

Quality of Life for Patients with leukemia Undergoing Chemotherapy

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Abstract: Patients with leukemia undergoing chemotherapy have problems and side –effect which considered life – threatened and affect their quality of life. *The aim of this study* was to assess the the quality of life for patients with leukemia undergoing chemotherapy. *study Design:* A descriptive study. *Setting:* the study was conducted at the inpatient and outpatient clinics in Hematological Unit affiliated to Ain Shams University Hospital. *Study subjects:* A purposive sample of adult patients newly diagnosed with leukemia (No=100). *Data collection tools:* Structured interview questionnaire for the patients with leukemia undergoing chemotherapy and Quality of Life Cancer survivors Questionnaire. **Result:** The present study revealed that, the mean age of the study group was 34.28 ± 5.07 . As regards their educational level, 70% of the study group were read and write. In relation to QoL including physical dimension, the current study shows that, 50% of the study patients had poor physical QoL. In relation to QoL including psychological and emotional dimension, the current study shows that, 58% of the study patients had poor psychological QoL. In relation to QoL including social dimension, the current study shows that, 64% of the study patients had poor social QoL. In relation to QoL including spiritual dimension, the current study shows that, 60% of the study patients had poor spiritual QoL **Conclusion:** more than half of the patients in the study group have poor quality of life. **Recommendation:** Further research are recommended related to patients' quality of life to assess their improvement and prognosis and also, further researches to assess factors affecting on quality of life for patients with leukemia.

Keywords: Leukemia, Chemotherapy, Quality of life, Patients.

1. INTRODUCTION

Leukemia is a life-threatening illness that significantly affects a patient's physiological, psychological, social and spiritual well-being. Leukemia is a form of cancer that targets the blood. Blood contains different types of cells such as red blood cells, white blood cells (WBCs), and platelets. The normal life cycle of these cells (formation, growth, function and death) is controlled in part by the bone marrow. In many instances, if the control over WBCs life cycle is disturbed, leukemia is the result. The number of WBCs will be higher than other blood cells, they will stop dying normally and they will not carry out their function in the body, such as fighting infections and healing wounds (Black & Hawks, 2018)

Leukemia may be classified based on the pace of progression. The beginning of leukemia may be sudden (acute) or slow and gradual (chronic) . types of leukemia. The four main types include Acute Myelogenous Leukemia (AML), Chronic Myelogenous Leukemia (CML), Acute Lymphocytic Leukemia (ALL) and Chronic Lymphocytic Leukemia (CLL) . There are some other forms of leukemia which are normally infrequent; these are hairy cell leukemia, T-cell polymorphocytic leukemia, large granular lymphocytic leukemia and adult T-cell leukemia (Smeltzer et al., 2017).

Leukemic patients receiving chemotherapy need information about the drugs they take and the self-care they must practice in order to help prevent serious complications. "For the self-care behaviors to be effective, leukemic patients are

required to know the range of side effects they are likely to experience; they also need precise instruction on how to manage the side effects, Common side effects of chemotherapy include the fatigue or weakness, alopecia or hair loss, including loss of eyelashes, eyebrows, and body hair, nausea, vomiting, diarrhea, or constipation, poor appetite or changes in taste, numbness, tingling, and pain in the hands or feet, problems with memory or concentration, dry skin, changes in skin color, or easy bruising, weight loss or gain (Savard, Ivers & Morin, 2015).

Self-care guidelines is the essential component for patients with leukemia to cope with the illness and chemotherapy. Quality of life is defined by (Prigerson et al., 2015) as an individual's subjectively determined personal satisfaction with daily life as influenced by evaluation of physical, psychological, social and spiritual well-being. Quality of life is a multidimensional concept based on individual needs, choices and control and influenced by individual and environmental or contextual factors. Quality of life is the multidimensional evaluation by both interpersonal and social normative criteria of the personal and environmental system .

Nursing management for patients with leukemia should emphasize on comfort, minimize the adverse effects of chemotherapy, promote preservation of veins, manage complications, and provide teaching and psychological support. Nursing management for patients with leukemia, not only provides nursing care, but also focuses on providing complex care for patients such as: preparation, giving chemotherapy drugs, management of acute and chronic leukemia and psychological support for patients with leukemia. Also the nursing practice, with the nursing role in community health nursing, involves the same primary, secondary, and tertiary prevention focused on nursing care (World Health Organization, 2016).

