Namibian nurses experience of patients adherence to the treatment plan
- An empirical study of nurses work related to patients diagnosed with multi drug resistant Tuberculosis

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Abstract

Background: A low adherence is one of the reasons behind the development of drug resistant Tuberculosis. One of the identified factors connected to adherence is the relations between health care personnel and patient. Nurses all over the world daily work close to the patients supporting them to achieve a high adherence to their treatment plan. Still there is an underrepresentation in a scientific view of exploring and evaluating this work.

Aim: The aim of this study was to explore how the Namibian nurses experienced adherence to treatment in patients diagnosed with multidrug-resistant tuberculosis.

Method: A qualitative research technique was used to collect data. The interviews were constructed in a semi-structure with partly open questions. The data was analysed with Graneheim and Lundman (2004) analysis model.

Result: Strategies that was used by the nurses to enable a high adherence was providing information, counselling and education to the patient together with a practical support of delegating DOTS and providing the patient with medicine. There was a divided opinion on how to communicate with the patient depending on the nurses personal and fundamental views of adherence. A doctor centred view resulted in a one way communication by informing the patient. A patient centred view of adherence resulted in a two way communication when the nurse aimed to learn about the patients own point of views.

Conclusion: To enable a high adherence there has to be a two way communication which demands high communicational skills from the nurse.

Keywords: Adherence, communication, knowledge, lifeworld, therapeutic relationship.
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I Provided information – interview

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Abbreviations

DOTS           Directly Observed Treatment, Short-course
HIV            Human Immunodeficiency Virus
MDGs           Millennium Development goals
MDR-TB         Multi Drug Resistant-Tuberculosis
MoHSS          Ministry of Health and Social Services (Namibia)
MOTT           Mycobacteria Other Than Tuberculosis
NTLP           National Tuberculosis and Leprosy Programme (Namibia)
PMDT           Programmatic Management of Drug resistant Tuberculosis
TB             Tuberculosis
WHO            World Health Organization
**Introduction**

Tuberculosis has been a threat to people’s health since thousands of years back. Even in the ancient Egypt the disease is described in hieroglyphics.

In 1993 the World Health Organization [WHO], declared Tuberculosis [TB] as a threat on global public health. TB counts as the second leading cause of death, ranked after HIV, from an infectious disease worldwide. In the year of 2013 WHO estimated a number of 9,6 million new TB cases and 1,5 million persons already diagnosed died in the disease. There has been a positive progress fighting the illness and the mortality rate has fallen by 47% since 1990. Still, there are great challenges left before the threat is neutralised. One of these challenges is the worldwide developing of drug resistant TB [DR TB]. At present 5% of all the TB cases in the world estimates to have had a drug resistant version of TB.

When TB medication is used in an inadequate way, a regular TB bacterium survives and develops an increasing amount of resistance to the standard treatment. The multi drug resistant TB [MDR-TB] causes a higher suffering for the patient by the use of stronger medicines with harder side effects, longer treatment periods and a higher economic burden.

One of the main reasons for the medication failures is a low adherence to the treatment. Research of today agrees that there is a great need for patients of achieving a high adherence to the medication but is failing in finding solutions on how to achieve it. Historically there has been a doctor centred view on the terms of adherence. It is built on the idea of a patient responsibility of adapting to the doctors solutions. This has resulted in a research focus of medicine based solutions. The assumption is that a high adherence only can be reached by the development of a medication free from side effects and that the patient has a need of learning to become the good obeying patient.

This has been criticized as taking the patients own abilities and powers away. Instead the solutions needs to be patient centred. The health care providers have the responsibility to find new solutions, based on the patients own abilities, strategies and experiences. To reach a high adherence the solutions needs to be based on the patients own lifeworld.

One of the core activities in nursing is the therapeutic relationship; the link that is formed between patient and nurse. This link has key factors such as empathy and trust and is of great importance in the work of supporting patients in their time of need. The quality of the therapeutic relationship is a strong indicator of therapy outcomes. In the work of supporting MDR-TB patients in their adherence to the treatment plan the nurse must master the complex social process of the therapeutic relationship to empower the patient and promote health.

**Background**

**Tuberculosis**

Tuberculosis is a well-known disease. It is described in the hieroglyphics of the ancient Egypt and has been a threat to people’s health since thousands of years back (Swahn, Malmquist & Hagberg, 2015).

WHO declared Tuberculosis as a threat to the global public health in 1993 and since then there has been a positive progress in the efforts of neutralise that threat. The mortality rate has fallen by 47% since 1990. Today TB is ranked as the second leading cause of death, by an infectious disease worldwide where 1,5 million persons died in 2013. Only HIV results in a higher numbers of deaths in the world. In the year of 2013 WHO estimated a number of 9,6 million new TB cases (WHO 2015a).
TB is an infectious disease caused by the bacillus Mycobacterium tuberculosis. The bacteria can infect different parts of the body where pulmonary TB is the most common and infectious form. The bacteria spreads through the air, mostly by coughing from a person with an active infection (WHO, 2015a).

The bacteria lives inside the cell and the immune system can’t eliminate the microbes by itself. Not all bacteria cause an active infection. If the immune system is strong and well-functioning the bacteria will be kept isolated. It can’t reproduce and spread and therefore not be able to infect other people. If the immune system is weakened the bacteria will spread and the infection becomes active. Common causes are HIV, high age or malnutrition.

When bacteria enter the lungs it hides inside the white blood cells, the macrophages, where they reproduce.

Symptoms of TB are coughing, nightly sweating, and loss of weight. The symptoms aren’t caused by the bacteria but a result of the body’s defends mechanisms. When the immune system tries to fight the bacteria it results in damages of the lung tissue. Sometimes the damage on the tissue is permanent even if the TB is successfully treated (Melhus, 2013).

The most common method for diagnosing TB worldwide is sputum smear microscopy in which bacteria are observed in sputum samples examined under microscope. Treatment for regular TB is a combination of four different antibiotics; isoniazid, rifampicin, ethambutol and pyrazinamide. The standard period for medication is six months (WHO, 2015a).

Drug resistant Tuberculosis
It’s important that the treatment is successful in defeating all of the bacteria during the treatment period. If not, there is a great risk of surviving bacteria developing a resistance to the antibiotics. Drug resistance can be caused by an ineffective treatment where the dosage is too small, the combination of antibiotics is unsuccessful or the patient for some reason is unfulfilling the treatment (Malmquist, Ripe & Hagberg, 2015). The drug resistant forms of TB is growing worldwide and are an increasing threat for the global health (WHO, 2015a). At present, 5% of all the TB cases in the world estimates to have had a drug resistant version of TB (WHO, 2015b).

MDR-TB bacteria are resistant to the two most powerful anti-TB drugs; isoniazid and rifampicin. Therefore more expensive and more toxic drugs are required to enable a cure. The MDR-TB treatment takes longer time to execute and have a lower rate of treatment success (WHO, 2015a). There is a risk for MDR-TB to develop into extensively drug resistant tuberculosis [XDR TB]. The bacteria are then resistant to the three anti-TB drugs isoniazid, rifampicin and ofloxacin and also one of the three injectable second line drugs (Ricks et al., 2012).

World Health Organization
WHO is a directing and coordinating authority on International health within the United Nations System. The organization involves approximately 7000 people from more than 150 different countries with a head office in Geneva Switzerland (WHO, 2015c).

Since the declaration of TB being a threat to public health WHO has improved the effectiveness of diagnosis and treatment worldwide by the developing of different TB strategies (WHO, 2015a). The latest global strategy, from 2015, is called The End TB Strategy. The vision is; zero deaths, disease and suffering due to tuberculosis, with the goal of ending the global TB epidemic (WHO, 2015e).

Directly Observed Treatment Short [DOTS]
Directly Observed Treatment, Short-course [DOTS] is one of the WHO strategies. The main purpose with DOTS is a specific person ensures the medication being swallowed by monitoring the patient. Further, this strategy also has five components that WHO are working with (WHO, 2015d).

