HOPELESSNESS AS A BASIS FOR TUBERCULOSIS DIAGNOSTIC DELAY
IN ARKHANGELSK REGION: QUALITATIVE STUDY

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ABSTRACT

**Background** Data about diagnostic delay in Northern Russia are scarce, but such knowledge could enhance the care of tuberculosis. The Arkhangelsk region is situated in the North of Russia, with the population is more one million. The aim of the study was to understand factors influencing diagnostic delay among patients with tuberculosis in the Arkhangelsk region and to develop a theoretical model in order to explain diagnostic delay from the patients’ perspectives.

**Methods** Twenty-three patients with experience of diagnostic delay of tuberculosis were interviewed in Arkhangelsk. We used a qualitative approach: focus-group discussions for data gathering and Grounded theory, using the Paradigm Model, for analysis of the phenomenon of diagnostic delay.

**Findings** The study resulted in a theoretical model of the pathway of delay of tuberculosis diagnosis in the Arkhangelsk region as an answer to the questions: “Why and how do patients in the Arkhangelsk region delay tuberculosis diagnosis?” The model includes categories of casual conditions, context and intervening conditions, action/interaction strategies and consequences. Patients blamed policy, the administrative system and doctors for their bad life. It was accompanied by avoidance of health care, denial of own situation and self-treatment. Only a deadly threat was a motivator for some patients to appeal for medical help. “Being overpowered by hopelessness” was identified as the core category. It affected their self-esteem and influenced their whole life, including family, work and social relations, and appearing even stronger in alcohol use. It reflects the passive position of a person, including the patients’ feelings of inability to change anything in their life, to get a job or disability benefit.
**Conclusion** The main contributing factor to unsuccessful health seeking behavior of patients with tuberculosis was identified as “Being overpowered by hopelessness”. This should be taken into consideration when creating any preventive programs and diagnostic algorithms.

**Running head: hopelessness and tuberculosis diagnostic delay in Russia**
BACKGROUND

In spite of extensive studies of diagnostic delay internationally, data about the situation in Russia are scarce, such knowledge could enhance the care of tuberculosis.

Diagnostic delay for tuberculosis patients is usually defined as the duration of time from onset of symptoms to the initiation of treatment. It includes patient delay (from onset of symptoms to the first interaction with health services) and systems delay (from the first visit to health services to initiation of treatment) [1, 2].

In the Arkhangelsk region, the incidence of tuberculosis decreased 43.2% during 2000-2011 (from 104 to 40,2 per 100 000), and the rate of deaths dropped during the same period from 16.2 to 6.5 per 100 000 [3]. Nevertheless, diagnostic delay has led to a large number of deaths because therapy has been unsuccessful in drug-resistant strains of *Mycobacterium tuberculosis* that have been found in 47% of new cases in Arkhangelsk. It is possibly enhanced by delay in diagnosis and treatment [4-6]. The association between delay and drug resistance may be further promoted by the fact, that patients with drug-resistant forms of tuberculosis are more likely to abuse alcohol [7, 8]. Delay in diagnosis of multidrug resistant tuberculosis (MDR-TB) is of particular concern due to the risk of spreading this form of tuberculosis in the society.

In this situation the diagnosis and treatment of TB became an important public health concern. Risk factors for diagnostic delay include poverty, low educational level, poor knowledge about tuberculosis, single status, large family size, being a farmer, belonging to an indigenous group, not having health insurance [9, 10], rural residence, seeking care from traditional or unqualified practitioners, inappropriate antibiotic treatment [11], old age, immigrant or illegal resident status, and female sex [12], and beliefs and attitudes [10, 13, 14].

Health behaviour is related to general behaviour and behavior is modifiable. But the individual is not a rational decision–maker; decision-making in reality has an unpredictable nature. So the central point is the individual and his/her cognitive processes
Socially impaired groups have specific types of health-seeking behaviour, based on their beliefs and include more than one type of care. Usually they use self-treatment, visits to healers and to official medical specialists. The recognition and interpretation of symptoms by the patients and their society is a precondition for seeking care from a specialist and for successful diagnosis and treatment [16, 17]. Their understanding depends on the existing views of the likely meaning of the symptoms and the availability and accessibility of various potential sources of assistance (traditional, spiritual, Western medicine) [16, 17]. For example, the presence of various sources of assistance, coupled with ignorance of the symptoms of TB, stigma and access problems led to significant delays in diagnosis and treatment of tuberculosis in Ethiopia [18].

