

Health Related Quality of Life among Patients with Interstitial Lung Disease

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Abstract

Background: Interstitial lung diseases comprise more than 200 rare diseases, which are characterized by varying degrees of inflammations and fibrosis of the lung, and are associated with serious quality of life impairments in affected people. **Aim of study:** Was to assess health related quality of life among patients with interstitial lung disease. **Research design:** A descriptive research design was utilized to conduct this study. **Setting:** The study was conducted at the Chest Out-Patient Clinics at Benha University Hospital and Chest Hospital in Benha City. **Sample:** A convenient sample of 70 patients with confirmed diagnosis. **Tools:** Two main tools were used **I:** A structure interviewing questionnaire which included 5 parts a) socio-demographic characteristics of patients with interstitial lung disease, b) Medical history of patients. C) Home environment of patients, d) Knowledge of patients regarding interstitial lung disease and e) Reported practices of the studied patients with interstitial lung disease **II:** Quality of life scale was adopted to assess physical, psychological and social domains of quality of life. **Results:** 38.6% of patients had poor total knowledge score about interstitial lung disease. On the other hand, 52.9% of them had satisfactory total practices score toward interstitial lung disease. Regarding quality of life 52.9% of patients had low quality of life and only 7,1% of them had good quality of life. **Conclusion:** There were statistically significant relations between total knowledge, practices and quality of life score of the studied patients and their educational level. There was a statistically significant correlation between total quality of life of studied patients and their total practices. While there was highly statistically significant correlation between the studied patients' total knowledge and their total practices. **Recommendations:** Educational programs should be conducted at Out- patients Clinics to improve knowledge, practices and quality of life of patients with interstitial lung disease.

Key words: Interstitial Lung Disease, Quality of Life, Health

Introduction

Lung diseases had an enormous and growing public health impact worldwide and one of them is Interstitial Lung Diseases (ILDs). ILDs also known as diffuse parenchymal lung diseases which comprise more than 200 different noninfectious and chronic diseases that affect the alveoli, alveolar septa, respiratory bronchioles, blood vessels, lymph vessels, i.e. the pulmonary parenchyma. These disorders are caused by numerous known agents, may be idiopathic,

granulomatous or rare. The diagnosis of ILDs is based on the analysis of clinical, radiological and pathological aspects (Tawadros, 2020).

Interstitial lung diseases are a heterogeneous group of disorders with considerable variation in clinical courses and prognoses. Several studies have reported the incidence, prevalence and spectrum of subtype of ILDs. The incidence of ILD is estimated between 4.6 to 31.5 per 100,000 in developed countries (Europe and North

Health Related Quality of Life among Patients with Interstitial Lung Disease

America). The spectrum of ILD varies around the world because of different environmental factors, occupational exposure, sociocultural, economic practices, and health insurance policies (**Guo et al., 2020**).

Pulmonary fibrosis is another term of ILD and is a set of disorders extremely varied in the etiology. Disease classified into ILD of known cause or association and ILD of unknown cause (idiopathic). Identifiable or idiopathic injuries trigger an abnormal healing response resulting in triggers, pneumo-toxic drugs, occupational exposures, radiation therapy, smoking and systemic diseases (e.g., connective tissue disease). Idiopathic Pulmonary Fibrosis (IPF) is the most common type of interstitial lung diseases, it represents 65% of all patients with ILD (**Goodman et al., 2020**).

Interstitial lung diseases occur worldwide. As ILD progresses over time it is often associated with significant disease burden, and as a result, progressive dyspnea and poorer quality of life may occur. Signs of pulmonary hypertension and right heart failure may also be present. Many of the ILDs deteriorate over time despite treatment of the underlying disease process; therefore, symptom management and improving quality of life is an essential target for treatment. Symptom management in ILD has mainly focused on dyspnea and cough. However, sleep quality is also an important consideration in this population, as poor sleep quality can contribute to decreased quality of life (**Cho et al., 2019**).

