

Preventative Nursing Care towards Decreasing the Prevalence of Leprosy in India

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ABSTRACT

Background: The number of people affected by leprosy has fallen significantly in India, the prevalence was reduced by 80 % between 2001 and 2005. However, the public health sector is still poor, which contributes to a high level of disease. In addition, there is stigma attached to leprosy, which continues to challenge healthcare and nursing care. **Aim:** The aim of this research was to find out what sort of health care is provided in India in order to prevent leprosy. The nursing care available for people troubled with the infection was investigated. **Method:** The work was based on a combination of research reviews consisting of 22 research articles and two in-depth interviews. 6 of the articles are qualitative, 1 is cross-sectional, 2 are literature reviews and 13 are quantitative studies. **Result:** Using these findings as base, preventative strategies were suggested which could improve the quality of healthcare and nursing care, which may provide possible ways of decreasing the number of leprosy cases in India. Further improvements are necessary to fight the disease. Stigma is one of them; it is based on ignorance and prejudice, stresses the need of education surrounding the disease, challenging employees, patients and the general public. Also, knowledge of hygiene could be improved along with general improvement in nursing care. **Discussion:** Combining research reviews and in-depth interviews has been of great value to the outcome of the results. An overall high level of nursing care is hard to achieve in India due to challenges in terms of healthcare investment, lack of knowledge about leprosy, inadequate hygiene routines, inequality and the lack of educated staff. Nurses must be qualified, have good listening and communication skills and evaluate which health education method should be used in order to be able to educate others about the disease. This is the most important element in the eradication of leprosy.

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INTRODUCTION

A subject involving the developing world was a natural choice for this dissertation, because my goal as a nurse is to work in the third world. My curiosity for leprosy arose after seeing people with the disease begging in the streets in India a number of years ago. Questions about how these people were being cared for and how this disease could be eradicated arose. This emotional experience lingered in my mind and writing this dissertation gives me an opportunity to further explore the subject.

Leprosy is not as common as it used to be. Much of work has been done to reduce the number of cases worldwide. However, it is still widespread in developing countries and in particular has a high prevalence in India (World Health Organization, 2009). Leprosy has long been associated with social stigma and taboo especially in the third world. This infectious disease was mentioned in the bible and even then, it was met with fear and revulsion (Edmond, 2006). The people affected were seen as having a lower value than others and being unclean. Sufferers were also forced to wear a bell around their necks in order to warn people that they were in the vicinity. The disease still has stigma attached to it due to both a lack of knowledge and cultural issues. One of the goals of this dissertation is to highlight the stigma associated with leprosy and how attitudes toward it could be improved through quality healthcare, in terms of education and information, which could eventually lead towards better preventative care and thus the eradication of the disease.

According to United Nations (2010), 41.6% of the inhabitants in India live in extreme poverty and people in general have an average life expectancy of 63 years, which puts stress on improving nursing care. The health system in India is mainly privatized and access to health providers differs largely between states with the least availability in the poorest areas. Educated practitioners tend to work in urban rather than in rural areas and there is an urgent lack of resources in many regions. Moreover, the Government does not take enough responsibility for healthcare, which affects the incidence and transmission of leprosy among other infectious diseases. Healthcare is mainly provided by Non Governmental Organisations (NGOs) in addition to Indian Traditional Systems of Medicine and a range of healers in many parts of the country.

The aim of this research is to discuss how the current healthcare system and nursing care can prevent leprosy in India and investigate ways that the system can be improved to decrease the prevalence of leprosy. Hygiene in nursing care standards and educational needs are also discussed.

BACKGROUND

Leprosy is caused by *Mycobacterium leprae* and exposes injury to the skin and peripheral nerves. It is dreaded because of the damage caused to hands and feet as well as causing blindness and facial disfigurement. The skin, peripheral nerves, mucosa of the upper respiratory tract and the eyes are the areas most affected (World Health Organization, 2010). It is a chronic infectious disease; however it is curable and if treated in the early stages can prevent the occurrence of disability (Kar *et al.* 2010, World Health Organization, 2010). If the disease remains untreated, progressive and permanent damage can be caused to the skin, nerves, limbs and eyes (World Health Organization, 2010).

Leprosy is not highly contagious; it is spread via droplets from the nose and mouth, during close and frequent contacts with untreated patients (World Health Organization, 2010). As expressed by Ramaprasad *et al.* (1997, cited in Cairns *et al.* 2004), the nose is a major route of entry as well as exit for *M. leprae*. Observations from households with people affected by leprosy have shown a higher rate of the disease, yet most new patients do not report a history of contact (Cairns *et al.* 2004). One challenge is that *M. leprae* reproduces very slowly and the incubation period is about five years, however symptoms can take as long as 20 years to appear (World Health Organization, 2010).

“The very slow rate of multiplication of M. leprae, the long incubation period (years rather than days) and the variable host immune response make it extremely difficult to link exposure to disease outcome” (Cairns *et al.* 2004:270).

Brief history of leprosy

Leprosy was mentioned for the first time in 600 BC and recognized in the ancient civilizations of China, Egypt and India (World Health Organization, 2010). Leprosy can also be called Hansen’s disease as it was identified by Gerald Henrik Hansen in 1873 (Edmond, 2006). He discovered what would prove to be the leprosy bacillus, the first bacterium to be identified as causing disease in humans (World Health Organization, 2010).

“In medieval and early modern Europe leprosy was very often a generic term for a wide range of skin diseases and, clinically speaking, it is only the early nineteenth century that a sustained attempt was begun to distinguish leprosy from other skin disorders, and to distinguish between different types of leprosy itself.” (Edmond, 2006:5).

Treatment of leprosy first appeared in the late 1940s with the introduction of dapsone, unfortunately leprosy bacilli became resistant to dapsone which occurred gradually (World Health Organization, 2011). Furthermore, in the early 1960s an introduction of multidrug therapy (MDT) took place, based on rifampicin and clofazimine (World Health Organization, 2010). The therapy was further developed in 1981, with the addition of dapsone and this particular combination kills the pathogen and thereby cures the patient (World Health Organization, 2010).

Today, the diagnosis and treatment of leprosy is easy and most countries affected by the disease are motivated to fully integrate leprosy services into existing general health services. This is especially important for those communities most at risk from leprosy, often the poorest of the poor (World Health Organization, 2011). Access to information, diagnosis and treatment using MDT remain the major options available to eliminate this public health issue (World Health Organization, 2011). MDT has been provided by the World Health Organization free of charge to all patients worldwide since 1995, and is a simple yet highly effective cure for all types of leprosy (World Health Organization, 2011).

Leprosy today, facts and figures in the world

It is estimated by the World Health Organization (2011) that there are almost two million people in the world who are visibly or irreversibly disabled because of leprosy and in addition to which they require being cared for. Successful global developments, as mentioned above, have taken place in tackling the leprosy situation (Cairns *et al.* 2004). According to Banerjee *et al.* (2010), the global caseload has been eliminated by nearly 90% over the last 20 years. Prevalence has been reduced to less than 1 in 10,000 individuals and is therefore no longer considered to be a major public health problem (World Health Organization, 2011, Banerjee *et al.* 2010). According to historical experience in Scandinavia and Europe the eradication of leprosy can be defined as being less than one case per 10 000 people (Shetty *et al.* 2009).

The Democratic Republic of the Congo and Mozambique reached this stage of elimination during 2007 (World Health Organization, 2011). The few countries where leprosy still occurs are not far from eliminating the disease. However, areas of high prevalence still remain in some areas of Angola, Brazil, the Central African Republic, the Democratic Republic of Congo, India, Madagascar, Mozambique, Nepal, and the United Republic of Tanzania (World Health Organization, 2011). Nonetheless, these countries remain strongly committed to decreasing the incidence of the disease, and continue to intensify their activities to control leprosy (World Health Organization, 2011).

Stigma and leprosy

Stigma can be defined as:

“.....an attribute that is deeply discrediting, and the stigmatized individual is one who is not accepted and is not accorded the respect and regard of his peers, one who is disqualified from full social acceptance” (Jopling 1991, cited in Arole *et al.* 2002:186).

Leprosy has afflicted mankind since ancient times and was mentioned in the Old Testament of the Bible as a symbol of sin. It once affected every continent in the world and it has established an image full of prejudices and ignorance, which could be expressed as rejection and exclusion from society. In the past, before the advent of treatment, people were sent away from their villages due to fear of contracting the disease (Heijnders, 2004, World Health Organization, 2010). As pointed out by Kazen, B. (personal communication 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation), once the leprosy patients had been isolated outside the cities then treated and cared for. It was believed that leprosy would be passed on through touch. Compulsory segregation of lepers took place in mainly European settlements in the late nineteenth century (Edmond, 2006).

As pointed out by Arole *et al.* (2002), throughout history, leprosy has been claimed to be a result of many things; genealogy, sexual contact, sin or witchcraft. A person afflicted with leprosy could even be regarded as being a witch themselves (Arole *et al.* 2002). In many parts of the world, people with leprosy are exposed to discrimination. However, there is a wide variation in ways that stigma manifests itself. Sierra Leone is a prime example of this and one of many places in the world where leprosy is regarded with suspicion. One could argue (Arole *et al.* 2002) that a person's status interferes with the way in which a person is viewed and

acknowledged in a community. Many people become beggars in endemic areas (Kaur & Brakel, 2002). A Nepalese man infected with leprosy expressed it thus:

“ . . . In our village there is a saying that if one of the villagers gets this disease and if another person is close with the infected person, or sits with, eats the jutho (a person food leftovers) of, or if the husband, or the wife has the disease, then the other person will be infected with the disease. . . In my village the people do not tell me not to walk with them, sit or eat with them, they did not say or do anything. My disease is not clear and that is why most of them could not find out” (Heijnders, 2004:440).

Leprosy in India

According to Shetty *et al.* (2009) leprosy has been a major concern for the public health in India for centuries. A National Leprosy Control Programme (NLCP) was introduced around 1954, using surveys and education to control the spread of leprosy (Siddiqui *et al.* 2009, Pandey *et al.* 2006). The programme had separate staff and did not interact with the general health system. In 2000 it was estimated that the country accounted for 64 % of cases globally. The prevalence of the disease was reduced by 80 % between 2001 and 2005 (Shetty *et al.* 2009). Thus, it is as pointed out by Siddiqui *et al.* (2009), not seen as a major national health problem. However, several states in India are lagging behind in the race to eradicate leprosy; Uddar Pradesh is one such a state (Barkataki, Kumar, & Rao, 2006).

The NLCP was renamed to the National Leprosy Elimination Programme (NLEP) and they implemented MDT in India in 1984, with participation from many NGOs (Madhavan *et al.* 2007). The change of name also involved a change of focus from control to elimination (Pandey *et al.* 2006). Leprosy control became even more advanced in 1997 and is today provided by the general health system in all states (Madhavan *et al.* 2007). The NLEP has been integrated into the general health service since 2001 (Siddiqui *et al.* 2009, Shetty *et al.* 2009). NLEP was further improved in 1993 with a project strengthening the existing resources funded by the World Bank, which led to a 2 million decrease in leprosy (Pandey *et al.* 2006).

The Government has developed strategies to integrate leprosy programmes into Primary Health Care, such as training staff to diagnose leprosy, educate, distribute information, and maintain MDT stocks and information programmes (Siddiqui *et al.* 2009). The process had great support in District Technical Teams consisting of NGOs and medical officers with support from the International Federation of Anti-Leprosy Associations (ILEP). After the integration of the programme, where Orissa, in the eastern part of India, was one of the first states carrying it out, the General Health Service (GHS) played a significant role in terms of detection, treatment and prevention (Siddiqui *et al.* 2009).

Leprosy colonies accommodate leprosy patients, who have been cured by the disease as well as those who have disabilities caused by the disease who require constant support and care. The Prem Nagar Leprosy Colony is a settlement of 1500 people located next to the TLM Betsheda Leprosy Hospital in Champa in Chattisgarth in India. Most of the people in the colony are no longer under treatment but suffer from recurrent plantar and hand ulcers. Care of leprosy related disabled people has been neglected in India and led to the Prevention of Disability (POD) programme in 1997, which involves the training of a restricted number of health workers in POD camps in Primary Health Centres (Madhavan *et al.* 2007). The programme

was only provided by NGOs (Madhavan *et al.* 2007). Disability prevention is the priority post MDT and the detection of new cases of leprosy is also prioritized (Madhavan *et al.* 2007).

“The ultimate aim is to enable the Government to establish sustainable POD care services in a large area. The NGO project which has longstanding experience in implementing leprosy control activities including provision of appropriate services to those affected with disabilities will play the enabler role: identifying along with the district programme officer a core team for planning and implementing POD in the district, and guiding the team for capacity building of peripheral staff in the Government health system to help people living with disabilities take care of themselves” (Madhavan *et al.* 2007:354).

Healthcare and nursing care in India

Henderson, who graduated from Teachers College in Columbia University with a M.A. degree in nursing education, is famous for her definition of nursing:

“The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge” (Henderson, 1966:15)

It is difficult to live up to this definition in India, due to a rapid urbanization and industrialization in India at the moment. People who move into cities are disadvantaged in terms of health care having little or no access to services (Babu *et al.* 2010). There has been an economic boom in India since 1991 (De Costa & Diwan, 2007). However this growth is not uniform across socio-economic groups and the poor see very little of this development. Similarly, public health services have not received financial benefits either. The lacks of available public health facilities have been documented and greater regulation of the private sector has repeatedly been demanded (Bhatia & Cleland, 2004).

As pointed out by De Costa and Diwan, (2007), 77.4% of all health expenditures are made within the private health sector. India’s health care system is one of the most privatized in the world (World Health Organization, 2007). About 80% of outpatient visits occur in the private sector (National Sample Survey Organization, 2006) and further expansions are expected (Bhatia & Cleland, 2004). However, the state provides 50% of all inpatient services in India (Misra *et al.* 2003, cited in Ager & Pepper, 2005). Most hospital beds and pharmacies are in urban areas and are privately owned.

