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Interstitial lung disease Saudi patients; what about their health-related quality of life in 2024

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ABSTRACT
Background: More than 200 rare diseases are classified as interstitial lung diseases. These conditions are distinguished by different levels of lung inflammation and fibrosis, and they are linked to significant reductions in the quality of life for those who are afflicted.
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 Taif University Hospital, Saudi Arabia.
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 ofthe 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 qualityof lifescoreof 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 Clinicsto improve knowledge, practices and quality of life of patients with interstitial lung disease.

Keywords: Interstitial Lung Disease, Health related Quality of Life.

INTRODUCTION

Interstitial lung diseases (ILDs) are one of the lung illnesses that have a significant and expanding global public health effect. ILDs, often referred to as diffuse parenchymal lung disorders, are a group of more than 200 chronic, noninfectious diseases that impact the pulmonary parenchyma, including the alveoli, alveolar septa, respiratory bronchioles, blood vessels, and lymph vessels. These conditions, which might be idiopathic, granulomatous, or uncommon, are brought on by a variety of recognized causes. ILDs are diagnosed by analyzing clinical, radiological, and pathological features (Tawadros, 2020).

The clinical histories and prognoses of the diverse group of conditions known as interstitial lung diseases vary greatly. The incidence, prevalence, and range of ILD subtypes have been documented in a number of investigations. In industrialized nations (North America and Europe), the incidence of ILD is estimated to be between 4.6 and 31.5 cases per 100,000. Due to various environmental influences, occupational exposure, social norms, economic practices, and health insurance regulations, the spectrum of ILD differs globally (Guo et al., 2020).

Another name for ILD is pulmonary fibrosis, which is a group of conditions with a very diverse origin. ILD of unknown origin (idiopathic) and ILD of known cause or association are the two categories of disease. Idiopathic or identifiable injuries set off an aberrant healing response that can lead to systemic disorders (such connective tissue disease), occupational exposures, radiation therapy, smoking, triggers, and pneumotoxic medications. The most prevalent form of interstitial lung disease, idiopathic pulmonary fibrosis (IPF), accounts for 65% of all ILD patients (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. Manyofthe 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 andvaries depending on the underlying diagnosis. Lung damage from ILDs is often irreversible and progressive, so treatment normallycenters on relieving symptoms, improving qualityoflifeandslowingthedisease'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 rolein caringforpatients 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' activitiesof 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).

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 andtheir 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 Taif university, Saudi Arabia.

Sampling
Convenience sample was used which includes all adult patients with interstitial lung disease, it includes 70 patients who are attending to previously mentioned setting 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 waswritten 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
The total Knowledge score was considered good if the score of the total knowledge >75% (>22 points), while consideredaverageifitequals50-75%(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,Measuresused todecreasedyspnea, Measures used to deal with cough, breathing exercise, Using the nebulizer, Using oxygenat 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 ≥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.
Thetotal qualityof lifescore =78
The total quality of life score was consideredgoodifthescore>75%(>58 points), while considered average if it equals 50-75%(39-58points),andconsideredpoorif it equals < 50% (<39 points).

Tools validity
The tools validity was done by five Experts who reviewed the tools for clarity, relevance, comprehensiveness, applicability and easiness for implementation andaccording 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 sheetconsumed about 30-45 minutes. No modification was done, so the pilot study sample was included to the total sample.

Fieldwork
The actual field work was carried out over about 6 months from the beginning of January to June 2024. The investigatorvisitedtheChestOut-Patient Clinic to collectdatafromPatients withinterstitiallung 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- 2patients/daydependingontheirresponsesof the interviewers.

Statistical analysis
All data collected were organized, tabulatedandanalyzedbyusingtheStatistical Package for Social Science (SPSS) version21, 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, spearmean correlation test (r) was used for correlation analysis and degree of significance was identified. The observationof 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%ofthe patients had secondary education and 44.3% of them were employee.

