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Patients' Experience of Tuberculosis Treatment Using Directly Observed Treatment, Short-Course (DOTS): A Qualitative Study

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Background: Despite effective diagnosis and treatment, prevalence of tuberculosis (TB) is still growing. The directly observed treatment, short-course (DOTS) strategy to treat TB was introduced by the World Health Organization more than a decade ago. Little is known about patients' experience of TB treatment, according to DOTS, in Iran.
Objectives: This study aimed to understand the patients' experience of tuberculosis treatment according to DOTS in Iran.
Patients and Methods: This study is a qualitative study, using content analysis to examine patients' experience of TB treatment and to understand their compliance during DOTS. In this study, a semi-structured interview with open questions was answered by 40 patients, who had a diagnosis of pulmonary and extrapulmonary tuberculosis, and improved during the course of their treatment. The method of sampling was purposive sample and the interview process lasted until data saturation.
Results: Data analysis resulted in the extraction of six themes, which reflect the experiences of the study participants. The themes are: 1) individual factors; 2) change of the attitudes and beliefs of patients on TB treatment; 3) support terms of patients with tuberculosis; 4) the role of health care professionals; 5) social factors and 6) the financial burden.
Conclusions: Successful completion of TB treatment requires an effective partnership between the patient and health care professionals, and a harmony between the cultural context, attitude of the patient, family support and health literacy. Future health policies should address these issues to improve patients' adherence to DOTS.

Keywords: Tuberculosis; Treatment; Qualitative Research; Iran

1. Background

Tuberculosis (TB) is one of the oldest diseases known to humankind, and it is the second leading cause of death from an infection worldwide today. The World Health Organization (WHO) estimates that the global incidence of TB in 2012 was 8.6 million cases, with 1.3 million deaths, predominantly occurring in developing countries (1-6). The Stop TB program, developed by the WHO and its partners, aims to reduce the burden of disease in accordance with the global targets set for 2015 (2, 7, 8). Tuberculosis is the second cause of death from infectious diseases after HIV in the world (9). The initial optimism that DOTS would have a dramatic effect on TB incidence rates in developing countries has not been supported by the evidence accumulated so far (10). The WHO recommended treatment strategy for detection and cure of TB is DOTS, which is the most effective strategy available for controlling the TB epidemic today (11, 12). The DOTS regimen has higher cure rates and a lower incidence of adverse reactions compared, with the non-DOTS regimen (13). The TB is an important health problem in Iran and the issue has become even more and therefore, as a result of increasing drug-resistant strains, drug resistance complicates efforts to control TB. Moreover, the problem of extensively drug-resistant strains has recently been introduced (14, 15). Despite effective drugs and diagnostic methods, TB is one of the main killers of humanity throughout history and is still growing (16, 17). Patient adherence and appropriate monitoring systems in healthcare can lead to the prevention of outbreak of multidrug-resistant TB. It is important to know patients' experience of TB treatment, according to DOTS.

2. Objectives

This qualitative study aims to investigate experience of

TB treatment in patients, who were treated according to DOTS, in Iran.

3. Patients and Methods

A qualitative method, with directed content analysis approach, was used. The goal of a directed content analysis approach is to validate or extend conceptually a theoretical framework or theory. Existing theory or research can support the research question, to begin identifying key concepts or variables, as initial coding categories (18).

3.1. Data Collection

The data were collected through semi-structured in-depth interviews, with 40 participants from December 2013 to April 2014. After transcription and analysis of each interview, in case of ambiguity and for probing into participants' experience, the interview question was repeated to clarify different aspects of the subject, if needed. Each interview lasted between 40 to 60 minutes and all the interviews were conducted in a private room. During interviews, memos and reflections were written by the interviewers. The interview guide consisted of open-ended questions, allowing respondents to fully explain their own experiences. Participation was voluntary and written consent was obtained from all respondent. The study was approved by the Ethics Committee of Lorestan University of Medical Sciences, Lorestan, Iran. The participants were reassured about confidentiality and anonymity. The authors of this manuscript have certified that they comply with the principles of ethical publishing.