Significance of the study:-

The incidence of leukemia is increasing and mortality rate among the affected patients increases, about 60,140 individual diagnosed with leukemia and nearly 24,400 die with this disease in United States during the year 2016. Complication of leukemia and side effect of its treatment may be frightening, painful and often embarrassing to patient with leukemia (National Cancer Institute, 2016).

High incidence of leukemic patients that admitted to the Hematology Unit affiliated to Ain Shams University Hospital was 1250 and receive chemotherapy (Ain Shams University Hospital, 2014 -2015) poor management will affect negatively on their physical, psychological, social and spiritual quality of life, (Berger, Shuster & Roenn , 2013).

2. AIM OF THE STUDY

This study aims to assess the quality of life for patients with leukemia undergoing chemotherapy to detect their needs.

Research question:

What are the quality of life domains of patients with leukemia undergoing chemotherapy?

Subjects and Methods:

Subjects and methods for this study were portrayed under four main designs as the following:

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

-Technical Design:

The technical design included research design, setting, subjects and tools of data collection.

A - Research design:

This study was conducted through using A descriptive design.

B- Research Setting:

The study will be conducted at the inpatient and outpatient clinics in Hematological Unit affiliated to Ain Shams University Hospital.

c- Subjects:

A purposive subjects of 100 patients newly diagnosed with leukemia and undergoing chemotherapy was admitted to the previously mentioned settings and selected to certain inclusion and exclusion criteria . **The sample size was calculated according to power analysis equation calculating the flow rate of patients diagnosed as leukemic patients. They were admitted to Ain Shams University Hospitals as follows:**

- Type I error (α) = 0.05
- Type II error (β) = 0.1
- With power of test 0.90 (1-B) 90%

Inclusion criteria:

- Adult patients from both sexes newly diagnosed with leukemia undergoing chemotherapy and free from other chronic diseases .
- Leukemic patients undergoing chemotherapy with different educational level , agree to participate in the study And free from mental or psychiatric disorders.

d-Tools of data Collection:

Three tools were used for data collection:

Tool I: Structured Interview Questionnaire for the leukemic patient's undergoing chemotherapy:

It will be developed by the researcher based on recent literature review (Young (2006) ; Daniels, Nicoll & John (2007); Black & Hawks (2008); Gates & Fink (2008); Canellos & Carpenito-Moyet (2010); Courneya & Friedenreich (2011); Decker & Lee (2011); Dunphy & Winland-Brown 2012); Berger, Shuster & Roenn (2013); and Bauer (2014):) .

It includes three parts as following:

Part 1: Demographic Data of the leukemic patients undergoing chemotherapy.

It include patients `age, gender, occupation, marital status, level of education...etc.

Part 2: Medical Health Profile of the leukemic patients undergoing chemotherapy(clinical data sheet) :

It will be used to collect data about medical history for patients with leukemia which include present and past history of the disease, family health history and treatment regimen.

Part 3: patients `Knowledge regarding leukemia disease and treatment:

This part divided into the following section:

A- It was concerned with assessment of patients knowledge regarding leukemia such as definition, causes and risk factor, signs and symptoms, complication of leukemia and treatment methods . It was composed of (7) multiple choice questions.

B- It was concerned with assessment of patients` knowledge regarding chemotherapy and its effect such as definition, aims , , side effects and routes of administration . It was composed of (5) multiple choice questions.

- Scoring system:

Each correct answer was graded (1) and incorrect answer was (0). The total score of patients' knowledge assessment were (15) grades: Knowledge regarding leukemia (7) grades and regarding chemotherapy description (8) grades

- Total score was considered as the following:

- $\geq 60\%$ (≥ 86 grades) was satisfactory.
- $\leq 60\%$ (≤ 86 grades) was unsatisfactory.

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Tool II: Quality of Life Cancer survivors Questionnaire: (Quality of Life Patient/Cancer Survivor Version) :

It was adapted from **Ferrell, Hassey & Grant, (2012)**. It was used to assess the QOL dimensions for patients with leukemia and undergoing chemotherapy, translation from English to Arabic was done and back translation for this tool was done to assure accuracy. The scale included (40) items as the following: physical wellbeing (8) items , psychological wellbeing (18) items , social wellbeing (8) items , spiritual wellbeing (6) items .

Scoring system

The patients response for each statement was made on a 10 point likert response scale, where 0= no problem , from1 – 3= mild problem , from 4-6 = moderate problem and from 7 – 10 = sever problem .

