'Worlds apart':

Patients' and nurses' perspectives of factors that impact on nursing care of patients with pulmonary tuberculosis in Australia and Malawi

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Statement of authorship

This thesis contains no material published elsewhere or extracted in whole or in part from a

thesis by which I have qualified for or been awarded another degree or diploma.

No parts of this thesis have been submitted towards the award of any other degree or diploma

in any other tertiary institution.

No other person's work has been used without due acknowledgment in the main text of the

thesis.

All research procedures reported in the thesis received the approval of the relevant Ethics

Committee (where required) or a relevant safety committee if the matter is referred to such a

committee.

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Statement of appreciation

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Dedication

This thesis is dedicated to the memories of my late father Chatonga S.J. Dulanya, who emphasised the importance of education and in whose honour I chose this career; to my late sibling Amos, I wish I could have helped prevent your untimely death; to my late sibling Kennieth, who succumbed to TB/HIV and challenged me to inquire further and proceed with this project; to my lovable and loving mother and siblings who, though at a distance, have always been by my side.

Abstract

Tuberculosis (TB) is a major public health threat, which is affecting a third of the world's population and is reportedly the second most common illness causing death worldwide, secondary to HIV/AIDS. The developing world is mostly vulnerable, with factors like poverty, malnutrition, overcrowding, poor access to healthcare services, impact of HIV/AIDS and limited or lack of diagnostic facilities and trained healthcare personnel — all compounding the extent of this global epidemiology.

This research was an exploratory enquiry on patients' and nurses' perceptions of factors that impact on TB care in Australia and Malawi. The main aim of this research was to investigate the factors that enhance and/or impinge on the provision of nursing care to TB patients from the perspectives of patients and nurses. A secondary aim was to develop a model of TB care to improve patients' outcomes.

This research design was cross-sectional utilising a mixed methods approach. The conceptual framework was primary health care. The methodological framework was critical paradigm. There were five methods, one quantitative and four qualitative. The largest research method was survey questionnaire. The qualitative methods were open-ended survey questionnaire comments, interviews, field notes/reflective journaling and photography.

Patient data was collected from 44 participants in Australia and a further 150 in Malawi. Nurses' data was collected from 26 participants in Australia and a further 20 in Malawi. Convenient sampling was applied. Descriptive and inferential statistics including multivariable logistic regression models were constructed to assess predictors of dissatisfaction from patients.

The overall quantitative and qualitative results indicated that patients and nurses were dissatisfied with TB care in Australia and Malawi. Dissatisfaction was predominant throughout all components of care: healthcare systems, patients and nurses. Dissatisfaction has 4 embedded components: insensitivity and judgmental attitudes, inadequate resources, lack of knowledge and experience and nurses are 'victims'. The results also revealed a second minor theme of satisfaction experienced by a minority of patients and nurses, primarily in Malawi.

The quantitative results revealed there were no statistical significant differences in the demographic characteristics of Australian and Malawian patients. Multivariable logistic regression analysis controlled for covariates such as age, gender, marital status, employment status, being inpatient or outpatient, physical and mental wellbeing. Being inpatient and altered physical and mental health were the major variables that predicted dissatisfaction. Again, there were no statistical significant differences between the Australian and Malawian nurses in terms of their demographic characteristics. The level of education, qualifications, specialty of practice, duration of practice and infection control practices showed statistical significant differences.

Based on the results and recommendations to improve care, a TB model of nursing care was developed. The model incorporates primary health care and health promotion principles. The model aims to give a voice to patients and change the status quo of this 'marginalised' group. It will therefore assist healthcare professionals to improve the health of TB patients.

Research outputs, awards and scholarships

Publications

¹Dulanya, J., Campbell, M., & Leigh, M. C. (2007). Trying to make a difference: The Malawian experience of a Tuberculosis (TB) nurse specialist. *Contemporary Nurse*, *24*(1), 93-102.

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- **Dulanya, J.** (2008). *Comparing and contrasting TB research findings in Australia and Malawi.*Australia and New Zealand Council of Deans of Nursing and Midwifery Annual Conference, La Trobe University, Melbourne, Australia. October, 17-18.
- **Dulanya, J.** (2006). *Preliminary results: Factors that impact on nursing management of Tuberculosis (TB) management in Australia and Malawi*. Victorian and Tasmania Deans of Nursing and Midwifery Conference. The University of Melbourne, Melbourne, Australia. September, 18-19.

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- **Dulanya, J.** (2005). *Elvie Anderson Benefactor Bursary*. Australian Federation of University Women.
- **Mukasa, J.** (2012). Faculty of Health Sciences Scholarship Scheme (FHSSS) Scholarship, Australian Catholic University, Melbourne, Australia.

¹ Jean Dulanya is the maiden name of Jean Mukasa

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List of acronyms

AACN American Association College of Nursing

ABS Australian Bureau of Statistics

ACDON Australian Council of the Deans of Nursing

ACU Australian Catholic University

ADL Activities of daily living

AFR African Region

AHPRA Australian Health and Practitioner Regulatory Agency

AIDS Acquired Immune Deficiency Syndrome

AIHW Australian Institute of Health and Welfare

AIN Australian Institute of Health and Welfare

ANA American Nurses' Association

ANMC Australian Nursing and Midwifery Council

ASCM Advocacy, Communication and Social Mobilisation

BCG Bacille Calmette Guerin

BTS British Thoracic Society

CDC Centre for Disease Control

CXR Chest XRay

DFAT Department of Foreign Affairs and Trade

DHEOs District Health Educational Officers

DHS Department of Human Services

DMOs District Medical Officers

DOTS Direct Observation Therapies

DTO District TB Officer

EUR European Region

EEUR Eastern Europe Region

HA Hospital A

HB Hospital B

HC Hospital C

HD Hospital D

HE Hospital E

HS Human Services

HIV Human Immunodeficiency Virus

IDU Infectious Diseases Units

IELTS International English Language Testing System Score

KCH Kamuzu Central Hospital

MACRO Malawi AIDS Counseling Resource Organisation

MCH Mzuzu Central Hospital

MDPC Ministry of Development, Planning and Cooperation

MDRTB Multi-Drug Resistant TB

MOH Ministry of Health

MSCE Malawi School Certificate of Education

NESB Non-English Speaking Backgrounds

NOK Next of Kin

NRAS National Registration and Accreditation Scheme

NRHSC National Research Health Sciences Committee

NTBAC National Tuberculosis Advisory Committee

NTCC National Tuberculosis Curriculum Consortium

NTCP National TB Control Program

NUM Nurse Unit Manager

PCA Personal Care Assistant

PDS Patient Dependent System

PPD Purified Protein Derivative

PPE Personal Protective Equipment

QECH Queen Elizabeth Central Hospital

QFTG QuantiFERON TB Gold Test

RN1 Division 1 Registered Nurse

RCNA Royal College of Nursing Australia

SAT Self Administration Therapies

SEAR South East Asian Regions

SPSS Statistical Package for Social Science

TB Tuberculosis

TEFL Test of English as a Foreign Language

TST Tuberculin Skin Test

TV Television

UK The United Kingdom

UN United Nations

USA United States of America

USAID United States Agency International Development

VCE Victorian Certificate of Education

VET Vocational Education and Training

WHO World Health Organisation

WPR West Pacific Region

XDRTB Extensive Drug Resistant TB

ZCH Zomba Central Hospital

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CHAPTER ONE: STUDY OVERVIEW

1.1 Introduction

This introductory chapter provides an outline to the research on the impact of factors influencing nursing care of TB patients from the perspectives of patients and nurses. The study, conducted in two countries: Australia and Malawi, represents two different worlds – the developed and the developing.

