



Quality of life related to health hygiene and social work interventions among Tuberculosis patients

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Abstract

Due to long duration of treatment and use of several agents, tuberculosis can lead to poor health related quality of life among patients. The present study was designed to assess health related quality of life among tuberculosis patients in Chikkamagaluru and Shivamogga districts of Karnataka state, India. A descriptive cross-sectional study design was used. SF-36 was self-administered to a sample of 368 tuberculosis patients receiving self-administered or directly observed types of treatment, in baseline, initial, or continuous phase of treatment. The results of the current study highlighted a significant impact on several domains of quality of life and health hygiene of TB patients. Highest scores had been observed for the domain of physical functioning whereas, lowest scores were observed for the domain of general health perceptions of TB patients followed by bodily pain. The results of the present study concluded that TB patients had poor quality of life and health hygiene as Tuberculosis had a negative effect on all domains of life of the Tuberculosis patients. Social interventions were suggested by the researcher to inhibit the psycho-social impulses of the Tuberculosis patient, so it enhance the quality of life and health hygiene of the patient.

1. Introduction

Tuberculosis (TB) remains a major public health and economic problem worldwide. World Health Organization declared TB alongside HIV as a leading cause of death and most of these deaths occurred in the developing world. Increased knowledge and awareness about the disease is important along with early detection, diagnosis, and treatment in order to control TB. Though much attention has been given to clinical outcomes of therapy and microbiological cure, patient reported health related quality of life which can have a major influence on the clinical outcomes has been neglected. Treatment decisions should be based on patient preferences, which are also related to mental and social health in addition to physical health, to achieve better clinical outcomes. The untreated patients can become a source of transmission of infection leading to spread of disease whereas irregularities in treatment can lead to drug resistance. Health related quality of life is the impact that perceived health status has on the normal functions of life. Reduced health related quality of life can lead to depression and medication non adherence which can further lead to worsening of the medical condition. Tuberculosis has been one of the leading causes of mortality and morbidity in the world especially in the developing countries. Conventionally the effectiveness of tuberculosis treatment has always been observed and measured in terms of clinical outcomes. However, it may also lead to disease-related depression. So with the emergence of new strategies for treatment and control the focus of TB management has been shifted from mortality to disease-related morbidity and patient reported quality of life. Twenty-two countries carry 80% of the global incident cases of tuberculosis (TB). These countries were designated high-burden countries (HBCs) by the World Health Organization (WHO) in 1998, and they have received accelerated assistance to increase case detection rates and improve treatment outcomes. All of the HBCs had adopted Daily Treatment Regimen, national tuberculosis Elimination programs (NTEP) providing access to standardized TB care through public sector health facilities.

According to WHO report 26.9 lakh people are suffering from T.B and 71000 people are suffering from TB with HIV in India, among them more than 436000 people died in 2019 itself. 94348 new cases detected in Karnataka in the year of 2019, 5309 cases died among them. According to Indian TB report 2020, 91703 adult cases and 4909 pediatric cases including public and private sector cases diagnosed in Karnataka

state in the year of 2019. While 2400 cases detected in the Chikkamagaluru and Shivamogga districts in the year of 2020 among them an average 148 cases are co infected cases (TB-HIV) and 55 cases are pediatric and 160 patients died in this year. It shows that TB increasing in the country year by year. These statistics shows the severity of the Tuberculosis in the country. It may leads to some social deformities and mal adjustment, physical, psychological deformities like chronic stress, depression, anxiety and psychological imbalances in the patients. They desperately need the help of social support group. They express a lot of psychosocial, economical, emotional and behavioral issues in the process counseling. So this is very useful to mental health professionals, Medical Social workers and community workers to understand and channelize the T. B patient's self in a right manner.

