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Assessment of Caregiver Coping Levels and Quality of Life of their Patients Undergoing Chemotherapy

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Abstract: **Cancer is a generic term for a large group of diseases that can affect any part of the body. Cancer chemotherapy refers to the administration of cytotoxic agents to provide cure, control, or palliation of a neoplasm. Aim of the Study: This study was conducted to assess of the caregiver coping levels and quality of life of their patients whom undergoing chemotherapy. Materials and Methods: A descriptive exploratory design was utilized was used in this study. Setting the current study was conducted in oncology units at Beni-Suef University Hospital. The study subjects; A purposive sample of (100) patients after 3sessions of chemotherapy and their caregivers from previous mentioned setting. Tools of the study consist of three tools, the first tool was interview questionnaire sheet the second tool was adaptive coping strategies questionnaire the third tool was quality of life scale Index. Results: It was found that (70%) of the studied patient were female with mean age, also only (58%) of them illiterate and majority does not work.**

Keywords: **Assessment, quality of life, coping caregivers.**

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1. INTRODUCTION

Cancer is a generic term for a large group of diseases that can affect any part of the body. One defining feature of cancer is the rapid creation of abnormal cells that grow beyond their usual boundaries, and which can then invade adjoining parts of the body and spread to other organs, the latter process is referred to as metastasizing **(Leon & Bignold, 2019).** Cancer chemotherapy refers to the administration of cytotoxic agents to provide cure, control, or palliation of a neoplasm. Cancer cells are destroyed to the point that cancer can no longer be found in the body, the cancer cells will not grow back. Chemotherapy may keep cancer from spreading or slows its growth. It may also destroy cancer cells that have spread to other parts of body. It may be given as part of palliative care it can be used to shrink tumors that are causing pain or pressure **(Lister , Dougherty & McNamara, 2018).**

Caregivers are the most important physical and emotional care providers. In addition, they need to perform various other activities such as helping the patient cope with symptoms and coordination of medical care. As well as physical care, they also take on emotional care such as enabling social support, helping them make decisions and searching for obtaining information **(Girgis, Johnson, Aoun & Currow, 2010).**

Estimated number of incident cancer cases 2013–2050, during the period 2013–2050, population of Egypt is expected to increase to approximately 160% the 2013 population size. Applying the current age-specific incidence rates to successive populations would lead to a progressive increase in number of incident cases from 114,985 in 2013 to 331,169 in 2050, approximately 290% of 2013 incidence. This increase reflected both population growth and demographic change mainly due to ageing of population. Population growth alone would increase the number of incident cases by 55.2% in 2015. This fraction progressively decreased to become 32.8% in 2050. The fraction due to ageing gradually increased to reach 67.2% in 2050 **(Ibrahim, 2014).**

Patients with cancer undergoing chemotherapy face serious challenges to their Quality of life (QoL). According to the World Health Organization (WHO), (QoL) defined as individual perception of life, values, objectives, standards, and interests in the framework of culture. The amount of symptoms distressed experienced by an individual has been related to QoL in a number of people with cancer (**Acton, 2012).**

So the aim of this study has been conducted to improve quality of life of patients undergoing chemotherapy and increase coping levels of chemotherapeutic patients' caregivers.

Aim of the Study:

This study was conducted to assess the caregiver coping levels and quality of life of their patients undergoing chemotherapy.

Research Questions:

What are the caregivers coping levels and quality of life of their patients undergoing chemotherapy?

2. SUBJECTS AND METHODS

The study was portrayed under the four main designs as follows:

1. Technical design.
2. Operational design.
3. Administrative design.
4. Statistical design.

1)The technical design:

-It includes research design, setting, subject and tools for data collection.

A) Research design:

A descriptive exploratory design was utilized was used in this study.

B) Setting:

This study was carried out at clinical oncology department at Bani-Suief University Hospital**.**

C) Subjects:

A Purposive sample of 100 adult patients and 100 caregivers who met the inclusion criteria and agree to participate in the study.

