86.6±2.3	
No	80.9±13.9	
Working condition		
Not working	84.6±8.5	F:7.692
Housewives	85.0±11.3	P:<0.001*
Employee	76.7±13.8	
Skilled works	74.8±13.6	
Free work	74.3±16.4	
Income		
Not enough	81.3±12.4	F:0.652
Enough	79.8±13.3	P:0.420
Relation to the elderly		
Husband/wife	81.0±9.0	F:4.959
Son/daughter	82.2±15.7	P:0.001*
Brother/sister	81.3±11.8	
Other degree relative	81.6±13.5	
Just Neighbor	56.8±10.7	
Living with elderly		
Yes	81.9±12.4	F:8.354
No	75.0±12.9	P:0.004*
Duration of elderly patients caregiving		
Less than 1 year	76.3±16.0	F:6.979
One year to less than two years	78.7±11.3	P:<0.001*
Two year to less than three years	75.1±13.5	
Three years and more	84.1±11.1	
Duration of caring for the elderly patients all over the day		
All the day	85.3±8.9	F:43.280
Part of the day	74.9±14.5	P:<0.001*

F: ANOVA test

P: P value of ANOVA test

*Significant at P value≤0.05

Table (6): Correlation between elderly patients' socio-demographic characteristics, health profile, and caregivers' total compassion fatigue percent score

Elderly patients' socio-demographic characteristics and health profile	Total Compassion Fatigue Percent Score	
	Mean±SD	Test of significance
Sex		
Male	81.34±13.2	F:0.191
female	80.6±12.4	P:0.662
Age		
60 to less than 75	78.3±13.2	F:7.963
75 to less than 85	83.0±11.5	P:<0.001*
85 and more	90.0±7.8	
Education		
Illiterate	79.9±13.4	F:0.887
Basic	84.0±10.1	P:0.473
Secondary	82.4±13.0	
Above average	79.5±7.8	
University	79.2±10.8	
Marital status		
Married	82.7±10.5	F:8.713
Single	69.6±16.5	P:<0.001*
Widow	80.2±14.0	
Divorced	57.6±7.7	
Health problems other than cancer(comorbidities)		
Osteoarthritis	87.3±8.5	F:233.078
Renal problems	87.1±5.0	P:1.470
Hypertension	81.5±12.9	
Diabetes mellitus	78.9±13.8	
No	79.8±10.8	
Physical disabilities		
mobility problems	96.7±5.8	F:5.596
Visual problems	78.7±14.1	P:<0.001*
No	73.2±12.3	

F: ANOVA test

P: P value of ANOVA test

*Significant at P value≤0.05

Table (7): Correlation matrix between psycho-somatic manifestations and total compassion fatigue score among caregivers of elderly patients receiving chemotherapy

Psycho-somatic manifestations manifested by caregivers	Total Compassion Fatigue	
	R	P
Psychological symptoms classification	0.785	0.000*
Circulatory/Breathing symptoms classification	0.783	0.000*
Gastrointestinal symptoms classification	0.717	0.000*
Pain /aches classification	0.762	0.000*
Total Psycho-somatic symptoms classification	0.864	0.000*

r: Pearson Correlation

P: P value of significance **. Correlation is significant at the 0.01 level (2-tailed).

Discussion

Caring for an elderly patient receiving chemotherapy is a disturbing and mandatory day-to-day responsibility that consumes tremendous physical as well as psychological effort. The caregivers are always under the effect of conflicts between their love and caring roles and, at the same time, their other responsibilities and other roles. Additionally, the process of receiving chemotherapy by itself is a stressful procedure that exhausts not only the cancer patients but also those who care for

them, especially if the patients are elderly with the expected limitations, dependency, associated disabilities, and extra complications that could be because of the ageing process. Caregivers need to cope and adapt in order to be able to continue providing optimum care. It is not rare to find oneself emotionally exhausted as a result of the caring process, and this emotional burden was stressed by the National Cancer Institute in the USA in 2019.

Compassion Fatigue (CF) is a term that refers to the emotional and physical exhaustion

that can affect those who provide care. This process was described as a trauma for those who care for others that takes place during providing help, and accordingly, the caring ability is to a great extent compromised (Cavanagh et al., 2020). Therefore, compassion fatigue is considered a result of being compassionate or attending to the suffering of another person (Sarraf & Feuz, 2018; Nolte et al., 2017; Sinclair et al., 2017). The present study revealed that most of the caregivers' responses indicated a high level of compassion fatigue (tab. 3). This could be attributed to the fact that most of the caregivers were sons and/or daughters (tab. 1); the significant and special tie in this relation, giving the persistent stress of feeling unable to relieve the pain of a very special person, in addition to having always the fear of recurrence, metastasis, and relapse, may make the process of nurturing their parents very difficult and make CF highly expected.

The resultant high level of CF was also expected as the majority of the caregivers were living with their parents, which exposed them to daily anguish and continuous pressure. This result can also be understood as more than half of the studied caregivers were female, married, and had children. All these characteristics contribute to being under a lot of burden and demands that could cause a state of huge physical as well as emotional exhaustion, leading to a state of compassion fatigue. This is in accordance with Day et al., (2014), who concluded that female daughter caregivers who were caring for elderly parents most of the day were more likely to develop compassion fatigue. It is also worthwhile to mention that Figley (2002), who was one of the founders of studying compassion fatigue, stressed that the combination of stress factors and overloads contribute to an increased risk of developing compassion fatigue among caregivers.