This introductory chapter will address the scope of the study and personal motivations for the study to be conducted. An overview of TB is put forth followed by an outline of each country where the research took place, highlighting socio-cultural and religious influences, health care systems and approaches to nursing education. The significance of the research, research aims and questions complete the chapter.

1.2 The scope of the study

This research study investigates the factors that influence the care of TB from the perspectives of patients and nurses within two contrasting countries. This cross-sectional mixed methods study, framed in critical paradigm, was guided by the principles of primary health care (PHC), health promotion and Millennium Development Goals (MDGs). This research compared and contrasted factors identified as integral in the provision of care to TB patients and recommends practice changes in care.

1.3 The Researcher: Personal motivations for the study

The project emerged from my work in an Infectious Diseases Unit of a large metropolitan hospital in Melbourne, Australia where I was employed as a Division 1 Registered Nurse (RN1) from 1997 to 2009. During this time, the Nurse Unit Manager (NUM) and I discussed the problems associated with the care of TB patients, particularly how the patients cope with their illness while hospitalised and especially during the period of respiratory isolation.

With personal observation over time, I noticed that TB patients appeared to be isolated in many ways. Some observations were based on how staff would approach patients who were placed in

respiratory isolation. I noted that some catering staff would not enter the patients' rooms to deliver meals and some rooms would not be cleaned daily. Some nurses would only go into TB patients' rooms to administer medications and obtain vital signs therefore there was limited time spent with the patients. As a result of these issues of concern, I took an interest in investigating how these circumstances were affecting patients. The majority of these patients were from non-English speaking backgrounds (NESB), therefore, they were not only physically isolated, they were also isolated by language, culture, emotions and stereotypes associated with the illness.

I was particularly interested in investigating how isolation affected patients' wellbeing and recovery from TB. Together the Nurse Unit Manager (NUM) and I applied for funding to conduct a research project in this area. However, overall funding was limited and this project was not funded. Notwithstanding this, I decided to take on the project as a personal endeavour and enrol in a PhD. A year later, my brother succumbed to TB and this experience confirmed my personal drive to pursue the study. As the study developed, I realised the topic of isolation might limit my exploration of TB care as the literature confirmed there are many influences that could determine care provision of TB patients. As such, the topic evolved to what it is today — investigating and understanding patients' and nurses' perceptions of factors that impact on nursing care of TB patients. As the project is investigated in a critical paradigm, the study also addresses the social world and context for both patients and nurses. The extent to which nurses contribute to the wellbeing of TB patients in different cultural and healthcare settings based on the perspectives of patients and nurses is intentionally explored in order to improve future care.

With regards to location of the study, there were several factors that I took into consideration. Firstly, I had accessibility to conduct this research in both Australia and Malawi. I am a native of Malawi and studied primary and Ordinary (O) level of secondary schooling in that country. I therefore have background knowledge of the cultural norms and societal expectations of the country. Secondly, I am a naturalised Australian citizen. I completed Advanced (A) level secondary schooling as well as university undergraduate and postgraduate education in

Australia. As in Malawi, I am conversant with Australian culture, norms and expectations within society.

While Malawi is a developing country with limited resources, the success rate in the treatment of TB compared to other African countries has been exemplary. It has been claimed that 90% of TB cases were successfully treated in the 1970s (Salaniponi, 2002). However, Salaniponi reported, "from 1989, we saw those excellent results were eroded by the advent of HIV" (2002, p.1), as TB became a common secondary infection for people affected with HIV/AIDS. Nevertheless, the success rate at 69% was still deemed strong in that part of Africa. I was therefore motivated to investigate how the country achieved the success rate despite the poor outlook for both HIV and TB. Comparatively, in later presentation, it has been highlighted that the incidence of TB in Australia has been relatively low over the last decade. Again, I was inquisitive to find out how the country maintained these trends. Overall, it was decided that these two countries, Australia and Malawi, the developed and the developing, would be benchmarks and draw lessons from each other.

1.4 Incidence of TB in developed and developing countries

For centuries, humankind has been afflicted by many diseases, which have claimed millions of lives. While TB is preventable it is a highly infectious disease that has afflicted men, women and children throughout the generations. TB was first known in the times of Hippocrates as Phthisis or consumption, meaning "wasting away" (Beddie, 2001, p.51; Cramer, 2003). It was not until 1839 that the term Tuberculosis was first coined. Hippocrates (446-370BC) argued, "the spitting of pus follows the spitting of blood, consumption follows the spitting, and death follows consumption" (Lillington & Lowie, 2001, p.17). Hippocrates' theory still gives voice to the current understanding of the transmission of TB.

Historically, TB has been associated with economic hardship, urbanisation and other socioeconomic factors (Hanson, 2002) therefore the prevalence of TB is disproportionally higher in the developing world and among disadvantaged minorities within countries. Singh et al. (2002), discussing India, stated that the majority of patients are the 'poorest of the poor' and

their income is below the national average poverty level. The spread of TB is dominated by poverty and the inter-related factor of low calorie intake therefore both problems are responsible for an increasing number of patients being diagnosed with TB. Most patients are employed in highly manual occupations, requiring intense physical labour. It has been reported that in Malawi, people on low-incomes cannot afford the required minimum calories to stay fit to fight TB (van Lettow et al., 2005). "Malnutrition predisposes the development of clinical disease and Tuberculosis often exacerbates malnutrition" (van Lettow et al., 2005, p.211). Therefore, poverty and overcrowding associated with urbanisation, malnutrition and poor hygiene such as careless 'spitting', exposes one to the illness and endorses the likelihood of one being in the high-risk bracket of acquirig TB as well as its potential co-morbidities.

The nature of TB patients who present to TB facilities across the world is varied. Institutionalised residents of prisons or nursing homes, homeless people, users of illicit intravenous and other drugs, especially those associated with HIV infection, compounded by impoverished populations with limited access to medical services, have a high incidence of tuberculosis infection (Getahun, Gunneberg, Granich, & Nunn, 2010).

Overall in Australia, the risk of TB is minimal, however, it remains slightly higher in Aboriginal and Torres Strait Islander populations (Konstantinos, 2010). The majority of patients diagnosed with TB in Australia have originated from high-burden TB countries within the Western Pacific and South East Asian regions (Lumb et al., 2008; Lumb et al., 2011). Most of these areas are disadvantaged, are poverty stricken and have limited access to medical care. These issues characterise the Malawian population. The impact of HIV and its effects on the prevalence of TB in Malawi cannot be understated (World Health Organisation [WHO], 2006; Chimzizi & Harries, 2007). It remains a significant public health problem.

In 1993 the World Health Organisation (WHO) declared TB an emergency. In August 2005, the WHO stated that the TB epidemic in Africa was a regional emergency. TB had infected a third of the world's population with most new cases occurring in the developing countries (Chemtob, Laventnal & Water-Ravell, 2003; Boutayeb, 2006). According to the WHO (2011), there were 8.8 million new cases of TB in 2010, approximately 1.5 million deaths from the disease. It is stated

that from 2006, the number of TB cases as well as mortality rates have been falling in all regions, except in Africa (WHO, 2011). These figures highlight the burden of disease affecting individuals, families and many communities. TB is most prevalent in Sub-Saharan Africa, an area which includes Malawi, and is claimed to be the major cause of morbidity, disability and death (Bowie, 2006; World Health Organisation (WHO), 2009).

