

Effect of Self-Care Management Program on Quality of Life among Acquired Immune Deficiency Syndrome Patients

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Abstract: **Background:** Acquired Immune Deficiency Syndrome (AIDS) is one of the chronic and progressive diseases that have complex health problems, which affect the quality of life. The aim of this study was to evaluate the effect of self-care management program on quality of life among Acquired Immune Deficiency Syndrome patients. **Research design:** Quasi-experimental research design was used in this study. **Setting:** This study was conducted at AIDS Outpatient Clinic in Fever Hospital at Benha City. **Sample:** Simple random sample of 25 % of attended AIDS patients in last year (2018-2019), the total sample was included (100) patients. **Tools:** Two tools were used. **Tool I):** A structured interviewing questionnaire which consisted of three parts a) socio-demographic characteristics, b) AIDS patients` knowledge and c) AIDS patients` self-care reported practices. **Tool II):** Scale to measure quality of life among AIDS patients. **Results;** 64% of AIDS patients were males, 39 % of them their aged 35 years or more with mean age was 41.73 ± 11.90 , 51% of patients had AIDS for 5years or more and 57% of them during symptomatic stage. 67% the studied AIDS patients had poor knowledge regarding AIDS before program compared with 11% post program. 29% of the studied AIDS patients had satisfactory self-care reported practices before program, which increased to 79% during the post program. 39% of the AIDS patients had poor total scores of quality of life preprogram, which decreased to 16% post program. There were positive statistically significant correlations between AIDS patients` total knowledge scores and AIDS patients ` total self-care reported practices scores, and AIDS patients ` total quality of life scores post program. This study concluded that: Self-care management program succeeded to improve knowledge; self-care reported practices and quality of life among AIDS patients. The study recommended that: Continuous self-care management program for AIDS patients to increase their knowledge, self-care practices and improve their quality of life.

Keywords: Acquired Immune Deficiency Syndrome Patients, Quality of life and Self-care management program.

1. INTRODUCTION

The Human Immunodeficiency Virus (HIV) infection and its associated pandemic of Acquired Immune Deficiency Syndrome (AIDS) have burdened the population with serious public health and socioeconomic challenges over the years. The disease does not only affect the patients' physical condition, but also affects the socio cultural relations, mental health, and financial aspects of life. (Rentala& Shriharsha, 2019).

Acquired Immune Deficiency Syndrome is one of the chronic and progressive diseases that have complex health problems, which affect the quality of life. This situation can inhibit normal activities in daily life that it requires comprehensive care. State that AIDS patients in the daily lives are required to be able to face complex problems, both physical, psychological, and spiritual. The complexity of the problems faced has an impact on the quality of life (Rajeev et al., 2016).

Acquired Immune Deficiency Syndrome has spread rapidly to many countries over the years and became a global health challenge. The disease continues to affect millions of people irrespective of age or sex. Estimates show that globally at the

end of 2013, 35 million (33.2–37.2 million) people were living with the infection and 1.5 million deaths were recorded due the diseases. The toll of AIDS continues to be harsh in developing countries particularly those in sub-Saharan Africa. As of 2012, 71 % of people living with HIV worldwide were in sub-Saharan Africa which also accounted for 70 % of new infections and approximately 74 % of all deaths related to AIDS. Worldwide, over 40 % of new infections are among young people 15–25years. The youth are much more prone to HIV infection as well as other sexually transmitted infections as a result of a lack of correct health information, engagement in risky behaviors, economic exploitation, regional and national conflicts and a lack of access to adequate reproductive health services. Every day 5000 young people in the world become infected with HIV, which translates into almost 2 million new infections per year (**Nubed and Akoachere, 2016**).

Human Immunodeficiency Virus is a virus that attacks the immune system, the body's natural defense system. Without a strong immune system, the body has trouble fighting off disease. Both the virus and the infection it causes are called HIV. White blood cells are an important part of the immune system. HIV invades and destroys certain white blood cells. The body can no longer defend itself against infection. Without treatment, HIV infection progresses and when advanced, AIDS can develop (**Gillespie et al., 2019**). HIV is found in semen, blood, and breast milk, vaginal and anal fluids. Most people get HIV by having unprotected vaginal or anal sex with someone who has HIV. HIV can be passed when sharing drug equipment, such as syringes, with someone who has HIV. The virus can also be passed from a mother to baby during pregnancy, birth, or breast-feeding (**Kumar et al., 2018**).

People may not have any symptoms when first infected with AIDS. May however, have a flu-like illness within a month or two after exposure to the virus. This illness may include symptoms such as fever, headache, and fatigue, enlarged lymph nodes (glands of the immune system easily felt in the neck and groin). As the immune system weakens, a variety of complications will emerge. For many people, the first signs of infection are large lymph nodes or "swollen glands" that may be enlarged for more than 3 months. Other symptoms often experienced months to years before the onset of AIDS include: Lack of energy, weight loss, frequent fevers and sweats, persistent or frequent yeast infections (oral or vaginal), persistent skin rashes or flaky skin pelvic inflammatory disease in women that does not respond to treatment, short-term memory loss, some people develop frequent and severe herpes infections that cause mouth, genital, or anal sores, or a painful nerve disease called shingles (**Sharma et al., 2016**).

The diagnosis of AIDS is based on a person with HIV contracting a disease that is listed as an "AIDS-defining" disease. For a person with an immune system that is weakened by HIV, these diseases are very serious and can be life-threatening. In addition to the impact of taking antiretroviral therapy, the progression of HIV infection depends on the immunity system and other factors, including the health and lifestyle of the person and the strength of his or her immune system (**Eticha & Gameda, 2019**).

Quality of Life (QOL) is an important component in the evaluation of the wellbeing of people living with AIDS. Farther more quality of life refers to health status when taking into consideration multiple dimensions including social, psychological, physical and functional well-being. World Health Organization (WHO) defines quality of life as individual's perceptions of the position in life in context of the culture and value systems in which living and in relation to the goals, expectations, standards and concerns. Also WHO indicates quality of life is a subjective feeling. There are many factors which affect the quality of life of patients, the identification of these factors is important in order to provide better health and social care services. Assessment of quality of life has become an important outcome measure in the management of AIDS and reflects improvement or otherwise of the health experience and satisfaction with care among patients living with AIDS (**Ferreira et al., 2018**).