2. Methodology

A descriptive cross-sectional study design was used to assess quality of life related to health hygiene and its domains such as physical functioning, bodily pain, general health, role limitation, and mental health of tuberculosis patients in Chikkamagaluru and Shivamogga districts of Karnataka state, India.. For data collection approval from the hospitals was taken. Informed and verbal consent for participation were also taken from the respondents. Respondents were ensured about the confidentiality of information verbally as well as confidentiality undertaking being signed by the principal investigator. Study site for this research was public and private healthcare facilities treating TB located in Chikkamagaluru and Shivamogga Districts. The sampling frame comprised TB patients treated in public and private healthcare facilities in two districts of Karnataka state, India. Study respondents included patients suffering from tuberculosis. Patients suffering from tuberculosis, aged 18 years or above, receiving self-administered or directly observed types of treatment, in baseline, initial, or continuous phase of treatment, smokers and nonsmokers, were included in this study. Patients aged less than 18 years, and more than 80 years and patients with any compelling conditions were excluded from this study.

2.1 Sample Size and Sampling Procedure

Calculation of sample size was performed by using Rao soft sample size calculator to determine the size of sample representing the population of tuberculosis patients. Sample size was calculated as 300 to

achieve 95% confidence interval with 5% margin of error. As no list of tuberculosis patients was available, convenience sampling technique was used to select the respondents. According to convenience sampling all the respondents that were available at time of data collection were selected.

2.2 Data Collection Tool

Pre validated data collection tool Short form health survey (SF-36) was used. The tool was slightly modified according to study objectives and socio demographics in view of the country. SF 36 included eight domains including physical functioning, role limitation due to physical problems, bodily pain, general health, vitality, social functioning, role limitation due to emotional problems, and emotional well-being. Respondent was greeted and evaluated. If the respondent did not read English or was bilingual, approved language version to use was determined or interviewer administration was used. If visual problems existed, a large-font form was administered or interviewer administration was used. The survey was introduced. Survey form was given to the respondent. Respondent was instructed on how to fill out the form. Any respondent questions were answered before, during, or after the administration. Form was retrieved upon completion and checked for completeness before the respondent left. Finally, respondent was thanked for completing the form.

2.3 Scoring of the Tool

Item response data was entered. Scoring of the SF-36 was begun with ensuring that the survey form was complete and the respondent's answers were unambiguous. The item response values were recorded. Several steps were included in this process, including changing out of range values to missing, recoding values for 10 items, and substituting person-specific estimates for missing items. After item recoding, a total raw score was then computed for each health domain scale. The total raw score is the simple algebraic sum of the final response values for all the items in a given scale. Health domain scale total raw scores were transformed to 0–100 scores using the following formula: $(\text{Actual raw score} - \text{Lowest possible raw score}) / (\text{Possible raw score range}) \times 100$. Health domain scale 0–100 scores were transformed to scores using health domain scores. A linear -score transformation is used so that each health domain scale has a mean of 0 and a standard deviation of 1 with mean from the 0–100 score for that scale, and then dividing the difference by the given scale's standard deviation. Then scores were transformed to score. To do so, each score was

multiplied by 10, and then 50 was added to the resulting product. Health domain scores were used to score Physical and Mental Component Summary measures.

2.4 Reliability and Validity of Tool

SF-36 is a pre validated tool but still two focus group discussions had been conducted at different time intervals with experts from hospitals, academia, and regulatory and pharmaceutical industries for face and content validation of the tool. Beside this pilot testing had been conducted at 10% of the sample size to test the reliability of the tool after data collection. The value of Cronbach's alpha was 0.977 for SF-36, which was satisfactory considering that 0.68 is the cutoff value being disapproved.

2.5 Data Collection and Analysis

Data was collected by the principal investigator. The respondents were identified and after obtaining written/verbal consent from them, the questionnaire was hand delivered to them. The questionnaire was collected back on the same day to avoid study biasness. After data collection, data was cleaned, coded, and entered in SPSS version 21.0. Skewness test was performed and histograms with normal curves were used to check the normal distribution of data. Descriptive statistics comprising frequency and percentages was calculated. The nonparametric tests including Mann-Whitney and Kruskal-Wallis were performed to find out the difference among different variables.