Health seeking behavior is the result of the interaction between changes in physiological activity, autonomic arousal, affective integration, and the processes of cognitive interpretation. This interaction leads through subjective distress to an adaptation behaviour (coping). The psychological processes are central and are inevitably involved with the biological milieu and sociocultural environment; they cannot be considered in isolation from these contexts [19]. Specific personal and social values, that people affect experience of the disease, are usually based on people’s knowledge, beliefs and ideas about health and disease, its causes, signs and symptoms, severity, transmission, treatment and prognosis [19].

To gain an accurate picture of health-seeking behavior, we need to pay special attention to the culturally-specific characteristics of patients (their knowledge, believes, perceptions etc.), the context and the accuracy of data collection methods [19].

Despite the availability of information about diagnostic delay globally, little is known about delay in seeking TB care and its determinants among patients in the North-Western Russia.
The purpose of this study was to improve understanding of patients’ perceptions of factors influencing diagnostic delay among patients with tuberculosis in Arkhangelsk and to develop a theoretical framework/model to explain the diagnostic delay from the patients’ perspectives.

METHODS

Setting
The Arkhangelsk region is situated in the North of Russia, 1200 kilometers North of Moscow with a total area of 589913 square kilometers. The population is 1,213,533 people (2012) [20, 21]. The majority of citizens of the region are people who have lived there for a long period of time, although many of them originate from dissidents deported to this area long ago. The main fields of work are fishing, timber industry, pulp industry and engineering (defense industry) [20-22]. People, living in the villages, work in the timber industry and with fishing as well.

There are 7 outpatient and 10 inpatient clinics in Arkhangelsk and satellites, 32 united in- and outpatients health centers (mainly not in Arkhangelsk), which refer all tuberculosis patients to the Arkhangelsk anti-tuberculosis dispensary for treatment. The dispensary caters for in- and outpatients. All patients with multidrug resistant tuberculosis and patients with sensitive forms of tuberculosis with positive results of smear microscopy start anti-tuberculosis treatment in hospital. The initial phase of treatment takes six – nine months. The continuation phase is provided in outpatient clinics in the place of residence in case of negative results of the smear microscopy.

The penitentiary system in the region also has new tuberculosis cases. The system has its’ own separate health care with anti-tuberculosis service included. The problem of diagnostic delays does not have high priority here. Firstly, all prisoners are under strict control including the control of their health. Secondly, sometimes it is considered profitable for prisoners to have a disease in order to get a lighter detention in the prison hospital. Some prisoners try to get infected. Because of this, we chose to investigate diagnostic delay in patients from the civil sector.
Study design

Grounded theory and in particular the Paradigm Model by Strauss and Corbin [23, 24] was used to explore the phenomenon of diagnostic delay.

Grounded theory is used for systematic generation of theory from data using both inductive and deductive thinking. One of the goals of a grounded theory study is to discover the participants’ main concern to understand what is going on by using empirical research. The researcher also studies how the participants continually try to resolve their concerns regardless of time and place [23, 24].

Health perceptions and perceptions concerning tuberculosis services and factors influencing diagnostic delay were discussed by both men and women in focus group discussions (FGDs). The findings of FGDs were to generate a tentative model, based on empirical data. The tentative model allows to explore reasons for tuberculosis diagnostic delay from a patients’ perspective [23, 25, 26].

As knowledge of reasons for diagnostic delay from the patients' perspective was limited, FGDs were chosen as one of the best methods of data collection given the short period of time of the study. We also obtained a wide variety of opinions from a group new to the field (they had diagnosis of tuberculosis for the first time) through their mutual influence on each other in the process of discussion [27]. This avoids the consequences resulting from in-depth interviews. The FGDs provided the understanding of ideas and concepts used in the cultural context. The method provided a diversity of opinions as well as reasons for diagnostic delay to increase knowledge without aiming at reaching consensus or influencing them in any way [28]. The other advantage of this approach was the relative efficiency in gathering equivalent amounts of data to that of individual interviews [29]. FGDs encourage participation of patients who perceive individual interviews to formal and isolated [30]. The group setting facilitates discussion of taboo topics. Also, being among peers gives the security that can assist the group to speak about ideas different from the culture of the researcher [29]. The focus group format offers the opportunity to expresses more criticisms of socially accepted norms, as compared to interviews [31, 32].
Grounded theory was chosen because we aimed at generating a new theory of reasons for diagnostic delay from the participants’ perspective [23, 33].

The research team consisted of researchers with different backgrounds from Russia, Canada, Sweden and Norway: three tuberculosis specialists (D.E., G.B and A.M), one nurse (E.J) with expertise in public health and qualitative research, one epidemiologist (A.G) and one psychiatrist with experience of public health and who was not involved in the tuberculosis management (principal investigator, V.K). The investigators brought their own perspectives to the analysis. Two clinical psychologists in the anti-tuberculosis dispensary assisted in the focus-group discussions (FGDs). Coding was done by the principal investigator and later shared and discussed with the other authors.

