Patient education and adherence to tuberculosis treatment
– Indonesian nurses share their experiences

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Abstract

Aim
The aim of this qualitative study was to explore Indonesian nurses’ experiences of patient education and patients’ adherence to TB treatment.

Background
Tuberculosis (TB) is an infectious disease that 9.6 million people in the world suffer from. Indonesia is one of the world’s 22 high-burden countries with over 320,000 cases of TB in 2014. The UN’s (United Nation) goal is to have ended the TB epidemics by the year 2030. Nurses play a central role in accomplishing adherence to treatment and prevention of TB.

Method
To fulfill the aim a qualitative method using semi-structured interviews was used. The interviews were recorded and transcribed. The transcribed data was analysed by using a qualitative content analysis with a manifest approach.

Findings
The findings, based on the result of nine interviews, showed four themes: “Strategies for patient education”, “Factors affecting patient education and adherence to treatment”, “Outcomes of patient education” and “Feelings and opinions about patient education”.

Conclusion
This study showed that the nurses use different strategies when practicing patient education. It was also shown that the nurses are well aware about patient-related factors and how they affect patient education and adherence to TB treatment.

Keywords
Tuberculosis, nursing care, patient education, adherence
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1 Introduction

Tuberculosis (TB) is found in several parts of the world and the incidence is especially high in Africa and Asia according to the World Health Organization (WHO) (WHO 2015).

Indonesia is one of the 22 high-burden countries for TB in the world. According to the latest report from WHO there were 9.6 million people in the world infected with TB in 2014. More than 324 000 of them were found in Indonesia. 1.5 million of the people infected with TB died in the disease in 2014 (WHO 2015). Indonesian health care has since the beginning of the 20th century worked to combat TB and changed its strategies in accordance with the latest research (WHO 2009a).

In Sweden the TB incidence has increased annually since 2011. According to the latest update from Folkhälsomyndigheten the TB-cases have increased with 6 percent between January and June in 2015 compared to the same period the previous year. Of the people who got sick from TB in Sweden 89 percent were foreign-born and this group has increased due to the increasing immigration to Sweden. Most of the people infected with TB have immigrated from Africa and Asia. The multiresistant version of TB has also been increasing (Folkhälsomyndigheten 2015b).

TB is one of the diseases considered dangerous to the public and is required to be notified to the qualified authority according to Swedish law. Immunisation against TB is no longer given routinely to new-borns but is offered to risk groups for example immigrating families and health care staff (Folkhälsomyndigheten 2015a). Instead, preventative interventions and infection control are important (Jarvis 2010).

Nurses in Indonesia work with patients suffering from TB in both the regular healthcare setting and through programs set up by the WHO (2009b). In Sweden, where TB has not been a problem in for quite some time, it would be a good opportunity to learn from the Indonesian nurses. It is especially relevant now since the incidence has increased in Sweden.

2 Aim

The aim of this qualitative study was to explore Indonesian nurses’ experiences of patient education and patients’ adherence to TB treatment.

3 Background

3.1 Tuberculosis

TB is caused by the Mycobacterium (M.) Tuberculosis complex, which is a group of five different mycobacterium, where M. tuberculosis is the most common cause of TB in humans. The bacteria are virulent because of their ability to survive inside macrophages, the immune systems’ phagocytic cells. TB can enter the body in different ways and then spread to different parts. The most common way to get infected is by inhaling the bacteria and the initial infection site is therefore the lung. Other ways for
the bacteria to enter the body is through the mouth or skin. When inhaling the bacteria the alveolar macrophages replicate and form lesions. Phagocytic cells carry the bacteria to the lymph nodes where additional infection develops. This primary TB usually passes undiscovered and it is the post-primary TB infection that gives the characteristic symptoms of wasting and fever. This post-primary TB, usually called reactivation, tends to develop in the upper lobes of the lungs. The lesions the bacteria formed will expand and erode. A cavity will be formed making the environment in the lung ideal for growth of the bacteria. When the cavity has formed, the bacteria has access to the sputum and the patient will become infectious. At this point there is a risk of transmission of the pathogen to others by for example coughing (Grange 2012).

TB is treated orally with the administration of antibiotics, following a regime that is divided into two phases. First an intensive 2-month phase and then a continuous 4-month phase. This is a regime in accordance with the WHO recommendation (Grange 2012). Drug-resistant TB is a problem and has existed since the discovery of antibiotics. However, multidrug-resistant (MDR) TB and extensively drug-resistant (XDR) TB is a manmade phenomenon due to improper TB treatment. Inadequate TB treatment, together with diagnostic delay and conditions that promote infection transmission and development of disease, has increased the spread of MDR-TB and XDR-TB (Chang & Yew 2013). If MDR or XDR is detected in the patient, another treatment regime will have to be used instead (Grange 2012).

The only vaccine that is currently available is the bacilli Cammette-Guerin (BCG) vaccine. In many countries the BCG vaccine has, since 1974, been a part of the immunization schedules. It has been administered to neonates in high-risk TB populations as part of the WHO Expanded Program on Immunization. However, a number of studies show that the BCG vaccine has several limitations (Principi & Esposito 2014). Infection control is therefore important to minimise the risk of transmission. There are three levels of TB control. First level is administrative control where early recognition and treatment is included, second level is environmental control where adequately ventilated rooms are included and third is the personal respiratory protection which includes the using of mask (Jarvis 2010). Low-cost, patient-specific infection control interventions have been proposed for developing countries and include cough hygiene protocols, face masks, improved natural ventilation, patient isolation and avoidance of sharing beds with uninfected persons (WHO 2009b).

3.2 Indonesia

Indonesia, located in Southeast Asia, has 254 million citizens (WHO 2015) and is the fourth most populated country in the world. It consists of 18,000 islands, whereof 6000 are inhabited (Daleke 2014b). In Indonesia about 400 different native languages are spoken. Bahasa Indonesia (Bahasa) is the official language but is only the first language of about 15 million Indonesians. Most Indonesians speak two or three languages and Bahasa is a link between people with different native languages (Daleke 2014a).

School is compulsory for nine years but after the sixth year about one fifth of the students drop out. Children from the rural and poor areas are more likely to drop out early. Elementary school is free of charge but additional costs such as for books and school uniforms are the responsibility of the student (Daleke 2014d). The extent of the population living in poverty varies between different sources. According to the official estimate about 10 percent of Indonesians live in poverty but according to the World Bank 40 percent live below the poverty line. The definition of poverty is to live on less
than 2 United States Dollar (USD) /day. In Indonesia poverty is highest in the rural areas of the country (Daleke 2014c).

In 2004 a new social insurance system was introduced in Indonesia with the goal of offering free healthcare to all citizens by 2019. Today only half of the population is included in the social insurance system and purchasing of private insurance has increased for those people who can afford it. Healthcare has become more easily accessible over the last twenty years because more public health centres have been built throughout the country, which has led to a better health among the population (Daleke 2014c).

3.2.1 Combating tuberculosis in Indonesia
The number of TB cases in Indonesia has decreased slightly in the past two decades, however it is still a current problem requiring attention (WHO 2015).

Combating TB was one of the UN’s Millenium Development Goals (MDG). This declaration was signed in the year 2000 and consisted of eight goals that all UN Member States have agreed to try to achieve by the year 2015 (WHO 2006). Although good results in the MDGs were achieved (UN 2015), TB is still an extensive problem and new goals have been set up. By 2030 the goal is to have ended the TB epidemics (UN 2015).

