ACTA FAC MED NAISS

UDC 616.002.5:159.9

Professional article

ACTA FAC MED NAISS 2008; 25 (2): 81-86

Milan Radovic, Lidija Ristic
Milan Rancic, Ivana Stankovic

Clinic for Pulmonary Diseases and Tuberculosis – Knez Selo, Clinical Centre Nis
Faculty of Medicine
University of Nis
Serbia

THE INDIVIDUALIZED MODELS OF TREATMENT AND HEALTH CARE IN OVERCOMING THE STIGMATIZATION OF PATIENTS WITH TUBERCULOSIS - A "NEEDS - BASED APPROACH"

SUMMARY

Many problems and troubles jeopardize the welfare of patients with tuberculosis (TB), compromising their ability to adequately accept necessary medical care, as well as to complete full treatment regimen. Among the most insidious effects of TB, there are different manifestations of "marking" - stigmatization of these patients.

Overcoming the stigmatization is the crucial question in effective TB control, and requires understanding of all medical, social and cultural aspects of this disease, ability for simple and educational communication with patients, their families and local community. Stigmatization antidote is the establishment of "user-friendly" treatment service - that way the community can see as many successfully cured patients as possible. Modern means of TB control must be based not only on global DOTS strategy, on the one hand, but also carefully designed interventions in local communities on the other. They represent individualised approach to the patients, referring to their needs from the beginning of the treatment, based on understanding of TB pathophysiology and knowledge of relevant treatment models and health care of these patients. Since the TB patients have variable clinical course, their treatment requires adequate estimation, planning and evaluation on periodical base.

Individualised models of treatment and health care of TB patients are thoughtfully designed, in hospital conditions, to offer the highest quality of treatment and full care of non-judgemental understanding of the patient's needs to all the patients, regardless of their age, race, religion, gender, sexual orientation or disease severity.

Key words: **tuberculosis, stigma, treatment, care**

INTRODUCTION

Many problems and difficulties affect the general welfare of patients with tuberculosis (TB) and compromise their ability to obtain medical care and complete a treatment course. Among the most insidious and damaging of these are the various manifestations of stigma that are widespread throughout the world. The word stigma, by the definition, means "*a distinguished mark of social disgrace*". Its origin is obscure, but it is thought to date from the time when thieves and other criminals in the Roman Empire were branded on their foreheads as a perpetual sign of their social disgrace. The stigma of leprosy is well-known and is associated with the characteristic recognizable physical deformities caused by the disease (1). Although tuberculosis is rarely the cause of obvious physical deformity, those afflicted often meet with very negative social attitudes, which add greatly to

Corresponding author. Milan Radovic • Phone: +381641563885 • E-mail: mradovic@bankerinter.net

their suffering. In some regions, the actual and perceived link between TB and human immunodeficiency virus (HIV) has added a new stigmatizing factor (1,2).

Many patients with TB do not require hospitalization and could be appropriately treated as out-patients with back up and support of the specialist multidisciplinary team of health care professionals, usually known as the "TB team". Admission to hospital may be necessary if the patient is particularly bad, has multi-drug resistant TB or other problems with therapy, is unable to care for him / herself at home or has other serious medical conditions, such as a disease caused by infection with HIV. The quality and sensitivity of the care that patients receive in hospital can have an impact on their future relationship with the health service for the duration and following up of their treatment (3,4). TB presents many challenges, as if is widely stigmatized through fear of contagion, and is strongly associated with poverty, homelessness, alcohol and/or drug dependency, HIV disease and malnutrition. In view of the complexities of the disease, a holistic and individualized needs-based approach is required for the provision of optimal care and support (5).

THE NATURE AND IMPACT OF TB STIGMA

Stigma may affect the patient adversely at all stages of the disease - treatment seeking, diagnosis and adherence to therapy - and may persist long after complete curing. Since societies may not want to acknowledge the extent, or even the existence of the disease in their environment, establishment and maintenance of effective tuberculosis control services can be inappropriate (6-8).