**Participants**

From January to May 2011 five focus-groups (two – ‘women’ and three – ‘men’) consisting of five-six informants were recruited from patients at the anti-tuberculosis hospital, using a purposive sampling complemented with theoretical sampling based on emerging concepts, categories and subcategories. We used typical case sampling as a purposive sampling technique. We were interested in the **typicality** of patients in order to compare the findings from a study using typical case sampling with other similar samples. A theoretical sample was based on coding, comparison and writing of memos. We used theoretical sampling to develop the theory by questions raised during the analysis. It also allowed us to propose relationships, fill gaps in the existing data and bring to light what we did not yet know. Theoretical sampling was carried out by selecting participants and by modifying the questions asked in data collection. It helped to clarify uncertainties, test our interpretations, and build the emerging theory [23].

All patients were recruited at the initiation of their hospital treatment course. Eligible patients were adults on hospital treatment, who had coughed for four weeks or more and had a smear-positive sputum. All patients were new cases with a drug-susceptible form of tuberculosis and came to a department, specialized on cases of tuberculosis with diagnostic delay. Doctors at the hospital, who were not part of the research team, evaluated the information about the diagnostic delay. This evaluation was used as a part
of the analysis giving additional information for generation of categories.
Recruiting for the FGDs was done by doctors, who did not take part in the research, when
the patients had come to the hospital. This is the most suitable way of getting a ‘fresh
perception’ of the symptoms from the informants. Men and women were placed in the
separate focus groups. Patients with psychiatric diagnoses were excluded because they
were judged incapable of group participation.

Twenty-three informants (14 men and nine women) aged 27 to 53 years, were included.
All informants had lived in the Russian North for several decades. All informants were
poor people. Eight persons had previously been in prison (all men), 12 informants
suffered from alcohol abuse, 17 were smokers (three of them women) according to
medical documentation and self-report. The educational level was not high: two persons
had no school education, 12 had graduated from school (nine years), and nine persons
from college. Only three persons lived with families; all others lived alone and had
contact with relatives (mother, sister, brother). They described their relatives as a family
in the discussion. The profile of the patients was incidental but matched criteria of
purposive sampling because it represented a typical study population.

Two co-moderators worked as psychologists with the patients before the FGDs in order
to create trust with the informants. The moderator discussed with the co-moderators after
the FGDs using a peer debriefing process, but not before. The moderator also talked with
the informants before the FGDs in order to create trust and to get informed consent.
Consequently, FGDs were created based on prolonged engagement.

**Procedure**
We used purposive sampling to clarify and develop explored concepts and to saturate
them according to the emerging codes and categories [23, 24], data collection and
analysis were done simultaneously. We conducted an initial analysis of each FGD before
holding the next one and if important issues emerged, these were then brought up in the
next FGD [23]. When the next FGD did not bring new information or the results of the
next interview could be anticipated, the process of data collection was considered saturated.

We conducted FGDs using a semi-structured interview guide. The FGDs focused on patients’ perceptions, knowledge and health-seeking behavior related to tuberculosis and its management as well as on obstacles and facilitating factors for seeking medical help. The initial interview guide included questions such as the following:

“Kindly, tell me what you know about tuberculosis?”

“Why don’t people go to health services, when they have symptoms of tuberculosis?”

“What may stimulate people to go to health care services in case of tuberculosis symptoms?”

“What may be done to motivate people to go much earlier for diagnosis?”

The FGDs lasted 45-60 minutes and were audiotaped and transcribed verbatim by the principal investigator. We conducted FGDs in the usual environment of the wards of the patients and determined the number and composition of groups according to the ward where they were treated. This was done to follow the guidelines of infection control of the department. Informants, moderator and co-moderators sat in a circle. Patients and researchers used facemasks to prevent transmission of infection. The FGDs were moderated by a principal investigator (a psychiatrist who doesn’t work in the anti-tuberculosis system) and two co-moderators (psychologists who worked in the anti-tuberculosis hospital). The psychologists were a part of system but the patients were not acquainted with them as they were with doctors or nurses, but viewed them as persons who offer more personal and informal of professional interrelation. The co-moderators took notes and posed questions sometimes, but mainly remained observers in the groups. The moderator took notes during and after each FGD, enabling preliminary analysis.

