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Quality of Life for Family Caregivers of Patients with Lymph Nodes Cancer

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ABSTRACT

Background: Lymph nodes cancer is one of chronic diseases that require long-term care. Family caregivers as the closest one who lives with the cancer patient takes a significant role in providing care. This causes an important burden on caregivers and decreases their quality of life. **Objective:** The aim of the current study is to assess the quality of life for family caregivers of patients with lymph nodes cancer.

Subjects and methods: A descriptive study was conducted in outpatient Cancer Clinic of General Fayoum Hospitals. Purposive sample was used and included 240 family caregivers. Tools of the study included: (1): Interviewing Questionnaire sheet that included two parts, Part I: Demographic characteristics, Part II: Knowledge Assessment Sheet, (2): Caregiver Quality of Life Index.

Result: Up to 80% of the sample under investigation knew too little overall about lymph node cancer. There were statistically significant associations between the total knowledge scores of family caregiver of lymph node cancer patients and their age, educational attainment, and monthly income, as well as statistically significant associations between some socio-demographic data and their quality of life. Additionally, there was a highly statistically significant positive correlation between the total knowledge scores and the total quality of life. **Conclusion:** Majority of family caregivers with cancer patients had poor quality of life and unsatisfactory knowledge. Implementation of educational programe for family caregivers with cancer patients to enhance their quality of life is needed.

Keywords: Quality of life, Family caregivers, Lymph nodes cancer.

INTRODUCTION

Lymph node cancer is a kind of cancer that develops in the immune system's lymphocytes, which are responsible for battling infections. These cells can be found in the bone marrow, lymph nodes, spleen, thymus, and other organs. During lymphoma, lymphocytes alter and proliferate uncontrollably **(1)**.

Infections, damage to the lymph nodes, drugs, immune system abnormalities, and cancer are some of the causes of lymphadenopathy. Lymphoma and leukemia are the tumors that most frequently cause larger lymph nodes. The following are warning signs and symptoms of cancerous lymph nodes: lumps under the skin, especially in the neck, under the arm, or in the groyne; fever (which may come and go over several weeks); night sweats; unintentional weight loss; itchy skin; fatigue; loss of appetite; cough; difficulty breathing; and chest pain. Numerous issues can result from enlarged lymph nodes: Pain, coughing or hoarseness due to chest lymphadenopathy, tingling and numbness for lymphadenopathy damaging the spinal cord's nerves **(2)**.

Incidence and death rates for cancer of the lymph nodes were 0.98 and 0.26 per 100,000 in 2020. High-income nations showed a greater incidence, whereas low-income nations showed a higher mortality. At the population level, smoking, obesity, and hypertension prevalence were linked to incidence and death. Incidence increased despite the trend toward declining mortality, particularly among females, the younger population, and patients from Asian nations **(3)**.

The likelihood of lymph node cancer occurring is double. First, primary lymph node malignancies, also known as lymphomas, are tumors that originate in the lymph nodes. Secondary lymph node malignancies start in other parts of the body before metastasizing to the lymph nodes. The lymphocytes are the site of genesis for lymphoma, the most prevalent kind of blood cancer. These cells can travel to the lymph nodes, spleen, bone marrow, and other organs after they have mutated and became malignant. Hodgkin lymphoma and non-Hodgkin lymphoma are the two main categories of lymphoma **(4)**.

An adult family member or other person who provides unpaid in-home and out-of-community care to an elderly Vermonter or a person with a condition is referred to as a family caregiver. Symptoms of deteriorating health, anxiety, anger, sadness, social disengagement, changes in food and weight, and an excessive dependence on drink and drugs are all experienced by family caregiver. They carry out duties akin to those they did at the care recipient's home, including feeding, grooming, managing money, shopping, and providing transportation. They also offer companionship and emotional support **(5)**.

