NURSES’ COMMITMENT TO THE CARE OF TUBERCULOSIS PATIENTS

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ABSTRACT: The objective of this qualitative study that followed the principles of the Grounded Theory was to understand the commitment of nurses in the care provided in primary health care to people with tuberculosis. The setting consisted of eight primary health care units. A theoretical sample was designed with 28 participants, including nurses, doctors, nursing assistants, technical staff, epidemiological surveillance professionals and people with tuberculosis. In-depth interviews were used for data collection. Data were analyzed using the Atlas.ti® software, by means of open, axial and selective coding. The singularities of care demanded commitment from the nurses towards tuberculosis patients, and included three components: the ethical-professional, the institutional-political and the social. This commitment was considered to be the driving force of a service that strives to guarantee quality care and access to tuberculosis patients, so that the disease is treated and patients can recover, have a healthy life and attend their social roles satisfactorily.

DESCRIPTORS: Tuberculosis. Nursing care. Primary health care.
INTRODUCTION

Tuberculosis (TB) still remains a major public health issue across the world. According to the latest estimates, there were 9.6 million new cases of tuberculosis in 2014 and 1.5 million deaths in that same year. Although these figures are significant, the tuberculosis mortality rate has fallen by 47% since 1990 and the incidence rate has also dropped in most countries, as a result of investments that have been made. Effective TB diagnosis and treatment saved about 43 million lives between 2000 and 2014. In Brazil, despite a decrease in TB incidence over the last 17 years, with a 38.7% decrease in the incidence rate and a 33.6% decrease in the mortality rate, the country is still among the 22 countries with the highest TB rates.1,2

One of the milestones of this change was the World Health Organization declaration that considered TB as a global public health emergency. Since then, several strategies for TB control have been launched, among them the Directly Observed Treatment, Short-course (DOTS), which is a reality in Brazil, despite the difficulties already encountered by some studies.3-5

In this context, the fight against tuberculosis continues, and improving its indicators even more and ensuring proper access to treatment has been a great challenge faced by different health professionals every day. Some of the most difficult aspects are still the challenge to decrease the incidence rate within some segments of the population, especially among the most vulnerable, and ensuring access and quality of health services.1,2 In Brazil, the National TB Control Program (PNCT) acknowledges the importance of extending TB control to all health services, allowing for the integration of TB control into primary care, which includes Family Health Strategy (FHS), in order to provide effective access to diagnosis and treatment of this disease.3

Nursing participation in the PNCT involves a set of recommended actions which defines the essential role played by nurses in the process of control of the disease. This nursing work has been historically influenced by the fact that nurses have had a significant role in TB control. The historical participation of nurses underscores the acknowledgment of the disease as a public health issue in Brazil and the inclusion of health education as an essential tool for raising collective and individual health awareness through actions performed by visiting nurses in the 1920s.6,7

From a historical perspective of the fight against this disease in Brazil, the nursing profession has provided legitimate statements about matters related to the care of people with TB, owing to their experience in controlling this disease, in both the hospital setting and in public health, including prevention, treatment and the training of human resources to take action against the disease.7,8 The role of nursing in the care of TB patients is currently being broadened with more effective contributions in primary care, and it also includes the production of new knowledge by means of relevant studies in the field.5,9-10 In addition, the managerial, organizational and educational nature of the profession often allows for the enacting of different roles by the nurses in the implementation of activities within health services that control and prevent TB.5,6,11-13

Humanization of health services is included in these aspects of nursing care, and this has become a challenge for nurses as its purpose is to keep in mind one’s values and an ethical commitment to patients.6 This highlights commitment as an attribute of care, and is defined as an emotional and complex response involving the desires and obligations of health professionals when making choices in the delivery of care.14

It was noted that the process of care of a TB patient implies more than the supply of medicine and the performance of tests. There is a need for the effective involvement of health professionals in care delivery, so that the effects of the disease on lives and factors that may influence treatment are understood. This contributes to delivery of service that is adapted to each patient’s context. These considerations about the nursing care of TB patients encouraged the conduction of this study with a focus on the nurses’ performance, in order to understand their commitment to the care delivered to TB patients in primary health care.