The Director General of the WHO alleged "a disease that many of us believed would disappear in our lifetime is killing more people today than at any time in our history" (Brundtland, 1998, p.1). While this was stated over a decade ago, it still remains highly relevant today. While TB cases have been increasing in other parts of the world, the trend has highlighted that the incidence in other countries is decreasing. Table 1.1 below provides an overview of the prevalence of TB over the preceding eight years. The table represents a selection of developed and developing countries to contrast its prevalence in these respective countries. The first four countries represent the developed world, the other six represent the developing world. It is evident that, globally, the incidence of TB is declining. This table emphasises the low incidence of TB in Australia over the last decade. Similarly, two other developed nations, the United States of America (USA) and the United Kingdom (UK) indicate less incidence of TB. While the UK highlights that TB incidence was higher than Australia and USA, it nevertheless is marginally lower than the African countries that are outlined. In contrast, while South Africa is considered a developed country (UN, 2010), it has had a continual increase in TB rates over the last decade.

Conversely, Malawi has a much higher incidence of TB than Australia. However, this data indicates that the prevalence has been declining over the last decade as it has been in the surrounding countries; Zambia and Tanzania. While this is the case, it is argued that few countries in Africa have accurate and vital registration systems. Most systems are not more than 50% complete, therefore it is impossible to accurately map the data. It is also argued that most of these data do not reflect the HIV/AIDS epidemic (Jamison et al., 2006). In addition, it is speculated that no country has ever surveyed TB incidence nationally due to logistic and financial constraints, therefore, no direct measurement of the incidence of TB is available (Glaziou et al., 2011).

Table 1.1: Incidence of TB per 100,000 people

GEOGRAPHICAL LOCATION					YEARS				
	2002	2003	2004	2005	2006	2007	2008	2009	2010
Global	141.0	141.0	140.0	139.0	137.0	135.0	133.0	130.0	128.0
Australia	6.0	5.9	6.0	6.0	6.1	6.2	6.2	6.3	6.3
UK	12.0	13.0	14.0	15.0	15.0	14.0	13.0	13.0	13.0
USA	6.1	5.8	5.7	5.5	5.3	5.1	4.8	4.4	4.1
South Africa	780.0	852.0	898.0	925.0	940.0	948.0	960.0	971.0	981.0
Malawi	422.0	401.0	378.0	354.0	328.0	301.0	273.0	243.0	219.0
Mozambique	515.0	518.0	520.0	524.0	527.0	531.0	535.0	539.0	544.0
Swaziland	1000.0	1072.0	1120.0	1147.0	1171.0	1198.0	1227.0	1257.0	1287.0
Tanzania	239.0	235.0	225.0	213.0	200.0	192.0	190.0	183.0	177.0
Zambia	645.0	617.0	591.0	566.0	543.0	521.0	500.0	482.0	462.0

Contrasting the Malawian trend are the other developing countries, Mozambique and Swaziland, which portray the prevalence of TB is increasing. Overall, it is acknowledged that TB incidence is much higher in the developing world and particularly in the Sub-Saharan Africa. Similarly, the prevalence of HIV/AIDS in this part of Africa in 2009 was at 5% for the 15-49 year-old population, which was the highest in the world, contrasting to 1% worldwide. Accordingly, life expectancy in 2009 for this region was at 54 years of age, being the lowest in the world compared to 69 years globally (World Bank, 2011). These health trends deduce that the burden of TB disease in Sub-Saharan Africa as a major public health problem cannot be underestimated and neglected. As stipulated earlier, most TB cases arise from the developing countries. According to the WHO, India, China, Bangladesh and the Philippines were responsible for over 50% of cases reported (WHO, 2007). The WHO reported that the global TB incidence continues to rise by 1% per year (WHO, 2007). In some regions, such as the United States of America (USA), it is argued that TB treatment is neither a priority nor a concern because the disease is quite rare. In 2006, there were only 13,767 cases reported, 56.7% of these being foreign-born (Fisher Wilson, 2009). While the WHO affirmed there are stable or falling rates in other WHO

regions (WHO regions being South East Asian Regions [SEAR], West Pacific Region [WPR], Eastern Europe Region [EUR], American Region [AMR], European Region [EUR] and the African Region [AFR]); it endorsed that the rising incidence in Africa alone is enough to offset this trend (WHO Report, 2006). In Sub-Saharan Africa, there continues to be an upsurge of TB, mainly because of co-infection with Human Immunodeficiency Virus (HIV). This has placed an immense burden on efforts to control TB. Statistics have confirmed that 29% of TB in Africa is attributable to HIV/AIDS (WHO, 2006) and TB is the leading disease causing death for people living with HIV/AIDS.

Other regions with increased incidence and case-loads are Eastern Mediterranean and South-East Asian Regions (Roche, Krause, Kostantinos & Bastian, 2008). The United Kingdom (UK) also reported a high incidence of TB, with an estimated 8,000 new cases per year (Health Protection Agency, 2007). This burden not only impacts on those afflicted by the illness, it also affects their families, communities and society as a whole. Laxminarayan et al. (2007), argued that the greatest burden of TB rests with productive adults who, once infected, are weakened and are unable to work. Arguably, apart from work and productivity, the physical, social, psychological and emotional costs associated with TB treatment are insurmountable.

1.5 Incidence of TB in Australia and Malawi

1.5.1 Australia

During colonisation, the mortality rate among Anglo-Saxon Australians began with TB, or the White Plague (Cumpston & Lewis, 2001). Sutherland, a seaman on the ship, *Endeavour*, died of phthisis in 1770 and was the first British man to be buried in Australia (Beddie, 2001). It was stated "there is no reason for supposing that Aborigines in their primitive condition were infected with TB" (Cumpston & Lewis, 2001, p.16). Furthermore, it was reported that Indigenous people did not suffer from TB prior to 1788 and there was a high prevalence of TB among the first Europeans who arrived in Australia.

Today, the incidence of TB in Australia is relatively low, with 900-1100 cases reported annually. These figures have remained stable since 1985 (Roche, Bastian & Krause, 2007). In 2006, for

every 100,000 people in Australia, 5.8 cases of TB were reported, a slight increase from 5.3 cases in 2005. The incidence of TB is higher among migrants and Indigenous Australians, at 20.7 and 6.6 cases per 100,000 respectively. In contrast, there were 0.9 cases per 100,000 for the non-Indigenous Australian-born individuals (Roche, et al., 2008). The Northern Territory has the highest new and relapsed cases of TB, seconded by the State of Victoria which accounts for about a third of the TB cases (Roche et al., 2005; Barry, Konstantinos and the National Tuberculosis Advisory Committee [NTBAC] (2009). It is therefore evident that the incidence of TB is greater among overseas-born and Indigenous populations than non-Indigenous Australians.

Barry, et al. (2009) stated thirty-one cases of TB were reported among healthcare workers in Australia; twenty-nine of whom were born overseas. Of these, the number of nurses is not known. It was reported there was no TB transmission within Australian health care settings and treatment success rate was more than 95% in 2006 (Barry, et al., 2009). Nevertheless, the number of healthcare workers affected is much lower than in Malawi cases and the impact on nursing care has not been documented.