3.Results

3.1. Demographic Characteristics

Out of 382 respondents, 46.6% (178) were male and 53.4% (204) were female. Of the total respondents, 16.8% (64) were illiterate and 39.5% (151) were metric. Regarding the job status of the respondents, 38.2% (146) were employed whereas 30.6% (117) were unemployed. Out of all the respondents 22.5% (86) were smokers whereas 77.5% (296) were nonsmokers. Out of all the respondents, 86.1% (329) had duration of illness of less than 1 year. Of the total respondents 34.8% (133) were in initial phase of treatment. Regarding the type of treatment, 51.6% (197) respondents were in self-administered type of treatment and 48.4% (85) were under directly observed therapy.

3.2. Domains of Health hygiene Quality of Life

The results highlighted that lowest scores were observed in the domain of general health followed by domain of bodily pain whereas highest scores were observed in the domain of physical functioning .

3.3. Comparison Quality of life and Health Hygiene Domains by Demographic Characteristics

Comparison of quality of life and health hygiene domains in different age groups demonstrated a significant difference with TB patients aged more than 50 years having lower quality of life and health hygiene scores. Analyzing the scores of the respondents with different education levels reported a significantly higher MCS in TB patients having intermediate education. Significant difference was found in PCS of TB patients having different job status with employed patients having better quality of life and health hygiene scores. Furthermore, comparison of domain quality of life and health hygiene scores, different phases of treatment revealed a significant difference in with poor quality of life and health hygiene scores.

4. Discussion

Tuberculosis has remained a major public health problem worldwide resulting in increased morbidity and mortality. Due to prolonged therapy and infectious nature of the disease, physical, mental, and social distress are common among TB patients leading to poor disease outcomes. The results of the current study highlighted a significant impact on several domains of quality of life and health hygiene scores of TB patients. Highest scores quality of life and health hygiene scores. had been observed for the domain of physical functioning whereas lowest scores we quality of life and health hygiene scores observed for the domain of general health perceptions of TB patients followed by bodily pain and role limitations due to physical problems. Majority of TB patients enrolled in the current study considered their health to be fair. These findings are in line with a study conducted in Sudan where two-thirds of TB patients reported their health between good and fair . Similarly highest scores were observed in the physical functioning domain of SF-36 and lowest scores were observed in the general health perception area of WHOQOL-100 for TB patients in Turkey .

Constraints in physical functioning of TB patients are important to be considered on the account of their widespread prevalence that can lead to decreased quality of life and increased risk of depression and disability. The results of the present study revealed that vigorous activities such as running or lifting heavy objects, climbing several flights of stairs, and walking more than a km were limited a little for most of the TB patients. Most of the time they had to cut down time spent on work and accomplished less than they would have liked to achieve. Similar results were reported in a study conducted in Sudan where TB affected long distance movements of the TB patients and their activities were limited due to their health. Vitality in TB patients reflects the feelings of having energy as compared to fatigue. Bodily pain can interfere with normal activities of TB patients and subsequently affect their quality of life. The results of the present study showed that most TB patients felt tired and did not have a lot of energy most of the time. Bodily pain had mild to moderate effect on the daily activities of most TB patients. Similar situation has been reported in Sudan where pain had moderate effect on patient's quality of life. Tuberculosis can have an impact on social functioning due to social stigma associated with it. The results of the present study showed that social functioning of most of the TB patients was slightly affected. Furthermore, most of the TB patients had to cut down time for work, accomplished less, and did work and other activities less carefully only sometimes due to emotional problems. Similar findings were reported from a study conducted in Sudan where TB patients felt that their health had little effect on their social relations.