Community health nurses are medical professionals who play crucial roles in the lives of lymph node cancer patients and the people who care for them in their families. The nurse uses their clinical knowledge and technological experience to ensure that the family caregiver understand what is happening with their body throughout each step of treatment. They also assist in understanding the disease and the treatment process. Nurses tend to patients' emotional needs as well as their physical ones, listening to their worries as well. The nurses can assist patients find outside services that can lessen the emotional, financial, and familial strain that comes with receiving a cancer diagnosis **(6)**.

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In Egypt, lymph nodes cancer is considered the fourth most common tumor in adults; it includes Hodgkin lymphoma (HL) (23.4%) and non-Hodgkin lymphoma (NHL) (76.6%). The Middle East Cancer Consortium in Egypt reports that the age-standardized incidence rates for NHL are 16.3/100,000 (7).

Family members are frequently the primary caregiver for cancer patients because of the chronic nature of lymph node cancer. Although providing care for someone with cancer is a rewarding experience, it is also linked to worse quality of life (QOL), more severe psychological aftereffects, and a higher mortality risk for the caregiver. The quality of care that patients get is ultimately impacted by these consequences on the caregiver. Therefore, it is crucial to recognize, comprehend, and assist family caregiver, as well as their care receivers (8). So, this study aimed to assess the quality of life among family caregivers of patients with lymph nodes cancer.

The aim of the current study was to assess the quality of life for family caregivers of patients with lymph nodes cancer through the following objectives: (1) Assessing knowledge of caregivers about lymph nodes cancer; (2) Assessing the quality of life among family caregivers.

SUBJECTS AND METHODS

Research design: A descriptive research design was used in this study.

Setting: This study was conducted in outpatient Cancer Clinic of General Fayoum Hospitals.

Sample: A purposive sample was used in this study. The number of the sample that included in the study was 240 family caregivers.

Inclusion criteria for family caregivers:
- Provide care to the patient.
- Willing to participate in the study.

Exclusion criteria for family caregivers:
- Caregivers with psychiatric and mental disorders.

Tools for data collection: To achieve the purpose of the current study two tools were used:

Tool I: Interviewing questionnaire sheet: This tool was developed by the investigator, based on literature review, and included two parts.

Part (1) Demographic characteristics: It was concerned with demographic characteristics of the patient and the family caregivers such as (age, gender, marital status, educational level, and occupation, etc.

Part (2): Assess family caregivers' knowledge about lymph nodes cancer as: Meaning, types, signs and symptoms, etc.

Scoring system for knowledge: There were 12 questions in this section totaling 24 grades. Each statement received a score based on the family caregiver responses, with correct answers receiving two points and wrong responses receiving one point. Each item's total score was added together, and the result was expressed as a percent score.

As the following:

Knowledge	Score	%
Unsatisfactory knowledge	< 12	<50%
Satisfactory knowledge	≥ 12	≥ 50%

Tool II: Caregiver Quality of life (QOL) Index: This index was used for measuring quality of life for the family caregivers of patients with lymph nodes cancers. This was adopted from **World Health Organization** (9). It included items related to physical, psychological, social state, mental, emotional, level of independence, spiritual life, economic, satisfied with quality of life in general.

Scoring system for Caregiver Quality of life (QOL): The scale included 15 items from question 15-27 with 3 point Likert scale range from never= 1, sometime= 2, always= 3. The scoring was ranged from (15-45) grade the high score the greater tendency toward quality of life the total score was categorized as following:

Quality of life	Score	%
Poor quality of life	< 22.5	<50%
Good quality of life	≥ 22.5	≥ 50%

Validity: Three community health nursing specialists (3 professors) evaluated the questionnaire for internal validity and accuracy of content as part of the validity of tools process. Professors were also invited to assess the items for clarity and completeness (content validity). The two tools were modified to include suggestions as representation.

Reliability: Reliability of the tools was tested to determine the extent to which the questionnaire items related to each other. Cronbach's Alpha in this study found to be 0.89 for knowledge and 0.92 for quality of life.

Pilot study: The purpose of the pilot study was to evaluate the tool's usability, applicability, and comprehension. Pilot study included in the main study sample after being completed on 10% of the sample to assess the questions' clarity and the time required to complete the study instruments.