METHOD

This was a qualitative survey which used the Grounded Theory (GT) as a methodological reference. The GT uses the construction of a paradigm as an analytic tool, which enables the description
of conditions, situations or circumstances that
determine the formation of the phenomena stud-
ied. Among the circumstances that explain the
phenomenon, there is the causal condition for it to
happen, which in turn influences the existence of
this phenomenon.15

The study was conducted in eight primary
health care units, which belonged to the health
district with the highest incidence of TB in a north-
eastern Brazilian capital city. Data collection was
performed between September 2013 and February
2014, by means of in-depth interviews, based on
the guiding proposition “Talk about care of TB
patients”.

Participants were defined by theoretical sam-
ping. Four sampling groups were formed: the first
one was composed of 19 primary health care nurses;
the second was composed of five members of the
health care unit in which these nurses worked, con-
sisting of two doctors, two nursing technicians and
one nursing assistant; the third one was composed
of two epidemiologists who were responsible for
TB surveillance in the district where the health care
units were located, one nurse and one nutritionist;
and the fourth group was composed of two TB
patients who were undergoing treatment in these
health care units.

The inclusion criterion for the first group was
to have had vast experience in care of TB patients.
This criterion was easily met, since most nurses
who worked in the health care units of the chosen
district had been working in the Health Secretariat
for a long time, or since the beginning of the FHS.
The other participants, consisting of doctors, as-
sistants and nursing technicians were included in
order to understand some aspects highlighted by
nurses in their work with TB patients, especially
because they were part of the health staff that
worked with the nurses. Two epidemiologists
also agreed to be part of the study, which legiti-
mized the nurses’ perspective. The inclusion of TB
patients was the result of the need to analyze the
convergence between them and the nurses’ per-
spectives, and also had the purpose of confirming
the study’s interpretations.

The nurses had not met the researcher in per-
son before, contact was made by phone first, and
then an appointment was made. The other partici-
pants were appointed by nurses after the interview.

Data analysis was performed together with
data collection, by means of Atlas.ti®, version 7.1.8,
with license 710CF-CAB84-3697E-8CQ81-002JY.
By means of this program, all interviews were or-
ganized and encrypted by line by line, diagrams rep-
resenting the categories and showing the relation
between codes, subcategories and categories were
created. It also allowed for creating memos and
relate them to the subcategories. In this analytical
and comparative process, open, axial and selective
codings were performed. Out of this analysis, the
category “Committed to TB patients recovery” was
created, which was seen as a causal condition to
the studied phenomenon and titled: “Nurses’ care
of tuberculosis patients in primary health care”.
It was understood that this care is provided after
a commitment made by nurses in their practices.
The study was approved by the Research Ethics
Committee of the Universidade Federal de Santa Ca-
tarina, under CAAE number 20637113.9.0000.0121.
Ethical and scientific principles related to human
research were respected, as well as the process of
free and informed consent of participants, and all
data created were stored. Nurses were identified
by the ordered sequence of interviews and the
inclusion in Atlas.ti®, for which the interview was
a primary document.

RESULTS

The 19 nurses who participated in the study
were all women aged between 41 and 57 years old.
They had been qualified as nurses for more than 20
years, with the longest experience being 32 years.
The length of experience in TB care of most nurses
was more than 20 years. The doctors, assistants
and nursing technicians were aged between 48
and 62 years old and had been working in TB care
for 22 years. The epidemiologists were 29 and 52
years old and had been responsible for TB care for
nearly seven years. The TB patients were 29 and
65 years old, the youngest being a man who was a
sound setup operator, and the older patient was a
housewife. They were both at the final stage of the
treatment.

Data analysis allowed for highlighting the cat-
egory “Committed to TB patients recovery”, which
showed that in the care of TB patients, nurses were
effectively engaged and this engagement included
three analytical components: ethical-professional,
institutional-political and social. These three commitments took place simultaneously and were intertwined in the care performed by nurses. We considered as commitment everything that encouraged nurses to keep taking care of TB patients with responsibility, for their recovery and for their relationship with the community where they were located.