The state has adopted a model for health care provision in India. This model involves sub-centre staffed by an Assistant Nurse Midwife (ANM) and in most cases a Multi Purpose Health Worker (MPHW). Primary Health Centers (PHCs), staffed by a doctor, cover an area of a number of sub-centers. CHCs and Block Primary Health Centers cover a broader area, with inpatient beds, and are in general staffed by a team of doctors and other health workers (Ager & Pepper, 2005). MHWs are responsible for screening and referrals of suspected leprosy cases to PHCs and CHCs, whereas Medical Officers (MO) attend to diagnosis and treatment (Pandey & Rathod, 2010). Cases would then be referred back to SC for documentation and continuing treatment. District Hospitals, Specialised Hospitals and Medical Colleges offer referral and support for training and supervision (Pandey & Rathod, 2010).

Sub-District and District Hospitals provide extensive numbers of inpatient beds and specialist facilities. The idea behind this structure for health care is to target the effective and efficient delivery of basic, low-cost medical care at a local level, using a referral for more advanced conditions (Ager & Pepper, 2005). However, few patients are able to access the health system in this manner, especially in rural areas where the population has limited access to primary care services (Ager & Pepper, 2005). There are indications of users entering the health system directly at the secondary level, while others access non-state services, with a range of non-prescribed medicines, through private qualified or unqualified medical practitioners as well as those from indigenous medical systems (Ager & Pepper, 2005).

The public health sector is poor, which is a contributory factor to the high level of disease. The lack of resources is acute in some states, mainly in the poor rural areas. As pointed out by the World Health Organization (2010), treatment of leprosy needs to be fully integrated into general health services in order to reach all those affected. Qualified practitioners tend to work in urban areas whereas unqualified staff and traditional healers and medicine women attend to the poorer areas. According to Transparency International (2003) the global civil society organisation leading the fight against corruption, the health sector is the second most corrupt sector in the country, the police force being the first most corrupt. Political commitment needs to be sustained and financial resources must be made available in order to eradicate the disease (World Health Organization, 2010).

In the 'Standard Rules on the Equalization of Opportunities for Persons with Disabilities', States are given the responsibility for the development and supply of services for people with disabilities with the aim of improving the level of independence in their daily life. This responsibility is further examined in the 'Convention on the Rights of Persons with Disabilities' (CRPD) (Borg & Larsson, 2009). POD is responsible for the global strategy for leprosy control. POD can be defined as:

“a concept comprising all activities at individual, community and programme level aimed at preventing impairments, activity limitations and participation restrictions” (ALM, WHO, ILEP, 2006 cited in Borg & Larsson 2009:14).

Hygiene is also an important aspect of nursing care. Hygiene routines and procedures in health care settings in India are not always followed. One crucial element involves the resource distribution within the country. Another important factor is the lack of resources, which challenges the ability to keep material sanitary. Water Programmes for improving water supply and sanitation have received low priority. Almost all water supply systems suffer from purity issues and many wells are contaminated by germs and chemicals that contribute towards health risk.

“...it has been identified that the transmission of microorganisms from the hands of healthcare workers is one of the factors responsible for healthcare-associated infections, and hand hygiene is the most important measure for preventing and controlling such infections. It is necessary for the compliance and efficacy of hand hygiene techniques to be assessed” (Sahay et al 2010:535).

According to Deb *et al.* (2010), India has 128.3 million children in primary schools, with about 50 million in upper primary schools. Lack of resources causes the spread of diseases and increases their prevalence. This stresses the need for good hygiene even further.

“But it is also a fact that only 8% of the schools have sanitation facilities in school premises, only 44% have water supply facilities, 19% have urinals and 8% have lavatory facilities” (Deb *et al.* 2010:280).

Florence Nightingale’s nursing theory

Florence Nightingale is one of the founders of modern nursing. Her work changed both nursing and public health. Her work focused upon her beliefs and concerns about health, in particular focus on the poor. She emphasized that it is the nurses duty to provide personalized care to her patients and the importance of looking after both the patient’s mental and physical well being, whilst remaining sensitive to the patient’s needs. She also believed strongly that all people, regardless of status, deserved proper health care and living conditions (Nightingale, 1860).

Furthermore, she realised that the environment had a great impact on a person's health and therefore advocated health promotion and disease prevention. She stressed the importance of decent housing, clean water and air, nutrition, sanitary conditions, safe delivery of infants and good child care. Nightingale (1860) believed that pure air, pure water, good drainage, cleanliness and light were essential for healthy housing. She regarded contaminated water as a major health risk. The main diseases and illnesses, of the nineteenth century declined after improved sanitation and hygiene practices were put into place (Nightingale, 1860).

Nightingale (1860) believed that a patient's immediate needs must first be met before healing was possible. A patient's environment must be optimized in terms of pure water, clean air, light, noise control and diet before being able to treat other illnesses and diseases. According to Florence’s statistics sometimes the environment was not only the setting for disease, but also the very cause, and the ideas that came from her research impacted hospital planning and design. The hospitals during the late 1800s were crowded and unsanitary. Nightingale pointed out the necessity of a calm, quiet and warm environment for patients (Nightingale, 1860).

“It cannot be necessary to tell a nurse that she should be clean, or that she should keep her patient clean, - seeing that the greater part of nursing consists in preserving cleanliness. No ventilation can freshen a room or ward where the most scrupulous cleanliness is not observed. Unless the wind by blowing through the windows at the rate of twenty miles an hour, dusty carpets, dirty wainscots, musty curtains and furniture, will infallibly produce a close smell” (Nightingale, 1860: 87).

Nightingale (1860) argued that materials and surfaces being used should be maintained and kept clean. A sanitary environment was viewed as basic and fundamental both in terms of the place where patients were being nursed as well as for the ones providing nursing care. Nightingale (1860) believed that skin-cleanliness was just as important as ventilation. The nurse must therefore attend to the personal hygiene of her patients along with airing and clean sheets. In addition, it was equally important that the nurse herself washed her hands frequently

preferably with soap in hot water. She also stressed the importance of nurses wearing clean clothes (Nightingale, 1860).

Nightingale (1860) also made a point of *chattering hopes and advices*, as she called it. She encouraged nurses to sit down and speak with their patients trying to give comfort and consolation. This kind of support could give the person being cared for an opportunity to express hopes and desires and deal with the situation (Nightingale, 1860).

Information and patient education, nursing concept

There is an important relationship between nursing and education. The nurse integrates the theories of health education using information and teaching as tools (Pilhammar Andersson, 2007). Health education is one of the most essential factors in preventing illness (Ny, Dejin-Karlsson & Udén, 2006). Education and teaching patients and their relatives are a great part of a nurse's responsibilities. All patients have the right to receive information about alternative ways to sustain one's health. Patient education could be defined as patient empowerment (PE), aimed at enhancing the patient's knowledge to a similar level as the nurse (Pilhammar Andersson, 2007). This could be expressed as follows; every individual suffering from ill-health should be given as much education as necessary to make an informed decision regarding treatment and choices involving health (Tingström, 2009). Patients can in this way combine their decisions with previous experiences and existing knowledge which in turn can lead to self-care, healing and well-being (Björvell & Insulander, 2008).

According to Tingström (2009), the aim of education is to attain a different perspective or behaviour and it is important that the patient is able to process the information they are given. One important tool is to motivate the patient to attain an understanding of the problem area (Tingström, 2009). This could be achieved through a well-planned educational programme consisting of a combination of different information; possibly a course concerning health-related issues or supportive measures on how to deal with feelings and attitudes. It is essential for patients to have the opportunity to reflect, discuss and pose questions (Tingström, 2009). Tingström (2009) argues that the information and education given should be tailored for each patient and preferably be given in writing as well as spoken. The nurse must also take into account that learning differs for each individual depending on previous experience and culture (Tingström, 2009).

In order to achieve a good level of health education the nurse providing it must be qualified and have good listening skills (Björvell & Insulander, 2008). According to Pilhammar Andersson (2007), it is important for the teacher, the nurse in this case, to consider *what* is going to be taught, *how* it will be taught and *why* it is going to be taught and learnt. As pointed out by Tingström (2009), the nurse needs to obtain a full picture of the patient's existing knowledge of health, and consider what type of education is required. Also, the nurse should be aware of the patient's context and beliefs (Tingström, 2009). According to Björvell & Insulander, (2008), the patient should be the one in power and the one setting future goals. They further argue that in some cases it may be valuable to strengthen the patient's self-efficacy through praising progress or advancement. This means that the nurse's level of perception and awareness is essential.

Communication plays a significant role in health education. It is important to be aware of cultural constraints and conditions when giving health education. According to Ny, Dejin-Karlsson and Udén (2006), many women in India are ignorant of their own health and risks. Women are most likely to be the main health provider in the family and they desire information appropriate to their own experiences (Ny, Dejin-Karlsson & Udén, 2006). This underlines the relevance of the information given and the quality of communication skills.

“Communication involves the transfer of information between people including ideas, emotions, knowledge, and skills. The components of communication include the sender receiver, educational factors, sociocultural factors, patterns of communication, perception, and understanding” (Ny, Dejin-Karlsson & Udén, 2006:131).

Appropriate communication plays a significant role in health education, which can encourage internalization, which is a concept for the patients understanding of having to do something for their own good (Hansson-Scherman & Runesson, 2009). The nurse should look at the patient as a reflective individual in a learning process, rather than one of the dutiful masses as viewed via dualism (Hansson-Scherman & Runesson, 2009). According to Ashworth (1980, cited by Carlsson, 2009), communication between the nurse and the patient has following aims:

- To create a relationship with the patient to establish confidence in the nurse’s competence.
- To clarify the patient’s need according to his reality.
- To ensure that the patient is adequately informed about the situation.
- To help the patient use his own resources, in addition to those provided by the healthcare system in order to meet his needs.

AIMS AND OBJECTIVES

Throughout the world, there is still a stigma connected with the word “leprosy”. Leprosy causes problems in India, associated with physical, psychosocial and economic issues which are of major significance for women due to gender disadvantages especially in developing countries (Heijnders 2004, John, Rao & Das, 2010). This situation needs urgent and sustainable improvement through a better quality care system. The treatment of leprosy needs to be fully integrated into general health services and staff also need to be better educated (World Health Organization, 2010).

One way of dealing with this is to raise awareness through writing about it. This dissertation aims to study the health care provided towards prevention and elimination of leprosy in India. It focuses on the overall attempts undertaken to reduce the number of leprosy cases as well as to prevent transmission of the disease. In addition, the author proposes improvements for leprosy care.

Problem formulation

- What sort of healthcare is provided in India in order to prevent leprosy?
- What kind of nursing care is available for people suffering from the infection?

- How can the quality of healthcare and nursing care be improved to decrease leprosy?

METHOD

Interview

Two in-depth interviews were undertaken. An in-depth interview with Janusz Lipinski, desk officer for the International department at SOIR, The Swedish Organisation for Individual Relief was carried out 030211(see appendix 3). SOIR is an aid organisation, founded in 1938 and active in 15 countries in the world, working to reduce poverty and exclusion. SOIR endeavors to make long-term commitments with local partners, focusing on health promotion, education and income generating activities. Their aim is to empower people to start enterprises on a small scale. Lipinski has worked for the organisation since 1998, travels to India up to twice a year and is therefore a valuable source of information for this dissertation.

The other in-depth interview was with Birgitta Kazen, carried out 240211 (see appendix 4). She is a member of the board for the Swedish committee of the Leprosy Mission International Organisation. Kazen is a teacher in social rehabilitation and has worked with leprosy care for a total of 27 years in India, Sierra Leon and Ethiopia together. Her husband was a leprosy surgeon. They were based at a huge leprosy hospital outside Vellore and visited other leprosy hospitals. Kazen considers, according to her experiences, leprosy care work and stigmatizing to be rather similar throughout the third world. She was chosen to participate in this study on this basis.

The in-depth interview is a suitable qualitative method to use for getting a deeper understanding of a subject. It is more feasible that the responses received are less moderate. According to Trost (2005) who writes about qualitative interviews, it is an appropriate research method for nursing care. The method has been chosen to improve the answers for the problem formulated above.

Analysis

The aim of the research was introduced before the interviews took place. The interviewees started by a brief presentation about themselves and their experiences. Questions were prepared in advance; they were used as a guide during the interview process. The questions involved probing into hygiene and sanitary conditions, quality and access to nursing care and healthcare, general knowledge about hygiene and leprosy, provision of care for people with leprosy, the stigma associated with leprosy and the challenges involved. The questions were aimed at stimulating discussion rather than achieving a specific set of answers. This is according to Trost (2005) a reason for being a suitable method for research in nursing care. The attendants were also asked to add further information where appropriate.

The qualitative in-depth interviews with Janusz Lipinski and Birgitta Kazen have been analysed (see appendix 3 and 4). The material has been interpreted with the problem formulation as a guideline. Finally, some of the responses relevant to this study have been used. The analysis of the in-depth interviews resulted in three categories: nursing care provided for prevention and reduction of leprosy, challenges, and areas where improvements could be made.

Literature research

The areas of interest were identified and literature search was carried out. The aim was then formulated based on this search. 13 quantitative articles, 6 qualitative articles, 1 cross-sectional article and 2 literature articles make up the basis of this dissertation. Most of the articles were found through the PubMed database and the Cinahl database (see appendix 1). These databases were used because they focus on nursing care. However, PubMed has a greater range of suitable articles compared with Cinahl. Search terms used: prevent leprosy India, leprosy situation India, nursing leprosy India, care work leprosy India, healthcare leprosy India, leprosy India, community health leprosy India, quality of healthcare leprosy India, quality of healthcare leprosy, health service India and knowledge hygiene India.

While the *Leprosy Review* (reference 7, 11, 12, 13, 17 see appendix 2) and the *International Journal of Leprosy and Other Mycobacterial Diseases* (reference 4, see appendix 2) turned out to be useful journals with good sources of information some articles were found whilst browsing for other articles through PubMed. These were reviewed further and used as appropriate. The *Leprosy Review Journal* was also recommended by the organisation Doctors without Borders after I had turned to them for advice via email.

Sample

Criteria for inclusion

Articles about leprosy in India involving the healthcare aspect were used.