Field work:
- The Director of the Cancer Outpatient Clinic at General Fayoum Hospital provided formal approval for the study's conduct, as did the dean of the nursing school at Helwan University.
- To describe the nature and goals of the current study, the investigator conducted individual interviews with each patient and the family caregiver.
- The questionnaire took each family caregiver between 15 and 20 minutes to complete. Through the year 2020, data was gathered twice a week (Monday and

Wednesday) in the morning (from 9 A.M. to 12 P.M.), until the required sample was obtained.

- To gather the necessary data, the investigator started by giving the questionnaire sheet to family caregiver.
- Data were gathered through structured face-to-face interviews, and the investigator completed the whole instrument.

Ethical Considerations:

The Faculty of Nursing at Helwan University's Scientific Research Ethics Committee granted official approval for the intended study to be carried out. Before receiving verbal consent, individuals were fully informed about the study and their role and given the opportunity to withdraw from participation at any time. The ethical concerns will include disclosing the goal and nature of the study, outlining the option to withdraw at any time, and ensuring that the information is kept secret and cannot be accessed by anyone else without the participants' consent. Respect shall be shown for morals, values, culture, and beliefs.

Statistical Analysis:

The Statistical Programme for Social Sciences (SPSS), version 24, was used on a personal computer for data entry and statistical analysis. Frequency, percentage, median, range, mean, and standard deviation were employed as appropriate for descriptive statistics. To determine the relationship between the variables, Chi-square test was utilized. Correlation coefficient (r) test was utilized to determine how closely related the variables were to one another. To compare the mean score between the two investigated variables, Paired t test was performed. P value equals or less than 0.05 was regarded as significant.

RESULTS

Table 1 demonstrates the sociodemographic characteristics of the family caregivers.

Table (1): Sociodemographic characteristics of the family caregivers (n= 240)

	Variable	No.	%
Age (years)	20 - ≤25	120	50
	26 - ≤30	99	41.3
	>30	21	8.7
	Mean ± SD 23.83± 7.34	**Rang** 20-40	
Gender	- Male	85	35.5
	- Female	155	64.5
Marital status	- Single	90	37.5
	- Married	130	54.2
	- Widowed	8	3.3
	- Divorced	12	5
Educational level	- Don't read &write	25	10.4
	- Read and write	15	6.3
	- Basic education	30	12.5
	- Secondary education	120	50
	- University or more	50	20.8
Occupation	- Employed	180	75
	- Unemployed	60	25
Residence	- Urban	190	79.2
	- Rural	50	20.8
Monthly income	- Enough	90	37.5
	- Not enough	140	58.4
	- Enough and saved	10	4.1
Do you live with the patient	- Yes	130	54.2
	- No	110	45.8
Patient's relationship	- Husband/ wife	130	54.2
	- Brother/ sister	90	37.5
	- Son/daughter	20	8.3
Duration of patient care	- Less than one year	40	16.6
	- From 1 to 3 years	60	25
	- From 4 to 6 years	130	54.3
	- More than six years	10	4.1

Table 2 summarizes the results of question number 1; What is the level of Knowledge for family caregivers about lymph nodes cancer?

Table (2): Frequency distribution of the family caregiver regarding knowledge about lymph nodes cancer (n=240).

Items of knowledge	Correct		Incorrect	
	No.	%	No.	%
Meaning of lymph node cancer	80	33.4	160	66.6
Types of lymphoma	55	22.9	185	77.1
Signs & symptoms of lymph node cancer	140	58.4	100	41.6
lymphoma a hereditary disease	120	50.0	120	50.0
Causes for lymph node cancer	100	41.6	140	58.4
Diagnosis of lymph node cancer	130	54.2	110	45.8
High risk group of developing lymph node cancer	70	29.2	170	70.8
Complications of lymph node cancer	150	62.5	90	37.5
Ways to care for a patient with lymph node cancer	165	68.8	75	31.2
Methods of prevention of lymph node cancer	120	50.0	120	50.0
Treatment methods for lymph node cancer	150	62.5	90	37.5
Patient be cured from lymph node cancer after using the treatment	90	37.5	150	62.5

