

LIFE QUALITY MANAGEMENT FOR TUBERCULOSIS PATIENTS IN SIBIU COUNTY

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Abstract: Despite notable progress over the last decade, tuberculosis is still a public health issue in most of the countries in the WHO European Region. Countries outside the European Union (EU) and the European Economic Area (EEA) still have a high rate of TB disease and multi drug resistance (MDR), while EU countries have a significant number of TB cases among vulnerable populations. Socio-economic determinants (level of training, occupation etc.) and risk factors (e.g. co-infection with HIV) also contribute to these high values.(1)

INTRODUCTION

Patients with tuberculosis in Romania are a large, disadvantaged, stigmatized and almost sentenced to death category.

Despite the remarkable progress over the last 10 years in the fight against tuberculosis, this disease is still a major public health problem in most European countries. Considerable efforts to combat tuberculosis worldwide have saved 53 million lives since 2000 and have reduced the mortality rate by 37%. However, the rate of tuberculosis patients who developed multidrug resistance (MDR cases) is 490,000 worldwide in 2016.(2)

The incidence of new and recurrent cases of pulmonary tuberculosis in the county of Sibiu followed the downward trend of the endemic at national level, being well below the national average. If in Romania, the incidence was 66.7 per 100,000 inhabitants in 2016, in Sibiu it was 32.7 per 100,000 inhabitants. This incidence was declining in 2016 compared to 2015, when it was 44.7% per 100,000 inhabitants. These values rank us in 2016 in the second place in the country as a low incidence. And in children, the tuberculosis situation in Sibiu County is just as good. Thus, in 2016 there were 3 cases of tuberculosis in children compared to 10 cases in 2015 (Data source: County Coordinator of the National Program for Prevention, Control and Surveillance of Tuberculosis).(3)

Tuberculosis treatment requires a very long period of hospitalization / isolation and treatment (between 3 and 24 months), which can lead to the loss of the patient's workplace and therefore, an important source of income for family maintenance. Also, the treatment of pulmonary tuberculosis has strong side effects, both physically and psychologically. The side effects of medication, the risk of job loss or temporary improvement of health after a short period of drug administration, often cause the patient to abandon the treatment, a very dangerous situation, as it increases the risk of disease progression to tuberculosis resistant to treatment (TB-MDR) or extreme resistance to treatment (TB-XDR). These conditions require long periods of hospitalization and treatment is difficult to support, with a very low rate of healing.(4)

The correct and timely diagnosis of the disease, the inclusion of the patient in the complete therapeutic regimen, with good anti-tuberculosis drugs, coupled with adequate

nutritional intake, psychological support, family financial support, professional reinsertion assistance and stigma reduction measures, are the most acute needs of tuberculosis and multidrug resistant tuberculosis in Romania.(4,5)

Management of the quality of life of tuberculosis patients requires coherent and integrated cross-sectoral actions, carried out in the long run to deliver results.

PURPOSE

This study aims to identify the main factors influencing the quality of life of tuberculosis patients in Sibiu County and proposing a set of measures to improve the quality of life of these patients, who are part of the vulnerable, stigmatized groups of our society.

MATERIALS AND METHODS

The study was conducted at the Pneumophysiology Hospital in Sibiu during 2017, using as a tool the statistical data of the hospital and an anonymous questionnaire for hospitalized tuberculosis patients and those treated as outpatients. The questionnaire was accompanied by the interview of the patients, for the accuracy of data regarding the medical-social and quality of life of the patients. The number of patients to whom the questionnaire was applied was 50, randomly selected in terms of age, education, occupation or geographic background.

RESULTS AND DISCUSSIONS

Following the analysis and synthesis of the data, I have reached the following results:

In 2017, the total number of tuberculosis patients in Sibiu County was 145, of which 140 adults and 5 children (figure no. 1). From the total number of cases, 89 are new cases of disease, 22 cases of multi drug resistance (MDR), 19 recurrences, 4 cases with retroactive treatment (abandoned treatment) and 6 with re-treatment (therapeutic failure through non-treatment) (figure no. 2).

The gender distribution of patients is in favour of male gender (93 patients), compared to female gender (52 patients) (figure no. 3). Most patients come from the urban area (83), only 63 patients come from rural areas (figure no. 4). Distribution by age group is as follows: 33 patients are in the 35-44 age group, followed by 55-64 years (30 patients), 45-54 (24 patients), 25-34

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years (23 patients), 65 and over (20 patients), 15-24 years (13 patients), and children 0-14 years (2 patients) (figure no. 5).