TB is prevalent in populations such as ethnic minority groups, the poor, homeless, "travelers", prisoners and other institutionalized people, already bearing the stigma of social disadvantage and marginalization (2). These patients often fall victim to what Paul Farmer, a distinguished public health authority, has termed as a "*structural violence*" - the combination of societal features that prevent them from accessing health care and adhering therapy. Farmer has noted that, "throughout the world, those least likely to comply (with therapy) are those least able to comply". As a consequence, TB is not likely to be given the attention it requires until those who have control over healthcare provision perceive themselves or their political interests to be at risk (8,9).

Recently, the actual or perceived link of tuberculosis with HIV disease has accentuated the stigma in some regions, and this has led to delays in seeking treatment for TB and to poor adherence to therapy. Patients with HIV disease may conclude that, as their prognosis is bleak, there is no point in adhering to treatment of TB. In addition, healthcare providers may conclude that, as the patients will die of HIV disease, treatment of their TB is a waste of time and resources (10,11).

The attitudes that generate stigma are usually linked to local belief systems concerning the cause, nature and prognosis of the disease. Some beliefs about the cause of TB are fairly widespread and include "germs", alcoholism, nutritional factors, heredity, moral degeneration, curses, karma and divine retribution. Stigma may also be enhanced when a disease is used as a metaphor for some ill in society, although in this respect, TB acquired a somewhat "*romantic*" image, especially in Victorian art and literature (1,2).

As a consequence of stigma, a diagnosis of TB may be met with shock, denial, disgust, fear and anger (12). Shock may prevent patients from fully understanding explanations given to them about their disease and its treatment and it may also induce them to "shop around" for an alternative diagnosis. Fear and disgust lead to denial, which, in turn, may lead to poor adherence to therapy. Anger may well be directed against the healthcare providers (11,13).

OVERCOMING STIGMA

It is essential that healthcare workers, whether physicians, nurses or voluntary workers, should look beyond the disease and see the patient, for whom the signs and symptoms of TB may be just a part of a complex pattern of "disease". The quality of health services, particularly as perceived by the patients, and the friendliness and attentiveness of staff can have an enormous beneficial impact on overall well - being, as well as on the successful completion of treatment (5). It has been emphasized that all healthcare providers should act as "*destigmatizers*" and that training in social skills is required (7).

Community involvement can do much to reduce stigma and other factors that create barriers to effective TB control. Mere education on the nature of TB and its curability does not necessarily reduce stigma and enhance adherence to therapy. Initiatives and innovations must therefore be based on careful sociological research at the local level. While cultural factors play a central role in determining the impact of TB control programs, the provision of caring, locally respected and, above all, highly effective treatment is of even greater importance. If the community sees that patients are readily and permanently cured of TB, and that the prevalence of the disease is rapidly diminishing, negative attitudes

quickly change (14). Accordingly, the control of TB must be based on the implementation of both the global DOTS-based control strategy and interventions carefully tailored for the local community (6,12,15).

THE INDIVIDUALIZED MODELS OF TREATMENT AND CARE OF PATIENTS WITH TUBERCULOSIS

The quality and sensitivity of the care that patients receive in hospitals can have an impact on their future relationship with the health service for the duration of their treatment and follow-up (8,16). TB presents many challenges, as if is widely stigmatised through fear of contagion and is strongly associated with poverty, homelessness, alcohol and / or drug dependency, HIV disease and malnutrition (7,9). In view of this complexities of TB as a disease, holistic and individualized needs - based approach is required for the provision of optimal treatment and care (5,17).

Risk management effectiveness has been settled into the very heart of health governance, representing the first step in provision of a safe environment for medical treatment, nursing care and recovery from illness and trauma. The concept of risk management has always been a key feature of proactive TB infection prevention and control strategies, as a failure to control such risks can have disastrous consequences for health care organisations, practitioners and patients (18). The ongoing cycle of risk management *(Figure 1)* involves a continual evaluation in order to identify potential risks and assess the methods that are in place to control these. Effective reporting of adverse events, error and "near misses" is essential to the ongoing identification of risk and the development of effective risk management responses, as an effort to improve patient safety (19,20).

