Illness perceptions and quality of life among tuberculosis patients in Gezira, Sudan.

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Abstract

Aims: This study aimed to answer the following research question: What is the level of illness perceptions and quality of life among TB patients in Gezira state?.

Methods: A descriptive study design was used. Newly diagnosed smear positive TB patients registered in Gezira state in 2010 (n=425) formed the study population. The illness perceptions were measured by using Brief Illness Perceptions Questionnaire (BIPQ). Health Related Quality of Life (HRQoL) was assessed by means of the 12-item short form Health Survey questionnaire (FS-12).

Results: TB patients saw TB as having minor consequences, TB not being very well controlled by treatment, and TB as lasting long as a disease; they also associated several symptoms with TB. Furthermore, the patients had relatively poor physical and mental quality of life. Identity, consequences, personal control and emotional representations were associated with poor physical quality of life while concern about illness was associated with poor mental quality of life.

Conclusion: The illness perceptions of the TB patients might influence their adherence to treatment. The poor quality of life of the TB patients in the different areas of quality of life such as daily activities and work, calls for programmes to strengthen TB information, education and counselling.

Key words: Tuberculosis, patients, illness perception, quality of life, Gezira, Sudan

Background

Tuberculosis (TB) persists as a global public health problem of a serious magnitude requiring urgent attention[1]. Current global efforts to control TB have three distinct but overlapping dimensions: humanitarian, public health and economic. Alleviating the illness, suffering and death of individuals caused by TB is a major humanitarian concern and calls for a patient-centered approach[1].

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Illness perceptions are increasingly being shown to be related to important outcomes in a number of illnesses. There is also evidence that patients attending for medical investigations, who have already developed negative illness perceptions of their condition, are less reassured by findings showing no pathology[2]. A number of studies have shown that when patients hold generally negative illness perceptions about their illness (e.g. a large number of symptoms associated with the condition, more severe consequences, and longer timeline beliefs) these perceptions are associated with increased future disability and a slower recovery, independent of the initial medical severity of the condition[3].

Perceptions of illness have been found to vary with cultural, ethnic and socio-economic differences[4]. However, there are no published studies on the issue from Sudan. Perception of symptoms by persons suffering from pulmonary tuberculosis is found to be high[5]. Yet, studies have shown repeatedly that only a half of the persons aware of experiencing symptoms suggestive of tuberculosis approach a modern medical facility for alleviation of suffering[6-8]. Studying illness perceptions in relation to TB can bring information which helps in

improving the cure rates amongst tuberculosis patients, especially in improving the present low adherence to the administered therapy. It is extremely important that a holistic view of treatment is taken in view of the complex psycho-social characteristics of the disease.

The World Health Organization (WHO) defined quality of life (QOL) as the ability of individuals to perceive their position in life within the cultural, contextual and the value systems in which they live, being in accordance with their goals, expectations, standards and concerns[9]. Health-related quality of life (HRQoL) is a multi-dimensional concept that associates the physical, emotional, and social components of an individual with his/her medical conditions or treatment[10]. HRQoL is used to distinguish health effects from other factors influencing a subject's perceptions (such as environmental factors or job satisfaction)[11].

There are no published studies on HRQoL among TB patients from Sudan. A study from India has shown that the HRQoL among both active and inactive tuberculosis cases is deformed; the quality of life was affected by demographic and socio-cultural characteristics, depression, daily sleep period, treatment period and accompanying diseases[12].

TB affects all the predicted fields of quality of life, such as general health perception, corporal sense, psychological health, mental peace and functionality of physical and social roles[12]. Active tuberculosis, having drug side effects, social isolation and stigma from relatives, family members and friends, as well as causing various symptoms such as hemoptysis, chest pain, fever, profuse sweating, weight loss and fatigue, affects the quality of life[12].

The present study aimed to assess illness perceptions dimensions: identity, consequences, timeline, personal control, treatment control, concern, understanding, emotional representations; quality of life covering eight dimensions: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health as well as associations between them among TB patients in Gezira state, Sudan. The information gathered will enable the development of effective interventions to improve TB treatment adherence and to decrease TB consequences among Gezira population in a way which fits the local cultural characteristics of the population in the state.

Materials and methods
This study was carried out in Gezira state, which is one of the 17 states in Sudan. Gezira state lies between the Blue and the White Nile in the east-central region of Sudan. It has an area of 27,549 km² and population of about 2,796,330. The structure of the health care system in Gezira State is based on the primary health care and the "health area" concept, which is conceived as a decentralized health care system able to integrate at district level.