Treatment of ILDs is complex and varies depending on the underlying diagnosis. Lung damage from ILDs is often irreversible and progressive, so treatment normally centers on relieving symptoms, improving quality of life and slowing the disease's

progression. Medications, such as corticosteroids, can be used to decrease inflammation in the lungs. Oxygen therapy is another common treatment because it helps deliver extra oxygen to make breathing easier and lessen complications from low blood oxygen levels, such as heart failure. Pulmonary rehabilitation also recommended for improving daily life by giving patients techniques to improve lung efficiency, improve physical endurance and offer emotional support. In the most extreme cases, patients with ILDs will be recommended for lung transplantation (**Kreuter et al., 2021**).

Health-Related Quality of Life (HRQOL) has become a major topic of research in the context of chronic illness. HRQOL is defined as a rating of the subjective state of health and quantifies the influence of the illness on daily living and well-being. Thus, HRQOL is a multifaceted phenomenon, including physical, psychological and social dimensions. Especially in the context of chronic illness, treatment does not only aim at prolonging life expectancy or reducing symptoms, but also at promoting health related quality of life (**Abd El-Aziz, 2020**).

The community health nurse has an important role in caring for patients with ILD, which include determine understanding of patients and family regarding diagnostic tests and treatment modalities. The community health nurse should be aware of the health behaviors and provide special supportive nursing care, teaching and counseling for patients to improve high –quality of life (**Mohamed, 2019**).

Significance of the study:

Interstitial lung diseases are a chronic and progressive fibrotic lung diseases

resulting in substantial morbidity and mortality. ILD include more than 200 subtypes with different etiologies and courses. As the diseases progress, patients' activities of daily living become irreversibly impaired, accompanied by a high symptom burden and significant comorbidities. Meanwhile, the prognosis of these diseases is often poor, which seriously impairs QOL in affected people due to the insidious onset, limited therapeutic methods and obvious side effects of medicines (Margaritopoulos et al., 2017). According to census record (2019) at Benha Chest Hospital attended nearby 90 cases with ILD, and at Chest Out-patient Clinic in Benha University Hospital attended nearby 60 cases.

Aim of the study

The study aimed to assess health related quality of life among patients with interstitial lung disease.

Research questions:

- What is the patients' knowledge about interstitial lung disease?
- What is the patients' reported practice toward interstitial lung disease?
- What is the health-related quality of life among patients with interstitial lung disease?
- Is there a relation between socio demographic characteristic of patient and their quality of life toward interstitial lung disease?

Subjects and method

Study Design:

A descriptive study design was utilized to fulfill the aim of the current study.

Study setting:

This study was conducted at the Chest Out-Patient Clinic in Benha University Hospital and Chest Hospital in Benha City.

Sampling:

Convenience sample was used which includes all adult patients with interstitial lung disease, it includes 70 patients who are attending to previously mentioned settings through six months with the following criteria aged from 21 to 60 years.

Tools for data collection:

Two main tools were used for data collection:

Tool (1): A structured interviewing questionnaire: It was developed by the investigator and supervisors staff, based on reviewing related literatures and it was written in simple clear Arabic language: It comprised of five parts:

Part (1): Concerned with socio-demographic characteristics of the patients involved in the study. It included 8 questions.

Part (2): Concerned with medical history of adults suffering from interstitial lung disease. It included 9 questions.

Part (3): Concerned with home environment regarding interstitial lung disease which included 11 questions.

Part (4): Concerned with patients' knowledge regarding interstitial lung disease which included 15 questions

Scoring system:

The scoring system for patient's knowledge was calculated as follow (2) score for correct and complete answer while (1) score for correct and incomplete answer and (0) for don't know answer.

The total score of knowledge = 30

Health Related Quality of Life among Patients with Interstitial Lung Disease

The total Knowledge score was considered good if the score of the total knowledge >75% (>22 points), while considered average if it equals 50-75% (15-22 points) and considered poor if it is <50% (<15points).

Part (5): Concerned with patient's reported practices regarding interstitial lung disease which included: 6 items as (Nutritional practices, Measures used to decrease dyspnea, Measures used to deal with cough, breathing exercise, Using the nebulizer, Using oxygen at home).

Scoring system:

The scoring system for patients' practices was calculated as (1) score for done and (0) for not done.

The total practices score = 44

The total practices score was considered satisfactory if the score $\geq 60\%$ (≥ 26 points) and considered unsatisfactory if it < 60% (<26 points).