The score of each statement for every subgroup were summed up giving a total score for every subgroup , and then the total score for all domains were calculated. the subgroup and total domains were categorized into poor QOL , average QOL and good QOL as the following :

- Poor QOL= 0- ≤ 50%
- Average QOL = 50-≤ 75%
- Good QOL = 75% & more

II-Operational Design:

It **includes** preparatory phase, content validity and reliability, pilot study and field work.

The preparatory Phase:

This phase was carried out through developing the data collection tools after reviewing the recent related literatures in periodicals, internet research and other resources,

B. Content validity and Reliability

validity : face and content validity of the suggested tools was done through a group of 7 experts of medical surgical nursing department, Faculty of Nursing, Ain Shams University. The jury reviewed the tools for clarity, relevance, comprehensiveness, and simplicity; then based on the opinion of the jury minor modifications were carried out, and then the final forms were developed.

Reliability:

Alpha Chronbach test was used to measure the internal consistency of the 2 tools used in the current study As the following: 1 st tool: structured interview questionnaire (knowledge about leukaemia , chemotherapy) is (0.827) , 2 nd tool : quality of life is (0.825)

C. Pilot Study:

A pilot study was conducted on 10% of the study subjects (10 patients with leukemia undergoing chemotherapy) in order to test the applicability of the study tools, the clarity of the study tools, as well as estimating the average time needed to complete the tools. Accordingly, necessary modifications were made for the final development of the study tools. Some questions and items were omitted, added or rephrased and then the final forms were developed. Patients selected for the pilot study were excluded from the study subjects.

D. Field Work:

E. Data collection from patients for this study took about 7 months, started from beginning of June 2017 to end of December 2017. Data were collected three days/week. First, the researcher greeted the patients, introduced himself and explained the aim of the study. Data was collected as soon as patients felt well enough to participate and respond to the questionnaire, choice answers were recorded by the researcher.

F. Filling the tools took about 50-70 minutes distributed at the following: patient's demographic characteristics took about 5 minutes, patient's clinical data took about 5 minutes, prostate cancer knowledge took about 20 minutes and quality of life assessment took about 20 minutes.

3- Administrative Design:

An official letter was issued from the Faculty of Nursing, Ain Shams University to the directors of inpatients haematological and out patients clinics at Ain Shams University Hospitals at which the study was conducted, explaining the purpose of the study and requesting the permission for data collection from the study and control group.

Ethical Considerations:

The ethical research considerations in this study included the following:

- The research approval was obtained from the Ethical Committee in Faculty of Nursing, Ain Shams University before starting the study.
- The researcher clarified the objective and the aim of the study to the patients to obtain their cooperation. oral consent was obtained from the patients to ensure willingness to engage in the study.
- The researcher maintains anonymity of the subjects and confidentiality of the subjects' data.
- The patients were allowed to choose to participate or not and they were informed that they have the right to withdraw from the study at any time without giving any reason.
- Values, cultures and beliefs were respected.

Statistical Design:

The collected data were organized, categorized, tabulated and statistically analyzed using the Statistical Package for Social Science (SPSS) version (16.0) and (Excel 2010) to evaluate the studied subjects' changes throughout the study phases (Pre & Post), and to evaluate the differences between the groups under study as regards the various parameters. Data were presented in tables and charts. The statistical analysis includes: percentage (%), mean, standard deviation (SD), Paired T test, r-test, and P-value.

The observed differences and association were considered as follows:

- Non-significant (NS) difference was obtained at $p > 0.05$.
- Significant (S) difference was obtained at $p < 0.05$.
- Highly significant (HS) difference was obtained at $p < 0.001$.

3. RESULTS

Table 1. Shows the number and percentage distribution of socio-demographic characteristics among patients included in the study. The mean age of the study group was 34.28 ± 5.07 , Regarding gender of the study, it was found that 80.0% of the study group patients were males. As regards their job, about 70% of the study group their work was manual with non-statistically differences between them as $p > 0.05$.

Regarding to marital status of the patients under study, it was found that the percentages of the studied patients who are married were (76%). As regards their educational level, 40% of the study group was read and write.

Table (2): Reveals that, the satisfactory level of total knowledge of patients with leukemia undergoing chemotherapy in the study was 75% of the total.

Figure (1): this figure clarifies that 62% of the studied patients had poor quality of life regarding to all dimensions.

Table 3. Shows that, there were 53% of the studied patients had poor quality of life regarding to physical dimensions

Table 4: Shows that, there were 55% of the studied patients had poor quality of life regarding to psychological dimensions

Table (5): In relation to social and spiritual dimension of quality of life, table 5 shows that, 64% and 60% of the studied patients had poor quality of life respectively .

