Esc Anna Nery (print)2013 Sep-Dec; 17 (4):749 - 754

COMPLETENESS IN CARING: STUDY OF QUALITY OF LIFE IN CLIENTS WITH TUBERCULOSIS

Integralidade no cuidado: estudo da qualidade de vida dos usuários com tuberculose

Integralidad en el cuidado: estudio de la calidad de vida de los clientes con tuberculosis

Sheila Nascimento Pereira de Farias[1], Célia Regina da Silva Medeiros[2], Elisabete Pimenta Araújo Paz[3], Alexandrina de Jesus Serra Lobo[4], Liane Gack Ghelman[5]

Submitted on 06/17/2013, resubmited on 08/26/2013 and accepted on 09/09/2013

ABSTRACT

Objective: This study aimed to analyze the QOL of subjects in TB treatment at a health facility in Rio de Janeiro. **Methods:** Cross-sectional study with a descriptive-correlational design and a purposeful sample of 102 patients. We used the instrument ofthe TB Network and WHOQoL-bref. **Results:** The inferential analysis revealed that overall QOL is more associated with the psychological domain, followed by the environment, social relationships and, lastly, the physical domain. In view of the results,we can conclude that TB affects the entire universe of the individual, given its physical-organic, psycho-affective and social implications. **Conclusion:** In providing nursing care, it is important to value the patients' assessment of their life and health, besides theirindividuality and subjectivity, to assure comprehensive care.

Keywords: Tuberculosis; Quality of life; Nursing.

RESUMO

O objetivo deste estudo foi analisar a qualidade de vida dos sujeitos em tratamento da tuberculose em uma unidade de saúde do Rio de Janeiro. **Métodos:** Estudo transversal do tipo descritivo-correlacional, com uma amostra de intencional de 102 clientes. Utilizou-se o instrumento da Rede TB e o WHOQoL-bref. **Resultados:** Pela análise inferencial constata-se que a QV global está mais associada ao domínio psicológico, seguido do ambiente, das relações sociais e, por último, ao físico. Face aos resultados,pode-se concluir que a TB atinge todo o universo do indivíduo, dadas as suas implicações físico-orgânicas, psicoafetivas e sociais. **Conclusão:** Na prestação de cuidados de enfermagem, importa valorizar a avaliação que a própria pessoa faz da sua vida e saúde, além da sua individualidade e subjetividade, para assegurar a integralidade da assistência.

Palavras-chave: Tuberculose; Qualidade de vida; Enfermagem.

RESUMEN

Objetivo: Este estudio tuvo como objetivo analizar la calidad de vida de los pacientes en tratamiento de la tuberculosis en un centro de salud en Rio de Janeiro. **Métodos:** Estudio transversal descriptivo-correlacional, con una muestra intencional de 102 clientes. Se utilizó el instrumento de Red TB y WHOQOL-BREF. **Resultados:** Para el análisis inferencial, se constata que la QV global es más asociada con el dominio psicológico, seguido por el ambiente, las relaciones sociales y por último con el físico. Dados los resultados, podemos concluir que la tuberculosis afecta a todo el universo de la persona, teniendo en cuenta sus implicaciones físico-orgánico, psicoafectivas y social. **Conclusión:** En la prestación de cuidados de enfermería importa valorar la evaluación que la propia persona hace de su vida y salud, además de su individualidad y subjetividad, para garantizar una atención integral.

Palavras-clave: Tuberculosis; Calidad de vida; Enfermería.

[1] Universidade Federal do Rio de Janeiro - Rio de Janeiro - RJ -Brazil.
[2] Universidade Federal do Rio de Janeiro - Rio de Janeiro - RJ -Brazil.
[3] Universidade Federal do Rio de Janeiro - Rio de Janeiro - RJ -Brazil.
[4] Escola Superior de Enfermagem Dr. José Timóteo Montalvão Machado - Chaves - Portugal.
[5] Universidade Federal do Rio de Janeiro - Rio de Janeiro - RJ - Brazil.

Corresponding Author: Sheila Nascimento Pereira de Farias E-mail: sheilaguadagnini@gmail.com

DOI: 10.5935/1414-8145.20130020

INTRODUCTION

Integrality considers the service network with distinct complexity and competency levels, in which actions at the different levels are integrated and respond to the set of care an individual demands. It can be considered as the articulation among promotion, prevention of health problems, health recovery and restoration, so as to deliver care through actions that are structured in the same space, involving the constitution of knowledge and mutually interpenetrating actions in health work[1].