In terms of social status, patients with tuberculosis are: employed (50), without occupation (48), retired (41) and pupils (6) (figure no. 6).

Figure no. 1. Frequency of patients with TB in Sibiu County, 2017

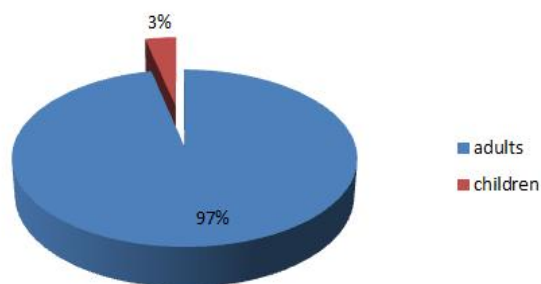


Figure no. 2. Types of TB patients

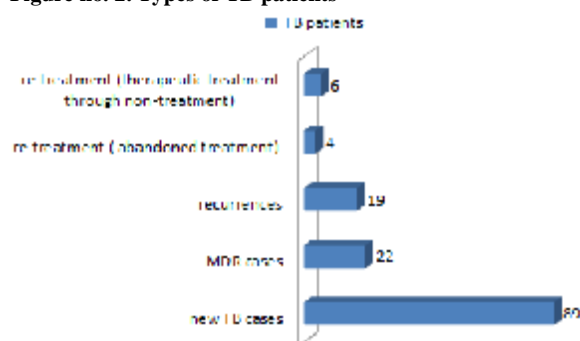


Figure no. 3. Repartition of patients by gender

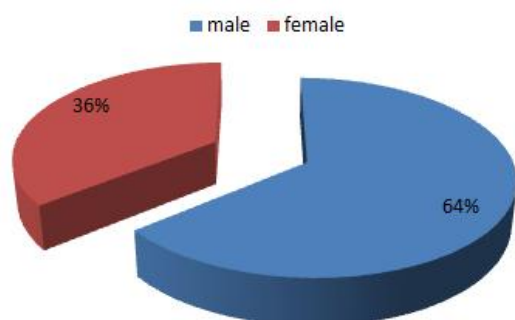


Figure no. 4. Distribution of patients on geographical areas

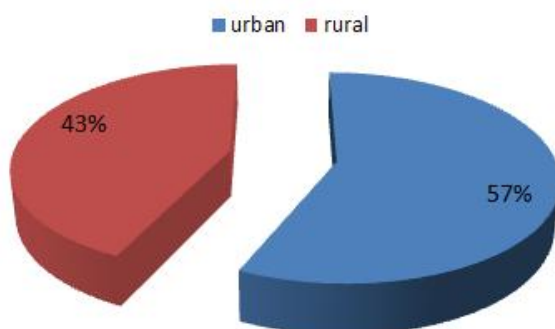


Figure no. 5. Age of studied patients

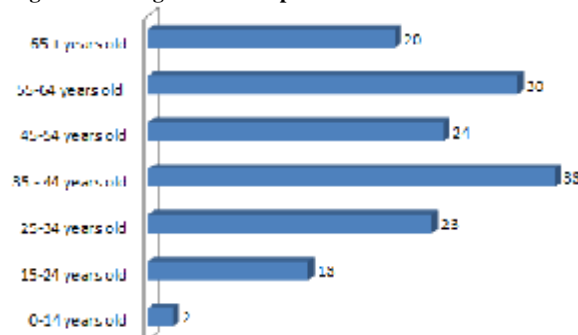
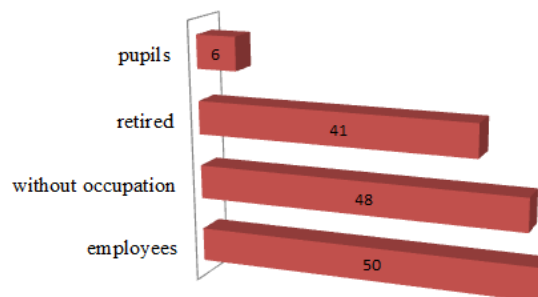


Figure no. 6. Social status of patients



Tuberculosis patients in Romania are struggling with the disease, with the shortcomings in the medical system, but also with stigma.

We have conducted a qualitative study evaluating the main needs of tuberculosis patients in Sibiu County.