Table (1): socio-demographic characteristics of the study group. (n=100)

	Study (100)		Chi-square	
	N	%	X ²	P-value
➤ Age				
18 > - 25	22	44.0	4.52	0.21
25 > - 35	26	52.0		
35 > - 45	32	64.0		
45 ≥ - 60	20	40.0		
Male	80	80.0	1.96	0.16
Female	20	20.0		
➤ Job				
1- Manual	59	59.0	5.18	0.07
2- Office work	29	29.0		
3- No work–house wife	12	12		
➤ Marital status				
Married	78	78.0	0.06	0.81
Single / Unmarried	22	22.0		
➤ Level of education				
- Read and write	70	70.0	1.33	0.24
- Basic education	15	15.0		
- High education	15	15.0		

Table (2): percentage distribution of the study group regarding to satisfactory level of knowledge regarding leukemia and chemotherapy (n= 100)

Item					χ ²	P- Value
	Satisfactory		Un Satisfactory			
	N	%	N	%		
Leukemia	32	32%	68	68%	0.184	0.668
Chemotherapy	7	7%	93	93%	0.154	0.695
Chemotherapy side effect	9	9%	91	91%	0.122	0.727
Total	25	25%	75	75%	0.102	0.776

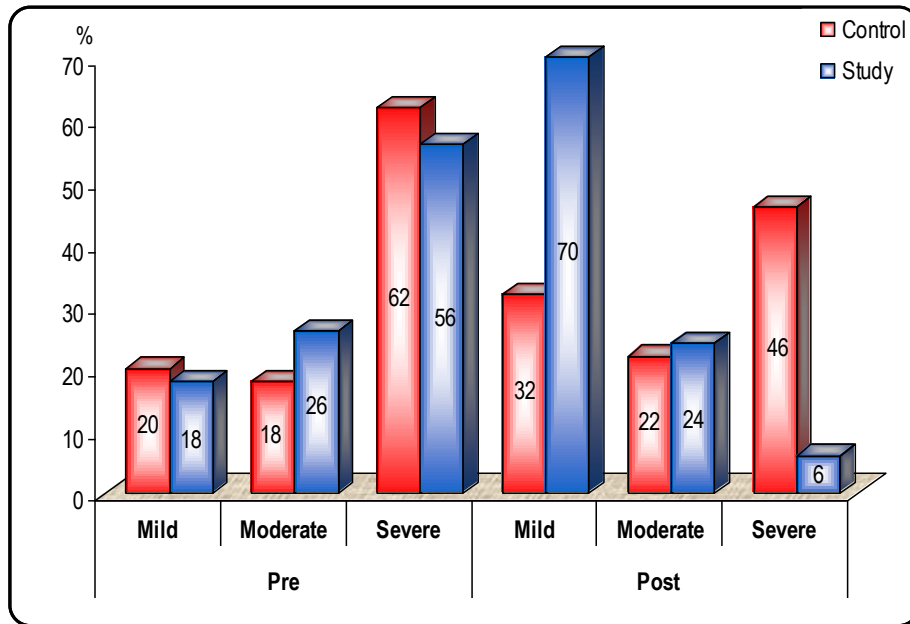


Figure (1) : percentage distribution of the study group regarding to total quality of life dimensions (physical & psychological & social and spiritual)

Table (3): percentage distribution of the study group regarding quality of life physical dimension (N=100)

	Study		Chi-square	
	N	%	X ²	P-value
Physical QOL				
Mild	25	22	2.17	0.34
Moderate	22	28		
Severe	53	50		

Table (4): percentage distribution of the study group regarding quality of life psychological dimension (N=100)

Psychological QOL				
	N	%	X ²	P-value
Mild	18	16	0.42	0.81
Moderate	27	26		
Severe	55	58		

Table (5): percentage distribution of study regarding quality of life (social dimension& spiritual) (n=100)

	Study		Chi-square	
	N	%	X ²	P-value
Social QOL				
Mild	13	16	0.74	0.69
Moderate	16	20		
Severe	68	64		
The spiritual QOL				
Mild	18	14	4.69	0.09
Moderate	18	26		
Severe	64	60		

4. DISCUSSION

Leukemic patients receiving chemotherapy need information about the drugs they take and the self-care they must practice in order to help prevent serious complications, for the self-care behaviors to be effective, leukemic patients are required to know the range of side effects they are likely to experience; they also need precise instruction on how to manage the side effects, So those patients needs self-care guidelines to improve quality of life (Redaelli , Stephens & Brandt , 2014).