Self-care management program encompasses all the activities which patients perform to control the illness, prevent future complications, and cope with the impact of both the disease and treatment on themselves and others, and includes: Collaborative goal setting, monitoring of symptoms, lifestyle behaviors such as eating a healthy diet, getting regular exercise, and smoking cessation, taking medication in the dose and frequency prescribed, communicating with the health care team, family members, and others, and ongoing problem-solving to overcome potential barriers. People with chronic conditions such as AIDS must make ongoing adaptations in the daily lives as they face the many emotional and physical challenges (**Institute for Healthcare Improvement, 2019**).

Community health Nurses (CHNs) can play an important role in preventing, reducing and management of AIDS patients. AIDS has debilitating effects on all aspects of the lives of individuals and families; ranging from physical health, as well as the psychological, economic and social aspects of life, so that the nurse should be provide counseling for AIDS patients and family about social and psychological support. Furthermore the CHNs provide management of AIDS related opportunistic infections, access to drugs, prophylaxis for opportunistic infection, hospitalization, nutritional support, and interventions. Maintaining health care is important to improve the quality of life and increase life expectancy. (Vanwingaard, 2013; Hasanah et al., 2019).

Significance of the study:

Egypt like other countries in the MENA region has been one of the low prevalence countries of AIDS among general population (below 0.1%). However most recently, alarming numbers of new infections has been recorded, putting Egypt in the fourth place in relation to number of new cases in the region, with an increasing trend of new infections among youth. 11,000 are estimated to be living with HIV, 25-30% annual increase in new cases and 76% growing trend since 2010, were reported by the end of 2016. Egypt' HIV epidemic is on the rise, at a time where many countries are able to control the spread. Incorrect information among young people, and a hindering stigma and discrimination remain key challenges, in addition to the decreased funding especially to prevention (United Nation World Campaign, 2017).

Knowledge, practices and quality of life regarding HIV/AIDS is one of the corner stones in the fight against the disease. Adequate knowledge about HIV/AIDS is a powerful means of promoting quality of life and engaging in safe practices. It sheds light on what really is considered to be important to patients, and not what the medical profile depicts. This study help AIDS patients to make judgments about areas of need and will be of assistance in planning program to address these needs with the overall aim of study.

2. THE AIM OF THE STUDY

This study aimed to evaluate the effect of self-care management program on quality of life among AIDS patients through:

- Assessing the AIDS patients` knowledge
- Assessing AIDS patients` self-care reported practices regarding AIDS.
- Assessing the AIDS patients` quality of life
- Designing and implementing self-care management program for patients regarding AIDS according to their needs.
- Evaluating the degree of improvement of AIDS patients` quality of life.

Research Hypothesis:

Self-care management program will improve knowledge, self-care reported practices and quality of life among people living with AIDS

3. SUBJECTS AND METHOD

Study Design: A quasi- experimental design was utilized in carrying out this study.

Study Setting

This study was conducted at AIDS Outpatient Clinic in Fever Hospital at Benha City.

Sample type and size:

Simple random sample was used in this study. The total numbers of AIDS patients diagnosed in the last year (2018-2019) who attending at AIDS Outpatient Clinic in Fever Hospital was 400, 25% were chosen. The total sample was included (100) patient, they were selected according to certain criteria: Diagnosed with AIDS, and their age more than 25years.

Tools of data collection:

Two tools were used for data collection

Tool I- A structured interviewing questionnaire:

An in structured interviewing questionnaire developed by the researchers based on literature review and written in a simple clear Arabic language consisted of three parts

First part: a) It was included socio-demographic characteristics (sex, age, residence, marital status, educational level, occupation and family income)

Second part: It was designed to collect data about health profile of patients: It included a) present medical history as duration of AIDS, stage of AIDS, signs & symptoms which patients complain, diseases or other problems related AIDS, and treatment of AIDS, and b) past history (pervious surgery or blood transfusion and dialysis).

Third part: Was included patients` knowledge about AIDS. This part included 10 questions related meaning of HIV, meaning of AIDS, signs & symptoms of AIDS, methods of transmission, factors increase progressing of AIDS, complication, AIDS myths, diagnosis, prevention and treatment of AIDS.

Scoring system for knowledge questions was adapted as follows:

The correct answer was scored (2), the correct and incomplete was scored (1) and the don`t known answer was scored (0). For each area of knowledge, the score of the items was summed- up and the total divided by the number of the items, giving a percent score. The total knowledge scores were considered good if the score of the total knowledge >75 %, considered average if it equals 50-75 %, and considered poor if it less than 50%.

Fourth part: Self-care reported practices of the patients regarding AIDS. This part included questions about diet (17 items), physical activity (4 items), establish good sleeping routine (8 items), treatment adherence for AIDS (8 items), and stress and anxiety management (12 items).

Diet items include: Eat a variety of foods from the five food groups: fruits, vegetables, grains, protein foods and dairy. Eat an appropriate amount of food to maintain a healthy weight. Choose saturated low-fat foods (found in animal products such as fatty meat, whole and milk. Eat snacks regularly between meals (like nuts, fruits, milk, and carrots). Include more meat in the diet, especially those that are easily digestible, such as chicken or fish. Add more healthy fats such as avocado, olive oil, nuts and nut butter to diet. Use whole milk products instead of skim. Drinking fluids between meals. Ensure from applying food safety in the kitchen by: Drink only water from a safe water source. Eat and drink pasteurized dairy products only. Cook meat and eggs well. Do not use the same cutting boards or knives for both vegetable. Wash hands often, especially after eating raw meat, raw eggs, or unwashed fruits or vegetables. Wash fruits and vegetables thoroughly before eating. Do not store leftovers for more than two days and always reheat them in a high temperature. Use a thermometer to ensure that do not eat undercooked meat .Write the date on the food and clean the refrigerator regularly.

Physical activity items include: Arrange time for exercising program, recommend about 30 minutes of walking, biking or working around the house for 5 days per week. Drink water before, during and after exercise, so as not to dry out. Eat well to provide nutrients to build muscle. Avoid exercising when feeling nauseous (feverish, vomiting, dizziness, diarrhea).

Establish good sleeping routine items include: Get enough sleep and regular sleep patterns. Do exercise to increases the tendency to sleep by increasing energy. Eat healthy and light before going to bed. Take a warm bath. Read or listen to calm and relaxing music. Prevent noise from the bedroom. Keep the bedroom organize and a comfortable temperature. Avoid caffeine alcohol after lunchtime.