As expressed in the Brazilian constitution (art.198, 1988), "comprehensive care" should be prioritized for preventive activities when intervening in diseases and their complications, without impairing the clinical care activities. Integrality is not just a guidelines of the unified health system (SUS). It can be understood as a set of notions pertinent to expanded care articulating the professionals' actions in a comprehensive view of the human being, endowed with feelings, desires, afflictions and rationalities[2].

In health actions, it is emphasized that the interaction with clients should be guided by emancipatory values, based on guarantees of autonomy, on the exercise of solidarity and on the acknowledgement of the freedom to choose the health care one wishes to receive. The health team needs to make coordinated efforts to produce and promote user care, in the attempt to establish bonds, conducts and prioritizing their needs, which will further the response to their demands and satisfaction with the services[3].

To develop health actions for tuberculosis (TB) patients from a comprehensive care perspective, a comprehensive approach is needed to the subjects who deliver care. Thus, in the context of health practices, one can understand the actions focused on the primary care level whose meanings materialize integrality, as well as the strategies to consolidate the universalization and equity in care, which mirror the great challenges to put in practice the right to health in country with profound inequalities like Brazil[4].

TB is an important public health problem in Brazil, due to the considerable number of cases that affect the population each year. In the country, 68,147 new cases of TB were notified in 2008 (incidence rate of 35.59 per 100,000 inhabitants), 56,172 of which were of the bacilliferous pulmonary type (incidence rate of 29.33 per 100,000 inhabitants) and 9,712 cases of extrapulmonary tuberculosis (incidence rate of 5.07 per 100,000 inhabitants). Rio de Janeiro ranks second among the states with the largest absolute number of TB cases in Brazil. When considering the number of deaths due to TB, however, the state displays the highest mortality rate[5].

TB affects people in the best years of their lives to study, work and establish social relations. The illness leads to the interruption or postponement of personal projects, which can entail a complete change in the lives of some people. The changes the disease entails in daily reality can cause apathy or lack of desire to perform the activities the individual was used to[6].

The identification and appropriate treatment of pulmonary TB patients correspond to one of the priority measures to control the disease and has deserved special attention, keeping in mind that pulmonary TB is the most transmissible form of the disease, and that bacilliferous patients are an important source of infection for their domestic contacts. Nevertheless, a pulmonary TB case does not derive from a single cause and the presence of the bacillus in the pulmonary environment. Instead, the progression of the disease, the sum of physical, social and emotional factors contribute to illness due to *Mycobacterium tuberculosis*[5].

It is relevant to mention the frequent association between TB and other illnesses, such as kidney failure, tumors, silicosis, alcoholism, diabetes mellitus, and also with the use of corticoids. One of the most prevalent associations exists between TB and HIV infection though. In cases of pulmonary tuberculosis, it is very important to detect the affected patients' contacts, as these may have caught the disease and transmit it, contributing to an increase in the number of cases. It is fundamental that these contacts also visit the health service to undergo tests and receive clarifications about the disease. In general, when evaluating tuberculosis patients and their contacts, it is fundamental to take into account the different aspects of their lives, including the functional status, psychological wellbeing and position towards their own life, which will directly affect their quality of life (QOL)[7].

The World Health Organization has defined QOL as "an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns"[8]. Hence, health professionals can directly influence the QOL, whether in the positive or negative sense, through their interventions in the health-disease process. In this context, one needs to understand that, in TB patients, QOL is a complex combination of disease, poverty, stigma, discrimination and lack of treatment, combined with family life, work and social activities. Also, the disease affects not only the infected person, but also his/her family, community and country[9]. By assessing the health-related QOL, the goal is to discover how tuberculosis patients live with the disease and the influence of the treatment in their life context.

A better understanding of the TB patients' experiences can help to improve the therapeutic schemes, treatment adherence and these people's wellbeing, enhancing the success of their therapeutic process[10]. Lack of awareness or knowledge about the disease can make TB patients perceive the impact of tuberculosis in their life and health mistakenly, which can affect the information and adherence to the appropriate therapeutic scheme. Also, the integrality of care results in a better QOL. Thus, the aim in this study was to analyze the quality of life of users undergoing TB treatment at a health service in Rio de Janeiro.