From the 50 cases analyzed, I concluded that most of the patients have the quality of life affected, many of them being social cases. Patients with MDR are hospitalized for long periods of time, some of them have no families, or live in disorganized families and beyond the illness itself, most patients are chronic alcohol consumers, with all its repercussions.

Patients affected by tuberculosis and their families must understand very well that observing treatment from all points of view: the time, the rate of administration, the number of prescription drugs, is the only way to certain and definitive healing. Otherwise, the risk of developing resistant treatment tuberculosis (TB-MDR) increases. For this form of tuberculosis, treatment is longer, for approximately 2 years and the chances of healing and survival are up to 50%.

During treatment, 52% of patients have experienced toxic and allergic side effects: lack of appetite, stomach pain, joint pain, decrease or loss of hearing, visual disturbances, memory impairment, mental disorders etc. If the doctor is informed in time about the occurrence of these reactions, he/she will correct the treatment without interruption, so as to cancel negative effects.

During treatment with TB-MDR, the patient should eat 4-5 times a day and consume many calories, proteins and vitamins. Consumption of dairy products, fruit, vegetables, natural juices favours the improvement of stomach and intestinal function and combats the negative effects of drugs. Prolonged rest (8-10 hours a day) and outdoor walks are also recommended. Some patients in the first weeks of treatment are not allowed to undergo any physical exercise.

From the interview with tuberculosis patients, their main problems or/and needs are the following:

- The understanding from their families is the most important aspect, their dependence on the family being very high,

- either emotionally, financially and psychologically.
- Elimination of discrimination by society towards patients with tuberculosis, at work and school.
- Difficulties of accepting the long term treatment, because of the side effects which are difficult to bear, both physically and psychologically.
- The long term treatment and hospitalization of the patients mean long periods of inactivity. This makes social re-insertion difficult, first of all because of the reduced work capacity of the patients, but also because of stigma associated with tuberculosis.
- In terms of adherence to treatment, the study shows that 9 out of 50 subjects (18%) had discontinued treatment, at least once.
- The reasons for discontinuing treatment were either "I felt bad" (29%), "I felt better" (27%), or other reasons (44%, e.g. "I forgot to take pills").
- The main needs for increasing adherence and successfully completing treatment were: family support (52%), more qualitative nutrition (22%) and financial /social help (26%).
- The most difficult experiences during the treatment were: "to be hospitalized for so long" (52%), "not to be with the family" (28%), and "to support the side effects of the drugs" (20%).
- The main concerns after completing the treatment were: the fear that after completing treatment they may get sick again (52% of subjects), fear that they will not be hired again at the same place (28 % of subjects) or at a new place of work (20% of subjects).

CONCLUSIONS

The main issues faced by tuberculosis patients are those related to their discrimination at school (children) or at work (adults), or when they need health care in hospitals, other than Pneumophthisiology hospitals.

Improving the quality of life of patients with tuberculosis could be done by involving civil society in developing public policies on measures to protect affected individuals, but also to prevent the spread of the disease.

It is necessary to develop regulations on concrete, appropriate, social protection of patients.

Priorities for intervention in tuberculosis from the perspective of specialists:

1. *To reduce the risk of transmission of tuberculosis by:*
 - measures and support services for increasing adherence to treatment, especially for TB-MDR and TB-XDR;
 - active identification and follow-up of patients at risk for non-compliance treatment;
 - measures to reduce the side effects of treatment and medical support to overcome them;
 - improving the control of TB infection by: separating the TB section from pneumology and TB-sensitive patients with TB-MDR /XDR (by improving hospitalizing conditions, setting up special networks in medical units, separating sections etc.);
 - involvement of medical services in rapid diagnosis of TB-MDR /XDR infection.
2. *To reduce the risk of deteriorating the quality of life of people affected by TB as a result of reduced physical capacity and long periods of inactivity caused by long-term treatment or hospitalization by:*
 - revision of the paid medical leave period, from 1 to 2 years - as a special protection measure, especially for patients with TB-MDR /XDR, thus facilitating therapeutic success.

- the access of persons affected by TB to psycho-socio-professional services that provide professional skills assessment and, where appropriate, re-orientation and re-qualification (qualification /retraining courses);
- access of persons affected by TB to recovery services that ensure the possibility of re-enrolment to the effort - so that at the termination of the medical leave they are ready to resume their activity;
- public policies measures to reduce stigma and social discrimination associated with tuberculosis.

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