Patients admitted for investigation or treatment of TB may be in a rapidly changing clinical situation and their treatment and care must be assessed, planned and evaluated on a frequent basis (18). This requires a comprehensive understanding by the physician and nurse of the rationale that underpins strategic care, carefully designed to meet the immediate needs of patients, solve identified actual problems and prevent recognized potential problems from being realized. The care delivered must be evaluated frequently (often on a shift-by-shift basis) and modified according to the patient's response to physician and nursing interventions (21,22). The members of the multi-disciplinary TB team that supports the care of the patient - including respiratory physicians, specialist nurses such as respiratory or tuberculosis clinical nurse specialists, infection control nurses, physiotherapists, microbiologists, pharmacists and dieticians - possess valuable knowledge regarding dimensions of TB care that the nurse can access and use appropriately when planning, implementing and evaluating the patient's individualized nursing care. The nurse is ideally placed to act as the patient's advocate and to mediate effectively between the patient and other members of the healthcare team as it pointed in the "Burford Nursing Development Unit Model". The idea behind this model is to allow the nurse *"to connect"* with patients in a way that conventional nursing models do not always do. Essentially, it aims

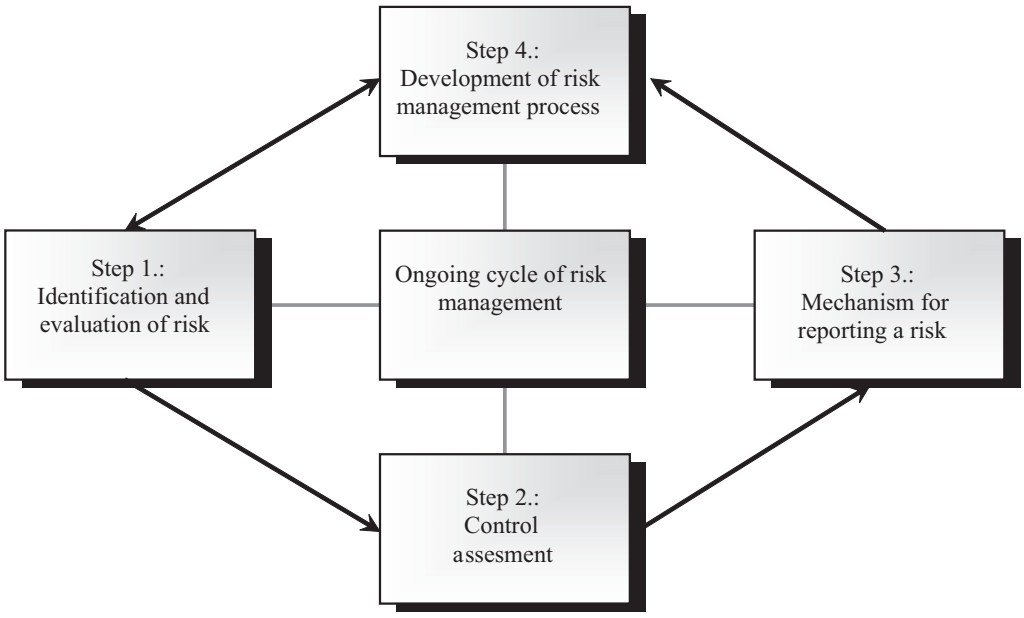

Figure 1. The ongoing cycle of risk management process on step by step basis, for the control assesment of potential adverse outcomes that threaten the delivery of safe and appropriate treatment and care for TB patients

to help the nurse to see *"people in relation to their illness"*, as opposed to *"a patient with an illness"* (23). In the acute care setting, gaining information to assist with this may often be neglected in favor of physiological assessment. When one considers the nature of tuberculosis, however, with its physiological, psychological and social impact on the patient, it would seem vital that a *comprehensive* assessment is carried out (7). To that end, it is suggested that both these assessments are used together, so that information is gained about the person living with TB (Burford NDU model) in addition to information about the needs that this disease generates for that person ("needs-based approach" model) (17,23).