In order to achieve the goals set up by the UN, WHO has developed the Stop TB Strategy. This is a six-point strategy that includes expansion of the high-quality Directly Observed Treatment Short-course (DOTS) treatment protocol and also aims to address the problem of multidrug-resistant TB. DOTS treatment protocol consists of five components; political commitment, case detection, standardised treatment, effective drug supply and monitoring- and evaluation system. The third component, standardised treatment, includes supervision and patient support. It highlights the importance of organisation and standardised treatment guidelines for different types of TB treatment to facilitate adherence and reduce the risk of developing multidrug-resistant TB. It also highlights the importance of supervision for patient adherence (WHO 2006). In 1995 Indonesia joined the DOTS treatment protocol but have struggled to combat TB through different National Tuberculosis Program (NTP) since the beginning of the 20th century. Since 1995 DOTS treatment protocol and the Stop TB Strategy has been implemented in the NTP (WHO 2009a).

3.3 Nursing care and patient education

3.3.1 Nursing care
Jean Watson defines nursing care as "a human science of persons and human health-illness experiences that are mediated by professional, personal, scientific, aesthetic and ethical human transactions" (Watson 2012, p. 66). Watson considers that this way to define nursing care requires the nurse to be not only a nurse but also a fellow human, researcher and a clinician. This way of defining nursing care takes advantage of different ways of thinking and acting where the nurse is engaged and personal when taking care of the patient (Watson 2012).

Watson describes her nursing theory as consisting of ten factors. The seventh factor emphasises the nurse’s role in educating the patient. Watson means that teaching and learning includes a reliant relationship between the nurse and the patient. The nurse needs to apply a holistic way of looking at the patient and take the whole person and his or her needs into account. The nurse should in the education show consideration to the
readiness of the patient, the patient’s previous experience, personal approach, behaviour and motivation rather than own personal preferences. Important in patient education is to emphasise the patient’s abilities and strengths and promote the patient as his or her own solver and resource, this is the responsibility and task of the nurse (Watson 2008).

3.3.2 Patient education
Patient education may be defined as “the process of influencing patient behaviour and producing the changes in knowledge, attitudes and skills necessary to maintain or improve health” (Rankin, Stallings & London 2005, p.4). The aim of patient education is to implement it as a holistic process with the goal of changing the behaviour of the patient and his or her family to improve and benefit their own health. Patient education is an assignment that all health care workers are responsible for (Rankin, Stallings & London 2005).

Self-Efficacy is according to Bandura, presented by Rankin, Stallings & London (2005), the confidence in which a person can carry out a behaviour necessary to reach a desired goal. To be able to succeed the person needs to perceive that the action is possible. According to Bandura’s theory there are four ways health care providers can help the patient believe that a change in behaviour is possible. This is through personal mastery, meaning the patient has the confidence that he or she can perform a desired behaviour; vicarious experience, meaning the experience the patient gains from observing role models; verbal persuasion, meaning the encouragement the patient gets so that he or she believes they have competence for enacting new behaviours; and physiological feedback, meaning the physical signals the patients perceive which shows whether or not the behaviour is appropriate.

Self-efficacy theories, such as Bandura’s, are characterized as interpersonal models of health behaviour and enable health workers to view their role as a possible instrument of change in the patients’ situation (Rankin, Stallings & London 2005).

3.3.3 Adherence
WHO defines adherence “the extent to which a person’s behaviour – taking medicine, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (WHO 2003, p. 4).

There are a number of factors contributing to poor treatment outcomes and some of them are because of inappropriate treatment delivered by healthcare providers, such as poor patient education (WHO 2014a). WHO has developed a number of nursing strategies to improve adherence in long-term treatments, as for example in TB. One of them discuss educating patients on their illness, how the treatment will help, the importance of adherence and possible side effects and how deal with them and (WHO 2003).

3.3.4 The responsibility of the nurse
According to the International Council of Nurses (ICN), the nurse has four fundamental responsibilities. These are to promote health, prevent illness, restore health and alleviate suffering. From these responsibilities ICN has designed ethical codes that are based on a view of humanity where all humans are equal regardless of gender, age, social status, race, colour, religion or sexual orientation. These ethical codes are divided into four different areas and consist of ethical guidelines that should be implemented in the work of a nurse. In one of these areas, called nurses and people, the nurse’s responsibility to ensure that the individual receives sufficient, accurate and timely information in a culturally appropriate manner is emphasised. This will be the basis of which the patient
will base consent for care and treatment. Indonesia, as well as Sweden, has joined the International Council of Nurses and is therefore working in accordance with these ethical responsibilities (ICN 2012).

To give information is also included in the competence description issued by the Health and Human services department of Sweden. The nurse should deliver adequate information and education to patients and their family and caregivers. Other responsibilities are to promote participation and adherence in treatment, ensure that the given education is understood and accepted and identify patients who do not express their need for education (Socialstyrelsen 2005).

3.4 Context

The study was carried out in Yogyakarta, a province located on the Java island, Indonesia. In this province 3.5 million people live and it consists of one municipality and four different districts. In Yogyakarta there are 118 community health centres, locally called puskesmas, and 45 hospitals, both public and private. About 35.9 % of the population receives social insurance from the government and 70 % live within 1-5 km from healthcare facilities. In general, public health programmes are financed by local and national governments and programs such as TB control receive support from external donors (Probandari, Utarini, Lindholm & Hurtig 2011).

4 Method

4.1 Design

To achieve the aim, a qualitative method with an inductive approach was selected. Qualitative research intends to describe and understand the world from the informant’s point of view (Kvale & Brinkmann 2014). Inductive approach aims to develop new theories or deepen already explained phenomena from the collected data (Polit & Beck 2012).

Semi-structured interviews were used for data-collection. A semi-structured interview is used to cover specific areas rather than ask specific questions (Kvale & Brinkmann 2014). Semi-structured interviews were considered the most suitable data collection method to achieve the aim, since it gives the authors possibility to ask pre-determined main questions and from there follow up with probing questions depending on the informant’s individual experience (Kvale & Brinkmann 2014). Choosing the most suitable method to achieve the aim increases the credibility of a study. Credibility is a concept used to describe trustworthiness of a study (Graneheim & Lundman 2004).

Qualitative content analysis was performed using the method presented in Graneheim & Lundman (2004), a method designed with the intention of being used in nursing research.
4.2 Sampling

The participants of the study were sampled by “criterion sampling”, a type of purposive sampling. It aims to pick out participants who fulfil specific criteria, such as having experienced a particular phenomenon (Polit & Beck 2012).

Inclusion criteria were an Indonesian registered nurse who works or has worked with patients suffering from TB. No exclusion criteria were formulated. The authors wished to recruit participants from hospital wards and primary health care clinics. Choosing informants with various experiences contributes to a richer variation of the phenomena being studied and increases the credibility (Graneheim & Lundman 2004).

The number of informants were not set in advance, the principle of data saturation were used. Saturation occurs when categories and themes in the data becomes repetitive (Polit & Beck 2012). Selecting the most appropriate amount of data is important for establishing credibility (Graneheim & Lundman 2004), therefore no specific number of informants was set in advance when performing this study. In this study saturation was considered reached when no new information relevant for the aim was expressed by the informants. The last interview provided information that confirmed what the other informants had already described. Saturation was reached after nine interviews.

4.3 Data collection

An interview-guide was created for use during the interviews. Researchers using semi-structured interviews can create an interview-guide with either predetermined questions of open character or subjects intended for discussion (Kvale & Brinkmann 2014). The interview-guide was written in English and began with an illustration of the nurse’s different assignments when working at a ward and highlighted that patient education was one of the tasks. This illustration was explained in the beginning of the interview to show the nurses that the authors understood their different tasks and to clarify the particular interest in patient education.

The interview-guide consisted of three initial questions:
How old are you?
For how long have you worked as a nurse?
For how long have you worked with TB patients?