Like Malawi, Australia has a National TB Program where the Australian Government works closely with each State and Territory. The strategic approach is to monitor the disease, to ensure the incidence remains low and that Australia continues to have the lowest rates of TB globally. The States and Territories provide and manage TB services in Australia and ensure a close working relationship between public health, laboratories, clinicians and TB services. The Commonwealth monitors the incidence and prevalence of TB on a national basis by obtaining information from health authorities in the States and Territories. The Department of Health and Ageing maintains national TB surveillance with national bodies on factors that will influence TB control (Communicable Disease Network Australia, 2002). It could be argued that due to the very low incidence of TB in Australia and availability of human resources, the impact of TB on Australian nursing has not been documented.

1.5.2 Malawi

The first recorded case of TB in Malawi dates back to 1879 when a missionary's cook was diagnosed with the disease. However, it was not until 1969 that the first structured TB programme was introduced along with the establishment of a national TB register (Stevenson, 2003). By the 1970s, "4,000 cases were officially recorded each year and 90% of the cases were successfully treated" (Salaniponi, Gausi, Chimzizi & Harries, 2004, p.1). However, those excellent results began to erode from 1989 with the advent of HIV (Salaniponi et al., 2004). Within a decade, TB cases surged to approximately 20,000 per year and the mortality rate rose from 5% in 1985 to 22% in 1998.

The 2001 statistics reported 27,000 TB cases in Malawi (Salaniponi, et al., 2004) and in 2003, there were more than 28,200 patients registered and treated for TB, an increase of 6% from 2002 (WHO, 2004). By 2008, the WHO estimated there were 51,172 new cases of TB (WHO, 2008). However, Malawi's National TB Control Program (NTCP) disputed this figure and indicated half of this amount was accurate. Between 2003 and 2007, it is claimed that TB case detection was estimated to be 42%, which fell short of the 70% target rate set by WHO (WHO, 2008). While the treatment success rate rose from 72% (2002 – 2005) to 78% in 2006, this remained below the set target of 85% dictated by the WHO (2009). These statistics indicate that each year TB has continued to be a major public health problem in Malawi.

Compounded with the shortage of nurses, the emergence of multi-drug resistant TB (MDR-TB), extensively drug-resistant TB (XDR-TB) and the prevalence of HIV/AIDS, TB management has become a major public health challenge in Malawi and, more broadly, in the Sub-Saharan Africa. It has been argued there is a critical shortage of health-care workers worldwide. This figure is estimated to be 4 million. Sub-Saharan Africa is the worst affected region harbouring 25% of the world's burden of disease yet it has only 1.3% of the world's health-care workers (Makombe et al., 2007).

1.6 The Disease of tuberculosis

1.6.1 Pathophysiology

TB is an infectious disease that is caused by the bacteria, *Mycobacterium tuberculosis*. The disease can affect many parts of the body including, but not limited to, lymph nodes, meninges, bones/joints, peritoneum, genito-urinary tract, brain, spine and kidneys. These forms are termed extra-pulmonary TB and cannot be transmitted. However, up to 50% of TB is pulmonary (DHS Report, 2004). Unlike all the other types, Pulmonary TB is infectious and is transmitted through the inhalation of tiny droplets from an infected person coughing or sneezing. The classic symptoms of lung infection are: chronic cough that lasts for weeks, fever, night sweats and weight loss (WHO, 2008b).

1.6.2 Diagnosis and treatment

There are many tests that have been developed in order to rapidly diagnose TB; however, the diagnosis of active TB is often difficult and false positives can occur (Jeong & Soo Lee, 2008). A summary of the tests available is presented in table 1.2. The table outlines the type of tests, the procedure, results, and the advantages and disadvantages.

Following a definitive diagnosis, the major drug treatment regime is Isoniazid, Rifampicin, Ethambutol and Pyrizamide. For the initial two-month period these four drugs are mandatory. Thereafter, Isoniazid and Rifampicin is continued for a further four-month period. With proper treatment and compliance, a cure of TB is approximately 95% (Centre for Disease Control [CDC], 2011).

1.7 The geographical settings of the study

There are profound socio-cultural and political differences between Australia and Malawi, as is often the case with comparisons in developed and developing countries. This section therefore begins with Table 1.3 which outlines the socio-economic status for each country as recently reported by the Global Health Observatory (2009). What then follows for each country is a

geographical and cultural overview, religious influences, features of the healthcare system and approach to nursing education.

Table 1.2: Summary of Tests for TB

	I			
TYPE OF TEST	PROCEDURE	RESULT & INTERPRETATION	ADVANTAGES	DISADVANTAGES
1. Tuberculin Skin Test (TST) or Mantoux test (Department of Human Services [DHS], 2005).	- Intradermal administration of Purified Protein Derivative (PPD)	Formation of a raised, red or hard area around injected site = + reading.	-Screens for latent TB	-Takes up to 3 to 5 days to achieve a result -Can provide false results in people vaccinated against TB Up to half of people given treatment for TB on basis of a + skin test have no TB -Test fails to detect half of population with latent TB; may show false negatives (Neustaedter, 2005) Unpleasant for patients; causes scarring; interpreting results is difficult.
2Mycobacterial cultures (Meier et al., 2005; Passalent et.al., 2006; Diel et.al, 2009).	-Smear microscopy	Isolates Myobacterium Tuberculosis - specific T cellsIf mycobacteria are present, attempts to remove the stain fail, therefore, the organisms are identified as acid- fast.	-More sensitive -Detects both active & latent TB.	- Up to 2 weeks for results, - delayed diagnosis & commencement of treatment Poor sensitivity for extrapulmonary TB.
3. QuantiFERON-TB Gold Test (QFT-G) = one type of IFN-g release assay (IGRA) (Mazurek et al., 2005).	-Blood samples mixed with antigens & controls then incubatedInterferon-gamma (IFN-gamma) measured.	White blood cells of patients with TB → release IFN-gamma in response to contact with TB antigens.	Requires only one blood sampleResults within 24 hoursIs not subject to reader bias.	-Blood samples must be processed within 12 hours after collection while white blood cells are still viableLimited data on use of QFT-G in children < 17 years of age, persons exposed to M. tuberculosis & in immunocompromised patientsDoes not easily identify individuals at risk for developing TB diseaseFalse positive results can occur.

TYPE OF TEST	PROCEDURE	RESULT & INTERPRETATION	ADVANTAGES	DISADVANTAGES
4. Chest X-Ray (CXR) (McPherson, et al., 2004)	-Radiographic examination of lung fields.	Pulmonary TB → infiltrates or consolidations and/or cavities seen in upper lungs.	-Generally safe. -Inexpensive -Convenient	-Not recommended in pregnancy -In HIV or other immuno-compromised people, X-ray may appear entirely normalAbnormalities on chest radiographs may be suggestive of, but never diagnostic of TB.
5. Oxford's Immunotec's T-SPOT TB test (Neustaedter, 2005).	-Analysis of blood samples for presence of immune system cells → activated by a protein produced by TB bacterium	-Results obtained by counting spots contained in the test wells / mediums.	-Specific (99%) -Accurate -Convenient -Efficient -Fast (results available within 24 hrs) -Sensitive (96%) - used to screen any group for TB infection.	-Spots can be counted inaccurately.
6. Breathalyser McNerney & Daley (2011).	- Optic sensor with coating that sits inside the tube & attracts bacteria	-Patient coughs into the tube, sputum sticks to the optic sensor & if TB is present in the lungs, there is a positive reading.	-Fast (results in under 10 minutes)-90% accurate -Cheap -Disposable device	-Only test for one type of TB therefore unlikely to entirely replace the current screening tests.