Data analysis
We carried out data analysis using grounded theory on three levels: open, axial and selective coding [23]. We used open coding, a line-by-line scrutiny of the data, in order to identify the codes expressed by the participants. We labeled related codes and grouped
them into categories. Fifteen categories emerged from the data. We identified relationships as illustrated in fig 1. We conceptualized categories by specifying the relationships between them during the axial coding. We identified a core category, which related to all other categories at the selective coding stage. We used selective and axial coding to knit the concepts of the theory together and generated theory through comparative analysis both subsumes and assumes verification, and accurate descriptions, but only in the frame of generation coding. In using the Paradigm Model we explored the relationships between the concepts [23].

The basic purpose of this model is to enable the researcher to think systematically about data and contextualize the phenomenon by relating categories and concepts in complex ways. The core category i.e. the central idea, event or happening is defined as the phenomenon. Other categories are then related to this core category according to the schema. This model helps the researcher to integrate all generated categories and concepts based on a systematic approach. Following Strauss and Corbin (1998) we used a coding family that consists of causal conditions, the phenomenon, the contextual conditions, the intervening conditions, the interactional strategies, and the consequences [23].

The analyses were carried out by the first author (V.K) in collaboration with the co-authors. Some authors had a pre-understanding of the context of tuberculosis care having been involved in tuberculosis management in the region or/and from previous study of tuberculosis. Being uninvolved in tuberculosis management, V.K was a moderator of FGDs to explore new ideas and to ensure the discovery of new knowledge. The analysis phase was conducted with members of the research team to compare codes, validate the interpretation of data, and also to resolve any discrepancies in the observed findings. Finally, credibility of the results was ensured by providing hospitals with study results.

We used the principle of theoretical saturation, all levels of codes were completed and no new conceptual information was available. We stopped data collection after 5 FGDs.
Ideas different from those of the evolving code list were considered important and given special attention during the analysis. Deviant case analysis was used considering extreme examples to increase trustworthiness of research through showing the context and limits of the emerging theory.

**Ethical considerations**

The research was approved by the Ethics Committee of the Northern State Medical University (Arkhangelsk). We informed each participant of the purpose of the research and they signed consent forms. Every informant was given the opportunity to refuse to participate in the group discussion at any time without negative consequences. One informant declined to participate in the discussion after being requested to sign the written consent.

Anonymity was maintained by omitting names and personal data. Only the principal investigator had access to names and other confidential information. Participants gave their consent to that the interview could be recorded and analyzed later.

**FINDINGS**

The main focus of this study is the drive of the participants’ actions and interactions i.e. how the participants handled the situation.

“Being overpowered by hopelessness” was identified as the core category. It reflected the views of the participants regarding factors influencing the delay to TB diagnosis.

The opinions in the groups were very similar. Some differences between men and women were observed. Men reported more often about patients’ delay, while women more often reported about health systems delay. We constructed a model based on Strauss and Corbin’s Paradigm model [23], which was named “The trajectory of TB diagnostic delay among patients in Arkhangelsk” (see Figure 1).

**Figure 1 is here**

The core category, “Being overpowered by hopelessness”, will be described with the help of the other 15 categories and the model (see Figure 1).
Being overpowered by hopelessness

The core category, that was interrelated and influenced by the other 15 categories, was “Being overpowered by hopelessness”. It appeared frequently in the data as an answer to the research question: “Why and how do people delay obtaining a tuberculosis diagnosis in the Arkhangelsk region?”

Hopelessness was described by three concepts: low self-esteem, blaming others and alcohol use.

Low self-esteem was illustrated with expressions such as: “What can I do, if I can’t protect myself?”, “What can I do, having no knowledge?” “What can I do being so poor?”

Blaming others was a way to diminish the guilt of the person him/her self. This was illustrated by expressions such as:
“What can I do, if I have to feed my family!?”, (Male FGD)
“What can I do, if the doctor is drunk all the time!?”, (Male FGD)

Low self-esteem is related to the question “Why did patients delay diagnosis?”; Blaming others is related to the question “How patients delayed diagnosis?”; Alcohol use is a concept explaining both “When” and “How” question, because “alcohol use” is a behavior belonging to a definite social group.

Causal conditions

“Causal conditions” is a set of events that lead to the occurrence of the phenomenon of tuberculosis diagnostic delay. Four categories “Fearing TB”, “Lack of knowledge about TB disease”, “Distrusting in the health system” and “Perceiving general powerlessness” were generated (see figure 1).
Tuberculosis is perceived as a stigmatizing disease. People try to deny the presence of the disease as long as possible, but then responsibility for the society and the family is “switched on”. In fact, stigma plays a minimal role in the family. Some relatives convinced the informants to go to a clinic to seek a diagnosis. Some informants went to the clinic because they worried about members of their family. Stigmatization was more visible in the context of work, causing worries concerning problems in working relationships and future possibility for work.