Criteria for exclusion

Non-English language articles were excluded.

The selection of articles involved relevant abstracts for the aim of the dissertation. The suitable papers were read in full and studied according to Friberg's (2006) criteria, which requires an obvious aim, a clear method a sample of people being studied, a distinct result and discussion. The articles also had to be published in scientific journals written from 2003 onwards, though a few exceptions were made and papers written in 2002 were also included. They had to be available in full-text via Gothenburg University databases.

Analysis

The selected articles (see appendix 2) were studied in-depth with particular focus on their results. Outlines and summaries were made for each articles result, which according to Friberg (2006) leads to a better overview. The different results were compared and contrasted. Themes and sub themes related to the aim were identified and the result was created thereafter.

The analysis was made using Friberg (2006) as a guide. The method intends to increase understanding of the area of research, sum up previous research and convert knowledge acquired into useful information to be used as health care guidelines. The literature study resulted in three categories: the nursing care provided for prevention and reduction of leprosy, challenges, and areas where improvements could be made. These are the same categories as in the analysis of the in-depth interviews.

RESULT

Healthcare and nursing care provided for the prevention of leprosy

According to Lipinski, J. (personal communication, 030211, desk officer for the organisation SOIR), people in India tend to go to pharmacies, available on almost all street corners, when suffering from moderate disorders. He points out that people only visit public institutions that are responsible for basic healthcare, when their conditions are more severe or life-threatening. The cost of health care is often the reason for not seeking care. Lipinski has observed differences in the quality and availability of nursing care. The rich tend to get first-class healthcare in private facilities while poor people either attend public clinics or seek no treatment at all. Access to healthcare is very limited in rural areas and many people die at home from what are otherwise curable diseases.

A strict hierarchical system still exists in India and the doctor performs most of the work while the nurses assist them or carries out tasks as ordered by the doctor. The pace of work in India (as in other countries in Asia) is more relaxed and less stressful when compared with the Western World. This might contribute to less efficient nursing care which may affect the welfare of the patients. However, most patient's relatives are with them whilst at hospital which may relieve the burden of the employees (Lipinski, J. personal communication, 030211, desk officer for the organisation SOIR). By contrast, Kazen, B. (personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation) considered the overall level of nursing care to be of a very high standard with many social workers involved within the hospital system.

Western medicine coexists with Indian systems of medicine and homeopathy as seen in Madhya Pradesh as well as in other areas of the country (DeCosta & Diwan, 2007). The Government supplies a wide range of healthcare facilities in India. People are offered medicine from governmental institutions for the treatment of leprosy (Lipinski, J., personal communication, 030211, desk officer for the organisation SOIR). Even though leprosy is easy to detect and treat, many millions of people suffer from leprosy in India. However, it is noticeable in some rural areas and among tribal villages that there is a preference to go to traditional healers or *disari* (a person operating in tribal villages who combines religious and medical functions) (Porter *et al.* 2002). Porter *et al.* (2002) points out that a large number of the community and patients in Koraput lack faith in the public health sector. In addition, many of the villages are up to 40 km from the nearest Community Health Centre and some of these provincial people were unaware of the centre existence.

There are a number of NGOs operating in India filling the gaps in the health services. Lipinski, J. (personal communication, 030211, desk officer for the organisation SOIR) has encountered many health projects run by NGOs. Some of them have undertaken a great responsibility for leprosy, such as the NGO called LEPRA in the Koraput district in Orissa. Yet, Porter *et al.* (2002) argue that the lack of service facilities at a governmental level still persists and the lack of availability of specialized services focusing on disability has resulted in leprosy patients

receiving inadequate care in this area. Through the provision of health education in communities, training local staff, setting up specialist referral services and refurbishing hospitals and surgeries, LEPRA is working alongside vulnerable communities to help people to take control of their own health (Lipinski, J., personal communication, 030211, desk officer for the organisation SOIR).

The Koraput Leprosy Eradication Project (KORALEP), organised by LEPRA, operates in the district, focusing on public health. It offers education, runs a laboratory, and provides professional physiotherapy, disability services and facilities to GHS (Porter *et al.* 2002). KORALEP works actively to find cases of leprosy symptoms, distribute surveys and treatment. The governmental hospitals in Orissa do not have sufficient drugs and the laboratories are not well equipped. The lack of specimen containers forces employees to use matchboxes, leaves and other items (Porter *et al.* 2002). Treatment is expensive and prescriptions have to be purchased by the patient, but MDT is supplied free of charge. Kazen, B. (personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation) point out that nursing care should be free of charge for leprosy patients as well as the medicines.

SOIR works with leprosy sufferers on many levels in different projects and with many aid partners, LEPRA being one of them. SOIR is fighting against leprosy and tuberculosis through sharing information and offering treatment in many parts of India. They support partner organisations regarding the rehabilitation and integration of leprosy patients with deformities and disabilities into society. SOIRs partners examine people and track down people infected with the disease but they have had to use fake names for their campaigns because otherwise people would not attend. Many hand-crafted goods sold to raise money by SOIR originate from these programmes (Lipinski, J., personal communication, 030211, desk officer for the organisation SOIR).

Borg and Larsson (2009) point out that some of the established leprosy centres provide assistive devices for daily living. There has been a noticeable demand for self-care in other parts of India. Sixty percent of the women who attend the Leprosy Mission Premananda Memorial Hospital in Kolkata during 2006 were satisfied with the outcome of their treatment. However, problems with recurring ulcers and reactions continued to appear (John, Rao & Das, 2010). They felt that the hospital was providing the best care, but found repeated visits to the hospital rather difficult due to the cost, time away from domestic responsibilities, and lack of cooperation from family members.

A study of integration of the second phase of the National Leprosy Eradication Programme was carried out in the Bargarh district in western Orissa in India. The study showed that the quality of leprosy diagnosis and treatment services was generally of a high standard (Siddiqui *et al.* 2009). It was noted that a high quality of leprosy treatment and counselling services in GHS especially in the rural parts of the district was provided. The LEPRA Society and more recently the government have organised POD camps, demonstrating practical skills in ulcer care and POD methods. Patient cards and registers were well maintained in all PHC clinics. However there was much variation regarding responsibility taken for the main treatment

register in rural healthcare settings compared with hospitals. Patient follow-up varied from 2–3 days to 2 months and was generally performed within a shorter time-frame in rural areas. The following illustrates the importance of continuous counselling and patient follow-up:

“Patient 3E, 35 years old, was diagnosed with MB leprosy 4 years ago after developing clawing of his right hand and anaesthesia in his right foot. The MO explained about leprosy, the importance of regular treatment and how to carry out self-care. He was a poor man and had to find work so he stopped taking MDT after 6 months and travelled back to his home village (he did not know that he could take the remaining treatment with him). He did not inform the hospital and does not think they tried to trace him. He has since developed painful neuritis in his hand and a maggot-infested tropic ulcer on his right toe. He was charged 200 rupees for antibiotics which he could not afford and the toe was amputated. He was back now but too scared to restart MDT in case he was given more bad news (Siddiqui et al. 2009:e8351).”

According to Siddiqui *et al.* (2009) the study in the Bargarh district showed that primary PHCs had inadequate routines for referrals and had no clear guidelines for the validation of leprosy cases. They argued further that it was not clear whether the patient had been seen for validation or whether validation was still pending and a missing result was noted as ‘validation pending’ although it was possible that some cases had been validated but had not been registered and treatment initiated. This led to misdiagnosis especially in urban areas. It was particularly evident in rural settings that some cases were still pending more than one month after the initial diagnosis. It was critical to follow up pending cases, although it was possible that a documentation error was responsible for some of these observations or that some patients were validated elsewhere. The validation of diagnosis is important to reduce the proportion of misdiagnosis and re-registration and to improve the leprosy diagnosis skills of the PHC MOs by performing validation in patient’s presence. Nonetheless PHC MOs, particularly in urban areas, were often not present at validation and had limited knowledge of patients after referring for validation. In addition, Paramedical Workers (PMWs) trained in treating leprosy and MPHWs often referred suspicious cases directly to validation, bypassing the PHC MO, which led to reduced exposure to leprosy patients and reduced their capacity to correctly diagnose leprosy. The validation process can delay the initiation of treatment and could lead to non validation. (Siddiqui *et al.* 2009).

“Patient 6C, 25 years old, was diagnosed with MB leprosy 6 months ago after noticing anaesthetic patches on his chest, back and knee and joint pains. He knew from TV and posters that this could be leprosy so he went straight to his local ‘PHC new’ clinic. However he was referred to the block PHC 8 km away for validation. The validating MO did not come so he was sent to another PHC clinic 12 km away for validation. Again he missed the validating team and was sent to the medical college 20 km away for validation. He was told that they were not permitted to validate his diagnosis. His diagnosis was eventually confirmed nearly 2 months after the initial diagnosis” (Siddiqui et al. 2009:e8351).

Kazen, B. (personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation) is under the impression that the quality of health care does not differ between urban and rural areas. She has been to a private hospital in India which had smaller rooms than hospitals catering for poor people. This was in 1978 but

back then the quality of health care did not have any differences between social classes, age or sex. However, she points out that the possibilities to obtain reconstructive and rehabilitative surgery and social and economical rehabilitation could differ depending on access and resources.

Challenges

Heijnders (2004) states that at present, many people with leprosy, experience stigmatization on many social levels; a reduced likelihood of employment and marriage and an overall exclusion from and discrimination by society. Many areas of life may be affected by stigma causing an inability to participate in everyday life. These could be: learning and applying new information general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major social areas in life, participating in the community, social and civic activities (Van Brakel 2003). Individuals might be excluded from leisure activities, and attendance at social and religious functions (Van Brakel, 2003). Restrictions in the participation of social events may be a result of stigma or physical effects from the disease (Borg & Larsson, 2009).

In a study carried out in Nepal, Heijnders (2004) noticed that people affected by leprosy expect to be separated from society once others discover they suffer from the disease. These expectations resulted in people adapting various coping strategies to prevent stigma. These strategies varied depending on how obvious the disease was. Some used concealment motivated by others who suffered from leprosy and who had been badly treated by their communities. The diagnosis of leprosy was expected to activate discrimination and interfere with ones' social integrity (Heijnders, 2004).

As stressed by Van Brakel (2003) the word leprosy is used as a curse word in many countries, which adds to the difficulty in reducing the stigma of leprosy. The stigma associated with the disease continues to be an obstacle for self-reporting, detection of cases and early treatment in many places (Van Brakel, 2003). Stigma and prejudice are obstacles for the eradication of leprosy in the country (Kar, Ahmad & Pal, 2010). Visible deformities and lesions or a combination of symptoms could be a source of stigmatization. In general it could be summarized that living with leprosy is viewed with fear by health individuals.

According to Lipinski, J., (personal communication, 030211, desk officer for the organisation SOIR), it is difficult to encourage people to have check-ups, because it is traumatic to be marked as a carrier and risk exclusion from society. As Lipinski, J. (personal communication, 030211, desk officer for the organisation SOIR) points out, people are afraid of the possibility of others in the community finding out about being diagnosed. Confidentiality does not exist in the same way as in many other countries. Being diagnosed with the disease or having obvious symptoms could therefore be dreaded by many in the developing world. Because of the stigma from family and society that still takes place, people are afraid to have the verdict: leprosy! The shame associated with the disease is feared (Kazen, B., personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation).

Heijnders (2004), points out that some patients, regardless of status, do not even inform their family members that they have the disease. This could result in withdrawal and people may

stop their treatment or leave their village with or without their families (Heijnders, 2004). Some people affected by leprosy withdrew temporarily when they had visible signs until their symptoms had improved.

However, some people inform their closest family members or extended family. It has been observed that people with low status tend to be questioned more often about their patches than those with a higher status (Heijnders, 2004). Some felt more or less forced to tell their families after being questioned about visits to health clinics or after their medicines had been found by someone in the family (Heijnders, 2004). Most of them did not give their leftovers to other family members and stored their food utensils separately, and in some cases even their bedding and personal belongings (Heijnders, 2004). Some withdrew from communal activities and started to sit, eat, and sleep separately, but continued to join the family in other activities. A few were no longer touched by others, or were asked to live separately from the family; however most of this separation was temporary (Heijnders, 2004).

A study of the knowledge and attitudes towards leprosy was carried out in the endemic state of Uttar Pradesh, it showed that most of the respondents, including leprosy patients, considered bad blood as the reason for leprosy (Barkataki, Kumar & Rao, 2006). However, according to Barkataki, Kumar & Rao, (2006) a high percentage of those who were literate knew that infection was the major cause. Almost 50% of the population in Uttar Pradesh and almost 40% suffering from leprosy consider leprosy as being an infectious disease. In contrast, nearly 80% of all literate respondents did not consider leprosy infectious. More of the illiterate leprosy patients felt there was no discrimination, but acknowledged that leprosy patients are not treated the same as others in some cases (Barkataki, Kumar & Rao, 2006). Almost, were stated, all the respondents were sure there was a treatment for leprosy, stated tablets and capsules as the treatment for leprosy but a relatively small percentage could specifically mention MDT. Yet, almost everyone stated that leprosy is a curable disease and leprosy related deformities are preventable. Nearly 70% or more of the respondents felt that leprosy affects social participation and 90% stated that the main reason for such restrictions was social stigma (Barkataki, Kumar & Rao, 2006). Fear and lack of knowledge surrounding leprosy and its treatment are the major reasons for stigma associated with the disease in India (Kazen, B., personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation).

Many hospitals show that fewer women than men use their services (John, Rao & Das, 2010). It could be argued that this is caused by both the stigma of the disease and the gender disadvantage that women suffer. A research project carried out on female patients attending a leprosy referral hospital in Kolkata, West Bengal, showed that 44% came alone, 30% were brought by their father or husband, and the remaining 26% had a family member or friend accompanying them, 93% of the women had problems associated with leprosy (John, Rao & Das, 2010). Most women cannot attend without the approval of their husbands and they often have to travel great distances to the hospital, which interferes with duties in their household (John, Rao & Das, 2010).