"NEEDS-BASED APPROACH" MODELS

Tuberculosis is a communicable disease with serious consequences if treated inadequately, and the patients' responsibility goes beyond achieving their personal recovery to ensuring that the people around them are safe (12,13). This can be very difficult without appropriate care and support. The members of a TB team has a responsibility to assess self-care deficits by exploring social, psychological, physical and medical issues in order to plan interventions relevant to the needs of each individual patient (20). As well as assessing problems and self - care deficits, it is also important to consider what positive factors - such as supportive family members, friends and a strong religious faith - exist, which will assist the patient, both in hospital and following discharge (11,14).

"Needs-based approach" models of treatment and health care, as conceived by Henderson, Roper, Logan and Tierney as well as Orern, are valuable tools by which the individualized nursing care of patients with tuberculosis can be planned and implemented efficiently and effectively (17,24,25).

Patients with TB have needs that they must meet for health to be maintained, which is also common for those with other illnesses. Fifteen needs are discussed (24,25). Each is described as *having potential problems* associated with it. Alongside each of these problems, there is a list *of possible causes.* Neither of these lists is designed to be exhaustive; rather, they are indicative of the problems affecting the patient and their causes that the nurse may most commonly encounter in the ward setting when caring for patients with TBN (25). The following list itemizes the needs that may be examined during the physician and nursing assessment:

1. The need for adequate respiration.
2. The need for adequate hydration.
3. The need for adequate nutrition.
4. The need for urinary and fecal elimination.
5. The need to control body temperature.
6. The need for movement and mobilization.
7. The need for a safe environment.
8. The need for personal cleansing and dressing.
9. The need for expression and communication.
10. The need for working and playing.
11. The need to maintain psychological equilibrium.
12. The need for adequate rest and sleep.
13. The need for spiritual care.
14. The need to express sexuality.
15. Needs associated with dying.

These models describe the needs and self - care requisites necessary for normal, healthy living. General *objectives of care* are described for each need. This is followed by a description of relevant *interventions,* introduced by identifying important elements of a *nursing assessment* (24). Their use allows for a systematic nursing assessment that will identify actual problems arising from deficits in self - care abilities. They further facilitate the recognition of potential problems associated with the patient's condition (social, psychological, physical and medical), specific illnesses, hospitalization and medical treatment (23). Because needs-based models used alone can be potentially dehumanizing, the nursing assessment must also include an examination of how this episode of illness is affecting the "*Person"* (as opposed to the body) (17). Identifying and documenting needs, self-care requisites and both actual and potential problems facilitates the planning of appropriate nursing interventions and allows the effectiveness of these interventions to be evaluated (23-25).

CONCLUSION

Stigma in its various forms has a deleterious effect on patients with TB, leading to delays in diagnosis, poor adherence to therapy and on the overall quality of their lives as well as the effectiveness of healthcare services. The families of the patients may also be adversely affected, and the problem is especially serious for ethnic minority groups and women. Overcoming stigma is central to effective TB control, requiring, on the part of health-care providers, an understanding of the social and cultural aspects of the disease, the ability to communicate clearly and the incentive to educate the patients, their families and the community. Probably the best antidote to stigma is the establishment of effective and user-friendly treatment services, so that

the community sees that patients are successfully and permanently cured.

The individualized models of treatment and care of patients with TB require skill, competence and confidence. These are based on a factual understanding of the pathophysiology of tuberculosis and a comprehensive knowledge of relevant models of medical treatment and nursing care designed to offer all clients, regardless of race, age, creed, gender, sexual orientation or disease, the highest quality of compassionate, non-judgmental nursing care.