Treatment adherence for AIDS items include: Follow treatment plan exactly as healthcare provider described it. Take medicine at certain times of the day, with or without certain types of food. Create a routine, add medication intake to the things that really do every day. Avoid harmful drug interactions. Set an alarm around the clock, watch, or phone at the time of taking medicine. Keep a daily log or use a calendar to keep track of the days of taking medicines. Keep a spare source in a handbag, backpacks, or at work if forget pills. See healthcare provider regularly.

Stress and anxiety management items include: Make a list of the factors that cause stress and anxiety to manage. Learn how to define the most important tasks every day to help in achieving highest priorities. Ask the doctor to make referral to a qualified counselor or mental health professional. Find a friend, relative, or member of the AIDS support group. Get

regular physical activity. Get enough sleep. Try to find positive aspects of change. Try to find stress relief activities, such as exercise or hobbies. Learn relaxation methods such as meditation, yoga, or deep breathing. Reduce the amount of caffeine and nicotine use. Eat small, healthy meals throughout the day. Join a support group, and talk about feelings with doctor, friends, family members, or other support people.

Scoring system for self-care reported practices:

Each question has 2 levels of answers: Done, and not done. These were respectively scored 1, 0. The scores of the items were summed- up and the total divided by the number of the items, giving a level score. These scores were converted into a percent score. The total of practices was considered satisfactory if the score >60 % and considered unsatisfactory if it less than 60%.

Tool (II): Scale to measure the quality of life of the patients with AIDS, adapted from (WHOQOL-HIV Group, (2002). It consisted of six domains

Domain I – Physical: Was assessed pain and discomfort, energy and fatigue, sleep and rest and symptoms of people living with AIDS

Domain II – Psychological: Was assessed positive feelings; thinking; learning; memory and concentration; self-esteem; body image and (physical) appearance; and negative feelings

Domain III- Level of independence: Was assessed mobility; activities of daily living; dependence on medication or treatments; and work capacity.

Domain IV – Social relationships: Was assessed feeling accepted by the people, personal relationships; social support; sexual activity; and social inclusion.

Domain V – Environment: Was assessed physical security and protection, home environment (housing); financial resources and access to quality health and social care; opportunities to acquire new information and skills; participation in and opportunities for recreation and leisure and physical environment (pollution/noise/ traffic/climate).

Domain VI –Spiritual and personal beliefs: Was assessed life to be meaningful, forgiveness and guilt, worries about the future, death and dying.

Scoring system: Each question has three levels of answers: Little, moderate and much. These were respectively scored 0, 1, and 2. The scores of the items were summed- up and the total divided by the number of the items, giving a mean score. These scores were converted into a percent score. The total quality of life was considered good if the score >75 %, considered average if it equals 50-75 %, and considered poor if it less than 50%.

Reliability and content validity of the tools:

Reliability of the tool was applied by the researcher for testing the internal consistency of the tool. It revealed 78% for knowledge, 80% for self-care reported practices and 64% for quality of life. All tools were reviewed by 5 expertise in community health nursing to test the content of validity. According to expert suggestions and comments modification was considered.

Ethical consideration:

Permission has been obtained orally from each patient before conducting the interview, given a brief orientation to the purpose of the study and building trust with patients. They were also reassured that all information gathered would be confidential and used only for the purpose of the study. No names were required on the forms to ensure anonymity and confidentiality. They were also informed about their right to withdraw at any time from the study without giving any reasons

Pilot study:

A pilot study was carried out on 10% (10) of the studied patients at the previously mentioned setting to test the study tools for clarity, and applicability to fill out the questionnaires. According to the results obtain from data analysis,

item didn't need for correction or modification so, the sample of the patients who participated in the pilot study was included from the main study sample.

Administrative approval

Official permission was obtained by submission of an official letter from the Faculty of Nursing to the responsible authorities of the Fever Hospital in Benha City to obtain the permission for data collection.

Self-care management program:

The current study was carried out through

1. Program assessment phase: The program was designed after extensive review of related literature, by the researchers. Based on results obtained from pre-assessment tools, it was revised and modified. Before implementation the program, the researcher visits the selected AIDS Outpatient Clinic in Fever Hospital at Benha City to explain the nature and purpose of the study, as will to discuss the plan of work to ensure their cooperation.

2. Program development phase: The program was developed based on the actual results that were obtained from pre-program assessment.

3- Implementation of the program:

An objective of the program was evaluate the effect of self-care management program on quality of life among AIDS patients

Contents of program: The content of the program was designed to meet patients' needs toward AIDS and to fit into their interest and level of understanding. Its contents were:

- Meaning of HIV, meaning of AIDS, sign and symptoms, factor increase progression of AIDS, and complication of AIDS.
- Myths, diagnosis, prevention and treatment of AIDS
- Self-care reported practices regarding AIDS
- Improving AIDS patients` quality of life

Teaching methods:

Methods used in teaching the program content included the following:

Lectures, discussion and presentation

Teaching aids:

Suitable teaching aids were specially prepared for the program application as: Handout, lab top CD, and posters.

Implementation of the program took 8 months from the start of February 2019 to the end of September 2019. The researchers were attended the previously mentioned study setting 3 days/week (Saturday, Tuesday and Thursday) from 9:00 am – 12:00 pm.; the study was conducted by the researcher for the studied sample in the selected settings at Aids Outpatient Clinic in Fever Hospital at Benha City. The researcher started the interviewing process individually, by introducing herself for the patient and explaining the aim of the study and content to establish an initial step. The program carried out in 6 sessions (2 theoretical, 4 practical). The duration of each session ranged from 30 to 45 minutes including times for discussion. Each session started by a summary about the previous session and the objectives of the new one. In addition to the outside factors such as noise and interruption, there are 8 patients refused to participate in the study replaced by other 8 patients.

Discussion, motivation and reinforcement during program sessions were used to enhance learning. Direct reinforcement in the form, a copy of the program was given as a gift for each patient to use it as future reference. At the end of each session, patients participated in a discussion to correct any misunderstanding. Also, they were informed about the time of the next session.

Fourth phase:

Evaluate self-care management program was carried out after session implementation immediately posttest.

Statistical design

The collected data were verified prior to computerized entry; statistical analysis was done by using the Statistical Package for Social Science (SPSS) version 21. Data were presented in tables by using mean, standard deviation, number, percentage distribution, and Chi- Square. Statistical significance was considered at: P- Value > 0.05 insignificant, P- Value < 0.05 significant, and P- Value < 0.001 highly significant.