According to John *et al.* (2010), women suffer in particular and find it difficult to follow medical advice such as avoiding prolonged walking and standing, and working with hot utensils as they have to care for their families and also provide an income. Also, the majority of women have no knowledge of leprosy prior to a visit to a leprosy centre. However, if they had received a better education they could have applied for treatment sooner (John, Rao & Das,

2010). A qualitative study in the eastern part of Nepal shows that women, when compared to other non-decision-makers, were more likely to experience negative family behavior (Heijnders, 2004).

Jain *et al.* (2002) emphasize that children are exposed to *Mycobacterium leprae* in leprosy endemic areas with about 13% of all leprosy cases below 15 years. In the study undertaken in Nepal it was also discovered that children below the age of 15 received a great deal of support, whereas family members above 50 who could not contribute to the family in any way were sometimes sent away (Heijnders, 2004). According to Horo *et al.* (2010) children are most sensitive to infection and children tend to be reported at a later stage compared with adults. This delay makes it difficult to distinguish when a child becomes infected. Unfortunately, some children drop out of school and develop irreversible disabilities and deformities, which would be averted by screening (Horo *et al.* 2010). Furthermore, early detection of childhood leprosy could improve the spread of the disease and contribute towards eradication of leprosy (Horo *et al.* 2010). The most effective way of preventing disabilities caused by leprosy and further transmission of the disease, lies in early diagnosis and treatment.

There may be stigma involved in lesions and POD care, while some MPHWs in rural healthcare settings in the Bargarh district in Orissa preferred not to treat ulcers (Siddiqui *et al.* 2009). There were assertions that staff in urban hospitals tried to dismiss leprosy patients as quickly as possible to avoid unease amongst other patients, medical staff and the leprosy patients themselves.

A "...34 years old, said that MOs (in an urban hospital) were extremely busy and usually had no time to explain leprosy to patients and convince them to take MDT. Also there was still stigma. Other patients would not stand next to leprosy patients. The MO immediately referred leprosy patients to the district nucleus. Ulcer cases did not generally come to the hospital. They usually went to nearby mission hospitals because there were no dressing facilities or the dressers would not dress leprosy patients, probably because of stigma because they would dress other wounds. Maybe other patients complain and tell him not to do it (this was denied by the dresser)" (Siddiqui *et al.* 2009:e8351).

Suggestions of improvements

According to a qualitative study in the eastern part of Nepal, the following situation could be applicable to the situation in India as a whole:

"Politicians should make some arrangements for the poor people, but they do not care about us. There would be difference between rich and poor if they took a little care of the poor people" (Heijnders, 2004:442).

Women and disabled people are the most affected groups in terms of lack of nursing care (Madhavan *et al.* 2007, Heijnders, 2004). Approximately one third of people affected by leprosy face social or economic problems and many people have chronic impairments due to leprosy, experiencing severe difficulties with the normal activities of daily life (Borg & Larsson, 2009). Assistive devices to facilitate activities and participation, such as services to prevent impairments and secondary deformities, appear to be used more in self-care and

domestic life, especially with respect to mobility, but less utilised in other areas (Borg & Larsson, 2009).

Hospitals can improve their services to more effectively address the needs of females without increased expenditure to provide a better quality service (John, Rao & Das, 2010). Waiting times need to be reduced, priority queues could be provided, adequate privacy should be considered mandatory and there is a demand for trained women professionals (John, Rao & Das, 2010). Counselling should be an integrated part of holistic care to help patients handle their needs (John, Rao & Das, 2010, Siddiqui *et al.* 2009). Furthermore, the collaboration between patients and health professional needs further improvement and further efforts should be made to promote early detection and treatment, with an increased focus on women (John, Rao & Das, 2010).

NLEP has led to the availability of daily diagnosis and treatment in all healthcare facilities at the primary care level, but the worldwide understanding of the spread of leprosy needs to be improved in order to eradicate the disease (Cairns *et al.* 2004). It is hard to find information about how to work preventatively with leprosy while the source of the infection is still uncertain (Lipinski, J., personal communication, 030211, desk officer for the organisation SOIR). It could take between 10 and 20 years before the disease appears, which makes it hard to distinguish the reason for infection. In a study undertaken in three communities in India, Cairns *et al.* (2004) suggest that the level of exposure is higher during the wet season while the disease is more common in tropical areas with high humidity. The long incubation period obstructs the seasonal influence of infection and more time spent indoors during the wet season might just as well be the explanation (Cairns *et al.* 2004). Today MDT is supplied by MPHWs; however people working in the general health system need the provision of further training by local health authorities (Pandey *et al.* 2006).

In urban areas of the Bargarh district, patients with leprosy related deformities or disabilities could be referred to the orthopaedic department within the hospital (Siddiqui *et al.* 2009). Though in rural areas where LEPRO Society was not active there was little knowledge of treatment options for patients in similar situations. Also, socioeconomic rehabilitation advice was an often neglected area of leprosy care but in many cases the most important to the patient. LEPRO Society and some PHCs were attempting to adjust this by assisting patients in applying for The Government of India (GOI) pensions for the disabled (Siddiqui *et al.* 2009).

According to Arole *et al.* (2002), integrated approach programmes to supporting leprosy sufferers through financial support, makes their lives easier through economic independence. Leprosy integration programme activities need strengthening to gain sustainable levels of both patient care and referral services. In Jamkhed in India leprosy has been integrated with other infectious diseases for the last 30 years. This has stressed the needs of empowering people with both skills and knowledge (Arole *et al.* 2002). The aim of the rural health project was to eliminate the risk of suicide, encourage self-reporting and improve nursing care.

A study carried out in Maharashtra compared the level of social stigma of leprosy in communities having vertical programme with communities having an integrated programme. The difference between vertical and integrated programme is that leprosy control activities in a vertical approach is carried out by separate staff than in other health systems (Arole *et al.* 2002). An integrated approach to community based primary healthcare has been effective in reducing stigma related to leprosy in society (Arole *et al.* 2002). Virtually stigma related to

leprosy exists in the latter. It appeared that 4 out of 10 patients moved out of their homes after diagnosis in the vertical approach whereas 3 out of 14 patients moved when diagnosed using the integrated approach. Moreover, the villages using the vertical approach showed a significantly greater number of cases of isolation regarding social functions, meals, interactions with friends and colleagues and the accessibility of local services. (Arole *et al.* 2002). Also, the integrated programme led to improved knowledge of the disease and leprosy patients were in general considerably more welcomed within the community (Arole *et al.* 2002).

Van Brakel (2003) discusses the idea of using a scale to measure the effects of stigma on leprosy sufferers or to evaluate attitudes and practices towards those affected. He suggests a number of different scales, for example the 'Dehabilitation Scale' invented by Dr. Hanna Anandaraj. This instrument is a 52-item scale that covers four areas related to stigma: family relationships, vocational conditions, social interaction, and self esteem. The items consist of positive or negative statements, with 5-points arranged from strongly agree to strongly disagree. The results are added together, divided by the maximum possible score, and multiplied by 100 to arrive at a final score.

Van Brakel (2003) further suggests that questionnaires could be another tool to measure stigma. He has observed that such an instrument has been used in association with health education interventions in order to examine to what extent knowledge input would modify attitudes and practices. Most questionnaires included items on knowledge regarding leprosy, as well as on attitude and practice. He further argues that little research has been done to measure the level or intensity of stigma. The development of a standard stigma scale for leprosy patients might facilitate situational analysis, advocacy work, monitoring and valuating interventions against stigma and research to better understand stigma and its determinant factors (Van Brakel, 2003).

Education

According to Porter *et al.* (2002), it has been discovered that there is a lack of education particularly with regard to leprosy in Koraput . The information, education and communication about infectious diseases for patients and staff are poor (Porter *et al.* 2002). In a study about health education among health workers and women in Southern India it was recognized that health aides sometimes provided incomplete information as a result of a lack of education (Ny, Dejin-Karlsson & Udén, 2006). The same study reported differences in the levels of health education between patients in the villages and at MHC clinics. Better health information was provided from nurses in the latter setting. On the contrary, Lipinski, J. (personal communication, 030211, desk officer for the organisation SOIR) argues that health care staff are in general well educated in their field.

In the Salem district efforts have been made to improve conditions for disabled people suffering from leprosy. The District Leprosy Officer had a number of meetings with the deputy director of health services, the municipal administration and a NGO leprosy centre working with POD services and it was decided that the Governmental general health staff should implement POD services with support from NGOs (Madhavan *et al.* 2007). Health workers were provided with training and disabled people were encouraged to practice self-care procedures, based on inspection, soaking, scraping, oiling and dressing (ISSOD). This involved daily inspection of hands and feet for damage and injuries, soaking in water for half an hour

using barrels available at home, followed by gentle scraping with a stone applying neem oil to deter insects and rodents and finally a dressing for those with ulcers (Madhavan *et al.* 2007). Neem oil should be applied when the skin is still moist and it can be obtained in the region. It is important that the cloth is clean and dry before usage. The self-care procedures in Salem district using ISSOD contributed to improving knowledge of leprosy for everyone involved (Madhavan *et al.* 2007).

According to Ny, Dejin-Karlsson & Udén (2006), many women in India are unaware of their own health and risks. Women are most likely to be the main health provider in the family and require information appropriate to their experience (Ny, Dejin-Karlsson & Udén, 2006), which highlights the relevance of the information given and the communication thereof. Health education materials need to be adapted to the culture in the country of use (John, Rao & Das, 2010). National programmes should give a higher priority to offering culturally acceptable health education to encourage early reporting of cases, which could improve the balance of equality (John, Rao & Das, 2010). Social and economic problems faced by women due to leprosy have been addressed in some cases in Kolkata by providing educational grants for children, loans for small businesses, vocational training, and in some cases reuniting them with their families (John, Rao & Das, 2010).

Most of the ulcers are preventable and could be looked after by the patients themselves, but they lack the education and motivation and depend on hospital care (Chakraborty, Mahato & Rao, 2006). According to Chakraborty, Mahato & Rao (2006), the majority of these patients are taught prevention and self-care of wounds during their stay in hospital. There is a demand for empowerment through further training of the leprosy sufferers, their families and community volunteers, to broaden their knowledge to prevent disabilities (Chakraborty, Mahato & Rao, 2006). A self-care programme to prevent leprosy-related disabilities in a leprosy colony in Champa, Chattisgarh, was successful after just one year. 251 of the inhabitants had leprosy and they showed a decline of ulcers by 41%, wearers of specially designed footwear (MCR) increased by 43%, over 90% of the patients and their families were practicing self-care activities and the number of admissions into hospitals for ulcer care dropped from 9% to 2% (Chakraborty, Mahato & Rao, 2006).

Siddiqui *et al.* (2009) through their study recognized that prevention of disability and ulcer care varied between different health care employees in Bargarh, possibly due to a lack of materials or training. MOs would advise self-care, prescribe antibiotics or refer patients to an assistant for dressing, whilst MPHWs, on the other hand, would generally advise self-care and few carried out ulcer care. As pointed out by Siddiqui *et al.* (2009), patients were advised to check families for leprosy symptoms in Bargarh as there were no longer active searches or surveys in the area and new case detection now relied on their own initiatives. However, the MPHWs often examined families in the home during patient follow-up visits in rural areas. The following exemplifies how effective self-care and exercises can be in terms of preventing disability:

A “patient...29 years old, was diagnosed with MB leprosy after noticing some weakness in her right little finger. She started MDT and was advised to soak her hands and apply oil daily. She was given exercises to carry out daily, morning and night, to straighten the hand. She has been determined to prevent this disability and has followed the advice consistently. After 6 months she no longer has a claw hand but some weakness remains” (Siddiqui et al. 2009:e8351).

John, Rao and Das (2010) discovered in a study in Kolkata that the majority of participants expected that leprosy was treatable with tablets, and that the treatment was free. Almost all patients expect to receive counselling, health education and skills in self-care. Siddiqui *et al.* (2009) stress that counselling should be offered to leprosy patients at all stages including during diagnosis, treatment and for those previously released from treatment (RFT). This ensures MDT reliability, stills fears and helps monitor possible drug side effects or complications (Siddiqui *et al.* 2009).

It was important in Bargarh to reassure patients if deformities had not disappeared as these patients may otherwise try to obtain more MDT from another PHC clinic. This could otherwise lead to re-registration of cases incorrectly and the leprosy prevalence rate would not be reliable. Initial counselling was generally carried out by validating staff, mostly in urban hospitals. However, in rural areas counselling during MDT and at RFT was usually carried out at the sub-centre by MPHWS. Unfortunately, in urban hospitals or busy PHCs in rural areas, there was often no time to counsel patients. (Siddiqui *et al.* 2009)

The GHS had the responsibility to ensure that all health workers, patients affected by leprosy and the public were informed of leprosy. This information was spread through leprosy training, counselling and community awareness through education and communication (IEC) campaigns, using a range of methods such as TV, radio, posters, pamphlets, IEC vans, film shows and folk dances. These efforts proved to be effective in creating leprosy awareness in the community and encouraging new cases to come forward for detection. In October 2005, the low disability rate, 2.34%, indicated that diagnosis was occurring at an early stage. In addition, stigma appeared to have been significantly reduced particularly in rural areas where patients were no longer excluded from communities to the same extent. Nevertheless, there was very little IEC activity in between IEC campaigns unless the LEPRO Society was active in the area, which had to do with time shortage and prioritizing. Leprosy training by District Technical Support Teams (DTSTs) was generally appreciated and considered useful and interesting and most PHC staff felt that they had gained knowledge about the signs and symptoms of leprosy, methods of diagnosis and MDT treatment procedures. It appeared that almost all PHC staff expressed satisfaction with the quality and frequency of training provided. However, practical experience with ulcer, POD and disability care was requested. (Siddiqui *et al.* 2009)

Hygiene

As pointed out by Lipinski, J. (personal communication, 030211, desk officer for the organisation SOIR), three hundred million people in India live on US\$ 2 a day. This affects living conditions and health negatively and according to the UN in 2002, more than one in three children in the cities suffer from malnutrition. One of the United Nations Millennium Development Goals is that more people should have sustainable access to improved water sources and sanitation by 2015. As stated by Cairncross *et al.* (2005) the mere provision of water supply and sanitation facilities is not enough to bring down morbidity rates to an acceptable level, whilst hygienic behaviour has a greater impact on health. There is an overall poor understanding of health and nutrition-related subjects in India, whilst the school system does not put emphasis on health education (Shah *et al.* 2010). It has been noted that school-

based health education programmes have had a positive influence towards healthy living all through adulthood (Shah *et al.* 2010). Lipinski, J. (personal communication, 030211, desk officer for the organisation SOIR) is under the impression that hygiene education is not part of school education and information is provided only when there is an epidemic outbreak or similar. However, as he points out, people in India are in general very clean, but the conditions are challenging with the lack of water supply.