The results of the present study highlighted that patients aged more than 50 years had impaired across all quality of life and health hygiene domains. This might be due to the fact that health declines with aging process. These results are in line with study conducted in China that also showed association between age and quality of life and health hygiene. In the same lines, studies conducted in Malaysia and Canada also reported lower physical health in elderly patients. The results of the present study indicated that females had poor physical health as compared to males. This might be due to the fact that women are more sensitive to changes in their health and have low levels of physical strength. Similar results were reported in a study conducted in USA where women had more health problems and were more likely to report fair or poor health than men. The results of the present study revealed that quality of life scores for unmarried patients were lower than

those of married patients; however, the results were not significant. Similarly, married subjects in Turkey had higher quality of life scores as compared to unmarried subjects but the results were not significant. The results of the present study highlighted that TB patients with intermediate or higher education had better mental component summary score as compared to illiterate patients. The results of the present study showed that socioeconomic status has an impact on quality of life and health hygiene of TB patients. Patients earning between Rs. 21 and 35,000 per month had better physical health whereas patients earning between Rs. 10 and 20,000 had better mental health. Unemployed TB patients had poor physical as com quality of life and health hygiene compared to employed TB patients. This might be due to the fact that education leads to more adaptability in life and motivation for self-care which overall improves vitality and social functioning. Moreover, high literacy can lead to improved employment status and financial and social matters resulting in better health seeking behavior. Studies conducted in Turkey, South Africa, Thailand, and Iraq also reported that higher quality of life was associated with higher education level and better income. On the other hand, it was interesting to notice no significant difference among TB smokers and nonsmokers enrolled in current study. However, these findings are in contrast to other studies conducted in Iran and Thailand in which cigarette smoking was associated with lower quality of life and health hygiene especially in the domain of social functioning.

The results of the present study revealed that TB patients suffering from disease for more than two years had poor physical health. TB patients at baseline had lowest followed by quality of life and health hygiene patients undergoing initial phase of treatment. Furthermore, TB patients taking treatment for less than 1 month reported poor as quality of life and health hygiene compared to TB patients taking treatments for longer periods of time. TB patients taking treatment for 4–6 months had better mental health whereas TB patients taking treatment for 7–9 months had better physical health. This might be due to the reduction in TB symptoms and positive effect of therapeutic interventions on quality of life and health hygiene of TB patients. These findings are in accordance with studies conducted in Canada and Iran that also reported poor quality of life and health hygiene at baseline with improvement after 2 months of therapy. The current study also reported that patients undergoing Daily Treatment Regimen did not show any significant difference in

physical functioning, role limitations due to physical problems, and general health perception as compared to patients undergoing self-administered type of therapy. However, treatment plans incorporating directly observed therapy from the start had showed better treatment outcomes in different countries .

5. Social work Interventions suggested

Social Worker working with the patients in clinical setting is concerned with helping us Tuberculosis patients, who are unable to make use of medical service effectively, because of social or psychological factors. There are tuberculosis patients who do not make any progress in spite of adequate medical services because illness intensifies there needs to gets attentions, love and care. Because of these some TB Patients do not want to leave the hospital. There may be other tuberculosis TB patients who may be face in financial crisis or may be discontinuing treatment because of ignorance and fear. Some TB patient may not accept hospitalization due to responsibility or problem faced by him at home. Illness affects different patients depending upon their responsibility and Social situation. Some TB patients need help. In helping these patients the medical social worker utilize his relationship with them, is knowledge of human behavior & about the behavior of people when they are ill, his knowledge of case work, skill and services of other agencies to help these patients.

When a medical social worker **attaches to a diagnostic clinic**, he needs to interview every patient at the time of diagnosis of patient. This interview gives the patients an opportunity to discuss his fear, anxiety, frustration and other reactions towards the diagnosis, as well as the doctors' recommendations for care. The medical social worker understands the dynamics of human behavior and he knows also the technique of interviewing. When through '**case work technique**' as it is called, he helps the patients realize and express the reasons why he feels the way he does, an attitude of objectivity and reasonableness usually results. Opportunities for expressing his partially repressed feelings to somebody who understands and accepts him non judgmental may help him to ally his anxieties and provide sense of support which can increase his ability to act upon his problems. A carefully planned interview in most instances help the patients to give up his irrational attitude so commonly found in those who are in distress, accept the reality of his situation, and accordingly.