4. RESULTS

Table (1): Percentage distribution of the studied AIDS patients according to their socio-demographic characteristics (n=100).

Socio-demographic characteristics	%
Sex	
Male	64.0
Female	36.0
Age/ year	
25-	27.0
35-	39.0
45	16.0
55+	18.0
Mean ±SD	41.73±11.90
Residence	
Rural	48.0
Urban	52.0
Marital status	
Single	25.0
Married	27.0
Widow	33.0
Divorced	15.0
Education	
Can't read or write	5.0
Read or write	29.0
Basic education	18.0
Secondary education	43.0
High education	5.0
Occupation	
Employed	22.0
Housewife	18.0
Private work	45.0
Retirement	5.0
Not working	10.0
Income	
Sufficient and saving	18.0
Sufficient	28.0
Insufficient	54.0

Table (1): Shows the socio- demographic characteristics of the studied AIDS patients. 64% of AIDS patients were males, 39 % of them their aged 35 years or more with mean age was 41.73±11.90, while 52% of them lived in urban areas and

33% of them were widow. Regarding to educational level, 43 % of AIDS patients were secondary education. This table also shows that, 45% of AIDS patients had private work and 54% of them had insufficient income.

Table (2): Percentage distributions of AIDS patients according to their health profile (n=100)

Health profile	%
Duration of AIDS/ years	
5-	51.0
10-	43.0
15-	6.0
Mean ±SD	9.41±2.31
Stage	
Asymptomatic	43.0
Symptomatic	57.0
*Current symptoms which suffer from	
Recurrent fever	43.0
Chronic lymph nodes, especially armpits, neck and groin	29.0
Chronic fatigue	57.0
Night sweats	48.0
Dark spots under the skin or inside the mouth, nose or eyelids	18.0
Ulcers or spots in the mouth, tongue, genitals or anus	9.0
Bumps, or rashes	20.0
Recurrent or chronic diarrhea	28.0
Rapid weight loss	27.0
Neurological problems such as difficulty concentrating, memory loss and confusion	42.0
Anxiety and depression	32.0
Treatment	
antiretroviral medications	100.0
Previous surgery or Blood transfusion	
Yes	33.0
No	67.0
Dialysis	
Yes	5.0
No	95.0
*Other diseases or problems associated with AIDS	
Tuberculosis	19.0
Respiratory infections	15.0
Bacterial and fungal infections	48.0
Hepatitis C and B	39.0
Oncology	10.0
Mental health conditions (eg depression)	0.0
Kidney or liver disease	13.0
Endocrine disorders	5.0
Sexually Transmitted Diseases (STDs)	5.0

*Responses are not mutually exclusive

Table (2): Shows that 51% of patients had AIDS for 5 years or more, 57% of them during symptomatic stage and had chronic fatigue. According to treatment of AIDS all patients used antiretroviral medications for treating AIDS. While 67% of patients didn't have previous surgery or blood transfusion, 95% of them didn't have dialysis and 48% of them had bacterial and fungal infections which associated with AIDS.

Table (3): Statistically differences between knowledge scores of studied AIDS patients pre and post program (n=100).

Items of knowledge	Pre- program %			Post- program %			x ²	p-value
	correct and Complete answer	correct and incomplete answer	Don't know	correct and Complete answer	correct and incomplete answer	Don't know		
Meaning of HIV	4.0	48.0	48.0	39.0	55.0	6.0	61.6	0.000**
Meaning of AIDS	0.0	62.0	38.0	49.0	51.0	0.0	88.0	0.000**
Symptoms of AIDS	0.0	91.0	9.0	60.0	39.0	1.0	87.2	0.000**
Transmission of AIDS	15.0	32.0	53.0	49.0	45.0	6.0	57.6	0.000**
Risk factor	0.0	37.0	63.0	42.0	57.0	1.0	106.3	0.000**
Complication	0.0	43.0	57.0	42.0	52.0	6.0	84.1	0.000**
Myths	10.0	52.0	38.0	15.0	64.0	21.0	7.14	0.028*
Diagnosis	10.0	24.0	66.0	20.0	74.0	6.0	78.8	0.000**
Prevention	5.0	47.0	48.0	64.0	35.0	1.0	97.2	0.000**
Treatment	11.0	69.0	20.0	68.0	32.0	0.0	104.9	0.000**

*Statistically significant difference $p \leq 0.05$ **Highly significant difference ≤ 0.001

Table (3): Shows that there was improving in studied AIDS patients' knowledge post program. Regarding treatment of AIDS 11% of the studied patients had complete correct answer before program compared with 68% at post program. Concerning prevention of AIDS 5% of the studied patients had complete correct answer before program which increased to 64% in the post program. In addition, the table also shows that there were highly statistically significant differences in the items related to the studied AIDS patients' knowledge

Figure (1): Percentage distribution of studied AIDS patients regarding total knowledge score pre and post program

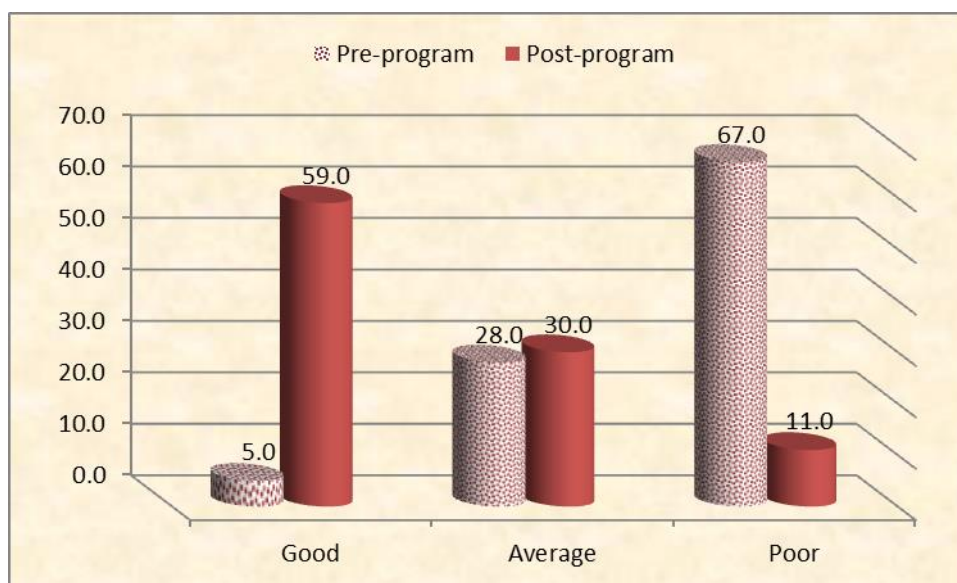


Figure (1) shows that; 67% of the studied AIDS patients had poor knowledge regarding AIDS before program compared with 11% post program implementation.