Inclusion criteria for caregivers':-

Both genders, able to read and write

and able to communicate clearly.

Inclusion criteria for patient:

Adult male and female patients' diagnosis with cancer, The patients receiving recently chemotherapy and free from any other disease.

D) Tools for data Collection:

Data were collected using the following tools:

First tool (I) Interview questionnaire sheet: It was developed by the researcher, **Garcia et al. (2018). Iversen & Bjertnaes (2012)** & **Yusuf , Adamu, Nuhu (2011):** And including two parts e.g:

First tool (A):- it will be concerned with socio demographic data related to patients and caregivers' such as age, gender, level of education, occupation.

First tool (B):- It was used to assess caregiver's level of knowledge regarding chemotherapy.

Scoring system:

Each correct answer was given one degree and the incorrect answer was given zero.

The total score of knowledge it was considered that

- ≥75% Satisfactory level of knowledge
- <75% unsatisfactory level of knowledge

Tool (II): Adaptive coping strategies questionnaire:

It was adopted from **Pérez, et al, (2017)** and it was used to assess adaptive coping styles in caregivers. **Scoring system:**

- **low coping**: score from 0 to 25
- **Moderate coping** : score from 26 to 64
- **High coping**: score from 65 to 100

Tool (III)* Quality of life scale Index*:

It was adopted from **Ali, (2017)** and it was used to assess the impact of chemotherapy on quality of life of cancer patients.

Scoring system:

the total score ranged from(0) to (114)the grads were given as follow –poor when the total score was less than 60%- fair when the total score 60% to less than 75%- good when total score was 75%to 100%.

Field Work:

1- An official permission for conducting the study was obtained from the director of Beni-Suef university hospital and head of oncology department.

2- Development of tool I, II &III after reviewing recent relevant literatures.

3- Data collection started and completed within 6 months from august (2019) to until the end of January(2020).

4- Before starting the interview a written consent was obtained from each patient and caregiver after the explanation of the study purpose, patient were interviewed using tools 1,2.

5- Also, the caregiver were interviewed using tools 3,4 as pre-test, the interviewing schedule were filled by the researcher for each patient but tools especially of the care giver's filled by the caregiver's each interview last 20-30 minutes depending to patient's capacity to response.

6- **Ethical Considerations**:

Ethical approval was obtained from the Faculty of Nursing , Helwan university to director of Bani-Suief university hospital, the director referral to director of oncology department to give permission, the director of oncology department referral to Ethical Committee of the Faculty of Medicine ,Beni-Suief university before starting the study in which the study will be conducted. In addition, written informed consent was obtained from each participant prior to data collection. The participants assured that anonymity and confidentiality would be guaranteed and the right to withdraw from the study at any time. Ethics, values, culture and beliefs were respected.

4.Statistical Design:

The collected data were organized, categorized, tabulated, and statistically analyzed of the present study was conducted, using the mean, Standard Deviation, Linear Correlation Coefficient and chi-square tests by (***IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.)***. A significant level value was considered when p- value <0.05*, and highly significant level value was considered when p- value<0.001** , while p- value >0.05 indicate non- significant result.

Data were presented in tables and graphs. The statistical analysis included; percentage (%), the arithmetic mean ($\overline{X}$), standard deviation (SD), chi-square (X^2), and Pearson correlation (r).

3. RESULTS

Table (1): Distribution of the studied patients according to their socio demographic characteristics (n=100).

Items	**N**	**%**
Gender		
Male	30	30.0
Female	70	70.0
Age (years)		
20- <35	10	10.0
Mean age 35 or more	90	90.0
Social status		
Single	5	5.0
Married	95	95.0
Residence		
Rural	82	82.0
Urban	18	18.0
Educational level		
Illiterate	58	58.0
Read and write	21	21.0
intermediate	15	15.0
University	6	6.0
Working after disease		
Work	19	19.0
does not work	77	77.0
Student	4	4.0
Nature of work		
Requires a mental effort	3	15.8
Requires a muscular effort	10	52.6
Both	6	31.6
Monthly income for treatment expenses		
Sufficient	32	32.0
Insufficient	68	68.0

Table (2): Distribution of sociodemographic characteristics for care giver's (n=100).