According to Deb *et al.* (2010), it was observed in a primary school situated in the largest slum of Kolkata, that the majority of diseases that the children were afflicted could be prevented by the promotion of hygienic practices through proper health education by the teachers, who are their first contacts outside the family. Therefore, coordinated and regular activities involving health and hygiene at schools are needed, with the emphasis on health check-ups (Deb *et al.* 2010). It was discovered that 18% of the children never washed their hands before eating. A closer look reveals that running water was used for hand washing by 59.23% of the children at home and 82.3% at school (Deb *et al.* 2010). Some of the children washed their hands in a common dish of water shared by several persons or a dish of water at home.

The sustainability of a change in hygiene behaviour was studied in Kerala and carried out by a NGO responsible for implementing hygiene promotion. There was a strong association between knowledge of when to wash hands, demonstrated hand washing skills and self-reported practice (Cairncross *et al.* 2005). Participants in the study were more likely to demonstrate hand washing correctly in households where women reported the practice and also mentioned that it is important, for health reasons, to wash hands before eating. Home visits took place during the campaign, since home visits are a particularly important component of any hygiene promotion; the number of such visits was associated with awareness of the need for hand washing before eating but not with other hygiene outcomes (Cairncross *et al.* 2005).

Hand hygiene compliance among health care providers is considered to be the most effective element to reduce infections (Sahay *et al.* 2010). It has been identified that the transmission of microorganisms from the hands of health care workers is one of the major health care-associated infections, and Sahay *et al.* (2010) stress that hand hygiene is the most important measure for preventing and controlling such infections. Many studies have shown that compliance with hand hygiene procedures has remained low. The overall hand hygiene compliance rate, in an emergency care unit in India, was 60.71% among nursing staff and 66.12% among doctors (Sahay *et al.* 2010). The overall hand hygiene compliance of properly performed hand washing dropped drastically on night duties compared with day duties. “No hand washing after procedure” was the most frequently observed practice in 41% of the cases, followed by “improper duration of hand washing” in 32% among the participants and “no hand washing done at all” observed in 27%.

In an empirical study carried out in Karnataka State in India, it was observed, that cleanliness was rated good for 39% of public health care facilities compared with 79% of private sector services (Bhatia & Cleland, 2004). As pointed out by Lipinski, J. (personal communication, 030211, desk officer for the organisation SOIR) the rehabilitation centres, supported by SOIR, have decent hygiene and sanitation conditions. Clean water is accessible in all of the centres, but to a limited extent. However, he claims these conditions would never be accepted in many other parts of the world.

The standard of the health centers and hospitals run by NGOs have often been very high. One of the cleanest hospitals she has been to did not even have running water. They had people employed specifically delivering barrels of boiled water. NGOs with their international contacts tend to be better at obtaining health care material such as disposal gloves. The creativity and skills to improvise often have a greater meaning than disposal material. (Kazen, B., personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation)

DISCUSSION

Discussion of method

The aim of this research had three areas of focus: healthcare provided in India in order to prevent leprosy, the kind of nursing care available for people suffered from leprosy and how the quality of healthcare and nursing care can be improved to decrease leprosy. This paper could have been more penetrating if the author had focused in hindsight on one of the three perspectives. This would however have demanded more time for this study. In addition there was a limited amount of information available about the subjects. However, the aims have been used as basis and give an overall perspective which is needed to raise awareness of the complexity of leprosy.

The people chosen for the in-depth interviews for this study were considered to be more than satisfactory. This enabled the author to gain a broader perspective of information concerning leprosy. First-hand experience of the work of the organisation SOIR in India was gained whilst visiting my sister who had undertaken a volunteer position in one of their projects in a slum area of New Delhi. The project involved educating children from an orphanage and disabled children from the area. The author contacted the organisation for advice after which Lipinski, J. offered to contribute with his knowledge voluntarily. Kazen, B. on the other hand was found via a recommendation when contacting the Leprosy Mission International Organisation for advice. The organisation held a talk about leprosy in Gothenburg a while ago which encouraged an interest in the organisation.

It can be challenging to receive reliable information from qualitative in-depth interviews. Questions for discussion allow the interviewee to develop their answers independently. This, most likely, results in a different response depending on the interviewer, which impairs comparability. It is advantageous to ask interviewee questions about areas of interest during the interview. This contributes to responses having a greater validity as well as an increased probability of finding suitable information.

It could be argued that the outcome of the interviews could have contributed more to the content of this work. This could have been achieved by giving the interviewees an opportunity to answer more freely. In addition, the outcomes of the interviews could have had different result if there had not been such a time limit for this dissertation, which in turn could have led to an extended interview time with Lipinski, J. and Kazen, B. and potentially more participants. A summary of the interviews and analysis of them are presented in appendix 3 and 4.

A literature research was also used as a method for research as it was suitable to the aim of this study. However, it was a challenge since it was difficult to find research articles written about leprosy related to the aspect of nursing care. Finding articles with an association to hygiene was also a struggle. Some articles on the databases found, on PubMed or Cinahl, were judged as being too old for the present study, required payment to access or were inaccessible from the University of Gothenburg's search engine, hence the number of articles. Most of the 22 articles used were quantitative researches, which had limited information for this study.

The journals used are from the USA, the United Kingdom, the Netherlands and India. The Leprosy Review and the International Journal of Leprosy and Other Mycobacterial Diseases were the most frequently used journals. It is likely that the result would have varied if the number of articles had been different. Critically speaking, using MeSH-terms through the search might have yielded different results. The search terms which enabled relevant information to be gained are presented in Appendix 1. More search terms were investigated in the search engine than used to write this paper, but were considered irrelevant to submit. The ones used are presented in further detail in Appendix 2.

All the articles used were written in English. Their results have been examined and interpreted. Due to the fact that English is not the authors' first language there is a risk for misunderstanding. The articles have been studied many times in order to minimize misconceptions.

Choosing to use a combination of a literature review and in-depth interview was partly based on the struggle to find adequate information for this study. In addition, the author's personal interest in the work undertaken by organisations in India was also a factor. The combination of the two methods has been valuable for the outcome of the result. However, some of the information contributed with slightly different perspectives and information. The absence of certain facts from appropriate research articles essential to complete the paper could be asked during in-depth interview and the questions could be led in a desired direction. This contributed toward putting the information into the same categories. Combining the outcomes from literature articles and interviews has provided a better perception of healthcare provided in India in order to prevent leprosy, the kind of nursing care available for people suffering from leprosy and how the quality of healthcare and nursing care could be improved to decrease in the incidence of leprosy.

Discussion of result

In many countries leprosy has been viewed as a disease that only affects the poor. According to Kazen, B. (personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation) leprosy usually affects poor people but the reason is unknown. However, the percentage of those who are poor and malnourished and who contract leprosy is small. It has been noted in studies that access to health differs between rich and poor, between male and female and also between the young and the old in India. Many hospitals show that fewer women than men use their services. It could be argued that this is caused by both the stigma surrounding the disease and the gender disadvantage that women suffer. One can suggest that integration of leprosy services into general health services in order to increase the accessibility of patient care and reduction in stigma could be introduced.

As mentioned earlier on in this study Lipinski, J. (personal communication, 030211, desk officer for the organisation SOIR), has observed differences in the quality and availability of nursing care. If you become ill in India, treatment is expensive and prescriptions have to be purchased by the patient. The nearest primary health centre is likely to be far away and the staff there tend to lack knowledge about infectious diseases such as leprosy, and do not have access to a laboratory. The referral process for a secondary care hospital is not appreciated and patients might prefer queuing in the PHC. This delay as well as the availability of resources to battle the disease could be some of the many as to why some contract leprosy. It could be argued that the wealthy have more advantage as concerns health and poor people tend to be disadvantaged health wise.

It is a challenge to attain an overall high standard of nursing care in India due to issues in terms of healthcare investments, lack of knowledge about leprosy, inadequate hygiene routines, inequality and the lack of educated staff. Poverty and the caste system put a strain on the ability to supply equal care. About 20% of children that are denied the chance to go to school throughout the world live in India (Lipinski, J., personal communication, 030211, desk officer for the organisation SOIR), which is a challenge when it comes to reaching out to people in terms of health education. Even though maintaining health is a human right, according to the Millennium Goals, there is a deficit of accountability for quality and equity in healthcare, both in terms of preventative efforts and the control of prevalent infectious diseases.

The World Health Organization (2007) states that, India's healthcare system is one of the most privatized in the world, however it could be argued that there is a need for the Government to provide a stronger public health sector in order to ensure access to healthcare for the entire population in India. The lack of service facilities on the governmental level is apparent (Porter *et al.* 2002), which makes it hard to provide good nursing care fully. The provision of footwear and guidance in self-care must have a higher priority than at present (Borg & Larsson, 2009). It has also been noted that there is a preference to visit traditional medicine practitioners in some areas of India (Porter *et al.* 2002). It could be suggested that a better collaboration between traditional India medicine and western medicine would be desirable in order to reach potential. The author would humbly suggest that this initiative should arise from a governmental body in order to achieve credibility. One method of care does not have to exclude a different method. Maybe the combination of the two could be the way forward to fight for the eradication of leprosy in India.

According to a study in the Bargarh district PHCs were shown to have inadequate routines for referrals and had no clear guidelines for the validation of leprosy cases (Siddiqui *et al.* 2009). It was not clear whether the patient had been seen for validation or not. That highlights the need for good administrative skills. This district uncertainty whether a diagnosis had been processed needed improved routines and clear guidelines possibly a need shared by other districts as well.

However, as pointed out by Lipinski, J. (personal communication, 030211, desk officer for the organisation SOIR), the overall level of nursing care in the country seems to be of a very high standard with many social care workers involved. If that is the case maybe the opportunity for change needs to come from a different angle. In order to combat the stigma that is attached to leprosy, health workers as well as the general population need to be appropriately educated. While there still is a very hierarchical system in India where the doctor does most of the work (Lipinski, J., personal communication, 030211, desk officer for the organisation SOIR), it could be argued that one starts at the top of the hierarchy, in this case the doctors, who could be

the instigators for change. This research paper has not looked into the education provided for doctors, but if there is a gap in the medical programme then the need to fill it is necessary to any changes toward the fight against leprosy.

According to Lipinski, J., (personal communication, 030211, desk officer for the organisation SOIR), it is difficult to get people to have check-ups, since it is traumatic to be marked as a carrier. Confidentiality does not exist in the same way as in many other countries. If it did exist patients would trust visiting a healthcare clinic. Nightingale highlighted the need for *chattering hopes and advices* (Nightingale, 1860). She encouraged nurses to sit down and speak with their patients to try to give comfort and consolation. It is important to create a relationship with the patient to establish confidence in the nurses' competence (Ashworth, 1980, cited in Carlsson, 2009). The support could give the patient being cared for an opportunity to express wishes and deal with the situation they are in (Nightingale, 1860). If the patient knew that the information and feelings he shared with the nurse would remain confidential this would be better basis to establish trust and encourage others to come forward for check-ups.

Leprosy may cause sensation loss in hands and feet, which can contribute with damage to these parts of the body. Lesions are often neglected which leads to infections with complex consequences. It is important to prevent the disease in order to not reach this stage of the disease. This puts a strain on the overall quality of health care and nursing. It stresses the demand for an overall quality of resources provided. Also, the patient needs to use their own resources in order to meet their needs (Tingström, 2009). Both private and public health care settings must strive for early detection. Ulcer self-care education is therefore necessary and a good start to further ensure that no or little injury is sustained by the patient (Kazen, B., personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation). Many NGOs, for example LEPRO and SOIR, run campaigns, share information and provide workshops about the integration of leprosy patients into society. Many hand-crafted goods sold by SOIR originate from these programmes. Buying these goods is a good way to become involved in leprosy awareness. It could be a way to contribute with nursing ideas through supporting the organisations and their members.

Heijnders (2004) mentioned in his study that people affected by leprosy expected that they would be separated from the society once others knew about their disease. Other studies have recognized that people afflicted tend to feel ashamed of the disease and in many areas people prefer not knowing whether they are carriers for fear of the consequences. Some used concealment coping strategies to prevent stigma. However, it is not mentioned whether these people were provided with any education about their conditions by nurses or healthcare staff. If patients had to routinely check family members for leprosy symptoms, as they did in a study in Bargarh, there would be a way to encourage each other to seek healthcare. It could also be a way of enabling closer family ties due to participation concerning each individual family member's health. Given an impression of the lack of education for coping with the disease and the surrounding factors, the author supports the idea of raising an educational information campaign about diseases via TV, radio, posters, pamphlets, IEC vans, film shows and folk dances. Nightingale (1860) proposed theories about *chattering hopes and advices* which are tools for quality nursing care.

However, in a study from Uttar Pradesh More of the illiterate leprosy patients felt there was no discrimination, but acknowledged that leprosy patients are not treated the same as others in

some cases (John, Rao & Das, 2010). One wonders whether a scale, such as something similar to the nursing VAS-scale, an instrument which makes it possible to measure the feeling of a patient to assist healthcare staff, might be of value as a tool to quantify stigma. It has been argued that there is a variation of stigma associated with leprosy in the world. Kazen, B. (personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation) is of a different opinion claiming leprosy to be an international problem with similar challenges, discussed on courses and congresses she has attended.