Table (4): Statistically differences between self-care reported practices of studied AIDS patients` pre and post program (n=100).

Items of practices	Before- program %		Post- program %		x ²	p-value
	Satisfactory	Unsatisfactory	Satisfactory	Unsatisfactory		
	%	%	%	%		
diet	34.0	66.0	68.0	32.0	23.1	0.000**
Activity	36.0	64.0	76.0	24.0	32.4	0.000**
Sleep	33.0	67.0	69.0	31.0	25.9	0.000**
Treatment adherence	44.0	56.0	71.0	29.0	14.9	0.000**
stress	29.0	71.0	66.0	34.0	27.4	0.000**

*Statistically significant difference $p \leq 0.05$ **Highly significant difference $p \leq 0.001$

Table (4): Shows that there was improving in the studied AIDS patients’ self-care reported practices post program. 36 % of studied AIDS patients had satisfactory self-care reported practices regarding activity before program, and then this percentage increased to 76% post program, 34% of them had satisfactory self-care reported practices regarding diet then this percentage increased to 68% during post program. Regarding treatment adherence 44% of them had satisfactory self-care reported practices compared with 71% during post program. There was a highly statistically significant difference in the items related to AIDS patients` self-care reported practices, where $p < 0.001$.

Figure (2): Percentage distribution of studied AIDS patients regarding total self-care reported practices score pre and post program

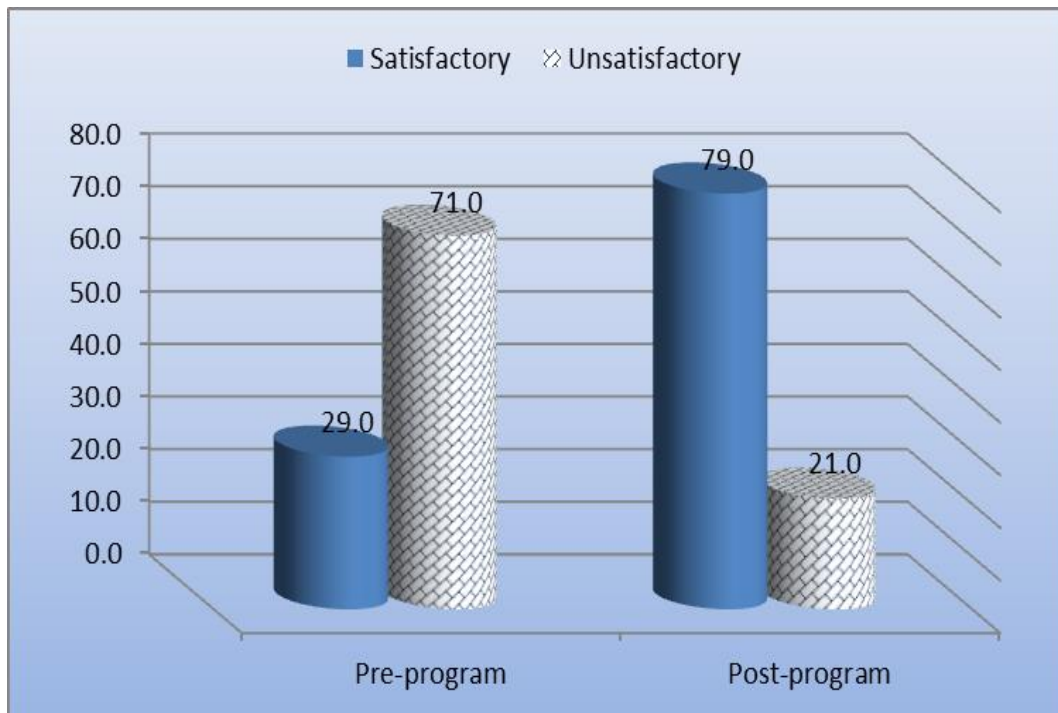


Figure (2): Reveals that 29% of the studied AIDS patients had satisfactory self-care reported practices before program, which increased to 79% during the post program.

Table (5): Statistically differences between quality of life scores of studied AIDS patients` pre and post program (n=100).

Items of knowledge	Pre- program %			Post- program %			x ²	p-value
	Much	Moderate	Little	Much	Moderate	Little		
	%	%	%	%	%	%		
Physical	9.0	57.0	34.0	27.0	45.0	28.0	10.9	0.004*
psychological	19.0	49.0	32.0	29.0	56.0	15.0	8.69	0.012*
Independence	28.0	39.0	33.0	30.0	64.0	6.0	24.8	0.000**
Social	15.0	38.0	47.0	27.0	66.0	7.0	40.5	0.000**
Environmental	14.0	39.0	47.0	14.0	68.0	18.0	20.7	0.000**
Spiritual	16.0	48.0	36.0	18.0	43.0	39.0	0.51	0.77

*Statistically significant difference $p \leq 0.05$ **Highly significant difference $p \leq 0.001$

Table(5): Illustrates that 47% of the AIDS patients had little social domain of quality of life preprogram, and then decreased to 7 % post program and 34% of them had little physical domain of quality of life preprogram, and then decreased to 28 % post program.

Table (6): Statistically differences between quality of life scores of studied AIDS patients` pre and post program (n=100).

	Pre- program		Post- program		T test	p-value
	Mean	±SD	Mean	±SD		
Physical	11.9	±2.40	10.7	±2.71	3.19	.002*
psychological	9.4	±1.74	10.6	±1.90	5.35	.000**
Independence	5.8	±1.38	6.7	±1.24	4.61	.000**
Social	6.8	±2.32	8.7	±1.53	6.52	.000**
Environmental	10.1	±2.79	11.7	±3.18	4.34	.000**
Spiritual	8.9	±1.59	8.3	±2.12	1.97	.051

*Statistically significant difference $p \leq 0.05$ **Highly significant difference $p \leq 0.001$

Table (6): Shows that there were statistically significant differences in the items related to quality of life of AIDS patients between pre and post program.