3.2. Data Analysis

All interviews were conducted, recorded, transcribed verbatim, then reviewed, coded and immediately analyzed. A directed content analysis approach was used for data analysis. According to the directed content analysis process, at first, each interview was read carefully several times to gain deep understanding of the data. If the goal of the research is to identify and categorize all instances of a particular phenomenon, such as emotional reactions, then it might be helpful to read the transcript and highlight all text that, on first impression, appears to represent an emotional reaction. The next step in analysis would be to code all highlighted passages using the predetermined codes (18). Then, important statements were underlined to identify the initial codes or meaning units that exist in the interview text. In the next phase, these similar meaning units (codes) were placed initially in subcategories of the PRECEDE planning model and then into its three main categories of predisposing, enabling and reinforcing. Any text that could not be categorized, with the initial coding scheme, would be given a new code. The data collection process was continued until data saturation.

Stages to qualitative data analysis involved in "Framework" are:

1) Familiarization: Authors listened to recorded interviews several times to become familiar, read the transcripts, reviewed the field notes and so on, in order to find key ideas and recurrent themes.

2) Identifying a thematic framework: The stage of identifying all the key issues, concepts, and themes by which the data can be examined and referenced. Drawing on a priori issues and questions derived from the aims and objectives of the study, as well as issues raised by the respondents themselves and views or experiences that recur in the data. The end product of this stage is a detailed index of the data, which labels the data into manageable chunks for subsequent retrieval and exploration.

3) Indexing: index systematically to all the data in textual form by annotating the transcripts with numerical codes from the index, usually supported by short text descriptors to elaborate the index heading.

4) Charting: rearranging the data according to the appropriate part of the thematic framework to which they relate, and forming charts. The charts contain distilled summaries of views and experiences. Consequently, the charting process involves a considerable amount of abstraction and synthesis.

5) Mapping and interpretation: using the charts to define concepts, map the range and nature of phenomena, create typologies and find associations between themes, with a view to providing explanations for the findings.

3.3. Consideration of Rigor

Prolonged engagement in the field, from September to December 2013, helped to establish a certain degree of trust and rapport with participants, providing an opportunity to collect the data. To make sure that the analysis reveals the patients' experience, member checking was performed during the data collection, and where needed, several changes were done. To confirm dependability and conformability of the data, the interviews and results of the analyses, the initial codes, subcategories and the categories determined were audited by several experts, the external check method using the co-author (Masoud Mirzaei and Masoud Behzadifar) expertise in health education. Maximum variation of sampling confirmed the conformability and credibility of data. Sampling strategies allowed for maximum variation to occur and a vast range of views and perspectives to be considered. Interviews continued until data saturation, when no new ideas emerged during the interviews.

4. Results

Mean age for the studied patients was 40 ± 17 years (mean ± standard deviation (SD)), age range (16-81) years. In terms of gender, the number of males and females were equal. The majority of individuals, in terms of mari-

tal status, were married (57.5%), Secondary and tertiary graduates (55%), had pulmonary tuberculosis (65%), and were under 25 years of age 25% of patients. Demographic data of the subjects are listed in Table 1.

We identified six major issues, under three subcategories of individual factors, related to patients' experience of tuberculosis treatment using DOTS, which included changing attitudes and beliefs about the treatment of tuberculosis patients, protecting patients' privacy role of health care, professionals and system, social factors, and the financial cost of treatment. Details of the emerged themes are presented in Table 2.

4.1. Individual Factors

Patients expressed the following individual factors: Acceptance by the illness, awareness of its treatment, lack of knowledge of the dangerous side effects of drugs used to treat, non-compliance, knowing that the treatment of the disease is free and not be scared of failure, fear of stigma, no use of tobacco, alcohol, and drugs, which may lead to treatment failure, abstain from drug use because of the lack of employment problems and social tensions, failure to stop medication due to side effects, such as redness, taste, urine changes, itching, etc., no fear of illness and worries that he is not married, select the medications provided by health centers and not another drug, taking care of the family (wife and children) with their adherence.

Table 1. The Study Patients' Characteristics [a]

Variables	Values
Gender	
Male	20 (50)
Female	20 (50)
Marital Status	
Married	23 (57.5)
Single	11 (27.5)
Spouse	5 (12.5)
Divorced	1 (2.5)
Educational level	
Illiterate	3 (7.5)
Under Diploma	9 (22.5)
Diploma	22 (55)
Higher diploma	6 (15)
Type disease	
Pulmonary tuberculosis	26 (65)
Extra pulmonary	14 (35)
Residency	
Urban	24 (60)
Rural	16 (40)
Age, y	
< 25	10 (25)
25–35	7 (17.5)
35–45	9 (22.5)
45–55	7 (17.5)
> 55	7 (17.5)

[a] Data are presented No. (%).