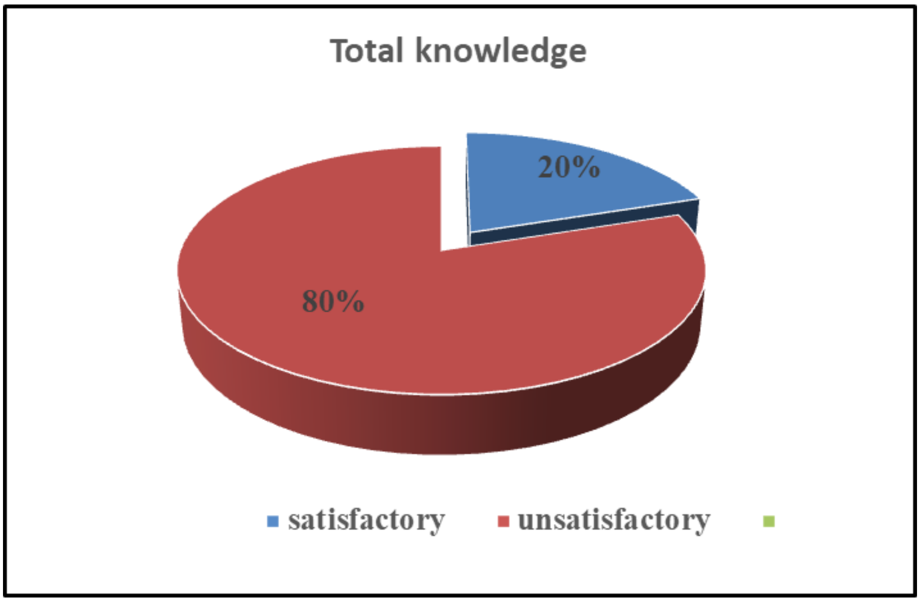

Figure 1 illustrates that 80% of study sample had unsatisfactory total knowledge about lymph nodes cancer, while 20.0% of them had satisfactory total knowledge about lymph nodes cancer.

Figure (1): Total knowledge score of study family caregivers about lymph nodes cancer (n=240).

Table 3 summarizes the results of question number 2; **Does the lymph nodes cancer patient affect the quality of life of family caregivers?**

Table (3): Frequency distribution of Quality of life for family caregivers of patients with lymph nodes cancer (n=240).

Quality of life	**Never**		**Sometimes**		**Always**	
	(1)		**(2)**		**(3)**	
	No	**%**	**No**	**%**	**No**	**%**
Physical condition and daily activity						
Discomfort	50	20.8	50	20.8	140	58.4
Energy and fatigue.	45	18.8	180	75	15	6.2
Sleep and rest	100	41.6	120	50	20	8.4
Movement and daily activity:	70	29.2	110	45.8	60	25
Personal care: -						
Good Personal hygiene	0	0.0	0	0.0	240	100
Clothing and physical appearance.	0	0.0	100	41.6	140	58.4
Food and drink						
Bowel elimination	0	0.0	80	33.4	160	66.6
	0	0.0	150	62.5	90	37.5
The psychological and emotional (mood) life						
Positive feelings	50	20.8	50	20.8	140	58.4
Negative feelings	140	58.4	50	20.8	50	20.8
Social and personal relationships:						
Personal relationships	0	0.0	100	41.6	140	58.4
Help from others	0	0.0	120	50.5	120	50
Enjoy leisure time and leisure activities	0	0.0	90	37.5	150	62.5
Quality of life in general:						
Satisfied with my overall quality of life	0	0.0	165	68.8	75	31.2
Satisfied with my general health.	0	0.0	130	54.2	110	45.8

Table 4 summarizes the quality of life of family caregivers of patients with lymph nodes cancer.