Moreover, the results also reflected a period of caring for the elderly parents for 3 years and more, mainly for a full day of indoor and outdoor duty, which is expected to be a very long period of physical and emotional drain and consequently lead to a high CF level (tab. 1). It has been found that regular interaction with the sufferers' unpleasant

periods results in emotional exhaustion and fatigue over time (Beaumont et al., 2016). Furthermore, fragile and vulnerable elderly patients are more likely to have a higher level of caregivers' fatigue because of feeling compassionate; the strong relationship identified between elderly patients aged 85 years and more and the caregivers' compassion fatigue level is valid evidence of this (tab. 6).

The current study highlighted that most of the informal caregivers reported having a high level of psychosomatic symptoms. These symptoms include either physical symptoms such as pain or aches or psychological symptoms such as depressive mood, nervousness or anxiety, or sleep problems (tab. 4). Having a full day of duty caring for an elderly patient who is suffering from cancer receiving chemotherapy is considered a huge responsibility that cannot be stopped or postponed. Considering that more than half of the studied caregivers are aged 40 years or more (tab. 1) and more than three-quarters of them are also caring for other diseased family members (tab. 1); the effort of caring for an elder receiving chemotherapy could be more strenuous, especially for a lot of the studied caregivers who are obliged to manage their work as well as their caring responsibilities (tab. 1). This goes with what Boyle (2015) mentioned about the depletion or suppression of renewal or restoration of caregivers' abilities that resulted from prolonged stress, exhaustion, and fatigue, adding to this the reported chronic health problems of the studied caregivers including osteoarthritis, hypertension, and DM, among others (tab. 1).

Other factors that may add to the previous suffering of the studied caregivers are the reported lack of psychological support as well as stopping or decreasing recreational activities (tab. 1). Moreover, the hardship of caregiving for elders who had mobility or visual problems, which manifested in a lot of the studied cases (tab. 2), It is also worthwhile to mention that the financial pressure resulting from insufficient income that was reported by most of the caregivers as well as the elderly patients themselves could be a leading cause for the caregivers to experience psychosomatic complaints. The previous profile can explain

why the caregivers cannot say no to the caring responsibilities, but their bodies object to this continuous strain by experiencing psychosomatic manifestations that can be considered a cry for help that symbolizes not being able to tolerate more or even just to have a compulsory break. Literature reported that caregiving for elders with memory or other cognitive problems, which were also reported in the present study results (tab. 2), was associated with psychosomatic manifestations such as depression, anxiety, and stress (Schoenmakers et al., 2010; Day, 2014; Zacharopoulou et al., 2015).

The hallmark finding of the current study is that there is a strong and positive correlation between experiencing compassion fatigue and higher rates of psycho-somatic manifestations among caregivers who care for elderly cancer patients receiving chemotherapy (tab. 7). As the caregivers become overwhelmed with their inability to help their beloved elders, this may lead to a lot of psychosomatic manifestations that represent their inner state of fatigue resulting from the compassion process. Increased caregivers' spiritual activities, which were reported by more than half of the studied caregivers, could be a way to manage these hard feelings, especially in the face of the idea of death that is accompanying each step of the cancer and chemotherapy journey (tab. 1). In this regard, literature has highlighted the relationship between experiencing CF and higher rates of depression and anxiety among caregivers (De Panfilis, 2006; Jones, 2020). Furthermore, higher levels of compassion fatigue, when synchronized with a lack of support and other increased financial and social demands on the caregivers, promote maladaptive coping styles, most typically in the form of elevated psychosomatic manifestations. (Drury, 2014; Hegney et al., 2014; Muliira & Kizza, 2019).

Conclusion and recommendations

Informal caregivers of elderly cancer patients receiving chemotherapy have a significant level of compassion fatigue that is more evident among female caregivers and also among daughters and sons of the diseased elderly. Compassion fatigue was also more evident among those who care for the elderly for longer

duration across the daytime. Compassion fatigue has a considerable positive link with psychosomatic manifestations that are manifested among informal caregivers and are directly linked to their caring process.

In the light of the study findings, the following recommendations are suggested:

1. Ongoing assessment by responsible nurses must be done for informal caregivers of elderly cancer patients receiving chemotherapy to monitor their level of compassion fatigue and any manifested psychosomatic complains.
2. Education programs must be designed to help and direct informal caregivers on available helping measures such as respite care, physical exercises, a balanced diet, adequate sleep and rest. This will help in improving their emotional, social, and spiritual well-being to alleviate and prevent future complaints and suffering.
3. Self-help group sessions should be introduced for all informal caregivers of elderly cancer patients receiving chemotherapy, especially those who have a high level of compassion fatigue, and should be followed up on a regular basis to help them managing their fatigue and subsequently, improve the quality of care provided.
4. Stress reduction techniques as well as healthy coping strategies should be taught to informal caregivers, and they should be encouraged to seek help if necessary.

Future directions for research and practice:

1. Studying the effectiveness of compassion therapy on prevention and management of compassion fatigue and its resulting psychosomatic manifestations among informal caregivers of elderly cancer patients.
2. Oncology hospitals should adopt policies and practices, in relation to recognition, teaching, training, and providing resources, to support informal caregivers of elderly cancer patients.
3. Self-care practices should be taught and encouraged as a part of the caregiving process.

Limitations

The findings of this study should be regarded with caution because they were based on self-reported measures, and individuals' perceptions may alter over time. However, the authors attempted to address this constraint by including a qualitative section that reflects the real perceptions of the informal caregivers studied.

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