Figure (3): Percentage distribution of studied AIDS patients regarding total quality of life scores pre and post program

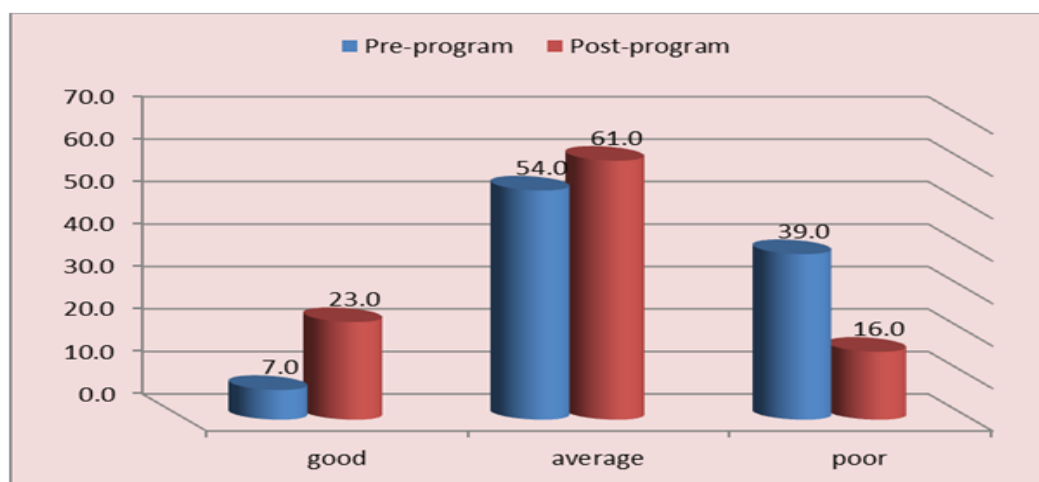


Figure (3): Reveals that 39% of the AIDS patients had poor total scores of quality of life preprogram, which decreased to 16% post program.

Table (7): Relation between total knowledge scores and socio-demographic characteristics of studied AIDS patients pre and post program

Socio-demographic characteristics	Total knowledge scores					
	Pre program			Post program		
	Poor (n=67)	Average (n=28)	Good (n=5)	Poor (n=11)	Average (n=30)	Good (n=59)
	%	%	%	%	%	%
Sex						
Male	80.6	35.7	0.0	72.7	60.0	64.4
Female	19.4	64.3	100.0	27.3	40.0	35.6
	$\chi^2=26.62$ p-value= $\leq 0.05^*$			$\chi^2=0.576$ p-value=0.75		
Age						
≤ 25 years	34.3	14.3	0.0	36.4	33.3	22.0
35-	37.3	50.0	0.0	27.3	40.0	40.7
45	14.9	17.9	20.0	18.2	13.3	16.9
55-	13.4	17.9	80.0	18.2	13.3	20.3
	$\chi^2=18.84$ p-value= $\leq 0.05^*$			$\chi^2=2.522$ p-value=0.866		
Marital status						
Single	37.3	0.0	0.0	27.3	16.7	28.8
Married	20.9	46.4	0.0	18.2	30.0	27.1
Widow	26.9	35.7	100.0	27.3	40.0	30.5
Divorced	14.9	17.9	0.0	27.3	13.3	13.6
	$\chi^2=27.03$ p-value= $\leq 0.05^*$			$\chi^2=3.524$ p-value=0.741		
Education level						
Can't read or write	6.0	3.6	0.0	9.1	0.0	6.8
Read or write	35.8	0.0	100.0	18.2	16.7	37.3
Basic education	14.9	28.6	0.0	27.3	26.7	11.9
Secondary education	43.3	50.0	0.0	36.4	50.0	40.7
High education	0.0	17.9	0.0	9.1	6.7	3.4
	$\chi^2=36.69$ p-value= $\leq 0.05^*$			$\chi^2=10.03$ p-value=0.262		
Occupation						
Employed	6.0	64.3	0.0	27.3	26.7	18.6
Housewife	11.9	17.9	100.0	9.1	10.0	23.7
Private work	59.7	17.9	0.0	27.3	53.3	44.1
Retirement	7.5	0.0	0.0	9.1	6.7	3.4
Not working	14.9	0.0	0.0	27.3	3.3	10.2
	$\chi^2=69.16$ p-value= $\leq 0.05^*$			$\chi^2=10.06$ p-value=0.26		

*Statistically significant difference $p \leq 0.05$ **Highly significant difference $p \leq 0.001$

Table (7): Shows that there was significant difference between total knowledge scores and sex, age, marital status, education and occupation preprogram

Table (8): Relation between total self-care reported practices scores and disease characteristics of studied AIDS patients pre and post program (n= 100)

Disease characteristics	Total self-care reported practices			
	Pre program		Post program	
	Unsatisfactory (n=71)	Satisfactory (n=29)	Unsatisfactory (n=21)	Satisfactory (n=79)
	%	%	%	%
Duration of disease				
5 -9	57.7	34.5	57.1	49.4
10-	39.4	51.7	38.1	44.3
15-	2.8	13.8	4.8	6.3
	x ² =7.042		p-value=<= 0.05*	
			x ² =0.413	
			p-value=0.813	
Stage of disease				
Asymptomatic	43.7	41.4	57.1	39.2
Symptomatic	56.3	58.6	42.9	60.8
	X ² =0.044		p-value=0.834	
			X ² =2.169	
			p-value= 0.141	

*Statistically significant difference $p \leq 0.05$ **Highly significant difference $p \leq 0.001$

Table (8): Shows that there was significant difference between total self-care reported practices scores and duration of disease of studied AIDS patients preprogram and there was insignificant difference between total self-care reported practices scores and stage of disease of studied AIDS patients pre and post program .

Table (9): Relation between total quality of life scores and disease characteristics of studied AIDS patients pre and post program (n= 100)

Disease characteristics	Total quality of life scores					
	Pre program			Post program		
	Poor (n=39)	Average (n=54)	Good (n=7)	Poor (n=16)	Average (n=61)	Good (n=23)
	%	%	%	%	%	%
Duration of disease						
5 -9	59.0	50.0	14.3	68.8	55.7	26.1
10-	41.0	38.9	85.7	31.3	36.1	69.6
15-	0.0	11.1	0.0	0.0	8.2	4.3
	X ² =10.67			p-value=<= 0.05*		
				X ² =10.58		
				p-value <= 0.05*		
Stage of disease						
Asymptomatic	41.0	46.3	28.6	50.0	39.3	47.8
Symptomatic	59.0	53.7	71.4	50.0	60.7	52.2
	X ² =0.89			p-value =0.639		
				X ² =0.871		
				p-value =0.647		

*Statistically significant difference $p \leq 0.05$ **Highly significant difference $p \leq 0.001$

Table (9): Shows that there was significant difference between total quality of life scores and duration of disease of studied AIDS patients' pre and post program.