The following citations illustrate these findings:

*It is a shameful disease. It is impossible to tell somebody about it. It is not the same as for cancer, for instance. You can talk about cancer, but not about tuberculosis. The husband of my sister had tuberculosis, we were afraid of associating with him…It is said that tuberculosis is incurable; it may be a hidden disease…It is a terminal illness…*(Female FGD)

*I had the possibility to get a post…. I could go by bus, but that is not a good thing to do, so I walked there. Before I was diagnosed with tuberculosis I infected everybody around me in 20 days, it is scary! *(Female FGD)

Family life was under pressure because of tuberculosis, but there were two different perceptions. The family supported most of the patients and even pushed them to the health system, being a positive factor for early diagnosis.

*Everybody reassures me…Supports me! How could it be otherwise?!* (Female FGD)

Very few informants related contradictory experiences

*A woman said, that she would not be allowed to stay in her home after she is released from hospital, because she may infect her granddaughter.* (Female FGD)

As for the relation with friends and other acquaintances, the support depended on the situation and the level of closeness in the relations.

*I think people will avoid me! The friends advised me to go to the clinic. They said, you will recover and will be as others.* (Female FGD)
Fear of TB interrelated with lack of knowledge about symptoms of tuberculosis. Many informants stated that they were not aware of it as a severe disease when they felt bad. Some said that tuberculosis have to have ‘special’ symptoms, not those similar to symptoms of a cold.

The following citations illustrate the causal conditions:

*It is very hard to discover the person, who is the source of infection..... You meet at least 100 persons per day... The disease is fatal. It is impossible to discover (the source).* (Female FGD)

*If I knew that it is tuberculosis I would run to the clinic immediately!* (Male FGD)

*I did not know that tuberculosis is such: these symptoms were simple; I have had similar ones many times before* (Female FGD)

The participants related that people distrust the health system perceiving it as ineffective because of experiences of different mistakes made by medical specialists. These mistakes were just a part of the diagnostic process or led to the impact on making the right diagnosis and treatment. Very often doctors and medical assistants were described as incompetent. Informants stated, that “good doctors” do not go to a village to work, and only “alcoholics and incompetent specialists work in the districts”. If a doctor assistant was good (according to patients’ opinion), he/she would still be considered not to have enough knowledge because of a lower education than the doctors. This exacerbates the existing lack of facilities in the small health centers.

*Several days I was treated for pneumonia, but unsuccessfully.* (Male FGD)

*They prescribed antibiotics for me.... I took them at home... Then I went to the hospital, they relieved the cough, but not the fever. After half a year I went to the hospital again... After one month I was discharged.... I have been working and working... I wondered why I had been losing weight? The temperature was 39 degrees. My lymph nodes had become affected... fluorography did not show the disease in my case....* (Male FGD)
The doctor visited me but only prescribed medicines. They did not discover my problem… something wheezed … they gave tablets to me…. I went to the sauna… then I visited the clinic, they said…. Your lungs do not breathe… It was a rib fracture in my case… If you say to the doctors, that it is painful to breath they just say: “It is a cold, everything will be OK…” (Male FGD)

Perceiving general powerlessness refers to the perception, that there is no possibility to influence one’s own life or health. People feel that they cannot change anything in their life and delegate authority to somebody or something else. Very often, they complained about authorities, from municipal to federal levels. This is the position of an observer, not an actor in his/her own life. However, the difference from an observer position is that suffering is “included” as a part of such a life.

Half of the people in the village never make a health check-up. If you catch severe disease, you can do nothing! (Female FGD)
Half of the people in the village are made up of sick persons. Nobody checks themselves. I meet everybody. Some persons have not even enough money for food. (Female FGD)

If people were divided into two groups according to the possibility to change their lives, TB patients would belong to the group with low will power to change. In this group the willingness might be higher or lower, some considered that they can change (create good relationship in their family, change a workplace, educate their children etc.), but some did not. Perceiving general powerlessness could also be seen in the individual’s own health. Some might consider improving their own health, some will not. Such behavior concerning health-seeking behavior could be ranged from self-treatment in case of illness to just waiting for relief or an emergency situation.

These attitudes of patients lead to passive behavior that mitigates against early diagnosis.

Context and intervening conditions
Contextual and intervening conditions are a set of conditions that create circumstances of problems through which groups of individuals respond by their action/interactions. Three categories “Ineffective health system”, “Wide spread alcohol in population” and “Wide spread poverty in population” were identified and related to the contextual and the intervening conditions influencing the phenomenon (see figure 1).

The prolongation of the diagnostic period was related to remoteness of health facilities. Many settlements are situated 50-100 km from any medical specialist in the Arkhangelsk region.