Table (4): Mean score of Quality of life for family caregivers of patients with lymph nodes cancer (n=240).

Quality of life domains	**Mean ± SD**
Physical condition and daily activity	9 ± 9.85
Personal care	3.65 ± 1.3
Psychological and emotional (mood) life	2.79± 0.65
Social and Personal Relationships	11.85 ± 2.78
Quality of life in general	6.05 ± 0.91
Total QOL mean	61.75 ± 9.16

Figure 2 illustrates that 71.8% of the family caregivers had poor quality of life while 28.2% of them had good quality of life.

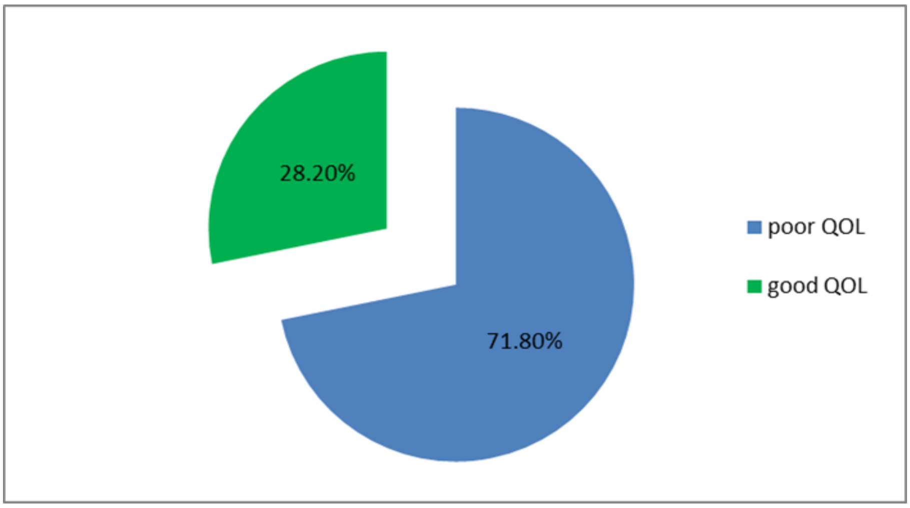

Figure (2): Total Quality of Life score for the family caregivers of patients with lymph nodes cancer (n=240).

Table 5 summarizes the results of question number 3; **Is there a relation between demographic characteristics and quality of life for family caregivers? T**here were highly statistically significant associations between total scores of Qol of family caregivers and all items of their demographic characteristics except gender at (P <0.001).

Table (5): Associations between sociodemographic characteristics of the family caregivers of patients with lymph node cancer and quality of life scores (n=240)

Demographic characteristics	**Total QOL**				**χ^2**	**P-value**
	Poor (n=172)		**Good (n=68)**			
	No.	**%**	**No.**	**%**		
Age (Years)					**19.47**	**<0.001****
20 - ≤ 25	100	58.2	20	29.4		
26 - ≤ 30	57	33.2	42	61.8		
30	15	8.6	6	8.8		
Gender					1.003	0.32
Male	75	43.6	10	14.7		
Female	97	56.4	58	85.3		
Marital status					**17.42**	**<0.001****
Single	80	46.6	10	14.7		
Married	82	47.7	48	70.7		
Divorced	4	2.3	4	5.8		
Widowed	6	3.4	6	8.8		
Educational level					**19.21**	**<0.001****
Don’t read &don’t write	15	8.7	10	14.8		
Read and write	10	5.8	5	7.3		
Basic education	15	8.7	15	22.0		
Secondary education	102	59.4	18	26.5		
University or more	30	17.4	20	29.4		
Occupation					**18.08**	**<0.001****
Employee	140	81.4	40	58.8		
Unemployed	32	18.6	28	41.2		
Residence					**15.97**	**<0.001****
Urban	150	87.3	40	58.8		
Rural	22	12.7	28	41.2		
Monthly income					**17.02**	**<0.001****
Enough	45	26.2	45	66.2		
Not enough	120	69.7	20	29.4		
Enough and saved	7	4.1	3	4.4		

(**) High statistically significant at P<0.01 (*) statistically significant at P≤0.05.