Stigmatization of leprosy could be prevented by more information, increasing knowledge about the disease, carrying out active case detection in order to find people affected of an early stage. The resources for work undertaken for leprosy is in decline, which is a source of worry (Kazen, B., personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation). The self-care procedures in the study in the Salem district where they used ISSOD technique seemed to be successful. If resources were reduced when an effective educational method about self-care has been found this would mean a reversal in progress made in fight against the disease.

In India the stigma connected with leprosy could involve the lack of understanding of leprosy as a contagious disease among less educated people. Stigma is passed on by older family members, who relate their beliefs to the younger generation. Integrating other leprosy sufferers into society helps to counter spontaneous public discrimination and permanent stigma (Heijnders, 2004, Arole *et al.* 2002). This was discovered in research from 2002 and 2004 and still the impression given is a lack of integrated approaches.

Van Brakel (2003) emphasizes that the word leprosy is used as a curse word in many countries, which adds to the difficulty in reducing the stigma of leprosy. Could there be reasons to come up with a slang word for the disease, maybe a word being more general like infection or loss of sensation? Perhaps that would de-dramatize the disease called leprosy. As long as stigma associated with leprosy exists there is a need for improvement of the nursing care provided in India.

There is an important relationship between nursing and education. Education and teaching patients and their relatives are a great part of a nurse's responsibilities. As pointed out by Ny, Dejin-Karlsson & Udén (2006), health education is one of the most essential factors in preventing illness. It is critical that medical staff is educated to a high standard in order to provide the appropriate tools to teach patients. Since there seems to be a lack of health education and empowerment of patients in India, one suggests that the focus lies upon education and teaching as the most important element in the combat of eradication of leprosy. The patient must be raised to a similar level as the nurse in order to sustain health and empowerment (Pilhammar Andersson, 2007). However, this is hard to achieve since there is a hierarchy among nurses and doctors making patient empowerment difficult. All patients have the right to receive information about alternative ways to achieve health and every individual suffering from ill-health should be given as much education as needed to make an informed decision regarding treatment and choices involving health (Tingström, 2009). In this way patients can combine their decisions with previous experiences and existing knowledge which in turn can lead to self-care, healing and well-being (Björvell & Insulander, 2008). However, patients throughout India do not get enough education in the nursing care provided, while there is still a high prevalence of the disease.

The nurse must be qualified, have good listening and communication skills and be sensitive to the patient's needs when selecting the appropriate method for health education (Björvell & Insulander, 2008). The nurse must plan health education carefully and consider gender and cultural differences (Pilhammar Andersson, 2007). All of these requirements need further improvement to eradicate leprosy in India. Written and verbal information is preferred for patients in the Western World, while a well adopted approach to verbal information is of more importance in India with a high number of analphabets. John, Rao & Das (2010), state that sustainable healthcare prevention and the eradication of leprosy would suggest efficient, appropriate, holistic and early treatment at affordable cost, which requires culturally acceptable care to address both physical and psychosocial problems. One wonders if there is an overall less dramatic attitude towards death and suffering in India than in the Western World. According to Lipinski, J. (personal communication, 030211, desk officer for the organisation SOIR), they believe in reincarnation and look at life as a cycle without dramatizing death.

It is very important to change the image of leprosy and to increase the focus on women (John, Rao & Das, 2010), at local, national and global levels and to create a new environment in which patients will not hesitate to come forward for diagnosis and treatment at any health facility. According to Tingström (2009), the nurse needs to acquire a full picture of the patient's existing knowledge about health. The patient should be the one in power and the one setting future goals (Björvell & Insulander, 2008). Patient-centred tailor-made nursing care is needed for these patients in order to improve their lives (Tingström, 2009). The author agrees with Pilhammar Andersson (2007), that it is important for the nurse to consider *what* is going to be taught, *how* it will be taught and *why* it is going to be taught and learnt. This would definitely suit the needs of leprosy patients and the further implementation of this approach could improve nursing care in India.

Health services have often left women and their family to keep their distress secret (John, Rao & Das, 2010). Visiting leprosy care centres far from their homes, missing appointments or seeking help through alternate medical systems is often done covertly. Caution must be taken to avoid stigmatization through poor patient-health professional interactions. In the case of women, because of their lack of autonomy or because of their financial situation, there is a greater need to offer more palpable assistance to promote early reporting, prompt and regular treatment without disturbing their domestic roles and responsibilities (John, Rao & Das, 2010). According to Cairncross *et al.* (2005), home visits work for receiving educational information. One wonders whether there could be something similar to district nurses in India. Would that make patients more internalized than compliant towards the nurse advice on treatment?

There tends to be a greater emphasis on the medical treatment of the problems in most hospitals and healthcare settings. National programmes and leprosy NGOs must give priority to culturally acceptable health education in order to promote early reporting (John, Rao & Das, 2010). Early diagnosis and treatment with MDT continue to be the key elements in eliminating the disease as a public health problem. Quality nursing care, such as the nursing care concept "education and information", provided by professionals is therefore essential.

A disfigured and decrepid appearance because of a lack of treatment over many years is a frightening sight. Centuries of prejudices about the disease being a punishment for some terrible act is difficult to eradicate. Kazen, B. (personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation)

argues that the stigma involved will decline if the disease can be diagnosed earlier than previously and if treatment started before disabilities occur. If these occur correctly with the patient becoming in different Community Based Rehabilitation programmes as well as the patient become financially independent then stigma might be lessened. It has already taken place in many parts of the world but it is a process that will take time.

While the aim of education is to obtain a different perspective or behaviour, it is important that the patient is able to process the information he is given (Tingström, 2009). Therefore, it is essential for patients to receive the opportunity to reflect, discuss and ask questions (Tingström, 2009). According to John, Rao and Das (2010), family-based counseling and meeting other patients who are in similar situations as themselves could help both to boost the confidence of leprosy sufferers and also reduce misconceptions surrounding the disease, its complications, management and to facilitate local nursing care, provided by individuals or family members. There is a particular need for health services for female patients, as nearly 60% of women delay seeking hospital care, and the majority conceals the disease (John, Rao & Das, 2010). An increase in female staff and trained women volunteers could be helpful in order to improve these factors. On the other hand, this could be challenging in a resource-poor situation, where most hospitals may be unable to offer quality care due to lack of trained staff; in particular qualified women. The time-shortage suffered by professional staff to give adequate time to each patient and listen to their problems and counsel them could disappoint the patient and fall short of his expectations (John, Rao & Das, 2010).

In addition, most health professionals either have no training or lack the time to advise on the cultural and psycho-social needs of leprosy patient (John, Rao & Das, 2010). One challenging complication with leprosy is recurrent plantar ulceration which results in long-term hospitalization. This means that high quality of nursing care is essential and the ability for the nurse to educate her patient becomes even more apparent. Women and the poor drain hospital resources due to the great expense of time and cost because of recurring leprosy-related problems such as plantar ulcers (John, Rao & Das, 2010). There is an obvious relationship between health and the socio-economic status where minorities, because of discrimination, are the worst affected. It was discovered that in urban areas of the Bargarh district, patients with leprosy-related deformities or disabilities could be referred to the orthopedic department within the hospital. But, in rural areas there was little knowledge of treatment options for patients in similar situations. Socio-economic rehabilitation which is one very important factor to support the expense of time and cost was also neglected. The LEPRO Society and some PHCs should try to inspire other healthcare employees to assist patients to apply for The Government of India (GOI) pensions for the disabled in order to improve their quality of life.

The medical staff must be well informed about leprosy in order to provide education for their patients, which in turn leads to the proper education of patients. Healthcare services are responsible for educating and encouraging people to report cases at an early stage. Informational leprosy campaigns in high risk areas are essential so that patients and their families are encouraged to come forward and receive treatment (World Health Organization, 2011). This highlights the need for quality nursing care and for healthcare providers to be observant. Healthcare workers must maintain their competencies and skills to diagnose and manage leprosy cases as well as to prevent the disease and observe the occurrence of disabilities. According to Siddiqui *et al.* (2009), urban areas may benefit from increased training in leprosy diagnosis while increased counselling at RFT was required in rural healthcare settings.

As previously mentioned in urban hospitals, in the Bargarh district in Orissa, there was a preference not to treat lesions and the employees tried to dismiss leprosy patients as quickly as possible to avoid unease amongst other patients, medical staff and leprosy patients (Siddiqui *et al.* 2009). Therefore, general knowledge among medical staff and the general public must be improved in order to provide nursing care to a professional standard. All the aforementioned contribute to an unequal healthcare situation for people with leprosy. It is urgent for these people to receive a good level of nursing care.

Improved hygiene routines in healthcare settings involving nursing care do not necessarily have to cost much. This was discovered by Florence Nightingale (1860) in the nineteenth century. Her beliefs have been proven right and her theory could still be of use in nursing care today. Her statements concerning improved hygiene and better sanitary conditions could be applicable in India today. This does not assume that medical staff has a lower standard of their cleaning routines than in other parts in their world. However, having more infectious diseases than in many other European countries, the needs for spectacular health routines are essential. Furthermore the World Health Organization (2009), argues that leprosy is highly prevalent in India. Hand hygiene among healthcare providers is the most effective element to reduce infections (Sahay *et al.* 2010), which Nightingale (1860) emphasized in the fight against the spread of infectious diseases.

Nightingale (1860) suggested frequent hand washing with soap and hot water for caregivers. Sanitation was viewed as basic and fundamental both in terms of the environment where patients were being nursed as well as for those providing the nursing care. According to, Lipinski, J. (personal communication, 030211, desk officer for the organisation SOIR), clean water is accessible in all health centres, but in limited amounts. Therefore, appropriate settings for nursing care are essential in order to attain a decent level of nursing care and the provision of clean healthy water must be maintained and further improved in many parts of India. On the contrary, having running water does not mean that the hospital is not clean. One of the cleanest hospitals Kazen, B. (personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation), has been to does not even have running water but a system of boiled water.

It could be argued that teachers need to educate pupils in school about personal hygiene, which is obviously related to health concerns. It is also relevant for people to have a good level of private knowledge as early in life as possible of basic hygiene care. In developing countries public health concerns are usually raised over the institutional setting such as hospitals. It is equally important to acknowledge the home as a setting where the spread of disease can occur. Unfortunately, low standard of housing has lead to poor home hygiene. In addition, personal and domestic hygiene practices cannot be improved without improving basic amenities such as the water supply. Most cities in developing countries suffer from over-crowding, congestion, poor quality water supplies and insufficient sewerage facilities. Growth of the population, the burden of poverty and a lack of access to safe water and sanitation all contribute to a growing burden of diseases. It could be argued that preventive and environmental health is neglected and the authorities are in favour of curative services. This has created a scenario in which the over-burdened hospital services and healthcare infrastructures are unable to cope with the burden of diseases. This puts pressure on the provision of quality healthcare, and thus leprosy is one disease that is most likely going to become affected negatively.

CONCLUSIONS AND RECOMMENDATIONS

Some of the leprosy problems still challenge current medical-technical knowledge for the prevention of or treatment of the disease and more research is needed to solve these clinical problems (John, Rao & Das, 2010). According to Horo *et al.* (2010) children are most sensitive to infection and children tend to be reported at a later stage as compared with adult reporting. This delay makes it difficult to distinguish when a child becomes infected and this provides us with a pointer for the need of better healthcare education in schools. Having health check-ups as a part of the school routines, would make it easier to prevent diseases such as leprosy. The disease disappeared in Sweden and in most of Europe before the medicine now used was invented. There are many theories for the reasons why but even more unanswered questions surrounding leprosy (Kazen, B., personal communication, 250211, member of the board for the Swedish committee of the Leprosy Mission International Organisation). In summation, more in-depth knowledge is needed and there is an urgent need to spread information to be able to eradicate the disease in India completely.

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APPENDIX

Appendix 1: Literature research, Sample

Database/Date	Search terms	Restrictions	Hits	Number used	Selection	Reference number in appendix 2.
PubMed, 230111	Prevent leprosy India		47	2	2003-2011, peer reviewed, research articles	6,16
PubMed, 270111	Nursing leprosy India	2005-2011, peer reviewed, research articles	10	3		1,2,3
PubMed, 270111	Care work leprosy India		20	1	2003-2011, peer reviewed, research articles	5
PubMed, 280111	Quality of healthcare leprosy India	2005-2011, peer reviewed, research articles	9	1		19
PubMed, 280111	Quality of healthcare leprosy	2005-2011, peer reviewed, research articles	51	2		14,15
Cinahl, 080211	Health service India	2005-2011, peer reviewed, research articles	16	1		9
PubMed, 120211	Care hygiene India		132	3	2003-2011, peer reviewed, research articles	8,20,21

PubMed, 120211	Patient self-care education India		71	1	2003-2011, peer reviewed, research articles	10
PubMed, 120211	National Health Care Programme India		120	1	2003-2011, peer reviewed, research articles	18
PubMed, 230211	Knowledge hygiene India		60	1	2003-2011	22

Appendix 2: Article overview

The reference numbers in this section is interlinked with appendix 1.

Reference number: 1

Author: John, A.S., Rao, PSSS. & Das, S.A.

Title: Assessment of needs and quality care issues of women with leprosy

Journal: Leprosy Review

Year: 2010

Country: United Kingdom

Aim: To determine the needs and quality care issues of women leprosy patients attending a hospital/health care facility.

Design: Qualitative study.

Method: 104 women were interviewed in-depth clinically assessed.

Result: Most women delayed going to hospital, until their husband/guardian felt it was necessary. It has to be improvement of quality healthcare for women.

Reference number: 2

Author: Madhavan, K., Vijayakumaran, P., Ramachandran, L., Manickam, C., Rajmohan, R., Mathew, J. & Krishnamurthy, P.

Title: Sustainable leprosy related disability care within integrated general health services: findings from Salem District India.

Journal: Leprosy Review

Year: 2007

Country: United Kingdom

Aim: To study appropriate services for people living with leprosy-related disabilities. Self-care training, guidance and monitoring by the general health staff facilitated by a non-governmental organisation leprosy centre was introduced.

Design: Quantitative study.

Method: The staff identified 1232 people with leprosy-related disabilities and trained them in self-care.