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
Levelof education		
Can’treadandwrite	6	8.6
Basic education	22	31.4
Secondaryeducation	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
Monthlyincome		
Enough	34	48.6
Not enough	36	51.4
Occupation		
Employee	31	44.3
ManualWork	27	38.6
HouseWife	5	7.1
Retirement	7	10.0

Table 2: Describes that, 35.7% of studied patients exposed to harmful substances, 52.9% of them had onset of the disease from 1-3years 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 hospitalwhen 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.

Medical history	No	%
Exposure to harmful substance	**25**	**35.7**
Onset of the disease		
Lessthan 1year	17	24.3
1-3 years	37	52.9
4-6 years	8	11.4
Morethan 6years	8	11.4
Method of diagnosis		
Accidentlywhilegoingto doctor	10	14.3
Presenceofsomesigns andsymptoms	59	84.3
Duringhealthcheckup	1	1.4
Symptoms		
Dyspnea	50	71.4
Drycough	37	52.9
Fatiguemostofthetime	26	37.1
Chestpain	23	32.9
Cyanosis	15	21.4
Action taken when symptoms appeared		
Visitphysicianorhospital	43	61.4
Triedtorelieve symptoms usingpopular recipes	27	38.6
Previous hospitalization due to disease	37	52.9
Period of hospitalization		
Lessthan 3times	29	78.4
From5-10 times	8	21.6
Other respiratory diseases	18	25.7
Type of respiratory diseases		
Pulmonarytuberculosis	2	11.1
Pneumonia	1	5.6
Bronchialasthma	15	83.3
Family history of respiratory diseases	37	52.9
Type of respiratory family history diseases		
Pulmonarytuberculosis	4	10.8
COPD	9	24.3
Bronchialasthma	24	64.9

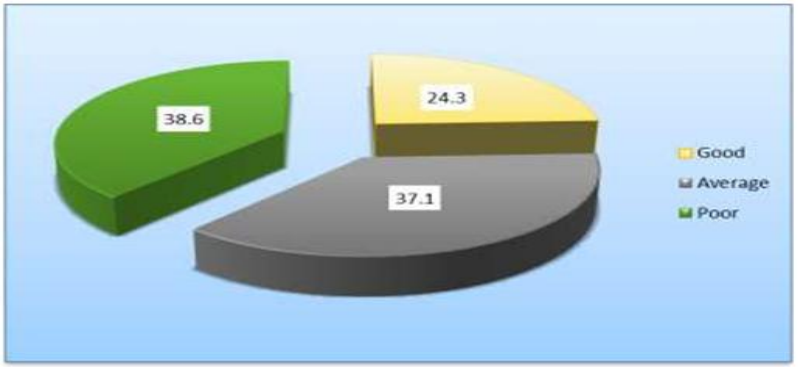

Figure 1: Clears that 38.6% of studied patients had poor knowledge score about interstitial lung disease, 37.1%

of them had average knowledge score, and few of them 24.3% had good knowledge score about interstitial lung disease.

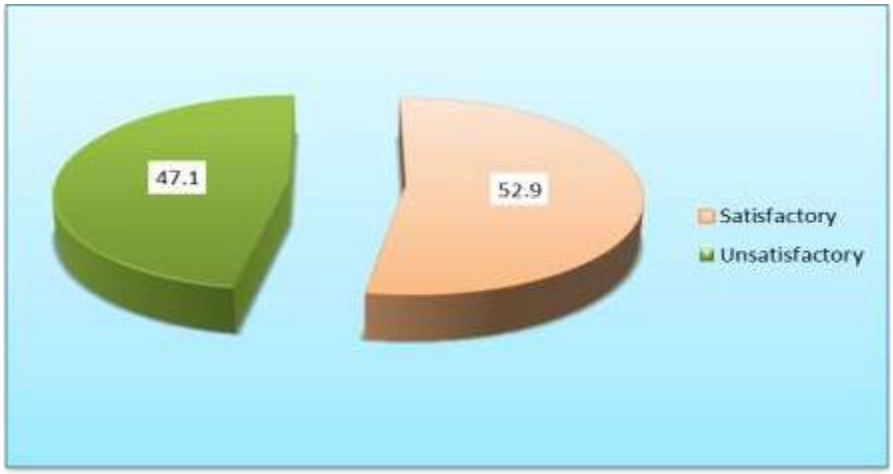

Figure 2: Shows that 52.9% of studied patients had satisfactory level of practices and 47.1% of them had unsatisfactory level of practices about interstitial lung disease.