A descriptive cross-sectional study design was used to determine the illness perceptions and quality of life among TB patients in Gezira state. New smear positive TB patients registered in the TB microscopic units in the state in the period from January to December 2010 were the study population. The sample size was divided between the TB management units according to the number of registered patients from January to December 2010.

The sample size was calculated for patients from the equation n=z2 pq /d2, where; n =sample size, z=level of confidence=1.96, p=0.5, q=1-p=0.5, d=desired margin of error=0.05.Thus the sample sizes were 425 TB patients.

Local guidelines of research ethics were followed and a written consent was taken from the respondents. Objectives, process and expected outcome of the research were explained to the participants and their right to withdraw from the study at any time was explained without any place for unwanted consequences for their current care. Absolute confidentiality of the information gathered was followed before, during and after finishing the study.

The Brief Illness Perceptions Questionnaire (BIPQ)[13], which has been found feasible and sensitive enough for population studies[13], was used to measure illness perceptions. Translation to Arabic language and back translation was conducted. BIPQ contains the following nine items, each measuring the previously established illness perception dimensions: identity, consequences, timeline, personal control, treatment control, concern, understanding, emotional representations, and the 9th item about the causes of TB. The scale was a five-point Likert scale, with higher scores indicating stronger endorsement of that item (high identity scores indicate that the participants experienced more symptoms; high consequences score means that the participants saw their illness having major consequences; the high timeline score means that the participants thought that their illness will last for a long time; high personal control score means that the participants perceived having good control of their illness; high treatment control score means that the participants thought the treatment being extremely helpful in managing their illness; high coherence score means that the participants understood their illness; high emotional representation score means that the participants' illness affected their emotions extremely; and high illness concern score means that the participants were highly concerned about their illness). The TB causes item responses can be grouped into categories such as stress, lifestyle, heredity etc. determined by the particular illness studied. Categorical analysis can then be performed, either on just the top listed causes or all three listed causes.

In the questionnaire, the items for TB patients were formulated as follows: e.g. *how much control do you feel you have over your TB disease?*

Health Related Quality of Life (HRQoL) was assessed by means of the 12-item short form Health Survey questionnaire (FS-12), translation to Arabic language and back translation was conducted. The SF-12 is a generic measure of health status, encompassing 12 questions covering eight dimensions of health significantly affected by medical condition: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health. This eight-scale profile has been summarized into two components: physical component summary (PCS) (including limitation in self-care, physical, social, role activities, severe bodily pain and frequent tiredness) and mental component summary (MCS) (including the presence of psychological distress, the limitation in usual social and role activities due to emotional problems). Later, physical and mental components for all TB patients were categorized into three levels: poor, fair and good. Cronbach's alpha was calculated for the physical and mental components scale showing the reliability of 0.89 for the 8 items and 0.88 for the 4 items included in the scale respectively.

The analysis of the quantitative data was done using Statistical Package for Social Sciences (SPSS) version 19.0 program. Multinomial logistic regression was conducted as dependent variable has more than two categories to predict multivariate relation of TB illness perception and quality of life among the TB patients

Results
The proportion of men was slightly higher than women; half of the patients were married and one third singles; 20% had no education and 7% had university education. The patients lived more often in the rural than in urban areas. Further, half of TB patients were without work. To answer the research question: What is the level of illness perceptions and quality of life among TB patients (n=425) in Gezira state, Sudan, the following main findings are summarized:

Illness perceptions
The TB patients perceived that TB lasted long (timeline); they indicated several symptoms to TB (identity); they saw TB not being well controlled by treatment (treatment control) but they saw minor consequences from TB (consequences). Most of the patients mentioned that the most common causes of TB were: poor nutrition, poverty and contact with TB patients.

Health related quality of life
Two thirds of TB patients rated their health between good and fair while 12 % rated their health as poor. About half of the TB patients reported that their disease affected their movement for long distances; 42 percent mentioned that their health affected their activities a lot. About two thirds said that their health affected their work and activities (Table 1). Half of the patients felt depressed and reported that their work performance was affected by this depression (Table1). Feeling pain had moderate effect on the activity of two thirds of the TB patients.

Table 1: Health Related Quality of Life (SF-12) among TB patients (n= 425)) in Gezira state, Sudan.