Table 1.3 Socio-economic indicators: Australia and Malawi

INDICATOR	AUSTRALIA	MALAWI
Total population	21,902,000	15,263,000
Gross national income per capita (US Dollars)	38,350	810
Life expectancy at birth males/females (years)	79/82	44/51
Probability of dying under five years of age (per 1,000 live births)	1	110
Probability of dying between 15 and 60 years, males and females per 1,000 population	62:Combined M&F	691: M 496: F
Total expenditure on health per capita (US Dollars)	3,945	25
Total expenditure on health as % of GDP (2009)	8.7	6.2
Nursing/Midwifery personnel density (per 10,000)	95.9	2.8
Nursing and midwifery personnel	201,300	3,896
Number of physicians	62,000	257

1.7.1 Australia

1.7.1.1 Geographical overview, people and climate

Australia is a country situated between the Indian Ocean and the South Pacific Ocean, and is referred to as the smallest continent in the world. The country is divided into eight administrative divisions, consisting of six states: New South Wales, Victoria, Western Australia, South Australia, Queensland, Tasmania, and two territories: Australian Capital Territory and Northern Territory. Australia has a land mass of 7,686, 850 sq. km which is almost sixty-five times the size of Malawi. Despite this, Australia's population is 21,902,000 (Global Health Observatory, 2009), which is just over one and a half times the population of Malawi. The study took place in Melbourne, Victoria, located in the South Eastern part of the country (see Appendix 1).

The majority of people in Australia (95%) are of British descent, who colonised the country in 1788. The Indigenous people of the country (Aborigines) make up only 2% of the population and 25% of people living in Australia are reported to have been born overseas, that is: 5.5% in the United Kingdom, 11.3% in Europe and 7.3% in Asia (ABS, 2008). Under sovereign monarchy, the official name is the Commonwealth of Australia. English is its official language. Australia has several climatic zones, the temperate climate in the southern part, arid climate in the central region and tropical in the northern end (Bureau of Meteorology, 2009).

According to the ABS (2008), life expectancy at birth for non-Indigenous Australians stands among the highest in the world at 79 years for males, 83.7 years for females. This is in contrast to the Indigenous Australians whose life expectancy at birth across Australia for females and males is 67.2 years and 72.9 years respectively, almost 10 years below non-Indigenous life expectancy (Australian Indigenous Health*bulletin*, 2009). These, however, are deemed to be improved figures from those reported by the ABS (2005) for life expectancy between 1996 – 2001, which was 59.4 years for Aboriginal males and 64.8 years for Aboriginal females.

1.7.1.2 *Religion*

Australia is a multi-religious country. Christianity is reported to be the main religion at 52%; Protestants and Anglicans being the most prominent. Roman Catholics make up 25%, the Greek

Orthodox make up approximately 3% of the religious sector and Muslims/Buddhists comprise less than 1% of the religious sector (ABS, 2009). While these figures portray the religious affiliation for the population, it is postulated that very few people actively attend church services, unlike in Malawi.

While many Australians claim to be religious, the mention of God in public circles brings some discomfort as the majority of Australians are non-practising. Peach (2003) highlighted the differences in the role of religion between the United States (US) and Australia. He stated 95% of US citizens believe in God as opposed to 61% of Australians; 78% US citizens prayed regularly in contrast to 67% Australians who prayed occasionally and 42% of US citizens attended religious services in the previous week in contrast to 25% Australians attending church monthly. Eckersley (2007) stated, for a developed nation, America stands out in the strength of their religious beliefs and differences. It is speculated the proportion of US citizens with a stated religious belief has been stable since the 1930s. In contrast, Australian figures declined by 12% in the 1960s to 1980s. Eckersley (2007) stipulated that the figures are even less now. He argued that cultural factors that work against religion in the western world are materialism and individualism where individualism frees one from social regulation, including religion. These consequently result in personal consumption and self-satisfaction with tremendous costs to one's health and well-being (Peach, 2003; Williams & Sternthal, 2007). This suggests that religion does not play a central role in the lives of Australians; portraying that religion is not crucial in the way many Australians deal with health and illness.

1.7.1.3 The healthcare system in Australia

Like Malawi, the healthcare system in Australia incorporates both public and private sectors. The public sector is a shared responsibility between the Australian Commonwealth Government and the State/Territory governments. For example, the Commonwealth Government funds the universal medical services. It provides financial assistance to public hospitals and pharmaceutical needs as well as funds for health research and training. The states/territories are responsible for direct health services such as public health awareness, community health, acute and psychiatric health services and disease control (Department of Foreign Affairs and

Trade [DFAT], 2008). The public health system is subsidised by Medicare, that is, funds raised from taxes to provide healthcare.

The private sector, as the name denotes, is privately owned and operated. Individuals treated in private institutions need to have private insurance. Private patients can choose to be cared for at public institutions whereas public patients who do not have health insurance cannot be treated at private hospitals, unless they are willing to pay out all expenses associated with their care. The private sector reportedly provides one-third of hospital beds in Australia (DFAT, 2008).

1.7.1.4 Nursing in Australia

Nursing education in Australia is quite diverse, especially at the post-graduate level. At the undergraduate level, there are regulated and unregulated nurses. Regulated, or licensed nurses include enrolled nurses (also referred to as registered nurses, division 2 [RN2]). Students undertake vocational education and training (VET) for one year to obtain a certificate, or a diploma in Queensland, enabling them to practice as enrolled nurses.

Registered nurses, division 1 (RN1) complete a three-year university-based bachelor degree program. During this time, candidates are expected to meet the Australian Nursing and Midwifery Council (ANMC) competencies as well as industry standards (Department of Education, Science and Training, 2008). Unlike Malawi, midwifery is not incorporated into general nursing training in Australia. To be registered as a midwife in Australia, requires completion of a three-year university program in midwifery, or, post-registration, students may choose to study a fourth year and obtain a Bachelor Degree in Nursing or Midwifery with Honours.

Unregulated/unlicensed carers are not required to have formal training, other than meeting the occupational health and safety standards set by the workplace, though they may complete a short course in providing basic care of persons. They may go through a short course in providing basic care of persons. Carers may work in aged care settings as personal care assistants (PCAs), assistants in nursing (AINs), aged person carers or disabled person carers. The Australian Council of Deans of Nursing (ACDON) (n.d, p.1) stated:

Registration Boards or Councils can regulate only those who are claiming to be nurses. They have no control over those other workers, variously named, who are actually performing nursing activities (whether trained or untrained). Certain activities of nursing may appear deceptively simple (e.g., bathing, walking, dressing wounds); however, there is often required a higher level of assessment and monitoring associated with the skill, to ensure safety of care. For such higher level skills, a considerable body of knowledge is required and higher order skills.

This signifies the importance of having registered or licensed workers in order to deliver the best care possible to patients.

For the purpose of this research project, entry requirements for a course in nursing in Australia are discussed at the undergraduate level. For Australian domestic students, the entry requirement is the Victorian Certificate of Education (VCE) or equivalent, Certificate II or III in studies related to nursing. For international students, applicants are required to meet the equivalent of Australian high school completion and English proficiency, which is tested, by International English Language Testing System Score (IELTS) or Occupational English Test (OET) (Australian Health Practitioner Regulatory Agency [AHPRA], 2011).