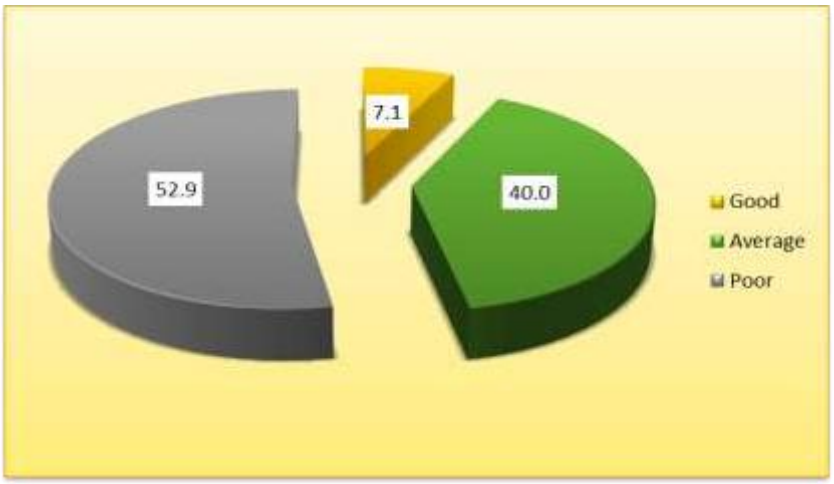

Figure 3: Describes that 52.9% of studied patients had low quality of life, 40% of them had moderate quality of life and few of them 7.1% had good quality of life.

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 statisticallysignificant correlation between the studied patients' total knowledge and their total practices (p- value < 0.001).

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

DISCUSSION

More than 200 rare diseases are classified as interstitial lung diseases. These conditions are distinguished by different levels of lung fibrosis and inflammation, and they are linked to significant reductions in the quality of

life for those who are afflicted. For patients, physicians, and researchers alike, quality of life (QOL) is becoming a more significant outcome in interstitial lung disorders (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 enoughmonthly income.Also, the present study showed that less than half of the patients had secondary education, and less than half of them were employee.

Asregardingmedicaldataofthestudied 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 themhad 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 mentioned that the most common symptom of thepatient with pulmonary fibrosis weredyspnea, cyanosis, and cough and more than one third (36%) of the studied patients exposed to harmful substances.

Also these results supported by Ishaket al., (2021), who mentionedthat slightly less than two third of the studied sample expose to passive cigarette smoking (65%), less than half expose to birds especiallypigeons(45%). Lessthanonethird exposure to industrial wastes (30%). In addition these result confirmed with (Wapenaar-deKorver,2019),whoreported 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 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 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 studyshowed that less than two fifth of the studied patients had poor knowledge score about interstitial lung disease,morethanonethirdofthemhad 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 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 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 berelated 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 reported that more than half of the studied patients had good self-care practices. But this result disagreed with Ignacio et al., (2019), whomentioned that the most (82%) of the studied patients had incompetent practices regarding interstitial lung disease.

Regardingstudiedpatients'totalquality 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 etal., (2018), who reportedthat 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 reported that patients with idiopathic pulmonary fibrosis had animpaired HRQOL.

Concerning the correlation between total knowledge, practices and quality of life among studied patient with interstitial lung disease, the present study showed that thereis 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 practiceshadgoodimpactonthepatients' behaviorsothequalityofthelifewill improve.

These result agreed with Scallan et al., (2020), whoreported that there was statistical significance correlation betweenpatients quality of life and the patients knowledge and practices. Also these results supported by Bárczi et al., (2017), reported that therewere apositivecorrelation between the patients knowledge and quality of life.

CONCLUSION

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