Tool (2): Quality of life questionnaire for adult patients with interstitial lung disease adopted from (**Abdelrahman, 2015**) which was modified by the investigator to assess physical, emotional, and social domains of quality of life and its component.

Scoring system:

The scoring system for patients' quality of life was calculated as follows:

2= Always, while 1= Sometimes and 0= Never. These were respectively scored for positive items, and reversed for negative items.

The total quality of life score =78

The total quality of life score was considered good if the score >75% (>58

points), while considered average if it equals 50-75% (39-58 points), and considered poor if it equals < 50% (<39 points).

Tools validity:

The tools validity was done by five members of Faculty's Staff Nursing Experts from the Community Health Nursing Specialties who reviewed the tools for clarity, relevance, comprehensiveness, applicability and easiness for implementation and according to their opinion minor modification were carried out.

Reliability:

Reliability of tools was done by Cronbach Alpha test. Cronbach alpha for knowledge was 0.779, while for practice was 0.743 and for quality of life was 0.711.

Ethical consideration:

All ethical issues were assured, oral consent has been obtained from each patient before conducting the interview and given them brief orientation to the purpose of the study. They were also reassured that all information gathered would be treated confidentiality and used only for the purpose of the study. Patients had right to withdraw from the study at any time without giving any reasons.

Pilot study

The pilot study was carried out on 7 patients who represented 10% of the sample size. The pilot study was made to assess the tool clarity, applicability and time needed to fill each sheet, completing the sheet consumed about 30-45 minutes. No modification was done, so the pilot study sample was included to the total sample.

Field work:

The actual field work was carried out over about 6 months from the beginning of June 2021 to the end of November 2021. The investigator visited the Chest Out-Patient

Clinic in Benha University Hospital from 9 am to 12 pm, two days per week (Sundays and Thursdays) while visited the Out-Patient Clinic in Chest hospital from 9 am to 12 pm, two days per week (Saturdays-Tuesdays) to collect data from Patients with interstitial lung disease to assess their knowledge, practices, home environment and provide them with instructional guideline about interstitial lung disease to help to improve quality of life. The average time needed for the sheet was around 30-45 minutes, the average number interviewed at the Out-Patient Clinics were 1-2 patients/day depending on their responses of the interviewers.

Statistical analysis:

All data collected were organized, tabulated and analyzed by using the Statistical Package for Social Science (SPSS) version 20, which was used frequencies and percentages for qualitative descriptive data and X^2 was used for relation tests, mean and standard deviation was used for quantitative data, spearman correlation test (r) was used for correlation analysis and degree of significance was identified. The observation of associations was considered as the following: Highly significant (HS) $P < 0.001$, significant (s) $P < 0.05$ and not significant (NS) $P > 0.05$.

Results:

Table (1): Shows that, 51.4 % of studied patients aged from 40 < 50 years old with mean age 49.51 ± 5.94 years, 80% of them were male and married and 51.4% of them didn't have enough monthly income. Regarding educational level, 41.4% of the

patients had secondary education, 81.4 % of them were living in rural area, and 44.3% of them were employee.

Table (2): Describes that, 35.7% of studied patients exposed to harmful substances, 52.9% of them had onset of the disease from 1-3 years and 84.3% of them the disease was diagnosed by presence of some signs and symptoms. While 71.4% of them had dyspnea, 61.4% of them visit physician or hospital when symptoms appear, 52.9% of them had previous hospitalization. This table also showed that 52.9% of them had family history of respiratory diseases as 64.9% of them had bronchial asthma.

Figure (1): Clears that 38.6% of studied patients had poor knowledge score about interstitial lung disease, 37.1% of them had average knowledge score, and few of them 24.3% had good knowledge score about interstitial lung disease.

Figure (2): Shows that 52.9% of studied patients had satisfactory level of practices and 47.1% of them had unsatisfactory level of practices about interstitial lung disease.

Figure (3): Describes that 52.9% of studied patients had low quality of life, 40% of them had moderate quality of life and few of them 7.1% had good quality of life.