After nurses/midwives are assessed and have successfully completed the undergraduate national framework of the Australian Nursing and Midwifery Council (ANMC) standards, they can register to practise through the nurses' boards in their respective states. However, from 1st July 2010, State and Territory Registrations were abolished and national registration, called the National Registration and Accreditation Scheme (NRAS) for Health Professionals (Australian Health and Practitioner Regulatory Agency [AHPRA], 2011), was implemented. Under the previous system (State and Territory Registration), nurses could only practise in the State or Territory in which they were registered. If a nurse wanted to work in another State/Territory, they needed to apply for an additional licence for that particular State. National registration means that nurses need only one licence in order to work in any State/Territory of Australia. Post-registration, nurses and midwives can choose and study a specialty. The opportunities for post-graduate study either in clinical, administrative or academic areas are immense, unlike in Malawi.

Globally there has been a shortage of nurses in active practice. However, Australia appears to have reversed this trend. It has been reported that the number of registered and enrolled nurses employed as nurses in Australia between 2001 and 2005 increased by 7.1%, from 228,230 to 244,360. In 2005, 81.2% of nurses employed in Australia were registered as division 1 (Australian Institute of Health and Welfare [AIHW], 2009). In 2006, there were 379,949 persons with nursing qualifications (ABS, 2006]. While there has been an increase in the number of nurses, it is argued that the rate relative to the population decreased in capital cities and overall (Australian Health Institute, 2008).

1.7.2 Malawi

1.7.2.1 Geographical overview, people and climate

Malawi is a land-locked country located in the South-Eastern part of Africa. The country is sandwiched between Mozambique in the eastern and southern part, Zambia in the west and Tanzania in the north. Malawi has a land mass of 118,480 square kilometers (sq km); 94,080 sq km of land and 24, 400 sq km of the Lake (Lake Malawi), the third largest lake in Africa. Twentynine districts make up the country. The study took place in one hospital in the Central Region and two hospitals in the Southern Region of the country (see Appendix 2).

The climate in Malawi is sub-tropical, and has a rainy season from November to May and dry season from June to October. Formerly known as Nyasaland, Malawi was established in 1891 as a British Protectorate. The country gained its independence in 1964 and obtained the official name of the Republic of Malawi. It has a multi-party democratic government that overthrew a dictatorial life-president in 1993. Centrally located, its capital city is Lilongwe. English is the official language and Chichewa is the national language, in addition, indigenous languages and dialects are used regionally (Moyo, 2003).

Malawi's population is recorded as 13,263,000 (Global Health Observatory, 2009). The population estimates take into consideration the effects of infant/childhood mortality, mortality due to AIDS resulting in lower life expectancy, lower population and growth rates and changes in the distribution of population by age and sex than would otherwise be expected (National Statistics Office of Malawi). Life expectancy at birth is estimated to be 44 years for males and 51

years for females (Global Health Observatory, 2009). It could be postulated that this is the outcome of increased childhood mortality due to malnutrition and the high incidence of infectious diseases such as TB, HIV or AIDS.

According to the WHO (2009), 554 in 1000 males and 514 in 1000 females in Malawi die from infectious diseases. These people are aged between 15 and 60 years (WHO). Other challenges are related to geographical isolation and financial difficulties that make access to healthcare very difficult. Even when one accesses a healthcare facility, there is lack of medication supply, which compounds the already-existing problems. Lack of availability of medications can be attributed at times to health workers stealing drugs from health facilities in order to supplement their low salaries (Muula, Panulo & Maseko, 2006).

1.7.2.2 **Religion**

Malawi is a multi-religious country. Christianity has a huge presence in the country, at 55-60%; Protestants being the most prominent. Roman Catholics make up 15-20%, the Muslim religion accounts for 15% of the religious sector. Other Indigenous, traditional religious sectors and beliefs that people are engaged in are estimated at 5% (Spika, 2009). These beliefs are strongly embedded in how Malawians deal with health, illness and death. For example, people abstain from certain behaviours such as smoking and alcohol use and adhere to dietary principles such as vegetarian diet due to religious influence. This, in turn, can lead to a healthier lifestyle.

Malawians also create social networks through religious affiliations. For example, several religious groups visit the sick in hospitals and support patients through prayer and song. Basu (2011) claimed that religious people experience a better mental health, more positive psychological states, more optimism and faith. These factors consequently result in a better physical state due to less stress (Basu, 2011; Spika, 2009; Williams & Sternthal, 2007). Furthermore, Malawians commit themselves to a higher power than themselves in the way they deal with illness and death. During times of loss, they find consolation and believe that it is 'God's will' and no human can do anything about the situation. This assists them to adjust early to the losses.

Oman and Thorensen (2003) argued that religion empowers individuals by connecting them to a superior force thereby giving them psychological stability. Basu (2011) reiterated in an effort to eradicate TB, malaria, mental illness and HIV/AIDS, religion plays a pivotal role, particularly through the mobilisation of resources, community, empowerment and distribution of health information. This is significantly highlighted in the assistance rendered to AIDS patients through hospices and community outreach (Basu 2011). In doing so, the community is integral in bringing together the process of caring for patients in all African countries.

1.7.2.3 The healthcare system in Malawi

The healthcare system in Malawi incorporates both public and private sectors. It is claimed that this combination dates back to the time before independence in 1964, when mission hospitals which were owned by churches, co-existed with government district hospitals (Ngalande Banda & Simukonda, 1994). The public system is run by the government and provides free services. As these services are extremely overcrowded especially in the outpatients departments, people seek treatment at private clinics (Talashek et al., 2007). Lack of funding also affects delivery of services and patient outcomes (Ngalande Banda & Simukonda, 1994).

Before independence, the government stunted the growth of the private sector through strict legislation and registration. However, since 1987, with the change in policy towards private health care provision of the Medical Practitioners and Dentist Act, there has been an explosion of unregulated and liberal registration of private practitioners. These registrations are owned by private individuals and/or organisations. In order to utilise the private sector one has to cover all costs. While some companies fund private health insurance for their employees, this option is available to a small minority of the people. It is clearly evident that the majority of people in Malawi cannot afford to pay for private health insurance. While private hospitals are well-equipped and have considerably improved patient-staff ratios, their services remain unreachable to all apart from the privileged few (Makoka, Kaluwa & Kambewa, 2007; Oxfam, 2009).

The public hospital system is described as a three-tiered approach (Steinlechner, Tindall, Lavy & Chimangeni, 2006) that is, there are three levels of care. The third 'tier' refers to rural hospitals

that are nearest to peoples' homes. These are very poorly resourced, there are no medical or surgical personnel, one or two nurses and hardly any medical supplies and equipment to meet basic health needs. The second 'tier' of health care refers to that offered in district hospitals. There is one district hospital in each of the twenty-nine districts of Malawi. These are centrally located within each district. Cases that cannot be handled at a rural level are usually transferred to the district level.

The district hospitals are larger than the rural hospitals, yet they still lack the amount of necessary human resources and supplies to meet growing health demands. Oftentimes there is one resident doctor to cover a few consecutive shifts with a district health officer. The district health officer is often inexperienced due to recruitment directly from internship even though they are charged with the responsibility of overseeing an excess amount of clinical work. The district health officer is assisted by two or more paramedical clinical officers who undergo four years of practical training (Lavy, Tindall, Steinlechner, Mkandawire & Chimangeni, 2007). While it is stated that all these district hospitals have operating theatres, none of them has a permanent surgeon. Lavy et al. (2007), emphasised there are only fifteen trained general surgeons and none are stationed at the district hospitals. Surgeons from top tier central hospitals, (described below), periodically visit the district hospitals, run clinics and occasionally perform surgical procedures.