After helping the patients to accept the diagnosis and medical recommendation, the medical **social worker keeps in close touch with the patients and his family**. He sees to it that there are no obstacles in carrying out the treatment plan. His activities are numerous. If he finds that chief obstacle in taking treatment on the part of the patient lies in the lack of financial provision for the family when he is away from home treatment, he tries to secure the same to some extent. A medical social worker keeps in close touch with community resources. In case of financial help for the patients, he gets it from various trusts and charities in the community of which neither the doctor nor the patient is aware. If there are complications in the domestic relationship that come in the way of the patients' treatment, the medical social worker deals with them too. For example, the husband who has recently married and is still doubtful about the strength of his marital relationship wonders what his spouse will do when he is in the hospital. He may not want to go away from home for treatment or if he is already in the hospital he may become more and more suspicious. A medical social worker understands that in such situation latent anxieties emerge and that much of anxiety arises from feelings of inadequacy engendered by the long period of illness. Skilful interpretation, a positive relationship between the patient and the medical social worker and cooperation of the members of the family can help the patient to rid himself of his suspicions.

The medical social worker is an extremely important person amongst the staff of a tuberculosis hospital or Health settings which are take care of TB patients. He works as a **liaison between the doctors, patients and administration**. He guides tuberculosis patients to correct places of diagnosis, investigation and treatment, helps the needy with medicines, medical appliances etc. medical social worker gives psychological support to tuberculosis patients, which is absolutely essential for effective treatment. He helps the patients before, during and after treatment. Follow up work is carried on which often involves home visits. The medical social worker sees to it that the tuberculosis patient leaves the hospital not only cured of their disease but also fully satisfied and mentally happy.

The tuberculosis patients who have no **facilities for accommodation** become frustrated in addition to their actual disease. Medical social worker thus inherits an added importance for satisfying the psychological,

mental needs of patients, especially out station patients. So that they get medical attention in the right frame of mind and leave hospital totally satisfied.

Structured interviews and discussion are conducted with the patients' relations and employees and other persons concerned for the rehabilitation of the abandoned patients, elderly patients, helpless patients, mentally sick and handicapped by tuberculosis person in home and institutions. The medical social worker helped in finding suitable jobs to TB patients according to their aptitudes and limited capacities and capabilities. Tapping out various community resources for getting expensive drugs, prosthesis and various aid and equipments. Medical social worker helps the poor TB patients through exemption of hospital levy charges after proper assessment of economic status of the patients.

7. Limitations of the Study

This study was conducted in the two districts of Karnataka, India and results may not be generalizable to other parts of the country. Time and financial constraints were also faced during the conduction of study.

8. Conclusion

The results of the present study concluded that TB patients had poor quality of life and health hygiene in spite of the new therapeutic strategies and free availability of medicines. The disease had a negative impact on of TB quality of life and health hygiene patients across all domains of female quality of life and health hygiene and patients aged more than 50 years was found to be more affected due to TB. Beside this less educational qualification and duration of disease had negative effect on mental of TB patients quality of life and health hygiene while better socioeconomic status showed positive effect on of TB quality of life and health hygiene patients. All the stakeholders need to work together for improving physical and mental health related quality of life of TB patients in order to improve medication adherence, well-being, and functioning of TB patients. The poor health related quality of life among TB patients in Chikkamagaluru and Shivamogga districts of Karnataka, India raises serious concerns on performance of TB Daily Treatment Regimen program and calls for revamping the program in terms of its effectiveness.

7. Future Implications

Extensive research should be conducted to design appropriate interventions for improving quality of life and health hygiene in TB patients to decrease the rates of treatment failures and improve treatment response. Interventional studies focusing on health educational programs targeting patients with low educational background must be designed. Studies assessing quality of life and health hygiene of TB patients at baseline and initial phase of treatment to prevent treatment defaults must be conducted.

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