Table (3): Shows that there was a statistically significant correlation between total quality of life of studied patients and their total practices (p- value < 0.05), and there was highly statistically significant correlation between the studied patients' total knowledge and their total practices (p- value < 0.001).

Health Related Quality of Life among Patients with Interstitial Lung Disease

Table (1): Frequency distribution of studied patients regarding demographic characteristics (n=70).

Demographic Characteristics	No	%
Age		
20 < 30	2	2.9
30 < 40	6	8.6
40 < 50	36	51.4
≥ 50	26	37.1
Mean ±SD	49.51 ± 5.94	
Gender		
Male	56	80.0
Female	14	20.0
Level of education		
Can't read and write	6	8.6
Basic education	22	31.4
Secondary education	29	41.4
University education	13	18.6
Marital status		
Single	12	17.1
Married	56	80.0
Divorced	1	1.4
Widow	1	1.4
Monthly income		
Enough	34	48.6
Not enough	36	51.4
Residence		
Urban	13	18.6
Rural	57	81.4
Occupation		
Employee	31	44.3
Manual Work	27	38.6
House Wife	5	7.1
Retirement	7	10.0

Table (2): Frequency distribution of studied patients regarding to their medical history (n=70)

Medical history	No	%
Exposure to harmful substance	25	35.7
Onset of the disease		
Less than 1 year	17	24.3
1-3 years	37	52.9
4-6 years	8	11.4
More than 6 years	8	11.4
Method of diagnosis		
Accidently while going to doctor	10	14.3
Presence of some signs and symptoms	59	84.3
During health check up	1	1.4
Symptoms		
Dyspnea	50	71.4
Dry cough	37	52.9
Fatigue most of the time	26	37.1
Chest pain	23	32.9
Cyanosis	15	21.4
Action taken when symptoms appeared		
Visit physician or hospital	43	61.4
Tried to relieve symptoms using popular recipes	27	38.6
Previous hospitalization due to disease	37	52.9
Period of hospitalization		
Less than 3 times	29	78.4
From 5-10 times	8	21.6
Other respiratory diseases	18	25.7
Type of respiratory diseases		
Pulmonary tuberculosis	2	11.1
Pneumonia	1	5.6
Bronchial asthma	15	83.3
Family history of respiratory diseases	37	52.9
Type of respiratory family history diseases		
Pulmonary tuberculosis	4	10.8
COPD	9	24.3
Bronchial asthma	24	64.9

Health Related Quality of Life among Patients with Interstitial Lung Disease

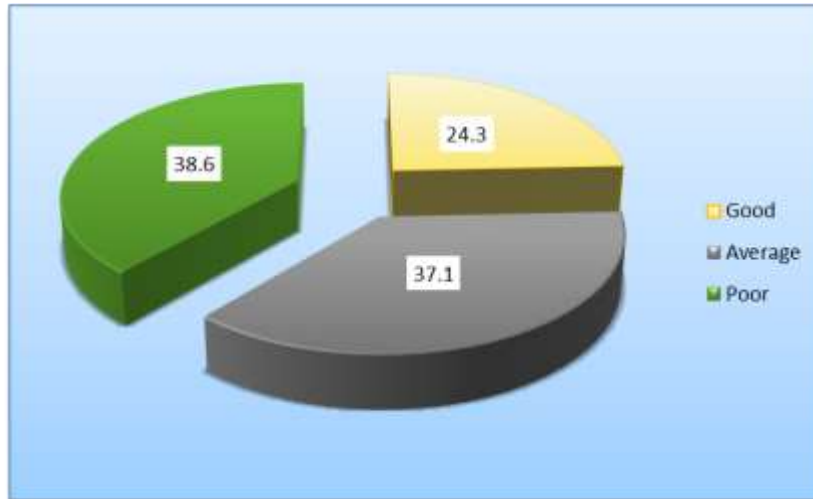


Figure (1): Percentage distribution of studied patients regarding to their total knowledge level about interstitial lung disease (n=70)