Table (10): Correlation between studied AIDS patients ` total knowledge scores, total self-care reported practices scores and total quality of life scores pre and post program

Items	AIDS patients `total knowledge scores			
	Pre program		Post program	
	r	P-value	r	P-value
AIDS patients ` total self-care reported practices scores	0.394	0.000 ^c	0.261	0.011 ^c
AIDS patients ` total quality of life scores	0.302	0.002	0.237	0.020 ^c

Table (10): There were a positive statistically significant correlation between AIDS patients` total knowledge scores and AIDS patients ` total self-care reported practices scores, and AIDS patients ` total quality of life scores post program.

Table (11): Correlation between studied AIDS patients ` total self-care reported practices scores and total quality of life scores pre and post program

Items	AIDS patients ` total self-care reported practices scores			
	Pre program		Post program	
	r	P-value	r	P-value
AIDS patients ` total quality of life scores	0.508	0.000	0.551	0.000

Table (11): There was a positive statistically significant correlation between AIDS patients ` total self-care reported practices scores and AIDS patients ` total quality of life scores

5. DISCUSSION

Human Immunodeficiency Virus and AIDS is a chronic infection that affects not only the patients` physical condition, but also their social relations, mental health and financial aspects. AIDS has become a major health problem worldwide. Quality of life is used as an important outcome indicator for healthcare decision-making and intervention effects evaluation. Quality of life can be defined as a subjective multidimensional evaluation of one`s functioning and well-being in day-to-day life (Liping et al., 2015).

According to the socio-demographic characteristics of the studied AIDS patients revealed that, more than half of them were male (table 1). This finding supported by Karkashadze et al. (2016), they studied the "assessment of quality of life in people living with HIV in Georgia, (N= 201)", they reported that less than three quarter (73%) of studied people were male.

Concerning age of studied AIDS patients revealed that, more than one third of them their aged 35 years or more with mean age were 41.73±11.90, more than half of studied AIDS patients lived in urban areas and one third of them were widow (table 1). This finding in the same line with Kumar et al. (2014), they studied the "determinants of quality of life among people living with HIV/ AIDS a cross sectional study in central karnataka, India, (N= 200)", they reported that the mean age of the study subjects was 33.77 years, the majority of the participants in study were residing in rural area and less than half of them were either widowed or living single or separated/ divorced from their spouse.

Regarding to educational level of studied AIDS patients, less than half of them were had secondary education, also less than half of AIDS patients had private work, while more than half of them had insufficient income(table 1). This finding

supported with **Yeboah et al. (2017)**, they studied the "quality of life of people living with HIV/AIDS in the Ho Municipality: A cross-sectional study, Ghana (N= 158)". They reported that the majority of the participants had primary and secondary school education while more than three quarters of participants were employed in the informal sector and had insufficient income.

Also, this study results revealed that, more than half of patients had AIDS for 5 years or more (table 2). This finding disagreed with **Karkashadze et al. (2016)**, they reported that the average time period since diagnosis of HIV was four years for participants with good quality of life and two years for those with poor quality of life.

The present study revealed that more than half of studied patients during symptomatic stage (table 2). This results disagreed with **Yeboah et al. (2017)**, they found that the majority of the participants were in the asymptomatic stage of the disease (79.75%).

In addition, the present study revealed that more than half of AIDS patients suffer from chronic fatigue (table 2). This finding was in the same line with **Folasire et al. (2015)**, they studied "Quality of life of people living with HIV and AIDS attending the Antiretroviral Clinic, University College Hospital, Nigeria, (N=158)", they found that more than one quarter of participation (25.3%) had symptoms that included dry or productive cough, itchy skin, body rashes, fatigue and a white patch in the mouth.

According to treatment of AIDS all patients used antiretroviral medications for treating AIDS (table 2). This results agreed with **Ferreira et al. (2018)**, they studied "quality of life predictors for people living with HIV/AIDS in an impoverished region of Brazil", they reported that the majority of studied sample use of antiretroviral therapy.

Also, this study showed that more than two thirds of patients didn't have previous surgery or blood transfusion, most of them didn't have dialysis (table 2). This finding contradicted with **Karkashadze et al. (2016)**, they reported that more than half (57.7%) of studied sample had heterosexual contact and blood transfusion were most route of transmission of AIDS.

Concerning knowledge score of the studied AIDS patients about meaning of HIV minority of the studied patients had complete correct answer before program compared with more than one third at post program (table 3). This might be due to less than half of AIDS patients were had secondary education and didn't receive any knowledge about disease.

The current study showed that one fifth of studied AIDS patients had complete correct answer about rout of transmission of AIDS before program (table 3). This finding contradicted with **Saad et al. (2015)**, they studied "implication of HIV/AIDS knowledge on quality of life of women in Malaysia (N= 820)", they found that the majority of studied sample had better knowledge and awareness on how HIV/AIDS transmit and it's prevention.

As regards prevention of AIDS minority of the studied patients had complete correct answer before program which increased to less than two thirds in the post program (table 3). This finding contradicted with **Saad et al. (2015)**, they reported that majority of respondents are aware about methods of prevent HIV/AIDS.

Regarding treatment of AIDS minority of the studied patients had complete correct answer before program compared with more than two thirds at post program (table 3). This might be due to the doctor ordered the treatment for long period and all the studied AIDS patients take antiretroviral medications for AIDS.

The present study revealed that there was improving in studied AIDS patients' knowledge items after program phase's implementation (table 3). This might be due to the self-care management program improved AIDS patients knowledge regarding AIDS

Concerning the total knowledge score of studied patients regarding AIDS, the result of current study revealed that more than two thirds of studied AIDS patients had poor knowledge regarding AIDS before program, compared with minority of them post program (figure 1). This might be due to insufficient counseling about AIDS which provide by health team at AIDS Clinic. This finding disagreed with **Saki et al. (2016)**, they studied "a survey of knowledge, attitude, and practice of aids patients with regard to the prevention of disease transmission in Iran (N= 130)", they found that less than half of patients had moderate level of knowledge about AIDS.