Followed by four main questions:
Can you describe one situation when you experienced that the patient education went well?
Can you describe one situation when you experienced the patient education went less well?
From your experience, can you describe what factors you think affect whether the patient follows your advices or not?
From you experience in total, what do you think characterises a successful patient education?

The main questions were open-ended and to achieve exhaustive answers the authors used probing-questions. That means to ask the participant to, for example, tell more about what has been said, develop something he/she mentioned or specify some other examples that he/she has experienced (Kvale & Brinkmann 2014).
4.4 Procedure

The authors established contact with the Faculty of Nursing at the University of Gadjah Mada (UGM), Yogyakarta. On request from the authors, the contact person at UGM established contact with current clinics to recruit respondents to the study.

An interpreter, with former experience of interpretation between English and Bahasa in a health care context, was hired to reduce the risk of the language barrier. The language barrier was considered as a factor that could influence the informant’s ability to understand the questions and express them by themselves. The informants spoke local language and Bahasa as their first language. The authors did not speak English as their first language but had satisfying skills. Using an interpreter with good skills in both English and Bahasa was therefore considered a good option to enable communicating between the authors and informants. When using an interpreter there is a potential threat to validity (Kapborg & Berterö 2002). Validity is a concept used in qualitative research and it describes how well the used instrument actually measures what it was aimed to measure (Polit & Beck 2012). The interview-guide was discussed with the interpreter before the first interview to make sure the interpreter knew what the authors meant with the questions.

Contact was established with one ward for airborne diseases at a general hospital, one ward at a hospital special for lung- and pulmonary diseases, one puskesmas for lung and pulmonary diseases and one general puskesmas. When sampling in a qualitative study selecting settings with high potential for rich information is important to consider (Polit & Beck 2012). The interviews took place in June 2015.

Before the interviews took place, the authors took measures aimed at increasing their skills in interviewing. For example the authors interviewed each other to become familiar with the interview guide and to practice the interview situation. Polit & Beck (2012) mean that it is beneficial to set up a training interview with a third person to prepare for the interview situation. Since the authors did not have the opportunity to train on a third person, using each other in the training situation had to suffice.

When coming to the unit the authors received permission to perform the study by the Head of Activity. The Head of Activity read through and signed an information letter about the study. Before the interview, the informant also read through and signed an information letter about the study.

The first interview was set up as a pilot-interview to investigate whether the interview-guide worked to get satisfying results. After performing and transcribing the interview, the interview-guide was modified by removing one question in the guide since it did not achieve the aim of this study. The pilot-interview was later included in the analysis process since the information gained from it was satisfying in relation to the aim of the study.

In the first interview the interpreter made notes and translated what the informant said after finishing their story. The authors thought this might lead to things being missed out due to the length of the informant’s story. In the second interview the authors asked the interpreter to interpret shorter sequences in order to not miss out on details of the story. This was later considered to limit the informant and the interpretation in the rest of the interviews was decided to be carried out as in the first interview. According to
Polit & Beck (2012) it is especially important not to interrupt informants since the interviewer’s task is to listen to the story of the informant.

During the interviews, one of the authors acted as a leader of the interview and the other as an observer. The authors took turns in acting as a leader and an observer. The role of the observer was to ask probing-questions if needed, in order to get more exhaustive answers. The authors asked questions in English, which the interpreter translated into Bahasa. The respondent answered the question in Bahasa and the interpreter translated it into English. When translating the interpreter talked about the informant as a third person.

After each interview, the authors together with the interpreter evaluated it in order to identify what could be done differently in the following interviews. Since the authors do not know Bahasa there was no guarantee that the translation was correctly performed during the interviews and this can decrease the validity of the study (Kapborg & Berterö 2002).

All interviews were recorded with a dictaphone. The length of the interviews varied between approximately 35 and 58 minutes, with a median of 48 minutes. After each interview both authors transcribed the interview verbatim together. In the transcripts mispronunciations, slang and grammatical errors were included. Elisions, non-linguistic observations such as facial expression or body language and non-verbal sounds such as laughs and sighs were not included. This was considered reflecting the interpreters’ way of speaking rather than the informants. Level of transcription should correspond with level of analysis (McLellan, MacQueen & Neidig 2003), which in this study was to be on manifest content. The completed transcribed material was compared with the recordings. The interpreter also transcribed the interviews verbatim, this in order to make it possible for the authors to compare and assure their transcription was done correctly. Having two persons who independently transcribe the same interview increases the reliability, which is defined as the consistency and trustworthiness of the study (Kvale & Brinkmann 2014). The transcribed material amounted to 60 pages, font Arial size 10.

4.5 Analysis

Data was coded and analysed according to Graneheim and Lundman (2004), which focus on the manifest content, meaning the spoken word in the interviews. Manifest content describes the visible and obvious components compared to latent content, which involves interpretation of underlying meaning. Both latent and manifest content deal with interpretation but the depth and level of abstraction varies.

The transcribed data was read trough several times by both authors separately. Meaning units achieving the aim were highlighted and then compared. The meaning unit consisted of sentences containing aspects related to each other through their content and context. For example several sentences in one interview discussing the aspect of asking the patient to demonstrate when educating were put together to one meaning unit. A meaning unit that was not too broad nor too narrow was selected to enhance the credibility (Graneheim & Lundman 2004). After meaning units from all the interviews had been selected they were grouped into content areas, which all shed light on a specific area of the content, for example asking patients to demonstrate as a strategy. The content areas were identified with little interpretation. Meaning units were then shortened but with preservation of the core into condensed meaning unit. Abstraction of
the condensed meaning units into codes, sub-categories, categories and themes were then preliminary made. The themes describe the underlying meaning of the condensed meaning units, codes and categories. Differences between and similarities within the categories and themes were discussed between the authors in order to avoid overlapping. The final themes in this study were made to cover all the areas the nurses experienced and intended to not leave out relevant data or include irrelevant data in order to achieve credibility (Graneheim & Lundman 2004). An example of the analysis process is shown in Table 1.

Table 1. Example of the analysis process.

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensed meaning unit</th>
<th>Code</th>
<th>Sub-category</th>
<th>Category</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“she again and again explain to the patient” (Informant 9)</td>
<td>Explain again</td>
<td>Repeat information</td>
<td></td>
<td>Repeat</td>
<td></td>
</tr>
<tr>
<td>“she educate the patient again, even though she already did the education”</td>
<td>Educate the patient, even if she already given education</td>
<td>Repeat information</td>
<td></td>
<td>Repeat</td>
<td></td>
</tr>
<tr>
<td>“they will ask the family to demonstrate how do they wash hand or hand rub and also how to wear mask appropriately” (Informant 1)</td>
<td>Ask the family to demonstrate hand washing and how to wear mask</td>
<td>Demonstrate hand washing and to wear mask</td>
<td>Practical performance</td>
<td>Strategies for patient education</td>
<td></td>
</tr>
<tr>
<td>“after they do the patient education they will ask to the patient and the family how to cough correctly, how to do the self hygiene correctly” (Informant 2)</td>
<td>After education ask patient and family to demonstrate to cough and do self hygiene correctly</td>
<td>Demonstrate how to cough and do self hygiene correctly</td>
<td>Practical performance</td>
<td>Strategies for patient education</td>
<td></td>
</tr>
</tbody>
</table>

During the analyse process the authors continuously went back to the raw data in order to work as close as possible to it. By working close to the data, it is more believable that the findings represent the voice of the informant. Working close to the data also ensures that the analysis was made correctly on the base of the raw version of it. Polit & Beck (2012) mean that these measures increase the confirmability of the study. Confirmability is another concept used to describe the trustworthiness and the extent to which the findings of a study reflect the voice of the informant and not the bias of the author (Polit & Beck 2012).