- A political responsibility in finance, planning and educating.
- Do the laboratories better in detecting the new TB cases and monitoring MDR-TB.
- Standard program for the treatment of TB.
- Supplying with anti-TB medicine.
- Surveillance and develop the work and reports to WHO.

Namibia and the threat of tuberculosis
The republic of Namibia is a country in the southern Africa with a population of 2,3 million inhabitants (WHO, 2015g) where 368 000 persons live in the capital city Windhoek. The country has been independent for the last 25 years (Central Intelligence Agency [CIA], 2015). Germany governed the years 1884 and 1920. Later on South Africa took over the leadership until the year of 1990 (Jönsson, 2016). There are many different ethnic groups in Namibia where the Ovambo, Kavango, Hereo, Nama, Damara makes the largest ones in number. Therefore, a lot of different languages are spoken as mother tongue. The official language today is English (CIA, 2015).

Health Care is, except education, the biggest post in Namibia public expenditure (Ministry of Finance, 2015). There are 26,7 hospital beds and 3,7 doctors per 10 000 inhabitant (CIA, 2015).

Namibia is one of the countries that struggles with a high TB prevalence by reporting 627 cases per 100 000 people. In Namibia the treatment success rate is at 86 % for new TB cases in 2013 and 71% for previously treated TB cases in 2013. For MDR-TB cases that started their treatment 2012 the success rate is at 68 % and for XDR-TB cases 20% (WHO,2015f).

The National Guidelines for the Management of Tuberculosis
1991 Namibian Ministry of Health and Social Services, [MoHSS] established a national program for the control of TB and leprosy. The WHO’s DOTS strategy was adopted as part of work of intensify TB control efforts.
1995 the first guidelines for TB treatment was offered to the public health care in Namibia and there has been a regular update highly influenced by WHO’s recommendations. The guidelines are intended to be used by all health care workers involved in the management of TB suspects and patients. The responsibility of the guidelines being correctly implemented is on a regional and national level of the health care system. The implementation will be done by offering orientation, training and supervision to the health care personnel.
The guidelines contains information about organisational and programme management, the principles of TB control, diagnosis and management of all forms of TB in adults and children, HIV, infection control and prevention, advocacy, communication, social mobilisation, monitoring, evaluation, management of anti TB medicines and Mycobacteria Other Than Tuberculosis [MOTT]. There is also statistics and suggestions of forms suitable for the TB care (MoHSS, 2012).

Penduka
Penduka is a non-governmental development organisation providing work for women in Namibia. It was founded in 1992 and is based in Windhoek. Their purpose is to support Namibian women suffering from a low social status by offering them the means necessary for changing their life situation. The organisation provides work for nearly 660 women and supports nearly 1000 TB patients at different local clinics. The organisation is not dependent on donors or subsidies. Penduka organises exchange programmes between the Netherlands and other European countries, gives out interest free loans and helps women getting loans for their studies or to buy a house.
The organisation also has a partnership with the MoHSS in Namibia. Penduka offers social workers to support TB patients with a free meal every day, distributing medications by DOT and offering weekly education sessions in the form of a buddy system (Penduka, 2016).
Theoretical framework and definitions

The Therapeutic Relationship
The link between patient and nurse, the therapeutic relationship, is one of the core activities in nursing. It’s a complex social process that today isn’t fully understood, mastered or defined. It is often taken for granted and therefore the potential stays hidden for both nurse and patient. The therapeutic relationship is of great importance in the work of supporting the patient through periods of stress, promoting learning, personal growth and self-exploration in an environment of trust and support. There are some key factors that relates strongly to the therapeutic relationship; trust, respect, empathy and power. Trust and respect are necessary in building and maintaining a social process that is constructive and positive for the patient. The nurse empathic ability is necessary to identify and enable solutions and strategies that fully serve the patients own interests and will. The nurse must protect the patient interests and work to empower the individual strengths (Chambers, 2005). According to Horvath and Symons (1991) the quality of the therapeutic relationship is a strong indicator of therapy outcomes.

Lifeworld
…”individuals and their existence can never be satisfactory understood if they are not looked upon as living wholes. We are all individuals living in a common world, relating to the world context and each other, all looking for meaningfulness and yet meaning in unique ways… …their own experience and understanding of themselves, their lived bodies, and the meaning that their life situations hold for them.” (Dahlberg, Dahlberg & Nyström, 2008, p. 88).

Definitions
The nurses responsibility
Nurses have four fundamental responsibilities: to promote health, to prevent illness, to restore health and to alleviate suffering. The MDR-TB care shall be conducted with respect for the patients human rights where dignity, respect and the right to choose is of great importance (International Council of Nurses [ICN], 2012).

Adherence
The WHO definition adherence to TB treatment as the extent to which the patient’s history of therapeutic drug-taking coincides with the prescribed treatment WHO adherence (WHO, 2003).

Experience
The definition of experience in this study is the nurse performed work, identified problems regarding performed work and the nurse identified needs of more knowledge to improve the work performance. It is built on the ICN (2012) statement that “The nurse carries personal responsibility and accountability for nursing practice and for maintaining competence by continual learning” (p. 3).

Two different views on the concept adherence
Historically there has been a doctor centred view on why the patient doesn’t follow the, by health care, recommended treatment. The perception of a good patient as one following doctors orders, has resulted in research that focuses on non-compliance. There is an assumption that the solution of a medical treatment without side effects, is the best way to reach a high adherence. It has also put a focus on the patients need of learning the right behaviour to be able to follow the health care choice of solution (Trostle, 1988).

Conrad (1985) presents an alternative, patient centred, approach for supporting the patients in following the recommended treatment. Focus lies in learning why the patient doesn’t take the medicine. A patient is a thinking and reflecting person who practice “self-regulation”. It means that the patient is testing, controlling dependence, destigmatize and creates a practical practise. The patient isn’t skipping the
treatment because of knowing better or not caring. Patients are practicing control over the disease based on their own experiences and thoughts.

**Low adherence impact on the world and on the patient**
Many patients experience difficulty in following treatment recommendations and a low adherence is a problem worldwide. It causes a high economic burden on the health care system, a higher amount of suffering for the patient and makes medicine treatment less effective. Adherence to long-term treatment therapy for chronic illnesses is today at 50% or lower. Poor adherence to long term therapies, such as MDR-TB treatment, severely compromises the effectiveness of the treatment and the poor is disproportionately affected (WHO 2003).

There is a need for health systems and providers to develop means of accurately assessing adherence and the influencing factors to create an intervention that address the particular illness-related demands experienced by the patient. There are no identified care solutions today that can ensure full adherence for a patient following the treatment plan. One of the identified factors connected to adherence is the relation between health care personnel and patient (WHO, 2003).

**The research today**
Looking at today’s research, the adherence to MDR-TB treatment appears to cover five different key areas; medicine, environment, society, economics and nursing.

There is a high focus in the medical area on evaluating existing drug regimen and if there is a potential risk for the patient (Joseph et al., 2011). There is a need for medical improvements that result in a lower risk of side effects and a higher potentiation of treatment (von der Lippe, Sandven & Brubakk 2006). Research focusing on identifying social factors also searches for new ways to reduce negative impact on the patient’s adherence. Identified factors that have a negative impact on the patients adherence is alcohol abuse, smoking (Skrahina et al., 2012), socioeconomics (Li et al., 2014) and stigma (Horter, Stringer, Venis & du Cros, 2014).

Research on environmental factors investigates whether the organisational solutions have a good or bad effect on the patient’s adherence. Results speak for a decentralised health care (Farley et al., 2014), and routines that prevent spreading TB to other patients at the hospital (Farley et al., 2012). There is also an economic focus on the costs that TB cause on an international and national level and strategies to reduce it (Pooran, Pieterson, Davids, Theron & Dheda, 2013). In nursing science there is a focus on how to make the treatment more patient centred (Horter et al., 2014), providing emotional support to help the patient complete the treatment (Chalco et al., 2006). Other areas are evaluating the health care personal's attitudes impact on the patients adherence (Farley et al., 2012).