Quality of life items		TB patients	
		frequency	%
1.Health status			
1.	Excellent	45	11.0
2.	Very Good	37	9.0
3.	Good	143	34.9
4.	Fair	136	33.2
5.	Poor	49	12.0
2.Limited activities			
1.	Limited a lot	165	41.9
2.	Limited a little	197	50.0
3.	Not Limited at all	32	8.1
3. Moving for a long distance			
4.	Limited a lot	206	50.5
5.	Limited a little	179	43.9
6.	Not limited at all	23	5.6
4.Work or other regular activities affected by physical health			
7.	Yes	316	74.4
8.	No	109	25.6
5.Activities limited in the kind of work or other activities			
9.	Yes	329	77.4
10.	No	96	22.6
6.Activities affected by feeling depressed			
11.	Yes	195	45.9
12.	No	230	54.1
7.Work or other activities affected by emotional problems			
13.	Yes	195	45.9
14.	No	230	54.1
8.Pain interfere with your normal work			
15.	Not at all	57	14.0
16.	A little bit	51	12.5
17.	Moderately	144	35.4
18.	Quite a bit	109	26.8
19.	Extremely	46	11.3

Table 1: Health Related Quality of Life (SF-12) among TB patients (n= 425)in Gezira state, Sudan.

	Quality of life items	TB patients	
		frequency	%
9.Felt calm and peaceful			
1.	All of the time	65	16.0
2.	Most of the time	137	33.8
3.	A good bit of the time	68	16.8
4.	Some of the time	73	18.0
5.	A little of the time	41	10.1
6.	None of the time	21	5.2
10. Having a lot of energy			
7.	All of the time	17	4.2
8.	Most of the time	94	23.2
9.	A good bit of the time	47	11.6
10.	Some of the time	151	37.3
11.	A little of the time	74	18.3
12.	None of the time	22	5.4
11.Felt downhearted			
13.	All of the time	20	5.0
14.	Most of the time	23	5.7
15.	A good bit of the time	22	5.4
16.	Some of the time	66	16.3
17.	A Little of the time	159	39.4
18.	None of the time	114	28.2
12.Physical health or emotional problems interfered with social activities			
19.	All of the time	20	5.0
20.	Most of the time	30	7.4
21.	A good bit of the time	33	8.2
22.	Some of the time	102	25.2
23.	A Little of the time	117	29.0
24.	None of the time	102	25.2

TB patients felt calm and peaceful most of the time; sometimes they felt that they had enough energy; and around two thirds felt downhearted very few times; and half of the TB patients mentioned that their health problems had minor effect on their social relations (Table 1). Around 80 percent of the TB patients had physical quality of life level ranging from good to fair while about 87% had good mental quality of life level ranging from good to fair (Table 2).

Table 2 Quality of life components among TB patients in Gezira state, Sudan

Quality of life components Physical component	TB patients (n =425)	
	Frequency	%
Poor	76	17.9
Fair	238	56
Good	111	26.1
Mental component	**TB patients (n = 425)**	
	Frequency	%
Poor	60	13.1
Fair	177	42.0
Good	188	44.9

In the multinomial logistic regression analysis for the association between the two quality of life components (physical and mental) and socio-demographic characteristics the crude odds ratios showed that: only TB patients who had lower education level had poor physical and mental quality of life (Table 3 and 4). Being younger, single and with low education were associated with fair physical quality of life while, low education and living in village setting were associated with fair mental quality of life (Table 3 and 4).

Table 3: Multinomial logistic regression analysis: physical component of quality of life and socio-demographic characteristics among TB patients (n= 425) in Gezira state, Sudan.

Degree of physical quality of life		P value	Odds ratio	95% Confidence Interval	
				Lower Bound	Upper Bound
Poor physical quality of life; reference good physical quality of life					
Age	Less than 30 years	0.60	0.74	0.25	2.21
	31 – 50 years	0.58	0.77	0.30	1.95
	More than 50 years*				
Gender	Male	0.58	0.81	0.38	1.73
	Female*				
Marital status	Married	0.22	1.88	0.68	5.14
	Single	0.41	1.65	0.50	5.48
	Divorce and widow*				
Education level	No school	0.10	2.21	0.87	5.67
	Middle level of education	0.01	3.25	1.37	7.70
	High education level*				
Residence	Town	0.29	1.94	0.56	6.69
	Village	0.18	2.24	0.69	7.22
	Camps*				
Occupation	No- worker	0.36	0.36	0.04	3.15
	Employee	0.16	0.26	0.04	1.67
	Laborer	0.33	0.40	0.07	2.53
	Employer*				
Fair physical quality of life; reference good physical quality of life					
Age	Less than 30 years	0.00	4.38	1.86	10.33
	31 – 50 years	0.00	4.85	1.81	12.97
	More than 50 years*				
Gender	Male	0.16	1.65	0.83	3.28
	Female				
Marital status	Married	0.11	1.70	0.89	3.23
	Single	0.02	3.03	1.18	7.76
	Divorce and widow*				
Education level	No school	0.02	3.01	1.22	7.43
	Middle level of education	0.13	0.24	0.04	1.51
	High education level*				
Residence	Town	0.20	0.34	0.07	1.74
	Village	0.72	0.74	0.15	3.75
	Camps*				
Occupation	Non-worker	0.10	0.26	0.05	1.32
	Employee	0.00	4.38	1.86	10.33
	Laborer	0.00	4.85	1.81	12.97
	Employer *				