4.6 Ethical considerations

Ethical permission to conduct the interviews was applied for, with help from the contact person, through the Gadjah Mada University. This was to make sure the relevant managers approved of the project and it’s aim before the interviews were conducted.

Before interviews were conducted informed consent, in accordance with the Declaration of Helsinki (World Medical Association 2013), from Head of Activity and all informants were signed. The informed consent explained the aim of the study, the procedure of the interviews and transcription. The form also stated that any recorded data will be destroyed after completion of thesis and that no personal data will be mentioned in the study. All participants were made aware that participation was optional and could be cancelled at any phase of the study without justification. Above-mentioned information is recommended in an informed consent letter (Kvale & Brinkmann 2014). Before the interview started the authors made sure the participants
had read and understood the informed consent. When seeking informed consent it is important that the informant is not in a dependent relationship with the researcher (World Medical Association 2013). The authors do not know if there was a dependent relationship between the informants and the contact person at UGM.

Confidentiality was considered to protect the privacy of the informants and their personal information (World Medical Association 2013). No private data was mentioned in the transcripts or thesis except for sex, age, years of experience and the kind of hospital the participants were currently working at. The different private data and citation cannot be traced to each other in the thesis. Recordings from the interviews were erased after completion of transcription by authors and interpreter. Transcripts were read by authors and supervisor and destroyed after the thesis was approved.

Risk of possible harm and expected benefits is recommended to be considered before conducting interviews (Kvale & Brinkmann 2014). The consequence to the informants of the study was considered before interviews were conducted. Benefits of the study should outweigh the burdens and risk to the informant (World Medical Association 2013). The spread of TB can in a way be seen as controversial subject since it can be reduced with the right precaution. The task of reducing TB is also engaging many people outside of Indonesia and the health care sector. The work the nurse does through patient education is one step in the worldwide engagement to gain control of the epidemic. Deficiency in giving accurate and sufficient education may be considered shameful or a burden for the informants. With this in consideration the interview-guide was tailored to minimize feelings of guilt or shame and the questions were designed not to be perceived as an interrogation. With this approach the authors found that the risk of possible harm to the participant decreased. The authors thought the result of the project could be beneficial for the clinics working with TB patients since it explains the experiences of the nurses.

To reflect on the role of the researcher before the interviews is recommend since the process and the outcome of the interview is dependent on the relation between the interviewer and the participant (Kvale & Brinkmann 2014). Before the interviews took place, the authors visited the clinics to gain understanding of the work and the context the nurses worked within. This is called prolonged engagement and is an important step in establishing credibility (Polit & Beck 2012). Discussion about where the interviews were to take place and how the interviewer, observer, interpreter and informant were to sit in the room during the interview situation was reflected upon. The informant got to choose a place within the facility of the clinic where they wanted the interview to take place.

5 Findings

The informants participating in this study were between 22 and 55 years old with a median age of 38 years. Their work experience as registered nurses differed from 2 to 32 years with a median of 16 years. Their experience of working with TB patients differed from 0,5 to 30 years with a mean value of 11 years. The informants consisted of 1 male and 8 females. All informants completed the interviews. Five interviews were conducted at hospital wards and four interviews in primary health clinics.

The findings are presented in four themes. Each theme is based on categories with corresponding sub-categories. The themes found are; Strategies for patient
education: Factors affecting patient education and adherence to treatment: Outcomes of patient education: and Feelings and opinions about patient education. Themes and categories describing nurses’ experiences of patient education are presented in Table 2. Each theme is illustrated with quotations.

Table 2. Themes and categories

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strategies for patient education</td>
<td>Practical performance</td>
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<td></td>
<td>Adapt the teaching</td>
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<td></td>
<td>Involve others</td>
</tr>
<tr>
<td>Factors affecting patient education and adherence to treatment</td>
<td>Educational level and socioeconomic factors</td>
</tr>
<tr>
<td></td>
<td>Attitudes</td>
</tr>
<tr>
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5.1 Strategies for patient education

In this study it was shown that the nurses have experiences of using different strategies for patient education. This theme includes three categories of strategies Practical performance, Adapt the teaching and Involve others.

5.1.1 Practical performance

All the nurses stated the importance of giving the information repeatedly to the patient and their family. In this way the information would always be in the mind of the patient and the family. Repeating the information would make the patients understand. Even if the nurses had already given the information once, they would keep repeating it. One nurse explained:

“…she hasn’t find, hasn’t found to give one patient education [give patient education once] and the patient understand, no she hasn’t find it yet, but she has to always to remind patient…” (Informant 3)

Another strategy the nurses used was to explain the consequences of treatment. Nurses explained the risk if the treatment was not followed and how this would affect the patient. For example, they would explain the risk of developing MDR, the need to undergo a longer treatment regime, the risk of symptoms getting worse and that it actually could lead to death. The risk of spreading the infection to people in the patient’s surroundings was also explained. Some nurses would explain the benefits of following the treatment and tell the patient they could be healed, even the ones infected for the second time. Giving motivation and encouraging the patient to have faith were words used in the interviews.
“...She tell the patient that, the patient who discipline about the taking the medicine they tend to be healed a hundred percent, but patient who are not healed they usually the patient [the ones] who don’t follow our instruction...” (Informant 8)

The nurses working in the clinics where home visits were possible explained the advantages of this. By doing home visits the nurse got insight into the patient’s habits, economy and environmental situation. This was considered beneficial since it gave more information about the patient compared to when the nurse met the patient at the clinic. One nurse said that there is more time to educate when doing home visits compared to in the clinic and another nurse said it is better to visit the patient at the house compared to the risk of the patient dropping out.

“...when she go to the house of the patient she also can assess the other things not only the patient but also the environment and the house, the situation there so it’s gonna be good for her to learn more about the patient and the situation...” (Informant 9)

Another strategy described in the interviews was the usage of different media to enhance the education and make it easier for the patient to understand the instruction. Pictures in the guidelines on the wall of the clinic and pictures in brochures were used. According to the nurses, the use of pictures makes it easier for the patient to understand the information. After educating the patient some nurses asked the patient and family to demonstrate how they perform the task. With this strategy the nurses will know if the patient understood the instruction. Some nurses also explained building relationship with the patient as an important strategy. It was considered beneficial to have a good relationship even when the medication was finished. One nurse explained that she tried to be a friend:

“...because the patient usually feel embarrassed about the situation, and then the patient also feel lonely....so she try to be a friend for the patient so the patient can tell her about the problem that the patient face...” (Informant 8)

5.1.2 Adapt the teaching
To adapt the teaching in different ways to meet the patient’s and the family’s needs was expressed by all nurses and adapting the language was the strategy being used the most. The nurses used, what they explained like, easy language which was defined as the terminology the patient could understand. The level of education and socioeconomic class were described as reasons influencing the way the nurses adapted their language. For patients and families with lower education and lower socioeconomic class the nurses would use local language and talk slower. For moderately educated patients mixed languages, Bahasa and a local language, were used and for higher educated patients medical terminology could be used to explain TB if the nurses thought the patient would understand. One of the nurses explained how the level of education could influence the teaching and how she adapt the language like this:

“...she call it “extra” information for the patient or family who just graduated from elementary school. Because she has to like translate the new terminology for them, into the language that they can understand.” (Informant 4)

A patient-centred approach was used in different ways. Adapting information depending on whether the patient accepted the situation or not was one strategy described. Ensuring the privacy of the patient if the patient felt embarrassed, and recommending affordable food depending on the patient’s economy were additional strategies.
explained. Understanding the patient’s situation, finding out their complaints, and evaluating the situation were also used as patient centred approach. Depending on the condition of the patient and the condition of the accompanying family, the nurse would determine whether it was more appropriate to give education to the patient or to the family.