**Statement**
The work conducted by WHO to reduce the global burden of TB has been successful. A lot of lives have been saved and suffering has been reduced to a great extent. Still, a remaining threat is the development of drug resistant TB bacteria. There is a strong connection between low adherence and the development of MDR-TB. WHO states that there is a link between a high adherence and the relationship between health care provider and patient but can’t provide any standardised solutions on how to actually improve this relationship.

Nurses worldwide struggles daily to find strategies on supporting the patients to achieve a high adherence to the treatment plan. But in a scientific view there is a low focus on evaluating or supporting the nurses in their work. There is a need for investigating the nurses and patients own experiences concerning the work methods that are used today.
Purpose
The purpose with this study is to explore how the Namibian nurses experience adherence to treatment in patients diagnosed with multidrug-resistant tuberculosis.

Ethics
When there is human participation in a research, ethics must be considered regarding every persons right to integrity, safety and the right to self-determination (Rosenberg, 2009). It is important that information is given to the participants. The information should state purpose and nature of the study, confidentiality of all data gathered, and the right to decline further participation at any time. The purpose is to ensure the participants right of self-determination (Polit & Beck, 2012; Olsson & Sörensen, 2011). Before the interviews were conducted, both oral and written information was given to the participants. It was done in three phases. First, the information was offered as a written letter where also the interview questions were included. Second, before the interview was conducted, the same information was given verbally. Third, the results are offered to the participants, if wanted, by their own request. The written information provided to the participants included an e-mail address for them to use if needed.

The purpose of the three phases is to ensure that the persons who participate do it in their own free will and gains from the knowledge that they contributed to (Polit & Beck, 2012).

The ethics committee of University West has approved this study.

Method
The purpose with this study was to explore how the Namibian nurses experience the adherence to treatment in patients diagnosed with multidrug-resistant Tuberculosis. To understand the nurse subjective experience the authors have chosen to do a qualitative study (Polit & Beck, 2012).

Sample
Five registered nurses from a state hospital in the central region of Namibia participated in this study. All five nurses worked with providing health care for patients diagnosed with Tuberculosis in a medical ward or open clinic located at the hospital. All participants were women and the age varied from 25 to 60. The five participants volunteered after receiving information together with a request of participating from the foreman, matron, at the ward (Polit & Beck, 2012).

Inclusion and exclusion criteria
Inclusion criteria were that the participants are made by trained nurses with experience from working close to patients diagnosed with Tuberculosis. All nurses had to be employed at the hospital during the time the interviews were conducted. Exclusion criteria were nurses with work chores that wasn´t directly connected to the direct patient care.

Settings
This study was conducted in a state hospital in the centre of Namibia. The interviewed nurses all worked with health care addressing different types of TB treatment at two differentwards. One of the wards specialised in regular TB treatment and provided full time care for patients until they stopped being contagious or if they were in need of extra medical support. The hospital ward also offered support to patients that were medicated at home by regular check-ups and daily DOTS appointments.

The second hospital ward treated patients with different types of multi resistant TB. This ward had harder restrictions of isolation and longer treatment periods for the full time care patients, compared to the regular TB ward.
Doctors and nurses worked closest to the patient on a day to day basis. There were also social workers from the organisation Penduka that supported the caring for the patients at the wards.

Data-collection
All nurses were interviewed separately in a specially selected room at the hospital. It was a conference room that offered a quiet place without disturbance and insight from others. Both interviewers were in the room during the interviews but only one interviewer was active in conducting the interview. The duration of the interviews were between 20 to 30 minutes and were audio recorded to ensure that the participants verbatim responses was gathered for the analysis (Polit & Beck, 2012).

A qualitative research technique was used to collect data. It allowed the interviewer to reach a greater understanding and a more diverse picture about the nurses work with Tuberculosis patients (Olsson & Sörensen, 2011).

The interview questions were constructed in a semi-structure with partly opened questions. This would ensure that the specific topics of Tuberculosis, adherence and the patient care was covered without interfering too much in the interviewed opportunities to answer freely in the topic (Polit & Beck, 2012).

The interview questions were created and developed by the interviewers and feedback was given by two mentors, one in Sweden and one in Namibia. The questions were revised to five key questions. These five questions were later tested in a pilot interview with a social worker at an HIV/TB clinic in Namibia, Windhoek. This was to ensure the questions were understood and interpreted as intended by the interviewers. A time limit for maximum 35 minutes was decided to make certain that the nurses had the time to participate and the interviewers were able to transcribe and analyse the results. In annex II you find the interview questions.

Analysis of research data
All five interviews were transcribed, verbatim, by both authors and all material was verified several times to avoid inaccuracies.

The data was analysed with Graneheim and Lundmans (2004) analysis model and was conducted in four main steps; 1. Sorting data into content areas, 2. Extractions of suitable content areas that constitutes the unit of analysis, 3. Dividing the text into meaning units and coding and 4. Sorting the codes into sub themes and themes.

First, the transcription was read and reread several times individually by both authors with the purpose to obtain a sense of whole. Both authors together, under mutual discussion, sorted the data into eight different content areas: “Yes and no answers that wasn’t further described by the interviewed”, “the Angolan patient”, “economic support to the patient on a national level” “descriptions of the hospital environment”, “descriptions of medical routines”, “nurses experiences regarding patients adherence to the treatment plan”, “safety rules” and “descriptions of MDR-TB patients”.

In the second step, suitable content areas were extracted and brought together into one text. Content areas selected to constitute the unit of analysis was “the Angolan patient”, “nurses experiences regarding patients adherence to the treatment plan”, “descriptions of MDR-TB patients”. There was a discussion between the authors on the matter of excluding “descriptions of medical routines” or not. The authors finally agreed that it should be excluded on the reason of belonging to science of medicine rather than nursing.

In the third step, the unit of analysis was to divide the text into meaning units that were condensed and finally labelled with a code. This was made first separately and then together between the authors.
The fourth step, was made by the authors together comparing the codes, based on differences and similarities, and then sorting them into sub themes and themes.
An example taken from the final analysis:

<table>
<thead>
<tr>
<th>Nr.</th>
<th>Meaning unit</th>
<th>Condensed meaning unit</th>
<th>Condensed meaning unit</th>
<th>Sub-theme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>020</td>
<td>Mh! Although maybe he get well, he discharge! He finish his t.. treatment... ahh.. treatment! his course for TB! When he is going home; he just starts smoking, drinking, and maybe after five months, or three month or two weeks. He.. he start again. Coughing! Sick! Mmm... Yes!</td>
<td>Although the patient gets well and discharged after finishing the TB treatment. When he gets home, he will just start smoking and drinking again. Maybe after five months, or three months or two weeks he starts to cough again. He has been infected and is sick.</td>
<td>A patient can be successfully treated at the ward. When returning home the patient fall into old habits of abuse and then obtain a new infection.</td>
<td>Prioritising the feeling of well over the work of becoming well</td>
<td>The patient not being able to achieve a high adherence to the treatment plan</td>
</tr>
</tbody>
</table>

Result

Four main themes, with twelve related sub themes, emerged after the analysis was completed. The first theme “The nurses own descriptions of MDR-TB patients” compile the nurses own descriptions and views on this specific type of patients.

The second main theme “The patient not being able to achieve a high adherence to the treatment plan” retells the nurses different experiences concerning patients with a low adherence to the treatment plan. “Supporting the patient in reaching a high adherence to the treatment plan”, the third main theme, describes the nurses own strategies on how to achieve a higher adherence for the patient.

The fourth main theme “The need of further development and improvement of the offered care existing today” gives a picture of what the nurses want to improve in the future care.

Together the four themes render the nurses combined experiences in how they perceived the patient, identified the areas of support, how they provided that support and what they wanted to improve for achieving higher quality on the provided care.

Overview of main themes and related subthemes:

<table>
<thead>
<tr>
<th>Main Theme</th>
<th>Sub Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>The nurses own descriptions of MDR-TB patients</td>
<td>The MDR-TB patient – a different medication but also a different need of support</td>
</tr>
<tr>
<td></td>
<td>“The difficult patient”</td>
</tr>
<tr>
<td>The patient not being able to achieve a high adherence to the treatment plan</td>
<td>Low adherence caused by a low amount of cooperation</td>
</tr>
</tbody>
</table>
Prioritising the feeling of well over the work of becoming well

When being sick isn’t an option and the hospital ward threatens to take all that matters in life away

The patients need of making the time at the hospital ward useful

The invisible patient

Supporting the patient in reaching a high adherence to the treatment plan

Reaching a higher adherence – a matter of informing or listening to the patient?