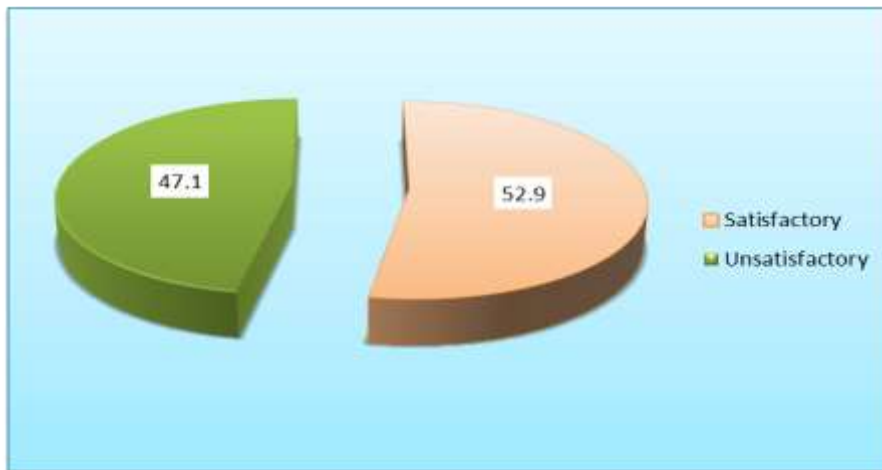


Figure (2): Percentage distribution of studied patients regarding to their total practices level about interstitial lung disease (n=70).

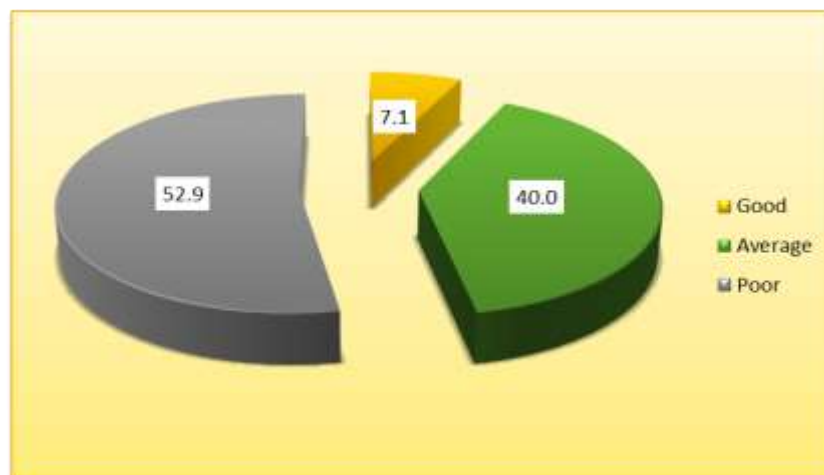


Figure (3): Percentage distribution of studied patients regarding to their total quality of life level about interstitial lung disease (n=70).

Table (3): Correlation between total knowledge, practices and quality of life among studied patient with interstitial lung disease

Items		Total knowledge	Total practices	Total quality of life
Total knowledge	r	1	.432	.170
	p-value		.000**	.159
	n	70	70	70
Total practices	r	.432	1	.249
	p-value	.000**		.038*
	n	70	70	70
Total quality of life	r	.170	.249	1
	p-value	.159	.038*	
	n	70	70	70

Discussion:

Interstitial lung diseases comprise more than 200 rare diseases, which are characterized by varying degrees of inflammation, fibrosis of the lung, and are associated with serious quality of life impairments in affected people. QOL is an increasingly important end point in interstitial lung diseases amongst patients, clinicians, and researchers alike (Maqhuzu et al., 2020).

According to the socio-demographic characteristics of the studied patients, the current study showed that more than half of the studied patient aged from 40 < 50 years old with mean age 49.51 ± 5.94 years, the most of them were male, married and more

than half of them didn't have enough monthly income. Also, the present study showed that less than half of the patients had secondary education, the most of them were living in rural area and less than half of them were employee.

As regarding medical data of the studied patients, the present study showed that, more than one third of the studied patients exposed to harmful substances, more than half of them had onset of the disease from 1-3 years and the most of them disease diagnosed by presence of some signs and symptoms. While more than two thirds of them had dyspnea, less than two thirds of them visit physician or hospital when symptoms appear, more than half of them had previous hospitalization. Concerning other respiratory diseases, the current study showed that one quarter of them had other respiratory diseases and more than half of them had family history of respiratory diseases as bronchial asthma.