**Ethical-professional commitment**

The ethical-professional commitment included the ethical and professional health and nursing principles as factors that motivated their actions in the care of TB patients. These ethical principles included: doing good; doing no harm to TB patients; being responsible for people’s recovery; respecting people and their background and decisions; being aware of situations of risk in which people are found; helping people to free themselves from fear of the disease, and eliminating prejudice and stereotypes which hampered care and autonomous actions. In the nurses’ speeches, their concern with trying to do good for TB patients and doing no harm in response to the health services demanded were evident. Nurses made appointments in other services, went after people who did not attend appointments or pick up medicine by going to their houses, or referred people to another place so as to find a solution for their needs.

Another way of doing good was not to show rejection, and make an effort not to let people notice their concern with the possibility of contracting the disease. They considered the fact that TB is a disease that weakens the people affected, either physically or emotionally. In this context, nurses had to make a commitment to help people recover in a less painful way, such as making access to health services easier, and welcoming them in a respectful way.

Another aspect observed in the speeches was the fact that TB patients had to be respected, especially because of their poor living conditions, and to that end their decisions had to be discussed and taken into account. Nurses, especially those who dealt with patients in socially vulnerable situations showed greater concern with risks that could complicate the disease and hamper its treatment, such as drug use, abandonment by the family or the absence of resources for good nutrition and housing.

An aspect that drew nurses’ attention and was a source of worry for them was the stereotype and prejudice issue, which still exists in several settings, such as within the family, among friends, or in their workplace. All the efforts made were meant to help people realize that these prejudices were based on unfounded concepts. The need for maintaining good relations with TB patients was also included in this professional commitment, and it went beyond a more formal relationship and was perceived rather as a friendship or a partnership in which nurses, patients and their relatives fought together, driven by a common goal, the cure of the disease and a return to their previous TB free lives. To this end, they established a link that began with proper reception of the patients.

This link was considered to be the most effective way of ensuring treatment continuity, which involved more than making medicine and guidance available, as the nurses were also involved with their patient’s lives, and monitored their daily life. This link started with an easier access to the service, and it was represented by the availability of appointments whenever requested by the patients. It was characterized by the opening of dialogue within and outside the community, the sharing of feelings, the availability of professionals as a reference in the health care unit and home visits. These aspects included a set of actions which highlighted the importance of trusting nurses. In this process, empathy was an ever present element, which was made more likely since it concerned people who lived in a community in which the nurse had been present and participating for a long time.

*I think that, when you have a responsibility […], you have to do your best. That’s how I do, I think that’s the reason why I have no restrictions. I keep calm, I solve everything, I ask for the HIV [test] myself if they don’t bring it, I solve it all myself, Hold on, I’m going to solve it all for you! I solve all this, I don’t wait for anybody to do it. I do it all right away. […] some people feel discriminated […] also because they are not very enlightened, they don’t really understand the disease […] the essential thing, the most important is what I’ve said, it’s endurance […] I’ll tell how it is […] like, people still think that you can get TB just by looking at it […]* (P9: INTERVIEW 17).
Well, I think that we need to have a sense of commitment and responsibility to monitor patients and their families. That’s why sometimes they move around, you know? They move on and on. ‘Oh, I went to that place and they said they didn’t have this medicine’ [...] It’s also about fear, because the word “tuberculosis” is still considered by most people, even by some health professionals, as a poor people’s disease, very poor people who don’t eat, who don’t have food. So, as I observe, I can see that this is not the only thing, it’s not just that [...] (P2: INTERVIEW 4).

Professional commitment involved the need to have specific knowledge for the care of TB patients. This knowledge, garnered throughout their professional careers, was the result of professional and personal commitment. It involved technical matters of the profession and investment in knowledge, which allowed for meeting the needs of TB patients. They acknowledged that technical control, based on scientific knowledge, enabled them to act in a responsible and competent manner. From that perspective, nurses needed to invest in their training by means of capacity building and empowerment, made available by the health system or often by nurses investing in enhancing their qualifications by reading texts for instance. Another important highlight was that since the nurses had obtained their degrees more than 20 years ago, their undergraduate programs did not contribute much to specific services needed in primary care.