ACKNOWLEDGEMENTS

Dr Lidija Ristić is a member of the Republic Committee for Tuberculosis in Ministry of Health, Republic of Serbia and state representative, as a member of National professional team, in the project entitled: "Control of tuberculosis in Serbia through implementation of DOTS strategy", financially supported by the Global Fund for AIDS, tuberculosis and malaria.

Dr Milan Radovic was a member of educational team from the same Ministry, introducing and implementing the same project for primary health care physicians in Nis County during 2005.

REFERENCES

1. Kelly P. Isolation and stigma: the experience of patients with active tuberculosis.Community Health Nurs 1999; 16: 233-41.

2. Grange JM, Story A, Zumla A. Tuberculosis in disadvantaged groups. Curr Opin Pulm Med 2001; 7: 160-4.

3. Radovic M, Djordjevic I, Golubovic S, Pejovic G. Tuberculosis in adolescence – identification and treatment of high risk groups and high risk individuals. Facta universitatis, 2004; 11: 74-79.

4. Radović M, Golubović S, Đorđević et al. Karakteristike tuberkuloze u osoba starije životne dobi – inicijalno lečenje i ishod, Acta Med Medianae 2003; 42:59-63 (in Serbian).

5. Grange JM, Festenstein F. The human dimension of tuberculosis control. Tuber Lung Dis 1993; 74: 219-22.

6. Farmer EP, Walton DA, Beccerra MC. International tuberculosis control in 21st Century In: Friedman NL (ed), Tuberculosis-current concepts and treatment, CRC Press LLC, Boca Raton, Florida, 2001: 475-494.

7. Rangan S, Uplekar M. Socio-cultural dimensions in tuberculosis control. In Porter JDH,Grange JM (eds), Tuberculosis - an interdisciplinary perspective. London: Imperial College Press, 1999: 265-81.

8. Ministarstvo Zdravlja Republike Srbije. Predlog Nacionalnog programa za Tuberkulozu - Program Zdravstvene Zastite Stanovnistva od Tuberkuloze. Udruzenje Pulmologa Srbije, Belpak, Beograd, SCG, 2004: 15-60.

9. Radovic M, Djordjevic I, Zivkovic Dj et al. Tuberculosis, mortality-efficiency of new control/treatment strategies. Eur Respir J 2003; 22: 382-383.

10. Ngamvithayapong J, Winkvist A, Divan V. High AIDS awareness may cause tuberculosis patient delay: results from an HIV epidemic area, Thailand. AIDS 2000; 14:1413-19.

11. Sherman LF, Fujiwara PI, Cook SV et al. Patient and healthcare system delays in the diagnosis and treatment of tuberculosis. Int J Tuberc Lung Dis 1999; 12: 1088-95.

12. Radovic M, Golubovic S, Pejovic G, et al. Pecularities in implementation of national tuberculosis program in patients with smear negative pulmonary tuberculosis. Eur Respir J 2004; 24:190-191.

13. Ristic L, Radovic M, Rancic M et al. Illness perception in new diagnosed actively treated tuberculosis patients. Eur Respir J 2007; 30:740-741.

14. Hadley M, Maher D. Community involvement in tuberculosis control: lessons from other health care programmes. Int J Tuberc Lung Dis 2000; 4: 401-8.

15. Zivkovic Dj, Rancic M, Djorđevic D et al. Savremeni aspekt tuberkuloze danas i nacionalni program za tuberkulozu. Acta Fac Med Naiss 2001; 18 (2): 85-88.

16. Golubovic S, Stankovic I, Radovic M et al. Ponovni tretman obolelih od tuberkuloze nakon prekida lecenja. Majski pulmološki dani 2005-zbornik radova, Klinika za plucne bolesti Banja Luka, Banja Luka, Republika Srpska, 2005:99-102.