Table 2. Factors Affecting Adherence to Treatment [a]

Number	Issues Related to Patients' Experience of Tuberculosis Treatment Using DOTS	Factors Affecting Adherence
1	Individual factors	Acceptance of the illness, its treatment of awareness, lack of knowledge of the dangerous side effects of drugs used to treat, non-compliance, knowing that the treatment is cost-free for the patient, not be scared of failure, fear of stigma, no use of tobacco, alcohol, and drugs which may lead to treatment failure, abstain from drug use because of the lack of employment problems and social tensions, failure to stop medication due to side effects, such as redness, taste, or urine changes, itching, etc., no fear of illness and worries that he is not married, select medications provided by health centers and not another drug, taking care of the family (wife and children) with their adherence.
2	Changing attitudes and beliefs about treatment of tuberculosis patients	Patients statements to change the attitudes and beliefs of patients on TB treatment, including the belief of having appropriate medications, health centers, convinced that the monitoring staff for health improvement is more appropriate, to ensure effective and correct use of regular medication.
3	Laws protecting patients'	Rules for the support of patients with TB disease, in which the following points were considered: ensuring patient confidentiality and his lack of social and work prejudice, for his legal support of the premium of his rights.
4	Role of health care professionals and system	About the role of healthcare personnel, medical healthcare system, patients were referred to the following points: The role of staff in the health sector, especially education about treatment, the number of patients taking drugs and dealing appropriately with patients, providing adequate space for patients to service information and to patients on DOTS strategy.
5	Social factors	Patients suitable for the role of social factors in a patient with tuberculosis, patients avoid stigmatization by society and family, and healthcare avoidance for inappropriate behavior and personal encounters with appointed personnel.
6	Financial cost of TB disease	Patients on TB treatment informed of the role of the financial costs of free drug; Sputum tests and x-rays; Knowledge of the patient's illness causes social and economic problems that are not addressed, especially for the patient paid work, he noted.

[a] Abbreviations: DOTS, directly observed treatment short-course; TB, tuberculosis.

Table 3. Questions to be Asked by Patients [a]

Number	Questions
1	Tell me about your experiences of using the TB units services in terms of managing your illness.
2	Tell me your experiences about role of healthcare providers (doctor, nurse, health centers) for doing adherence of treatment controlling stress.
3	Tell me your experiences about the role of family for doing adherence of treatment controlling stress.
4	Tell me your experiences about social barriers for doing adherence of treatment.
5	What problems have you experienced in the course of treatment?
6	Is there anything else important you would like to talk about?

[a] Abbreviations: TB, tuberculosis.

4.2. Changing Attitudes and Beliefs About the Treatment of Tuberculosis

Patients expressed the need to change the attitudes and beliefs of patients about TB treatment using DOTS. This included acceptance of the disease, trust on DOTS health professionals, be convinced of the improvements of their health, to be ensured that effective and correct use of regular medication would recover them after treatment, according to DOTS.

"When they (healthcare professionals) said that I have TB, I did not believe it. After a few days, I accept the disease" (Female, 23 years).

"Before administering the treatment, healthcare professionals warned me about the consequence of withdrawal or irregular use of my medications, according to DOTS" (Male, 29 years)

4.3. Protecting Patients' Privacy

Patients were concern about their privacy during treatment. Patients should be ensured that their confidentiality is a priority for healthcare professionals, as one patient declared: "Now, that I am diagnosed with TB, and people are informed about it, no one talks to me and others leave me. I am afraid to tell anyone about my disease" (Female, 19 years old)

4.4. The Role of Healthcare Professionals

Patients expressed their needs for better education about TB treatment, in general, and DOTS, in particular. They requested more attention from the healthcare professionals, while their privacy was considered: "when I went to the health center to get my medication and test results, I preferred nobody would see me and to receive my education privately" (Female, 22 years old); "at the beginning of treatment, they (healthcare practitioners) told me that I have to take 6 months the treatment regularly and according to the protocol. They emphasized that non-compliance to treatment will reduce the chance of successful treatment" (Female, 22 years).