To offer a patient a satisfying solution

Delegating DOTS and organise transport – identifying and implementing solutions

The need of further development and improvement of the offered care existing today

Investing in greater knowledge of the health care personnel – a way of reaching a higher adherence

A need of a more suitable environment to provide safety for all patients

The nurses own descriptions of MDR-TB patients

**The MDR-TB patient – a different medication but also a different need of support**

The nurses overall description of MDR-TB patients were patients with different medicines and therefore in need of different care solutions concerning side effects. Often there was an earlier history of low adherence, with problems such as long transport distances to the hospital and a lack of food at home.

“My experience with the MDR-TB patients is that... I have learned that... they are patients who... would forget taking the medications for the TB treatment correctly.” (Nurse 1)

The MDR-TB patients also had an extra need for social support to handle negative emotions, specially adapted food and practical support to maintain their basic hygiene. These patients were also described as harder to monitor with a higher amount of work for the nurse and that it was of great importance that these patients followed the treatment plan correctly.

When describing the differences between a MDR-TB patient and a patient with regular TB there was two different areas of focus among the nurses. Three of the nurses gave descriptions connected to the medical treatment; such as side effects and a history of low adherence. The other two nurses focused on problems in the patients daily life, caused by MDR-TB, and the amount of work that it brought for both nurse and patient.

“The difficult patient”

When describing the problems connected to patients adherence to the treatment plan all nurses used the phrase “the difficult patient”. They also expressed a frustration of not being able to offer a better
solution in treating the patient. Still, when describing different solutions on how to deal with the patients that don’t want to adhere there were two different approaches.

Three of the nurses described the reason for not adhering as the patient not knowing better. Words such as childish and the patient doesn’t care were often used. Patients that didn’t want to obey the rules were described as problematic but there were no further views on why the patients didn’t want to cooperate. The main responsibility for understanding and obeying was laid on the patient. The nurse role was to make the medication possible and inform about the rules at the ward and how to follow the treatment correctly.

The other two nurses also had a focus on making the patient understand that the treatment wasn’t the best option. But there were more descriptions and a higher focus on specific problems together with ideas on workable solutions that was needed. They described that there was a patient’s point of view too and that they could understand why the patient didn’t see it as an option to adhere at all times.

The patient not being able to achieve a high adherence to the treatment plan

Low adherence caused by a low amount of cooperation
All five nurses described different types of problematics connected to patients with a low adherence.

One sort of problem were patients not attaining the amount of medicine that was needed to defeat the MDR-TB infection. The behaviour that was described by the nurses were patients trying to throw their medicine away or hide it. There were also patients that didn’t take the medicine at a regular basis.

Another type of problem, described by four of the nurses, were the patients not being monitored in a satisfactory way and therefore resulting in faulty medication or a threat of spreading the disease. The behaviour that was described were patients leaving the ward without permission. It could be just for the day or for good. Three of the nurses referred to patients that demanded to be allowed to go home or refused to be admitted to the hospital ward when diagnosed with MDR-TB.

Other types of problematics defined by the nurses regarding the insurance of monitoring the patients in a proper way, concerned the delegation of DOTS. When the nurse delegated DOTS to a friend or a family member there was often a problem for the person being delegated to keep full track of the patient. The reason, described by the nurses, was the delegated person prioritized work or family chores before monitoring the patient.

One nurse described that side effects caused by the medicine wasn’t always being treated in time for patients who were medicating at home. The same nurse also stated that poverty caused by unemployment, and the need of money for food and traveling to the hospital, were very common reasons for not attending medical appointments. Both problems caused a lower adherence to the treatment plan.

“Why they don’t come to hospital they say they don’t have money… Always there is no money. They can say that no money, no food… some of the people they are not working.” (Nurse 3)

Two of the nurses mentioned that low adherence to the treatment wasn’t always a product of problematic behaviour from the patient. Sometimes there wasn’t enough of medication supply at the pharmacy’s. There were also incidents caused by doctors and nurses who didn’t listen enough to the patient.

Prioritising the feeling of well over the work of becoming well
All nurses agreed that patients with an addiction problem were one of the biggest challenges in their work of supporting a high adherence to the treatment plan. The patients used their money on alcohol or...
drugs instead of food or transportation to the hospital. They ran away from the ward when the abstinence got too intense. The patients caused a risk to others when leaving the ward temporary for buying new drug supplies or when being angry or violent at the ward. To trace a patient with an addiction problem was described as very hard from three of the interviewed nurses. One of the nurses also described that even if the patient got through the treatment and recovered from the MDR-TB they often went back to old habits when returning home and resumed smoking and drinking. Often these patients got a new infection and returned to the ward.

“...and the ones that stay here... you can see that the moods of the patients... they are going out of the hospital. To go and drink and not taking the tablets... and then they must stay for a long time in the hospital.” (Nurse 5)

Two nurses emphasised the problem of not being able to track a patient immediately after they had left the ward unplanned. According to the nurses experience the patients who were hard to track had a higher risk of committing suicide. The patients that hadn’t been found directly often returned on their own to the hospital when it was too late for the medication to work.

When being sick isn’t an option and the hospital ward threatens to take all that matters in life away
All the nurses clearly expressed that the MDR-TB treatment was too long for the patients to endure. They also agreed on the time period spent at the ward, from eight months up to several years, also was a problem. Two of the nurses described the patients as under stimulated and restless. A third nurse retold patients own descriptions of feeling isolated from the community and the expressed frustration of pausing their lives when being treated at the ward.

Four nurses mentioned patients that didn’t want to participate in the treatment plan because they were in denial of being sick. This type of patient often kept asking the same questions like “why me?”

The four nurses also described patients that didn’t see it as a workable option to be sick and to stay at the hospital ward. The patients were needed at home as they were the sole provider for small children or needed to attend school or work. That caused a lot of stress and frustration for the patient when being isolated at the ward.

“They (the patient) are complaining of the stay in the hospital. They don’t want to stay so long in the hospital as I was saying. Maybe they are breast feeders and maybe they need to support their family...” (Nurse 5)

Two of the nurses mentioned stigma as a reason for the patients avoiding medication and attending the hospital. They described stigma from society as problematic for both patients and hospital staff. For some health care workers and patients it caused too much stress and they gave up their employments or ended their treatment.

The patients need of making the time at the hospital ward useful
To ease the treatment period for the patients the nurses saw a need of offering the patients some form of occupation during the day. One nurse suggested a gym or a walk plan so the patients could exercise. A second nurse saw an opportunity for activities connected to the improving of adherence and supporting the patient for a new beginning after their time at the ward.

“They need ready a proper area where they can stay. Like they are not supposed to be moving out and they need... something for exercise. Yeah. For them (patients) to rehabilitate them. Somewhere they can walk.” (Nurse 2)
All nurses described the importance of the patients moving around and using their bodies. Two of the nurses saw it as a problem that the patient didn’t exercise and therefore being under stimulated when treated at the hospital ward.

None of the nurses saw it as their responsibility to support the patient in the physical training and they all referred to the patients own commitment. Three of the nurses described it as the doctors responsibility by referring patients with an extra need of support to a physiotherapist.

The invisible patient
Throughout the interviews there was a description of a specific type of patient from three of the nurses; “the Angolan patient”. They described a high number of male Angolan citizens that were receiving MDR-TB treatment at the hospital. All three nurses suspected that the patients had been receiving a poorly conducted treatment in their home country and travelled to Namibia to receive a medical care of higher quality.

Two of the nurses described these patients as extra vulnerable and exposed to high amounts of stress. One nurse recounted for the suffering expressed from patients as they realised that they had been following an inadequate treatment plan in their home country. The treatment had cost them a lot of money and effort with the end result of the TB had developed into MDR- or even XDR-TB. To get well again they had to follow a new treatment plan, eat even stronger and more expensive medicine and live with the risk of dying.