Result: The healing of plantar ulcers in 70% of people at 1-year follow up.

Reference number: 3

Author: Kar, S., Ahmad, S. & Pal, S. (2010).

Title: Current Knowledge Attitudes, and Practices of Healthcare Providers about Leprosy in Assam, India.

Journal: Journal of Global Infectious Diseases

Year: 2010

Country: USA

Aim: To understand the knowledge of, and attitudes towards, leprosy amongst healthcare providers in Assam, India.

Design: Cross-sectional study based on both quantitative and qualitative parameters.

Method: A cross-sectional study was carried out in March 2007 in different health institutions in Assam.

Result: Among the program managers interviewed, only half were organizing training sessions, and 37.5% were involved in supervision of the program activities at the periphery level. Among the program managers who were involved with leprosy elimination, only half were organizing training session and 37.5% were involved in supervision of the program activities at the periphery level. Medical Officers consistently demonstrated higher knowledge about leprosy, followed by health supervisors and multipurpose workers (MPWs), including nursing staff.

Reference number: 4

Author: Cairns, W., Smith, S., Smith, M.S., Cree, I.A, Jadhav, R.S., Macdonald, M., Edward, V.K., Oskam, L., van Beers, S. & Klaster, P.

Title: An approach to understanding the transmission of Mycobacterial leprae using molecular and immunological methods: results from the MILEP2 study.

Journal: International Journal of Leprosy and Other Mycobacterial Diseases

Year: 2004

Country: USA

Aim: To investigate the relationship between M. leprae infection and the development of immune responses in a community using MDT and to clarify the pathogenesis of primary nasal infection in leprosy.

Design: Quantitative study.

Method: Three leprosy endemic communities in India were followed up over two years using nasal swab and saliva collections.

Result: 1.6% of nasal swabs were PCR positive and 68% of saliva samples. PCR positive results were in the wet seasons.

Reference number: 5

Author: Heijnders, ML.

Title: The dynamics of stigma in leprosy

Journal: International Journal of Leprosy and Other Mycobacterial Diseases

Year: 2004

Country: USA

Aim: This paper explores the different coping strategies employed by people affected by leprosy to manage stigma in Nepal.

Design: Qualitative study.

Method: 76 in-depth interviews.

Result: Stigma is a dynamic process. Even within the same culture and even the same village, social differentiation makes a significant difference on the impact of stigma and the coping strategies employed in managing stigma.

Reference number: 6

Author: Horo, I., Rao, PSSS., Nanda, NK. & Abraham, S.

Title: Childhood leprosy: profiles from a leprosy referral hospital in West Bengal, India.

Journal: International Journal of Leprosy and Other Mycobacterial Diseases.

Year: 2010

Country: USA

Aim: Monitoring childhood leprosy in terms of incidence and occurrence of deformities are crucial for better control and understanding the transmission of the disease.

Design: Quantitative study.

Method: All new untreated leprosy patients below 15 years registered at a referral hospital in West Bengal, India were studied. Data was collected from the patient's chart and family. Diagnosis was confirmed by medicals and classified based on WHO guidelines.

Result: Of 151 children studied, 16% had already developed grade 2 disability (WHO).

Multiple nerve involvement was seen in a quarter of children. These findings highlight the seriousness of leprosy among children and the great need to address these issues urgently.

Awareness, active case detection especially among contacts and motivation are the essential needs of the hour to prevent tragedy of deformed children due to a totally manageable

Reference number: 7

Author: Barkataki, P., Kumar, S. & Rao, P.S.S.

Title: Knowledge of and attitudes to leprosy among patients and community members: a comparative study in Uttar Pradesh, India

Journal: Leprosy Review

Year: 2006

Country: United Kingdom

Aim: The roles of literacy and gender in enhancing help seeking behaviour in leprosy need further research in order to maximize the effectiveness of health education programmes. A study on leprosy knowledge and attitudes was carried out in Uttar Pradesh.

Design: Quantitative study.

Method: A random sample of 130 leprosy patients. Questionnaire was prepared, tested and administered in Hindi, the local language, by a qualified interviewer. Statistical analyses were done in each group by gender and literacy, and compared.

Result: Almost everyone knew of leprosy. A vast majority in all groups mentioned bad blood, or divine curse as the cause. Less than 10% of illiterates and only about 40% of literates cited infection as the cause of leprosy. Almost all stated that leprosy was curable, though they couldn't mention MDT specifically. They felt that not all patients need have deformity. About 20-30% of the leprosy affected stated that there was discrimination. Nearly 70% felt that

leprosy affected social participation, over 90% attributing this to adverse social stigma. Adult literacy programmes combined with more innovative focused approaches to suit various target audiences can impact knowledge and attitudes better.

Reference number: 8

Author: Bhatia, J. & Cleland, J.

Title: Healthcare of female outpatients in south-central India: comparing public and private sector provision.

Journal: Health Policy and Planning

Year: 2004

Country: United Kingdom

Aim: The object of this study was to compare components of quality of care provided to female outpatients by practitioners working in the private and public sectors in Karnataka State, India.

Design: Quantitative study.

Method: Consultations conducted by 18 private practitioners and 25 public-sector practitioners were observed for 5 days using a structured protocol. Private practitioners were selected from members of the Indian Medical Association in a predominantly rural sub-district of Kolar District. Government doctors were selected from a random sample of hospitals and health centres in three sub-districts of Mysore District. A total of 451 private-sector and 650 public-sector consultations were observed; in each sector about half involved a female practitioner.

Result: Compared with public-sector practitioners, private practitioners were significantly more likely to undertake a physical examination and to explain their diagnosis and prognosis to the patient. Both in terms of thoroughness of diagnosis and doctor-patient communication, the quality of care appear to be much higher in the private than in the public sector.

Reference number: 9

Author: De Costa, A. & Diwan, V.

Title: Where is the public health sector? Public and private sector healthcare provision in Madhya Pradesh, India.

Journal: Health Policy and Education

Year: 2007

Country: Netherlands

Aim: To demonstrate the size and composition of the private health care sector in one of India's largest provinces, Madhya Pradesh.

Design: Quantitative study.

Method: It is based on a field cross-sectional survey of all healthcare providers in Madhya Pradesh. Seventy-five percent of the population is rural and 37% live below poverty line. This survey was done as part of the development of a health management information system.

Result: 80% of these private physicians work in urban areas. The 72.1% of all qualified paramedical staff work in the private sector, mostly in rural areas. It emphasizes the need to build strong public private partnerships to ensure equitable access to healthcare for all.

Reference number: 10

Author: Ny, P., Dejin-Karlsson, E. & Udén, G.

Title: Health Education to Prevent Anemia among Women of Reproductive Age in Southern India.

Journal: Health Care for Women International

Year: 2006

Country: USA

Aim: To measure communication among health workers and women in Southern India. Prevention of anemia during pregnancy was studied.

Design: Qualitative study.

Method: A standardized interview using a semi-structural questionnaire.

Result: Those women who received health education where they lived, from health workers they knew learned more about anemia prevention than others.

Reference number: 11

Author: Jain, S., Reddy, R.G., Osmani, S.N., Lockwood, D.N.J. & Suneetha, S.

Title: Childhood leprosy in an urban clinic, Hyderabad, India: clinical presentation and the role of household contacts.

Journal: Leprosy Review

Year: 2002

Country: United Kingdom

Aim: To describe the pattern of clinical presentation, the role of household or near neighbour contacts and the incidence of neuritis and reactions.

Design: Quantitative study.

Method: Case study for children below the age of 14 years who attended Dhoolpet Leprosy Research Centre over the decade 1990-1999.

Result: A history of contacts was available in 38.8 % with family contacts in 95% and other than family in 5%. Childhood leprosy cases continue to present in significant numbers to this outpatient clinic. The high incidence of reactions and nerve damage in children stress the importance of early detection and treatment.

Reference number: 12

Author: Borg, S. & Larsson, J.

Title: Assistive devices for people affected by leprosy: Underutilised facilitators of functioning?

Journal: Leprosy Review

Year: 2009

Country: United Kingdom

Aim: To explore to what extent the potential of assistive devices to facilitate activities and participation of people affected by leprosy has been utilized.

Design: Literature review.

Method: Analyzed research articles.

Result: Considerable attention has been given to the protecting role of assistive devices. The focus of assistive devices facilitating functioning has been on mobility aspects of self-care and domestic life.

Reference number: 13**Author:** Arole, S., Premkumar, R., Arole, S., Maury, M. & Saunderson, P.**Title:** Social stigma: a comparative qualitative study of integrated and vertical care approaches to leprosy.**Journal:** Leprosy Review**Year:** 2002**Country:** United Kingdom**Aim:** This study was conducted in the state of Maharashtra, India, to compare the level of social stigma towards leprosy in communities with a vertical and an integrated programme.**Design:** Qualitative study.**Method:** The data were collected in three areas of five villages each. The data were analysed using qualitative methods. A total of 24 leprosy patients with visible deformities participated in the in-depth stigma measurement exercise from 15 villages. Fifteen focus group discussions were conducted with families of leprosy patients and an equal number of participatory rural appraisals with communities were done.**Result:** Social stigma was virtually non-existent among the communities with the integrated approach and minimally experienced by leprosy patients in this model. A high level of self-stigmatization among leprosy patients was observed in the vertical approach and equally a high level of social stigma was found in their communities, which led to reduced interaction between the leprosy patients and their communities. The integrated approach to community-based primary healthcare is effective in reducing leprosy stigma in society.**Reference number: 14****Author:** Van Brakel, W.H.**Title:** Measuring leprosy stigma – a preliminary review of the leprosy literature.**Journal:** International Journal of Leprosy and Other Mycobacterial Diseases**Year:** 2003**Country:** USA**Aim:** To measure stigma related to leprosy.**Method:** Literature review.**Design:** Literature research.**Result:** The studies reviewed indicate that leprosy stigma is still a global phenomenon, occurring in both endemic and non-endemic countries. The consequences of stigma affect individuals as well as the effectiveness of leprosy control activities. Despite enormous cultural diversity, the areas of life affected are remarkably similar. They included mobility, interpersonal relationships, marriage, employment, leisure activities, and attendance at social and religious functions. This suggests that development of a standard stigma scale for leprosy may be possible.**Reference number: 15****Author:** Pandey, A., Patel, R. & Uddin, M.J.**Title:** Leprosy control activities in India: integration into general health system.**Journal:** Leprosy Review**Year:** 2006**Country:** United Kingdom

Aim: Operational research was undertaken in low/moderate endemic provinces to assess the progress of integration of leprosy control in general health system using defined categories, viz. structural integration, training status, availability of MDT and recording/reporting of cases.

Design: Quantitative study.

Method: Selection of nine provinces, 18 districts, 86 health facilities and 108 sub-centres was performed using multistage stratified random sampling technique. Data were collected by interviewing GHS/vertical staff, scrutiny of records and spot checking of MDT stock by Health officers of three leprosy institutions of the Government of India.

Result: 45% of medical officers, 71% of health supervisors and 75% of multipurpose workers were trained in leprosy. MDT treatment was available in .80% of health facilities. In only 2% of health facilities 3 months MDT stock of all types was present. 44% of sub-centres were delivering subsequent doses (second dose onward) of MDT. Reporting through a simplified information system was universal. This study emphasizes the need for reorientation training of Medical Officers, better MDT stock management and decentralized management of cases up to sub-centre level.

Reference number: 16

Author: Chakraborty, A., Mahato, M. & Rao, P.S.S.S.

Title: Self-care programme to prevent leprosy-related problems in a leprosy colony in Champa, Chattisgarh.

Journal: Indian Journal of Leprosy

Year: 2006

Country: India

Aim: Prevent leprosy-related physical disabilities in Champa, Chattisgarh, India.

Design: Quantitative study.

Method: A self-care programme was carried out in a Prem Nagar Leprosy Colony with a population of 1472.

Result: The outcome at the end of one year showed significant decline (41%) in ulcer rates, significant use of MCR footwear (43%), and significant proportion (over 90%) of patients and their families practising and helping in self-care activities.

Reference number: 17

Author: Porter, J.D.H., Ogden, J.A., Rao Ranganadha, P.V., Rao Prabhakar, V., Rajesh, D., Buskade, R.A. & Soutar, D.

Title: Lessons in integration-operations research in an Indian leprosy NGO.

Journal: Leprosy Review

Year: 2002

Country: United Kingdom

Aim: Since 1978, health systems supporting the treatment and control of infectious diseases have been encouraged to 'integrate' into the primary healthcare structure within countries. Countries are still looking for ways to achieve it. This study reports findings from a leprosy/Tuberculosis/AIDS awareness pilot project conducted by LEPRO India, a leprosy non-governmental organization (NGO), between 1996 and 2000 in Koraput district, Orissa. The project addressed the issue of integration.

Design: Qualitative study.

Method: Following a 'qualitative approach', this operations research project assessed the perceptions of communities and providers about leprosy and tuberculosis services. Providers

across the spectrum of this plural healthcare system were asked to provide comment on developing stronger networks with each other, with NGOs and with government, while patients and communities were asked to describe the resources available to them and the constraints they face in accessing healthcare in general, and for leprosy and TB in particular. LEpra staff was also approached for their views.

Result: Physical access to treatment was a major constraint, while the existence of local providers and family support structures facilitated health and healthcare. Providers expressed a willingness to collaborate (with LEpra and the government), but lacked training, adequate staff support and the appropriate equipment/technical resources. Also lacking were adequate information campaigns to inform the public about these diseases and their treatment.

Reference number: 18

Author: Shah, P., Misra, A., Gupta, N., Hazra, DK, Gupta, R., Seth, P., Agarwal, A., Gupta, AK., Jain, A., Kulshreshta, A., Hazra, N., Khanna, P., Gangwar, PK., Bansal, S., Tallikoti, P., Mohan, I., Bhargava, R., Sharma, R., Gulati, S., Bharadwaj, S., Pandey, RM. And Goel, K.

Title: Improvement in nutrition-related knowledge and behaviour of urban Asian Indian school children: findings from the 'Medical education for children/Adolescents for Realistic prevention of obesity and diabetes and for healthy ageing' (MARG) intervention study.