These results in accordance with Abramson et al., (2020), who studied "Occupational and environmental risk factors for idiopathic pulmonary fibrosis in Australia: case-control study" and mentioned that the most common symptom of the patient with pulmonary fibrosis were dyspnea, cyanosis, and cough and more than one third (36%) of the studied patients exposed to harmful substances.

Also these results supported by **Ishak et al., (2021)**, who studied " Environmental hazards and demographic and clinical data of childhood interstitial lung diseases in a tertiary institute in Egypt" and mentioned that slightly less than two third of the studied sample expose to passive cigarette smoking (65%), less than half expose to birds especially pigeons (45%). Less than one third exposure to industrial wastes (30%). In addition these result confirmed with **(Wapenaar-de Korver, 2019)**, who studied " Patient-reported and patient-recorded outcomes in interstitial lung diseases and pulmonary hypertension" and reported that less than two thirds (64%) of the studied sample started disease from 1-3 years and more than half of them (55%) had previous history of hospitalization related the disease.

More over this study agreed with **Dowman et al., (2017)**, who studied " The evidence of benefits of exercise training in interstitial lung disease: a randomized controlled trial" and reported that Dyspnea, cough, fatigue, functional limitation, and low quality of life (QOL) are manifestations of (83%) all interstitial lung diseases. The same was reported by **Dutta, (2019)**, who studied "objective assessment of severity of cough and gastro-esophageal reflux disease in patients with idiopathic pulmonary fibrosis and efficacy of pulsed cyclophosphamide and methylprednisolone therapy in patients with progressive interstitial lung disease" and stated that more than two fifths (43%) of the studied sample suffering from hypertension and the most of them suffering from asthma.

Regarding total knowledge of the studied patient, the current study showed that less than two fifth of the studied patients had poor knowledge score about interstitial lung disease, more than one third of them had

average knowledge score and less than one quarter of them had good knowledge score about interstitial lung disease. These results may be due limited health educational program about interstitial lung disease.

These results in the same line with **Morisset et al., (2016)**, who studied "The unmet educational needs of patients with interstitial lung disease. Setting the stage for tailored pulmonary rehabilitation" and reported that less than two fifth (39%) of the studied patients had poor knowledge regarding interstitial lung disease. But these results inconsistent with **Van Manen Et Al., (2017)**, who studied " What patients with pulmonary fibrosis and their partners think: a live, educative survey in the Netherlands and Germany" and stated that the all patients (100%) experienced misunderstanding, because people do not know what pulmonary fibrosis is.

Concerning the total practices, the current study showed that more than half of the studied patients had satisfactory level of practices while less than half of them had unsatisfactory level of practices regarding to their total practices. This result may be related to the most of the studied patient had the disease from more than 3 years, so they may be earning many skills and health practices. This result may be due to the most of the studied patients had low educational level and the most of them live in rural area where the health services are limited.

These results agreed with **Blackstock & Evans, (2019)**, who studied "Rehabilitation in lung diseases: 'education 'component of pulmonary rehabilitation" and reported that more than half of the studied patients had good self-care practices. But this result disagreed with **Ignacio et al., (2019)**, who studied "Pulmonary rehabilitation in

patients with interstitial lung disease" and mentioned that the most (82%) of the studied patients had incompetent practices regarding interstitial lung disease.

Regarding studied patients' total quality of life, the present study showed that more than half of the studied patients had poor quality of life, less than half of them had moderate quality of life and the minority of them had good quality of life. These results may be related to that the studied patient needs educational intervention to improve their knowledge and practices.

These results agreed with **Szentes et al., (2018)**, who studied " Quality of life assessment in interstitial lung diseases: a comparison of the disease-specific K-BILD with the generic EQ-5D-5L" and reported that three quarters (75%) of the studied patients with interstitial lung diseases have impaired health related quality of life. Also these results agreed with **Yount et al., (2016)**, who studied "Health-related quality of life in patients with idiopathic pulmonary fibrosis" and reported that patients with idiopathic pulmonary fibrosis had an impaired HRQOL.