Items	**N**	**%**
Age (years)		
<20	4	4.0
20- <35	50	50.0
35 or more	46	46.0
Relationship of kinship to the patient		

husband / wife	20	20.0
parents	5	5.0
Brother	24	24.0
Sons	51	51.0
Gender		
Male	43	43.0
Female	57	57.0
Educational level		
Read and write	36	36.0
intermediate	45	45.0
University	19	19.0
Social status		
Single	19	19.0
Married	78	78.0
Widowed	1	1.0
Divorced	2	2.0
Working		
Work	61	61.0
does not work	39	39.0
Residence		
Rural	80	80.0
Urban	20	20.0
Do you have children		
No	25	25.0
Yes	75	75.0
Do you suffer from health problems		
No	79	79.0
Yes	21	21.0
Type of health problem		
heart	1	4.8
blood pressure	14	66.7
sugar	5	23.8
liver	1	4.8
How many times spend with the patient		
6 hours	14	14.0
12 hours	6	6.0
12 hours	19	19.0
24 hours	61	61.0

Table (3): Distribution of the studied caregivers coping level regarding patients undergoing chemotherapy before phases (n=100).

Items	**No**		**Rarely**		**Sometimes**		**Much**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
1.Do you feel that your relative is asking for help and assistance more than is actually needed?	14	14	10	10	25	25	51	51
2.Do you feel that the time you spend with your relative affects your time?	23	23	10	10	42	42	25	25

3.Do you feel psychological stress resulting from the distribution of attention between caring for your husband and the performance of your responsibilities towards the family or work?	16	16	26	26	31	31	27	27
4.Do you feel ashamed about your neighbor's behavior?	49	49	19	19	21	21	11	11
5.Do you feel angry or angry in the case of your companion and your presence with your relative?	43	43	24	24	21	21	12	12
6.Do you feel that your relative is currently affecting your relationship with other family members or friends in a negative way?	38	38	22	22	32	32	8	8
7.Are you afraid of what the future holds for your relative?	1	1	0	0	35	35	64	64
8.Do you feel that your relative depends on you?	7	7	3	3	41	41	49	49
9.Do you feel tight when you are with your relative?	26	26	5	5	41	41	28	28
10.Do you feel that your health has been affected by your neighbor's care?	23	23	16	16	43	43	18	18
11.Do you feel that you lack some degree of privacy because of your relative?	22	22	29	29	25	25	24	24
12.Do you feel that your social life is upset because of your attention to your relative?	18	18	18	18	44	44	20	20
13.Do you feel uncomfortable inviting one of your friends because of your neighbor?	52	52	23	23	17	17	8	8
14.Do you feel that your relative is expected to sponsor you as if you are the only person you can count on?	8	8	33	33	45	45	14	14
15.Do you know that you do not have enough money to care for your relative as well as the rest of your expenses?	26	26	26	26	40	40	8	8

Table (4): Distribution of the study patient's level of physical condition during before the program (n=100).

Physical Condition	**No problem**		**A little problem**		**A medium problem**		**A big problem**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
1 - feeling of fatigue	15	15	34	34	40	40	11	11
2. Changes in appetite	12	12	23	23	38	38	27	27
3. Pain	9	9	14	14	32	32	45	45
4 - insomnia	6	6	9	9	30	30	55	55
5. Nausea	16	16	14	14	32	32	38	38
6- Diarrhea	14	14	10	10	19	19	57	57
7. Skin change	2	2	15	15	29	29	54	54
8. Hair loss	27	27	27	27	36	36	10	10
9. Dry mouth	6	6	15	15	30	30	49	49
10. Make a full assessment of physical condition	14	14	49	49	32	32	5	5
Total	12	12	21	21	32	32	35	35

Table (5): Distribution of the studied patient's level of psychological state before the program (n=100).