*It is 80 km to a doctor…. If somebody cuts off a leg at work, he will surely die…*(Male FGD)

These components of ineffectiveness of the health system in real life and in the informants’ perceptions created a complex context for care-seeking behavior. Moreover, tuberculosis was seen as an obstacle to work, personal and family relations. All informants described an influence of tuberculosis on important parts of their life, work, family and relations with friends. Usually tuberculosis was an obstacle for work, because of the diagnosis or a necessity to follow a very strict regime of taking pills in the anti-tuberculosis dispensary even during the outpatient period of treatment. So, they described a necessity to be absent half a day at work every day. This period is six months at a minimum, but may last much longer in some cases.

*A man went to get a job, but there was a shadow in the lung – he had to go to hospital.* (Male FGD)

*I got to this place (anti-tuberculosis hospital). Now I have a note in my medical card. I need to have a check-up twice a year. The employer will say: “You are useless to me!”* (Male FGD)

It is quite normal for some people to be stigmatized, because of their lifestyle of abuse of alcohol. The local society might be characterized by alcohol abuse. Alcohol behavior
might be “active” or “passive”: some people “live” in very closed societies, but some change company from time to time to have the possibility to drink together. So, frequency of drinking changes depending on these conditions, varying from once a month to everyday drinking.

Alcohol abuse is a clear problem for the Russian society, and its’ effect on health seeking behavior is very strong. Some persons do not seek care, because they are oblivious under high doses of alcohol; some of them have no homes, medical insurance or families and it is unlikely that such persons have a choice to drink or not.

Drinkers are different. You never know is he is ill or not… Always there is alcohol… All use one glass only….Explain to me why sensible men are sick longer than drinkers?
(Male FGD)

Such alcohol consumption leads to a decreased social level of a person, social motivation and finally stigmatization.

None of the patients could be described as a well-situated person. Moreover, patients have to pay for travel, for hotel accommodation in the central city of the region. The treatment is free-of-charge, but transport fees are high for many citizens, especially among poor people who suffer from tuberculosis. The time required for the diagnostic process was a delaying factor for many informants, because they were not able to stop earning money or maintaining the household. Many of them described how they completed work before going to the health system.

It is a problem with no solution - the level of life is very low. Pensioners and old people are ill, they have small pensions. Everything becomes more and more expensive…(Female FGD)

People become weaker when it is impossible to find a piece of bread…( Female FGD)
Our town is small, there is a note in my card, it is impossible to get a job……you don’t take pills because you are at work… You will not get pills. No treatment. What do you
do? Work? Maybe… you will get a job, but no treatment or food ration…. I work in a private place. It is necessary to go to the polyclinic to take pills. The workplace is far from the polyclinic. So, I am away from work for half of each day. The employer will say: “Get out!” (Male FGD)

**Action/interaction strategies**

Action/interaction strategies are purposeful or deliberate courses of the actions, which are taken by individuals or groups in response to events, problems or issues, which occur under certain conditions. We discovered four categories in the action/interaction strategies component of the Paradigm model (see figure 1). These categories imply behavior of persons in order to understand “how” people delay getting a TB diagnosis e.g. through: denying of own health condition, blaming others, avoiding health care services and resorting to self-treatment.

Denying one’s own health condition appeared in the typical phrase: “It won’t affect me!” This led to a lack of motivation to visit a doctor and low awareness of danger. Part of the informants had experience of relations with one TB patient (a neighbor or a member of the family) or a lot of contacts with TB patients (in a prison or in their neighborhood). They referred to their present or past experiences of getting infected by TB. This experience did not lead to awareness of danger.

*I related with tuberculosis ill people before, but I think never it will touch me! They [ill people] were in other side of life* (Female FGD)

*I was in prison. There was a lot of tuberculosis, I sow many deaths.* (Female FGD)

Blaming others was a typical way for informants to explain the reasons for diagnostic delay. Among the things blamed were health system or some specialists, situation in the life, government, policy etc. Blaming was used to acquit own mistakes and passive behavior.

*There is no information about tuberculosis. I found posters in the hospital only. If I had known it before, I would have gone earlier [to doctor],* (Male FGD)
It is so long queues to the GP in an outpatient clinic! How can I find time for it!? Moreover, very often they are not clever enough. (Male FGD)

Denying one’s own health condition and blaming others led to avoidance of health care that related to distrust in the health system. Informants were not aware of the severity of the disease considering it as a ‘simple cold’. Culturally, fever for one-two days is not a reason to seek medical help, but for taking pills only. Cough is ‘normal’ for smokers and it is not unusual to have it for many years. Distrust in the health system led to feeling it was useless going to the clinic.