5.1.3 Involve others
All nurses used the strategy of educating and involving the family. The family is often staying in the hospital and lives close to the patient. This was described as important reasons to educate them. The reason expressed the most, to why the family should be involved, was that the family members would have the role of reminding the patient. One family member was often chosen to be the Pengawas Minum Obat (PMO), a person with the obligation to make sure the patient takes the medicine.

“…she mention that the family should be here too for the education. And also she will choose one member of the family to be the PMO, the person who remind the patient about the medication…” (Informant 7)

Another strategy explained by the nurses was collaboration with other professions when the nurses could not convince the patient or when they needed other competences. Nurses who had the option collaborated with the kader when it was considered needed. A kader is a person from the village who is educated by the staff of the puskesmas and has the task and responsibility to educate the villagers. Nurses also collaborated with environmental health workers if needed after home visits and nutritionist if the patient was in need of a program regarding nutrition. One nurse explained the influences a person respected by the society has, and explained that she once asked a doctor at the clinic living close to a patient to visit this patient and educate. One nurse asked the senior nurse at the ward to educate the patient when she experienced the patient was not listening to her because of her young age. Referring patients to other puskesmas close to the patient’s house or to a ward working with DOTS was described being done when the nurse found the situation difficult.

5.2 Factors affecting patient education and adherence to treatment

Several different factors which affect the patient education and the patient’s adherence to treatment were identified in this study. Categories included in this theme are Education level and socioeconomic factors, Attitudes, Acceptance, Family support, Condition of patient and family, Treatment-related factors and Age.

5.2.1 Education level and socioeconomic factors
The nurses experienced that the level of education of the patient was an aspect that affected patient education. Patients with a degree from high school tend to understand the education from the nurse easier than a patient with no education at all or only a degree from elementary school. Patients with lower education were more difficult to educate, since they tended not to understand the teaching from the nurse. Patients with higher level of education were experienced to understand the education easier and faster.

“...from the economy or financially enough [from a satisfying financial situation] /.../ they tend to have the better education, they will be easier to understand about the disease and they will be easier to understand her, education from her…” (Informant 5)
The patients and families with a higher level of education often had a more satisfying financial situation and were described belonging to a higher socioeconomic class. Adherence was described being affected by the socioeconomic class. Several nurses said that patients from a lower socioeconomic class usually listen to the instructions and teaching from the nurse. This compared to the ones from a higher socioeconomic class who more seldom listen and accept the instructions from the nurse.

Distance was experienced affecting patient education indirectly since the transportation cost and the fact that some patients did not like to walk long distance prevented the patient to appear at the clinic.

5.2.2 Attitudes
Several nurses described that the attitude of the patient and family affect whether or not they adhere to the education. The nurses experienced that there are patients with, what some explained like, a typical non-compliance attitude. This attitude made them not want to listen and follow the education from the nurse.

“...some patient or the family they’re typical to non-compliance even though she already give the patient education again and again...” (Informant 4)

The patient’s attitude to conventional health care and beliefs in traditional medicine affected whether the patient adhered to the suggested treatment or not. Patients who were more comfortable with the traditional medication than the medication the healthcare offered tended to stop regular treatment and instead start to use alternative medication.

5.2.3 Acceptance
Readiness of the patient and family was explained important for the understanding and acceptance of disease. Denial of the disease made it more difficult to educate compared to if the patient and the family had accepted the situation. Acceptance of the TB was therefore a factor easing patient education.

“...patient, they want to accept that they have the disease. So that the patient can accept the situation it will be the easier for him to do the patient education...” (Informant 6)

Nurses explained that patients who do not accept their disease and diagnosis, will not accept the patient education either.

“...they deny about their disease like they don’t want to accept that they have TB /.../ the student deny that he has or she has a disease they don’t want to accept that they have the disease so they don’t want to accept the patient education.” (Informant 1)

5.2.4 Family support
The nurses experienced that support from family affects the patient education. It was perceived easier to educate and succeed with the education when the family was involved, because the family helps by reminding the patient about the treatment. Support from the family was therefore considered important.
5.2.5 Condition of patient and family

Tiredness of the patient and family was a factor of importance regarding the patient education. If the patient and accompanying family were tired and had been waiting for a long time, they would usually not care about the education from the nurse. It was also experienced being harder for the patient and family to understand the information and education provided by the nurse if the condition of the patient was less good. When the condition of the patient was not really urgent, it was considered easier for the patient and family to understand the education. One nurse expressed this in the following way:

“If the condition is not really emergency /.../ the family will understand, will, it will be easier for the family to understand about her instruction... if the condition of the patient come here already bad situation, bad condition, the family come they already cry and then in their thought it is just, “Ohh I want him or her [the patient] to be healed or condition will be better” and then the family will not care, will not really care about the rules here” (Informant 3)

5.2.6 Treatment-related factors

Some factors related to the treatment were described as problematic for the nurse in order to get an adherent patient. Side effects of the medication and the fact that the patient feels better after a period of treatment were factors experienced making the patient not follow the advice regarding treatment given by the nurse. Side effects, for example vomiting, were described as a factor that makes patients not want to continue treatment and therefore sometimes stop the medication on their own. One nurse told a story about a patient who at first felt sick and after a while with treatment felt better, this made the patient believe that she was already healed and she therefore stopped the treatment.

5.2.7 Age

The nurses had several experiences of when the age of the patient affected the patient education situation. Some nurses thought that it was easier to educate younger patients compared to elderly patients. There were different views of why. For example, one nurse felt like older patients have a harder time hearing and listening to the nurse, which makes it harder for the nurse to educate. Thus, it was considered that the younger patients are easier to educate because they do not have the same difficulties with hearing and listening. It was also explained that elderly patients more often tend to express that they understand the education even when they do not. Another nurse spoke about elderly patients often having a lower education level than the younger patients and this makes it harder for the nurse to educate the patient so that he/she is adherent to the advices from the nurse.

“…if the person is old they will be just like “oh yeah yeah yeah I got it I understand it” but actually they don’t understand it.” (Informant 4)

5.3 Outcomes of patient education

Findings of this study were that the nurses experienced different outcomes of patient education and this theme consists of the categories Behaviour from patients and Consequences for patients and people in their surroundings.
5.3.1 Behaviour from patient
The nurses experienced that the outcome of patient education could be seen in the
behaviour of the patients. Nurses explained that they could tell from the patient’s usage
of a mask if the patient education succeeded or not. Other behaviour described was if
the patient took the medicine adequately or if they were adherent to other advices.

“So, the patient, some of them work at a restaurant and then the nurse like come to the
restaurant an then they see the patient, that the patient doesn’t have a mask.”
(Informant 1)

5.3.2 Consequences for the patient and people in their surroundings
The outcome of the patient education could also be seen from the consequence for the
patient and the people in their surroundings. A consequence described was that when
the patient education succeeds, the patient tends to be healed from TB. Or like some
nurses explained it, when the patient education is not successful, the consequence could
be that the patient is not healed. One nurse expressed that when the patient education is
successful the bacteria test is negative. Another nurse meant that a result of less
successful patient education is that the patient might relapse in TB.

“…the consequences is about the patient is healed or not. If the patient education is
successful she said that the patient tend to be healed from the TB.” (Informant 5)

Another consequence described as an outcome of patient education was that the patient
could return to everyday life. For example the hospital stay could be shorter and the
patient would be able to perform daily activities and go back to work.

Some nurses meant that an effect of less successful patient education was that the
patient might spread TB to other people and when the patient education was successful
the patient would not spread the disease to other people.