- Referance group

Table 4: **Multinomial logistic regression analysis: mental component of quality of life and socio-demographic characteristics among TB patients (n= 425) in Gezira state, Sudan**

Degree of mental quality of life	Reference	P value	Odds ratio	95% Confidence Interval Lower Bound	Upper Bound
Poor mental quality of life; reference good mental quality of life					
Age Less than 30 years		0.58	1.38	0.45	4.21
31 – 50 years		0.51	0.73	0.28	1.88
More than 50 years*					
Gender Male		0.18	1.71	0.78	3.74
Female*					
Marital status Married		0.47	1.57	0.46	5.38
Single		0.85	0.87	0.20	3.78
Divorce and widow*					
Education level No school		0.10	2.27	0.84	6.12
Middle level of education		0.03	2.81	1.10	7.17
High education level*					
Residence Town		0.21	2.45	0.60	9.98
Village		0.08	3.28	0.86	12.52
Camps*					
Occupation Non worker		0.05	0.20	0.04	0.99
Employee		0.57	0.65	0.15	2.82
Employer		0.04	0.19	0.04	0.95
Employer*					
Fair mental quality of life; reference good mental quality of life					
Age Less than 30 years		0.82	0.91	0.40	2.06
31 – 50 years		0.87	0.94	0.48	1.87
More than 50 years*					
Gender Male		0.34	1.31	0.75	2.30
Female*					
Marital status Married		0.69	0.85	0.38	1.92
Single		0.36	0.64	0.25	1.66
Divorce and widow*					
Education level No school		0.97	1.01	0.53	1.95
Middle level of education		0.03	1.93	1.06	3.52
High education level*					
Residence Town		0.18	2.09	0.71	6.11
Village		0.00	5.61	1.98	15.88
Camps*					
Occupation Non-worker		0.93	1.06	0.29	3.90
Employee		0.83	1.15	0.32	4.16
Laborer		0.73	1.26	0.34	4.67
Employer*					

- Referance group

Table 5: **Multinomial logistic regression analysis: physical and mental components of quality of life and TB illness perceptions among TB patients (n= 425) in Gezira state, Sudan.**

Quality of life components dimensions	B-IPQ	P value	Odds ratio	95% Confidence Interval Lower Bound	Upper Bound
Physical component					
Poor physical component *	Consequences	0.87	0.99	0.82	1.19
	Timeline	0.95	0.99	0.75	1.31
	Personal control	0.05	1.33	1.00	1.77
	Treatment control	0.18	1.15	0.94	1.41
	Identity	0.29	1.29	0.80	2.09
	Concern	0.00	1.68	1.18	2.41
	Coherence	0.36	1.13	0.87	1.45
	Emotional response	0.10	0.82	0.65	1.04
Fair physical component*	Consequences	0.80	1.01	0.92	1.11
	Timeline	0.08	1.21	0.98	1.49
	Personal control	0.35	0.92	0.77	1.10
	Treatment control	0.87	1.01	0.88	1.16
	Identity	0.16	1.21	0.93	1.57
	Concern	0.90	1.01	0.85	1.20
	Coherence	0.00	1.32	1.11	1.58
	Emotional response	0.05	0.85	0.73	1.00
Mental components					
Poor mental component*	Consequences	0.43	0.90	0.70	1.16
	Timeline	0.11	0.80	0.62	1.05
	Personal control	<0.001	0.66	0.53	0.82
	Treatment control	0.11	1.19	0.96	1.47
	Identity	0.83	1.05	0.67	1.64
	Concern	0.09	1.30	0.97	1.74
	Coherence	0.04	1.29	1.02	1.64
	Emotional response	0.17	0.84	0.65	1.08
Fair mental component*	Consequences	0.78	0.99	0.91	1.07
	Timeline	0.84	0.98	0.79	1.22
	Personal control	0.60	0.95	0.80	1.14
	Treatment control	0.34	1.07	0.93	1.22
	Identity	0.94	1.01	0.76	1.34
	Concern	<.001	1.51	1.25	1.82
	Coherence	0.35	1.09	0.91	1.29
	Emotional response	0.39	0.94	0.81	1.09