METHOD

A cross-sectional, descriptive and correlational study with a quantitative design was carried out. The theoretical-methodological framework was based on the World Health Organization's Quality of Life concept[8]. The study involved 102 TB patients attended at a Primary Health Care Unit of the Rio de Janeiro Municipal Health Secretary, located in Planning Area 2.2, which functions between 7 and 17h and offers services in the following programs: woman's health, diabetes and hypertension, elderly health, Hansen's disease, immunization, TB control. The unit has a clinical laboratory for analytic tests, including direct smears for acid-fast bacilli and sputum cultures.

To participate in the research, the following inclusion criteria were defined: age 18 years or older; being enrolled in the tuberculosis control program at the polyclinic; having started the medication treatment; signing the free and informed consent form.

Data were collected between February and April 2010, before the scheduled medical appointment, in a room reserved for the research participants. The instrument formulated by the Brazilian TB Research Network-Rede TB was used to characterize the subjects and the WHOQoL-Brefto analyze the QOL[8].

The WHOQoL-Bref consists of 26 questions, 24 of which are distributed in four domains: physical, psychological, social relations and environment. In addition, two general questions are included, one related to the self-perceived QOL and the other to satisfaction with health. Each domain is represented by several facets and questions are formulated for a Likert response scale, with intensity (nothing - extremely), capacity(nothing - completely), frequency (never - always) and assessment scales (very dissatisfied - very satisfied; very bad - very good), all of them consisting of five levels (one to five). Likert-type scales are frequently used in population surveys. Five-level scores are more advisable because of their capacity to measure extremes as well as intermediary accessibility scores, making it feasible to classify it as satisfactory, regular and unsatisfactory[11].

The data were analyzed in the software *Statistical Package for the Social Sciences* (SPSS) version 17 for Windows, in accordance with the orientations of the World Health Organization.

The project was assessed by the Research Ethics Committees at Anna Nery School of Nursing - Teaching Hospital São Francisco de Assis (EEAN-HESFA) and the Rio de Janeiro Municipal Health Secretary and authorized under protocols 077/09 and 214/09, respectively.

RESULTS

Concerning the participants' sociodemographic characteristics (Table 1): 64% are men; 35% are between 18 and 29 years old; 40% are married; 52% informed that they did not finish primary education; 27% are employed and 62% receive between one and three minimum wages.

As regards the Quality of Life-related variables, it is observed in Table 2 that the mean domain scores were similar (without statistically significant differences), demonstrating a certain degree of homogeneity among these aspects in the analyzed individuals' lives. The highest mean domain score was found for social relations (63.82±15.43), followed by the psychological domain and the physical domain with very similar results (56.91±11.97 and 57.99±10.15, respectively). The social domain revealed the highest score (83.33), while the lowest was found in the environmental domain (21.88).

As regards Table 3, which displays the inferential analysis of global Quality of Life and its domains, a stronger relation is found with the psychological domain (r=0.860; p=0.000), followed by the environment (r=0.757; p=0.000), social relations (r=0.686; p=0.000) and, finally, the physical domain (r=0.581; p=0.000).

DISCUSSION

It is highlighted that most users are male, indicated unfinished primary education and gain a low income, indicating a higher prevalence of TB in individuals with these socioeconomic characteristics, as confirmed in other studies[12,13]. The low income and education evidence social vulnerability, which influences the collection of information about the disease and therapeutic care. In addition, most participants live with family and/or a partner, who grant them support for care and health maintenance. The family environment can offer further psychological, emotional and physical support in daily life[14].

Table 1. Sociodemographic profile of TB patients.

Variables		f	%
Gender	Female	37	36%
	Male	65	64%
Age	18-29	36	35%
	30-39	20	20%
	40-49	20	20%
	50-59	14	14%
	Over 60	12	12%
Marital status	Single	36	35%
	Fixed partner	14	14%
	Married	41	40%
	Separated	4	4%
	Widowed	7	7%
Education	Unfinished primary education	53	52%
	Finished primary education	32	32%
	Secondary education	10	10%
	Higher education	7	7%
Occupation	Unemployed	8	8%
	Employed	28	27%
	Housewife	18	18%
	Autonomous	20	20%
	Student	10	10%
	Retired	6	6%
	Maintenance	12	12%
Family income	No fixed income	13	13%
	Between 1 and 3 minimum wages	63	62%
	Between 3 and 5 minimum wages	25	25%
	More than 5 minimum wages	1	1%

Table 2. Mean Quality of Life score in different domains.