The final level, the 'top tier', refers to central hospitals mainly located in urban areas. There are four central hospitals in Malawi:

- The Queen Elizabeth Central Hospital (QECH), Blantyre, located in the southern region;
- Zomba Central Hospital, Zomba (ZCH), also located in the southern region;
- Kamuzu Central Hospital (KCH), located in the capital city, Lilongwe, in the central region. KCH has two wings: 1) the Central and 2) Bottom Hospital, which is the older wing;
- Mzuzu Central Hospital (MCH), located in the northern region of the country.

These last two facilities are the major tertiary referral hospitals for the country.

The central hospitals provide all necessary health services needed. They are equipped with advanced technology, medicines, medical and surgical personnel. However, these resources are in short supply to meet the ever-increasing influx of patients with TB, Malaria, HIV/AIDS, childbirth and accidents (Steinlechner et al., 2006). The KCH is claimed to serve approximately five million people per year. The hospital has a bed occupancy range of 600-1000, yet it is reported that this number is often exceeded (Semer, 2011; Helms, 2011). The radiology department of the hospital has plain films and ultrasound services but no magnetic resonance imaging (MRI) or computerised axial tomography scan (CAT scan). The Malawi Healthcare Organisation (2007), reports that the equipment in these hospitals is usually broken.

It is reported that the country has less than 100 doctors and approximately 3,000 nurses, because half of graduating doctors and nurses leave the country to practise elsewhere; a shortage labeled as "crisis" (Kushner, Mannion, & Muyko, 2004, p.1478). The United Nations (UN) (2009), reinforced that Malawi is among countries that are worst affected by a shortage of human resources. Statistically, Malawi has 2 doctors and 28 nurses to 100,000 Malawians; there is only one pathologist in Malawi, who works in Blantyre, the Southern part of the country. The country has 68% vacancies for doctors, 58% for nurses and 32% of allied health clinical positions to be filled (UN, 2009).

Gorman and Hohmuth-Lemonick (2009), affirmed that Malawi has one of the lowest ratios of healthcare workers to total population in the world. They stated that in 2004, Malawi had approximately a quarter of the minimum number of nurses that the WHO considers adequate for countries in the developing world; with 36.8 nurses to 100,000 population, contrasting the recommended ratios of 100 nurses to 100,000 population. The nurse-to-patient ratio ranges from 1:50 to 1:120 and 95% of nurse-midwives are stationed in urban areas (Gorman & Hohmuth-Lemonick, 2009; Moyo, 2007). The researcher concedes that these staff shortages affect the care that patients across the globe receive and TB patients are not immune to this impact.

1.7.2.4 Nursing in Malawi

There are two groups of licensed nurses in Malawi: enrolled nurses/midwives and registered nurses/midwives. Enrolled nurses complete three years of study and obtain a Diploma of Nursing. Included in these three years is a year of midwifery training. There are eight mission nursing schools dispersed throughout the country that are mostly in rural areas, where enrolled nurses can be trained, or alternatively, at Malawi Colleges of Health Sciences. The entry requirement to study as an enrolled nurse is a Junior Certificate of Education (Ordinary [O] level) (Muula, Panulo & Maseko, 2006); which is equivalent to a Year 10 level in Victoria, Australia.

Registered nurses study a generic four-year degree program that is offered to students enrolled immediately following secondary school completion for those with a Malawi School Certificate of Education (MSCE) or Advanced (A) level. This is also equivalent to the Victoria School Certificate (VCE) in Victoria, Australia. Post-basic degrees are also offered to enrolled nurses who have rendered at least two years of service. These courses are offered at the Kamuzu College of Nursing (KCN), University of Malawi. This university has two campuses; one in Blantyre (Southern region) and the other in Lilongwe (Central region). Again, midwifery education is incorporated in the Bachelor of Nursing and Midwifery Degree. Other courses that have recently commenced at the KCN include Bachelor of Science in Advanced Midwifery and Diploma in Nursing for enrolled nurses (Muula, Panulo & Maseko, 2006). The Malawi College of Health Sciences offers post-basic educational diploma programs for nurses. For instance, courses are now available in teaching and management. These additional courses enable graduates to be promoted to ward managers, locally referred to as Matrons, which is equivalent to the term Nurse Unit Managers in Victoria, Australia (Malawi Healthcare Organisation, 2007). Registration of nurses in Malawi is through the Nurses and Midwives Council of Malawi.

1.8 Current nursing trends in Australia and Malawi

In Australia, it was reported that the overall nursing supply between 2005 and 2009 increased by 6.2% from 1040 full-time equivalent to 1105 per 100,000 population; based on a 38- hour working week; as well as an increase in average number of hours worked per week (Australia

Institute of Health and Welfare [AIHW], 2011). While the average age decreased from 45.1 years to 44.3 years, the number of nurses over 50 years of age has increased. Swenston (2008), proposed that by 2010, 40% of nurses would be over the age of 50. As these nurses would be approaching retirement, the challenge would be to sustain, recruit and retain more nurses (Sherman, 2006; Westin, 2006; Swenston, 2008). All the above-mentioned trends relate to nurses working in general practice.

In contrast, while many nurses are educated and trained in Malawi, there is a poor retention rate as there is often a mass exodus of professional nurses into other countries. The WHO Report (2006) reinforced this, stating in 2005, out of 4,000 nurses in active service in Malawi, 453 of them were reported to be working in Organisation for Economic Co-operation and Development (OECD) countries. These are countries outside Malawi. This, bluntly put, indicates that 11.3% of nurses left the country and this trend continues. This erodes the workforce of healthcare workers that, in the end, affects service delivery and patients' outcomes. Record and Mohiddin (2006) reported that "the level of vacancies across the entire public health system is acute with an overall vacancy rate of 33 percent. However, this figure masks the severe shortage of nurses where 64 percent of established posts are unfilled" (p.1). These trends impact on the care patients receive, thereby determining health outcomes.

Moreover, the undergraduate nursing curriculum in most countries does not prepare graduates for specialty practice such as those regarding the specific needs of TB patients. Because of the global rise in statistics of TB patients, which will be discussed in chapter two, it should be emphasised that the National Tuberculosis Curriculum Consortium (NTCC), USA developed an undergraduate curriculum. This programme has TB core competencies and specific student objectives to address knowledge, ability, and/or skills required for an undergraduate nursing student. The aim is to specifically prepare graduates to provide qualified holistic care for patients, families, and communities affected by TB (Fair et al., 2006). To the researcher's knowledge to date, this is not the case with Australia's and Malawi's undergraduate curriculum.

1.9 Problem identification and significance of the problem

Nurses play a very significant role in many aspects of patient care. The epidemic levels of TB demand more human resources in the healthcare sectors, particularly, doctors, nurses, social workers and counsellors. At the forefront of these resources are nurses, especially with the shortage of medical personnel in the developing world. A comprehensive literature search has exposed there is paucity of scholarly and scientifically-based material related to factors that influence the nursing care that TB patients receive. Very few articles have addressed nursing aspects of TB care (Kirby & Madsen, 2004; Toth, Fackelmann, Pigott & Tolomeo, 2009). Most of the available literature has focused on biomedical and pharmaceutical models such as Direct Observation Therapies (DOTS) and Self-Administration Therapies (SAT) as well as a focus on coinfection of HIV/AIDS and TB. To date there has been no nursing research on factors that impact on TB care in Australia and Malawi. This study therefore highlights the need to have insight and understanding regarding what patients and nurses perceive to be crucial factors that hinder or promote the nursing care of TB patients. While the developing world – Malawi, has a very high incidence of TB and is poorly-resourced, the country has been exemplary in TB care. Conversely, Australia has maintained low figures for over a decade (refer to table 1.1) even though it is better-resourced. By comparing and contrasting these two settings, it is hypothesised that the two countries will draw lessons from each other in the management and care of TB patients.