“Most of them (patients from Angola) when they come they are pretty tiered. Yeah... because they are staying there in Angola they are just buying their medication. Just buying and buying and buying... And when they come here they are already tormented...” (Nurse 1)

The second nurse described patients with a very high economic burden. When they seek care in another country they had to leave their social support. The nurse described the patients as under a lot of stress when every third month being forced to apply for a new temporary visa. These patients often were victims of black mailing as their illness forced them to stay in the country even if the law prevented them from staying the full treatment period.

The three nurses expressed that the patients from Angola existed in a grey area when receiving the TB treatment. There wasn’t a specific system for these types of patients but they were still offered treatment to prevent further development and spread of MDR-TB. They were an “invisible” patient in the system.

To solve this problem all three nurses described an adapted work practice that had emerged over time. After receiving the obligatory treatment period at the ward the patients were sent home to Angola again with a sufficient supply of medicine for finishing the treatment. They had to return again for a check-up, to ensure a satisfactory treatment result had been achieved. There was special cases of MDR-TB were the patient was forced to stay a longer period in the country to be enabled to retrieve special attending to their treatment.

Supporting the patient in reaching a high adherence to the treatment plan

Reaching a higher adherence – a matter of informing or listening to the patient?
There were three different reasons given from the nurses for providing information to the patients. One reason was to improve adherence for patients with an earlier history of medication failure and patients in denial. Providing information was also a way of avoiding aggressive behaviour and frustration from patients and their family members. The third reason was to protect the patient rights to knowledge
about their own medical situation. Doctors, nurses, social workers and sometimes psychiatrists were all responsible for informing, counselling and to educate the patient.

The type of information the nurses provided were facts about the disease, type of medicine, physical status, reasons for a good nutrition and reasons for being at the hospital ward. The risks of infecting others and the importance of following the treatment to be able to return home was also mentioned.

It was also described as important to make time to listen and talk to the patient so the nurse could learn about the patients own experiences, worries, concerns and wishes.

“…and then do have the time to... raise their (patient) concern! So if you are.. if the patient is there and we don’t know what is his concerns.? What is his complain... So we have to communicate with the patient to get from them... what they need, and what they want!” (Nurse 5)

All interviewed nurses described a specific work routine of counselling a patient that was diagnosed with MDR-TB. Before the treatment started the patient and closest members of the family were informed about the medical situation. By signing a written consent, the patients ensured their own understanding of the information provided to them. That included the patients awareness of the risks for side effects, for a longer period of time to be separated from the family and also the health care requirements of following the treatment plan correctly. If the closest family members weren’t attending the meeting in person they were informed by phone.

“Yeah.! I have to inform them (patient and relatives). Sometimes I do the counselling before they are asked... This treatment for MDR we are not going to start before you give a counselling for the patient and the family member. We get the counselling with the psychology, than me (nurse), the social worker and then the doctor. We call the family member and give them information to!” (Nurse 3)

All nurses agreed on the importance of giving information to the patient. When describing who was responsible for providing and conveying information, the opinions were divided in two.

Three of the nurses had a focus on informing the patient about the rules of medication and encourage a good behaviour that would take the patient home and result in a good health. The nurses repeated a specific amount of information to make the patient understand what to do. Other types of communication with patients and their family members were referred to as the social workers responsibility. A low adherence was described as being caused by the patients “not knowing better”. The nurses provide the patient with information and the patient has the responsibility to comprehend the given information and obey the rules.

The other two nurses focused on the patients right to understand their own situation. They referred to communicating with the patient as an opportunity to enable a higher amount of knowledge. They described it as the nurses responsibility to reach an understanding with the patient. The nurses, along with doctors and social workers, were different sources of knowledge that the patients were in need of to understand their own situation. The two nurses stated that a high adherence could only be reached by talking to the patient.

Two of the five interviewed nurses also mentioned a language barrier that occurred when the patient didn’t speak the official language English. It was solved by health care personnel working together in translating for each other.

To offer a patient a satisfying solution
Three of the nurses described different situations, where different strategies were used for making the treatment more manageable. They mentioned that the hospital had a routine of not giving injections on
Sundays and described this routine as very popular among the patients at the hospital ward. There was also a tradition of offering patients juice to cover bad taste from the medicine.

“…and here at our department…for the injection. We give Monday to Saturday. They are of the injections on Sunday. Yeah. Sunday they (patients) are so happy! Not to get injections…” (Nurse 5)

The nurses also mentioned different solutions for supporting a patient feeling lonely or isolated. If possible, one of the solutions was to allow family visits.

Another solution was to allow the patient a temporary leave to visit family or friends. It was granted if the patient no longer was contagious. The nurses delegated DOTS to a person in close contact with the patient to ensure a high adherence outside the hospital ward.

The other two nurses described no specific solutions. Instead they spoke about patients using their own ability to find solutions. The first nurse described patients seeking friendship with each other for the social support. The second nurse mentioned patients going to church or finding day activities in the community.

There were two different ways, on how to view the patient among the nurses being interviewed. Three of the nurses had a focus on following the treatment plan. All three nurses referred to the hospitals standard solutions such as offering juice and the injection free Sunday. Leaving the ward was described as a privilege for those patients, who did as they were told.

The other two nurses stated that it was better trying to meet the patients half way. Even if it wasn’t an ultimate solution it was considered a better alternative than a patient that completely stops to participate.

“If you can refuse? You can’t do anything! Because if you just say no you are not going… Later on he is just leaving on his own…” (Nurse 4)

Delegating DOTS and organise transport– identifying and implementing solutions

Three of the nurses mentioned different situations where a delegation of DOTS was necessary to enable further medication outside the hospital.

The first situation, as mentioned earlier, was when a patient went on a temporary leave from the ward and the task of watching the patient taking the medicine was given to a private person without any professional connection to health care. A family member was described as preferable, but if that wasn’t possible a friend could be chosen instead. The person being delegated received information from the nurse by phone. The given information stated, that the hospital had granted permission for the patient to go home as long as the treatment plan was followed. The delegated DOTS performer also received information that an adequate dose of medicine was provided to the patient before leaving the hospital. One of the nurses emphasise the importance of making the delegated person aware of the necessity of watching the patient with their own eyes and not just trusting the patients verbal insurance of swallowing the medicine.

The second situation when a delegation of DOTS was described as necessary where when a patient couldn’t travel to an appointment at the clinic. The nurse delegated, by phone, the responsibility of fetching and deliver the medication to an assistant at the pharmacy and a social worker retrieved a DOTS delegation.

A third situation was more of an organisational sort. The nurse supported patients that had a long traveling distance between home and hospital. This was done by making sure that the patient had a place at a transport buss offered from the hospital.
There was a difference between the three nurses’ way of describing, who’s main responsible of identifying and enabling solutions for a higher adherence. Two of the nurses described it as their own responsibility for ensuring that the patient followed the treatment plan. The third nurse described the patient as main responsible for identifying and informing the nurse about problems. The nurse was only responsible for coordinating the solution.

The need of further development and improvement of the offered care existing today

Investing in a greater knowledge of the health care personnel – a way of reaching a higher adherence

The nurses defined different sources of knowledge and guidance supporting them in their work of caring for MDR-TB patients.

Three of the nurses saw a gain in using the national TB guidelines from a medical point of view. It also gave a support in stating the nurses responsibilities in conducting chores connected to the medical treatment. Two of the nurses also stated that there was a negative side of using the guidelines, as it was very medically focused. One of the nurses expressed a wish of improvement on a more detailed guidance in how to conduct nursing, not just medicine.

“Sometimes it’s good with the guidelines… sometimes its enforcing somebody to do it. And sometimes you are just behind the patient. You are not allowed the patient to do something for themselves.” (Nurse 3)

The other two nurses used other types of sources for information and guidance. They didn’t experience a need of using the guidelines. One nurse described the staff meetings with doctors, nurses and the matron as useful and the second nurse saw it as enough to follow the doctors prescription.