A fever was just two days and it was not so high. As for cough… I have had a cough for several years. I don’t remember how many exactly. It is usual for smokers, and I have been smoking for 25 years (Male FGD)

What is a medical assistant?! He has no good pills! I called for the emergency services. A young boy appeared. He didn’t even listen to me! I did not go to the doctor…. What for?! You have to pay for everything…. I had fever of 39.5, but he said: “your thermometer is wrong!” We have two doctors in our village. They drink alcohol all the time! (Male FGD)

Feeling unwell made informants initiate action and people treated themselves, in case of high fever or cough for instance. The self-treatment period could last until the patient became totally exhausted and ill.

I thought it was a cold, so I took pills… In the spring and fall I always get a cold (Male FGD)

There was a cough … I thought, it’s due to dust… I had a lot of family problems and there was no time to visit the doctor. I have been working for months with such a fever (Male FGD)

There are different approaches to self-treatment: drugs and physiotherapy. Taking pills was a typical behavior for the informants. They did it based on advice of others or from
own experience. Many informants had heat applied typically in a sauna or using a local heater or mustard plaster.

*I went to the sauna to get relief. I heated my chest... I didn’t know that this is dangerous......very fast...I took pills and ran to work...I took pills, and I became better*(Male FGD).

**Consequences**

The consequences are outcomes of the action/interaction strategies chosen by the actors. Two categories emerged (“Motivated to seek health care at death threat” and “Developed serious TB disease (i.e. MDR-TB)” related to such consequences as delayed TB diagnosis and decreased possibility of recovering (see figure 1).

Some informants reported different behavior and checked their health regularly or promptly after the first symptoms. Any deviations from normal feelings were motivators for them. Usually these persons belonged to the “well-being part” of informants and had good awareness of the disease and prognosis. In our research they focused on the health system’s delay.

For another larger part of informants, only a deadly threat became a real motivator to seek medical help. They could not take care of their houses or work because of weakness. It stopped their work, life and alcohol drinking as well. Approximately 30% of those, who had a diagnostic delay, came to the health system by ambulance (*unpublished data*). Naturally, the fear of death varied for different people, but the principle remained the same. For instance, one informant reported about his experience of being in prison, where he encountered a lot of tuberculosis, but he did not seek help right away when the symptoms appeared. Another person had experienced the death of his brother, but the result was the same.

The sources of motivation were different for different persons. Some of them were motivated from inside and aware of danger, some were taken to the doctor by relatives, some worried about social consequences and had a high level of social responsibility. The levels of motivation varied and could be ranged from low to high.
It is necessary to scare people to understand that this disease is deadly; everybody will run to the clinic! Nobody pays attention before getting sick! I discovered blood in my phlegm….. I remembered movies about the war, just run to the doctor! I was sick but did not allow it to interfere with my life and work. When I could no longer get up from the bed....(Male FGD)

Moreover, other consequences of the diagnostic delay included the increased risk of developing MDR-TB and spread of tuberculosis in the society.

Causal, contextual and intervening conditions play their role shortly after the start of symptoms, while Consequences are important close to the decision to go to the anti-tuberculosis dispensary (Figure 1).

DISCUSSION
The study allowed us to create a theoretical model of diagnostic delay of tuberculosis diagnosis in Arkhangelsk. The model indicates that the dominant part of the patients’ position was “Being overpowered by hopelessness”.

The core category “Being overpowered by hopelessness” reflects the passive position of a person, including the patients’ feelings of inability to change anything in their life, to get a job or disability benefit. They blamed the administrative system and doctors for their bad life. “Being overpowered by hopelessness” affected their self-esteem and it influenced their whole life, including family, work and social relations. So, health seeking behavior could in this sense be seen as determined to avoid diagnosis and treatment. According to the Illness Behavior Model [19], the biological, psychological and sociocultural dimensions interact to explain why and how people respond to somatic changes and seek help. In the model concepts of the disease-illness distinction, psychological mediation of affect and sociocultural variables are used [19]. According to this, we can say that “Being overpowered by hopelessness” placed people in a victim position.
People were aware of the conflict between treatment and work; they described how they were unable to carry out their work or could not get a job. They did not trust doctors, partly because doctors were perceived to only help in difficult cases, or because the treatment process was expensive for various reasons. Although the treatment was free, patients were often asked to make tests, for which they had to pay. Similar situation was described in Vietnam, when patients should pay for some things [34].