“…the unsuccessful patient education is the, it’s possible for the patient to spread the
disease to other family member.” (Informant 8)

5.4 Feelings and opinions about patient education
In the findings of this study patient education was shown to bring out several feelings in
the nurses. The nurses also expressed other opinions not related to strategies, factors or
outcomes. This theme consists of Feelings of happiness, Feelings of unhappiness and
Opinions.

5.4.1 Feelings of happiness
Nurses expressed feelings of happiness in different situations related to patient
education. Situations mentioned were when patients were adherent to their advices, for
example, when the patient took the medicine regularly, wanted to do examination in an
early phase or when the test result was negative. One nurse expressed it in this way
when the patient education was successful:

“It’s a happy thing for her and then she even cannot describe it how happy she is if it’s
successful.” (Informant 7)
To be able to help and support a patient through patient education and to give positive information, for example tell a patient that he or she is going to be healed, were other situations that brought happy feelings to the nurses.

5.4.2 Feelings of unhappiness
Feelings of unhappiness related to situations regarding patient education were expressed by some of the nurses. Situations when the nurses experienced unhappiness were for example when the patient was not adherent, when the patient education was considered less successful and when the test was positive. One nurse explained that it was confusing and frustrating when the patient and family did not follow her advice.

"She said that’s the one who makes her head ache... she said that it’s so confusing and frustrating when the patient is already told about the consequences and then but they still don’t follow her instruction...” (Informant 4)

Another one said that even though the nurse will not be punished because of unsuccessful patient education it is still a moral burden for the nurse.

“...for the patient education who that goes less well, she mention that there will be no punishment for her if the patient education not successful. But it’s the burden for her morally actually, if the education didn’t go well because she feels bad if it’s unsuccessful.” (Informant 7)

5.4.3 Opinions
Most of the nurses explained giving patient education to be the nurses’ responsibility. The disadvantage of giving education was that it took time. Some patients did not want to be taught by the nurse, but since it is the nurse’s job to inform, some nurses thought their responsibility was fulfilled if they said what was required of them. Patient education could be difficult and like one nurse explained it, not as easy as we think. Another nurse described that giving patient education was, except for being good for the patient and family, also a safety for the nurses. One nurse expressed the importance of never being bored about patient education.

"Keep being patient and never bored. Never be bored about educate.” (Informant 2)
6 Discussion

6.1 Discussion of method
A qualitative method using semi-structured interviews based on an interview-guide was chosen for this study. The aim was considered to be achieved by using this method.

An alternative to using qualitative method could have been a quantitative method and for example using questionnaires with fixed answers. The advantage would be that the sample would be bigger (Polit & Beck 2012) but this was presumed to give a less descriptive data. To do an observational study, observing nurses practicing patient education could have been an alternative qualitative approach instead of performing interviews (Polit & Beck 2012). This was considered to not give the informants the same opportunity to share their thoughts. Besides, the cultural context was considered to make it difficult for the authors to interpret non-verbal phenomena such as body language since it differs between cultures. In order to strengthen trustworthiness of the study it is important to choose the best methods (Elo et. al. 2014). The above alternatives were reflected upon and the chosen methods was considered the best available to achieve the aim and strengthen the trustworthiness of the study.

Informants from both hospital wards and primary health care were selected to get a richer variation in the experiences of the nurses. In this way the authors got the opportunity to interview nurses who meet patients through different phases of their treatment. Conducting interviews in these different settings was considered to give more representable information than if only one or the other was to be included. This was especially true since the presumptions for patient education differs depending on the formation of the health system. This can be seen in the findings under the theme Strategies for patient education.

Saturation was considered reached after nine interviews when the same information relevant for the aim was repeated. Data saturation is best valued and recognised if the data is primarily collected and analysed at the same time but still a common way of doing it is to collect data before analysing it (Elo et.al.2014). The interviews were transcribed, but not analysed, directly after they had been performed. From there the authors got a satisfying overview of the information given by the informants and could confirm that the last interview provided information that the others already had described. Using the principle of data saturation based on the transcribed material when performing this study was therefore considered a beneficial option.

Meaning units, on which the analysis of this study is based, was highlighted by both authors separately and then compared to make sure both agreed that the content was achieving the aim of the study. To achieve credibility the most suitable meaning unit should be selected (Graneheim & Lundman 2004). To further enhance the credibility both authors took part throughout the analysis process and went back to the raw material to decrease the risk of over interpretation. However, there is always some degree of interpretation when approaching a text (Graneheim & Lundman 2004) and it is important to ask how to ensure that the data accurately represent the information the informants provided (Elo et. al. 2014). The authors’ own interpretation in the analysis process can not be excluded and could have affected the result of the analysis. But by first finding suitable meaning units separately, analysing together and go back to raw material the authors tried to reduce the risk of interpretation and ensure the data represent the informants.
A pilot interview was set up to evaluate the interview-guide created for this study. It is beneficial to pre-test the data collection method to enhance the trustworthiness of the study (Elo et. al. 2014). After the pilot interview one question was removed since it made the informant focus more on the routines at the ward rather than on their own experiences. In qualitative research emergent design is a recognised approach. It means that the researcher makes continuous decisions by reflection on what has already been learned. Decisions about how to best receive data are example of decisions that are adapted as the study enfolds (Polit & Beck 2012). By doing a pilot interview and removing a question that prompted answers not relating to the aim the authors found that the trustworthiness of the study increased.

The final semi-structured interview guide consisted of four questions. When deciding to use interviews to collect data, one has to consider what kind of questions to ask (Elo et. al. 2014). In the interview-guide the first two main questions was formulated to give the informants the opportunity to base their sharing on two special experiences, when things went well and when they went less well. This was done to give the authors the possibility to, from those stories, follow up with probing questions, an approach described in Kvale & Brinkmann (2014). The authors found this to be a good way to get the informants to share a more detailed story about their experiences. The two last questions were formulated to give the informants the possibility to reflect on their experiences overall. These answers were often less detailed but in combination with the first two questions the authors found that they got rich answers and found the guide to assist in achieving the aim.

Follow-up questions are difficult to set up in advance in a semi-structured interview guide, the interviewer needs to have skills in asking adequate follow-up questions (Kvale & Brinkmann 2014). To be self-aware to what skills and limitations you have as an interviewer is important (Elo et. al. 2014). Since the authors had no previous experience with interviewing this was considered a limitation. By practicing the interview situation on each other and getting familiar with the interview guide may have improved the skills. On the other hand the follow-up questions are depending on the informants answer and cannot be predicted. After each interview the authors evaluated the interview with the interpreter and evaluated the transcribed data. This helped the authors to see what to improve and was found to give more rich answers in the following interviews.

An interpreter was used in order to lower the language barrier. By using an interpreter there may have been risk to the validity of the study (Kapborg & Berterö 2002). The translation between Bahasa and English was out of the authors’ control and they could not verify what was actually said in Bahasa and how it was translated into English. One way of eliminating this risk could have been to hire an additional person with skills in Bahasa and English. This person could have transcribed and translated the words said in Bahasa into English to have the opportunity to compare what later was said about it in English. Linked to time and cost reasons this was considered inappropriate when performing this study. Instead the interview-guide was discussed with the interpreter before the first interview to lower the risk of mistranslation of the questions to Bahasa. From the answers that were then given the authors got an indication that the translation was adequate. The authors also felt they could keep up with the discussion during the interview and there was no discussion between the informant and interpreter unless the interpreter needed to clarify something, which then was notified to the authors.