According to self-care reported practices of studied AIDS patients, this study showed that more than one thirds of studied AIDS patients had satisfactory self-care reported practices regarding activity before program, and then this percentage increased to three quarters post program, more than one third of them had satisfactory self-care reported practices regarding diet then this percentage increased to more than half during post program. Regarding treatment adherence less than half of them had satisfactory self-care reported practices compared with less than three quarters during post program (table 4). This might be due to a good proportion of patients had an understanding of the fact that AIDS is an immune deficiency disease and the activity, diet and treatment these plays important role in the production and functioning of the immune system.

The present study showed that there was improving in the studied AIDS patients' self-care reported practices items post program (table 4). This might be due to the effect of self-care management program on AIDS patients self-care reported practices.

Concerning total self-care reported practices score of studied patients regarding AIDS, the present study revealed that more than one quarter of them had satisfactory self-care reported practices before program, which increased to less than three quarters during the post program (figure 2). This might be due to the AIDS patients need health program efforts should be intensified to change practices. These results agreed with **Saki et al. (2016)**, they reported less than half of the patients showed moderate practice regard to the prevention of HIV/ AIDS transmission.

As regards quality of life scores of studied AIDS patients, the present study revealed that less than half of the AIDS patients had moderate physical domain of quality of life preprogram, (Mean= 11.9000, SD= ± 2.40160) and then increased to more than half post program (Mean= 10.7300, SD= ± 2.71864), and less than half of them had moderate psychological domain of quality of life preprogram (Mean= 9.4000, SD= ± 1.74657), and then increased to more than half post program (Mean= 10.6900, SD= ± 1.90531), also more than one third of them had moderate independence, social and environmental domain of quality of life preprogram, (Mean= 5.8700, SD= ± 1.38283), (Mean= 6.8500, SD= ± 2.32412), (Mean= 10.1400, SD= ± 2.79978) respectively and then increased to more than two thirds post program (Mean= 6.7300, SD= ± 1.24604), (Mean= 8.7400, SD= ± 1.53491), (Mean= 11.7857, SD= ± 3.18906) respectively and less than half of them had moderate spiritual domain of quality of life preprogram (Mean= 8.9000, SD= ± 1.59861), and then increased to more than half post program (Mean= 8.3980, SD= ± 2.12370), also shows that there were highly statistically significant differences in the items related to quality of life of AIDS patients between pre and post program implementation (table 5). This might be due to that lowest scores for quality of life in this group may be related to cultural, educational and socioeconomic differences between gender. This finding disagreed with **Yeboah et al. (2017)**, they found that the psychological domain recorded the lowest median percentage score (68.00) and highest component score was observed in the social relationship domain (75.00). Though not statistically significant, the median scores of the overall quality of life.

Also these results of the current study contradicted with **Kumar et al. (2014)** they found that the mean scores of the domains of quality of life. Quality of life scores were high for environmental domain (Mean = 11.61, SD= 1.83) and psychological domain (Mean = 11.24, SD = 2.06) indicating higher quality of life. Social relationship domain was having least score (Mean = 8.97, SD = 3.36).

As regards total quality of life scores of studied AIDS patients, the present study revealed that more than half of AIDS patients had average total scores of quality of life preprogram, and then increased to less than two thirds post program (figure 3). This might be due to decreased physical, psychological, social and emotional support for AIDS patients that affect their quality of life. This finding disagreed with **Folasire et al. (2015)**, they reported that the mean scores of quality of life were higher in the psychological domain (74.47 ± 13.94) followed by physical domain (71.60 ± 18.39) and environmental domains (70.10 ± 11.96), but the lowest score was observed in the social domain (63.83 ± 18.84).

The present study showed that there was significant difference between total knowledge scores and sex, age, marital status, level of education and occupation preprogram (table 7), this finding in the same line with **Saad et al. (2015)**, they reported that statistically significant difference between level of knowledge and age, sex, and level of education. This might be knowledge of AIDS patients were difference from male or female and young or old people and high or low level of education.

The results of present study showed that there was a significant difference between total self-care reported practices scores and duration of disease of studied AIDS patients preprogram and there was insignificant difference between total self-care reported practices scores and stage of disease of studied AIDS patients pre and post program (table 8). This might be due to health status of AIDS patients may provide a feasible, reliable, and valid method to assess the impact of AIDS and future management interventions to improve patient outcomes.

The current study revealed that there was significant difference between total quality of life scores and duration of disease of studied AIDS patients pre and post program (table 9). This finding was consistent with **Rentala & Shriharsha (2019)**, they studied quality of life among people living with HIV/AIDS and its predictors "A cross-sectional study at India (N = 450)", they reported that significant difference was found in quality of life of AIDS patients by their clinical stage ($P < 0.001$), there showed that correlations of quality of life with duration of HIV illness was negative $r = -0.016$ ($P = 0.742$). Also this finding in the same line with **Yeboah et al. (2017)**, they found that the symptomatic patients significantly difference presented with a lower overall quality of life, lower physical quality of life, and lower general perception of health.

The present study showed that there were a positive statistically significant correlation between AIDS patients` total knowledge scores and AIDS patients` total self-care reported practices scores, AIDS patients` total quality of life scores post program (table 10). This might be due to knowledge play an important role in changing practices so that affect quality of life.

The results of the present study showed that there was a positive statistically significant correlation between AIDS patients` total self-care reported practices scores and AIDS patients` total quality of life scores (table 11). This might be due to the good practices are a powerful means of promoting quality of life

6. CONCLUSION

Based on the results of the present study and research hypothesis, the study concluded that:

The self-care management program succeeded to improve knowledge, self-care reported practices and quality of life among AIDS patients. More than two thirds of the studied AIDS patients had poor knowledge regarding AIDS before program, compared with minority of them post program, one third of the studied AIDS patients had satisfactory self-care reported practices before program, which increased to less than three quarters during the post program and more than one third of the AIDS patients had poor total scores of quality of life preprogram, which decreased to minority of them post program. There were a positive statistically significant correlation between AIDS patients` total knowledge scores and AIDS patients` total self-care reported practices scores, AIDS patients` total quality of life scores post program.

7. RECOMMENDATION

Based on a finding of the present study the following recommendations:

- Continuous self-care management program for AIDS patients to increase their knowledge, self-care practices and improve their quality of life.
- Emphasize the importance of providing support and appropriate follow up care for AIDS patients in Fever Outpatient Clinic by a specialized team in order to prevent AIDS complications.
- Further research is proposed to explore the effect of self-care management program on AIDS among large sample size.

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