Domains	Mean±standard deviation	Maximum (%)	Minimum (%)
Physical	57.99±10.15	71.43	39.29
Psychological	56.91±11.97	75.00	25.00
Social Relations	63.82±15.43	83.33	25.00
Environment	50.70±11.11	68.75	21.88

Table 3. Inferential analysis of QOL with its domains.

	Global QOL	P value
Physical	0.581	0.000
Psychological	0.860	0.000
Social Relations	0.686	0.000
Environment	0.757	0.000

Quality of life assessment has received special attention in recent years, especially for individuals with chronic illnesses and/or undergoing extended treatment. This fact derives from the change in the way the patient's general condition is assessed, which started to involve not only the professionals responsible for the treatment, but also the patient him/herself. The perceived QOL is not only subjective, but also complex and dynamic, as an imminently human notion that has been related with the degree of satisfaction found in family, love, social and environmental life and the existential esthetics itself[12].

The satisfaction with life and feeling of wellbeing can often be affected by the diagnosis of a chronic illness like tuberculosis. Therefore, the conquest of a high-quality life can be constructed and consolidated, in a process that includes health promotion and professional activities adapted to the patients' needs[15].

Despite some confusion between the physical health condition and quality of life, it is considered that quality of life refers to a direct consequence of one's health condition[16]. In the analysis of the general scores, the quality of life of the TB patients can be considered good. In the study, the environment revealed to be the most negative domain. In that sense, the transmission of TB is directly associated with the population's living conditions. Therefore, the conditions of the focus patients' homes need to be investigated, prioritizing those cases with inappropriate ventilation and overcrowding, as closed environments facilitate the transmission and domestic contacts are at the greatest risk of catching the disease[5].

As regards the psychological domain, knowledge about the diagnosis and treatment implications are associated with emotional instability, demanding help for the sake of psychological adjustment and coping with the disease[17]. Besides the suffering the disease itself causes, stigma and social prejudice are relevant aspects that negatively affect the course of treatment and the quality of life of tuberculosis patients. Although the study subjects present better results in the physical and social relations domains, it is a fact that TB requires adjustments in daily life, as well as the redefinition of oneself and relations with other people. Social interaction abilities are fundamental in view of these patients' need to conquer and maintain social support networks to promote their QOL[15].

The uncomfortable symptoms of TB and the drugs can cause adverse reactions during treatment. Nevertheless, therapeutic advances have permitted a better impact on these people's physical and psychological health. Today, as a result of effective treatment, society no longer sees TB patients as a collective danger, although the prejudice is still present in society. TB patients can already understand that, when they get ill, the limitations felt do not condemn them to a social, family and professional death, although this feeling permeates their daily life sometimes. In most cases, the limitations derive from their own physical condition, which is strongly affected by the disease[12].

To promote conditions that improve the quality of life of tuberculosis patients from the perspective of comprehensive actions, the professionals working in the control program are challenged to solve contingency problems that directly affect patients and their contacts. The monitoring of the problems these subjects experience and appropriate support can further treatment adherence, increasing the number of therapeutic success cases. Therefore, healthcare managers need to include not only indicators of changes in the frequency and worsening of the disease, but also indicators of wellbeing, as that is the only way to understand the essence of care delivery[18].

Although TB is curable, it still exerts "a significant impact in the QOL" of the patients. Even if the study subjects indicated a good QOL, it should be acknowledged that TB changes people's lives, mainly with regard to the medication treatment.

CONCLUSION

According to the results, it can be concluded that TB affects patients' entire universe, in function of its physical-organic, psycho-affective and social consequences. It was verified that global QOL is more associated with the psychological and environmental domains. Therefore, it is highlighted that, in the relation that exists between quality of life and integrality, health actions need to be implemented and consolidated through an agreement among the patient, the professional and the family. It is emphasized that the guiding principle of comprehensive actions enhances the implementation of strategies to further the patients' quality of life, especially in care delivery to stigmatized conditions like TB, as the health professionals and their practices are key elements to improve the physical, psychological and social conditions of the individuals under their responsibility.

Hence, in nursing care delivery permeated by comprehensive health care in the response to each singular individual's health needs, whether these are implicit or explicit, it is important to value to subjectivity and individuality of each subject, justifying the importance of assessing what that person makes of his life and health. That is a core aspect when considering the reduction of damage and social vulnerability, with a view to a successful therapeutic process and the achievement of better quality of life levels for health service units.