Four of the nurses experienced a need of education for others in the working staff. Three nurses mentioned that there was a need for doctors and nurses in general, to be more aware of the greater gain in seeking new information on a regular basis. Areas that they proposed were communication with patients and improving the medical skills in performing tests and treatments.

One of the nurses suggested a someone specific that followed the patient through the whole treatment period at the ward and in the community. The purpose was to ensure that all work chores was done and completed with a result of high quality care for the patient. The existing solution of using social workers wasn’t seen as an optimal solution. The reason given was that Penduka wasn’t a source strong enough to carry out the task of supporting the patients through the treatment period.

“Yeah we (the nurses) have Penduka. But the Penduka is not ready giving enough attention. Because they have also other patients.” (Nurse 2)

The other two nurses described a need of more knowledge and training for the social workers from the help organisation Penduka. The social workers were in need of more knowledge as they conducted the educational- and social support to the patient.

A need of a more suitable environment to provide safety for all patients

All nurses expressed a discontent of having the TB ward in the same building as other types of medical treatments. They saw it as a risk for other patients to be infected when MDR-TB patients left the facility without permission. Two of the nurses also described a higher risk for the MDR-TB patients of being exposed to stigma when seeking care.
To make the treatment period at the ward more manageable for the patient three of the nurses suggested different types of environmental changes at the hospital. The given suggestions were a gym, a walk area or some sort of crafting studios.

**Discussion**

**Method discussion**

*Credibility*

According to Granheim and Lundman (2004) credibility refers to confidence in how well data and process of analysis address the intended focus.

To reach a variety of aspects regarding the researchers' questions the choice of participants is important. A selection of people with various experiences provides a broader spectrum of understanding (Granheim and Lundman, 2004). There was a high variety of age and experience between the five nurses as the authors assess as positive. Still, the study is based on a small amount of participants from one hospital which can cause limitations in identified aspects in the result.

In the process of analysis the first step was to organise the data through classifying and indexing. It is important to have a good system to convert the data into smaller and more manageable units that can be retrieved and reviewed by the researchers (Polit & Beck, 2012).

To ensure as high quality and scientifically accurate analysis as possible, the authors chose to use Granheim and Lundmans (2004) analysis model as it states the purpose of being suitable for nursing science.

Granheim and Lundman (2004) explains that reaching a higher amount of credibility selection of data is of great importance concerning the choice of including and excluding data in a way that doesn’t alter the results in a negative way. Both authors together, under mutual discussion, chose to exclude four of the eight different content areas: “Yes and no answers that wasn’t further described by the interviewed”, “economic support to the patient on a national level” “descriptions of the hospital environment” and “descriptions of medical routines”. The reason they were excluded, was that the authors didn’t find them relevant to the description of care in a nursing science context.

During analysis there is an importance to distinguish between ideas that apply to many and aspects of experiences unique to particular participants (Polit & Beck, 2012). The authors chose to do the analysis in two different ways. First, at a group level where all the nurses’ descriptions in one topic were compiled into one mutual picture. Second, at an individual level that explored the specific differences within the topics that were described.

A dynamic and rich presentation of the results together with appropriate quotations enhance the credibility of the study (Granheim & Lundman, 2004). Providing insight to the authors work of processing and interpreting the data, there are quotations from all nurses included in the result.

*Dependability*

Dependability represents the degree to which data is altered over time throughout the process of producing a result. It also includes the alterations made in the researchers decisions when conducting the analysis (Granheim & Lundman, 2004).

The authors qualifications, training and earlier experiences in handling and interpreting data is an important factor regarding the end result of the study (Patton, 1990). For practical reasons all interviews and the analysis have been conducted in English as the authors
comes from Sweden and the people being interviewed are Namibian citizens. Still, none of the participating persons speak English as their first language. Therefore there may be a risk of limitation in expressing nuances that can have influenced the analysis and interpretation of the results. The same is for cultural misunderstandings in expressing and interpretation of body language and unspoken cultural traditions.

To ensure that the nurses views and opinions were captured and interpreted as fairly as possible, the authors spent several weeks working in other wards at the hospital. By conducting work practice and trying to learn verbal expressions, dialects, body language and working methods the authors aimed for broadening the understanding of the Namibian health care system. The authors also asked for advice and guidance from a doctor, two nurses and also a professor for feedback regarding the work of understanding the Namibian culture, traditions and health care system.

All five interviews were transcribed, verbatim, by the authors and all material was verified several times to avoid inaccuracies. Accordingly to Polit and Beck (2012), the authors focus when verifying the transcription, lies on avoiding alterations such as “tidying up the text” by avoiding words as “ums” or “eh”, or accidental alterations of the data by spelling words wrong or leave out question marks etcetera (p. 557).

Polit & Beck (2012) specified that concepts might not be identified and a satisfying coding may not be reached until the analysers have fully grasped the data. It may need several readings of the material to achieve a satisfying result. The authors worked first separately in the first step and then together in the second to fourth step in the analysis. The purpose was to minimize the risk of a faulty identification and labelling when sorting and naming of codes, subthemes and themes.

When conducting this study it occurred to the authors that there are international differences in viewing and conducting scientific work in society. A great variety was also discovered regarding naming, meaning and interpretation of the scientific concepts of nursing between different countries. Therefore the authors chose to use the WHO definitions and English concepts as foundation to the conceptual framework and definitions. The purpose was to minimize the interference of national differences as much as possible.

*Ethical consideration*

There are no names or personal information mentioned in the study and all interviews have been handled with confidentiality. It has only been used for the purpose of the study. This is done to protect the participants integrity (Polit & Beck, 2012).

Polit and Beck (2012) describes that selecting participants to interviews sometimes needs to be done in the guidance of a key informant or an expert as the researchers don’t have the needed knowledge on how to proceed with the sampling.

As mentioned earlier, the five participants volunteered after receiving information together with a request of participation from the foreman, matron, at the hospital wards. In this study the authors choose to seek guidance and support of the matron as a key informant. As the request came from a superior there was a risk of participation wasn’t entirely without undue influence (Polit & Beck, 2012). The authors were aware of the risk when asking for help but assessed it as small.

When choosing quotations that are included in the result, confidentiality of the person being interviewed was prioritized.
Transferability
It is only the reader that can decide whether or not the findings are transferable to another context. To support the reader in this decision the authors can make suggestions together with a clear and distinct description of data collection and process of analysis. It is also helpful with a generous presentation of the results in combination with proper quotations from the transcription (Granheim & Lundman, 2004). The authors suggests that this study can be helpful in the work of supporting the patient in improving adherence to long term treatment as it address two different ways of interpreting a patients behaviour connected to low adherence. The authors aim has been to provide as clear and distinct description as possible of how this study has been conducted and what the result was.

Result discussion

The nurses description of an typical MDR-TB patient
The nurses given descriptions of MDR-TB patients are linked to the perception of a difficult patient and a higher amount of work. A great number of patients had a history of medication failure in earlier TB treatments. They are now in need of other types of medications that often causes more severe side effects and a longer treatment period.
The behaviour of a non-cooperating patient was described as refusing to take the medicine, lie, running away, not attending treatment at the hospital ward, skipping visits to the clinics and taking the medicine in a different way than prescribed. Patients were also described as sometimes aggressive, in denial, resigned and even suicidal. The nurses made a clear connection between MDR-TB and problems such as addiction, poverty, unemployment and being the single family provider for small children. The MDR-TB patients are in the interviews described as a type of patient in greater need of emotional, physical and economical support compared to patients with regular TB.

This concur with earlier research which states that low adherence to MDR-TB treatment is connected to low or none existing income, abuse of alcohol or drugs (Zvavamwe & Ehlers 2008; Kendall et al., 2013; Mulu, Mekkonnen, Yimer, Admassu & Abera, 2015) and living in rural areas (Kendall et al., 2013; Ibrahim et al., 2014). The treatment period at the ward have a negative impact on the patients life in forms such as loss of income, stigma from society (Deshmukh et al., 2015; Zvavamwe & Ehlers, 2009), isolation and deprivation of freedom. This can cause psychological distress, suicidal thoughts and attempts and also post-traumatic stress disorders (Peltzer & Louw, 2013; Peltzer et al., 2013) which results, for some patients, in violent behaviour (Baleta, 2007; Alsop, 2008).