Table 6 shows that there were highly statistically significant associations between total scores of knowledge of family caregivers of patients with lymph node cancer and their demographic characteristics as age, educational level, occupation and monthly income (P <0.001).

Table (6): Associations between demographic characteristics for the family caregivers of patients with lymph node cancer and total knowledge scores (n=240).

Demographic characteristics	**Total knowledge score**				**χ^2**	**P-value**
	Satisfactory (n=48)		**Unsatisfactory (n 192)**			
	No.	**%**	**No.**	**%**		
Age (Years)						
20 - ≤ 25	20	41.7	100	52.1	**19.47**	**<0.001****
26 - ≤ 30	25	52.0	74	38.5		
30	3	6.3	18	9.4		
Gender						
Male	20	41.7	65	33.8	1.003	0.32
Female	28	58.3	127	66.2		
Marital status						
Single	15	31.3	75	39.1	**0.84**	**0.773**
Married	26	54.1	104	54.2		
Divorced	4	8.3	4	2.1		
Widow	3	6.3	9	4.6		
Educational level						
Don’t read &don’t write	10	20.8	15	7.8	**19.21**	**<0.001****
Read and write	5	10.4	10	5.3		
Basic education	5	10.4	25	13.1		
Secondary education	25	52.1	95	49.4		
University or more	3	6.3	47	24.4		
Occupation						
Employee	30	62.5	150	78.2	**19.06**	**<0.001****
Unemployed	18	37.5	42	21.8		
Residence						
Urban	30	62.5	160	83.4	**3.418**	**0.64**
Rural	18	37.5	32	16.6		
Monthly income						
Enough	20	41.7	70	36.5	**17.02**	**<0.001****
Not enough	25	52.0	115	59.8		
Enough and saved	3	6.3	7	3.7		

(**) High statistically significant at P<0.01.

Table 7 shows that there was highly statistically significant positive correlation between total knowledge scores and total QOL scores for family caregivers of patients with lymph nodes.

Table (7): Correlation between total knowledge scores and total QOL scores for family caregivers of patients with lymph nodes cancer (n=240).

Total QOL scores	**Total knowledge scores**				**χ^2**	**P-value**
	Satisfactory (n=48)		**Unsatisfactory (n=192)**			
	No	%	No	%		
Poor (n= 172)	25	52.1	147	76.6	**18.26**	**<0.001****
Good (n= 68)	23	47.9	45	23.4		
R	**0.38**					

DISCUSSION

Regarding family caregivers age, the current study showed that, more than half of them their age were between 20 - ≤25 years, the mean age were 23.83± 7.34. This result was in agreement with **Kim and Given** **(10)** in Iran who stated that more than half of caregivers the age ranged from 20 to 35 years.

Regarding family caregivers gender, the current study showed that, more than two-third of them was females. This result was supported with **Glajchen** **(11)** in New York, who conducted a study found that more than two thirds of them were females. From the investigator point of view, this result may be due to one of the Egyptian cultures is that females are responsible for caring for the patient at home, especially cancer patients, because they suffer from many psychological problems during treatment periods.

Regarding family caregivers marital status, the current study showed that, more than half of them were married. This result was in accordance with **Chen *et al.*** **(12)** in Middle East who conducted a study found that more than half of caregivers were married.

Regarding family caregivers level of education, the current study showed that, more than half of them had secondary education. This result disagrees by **Schulz and Beach** **(13)** in New York, who conducted a study found that majority of them high level of education. From the investigator point of view, this result may be due to family caregiver that lived in rural area not interested with high level of education.

Regarding family caregivers place of residence, the current study showed that, majority of them live in rural areas. This result was in agreement with **Friðriksdóttir *et al.*** **(14)** in China, who conducted a study found that majority of family caregivers live in rural area.