The authors wanted the interview to be a conversation between the authors and the informant and reflected on their role as a researcher and how the interpreter may
influence the situation before the interview took place. The authors made a point to always look directly to the informant in the conversation to enhance that the conversation was between them and in a non-verbal way try to show interest in their story (Eide & Eide 2009). The majority of the informants turned to the interpreter when talking and in this way the interpreter may have influenced the relationship between the authors and informant and this may have affected the answers. This was reflected on in the evaluation with the interpreter after each interview and arrangements to clarify the interpreters role was made, such as avoid discussion among them during the interview.

The majority of the informants were more comfortable in speaking Bahasa than English and the knowledge of English was more common in the younger nurses. Using an interpreter enabled the authors to interview nurses in a way that was perceived more comfortable for the nurses and where the skills in language did not prevent informants to participate. By not including for example older nurses due to lack in English skills would have left out valuable information. To use an interpreter was therefore considered beneficial and strengthen the study. The age of the informants participating in this study varies between 22 and 55 years helps to increase the credibility according to Graneheim & Lundman (2004) who mean that variation in age is a factor that enriches the variation of the phenomena in the study. Age in our study was considered have a correlation with years of experience, which in turn was considered to give a good range of experiences.

Before conducting these interviews the cultural context of the study was considered. When doing cross-cultural interviewing it can be difficult to be aware of the great number of cultural factors that can affect the relationship between the interviewer and informant (Kvale & Brinkmann 2014). The authors visited the clinic before the interview to get an insight to the context the nurses worked within. The authors found this beneficial in their understanding of what the informants explained in the interview. The time the authors spent in the clinics and in the country in general gave some insight to the culture however, culture is complex and its influence is difficult to determine. There are several occasions throughout study where it could have played a role and in turn affected the outcome of the interviews.

Throughout the study the authors have made purposeful choices in the effort to carry out the study in a way that enhance trustworthiness. This has been demonstrated in the method of the study to further enhance the trustworthiness. In the findings of the study the authors have provided quotes from informants to represent their voices and to enhance the text. Furthermore, along with the data collection and analysis process, the context of which the study was performed in and informants’ characteristics have been described to enable the possibility to determine the transferability of the study (Graneheim & Lundman 2004). Transferability refers to whether the findings of a study can be generalised to different setting or group of people. By demonstrating all the procedures in the report, like aimed at in this study, the credibility increases (Polit & Beck 2012). In the authors opinion, the steps they performed in order to enhance trustworthiness are a strength in this study. The detailed description of the proceedings of the findings in this study can be transferred to similar context where care of TB patients is performed.
6.2 Discussion of findings

6.2.1 Strategies for patient education
Repeating the information and education was found to be a strategy that all the participating nurses used. This was expressed as a way for successful patient education and a strategy that made the patient understand the education. Patients in a previous study experienced that repetition of information for them was a valued way of receiving patient education, this especially after being discharged from the hospital (Svavarsdóttir, Sigurdardóttir & Steinsbekk 2015). To repeat information is a strategy described as successful when working with people who have low literacy skills and it is experienced to increase the understanding for the patient (Mayeaux et.al 1996). One can assume, related to the high number of dropouts from the school (Daleke 2014d) that in Indonesia there are many people with low education level and low literacy skills. Since it has been shown that repetition of education is a suitable way of educating patients with low literacy skills this could be an appropriate way of practicing patient education to those patients in Indonesia that could be assumed to have low literacy skills. However, since patients appreciate repetition, not only those who have low literacy, the authors’ conclusion made is that this strategy is useful in all patient education.

Explaining to the patient about consequences concerning finished versus unfinished treatment was a strategy commonly used by the nurses. Bandura’s theory means that by sharing vicarious experiences, giving examples from role models, the nurse could strengthen the process of change of the patients’ behaviour (Rankin, Stallings & London 2005). To share vicarious experience in patient education could in our opinion include for example to tell about the effects for patients who finished respective unfinished their treatment. This was an approach the nurses in this study used.

The nurses who had the opportunity to do home visits in their daily work found that was a strategy that simplified the patient education. They meant that home visits gave them more time to conduct patient education and also a chance to take the patients’ whole situation into account. To include the whole patient and its settings into the patient education is an approach mentioned by Watson (2008). In a study it was shown that patient education during home visits from nurses increased the adherence to treatment in patients with heart failure (Monteiro Mantovani, Brasil Ruschel, Nogueira de Souza, Mussi & Rabelo-Silva 2015). The way the nurses expressed that they could take the whole patient into account when doing home visits is a way of reasoning supported by Watson. According to the research this way of working could enhance the adherence of the patient. Our conclusion made from this is that home visits seem to have several benefits whereof adherence to treatment is one and this strategy can therefore be assumed to be an important step in the prevention of MDR.

To use different media, such as brochures and pictures, was another strategy nurses used to enhance the patients’ understanding of their disease. Different media is described as a strategy used to optimise patient education and to enhance the patients’ knowledge. To use different media was shown to be a more effective way of educating patients than for example a verbal meeting between patient and healthcare staff (Fredericks, Beanlands, Spalding & Da Silva 2010). Since there in Indonesia are many dropouts from school, one can assume that the literacy skill becomes lower. With this in mind, our presumption is that to use different pictures and brochures combined with verbal teaching in patient education could be an appropriate way of practice patient education.
The nurses described that to build a relationship with the patient was a successful way of practicing patient education. Watson (2008) means that patient education includes a reliant nurse-patient relationship and emphasises the importance of building trust between the patient and the nurse in the education situation. To build a relationship with the patient was a strategy that patients perceived to increase their trust in the nurse giving the education. The patients also experienced that the education was more successful when they felt trust in their caregiver (Svavarsdóttir, Sigurdardottir & Steinsbekk 2015). This was reflected also in our findings. To build a good nurse-patient relationship might lead to greater trust in the nurse and we therefore claim that this is a strategy that helps to create an advantageous way of delivering patient education.

The nurses spoke a lot about how they worked to adapt their education to the individual patient. The most common way of individualising the education was to adapt the language when they educated the patient. To give individually adapted patient education is in the line with ICN’s ethical codes (2012), which claims that it is the responsibility of the nurse to individualise information and education. According to Mayeaux et.al. (1996), to use a simpler language in the education was a beneficial strategy simplifying patient education for patients with low literacy skills. Patients themselves meant that good patient education includes that the caregiver adapts the language and in patient education uses an understandable way of speaking (Svavarsdóttir, Sigurdardottir & Steinsbekk 2015). Based on what is found in the findings of this study and in other research, our conclusion is that this strategy is beneficial in practicing patient education.

To involve the family of the patient was a strategy that all of the informants used in patient education. Patient education should be looked at as a holistic process where the nurse takes the whole patient into account (Rankin, Stallings & London 2005). Involving family as a way of conducting patient education has been discussed in previous research and to educate and make the family active in education was a strategy that made the patient feel like the nurse saw the whole person (Svavarsdóttir, Sigurdardottir & Steinsbekk 2015). The family has also been experienced as a factor beneficial in the findings of this study. Patients who were taken care of in rural hospitals considered that involving the family was an effective way of educating them (Scheckel et.al. 2012). It was also shown that including the family in the education and make them support the patient increased the adherence for treatment (Boogaard et.al. 2012). Involving the family could therefore, according to this, be an appropriate way of working with patient education with the intention to achieve adherence to TB-treatment. Including the family in the education can also be considered beneficial when trying to achieve a holistic approach, not least since patients’ experience it to be a beneficial way of receiving education.

Beyond using strategies that included involving family and caregivers, the nurses in this study also used strategies that promoted participation and adherence in the care and treatment and ensured that the given education was understood. This is an approach in line with the competence description issued by the Health and Human services department of Sweden (Socialstyrelsen 2005) and in our opinion it further enhance that the strategies could be helpful for the nurses in Sweden when working with patient suffering from TB.