4.5. Social Factors

Patients were concern about people reactions to their disease, in their community. They concerned about being stigmatized by society and family. Several inappropriate encounters were mentioned by patients:

"At the beginning of my TB, I had used mask to avoid transmission of the disease. However, several people showed signs of being uncomfortable and avoided me" (Male, 49 years old).

4.6. The Financial Cost of Treatment

Patients on TB treatment concerned about the cost of TB treatment, including medications and various tests. Several mentioned the economic burden of the disease on their everyday life. They expected the health system to compensate their treatment. One said:

"My economic situation is not good and I cannot afford the cost of treatment I have concerned that I will die from TB if I cannot afford the cost of treatment" (Male, 32 years old).

Several also mentioned that they have to follow DOTS accountably to avoid extra cost for the health care system and the country. As one said:

"My disease has cost for the country, I have to follow the protocol carefully to avoid extra cost on family's budget and the country" (Female, 24 years old).

They acknowledge partial and total reimbursement of costs:

"I am happy that I did not lose my job due to my disease (TB). I am grateful that my salary was paid during the course of my treatment. I look carefully for DOTS to be respected as on protocol and get back to work" (Male, 29 years old).

4.7. Lack of Patients and Carers Involvement in Decision-Making

Patients and carers were asked if they felt involved in making decisions about their condition. Seven patients and family cares reported that healthcare personnel did

not readily trust or act on their knowledge of their signs, symptoms and beliefs about their illness. This limited the capacity of patients and carers to participate in their care, because there was a perception that healthcare professionals were dismissive and failed to take the views of patients into consideration. The healthcare professionals agreed that the inclusion of patients in planning and decision making about their health could be very helpful in achieving a better health outcome. Limited time and human resources were seen, as significant barriers.

5. Discussion

This study has demonstrated that patients with TB, who received treatment according to DOTS, faced a range of challenges in completing the treatment. These include attitudes and beliefs about the treatment of TB, protecting patients' privacy, the role of health care professionals and system, social factors and the financial cost of treatment. Other studies mention patient perceptions of disease in high-prevalence areas, reducing the transmission of disease through early detection and immediate treatment of patients with TB (19). The role of individual factors on individual behavior therapy is effective (20). These involve patients' understanding of their illness, beliefs, attitudes toward treatment, as such factors affect the individual treatment. Lack of attention to factors, such as poverty and gender discrimination, may lead to treatment failure (21). When someone is identified as a patient, he needs to be motivated to treat according to his desire and make their adherence to the treatment the highest possible (21-24). Numerous studies reveal the influence of social environment on health and well-being. The role of community, family services and health systems, is essential in counteracting the feelings of stigma of the disease, and help patients to overcome wrong thinking and attitudes and follow the protocol more cautiously (25). Factors related to health care professional and system includes flexibility in patients' demands, depending on the type of services provided to patients, reducing the waiting time, creating a convenient location for the completion of the treatment and improving patients' satisfaction (26-28). Providing financial support will help to complete their treatment according to DOTS. Patients' concerns regarding the cost of treatment should be considered (29). When people with low incomes are faced with the costs of TB, they suffer from distress and are aware that therapies are expensive (30, 31). It is essential to ensure the preservation of their jobs, because in the absence of disease, the patient will have more confidence to continue his treatment, whereas neglecting these issues makes the patients not willing to treat themselves (32). To achieve the main goal in the early treatment of patients with TB, it is mandatory to manage prevention of infection and reduce the social and economic costs. Considering this is essential if we want patients to adhere to their treatment of TB, we should strive to learn effectively and interconnected factors should continuously be assayed. Successful completion of TB treatment requires an effective collaboration between the healthcare professional and the patient. The cultural context, the attitude of the patient, patient and family education and information, supported by the appropriate legislation are key factors to be considered to aid in reducing the livelihood concerns of patients and lack of patient adherence to treatment and health care costs.

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Authors' Contributions

Meysam Behzadifar and Masoud Behzadifar contributed to the development of the research protocol, implementation of the research, and drafted the manuscript. Dr. Masoud Mirzaei helped in analysis of the data and writing the manuscript. Drs. Maryam Saran, Masoud Behzadifar, Maryam Behzadifar and Abouzar Keshavarzi contributed to data collection and analysis and also scientific integrity of data collection and revision of the manuscript. Masoud Behzadifar was advisor to the study, contributed to the interpretation of data and revising the manuscript. All authors have read and approved the final manuscript.

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