Concerning the correlation between total knowledge, practices and quality of life among studied patient with interstitial lung disease, the present study showed that there is a statistically significant correlation between total quality of life of studied patients and their total practices (p- value < 0.05). While there is highly statistically significant correlation between the patients' total knowledge and their total practices (p- value < 0.001). These results may be related to that the good patients' knowledge and practices had good impact on the patients'

behavior so the quality of the life will improve.

These result agreed with **Scallan et al., (2020)**, who studied "RQ-LIFE-ILD-A Novel and Simple Tool to assess patient and physician perceptions of quality of life in idiopathic pulmonary fibrosis" and reported that there was statistical significance correlation between patients quality of life and the patients knowledge and practices. Also these results supported by **Bárczi et al., (2017)**, who studied "Quality of life of idiopathic pulmonary fibrosis patients" and reported that there were a positive correlation between the patients knowledge and quality of life.

Conclusion:

Less than two fifths of the studied patients had poor knowledge about interstitial lung disease, more than half of them had satisfactory total practices toward interstitial lung disease and more than half of the studied patients had low quality of life. The results concluded also that there were statistically significant relations between total knowledge, practices and quality of life score of the studied patients and their educational level. Also, there was a statistically significant correlation between total quality of life of the studied patients and their total practices. While there was highly statistically significant correlation between the studied patients' total knowledge and their total practices.

Recommendations:

- Educational program should be conducted at Out-patient Clinics to improve knowledge, practices and quality of patients with interstitial lung disease.

Health Related Quality of Life among Patients with Interstitial Lung Disease

- A colored illustrated booklet should be available and distributed to each patient with interstitial lung diseases about disease and health related behaviors to improve quality of life.
- Periodic scientific meetings among physicians, nurses and family should be conducted to discuss patients' problems and meet patients' needs.
- Further studies needed to be focusing on improving quality of life of patients with interstitial lung disease.

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جودة الحياة المتعلقة بالصحة بين المرضى المصابين بمرض الرئة الخلالي

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مرض الرئة الخلالي ليس مرضاً منفرداً ولكنه يشمل مجموعة من الاضطرابات التي تؤثر بشكل أساسي على النسيج الخلالي الرئوي. يعتبر تليف الرئة مصطلح اخر لمرض الرئة الخلالي. يمكن أن يحدث هذا المرض بشكل ثانوي لأسباب محددة أو قد يتم تصنيفه على أنه التهاب رئوي خلالي مجهول السبب ، تشترك هذه الاضطرابات في سمات متشابهة بما في ذلك السعال الجاف وضيق التنفس. تهدف هذه الدراسة الى تقييم جودة الحياة الصحية بين المرضى المصابين بمرض الرئة الخلالي. أجريت الدراسة في عيادات الصدر الخارجية بمستشفى بنها الجامعي ومستشفى الصدر بمدينة بنها. تم استخدام عينة مائة لخمسة لجميع المرضى البالغين الذين حضروا الى المستشفيات السابق ذكرها وتضمنت ٧٠ مريضاً. كشفت النتائج ان يوجد علاقة ذات دلالة إحصائية بين معلومات وممارسات و جودة حياة المرضى ومستواهم التعليمي بينما لا يوجد علاقات ذات دلالة إحصائية بين معلومات وممارسات وجودة حياة المرضى و اعمارهم وحالتهم الاجتماعية والدخل الشهري لهم ومكان اقامتهم. يوجد علاقة ذات دلالة إحصائية بين معلومات المرضى وبداية ظهور المرض. كما يوجد علاقة بين ممارسات المرضى والتعرض للمواد الضارة وطرق التشخيص وعلاقة اخرى بين جودة حياة المرضى ووجود مشاكل صحية أخرى. يوجد علاقة ذات دلالة إحصائية بين جودة حياة المرضى وممارساتهم تجاه مرض الرئة الخلالي. بينما يوجد علاقة ذات دلالة إحصائية عالية بين معلومات المرضى وممارساتهم تجاه مرض الرئة الخلالي. كما اوصت الدراسة بعمل برامج للتثقيف الصحى في العيادات الخارجية لتحسين معلومات وممارسات وجودة حياة المرضى الذين يعانون من مرض الرئة الخلالي.