The interviewed nurses and earlier research both describes MDR-TB patients as heavily burdened with high amounts of stress, related both to the disease and the daily life.
For the nurse to be able to support a patient through periods of stress, the therapeutic relationship is of great importance. One of the key factors of this social process is the nurses´ emphatic ability to identify, and enable solutions or strategies that serves the patients own interest and will (Chambers, 2005). Dahlberg et al. (2008) states that the individual and his/hers existence can´t adequately be understood if not looked upon as a living whole. This could be interpreted as when supporting a MDR-TB patient, the nurse needs to see the person behind the disease and not just medical treatment and sickness. This concurs with Conrads (1985) view on adherence, to see it from a patients perspective and not only focusing on a medical point of view.

Informing the patient – a one way communication to achieve adherence
Informing, counselling and educating the patient were described by the nurses as of great importance and the best solution in providing support to reach a high adherence. This concurs with Loveday et al. (2014), who states the importance of an ongoing education together with the patient to enhance the adherence to the treatment.
All nurses gave a similar description on how to inform the patient. It was done by giving specific information about the disease, facts concerning medications and the risks of not adhering to the given treatment plan.

All provided information is of a medical kind and concurs with the historical doctor centred view of adherence, by providing the patient with the information necessary to be “a good patient”. There is no need for the patient to understand why, just that it should be (Trostle, 1988).

Frustration was expressed from some of the nurses, that the patients kept asking the same questions and not always accepting the answers. The patients knew what they should do but still didn’t cooperate.

Liedman (2001) emphasises the difference between information and knowledge. Information is provided from one part to another. The receiver of information remains passive in the process and given information is never incorporated to the persons values and understanding. Therefore the provided information can’t be used as knowledge.

The interviewed nurses keeps on giving information to patients who remains passive in the process. Therefore the patient never reaches an understanding. This may explain why patients have a hard time accepting the information provided to them. The patients repeated questions also suggests, that the information provided to them never results as processed knowledge useful for the patient.

To gain knowledge, the person receiving information has to actively integrate it with their own values and understanding. This is not an automatic process and the nurse needs to control how the information is received and valued by the patient, to ensure the active process is enabled (Liedman, 2001).

All nurses stated that counselling the patient was important and obligatory before starting the treatment. The purpose was to ensure that the patient and family members had realised there would be a long treatment period away from the family, a risk of experienced side effects and severe consequences if instructions weren’t followed properly.

Education was also mentioned as an important tool for supporting the patient. The main purpose was to make the patients understand the danger of spreading MDR-TB, the need of quit smoking and the importance of good nourishment.

When providing the patient with counselling and education, the main purpose seems to be on how to change an unwanted behaviour according to a medical point of view. It also makes an argument for an understanding among the nurses, of the need for making the patient an active member in the process of obtaining new knowledge as mentioned by Liedman (2001). Still, the purpose is that the health care personnel needs to make sure that the patients have understood the hard efforts that are waiting. The main purpose of the provided knowledge is to make the patient understand what is expected of him or her to behave in a good way. All this concurs with the doctored centred view of adherence, where the main purpose of talking to the patient is to enable them to become a “good patient” (Trostle, 1988).

Dahlberg et al. (2008) states that all individuals are living in a common world, but finds unique ways of understanding and are relating to it based on their own lived experience.

This could be interpreted as the nurses providing all the patients with the same type of information, based on their own understanding and medical knowledge. How that information is received and interpreted by the patient is however unique for every individual, based on their earlier lived experience. A patient that doesn’t seem to listen, may just have drawn a different conclusion than what the nurses intended and acts upon that conclusion.

Talking to the patient – a two way communication to achieve adherence

All nurses expressed a need from the patients by talking, handling emotions and expressing frustration. They also agreed that the treatment was hard to endure for the patient and therefore brought a lot of stress and suffering. Still, there wasn’t any unity in how the patients emotional needs should be properly managed and supported. The same problem occurred regarding who was the main responsible
of counselling the patients during the rest of the treatment period. Doctors, social workers and all nurses, were mentioned depending on who was interviewed. This concurs with the WHO statement, that the patient centred view is seen as necessary but are still no standardised routines established on how to implement it (WHO, 2003).

Chambers (2005) describes the therapeutic relationship as a complex social process that yet isn’t fully understood, mastered or defined. It’s one of the core activities in nursing, but often also taken for granted and therefore unexplored and underused regarding hidden potentials for both patient and nurse. This could explain the absence of unity, on who’s main responsible for supporting the patient in their emotional stress and how it should be done.

Only two of the nurses emphasized the importance of listening to the patient with the main purpose of learning about the persons own worries and thoughts. It was, according to them, the only way to achieve a high adherence. This concurs with Liedmans (2001) statement, that knowledge is made by a two way communication. The nurses way of listening and interacting with the patient allows the patients own lifeworld to integrate with the nurses provided information. It suggests that a higher adherence is reached by the combined efforts, from nurse and patient, by converting different forms of information into knowledge.

A good therapeutic relationship allows the nurse to empower the patient by promoting learning, personal growth and self-exploration (Chambers, 2005). According to Horvath and Symons (1991), the quality of the therapeutic relationship is a key indicator of therapy outcomes.

There are two ways of communicating with the patient described by the interviewed nurses; “informing” or “talking to” the patient.

Halldorsdottir (2008) explains that only when the connection between nurse-patient has been developed into a stable relation, a true negotiation of care can be started. She describes influential factors, when establishing the therapeutic relationship, that enables or stops further communications with the patient. To enable the link of mutual communication, there has to be trust from the patient to the nurse. If the nurse is perceived as genuinely caring for the patient as a person, competent by having the necessary skills of treatment and communication, and also has the professional wisdom of knowledge combined with experience, the patient can agree on starting a bridge of communication. If the nurse has failed in mediating trust, there will be a wall created between patient and nurse. This wall makes further interaction negatively perceived or do not allow further communication at all. A high quality on the therapeutic relationship could empower the patient in their work of achieving health. A low quality could have negative consequences on the patient with the result of discouragement or even disempowerment. Both results are a subjective experience from the patient.

Iribarren, Rubinstein, Discacciati & Pearce (2014) describes, that there are a lot of barriers, on individual, social and organisational levels, that can cause a low adherence to MDR-TB treatment. To enable identification or the implementation of any solutions, there has to be a foundation of trust to the health care provider from both society and patient. This trust can only be reached by a good quality on the communication between patients, family members and health care providers (Iribarren et al., 2014).

This suggests that the nurses’ different views on how and what to communicate to the patient can have an empowering or disempowering effect on the adherence. There is more to communicating with the patient then just the nurse presenting medical information. The patients subjective experience of the nurses have an impact on the information and treatment that is suggested for them. If the patient doesn’t trust the nurse, the person will not listen to what they have to say.

The reason for not taking the medicine was described as the patient being in denial of their own medical situation. The person didn’t want to accept the fact of having MDR-TB. When the nurses
where asked about the patients own expressed reasons for not adhering, they described patients that didn´t see it as an option to be ill. They were family providers and were needed at home or had to attend school or work. Being treated for MDR-TB made that impossible. Other reasons described by the nurses were the fear of being badly treated because of stigma. The society doesn´t accept persons connected to TB. There are both patients and health care personnel who bends for the pressure. The patients conceals the fact of being infected and the health care personnel quit their job at the health care centres. This concurs with Peltzer & Louw, (2013), Peltzer et al. (2013) findings of MDR-TB and the implemented treatment in combination with stigma, can cause a high level of psychological stress to the patient.

King, Duke & O’Connor (2009) describes that in the face of change caused by a life threatening disease, life decisions are negotiated by patients to maintain a sense of self and wellbeing. When a patient perceives internal or external change, caused by the disease, the reaction is determined by whether the patient succeeds or fails in maintaining the self-esteem. If the patient feels in charge of the disease, they will actively find solutions accordingly to maintain their health. If the self-esteem is low, the patient feels that the sickness is in charge and won´t actively work on finding new solutions in reaching wellbeing in their life. A patient that maintained the self-esteem had lower stress levels and perceived life as good even if the disease caused drastically changes in their daily life. If the patient didn´t feel in charge the stress levels were high and the quality of life was perceived as low for the patient.