Psychological state	**Very good**		**Good**		**Bad**		**Very bad**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
11. To what extent have you adapted to the disease and chemotherapy?	18	18	24	24	26	26	32	32
12 - To what extent the quality of life you live is a good life?	12	12	39	39	23	23	26	26
13 - Do you feel as if you control the course of things in your life?	16	16	23	23	29	29	32	32
14 - I feel satisfied with my life?	30	30	20	20	27	27	23	23

15. What is your ability to concentrate or remember things?	47	47	27	27	23	23	3	3
16. Do I feel useful?	19	19	28	28	28	28	25	25
17. How sad I felt about the initial report of chemotherapy	18	18	6	6	34	34	42	42
18.What the exited level from chemotherapy methods?	10	10	7	7	23	23	60	60
19-To what extent are you concerned?	7	7	6	6	35	35	52	52
20-To what extent do you feel depressed?	7	7	5	5	33	33	55	55
21. To what extent are you afraid of complications of chemotherapy?	8	8	9	9	34	34	49	49
22-Are you afraid of cancer recurrence?	11	11	17	17	46	46	26	26
23-Are you afraid of spreading cancer in multiple places?	18	18	51	51	26	26	5	5
24 - Give a full assessment of psychological condition?	4	4	24	24	65	65	7	7
Total	16	16	21	21	32	32	31	31

Table (6): Distribution of the study patient's level of social state before the program (n=100).

Social status	**Very good**		**Good**		**Bad**		**Very bad**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
25- Does your illness affect your family's sense?	41	41	38	38	17	17	4	4
26- Is the amount of moral support that surrounds you others sufficient to support you during treatment?	77	77	16	16	4	4	3	3
27- To what degree does chemotherapy affect your personal relationship with others?	8	8	4	4	29	29	59	59
28-To what extent does chemotherapy affect your function?	4	4	5	5	7	7	84	84
29- To what extent does chemotherapy affect the activities performed at home?	10	10	9	9	47	47	34	34
30 - How much social isolation is caused by chemotherapy?	9	9	5	5	23	23	63	63
31- What is the cost of treatment is a material burden on your budget?	13	13	23	23	46	46	18	18
32 - A full assessment of social life?	6	6	69	69	23	23	2	2
Total	21	21	24	24	22	22	33	33

Table (7): Distribution of the study patient's level of spiritual state before the program (n=100).

Spiritual state	**Very good**		**Good**		**Bad**		**Very bad**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
33. Is the amount of moral support that you receive as a result of attending prayer, prayer or meditation sufficient to satisfy your spiritual needs?	45	45	12	12	23	23	20	20
34. How much uncertainty do you feel about your future?	16	16	5	5	16	16	63	63
35- Does chemotherapy cause positive changes in your life?	6	6	28	28	30	30	36	36
36 - Do you feel that there is a specific goal or task for your life or a specific goal to keep you alive	11	11	38	38	27	27	24	24
37- To what extent are you optimistic?	16	16	27	27	20	20	37	37
38 - Appreciate fully spiritual life	7	7	63	63	30	30	0	0
Total	17	17	28	28	25	25	30	30

4. DISCUSSION

The current study aimed to assessment the caregiver coping levels and quality of life of their patients undergoing chemotherapy.

Regarding the studied patients sociodemographic characteristics, the results of the study revealed that, most of them aged from 35 or more years with a mean age. This might explain that middle adult hood characterized by work and being productive person for both the family and society so feeling not being able to perform social roles could affect coping and quality of life. This result comes in agreement with a study done by **Lotfy (2012) and Abd El-Moneem, (2014)**. Who found that the majority of sample was in the middle adulthood. While disagreement with **Adamowicz& Zaucha (2016)** who revealed that the majority of studied patients were 50 years old or more.