Journal: British Journal of Nutrition

Year: 2010

Country: The United Kingdom

Aim: The aim was to evaluate the impact of a school-based health and nutritional education programme on knowledge and behaviour of urban Asian Indian school children.

Design: Quantitative study.

Method: We educated 40 196 children (aged 8-18 years), 25 000 parents and 1500 teachers about health, nutrition, physical activity, non-communicable diseases and healthy cooking practices in three cities of North India. A pre-tested questionnaire was used to assess randomly selected 3128 children, 2241 parents and 841 teachers before intervention and 2329 children after intervention.

Result: Major gaps exist in health and nutrition-related knowledge and behaviour of urban Asian Indian children, parents and teachers. This successful and comprehensive educative intervention could be incorporated in future school-based health and nutritional education programmes.

Reference number: 19

Author: Siddiqui, R.S., Velidi, N.R., Pati, S., Rath, N., Kanungo, K.A., Bhanjadeo, K.A., Rao, B.B., Ojha, B.M., Moorthy, K.K., Soutar, D., Porter, J.DH. & Rao, P, V.R

Title: Integration of Leprosy Elimination into Primary Health Care in Orissa, India

Journal: Plos one

Year: 2009

Country: USA

Aim: To aid busy PHC staff, compromised their leprosy knowledge and management capacity.

Method: A qualitative analysis of issues and perceptions of patients and providers, and a review of leprosy records and registers to evaluate programme performance were carried out in the state of Orissa, India.

Design: Qualitative study.

Result: This study highlights the need for effective monitoring and evaluation of the integration process. Inadequate monitoring could lead to a reduction in early diagnosis, a delay

in initiation of MDT and an increase in disability rates. This in turn could reverse some of the programme's achievements.

Reference number: 20

Author: Deb, S., Dutta, S, Dasgupta, A. & Misra, R.

Title: Relationship of personal hygiene with nutrition and morbidity profile: a study among primary school children in South Kolkata.

Journal: Indian Journal of Community Medicine

Year: 2010

Country: India

Aim: Majority of the health problems affecting school children are preventable by promotion of hygienic practices through proper health education by the teachers, who are the first contacts. The study was undertaken to find out the status of nutrition and personal hygiene among primary school children and their association with their varied morbidity profiles.

Method: A descriptive, observational, cross-sectional study was conducted in a primary school situated in the largest slum of Kolkata.

Design: Quantitative study.

Result: The participants included 103 boys and 81 girls, with a mean age of 6.2 years. The mean personal hygiene score of the girls was significantly higher than that of boys. Most of the boys (54.37%) and girls (74.07%) were normally nourished. Over 70% of the children were suffering from one or more morbidities, the most common morbidity in both the sexes being pallor, followed by worm infestation. Personal hygiene scores were significantly higher among those children who were normally nourished as well as those who did not suffer from any morbidity in the last 15 days.

Reference number: 21

Author: Sahay, S., Panja, S., Ray, S. & Rao, B.K.

Title: Diurnal variation in hand hygiene compliance in a tertiary level multidisciplinary intensive care unit.

Journal: American Journal of Infection Control

Year: 2010

Country: USA

Aim: The objective was to determine the compliance with hand hygiene guidelines among doctors, nurses, and paramedical staff during day and night duties in a multidisciplinary intensive care unit (ICU).

Method: A prospective, observational, 6-month study conducted in a 34-bed ICU within a tertiary care teaching hospital. All doctors, nurses, and paramedical staff in the ICU were included. An investigator, placed within the ICU setting, observed the hand hygiene practices during day and night. Day and night shift change times were 08:00 and 20:00 hours, respectively.

Design: Quantitative study.

Result: Of the opportunities for hand hygiene 59.9% were properly performed. Overall rates of compliance were 66.1% for doctors, 60.7% for nurses, and 38.6% for paramedical staff. Hand hygiene compliance dropped during the night for doctors (81% vs 46%, respectively), for nurses (64% vs 55%, respectively), and for paramedical staff (44% vs 31%, respectively). "No hand washing after procedure" in 41%, "improper duration of hand washing" in 32%, and "no hand washing done at all" in 27% of the events. "No handwashing done at all" occurred in 55%

of the time at night with doctors having the highest rate of noncompliance, making 163 (34%) contacts without handwashing.

Reference number: 22

Author: Cairncross, S., Shordt, K., Zacharia, S. & Kumari Govindan, B.

Title: What causes sustainable changes in hygiene behaviour? A cross-sectional study from Kerala, India.

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Aim: This study was designed and the field work carried out by a non-governmental organisation (NGO) responsible for implementing hygiene promotion. The sustainability of changed hygiene behaviour was studied at various periods up to nine years after the conclusion of a multifaceted hygiene promotion intervention in Kerala, India.

Method: Various methods including a questionnaire to assess knowledge, spot observation, demonstration of skills on request, and household pocket voting were used and compared for the measurement of the hygiene outcome. Pocket voting gave the lowest prevalence of good practice, which we infer to be the more accurate.

Design: Quantitative study.

Result: The evidence for a specific impact on behaviour from home visits and an awareness campaign is less strong, although the home visits had influenced knowledge. The interventions on men may have been indirect, via women or neighbours, underlining the need to direct interventions at men as well as women. The finding that hygiene behaviour persisted for years implies that hygiene promotion is a more cost-effective health intervention than previously supposed.

Appendix 3: Summary and analysis of the in-depth interview with Janusz Lipinski 030211

Summary:

It is difficult to find information about how to work preventatively with leprosy whilst the contagion is still uncertain. It can take between 10 to 20 years before the disease breaks out, which makes it difficult to distinguish the reason for infection. It is a problem to get people to seek nursing care if they are suspicious of infection. India still in denies about having the disease. It is difficult to get people to have check-ups, since it is traumatic to be marked as a carrier and to risk exclusions in the society. About 90% of human beings are immune from the disease and the treatment of leprosy is much simpler today. People are offered medicine from governmental institutions in both India and Nepal.

Leprosy could be prevented through raised awareness surrounding the curability of the disease and if help is sought in time no complications would occur. Preventative interventions and support for health centers contribute to better health status. Even though leprosy is easy to detect and treat, many millions of people are suffering of leprosy in India. The stubborn stigmatizations of leprosy sufferers prevent people from seeking treatment in time. The stigma has to do with lack of knowledge. On top of that, there are some people with the disease having terrible living conditions, which scares people. People are afraid of the risks of others in the community to finding out about their diagnosis. Confidentially does not exist in the same way as in Sweden for example.

Lipinski has seen many projects involving health run by NGOs. SOIR works with leprosy affected people on many levels with different projects and cooperation partners. SOIR is battling against leprosy and tuberculosis through sharing information and offering treatment in many parts of India. They support partner organisations work for rehabilitation and integration into society of leprosy patients with deformities and disabilities. SOIRs partners examine people and look for those affected but they have had to use fake names for their campaigns otherwise people would not attend. Many hand-crafted goods offered for sale by SOIR originate from these programmes. Through providing health education in communities, training local staff, setting up specialist referral services and refurbishing hospitals and surgeries, LEPRAs, a partner to SOIR, is working alongside vulnerable communities to empower people in terms of their health.

People tend to go to pharmacies, available on almost all street corners, when suffering from moderate disorders. People only visit public institutions that are responsible for basic health care, when their condition is more severe or life-threatening. The cost of health care is often the reason for not seeking care. The rich people tend to get first class health care in private facilities while poor people either attend public clinics or seek no treatment at all. Access to health care is very limited in rural areas. The inhabitants do not in general apply for healthcare as we do in Sweden. Many people die at home from curable diseases. They believe in reincarnation and look at it as a cycle without dramatizing death.

The rehabilitation centers, supported by SOIR, have got rather decent hygiene and sanitation conditions. Clean water is accessible in all of the centers, but in limited amounts. However,

these conditions would never be accepted in Sweden. There is still very hierarchical system in India with the doctors doing most of the work and while the nurses assist them or do tasks as ordered by the doctor. The pace of work in India (as in other Asian countries) is more relaxed and less stressful compared with the Western World. This might contribute to less efficient nursing care which may affect the welfare of the patients. However, most patients have got relatives with them whilst at hospital, which may relieve the burden on the employees.

Lipinski has the impression that hygiene education is not a part of school education. However, people in India are in general very clean, but the lack of a decent water supply causes problems. Information is provided but only when there is an epidemic outburst or something similar. Three hundred million of people in India live on US\$2 a day. This affects living conditions and health in a negative way. About 20% of children denied the chance to go to school live in India. According to UN 2002, more than one in three children in the cities suffering from malnutrition.

Qualitative content analysis:

The in depth interview came up with similar categories as the literature research; existing nursing and health care to prevent leprosy, challenges and suggestions of improvement involving education and hygiene conditions. The useful parts are a part of the result.

Appendix 4: Summary and analysis of the in-depth interview with Birgitta Kazen, 250211

Summary:

Kazen has together with her husband, who was a leprosy surgeon, been engaging in leprosy care work from January 1976 to the end of 2002. The first 14 years took place at the Masanga Leprosy Hospital in Sierra Leone and the rest of the time was spent at the All Africa Leprosy and Rehabilitation Training Centre (ALERT) in Addis Ababa in Ethiopia. The latter is a big international education and research center. They spent 6 months in an educational hospital in Karigiri outside Vellore in India in 1978. The nursing care provided was of a very high standard and many social care workers were involved in the hospital.

They were not employed by the Leprosy Mission International Organisation, but worked with employees from the organisation and from many different leprosy organisations. Kazen is a member of the board for the Swedish committee of the Leprosy Mission International Organisation since 2003. She is a high school teacher in literature and history. She worked with social rehabilitation of people who had been leprosy patients at the hospital in Sierra Leone. She was also responsible for a vocational school for young patients with leprosy as well as an orphan. Kazen was a coordinator for the hospitals international courses for doctors and physiotherapists in Ethiopia. Her experiences from India are more limited. However, leprosy is an international problem with similar challenges discussed on courses and congresses she has attended.

Kazen has worked together with many NGOs, some running general healthcare and medical healthcare as well as leprosy care. NGOs tend to have financial support from international organisations. Some of them have an international workforce. The NGOs Kazen has been in touch with have worked with education for the domestic staff. The standard of the health centres/hospitals run by NGOs have often been very high. One of the cleanest hospitals she has been to did not even have running water. They had people employed specifically delivering barrels of boiled water. NGOs with their international contacts tend to be better at obtaining health care material such as disposal gloves. The creativity and improvising often have a greater meaning than disposal material.

It is not just leprosy patients who get cared for in leprosy clinics and leprosy hospitals, other patients are accepted too. There is a reversed integration. There might not be any other options for those living in a politically unstable area.

In many countries leprosy has been viewed as a disease for poor people. Kazen does not think the quality of health care differs between urban and rural areas. Kazen has been to a private hospital in India that had smaller rooms than hospitals catered for poor people. This was in 1978 but back then the quality of healthcare did not have any differences. Care of leprosy patients used to take place outside the cities where the patients could be isolated. The nursing care should be free of charge for leprosy patients as well as the medicine. Social class, age or sex should not make any difference. The possibilities to get rehabilitative surgery and social and economical rehabilitation could differ depending on access and resources.

Doctors, psychotherapists and nurses working with leprosy related nursing care tend to be people with a non-profit making attitude towards their work. There is no profit or economical

benefit for working with leprosy and it is often demanding. Untrained staff often comes from the immediate surroundings. Often, one also finds in them a positive outlook.

Leprosy could cause the loss of sensation in hands and feet, which could contribute to damage to these parts of the body. The ulcers are often neglected leading to infections with severe consequences. Education of self-care to look after ulcers is therefore necessary and a good start to combat further harm to the patient.

The stigmatization surrounding leprosy is grounded in fear and ignorance. A disfigured and decrepit appearance because of lack of treatment over many years is scary. Centuries of prejudice of the disease as a punishment for some terrible act are difficult to eradicate. Kazen reckons that the stigma involved will decline while the disease can be diagnosed earlier than previously and treatment can start before disabilities occur at the same time the patients get involved in different Community Based Rehabilitation program and get the opportunity to get economically independent. It has already taken place in many parts of the world but it is a process and will take time.

Kazen believes it is hard to estimate whether people dislike getting examined. She has met people who are trying to hide suspected patches on their body. Because of the stigma from family and society that still takes place, people are afraid to have the verdict: leprosy! The shame inherent in the disease is feared. Leprosy usually affects poor people but the reason is unknown. Still, there is only a small number of the poor and malnourished people in the world contracting leprosy. The disease disappeared in Sweden and in most of Europe before medicine was invented. There are many theories for this but even more unanswered questions about leprosy.

The stigmatization of leprosy could be prevented by increased knowledge about the disease and active case detection in order to find people affected in at an early stage. The available resources for combating leprosy are in decline, which is a cause for concern.

Qualitative content analysis:

The in-depth interview came up with similar categories as the literature research; existing nursing and health care to prevent leprosy, challenges and suggestions of improvement involving education and hygiene conditions. The useful parts are a part of the result.

Appendix 5: Abbreviations

ALERT	All Africa Leprosy and Rehabilitation Training Centre
ANM	Assistant Nurse Midwife
CHC	Community Health Centers
CRPD	Convention on the Rights of Persons with Disabilities
DTST	The District Technical Support Team
GHS	General Health Service
GOI	The Government of India
IEC	Education and communication
ILEP	International Federation of Anti-Leprosy Associations
ISSOD	Inspection, soaking, scraping, oiling and dressing
KORALEP	The Koraput Leprosy Eradication Project
MDT	Multidrug Therapy
MO	Medical Officers
MPHW	Multi Purpose Health Worker
NLCP	National Leprosy Control Programme
NLEP	National Leprosy Elimination Programme
NGO	Non Governmental Organisation
PE	Patient Empowerment
PHC	Primary Health Centers
PMW	Paramedical Workers
POD	Prevention of Disability
RFT	Previously released from treatment
SC	Sub Centres
SOIR	The Swedish Organisation for Individual Relief