More than half of family caregivers have monthly incomes that are insufficient. This outcome was in line with research undertaken by **Coumoundouros *et al.*** **(15)** in Taiwan, who discovered that more than half of the participants had insufficient monthly income. According to the investigator, despite Egypt's high level of living not meeting all of its citizens' demands, particularly those of cancer patients, who have more fundamental needs,

Regarding family caregivers occupation, the majority of caregivers were employed. This result was in agreement with **Geng *et al.*** **(16)** in Turkey, who found that, the majority of caregivers were employed. According to the investigator, because of the high level of life, most family members must work to provide for their daily requirements.

Regarding family caregivers' relationship, the majority of their patient relationship was husband/wife. This result was in agreement with **Given *et al.*** **(17)** in Iran, who conducted a study found that, the majority of caregivers' patient relationship were husband/wife. From the investigator point of view, one of the Egyptian cultures is that the wife is the one who takes care of the house and the sick in house.

Regarding family caregivers' duration of patient care, more than half of them the duration of patient care were between 4 to 6 years. This result was in agreement with **Klassen *et al.*** **(18)** in Pakistan, who conducted a study found that, the more than half of family caregivers their duration of patient care between 4 and 8 years.

Regarding total score of the level of knowledge for family caregivers about lymph nodes cancer (question number 1), the current study represented that the majority of family caregivers had unsatisfactory knowledge about lymph nodes cancer. This result was supported by **Heidari *et al.*** **(19)** in Egypt who found that the majority of family caregivers had unsatisfactory knowledge about lymphoma. From the investigator point of view, theses result may be due to that all caregivers need attend any program or workshop to improve knowledge regarding lymph nodes cancer. Also, discriminating of the results might be due to more than half of the study sample secondary education.

Regarding if the lymph nodes cancer patient affect QoL of family caregivers (question number 2), more than two-third of the tested sample had low QoL, according to the current study's findings on overall QoL ratings. These findings were in line with research done in China by **Alavinejad *et al.*** **(20)**, who discovered that more than two thirds of caregivers had a low QoL. Additionally, these findings were in line with a research by **Popovi *et al.*** **(21)** that was done in Belgrade and found that three-quarters of the sample had a low QoL. According to the researcher, the majority of family caregivers struggle to control the sickness because they don't have enough information about it, which lowers their QoL.

Regarding if there is a relation between demographic characteristics and QoL for family caregivers (question number 3), there is a highly statistically significant relationship between QoL ratings of the examined sample and their age, location of residence, marital status, degree of education, and monthly income at P-value 0.001. These findings were in line with a study conducted in China by **Polis and Fernandez** **(22)** who noted a highly statistically significant relationship between the total Qol scores of the sample under study and their age, place of residence, marital status, level of education, and monthly income at (P= 0.001). According to the researcher, the family caregivers' youthful age and educational level have an impact on how their QoL might be improved.

Regarding relation between demographic characteristics, and total knowledge, the results of the current investigation revealed a highly statistically significant relationship between the sample's total knowledge scores and its age, educational attainment, and monthly income at P-value 0.001. These findings were consistent with a study by **Polis and Fernandez** **(22)** who conducted research in the USA and found a highly statistically significant relationship between the overall knowledge scores of the sample under investigation and their age, degree of education, and monthly income at P-value 0.001. From the perspective of the researcher, the family caregivers’ education level influences their awareness of the condition, and the higher their education level, the more information they have about the disease, which improves patient care.

Regarding the relationship between family caregivers overall knowledge scores and overall QOL scores regarding lymph node cancer, the current study found that there was a very significant positive connection between these two variables among the examined sample at P-value 0.001. These findings were in line with a research carried out in France by **Popović *et al.* (21)** who found a highly significant positive association between total knowledge and total QOL related lymph node cancer among the sample they were studying. From the investigator point of view, the more knowledge of family caregivers increases their QoL.

CONCLUSION

Majority of family caregivers with cancer patients had poor quality of life and unsatisfactory knowledge. Implementation of educational programe for family caregivers with cancer patients to enhance their quality of life is needed.

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