Finding of this study showed that, the most of the studies patients were females. This could be due to early of menarche and late age at menopause, null parity, and late age at first pregnancy have been associated with an increased risk of breast cancer. This result comes in agreement with a study done by **Torre (2017)** who done a research study was titled as " Global cancer in women "who found that the majority of patients were females. These findings were in disagreement with to those of the study done by **Labib (2012)** who found that, cancer is more prevalent among males than females.

Regarding the studied caregivers sociodemographic characteristics, the results of the present study revealed that, half of them aged from twenty to less than thirty five years old. This result is disagreement with **Coppetti (2018)** who done a research study was titled as" Caring ability of family caregivers of patients on cancer treatment**"** who reported that regarding family caregivers with this population, identified that the majority with a mean age of 48.68 years**.**

Concerning to gender of studied caregivers the present study show that, more than half of caregivers was female and more than three quarters of studied caregivers married This result agreed with **Lkhoyaali (2015)** who studied" The burden among family caregivers of elderly cancer patients" who stated that the majority were females and most of the participants were married and have familial responsibilities.

Regarding to caregivers total coping level the result of the current study showed that, more than one third reduction level of coping among the studied caregivers at before study phases. These findings is in agreement with **Kilic &Fatma (2019)** who found that family caregivers’ quality of life is negatively affected during the caregiving process.

Regarding quality of life (physical health dimensions). The most common physical side effects of chemotherapy include diarrhea, nausea vomiting and fatigue which decrease quality of life. More than half of studied subject reported diarrhea at before study phases. This result agreement with **Wagland (2014)** who found that the commonly studied problems such as nausea, vomiting and fatigue other problems which are not so commonly studied such as drowsiness, weight changes and dizziness are also reportedly highly prevalent for patients with common cancers. This finding also is in disagreement with **Hassan (2018)** who mentioned that the majority of studied subject reported sever feeling of fatigue before the program.

This result is disagreement with **Glińska (2013)** who done a research study was titled as" Evaluation of the psychological state of patients with advanced cancer and the impact of support on their emotional condition "who reported that that most subjects undergo mood aggravation. More than three quarter of patients were diagnosed with depressive states. Only less than one fifth of the population under investigation showed no signs of anxiety states.

Similarly the results done by **Mohamed (2012)** denoted that there was statistical significant improvement regarding all items of social dimensions of study group. In the same line **Ranjbar (2017)** stated that people with a better economic situation will experience less financial distress and because they are less worried about high costs of treatment, job loss and salaries, which result in better QOL.

This study is supported by the research study done **by Forouzi (2017)** who done a research study was titled by" Spiritual Needs and Quality of Life of Patients with Cancer" who found that the study suggest that information about the relationship between spiritual needs and QoL in patients with cancer. It should be improve QoL to meet spiritual need of these patients. In addition, the continuous and in-service education of cancer patients and nurses who work with them can be helpful in this area.

5. CONCLUSION

the researcher can conducted the assessment improving quality of life of patients and adaptive coping strategies of caregivers of patients undergoing chemotherapy. The study revealed that majority of studied caregivers had satisfactory.

6. RECOMMENDATIONS

In nursing practice:

- Develop a screening and assessment tool to assess quality of life of all patients undergoing chemotherapy.
- Integration of relaxation technique program for patients undergoing chemotherapy as it is effective, easily applicable and need low economic cost.

In nursing program:

- Educational program that include all physiological consequences of chemotherapy and how to manage it should be added to nursing curriculum of oncology courses.
- Establish of educational program to lighten couples of chemotherapy patients about cancer treatment option and answer their question.
- Provide in-service training program for nurses who actually working in oncology clinics and centers about physiological consequences of treatment and scientific base to manage it.

In further research:

- Replication of the study using a large probability samples acquired from different geographic areas.
- Conduct longitudinal study to assess patients response, adaptation to chemotherapy and coping caregivers process.

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