We cannot say that “Being overpowered by hopelessness” is specific for tuberculosis, but may be common for specific groups of people in Russia, who are vulnerable to tuberculosis. The reasons for it are complex. The most obvious are cultural traditions (such as the Orthodox religion), which provide determinism with both positive and negative values. Destroying the religious system in the beginning of the twentieth century led people to a sense of victimization that brought negative images into the life philosophy of ordinary people [35].

The core category provides new dimensions to several types of tuberculosis diagnostic delay, described by other authors, for example, patient’s and health system delay or more detailed classification: patient’s delay, doctors’ delay, health provider delay, diagnostic delay and treatment delay [13, 36, 37]. Socioeconomic development is one of the key features in our study like in many other studies, but these studies do not account for the individual position of patients [38]. The model can encompass all types of diagnostic delay [36].

Contrary to the study of Mfinanga et.al. [12] we did not identify women as vulnerable. A. Thorson and E. Johansson [34, 39], for example, found that women in Vietnam had two-weeks longer TB diagnostic delay than men and had other treatment because of the patient-doctor encounter. Our results are similar to studies from China that identified risk factors of poverty, low educational level and low awareness and knowledge about tuberculosis, and not having any insurance [9]. Flemming et.al. [40] and Shin et.al. [41] described alcohol problem as a risk factor for tuberculosis. This agrees with our findings.
Similar to Thomas et.al. [42], who performed a qualitative study of TB patients with alcohol problems, we found alcohol abuse as a risk factor for delayed tuberculosis diagnosis. Further, alcohol is often related to a low level of social position and peer pressure played a huge role in alcohol intake.

Strengths of this research included the multi-faceted research team that provided a good level of validity and allows data triangulation. FGDs allowed getting a room of meaning of having tuberculosis diagnostic delay because informants facilitated each other during communication [27]. We reached saturation after the fifth FGD that allowed us to create a model to explain phenomenon of diagnostic delay among patients in the Arkhangelsk region [23]. Limitations included the need to wear facemasks and respirators, which introduced limitations to the face-to-face communication.

Our model can be used as a framework for further FGDs and as an interview guide in further research. It would be interesting to find out from in-depth interviews, how the passive position has implication in private life. Such phenomena as patients’ self-esteem and motivation should be studied as influenced their whole life, including family, work and social relations. It is necessary to understand the ways of the incompatibility of treatment and work to develop management of tuberculosis. Distrust for doctors needs to be clarified by interviews with doctors.

An important finding of our study is that this model might be suitable in similar cultural context and other cultural traditions and can lead to demands for change.

These findings show that it is practically important to involve people in early medical examination by explaining that tuberculosis can be cured if they ask for medical care in time. It is possible to avoid a passive patient’s behavior, if the patient knows what and how to manage the situation with first symptoms.

**Conclusion**
The study of patients with delay of tuberculosis diagnosis allowed us to create a theoretical model of the pathway of delay of tuberculosis diagnosis in Arkhangelsk. The model includes categories of casual conditions, contextual and intervening conditions, action/interaction strategies and consequences. The core category was “Being overpowered by hopelessness” as a life position leading to passive behavior, which was common for informants. The core category provides an answer to the research question: “Why and how patients in Arkhangelsk delay tuberculosis diagnosis?” It reflects the views of the participants regarding factors influencing the delay to TB diagnosis. “Being overpowered by hopelessness” could be described by three concepts: low self-esteem, blaming others and alcohol use.

The model allows ordering implications for changes in the social and health system aimed to decrease alcohol consumption, improve anti-tuberculosis service by including family in support of patients and by reducing organizational obstacles for work related with taking drugs. Moreover it is necessary to inform poor people about tuberculosis symptoms. These actions can reduce diagnostic delay for tuberculosis patients and improve health-seeking behavior in the future.

**Competing interest**

The authors declare that they have no competing interests.

**Authors’ contributions**

All authors contributed to the planning the study, VK and AM collected the data, VK, AG, EJ analyzed the data, and all authors participated in writing the manuscript and approved the final version. DE edited the language in the final step. The authors do not have any conflicts of interest.

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First symptoms

**Causal conditions**
- Fearing TB
- Lack of knowledge about TB disease
- Distrusting in the health system
- Perceiving general powerlessness

**Context and intervening conditions**
- Ineffective health system
- Widely spread alcohol in population
- Widely spread poverty in population

**Being overpowered by hopelessness**

**Trajectory of TB diagnostic delay**

**Being overpowered by hopelessness**

**Consequences**
- Delayed TB diagnosis
- Developed serious TB disease (i.e. MDR-TB)
- Decreased possibility of recovering
- Motivated to seek health care at death threat

**Action/interaction strategies**
- Denying of own health condition
- Blaming others
- Avoiding health care services
- Resorting of self-treatment