The sample size should be considered as a study limitation. Other studies with expanded samples are suggested from a quality of life assessment perspective, as a relevant aspect in the treatment and control of tuberculosis in communities.

REFERENCES

1. Pinheiro R. Atenção básica à saúde: um olhar a partir das práticas de integralidade em saúde. REME rev. min. enferm. 2005 abr-jun; 9(2):174- 179.
2. Viegas, S.M.F, Penna, C.M.M. A Construção da integralidade no trabalho cotidiano da equipe saúde da família. Esc Anna Nery. 2013 jan-mar; 17(1):133-41.
3. Viegas SMF, Hemmi APA, Santos RV, Penna CMM. O cotidiano da assistência ao cidadão na rede de saúde de Belo Horizonte. Physis (Rio J.) (Online). 2010 [Citado 2012 maio 28]; 20(3):769-84. Disponível em: <http://www.scielo.br/pdf/physis/v20n3/v20n3a05.pdf>.
4. Valentim IVL, Kruel AJ. A importância da confiança interpessoal para a consolidação do Programa de Saúde da Família. Ciênc. saúde coletiva (Online). 2007 Jun [Citado 2012 maio 28];12(3):777-8. Disponível em: <http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413--81232007000300028&lng=en&nrm=iso>.
5. Ministério da Saúde (Brasil). Manual Técnico para o controle da TB: cadernos de atenção básica. Brasília (DF): MS; 2010.
6. Silva JR., Barbosa J. Tuberculose: Guia de Vigilância Epidemiológica. Jornal Brasileiro de Pneumologia. São Paulo; 2008.
7. LEMOS, Larissa de Araújo; FEIJAO, Alexsandra Rodrigues; GIR, Elucir and GALVAO, Marli Teresinha Gimeniz. Aspectos da qualidade de vida de pacientes com coinfecção HIV/tuberculose. Acta paul. enferm. (Online). 2012 [citado 2013 set. 05], 25(n. esp.):41-7. Disponível em: <http://www.scielo.br/scielo.php>.
8. Fleck MPA. A avaliação de QV: guia para profissionais de saúde. Porto Alegre (RS): Artmed; 2008.
9. Dhuria M, Sharma N, Ingle GK. Impacto of tuberculosis on the quality of life. Indian J. Community Med. 2008;33(1):58-9.
10. Dourado VZ. Influência de características gerais na QV de pacientes com doença pulmonar obstrutiva crônica. J Bras Pneumol. 2004 maio-jun; 30(3):207-14.
11. Arcêncio, R.A. et al. City tuberculosis control coordinators perspectives of patient adherence to DOT in São Paulo state, Brazil. Int. Tuberc. Lung. Dis; 2008 maio; 12(5):27-531.
12. Miranda AE, et al. Tuberculosis and AIDS co-morbidity in Brazil: linkage of the tuberculosis and AIDS databases. Braz J Infect Dis. 2009;13(2):137-41.
13. Neto LMS et al. Enteroparasitosis prevalence and parasitism influence in clinical outcomes of tuberculosis patients with or without HIV co-infection in a reference hospital in Rio de Janeiro (2000-2006). Braz J Infect Dis. 2009;13(6):427-32.
14. Neves, L.A.S et al, Perspectiva da qualidade de vida dos indivíduos com tuberculose. Rev. Esc. Enferm. USP. 2012;46(3):704-10.
15. Guo N, Marra F, Marra CA. Measuring health-related quality of life in tuberculosis: a systematic review. Health Qual Life Outcomes. 2009;18(1):7-14.
16. Rodrigues ILA , Souza MJ. Representações Sociais de clientes sobre a TB: desvendar para melhor cuidar. Esc Anna Nery. 2005 abr; 9(1):90-7.
17. Pungrassami P, Kipp AM, Stewart PW, Chongsuvivatwong V, Strauss RP, Van Rie A. Tuberculosis and aids stigma among patients who delay seeking care for tuberculosis symptoms. Int J Tuberc Lung Dis. 2010;14(2):181-7.
18. Eram U, Khan IA, Tamanna Z, Khan Z, Khaliq N, Abidi AJ. Patient perception of illness and initial reaction. Indian J Community Med. 2006;31(3):198.