Results obtained from the second sampling group, composed of the doctors, nursing assistants and technicians showed that, as a whole, though the team contributed somewhat to the care of TB patients, most duties were the responsibility of nurses. They acknowledged that nurses had the strongest link with TB patients and their families, and were committed to the service they provided. They come to us and make the diagnosis, request the medication and the next time they go straight to the nurse; if there is any complication they come back to us, or if the nurse is not there, we make the whole assessment ourselves, but most of the follow-up is done by nurses [...] (P19: INTERVIEW 20).

Institutional-political commitment

The institutional-political commitment involved responsibility and engagement with the health system in place, the performance of activities proposed by health policies in the country and, more specifically, the response to program actions established by the PNCT. Actions were conducted in a responsible manner so as to achieve the desired results, and they showed the commitment to guidelines and principles that govern the Unified Health System (SUS).

The nurses promptly listed the activities indicated in the PNCT, showing their interest in achieving successful treatment, although they faced some difficulties related to its full implementation. They noticed that there was an internal pressure in the health system which sometimes did not take into account the living conditions of TB patients, which prevented or hampered the treatment success, such as the use of drugs and alcohol. This context made clear that the care of TB patients went beyond the scope of nursing practice in the health sector and, at this point, nurses often felt powerless to act. The social and economic conditions of TB patients restricted the performance of the nurse’s actions aimed at completing the treatment and healing the patient.

Structural and logistic problems related to health services, such as the difficulty encountered in some places for taking medical tests, referral to specialists and the lack of material or equipment had to be overcome, in such a way that treatment could be carried out regardless of these difficulties.

There was a commitment to epidemiological surveillance by the municipality where the information regarding the care of TB patients was sent, and actual results were expected. The nurses had to account for any discontinuation of treatment and explain how the monitoring went and the factors that made them discontinue treatment. Information reported on PNCT forms, which were entered in the Notifiable Diseases Information System (SINAN), had a mark associated with their names, that is, the patient who discontinued treatment was linked to the health unit where the nurse worked.

We’re present [...] we do all we can to encourage them to come, so they think: ‘Oh yes, these professionals are interested’ [...] (P1: INTERVIEW 10).

It’s disappointing not to succeed, it gets bad. You
are also disappointed because you have to prove it to the TB program, it’s well designed. So you have to justify all the time the reason why the treatment was not successful, so you feel you have failed as well. You didn’t manage to have them complete the treatment, you also feel responsible for that defeat, absolutely (P18: INTERVIEW 19).

The third sampling group, composed of epidemiological surveillance professionals, showed that nurses were actually responsible for the performance of care of TB patients in primary care, and this responsibility involved the reception of patients, treatment introduction and the information of treatment completion or actions to be taken after its discontinuation. They highlighted that most nurses and professionals involved in the care of TB patients had responsibilities and commitments, and that the high incidence of the disease and discontinuation of treatment in the municipality were related to poverty issues, to homelessness and the use of drugs and alcohol, showing that social vulnerabilities had an important negative effect on disease control in the municipality.

Nurses have a closer contact, we are in touch with nurses, and in their absence, we talk to a technical assistant, a doctor or community agent. We usually look for nurses, who notify patients, who follow the treatment more closely. So, it’s with nurses (P25: INTERVIEW 26).

Social commitment

The social commitment was made clear in different aspects of nurses’ practice: engagement to control the disease transmission in the family and in the work place, so as to prevent its dissemination; respect for people’s right to health care; concern with epidemiological indicators of the disease and changes that have occurred in patients’ profile; and efforts to reintegrate people into social spaces they used to attend before falling ill.

Nurses worked hard to control the transmission of the disease, without cutting TB patients off or making them feel inferior because of an infectious disease. Patients and relatives were provided with instructions about care at home, such as isolating the patient. Another form of controlling transmission was to give priority to patients with bacterial TB and avoid exposing them to other populations, such as children, pregnant women, elderly people, people with diabetes, and also other professionals. There were also instructions regarding how to deal with coughing, since nurses did not have or did not wear proper masks to protect against the bacteria. It was recommended that people did not go to work, taking leave until further notice from the medical staff. These behaviors took place in the period of transmissibility of the disease, since a rational awareness was necessary, in addition to the recommendations not to discontinue treatment.

