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Full Length Article

Lived experience of patients on tuberculosis treatment in Tshwane, Gauteng province



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ABSTRACT

Tuberculosis is one of the communicable diseases that still contributes substantially to the worldwide disease burden and is still a major health threat worldwide. In order to gain a better understanding of being a patient taking tuberculosis treatment and to improve adherence to treatment, this phenomenological study was conducted to explore the lived experience of patients on tuberculosis treatment.

The population comprised patients in an identified tuberculosis clinic in Tshwane who had been on treatment for at least four months and who were able to communicate in English. The data gathering instrument was self-report by in-depth interview.

Some of the main themes that emerged include influence of personal social situation, influence of good social support and disclosure, experience of taking medication daily and knowledge about tuberculosis treatment.

Findings revealed that the personal social situations of the participants which include accommodation, unemployment and nutritional requirements influenced the adherence of the participants to treatment. It was discovered that good social support had an influence on adherence which could only be enjoyed when the treatment and diagnosis of tuberculosis is disclosed to the family members and friends. Some of the participants, who had been non-adherent in the past, attributed the reasons for their non-adherence to the side effects that they experienced. Lastly, participants also reported knowledge about tuberculosis, that is, knowledge about its causes, treatment and prevention, as crucial for adherence to treatment.

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1. Introduction and background

Despite the fact that tuberculosis is a curable disease, it is still a major cause of illness and death in South Africa and globally.

Tuberculosis is a complex disease that has biological, social, economic and cultural effects on the patient. These factors affects treatment adherence, which in turn affect treatment outcome. As with other long-term treatment, non-adherence

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to treatment is a problem in tuberculosis management treatment. Tuberculosis treatment presents particular challenges for adherence because treatment is long and involves taking a number of medications, side-effects are common, and patients usually feel better before treatment has been completed.

In the 2015 Global Tuberculosis Report, the World Health Organisation revealed South Africa as the second African country with a high tuberculosis incidence, behind neighbouring Lesotho with a smaller population (WHO, 2015, p. 159). South Africa was also reported as a country with a high incidence and prevalence rates with an estimated incidence of 450,000 cases of active tuberculosis in 2013 (WHO, 2015, p. 141).

Some of the factors that support the continued spread of tuberculosis include overcrowding, poor ventilation, unemployment, poverty and cultural beliefs (Selala, 2011, pp. 26–32).

The consequences of non-adherence to tuberculosis treatment includes prolong illness and disability for patient, infectiousness of patient causing tuberculosis transmission in the community, development of drug resistant tuberculosis and the possibility of death (Department of Health, 2014, p. 51).

According to The National Tuberculosis Management Guideline (Department of Health, 2014, p. 51) the aim of treatment is to successfully treat all patients who are started on treatment. However, little is known about the lived experience of being a tuberculosis patient taking treatment for long periods of time and few studies have been conducted in South Africa using the phenomenological route (Naidoo, Dick, & Cooper, 2009; Selala, 2011; Sissolak, Marais, & Mehtar, 2010).

1.1. Problem statement and objectives

The study was motivated by the problem of non-adherence to tuberculosis treatment, which has contributed to an increase in the number of drug resistant strains. Studies have shown that people diagnosed with tuberculosis and who are on treatment tend to discontinue their medication once they start feeling better, especially if they are not on directly observed treatment (Amuha, Kutwabami, Kittu, Odoi-Adome, & Kalyango, 2009, p. 10; Volmink, Matchaba, & Garner, 2000, p. 335).

The purpose of the study was to explore and describe the lived experiences of patients on tuberculosis treatment.

The objective of the study was to generate evidence which can be used to improve patients' adherence to tuberculosis treatment, in order to help to enhance tuberculosis cure and control.

The research question therefore was: What is the lived experience of patients who have been on tuberculosis treatment for at least four months?

1.2. Definition of keywords

Adherence to treatment means following the recommended course of treatment by taking all the medication, as prescribed, for the entire length of time necessary (Department of Health, 2014, p. 51).

Lived experience refers to the way individuals or groups make sense of a phenomenon, their world or situation (Speziale & Carpenter, 2002, p. 53).

Non-adherence refers to the failure of a patient to comply with or follow the treatment programme and medication regimen as prescribed (Smeltzer, Bare, Hinkle, & Cheever, 2013, p. 50).

Treatment is defined as the medical or surgical management of a patient (Stedman, 2013, p. 1590). In this study, treatment is the anti-tuberculosis drugs administered to the patient to destroy the tuberculosis bacilli.

2. Research design and methods

The design used for the study was exploratory, phenomenological and qualitative. Qualitative study is a form of social inquiry that focuses on the way people make sense of their experiences and the world they live in (Holloway & Wheeler, 2010, p. 3). A number of different approaches exist within the wider framework of this type of research and many of these shares the same aim: to understand, describe and interpret social phenomenon as perceived by an individual, group, or culture (Holloway & Wheeler, 2010, p. 3). Qualitative research methods of gathering data are ways of gaining insights through discovering meanings (Burns & Grove, 2009, p. 52) and also helps to obtain in-depth information on sensitive issues which otherwise might not be revealed in quantitative studies.

Phenomenological research identifies the essence of human experiences concerning a phenomenon as described by the participants in the study (Lobiondo Wood & Haber, 2006, p. 569). Lived experience of the world of everyday life is the central focus of phenomenological study, gives meaning to each individual perception of a particular phenomenon and is influenced by everything internal and external to the individual (Speziale & Carpenter, 2003, p. 53). Phenomenological method also identifies the way of thinking or perceiving a situation, event or phenomenon.

2.1. Target population and sampling

A purposive sampling method was used for selection of participants from the target population. The target population were the tuberculosis patients using a selected clinic in Tshwane and patients that met the criteria were invited to participate in the study. The inclusion criteria includes patients who have been on tuberculosis treatment for at least four months, who use the selected tuberculosis clinic, 18 years above, able to communicate in English and willing to participate.

2.2. Data collection

In-depth interviews were conducted by the principal investigator with the question “please, can you tell me from your own perspective, what has been your lived experience since you started tuberculosis treatment four months ago?” The patients that met all the criteria were approached after their clinic appointment and were then invited to participate in the

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