17. Henderson V. Basic principles of nursing care. Geneva: International Council of Nurses,1972: 16-37.

18. O'Neil S. Clinical governance in action. Part 2: Effective risk-management strategies. Proffesional Nurse 2000; 15: 684-685.

19. Golubovic NS, Djordjevic NI, Radovic M et al. Disorder of liver function tests (LFT) induced by antituberculous drugs. Eur Respir J 2005; 26:648-9.

20. Pratt RJ, Grange MJ, Williams GV. Tuberculosis. Oxford University Press Inc., New York, USA, 2005: 287-92.

21. Radovic M, Djordjevic D, Zivkovic Dj et al. Tuberkuloza larinksa kod bolesnika sa aktivnom plućnom tuberkulozom. Acta Fac Med Naiss 2001; 18: 96-100 (in Serbian).

22. Radovic M, Djordjevic D, Zivkovic Dj et al. Karakteristike tuberkuloze u osoba mladje životne dobi (tinejdzera) – inicijalno lecenje i ishod. Pneumon 2002; 40: 33-38. (in Serbian).

23. John C. The Burford NDU model; caring in practice. Oxford: Blackwell Sciences,1994: 4-36.

24. Orem DE. Nursing: concepts of practice, 2nd edn. New York: McGraw Hill, 1980: 18-66.

25. Roper N, Logan WW, Tierney AJ. The elements of nursing, 4th edn. London: Churchill Livingstone, 1996: 14-74.

INDIVIDUALIZOVANI MODELI LEČENJA I NEGE U CILJU PREVAZILAŽENJA STIGMATIZACIJE OBOLELIH OD TUBERKULOZE – PRISTUP BAZIRAN NA POTREBAMA OBOLELOG

Milan Radović, Lidija Ristić, Milan Rančić, Ivana Stanković

Klinika za plućne bolesti i TBC Knez Selo, Klinički centar Niš
Medicinski fakultet Univerziteta u Nišu

SAŽETAK

Mnogi problemi i poteškoće ugrožavaju opšte blagostanje obolelih od tuberkuloze (TB), kompromitujući njihovu sposobnost da adekvatno prihvate dobijanje neophodne medicinske nege, ali i kompletiraju pun režim lečenja. Među najpodmuklijim uticajem TB kao bolesti su različite manifestacije "obeležavanja" - stigmatizacije ovih bolesnika.

Prevazilaženje stigmatizacije obolelih od TB je centralno pitanje u njenoj efektivnoj kontroli i zahteva razumevanje svih medicinskih, socijalnih i kulturalnih aspekata bolesti, sposobnost za jednostavnom i edukativnom komunikacijom s pacijentom, njegovom porodicom i lokalnom zajednicom. Antidot stigmatizaciji pacijenata je uspostavljanje "*user-friendly*" servisa lečenja, kako bi zajednica uočila što više uspešno izlečenih pacijenata. Savremene mere za kontrolu TB moraju biti bazirane ne samo na globalnoj DOTS strategiji, s jedne strane, već i pažljivo skrojenim intervencijama za lokalne zajednice s druge, koje podrazumevaju individualizovani pristup obolelom, u skladu s njegovim potrebama od samog početka tretmana, zasnovanom na razumevanju patofiziologije TB i poznavanju relevantnih modela lečenja i nege bolesnih osoba. S obzirom da oboleli od TB ispoljavaju promenjivu kliničku sliku, njihov tretman iziskuje adekvatnu procenu, planiranje i evaluaciju na periodičnoj osnovi.

Individualizovani modeli lečenja i nege TB bolesnika se ciljano dizajniraju u hospitalnim uslovima, da ponude svim obolelim, bez obzira na godine, rasu, veroispovest, pol, seksualnu orjentaciju ili težinu bolesti, najviši kvalitet lečenja i nege ispunjen, pre svega, neosuđujućim razumevanjem potreba obolelog.

Ključne reči: **tuberkuloza, stigmatizacija, lečenje, nega**