As to the care of TB patients, the nurses highlighted people’s right to be served and monitored by the primary health care service, in which the creation of bonds, reception, humanization, quality and comprehensiveness are necessary, and in which the problem-solving characteristic of care actions should be a legitimate right, since health services are ensured by Brazilian law.

The concern with epidemiological indicators of the disease was shown in nurses’ speeches, as they were all impressed with the incidence in people who were not considered to be vulnerable since TB also affected well-educated and wealthy people, which differed from the profile drawn by then. They considered that the deaths occurring among TB patients could be avoided. Nurses seemed to be committed to returning TB patients to their normal lives and enable them to go back to their homes, workplaces and leisure spaces. To this end, they talked to and provided guidance to families; informed schools so that they welcomed back their ill students; referred patients to the doctor in order to review their ability to work; and also provided guidance for their return to social life, such as the participation in festive and commemorative events.

Well, as I knew that the child was warded off school, I went to the school in person with a written statement signed by the doctor, requesting the child’s immediate return to school. I explained to her mother, to the school coordinator and to the teachers who were there that the disease could not be transmitted anymore, since treatment was underway and that there were clear signs that it was effective and that she was not transmitting the disease. (P16: INTERVIEW 2).

What I have in mind is to break that communication chain that is the main thing [...] calling patients and asking: ‘who do you think passed you this disease? Do you know someone who is coughing like this?’ Sometimes they
come here with tuberculosis, but there are other people who transmitted the disease to them, who are still sick (P14: INTERVIEW 16).

The fourth and last sampling group was composed of TB patients and showed that the nurses were always present to provide care, and that they followed the whole treatment from the beginning, after diagnosis until discharge. They revealed that the nurses cleared doubts and provided guidance regarding the disease, treatment, necessary precautions and ways of dealing and living with the disease until its cure.

I was treated very well from beginning to end. [...] very good, her treatment was great, so was the staff’s. It’s a constant concern, regardless of the position they hold. [...] They say [nurses]: ‘I’m going to do like this’, and so they do, you know! I think it’s great when the person is smart and acts like this. Otherwise it’s disturbing when the person [the professional] says they are going to do something like this, and then, they do it another way, it’s very disturbing [...]. [...] it’s good to be in touch [with the nurse], whenever the person comes to talk, it’s always good to be friends, friendship is the basis of everything (P27: INTERVIEW 17).

DISCUSSION

Since this study was about care provided to people with a chronic infectious disease, which is found in a context that is difficult to deal with due to social, economic and even historical issues, the nurses often highlighted that professionals’ commitment as essential to successful treatment, consequently, a decrease in the number of TB patients could be observed.

The way in which care was provided by participating nurses was in line with the conception of care that preserves a healthy life and that is subject to an ethical conception that considers life as precious and good in itself. Care manifests as an attitude of concern, accountability and emotional involvement with others. Generally speaking, those who provide care feel involved and emotionally connected to the person being cared for.16-17

The ethical commitment revealed by nurses was based on the principles of kindness, non-maleficence, autonomy and fairness in the performance of care.18 The nurses reported practices that involved moral and professional conduct, which referred to the respect for human life, to obligations and suitable duties of nursing, and showed their positions with regard to right and wrong.