6.2.2 Factors affection patient education and adherence to treatment

Lower education was experienced obstructing the patients’ understanding of education in our study and has also been seen as a barrier to patient education in other studies (Ghorbani, Soleimani, Zeinali & Davaji 2014). For health literacy, defined as peoples’ ability to seek, understand and utilise health information, it is important to have verbal
communication skills and literacy skills, this according to patients (Jordan, Buchbinder & Osborne 2010). Health literacy has been described as content specific. Patients can be unfamiliar with vocabulary and instructions found in health-related materials but still be able to for example read and write in other contexts. Higher education is not mentioned to improve health literacy but can be assumed to do so, since education increases the skills in verbal communication and literacy. Furthermore, low literacy and low health literacy has been shown to be related but not interchangeable (Beagly 2011). In our study the higher education increased the understanding of the patient education but not the adherence. A reason can be low health literacy, since, as mentioned earlier, it is context specific and higher level of education does not have to imply better knowledge and understanding of, in this case TB and its treatment. However, this shows that education cannot be a predictor of how to frame the education and it emphasises, like discussed earlier, the importance of individualised patient education.

Transportation costs were mentioned in our findings to be an affecting factor. Costs for the patients related to distance can however be assumed to have decrease since the accessibility of primary health care has improved in Indonesia (Daleke 2014c). Transportation costs (Martins, Grace & Kelly 2008; Edginton, Sekatane & Goldstein 2002; Boogaard et. al. 2012) have been mentioned as a barrier for TB treatment in other studies. And, from the nurses’ point of view, the distance is still perceived as a problem and it indirectly interferes with their possibility to educate patients.

Throughout this study it has been clear that several circumstances, out of the nurse’s reach, affect the patient education. Indonesian children from rural and poor areas are overrepresented when it comes to school dropouts (Daleke 2014d). A reason could be that even if school is free of charge, there are still some additional costs that need to be paid to be able to attend school. This cost could probably be too high for some, especially the ones living below the poverty line. Poverty does therefore interfere with the possibility to get education and will probably affect the location of where you live. Education and distance, like discussed before, were factors the nurses experienced affecting patient education and this points out that there are several dimension from how this disease could be combated. It emphasises the importance to work with TB prevention on a political level as well as the nurse-patient level, just like the DOTS treatment protocol describes (WHO 2006).

Patients’ attitude to conventional healthcare and beliefs in traditional medicine was experienced to affect the adherence. Watson (2008) means that the nurse should always show consideration to the personal approach when giving the patient education. Beliefs in traditional medicine, which can include different beliefs in what causes TB, how to recover from it and how to prevent the spread of the infection, have been shown in other studies to have an impact on health-seeking behaviour and adherence to treatment (Martins, Grace & Kelly 2008; Edginton, Sekatane & Goldstein 2002). Patients’ superstitious beliefs as well as their attitude and unwillingness have been seen as barriers for patient education (Ghorbani et.al. 2014). Understanding the traditional beliefs of the patient has been shown to be an important factor to reduce morbidity and mortality (Edginton, Sekatane & Goldstein 2002) and the importance of this knowledge and cross-cultural training for nurses has been stated (Sissolak, Marais & Mehtar 2011). Our conclusion from this, is that one way for the nurse to show the individual consideration could be by learning the traditional beliefs in the region they work and to find out how this affects the individual patient’s attitudes towards conventional TB treatment. The nurses in this study did not mention anything about their own knowledge of the traditional beliefs and how they may use this in their work with patient education.
Acceptance of TB came up as a factor simplifying patient education and denial of TB made it more difficult. The readiness of the patient and family was described to be important to accept the disease and in turn accept the education. According to Watson (2008) the nurse should show consideration to the patient’s readiness when educating. In previous research a relationship between increased knowledge of TB and increased acceptability of patient-specific infection control measures has been seen (Gonzalez-Angulo et. al. 2013). A way to increase acceptability for the patient could, according to above mentioned fact, be by education with an approach that takes the patient’s readiness in consideration.

Non-adherence because of relief of symptoms (Martins, Grace & Kelly 2008; Edginton, Sekatane & Goldstein 2002) and the experience of side effects (Sissolak, Marais & Mehtar 2011; Edginton, Sekatane & Goldstein 2002) have been highlighted in many studies. Treatment-related factors, like the ones just described, was also mentioned in our findings to affect adherence. Non-adherence because of relief of symptoms has been associated with low understanding of the disease (Martins, Grace & Kelly 2008) and also lack of information about side effects has been found to cause non-adherence (Mishra, Hansen, Sabroe & Kafle 2006). WHO (2003) has recognised this problem and have developed nursing strategies, including patient education about treatment and side effects, to improve adherence in TB treatment. Findings in this study demonstrated that non-adherence due to treatment-related factors was a problem in the clinics we visited. In our opinion, it enhances the importance of patient education to reduce treatment-related dropouts related to lack of knowledge.

However, it has been shown that relief of symptoms can be a factor that promotes adherence (Naidoo, Dick & Cooper 2009) and that the curative effects of medication can strengthen the patient’s belief that TB is curable (Boogaard et. al. 2012). Physiological feedback is, according to Bandura, a strategy nurses can use to give the patient confidence in continuing a new behaviour (Rankin, Stallings & London 2005). In the findings of this study the nurses did only find the relief of symptom being a hindering factor for adherence. To inform about that relief of symptoms is a step in the recovery process could therefore be a way to work with patient education. By doing this the relief of symptoms can be used as a promoting factor and in the same time give physiological feedback to strengthen the patient’s confidence in continuing.

6.2.3 Outcomes of patient education
Consequences of patient education, according what was found in this study, could be seen in the behaviour of the patient by noticing usage of mask, medicine intake and how well advice was being followed. It could also be seen from the consequences for the patient through lab results, relapses or if the patient gets healed. Our conclusion is that the consequences are seen as criterions the nurses use to evaluate adherence. If compared to the definition of adherence used by WHO (2003) where adherence can be evaluated if patient’s behaviour corresponds with agreed recommendation, the nurses way of using the consequences as criterion is a good way to decide if patients are adherent.

6.2.4 Feelings and opinions of patient education
Several opinions about patient education have been expressed in this study. One opinion was that to deliver patient education was the responsibility of the nurse, a statement in line with ICN’s ethical code (2012). Nurses’ attitudes have been shown to have impact on patient education and nurses’ attitudes toward patient education have been shown to affect the education itself. For example, to have an approach that patient education is not included in the responsibility of the nurse can be a hindering factor for practicing
patient education (Ghorbani et.al. 2014). Therefore, to look at patient education as a task included in the responsibility of the nurse is a presumption if the patient education should be practiced and prioritised appropriately.

7 Conclusion

This study showed that the nurses used different strategies when practicing patient education. It also showed that the nurses were well aware about patient-related factors and how they affect patient education and adherence to TB treatment. Patient education could be looked at as a holistic process and it has been pointed out in research that the nurse itself has impact on the outcome of patient education. The impact the nurse has on the outcome of patient education was not anything the interviewed nurses discussed. However, the wide range of strategies the nurses used exemplifies well how a holistic approach can be practiced. The strategies and factors affecting patient education and adherence to TB treatment found in this study are found to be transferrable and useful in similar contexts.

8 Implications and further research

In this study we found a number of useful strategies that can be used in the daily clinical practice with patient suffering from TB. These strategies can be useful for nurses working with this kind of practice in Sweden. The findings also show what factors the nurse need to be aware of when practicing patient education, especially in a context similar to where the study was performed.

Based on the findings of this study it would be interesting to further explore the nurses’ experience and perception of their own role and influence in patient education. This would add more insight to the complexity of patient education and adherence in TB treatment.
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