As mentioned earlier, the two nurses strategy of talking to the patients concurs with the patient centred view of adherence that has its origins from the patients own lifeworld (Conrad, 1985). The patient centred work for adherence demands a link between patient and nurse to enable a process of mutual understanding of receiving and giving of information, that both parties can convert into knowledge. This link is necessary to support the patient in handling stress and finding new solutions to regaining or sustaining health (Chambers, 2005). Strang, Henoch, Danielson, Browall & Melin-Johansson (2013) states that allowing the patient to speak freely about their own feelings and thoughts, offers a support for the patient to find their own solutions. Strang et al. (2013) expresses that the patients have a need to talk about more than just medical treatments and diagnosis. According to Iribarren et al., (2014), the patient considers the nurse as essential in providing emotional and practical support together with encouragement.

Coordinate the health care to achieve a high adherence
Except for informing and talking to the patient, the nurses also described other types of solutions in the work of achieving adherence.

To ease the burden of every day medication, there was a practice at the hospital of having Sundays free from injections. There was also juice offered to hide the bad taste of the medicine. All nurses agreed that it made the patients very happy even if those were small gestures. The nurses also delegated DOTS to family, friends and social workers closer to the patient. It was made by phone and enabled the patients to leave the hospital. The delegations also supported the patients by removing the burden of traveling long distances and keeping track on the everyday medication.

When the nurses offer different solutions, even if they are small, to ease the burden of everyday medication, the patients show a positive feedback. According to Brown, Collins & Duguid (1989) and Hill, Miller & DeGeest (2011) there is of great importance that the patient feels respected, is satisfied with the treatment and also feels the existence of an effective partnership between heath care provider and the patient. A good result can only be managed if both the patient and caregiver actively participate in the treatment (Brown et al., 1989; Hill et al., 2011). The positive response from the patients could be interpreted as the patients feeling involved and
listened to, as a part of the partnership. Ebbeskog & Emami (2005) states, that patients feel insecure and dissatisfied when they are forced to accept treatment that causes them discomfort. The nurses’ work of supporting the patients own wishes and adapting the treatment could be seen as empowering the patients own solutions and free will. Conrad (1985) expresses that all work in achieving a high adherence, should have the origins from the patients own lifeworld. It gives a focus in providing the patient with the power to solve their own situation.

The nurses describe two different areas of work. One area of communicating with the patient and the other area of providing solutions closer to the patients own wishes. It concurs with Loveday et al. (2014), who emphasize the importance in offering an ongoing education combined with the obligation to make sure that the patient always receives appropriate treatment and support in the coordination of the given care solutions. The patient is in a vulnerable position and needs a broad support. This agrees with Dahlberg et al. (2008) statement that it’s necessary to view the individual from their own experience and understanding of themselves, their lived bodies and their life situations.

The importance of knowing how to enable a two way communication in the work of achieving trust from the patient
All the nurses agreed that there is a need for the patients to talk, but only two of the nurses saw it as the nurses’ own responsibility to support the patient by communication. When being interviewed, the nurses expressed a need of further knowledge on how to care and talk to the patient. One nurse described the national guidelines as a good list of chores, but very little guidance about handling difficult situations that could occur when performing these chores.

The quality of the therapeutic relationship between nurse and patient is a strong indicator of a therapy outcome (Horvath & Symons, 1991). Conrad (1985) describes a focus of learning why the patient doesn’t take their medicine and supports the patient from their own experience and thoughts. Dahlberg et al. (2008) states that to fully understand the individual, the nurses needs to learn about their own unique understanding about themselves. This suggest that to support MDR-TB patients in achieving a high adherence to the treatment plan, the nurse needs to enable a strong and empowering link to the patient. To be able to do so, the nurses needs to interact with patients suffering from high levels of stress and expressing emotions such as fear, anger and anxiety.

Strang et al. (2013) explains that facing patients expressing emotions such as fear, anxiety, worry and resignation, was a hard burden to bear for the nurses. The nurses often felt a need for more knowledge on how to handle situations, where patients expressed negative emotions and patients were overwhelmed with hopelessness. It’s possible that the strategy of just informing the patient, is seen as a better option than talking to a patient who is overwhelmed with hopelessness or other negative emotions. The nurses may avoid talking to the patients because of insecurity on how to do it in a constructive way.

Conclusion
There is a lot of barriers in the work of achieving a high adherence for the patients treatment plan. MDR-TB is a disease connected to a high amount of existential and physical suffering, hard life choices and stigma from the society. The nurse has a close contact with the patients on a regular basis and needs to provide both emotional and practical support to the patients. It’s important for the nurse to build a strong therapeutic relationship to the patient. To do so, the patient needs to be seen as an individual who lives and reacts on the world around them. The nurse needs to find and implement solutions based on the patients own lifeworld. To achieve a high adherence there needs to be a patient centred care built on trust. The nurse learning
about the patients emotional needs, enabling the process of knowledge and coordinating a personalized health care, all depends on a functioning two way communication between patient and nurse. To support the patient in achieving a high adherence, the nurses needs to have high skills in empathy, communication and emotional support.

**Practical implications**

The result of this study can be implemented in the care for patients with medical conditions such as asthma, diabetes and heart diseases. These type of patients needs to take their medications on a regular basis to maintain their physical health. The medicine prevents the illness from causing damage to the body and in some cases even saves the patients life. Examples of life threatening situations are asthma attacks and heart failure. The medicine can only work sufficient when taken as intended. A low adherence to a treatment plan causes suffering for the patient. This brings a higher level of stress and suffering.

A high adherence to the treatment plan can prevent the illness from causing long term damage on the body. Not needing to be dependent on a high amount of health care support, results in a higher life quality for the patient. It also makes it possible for the health care system to rearrange investments in a better way.

**Suggestions for further knowledge development within the nurse area of competence**

As a suggestion for further knowledge to the profession, there is a need of evaluating and improving the nurses awareness and use of the concept adherence and further investigate how to identify and implement the therapeutic relationship key areas.
References


Information regarding the explorative study of registered nurses experience of the adherence to treatment in patients suffering from multidrug resistant tuberculosis.

Tuberculosis is one of the most common infectious diseases in the world and causes over 9 million persons their health every year. The medication period is long and the disease is connected to stigma and social isolation. Nurses are facing great challenges every day in their roll to help the patient regain their health.

The purpose with this study is to explore how the Namibian nurses experience adherence to treatment in patients suffering from multidrug-resistant tuberculosis. It will be done by conducting five interviews with registered nurses. The results of the interviews will be compiled in to different themes describing diverse point of views that is connected to adherence in treatment of tuberculosis.

The interviews will last approximately 30 minutes, and will be audio taped for later transcription. The interview questions are attached to this letter for you to look at in advance.

The ethics committee of University West has approved this study.

The study will be presented in form of examination paper of bachelor thesis at University West Sweden.

All interviews are voluntary and the person being interviewed can at any time chose to end their participation. All information given will be treated with full confidentiality. No names or other information about the interviewed persons will be given in the study or passed.

Do you want to participate in this study by conducting one of the interviews? If so, please ensure that you have read all information given. If you have any questions, or want a copy of this study, you are more than welcome to contact us!

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The purpose with this study is to explore how the Namibian nurses experience the adherence to treatment in patients suffering from multidrug-resistant TB. Furthermore the purpose was to explore how the care can be formed for the individual patients.

1) Could you please tell us your experience from performing the care for patients suffering from MDR-TB?

2) Are there any guidelines regarding the care for these patients?

3) a) Are there any special needs in caring for these patients?
   b) How do you perform the individual care for the patient? 
      -Can give an example?

4) What are your experiences regarding patient adherence to MDR-TB medication?

5) Is there anything else important, concerning these patient’s, you want to mention?

Thank you for participating!