In the multinomial logistic regression analysis for the association between the two quality of life components (physical and mental) and the eight dimensions of illness perception (identity, consequences, timeline, personal control, treatment control, concern, understanding and emotional presentations) the crude odds ratios showed that TB patients who did not understood their illness (coherence) and had poor personal control over their illness, had poor mental quality of life (Table 5), while, only TB patients who had high concern about their illness (concern) had poor physical quality of life (Table 5).

Discussion

Illness perceptions are the organized cognitive representations or beliefs that patients have about their illness. These perceptions have been found to be important determinants of behaviour and have been associated with a number of important outcomes, such as treatment adherence and functional recovery[14,15].

The results of this study among TB patients in Gezira, Sudan, showed that these patients perceived their illness to be of long duration, having several TB symptoms and TB treatment not being very effective. These perceptions might affect negatively TB patients' treatment adherence. Further, the emotional reactions to TB as well as limitations in their social activities might be bar-

riers to seeking treatment and adherence to treatment. Adherence is a challenge for the TB control programme in Sudan, as the early case detection, prompt treatment and case holding are the golden strategies in controlling TB[24]. Having symptoms of TB such as chronic productive cough, hemoptysis, weight loss, and perceiving the nature of TB to be an infectious disease in some patients, might initiate the feeling of guilt of infecting others and aggravating the sense of stigma. The latter is considered as a barrier for seeking and maintaining treatment [28].

It is known that socio-demographic factors are associated with both illness perceptions and quality of life[24]. Thus it is important to tailor and deliver the appropriate TB interventions both for prevention and cure so that they suit socio-demographic characteristics.
In this study the overall quality of life among TB patients was found to be relatively poor. The association of illness perceptions with decreased quality of life has been found in a number of other illnesses (e.g. diabetes and renal disease)[16-21].

Illness perceptions of patients have been shown to significantly influence both psychosocial and physical well-being and thus affect the quality of life of the patients[22]. This study found that the patients highly concerned about their illness seemed to have poor mental quality of life. This is in line with findings of a study from Pakistan, which found that the majority of patients suffering from TB had impaired mental quality of life in form of depression[23].

Based on the literature, depression and anxiety are very high in patients with tuberculosis. Psychiatric complications such as anxiety and depression can greatly impact quality of life of TB patients[26]. In our study about half of the TB patients felt depressed, which is similar to Pakistan[23]; this might be due to the perception of the nature of TB as a chronic disease, severity of the symptoms and social stigma associated with the diseases[27,28]. Feeling of depression might affect the adherence to TB treatment, which results in high default rate. Default rate has been shown to be high in Sudan[27] and can thus bring failure to control TB. This finding is supported by the study from India[29].

TB patients scored low in social and physical activities dimensions of health related quality, which reflects their performance at work and generally in life and could lead with other factors to stigma and poor adherence to treatment[26].

The strengths of the study were: high response rate, and the data collected by trained health care workers and relative good reliability measured by Cronbach's alpha of the scales used. On the other hand, potential limitations were: social desirability bias in responding the interview questions and the fact that the study conducted in Gezira State might not explain the situation found in other Sudanese states.

Conclusion
The study showed that TB patients in Gezira, Sudan, perceived TB as having several TB symptoms, lasting long and not being well controlled by treatment. This perception might influence patients' seeking for TB treatment and adherence to it. Quality of life of the TB patients was low in both physical and mental components, and quality of life among the patients was impaired in different areas of life such as daily activities and work. TB patients who experienced more symptoms (identity), expected severe consequences (consequences), had poor personal control over their illness (personal control); and the patients whose illness affected their emotions (emotional representations) had poor physical quality of life. Only TB patients who had high concern about their illness (concern) had poor mental quality of life. This calls for programmes to strengthen TB information, education and counselling. Furthermore, considering the socio- demographic characteristics in tailoring and delivering appropriate intervention for each group might change illness perceptions into more positive, which again can have impact on patients' seeking and maintaining their treatment. These acts could enhance effective TB control among Gezira population.

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