Regarding the socio-demographic characteristics leukemic patients under the study , the findings of this study revealed that the mean age of the study group was (34.28±5.07), these results are in agreement with Santoyo et al ., (2016) .who studied “**The age and sex frequencies of patients with leukemia seen in two reference centers that conducted in the metropolitan area of Mexico City**” and mentioned that , the mean age in the patient with leukemia in these study was 34 years.

Also the current study showed that the majority of the patients of study group patients were males ; these results are similar to the result of Ewess (2016) , in a study titled “**effect of self-care guidelines on quality of life for patients with leukemia undergoing stem cell transplantation**” that conducted in Egypt reported that the majority of the study and control group patients were males with no statistically differences between them . this might be due to most of patients who knew their diagnosis and agreed to participate in the study were males .

Regarding marital status, the current study found that more than three quarters of the study group were married This is found by Ahmadi , Shariati, Fayazi and Latifi, (2016) , who studied “**The association between lifestyle and incidence of leukemia in adults**” and mentioned that , more than two thirds of the study subjects were married : these may be due to the studied patients age group for marriage during this age according to culture so , it require cooperation from partner for dealing with the entire condition .

As regards occupation, the present study findings revealed that more than one half of the patients in the study group their work were manual work , This finding is supported by Blair et al., (2010) in a study titled “**Occupation and Leukemia: A Population-Based Case- Control Study**” that conducted at Iowa and Minnesota that greatest portion of patients with leukemia their work required muscle effort .

Regarding educational level, the current study showed that, near two thirds of the patients of the study group patients were read and write , this results is similar to Sayyed, and Eissawy (2012) who studied “**the effect of teaching program for patients with leukemia on their Self-care**” that conducted El - Minia University and mentioned that more than half of the patient in the study were have average education .

The present study revealed that the half of the patients in the study have poor quality of life regarding physical dimension This result goes on the same line with Shahsavari, Matory, Zare, Taleghani and Kaji (2015) , who studied “**effect of self-care education on the quality of life in patients with breast cancer**” and mentioned that The intervention group had significantly greater improvements in quality of life status and self-care education caused a significant increase in the quality of life score related to physical dimension.

In relation to psychological dimensions of QOL, the result of current study shows that more than one half of the patients in the study have poor QOL regarding to psychological aspects This result goes on the same line with Novrianda and Khairina, (2015) , who studied “**the effect of educational intervention on the quality of life of acute lymphocytic leukemia who undergoing chemotherapy**” and mentioned that great changes in psychological aspect of quality of life and education is influencing on the behavior of patients and resulted in changes in knowledge, attitudes, and skills that aims to acquire and improve health.

Regarding social dimension of quality of life, the result of current study showed that more than two thirds of the patients in the study group have poor QOL . This results is supported by Rukshani, Kahandawala, Jayawardana and Gamage(2018) , who studied “**Factors associated with quality of life among cancer patients in Sri Lanka**” and mentioned that there was significant improvement of the social quality of life of the intervention group after the implementation of the education and family support, while the group who didn't receive education and was feeling alone, had poor quality of life .

Concerning to the spiritual dimension of QOL, the result of this study showed that about two thirds of the patients in the study have poor QOL regarding spiritual dimensions. This results goes in the same line with Golchin et al., (2008), who

studied “**effects of self- care program on quality of life in Patients with acute leukemia receiving chemotherapy**” and mentioned that there was significant improvement of the study group regarding QOL dimension in contrast the control group who have decrease in overall quality of life .

Regarding overall QOL dimensions, the current study showed that more than half of the patients in the study had poor QOL This result goes in the same line with **Esilbalkan, Karadakovan and Göker, (2009)** who studied “ **the effectiveness of nursing education as an intervention to decrease fatigue on turkish patients receiving Chemotherapy**” and mentioned that the educational intervention has improvement on the quality of life of the studied patients .

5. CONCLUSION

This study concluded that :

The results of this study concluded that:

More than half of the study patients have poor quality of life .

6. RECOMMENDATIONS

Based on the results of the current research, the following suggestions for future research and practice are proposed:

- * Assessment of QoL for patients with leukemia should be implemented periodically to prevent decline of patients and enhance quality of care for those patients.
- * Further researches are recommended to assess factors affecting on quality of life for patients with leukemia .
- * Replication of the current study on a larger probability sample is recommended to achieve generalization of the results and wider utilization of the self-care guidelines.

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