Nurses’ professional commitment included three aspects that are inherent to their profession. Nursing encompasses values that involve providing personal care to individuals, whether they are healthy or not and in the social context in which they are found, respecting their right to freedom and autonomy. Caring and sympathizing meant political-cultural commitment and engagement, with the promotion of a sound and humane protection of the human species, of this generation and those that followed.16

In view of the evident institutional commitment, nurses showed a strong sense of responsibility regarding TB in primary care. Nursing has played an essential role in the conduction of TB control measures. A study conducted with FHS nurses in northeastern Brazil is in line with these results and showed that they were committed to the care of TB patients and they performed the duties recommended by the TB control policy.6,10 Another study highlights that nurses are the professionals who most perform actions to control TB, even though they may not perform educational actions, which is essential to the care of these patients.5

Although the nurses have stated that they have technical knowledge to provide care to TB patients, treatment is often paid for by patients themselves and not by the health system, as opposed to what is stated in PNCT. This situation is similar to the results shown by another study, according to which TB control does not concern all professionals, and is considered to be insufficient by 30% of them.5

The context experienced by nursing in the fight against TB in the country, especially because of the care model first implemented based on hospitalization, shows that the fact that nurses have been trained to deal with the treatment of the disease, has put them in a position of responsibility. Treatment carried out outside the hospital reinforced the need for their intervention, since they already had some experience with TB patients.8

A recent study revealed that nursing intervention is focused on the recommendations of public policies based on epidemiological studies, with the implementation of multi-sector programs and
direct care service, which includes education of TB patients.\textsuperscript{11}

Successful TB treatment requires a shared commitment among health professionals and TB patients, with the creation of pacts that meet the needs of parties involved. The way in which health professionals are organized to perform their work is essential to their participation by TB patients, which results in treatment completion.\textsuperscript{9,19}

There was a great concern on the part of nurses in maintaining a relationship with TB patients and their families in order to avoid the risk of discontinuation or non-attendance. Creating bonds between TB patients and professionals results in greater trust and consequently an adequate level of health solutions. This bond, built on the basis of a welcoming attitude and as a result of the accountability of everyone involved, has the potential to ensure qualified and humane treatment by the promotion of a comprehensive care service.\textsuperscript{20}

In the social commitment mentioned by nurses, the reintegration of TB patients into their social spaces caused great concern and required actions from nurses. The distress of patients arises from the fact that TB is not only a physical disease, but it also has consequences at different levels, especially in social relationships, in which people can be isolated due to disease communication and misconceptions regarding this transmissibility.\textsuperscript{21}

Nursing professionals have great responsibility regarding TB prevention and control.\textsuperscript{11} Nurses reported their concerns in view of the incidence of the disease, patients’ profiles and more particularly, the discontinuation of treatment, the latter being highlighted when they talked about goals, objectives and responsibility.

TB is characterized by high incidence and low healing rates, thus representing a health issue to be faced by health professionals, managers and the population.\textsuperscript{22} Nursing has a prominent role in controlling the disease and has its own responsibilities.

The effective ethical-professional, institutional-political and social commitments of participating nurses for TB patients, which was not always evident in other studies, seems to be linked to nurses who had been working for a long time with TB patients in the same location, thus strengthening bonds and making access easier. This commitment can also be related to the meaning the disease has for them, and for the people who they deal with, a factor which has a historical basis. It can also be associated with the fact that the disease should have been under control in view of the pharmaceutical and microbiological progress made in this field. These three commitments took place simultaneously and were intertwined in care actions performed by nurses.

**CONCLUSIONS**

The study highlights the fact that all participating nurses had been working with TB patients for more than 20 years, and therefore had a vast experience in this care service. These nurses experienced great changes in the care models proposed by the health system of the country and of the municipality where they worked, which might have resulted in their strong commitment to the service and to people of the community where they had been working for a long time. It would be interesting if other studies were carried out with less experienced nurses so as to clarify these professionals’ commitment to TB patients.

The particularities of care of TB patients, which arise from their context of life and from the way the disease is treated, required great commitment from nurses. This commitment included three components: ethical-professional, institutional-political and social, and it was the initial condition in the provision of care.

To nurses, being committed meant being responsible for the care of TB patients, of their families and people who might contract the disease. This commitment was not only technical, but also involved the establishment of a relationship with patients and their families, a close follow-up and the accountability to municipal managers with regard to treatment. Health professionals’ commitment was a driving element of a service that tries to ensure TB patients access to high quality care services, in view of the difficulties encountered, so that the disease is treated and patients can recover, have a healthy life and attend social spaces. The commitment of a health professional is the starting point of all care services regardless of the patients’ living and health conditions.
REFERENCES