1.10 Aims and research questions of the study

The aim of this study was to investigate what factors impact on the nursing care of TB patients from both patients and nurses perspectives in order to achieve positive physical and emotional health outcomes for the patients. These factors will be categorised as characteristics of the (a) individual (b) treatment regime (c) patient-provider relationship (d) clinical setting and (e) disease; which was adapted from a framework used as a bench-mark for reviewing studies that examine factors affecting adherence in AIDS clinical trials (Ickovics & Meisler, 1997).

The main study aim was to investigate the factors that enhance and/or impinge on the provision of nursing care to TB patients from the perspectives of patients and nurses. The study also investigated whether any identified barriers can be eliminated, minimised or adjusted to

improve the outcomes of patient care. As such, a secondary aim was to develop a model of care to improve TB care. The following research questions, outlined in Table 1.4 form the premises of the investigation.

1.11 Presentation of thesis

This paragraph outlines how the thesis will be presented. Level one headings will be in Gill Sans MT, font size 14, bold. Level two headings will be in the same font, size 12 and bold as well as indented one centimetre from the left margin. Level three headings will be in size 12, bold italicised and indented two centimeters from the left. The main text font is Calibri, size 12 with 1.5 line spacing. Data quotes are presented in font size 12 and italicised with single line-spacing and indented by one centimetre from the left margin. Titles for tables and figures are centred and in Gill Sans MT, font size 10 and small caps. Table texts are in Calibri, font size 9. The thesis has utilised the American Psychological Association (APA) (6th ed.) style of referencing and presentation. Accordingly, the table titles are presented before the table and, for figures, the titles are presented after. In addition, the words 'care' and 'management' will be used interchangeably throughout this dissertation.

Table 1.4: Research Questions

QUESTION	RESEARCH QUESTION		
1.	What is the patients' and nurses' level of knowledge of TB and its management?		
2.	What are the patients' and nurses' perceptions regarding: I. provision of nursing care? II. impact of nursing care on the patients' wellbeing? III. availability and access to resources to improve quality of care? IV. changes needed to improve quality of care of TB patients in these facilities?		
3.	What are the characteristics and history of TB patients who present to inpatient and outpatient facilities in Australia and Malawi?		
4.	What are the characteristics, qualifications and experiences of nurses caring for TB patients in Australia and Malawi?		
5.	What are the relationships between patients' and nurses' demographic characteristics and their perception of nursing care in Australia and Malawi?		

1.12 Summary of structure of the thesis

This thesis has five chapters. Chapter one has introduced the foundation for the study, an overview of TB and the geographical settings for the study, the background of the researcher as well as the healthcare systems in both Australia and Malawi. The chapter has also identified the research problem identification and states the aims and research questions. The stylistic presentation concludes the chapter.

The second chapter will present the literature review, focusing on the available scholarly literature integrally linked to the research questions. The literature review also identifies current gaps thereby providing justification for this study.

Chapter three discusses the methodology, methods and processes utilised to answer the research questions. An extensive outline of the development of the questionnaire, translation and validation of the tool, choice of participants and how data was collected in Australia and Malawi is also discussed. The chapter also addresses the ethical considerations applied for the study.

Chapter four presents the quantitative and qualitative results of the study. The discussion of these findings follows which leads to the development of the nursing care model in the same chapter.

Chapter five concludes the study. The clinical and research implications and limitations of the study are addressed.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter will present a review of the available literature on TB management with a directed focus on the research aims and questions. The duration of the literature search spans 2004-2012, that is, from the commencement of the study until its completion. A critique of available literature on factors that affect TB care will be presented. An identification of research gaps and justification for this study is put forward.

The chapter review and critique is categorised into four main areas: risk factors; knowledge and delayed diagnosis; attitudes and perceptions; nurses roles and management. Geographical regions and countries are highlighted throughout the review. While the literature search articles have been retrieved predominantly from the last decade, older seminal documents were referred to in order to acknowledge and emphasise historical points. The literature relevant to each particular area is summarised in tables. The tabulated authors have been arranged according to date order, from most recent to older literature. The main contributors of significance to this research study have been highlighted. The chapter concludes with a justification for the proposed research study.

2.2 Literature search

To provide background to the research aims and questions, a broad review of literature was conducted. This review included national and international literature, government reports, journals, conference presentations, dissertations, digital and any other related grey literature.

2.2.1 Strategy

The search strategy encompassed both electronic and manual searching from 2004 until 2012. The broad topic of interest was 'Nursing management and /or care of TB patients'. Table 2.1 below outlines the inclusion criteria for the search.

Electronic databases with full texts were searched from a number of databases and the websites are as outlined in Table 2.2. In relation to manual searching, the literature search included peer-reviewed publications from journals, conference presentations, summits and

books. The review analysed global reports and included Australian and non-Australian literature and African literature specifically aimed at identifying studies from Malawi.

The search terms included: history of TB; global statistics of TB; incidence of TB in Australia; incidence of TB in Malawi; nursing management and TB; nursing care of TB patients; TB and isolation; TB and nursing; perception of TB and attitudes towards TB patients.

Table 2.3 below indicates search terms, the databases utilised and the number of hits identified in each search term. When reviewed it was evident that not all literature retrieved was directly relevant for the study and therefore was not utilised. The review clearly identified that there was a dearth of nursing literature investigating nursing care of TB patients, hence reinforcing the need for the current study.

Table 2.1 Inclusion criteria

CRITERIA	INCLUSION	
Study design	Published and unpublished research journals,	
	government documents, dissertations, conference reports, databases	
Years searched	2004-2012	
Topic	Nursing management of TB patients	
Phenomena of interest	Factors impacting on nursing care of TB patients	
Setting	Hospital (inpatients and outpatient wards) and the general community	
Language	English	
Availability	All formats published, unpublished, print, databases, dissertations, digital and other	
	related grey literature	

Table 2.2 Searched electronic databases

DATABASE	PLATFORM/WEBSITE		
CINAHL Plus	EBSCO http://web.ebscohost.com		
MEDLINE Complete	EBSCO http://web.ebscohost.com		
ProQuest Dissertations and Theses (PQDT)	ProQuest http://search.proquest.com		
Global Health Observatory (GHO)	WHO http://www.who.int/gho/en/		
World Bank Data	http://data.worldbank.org/		
PubMed	http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed		
Australian Bureau of Statistics (ABS)	http://www.abs.gov.au/ausstats/abs		
Australian Instutute of Health and Welfare	http://www.aihw.gov.au/data/		
The Cochrane Library	http://www.thecochranelibrary.com/		
Journals@Ovid	OvidSP http://ovidsp.tx.ovid.com		
Informahealthcare	http://informahealthcare.com/		
ProQuest Central	ProQuest http://search.proquest.com		

DATABASE	PLATFORM/WEBSITE
ProQuest Nursing & Allied Health Source	ProQuest http://search.proquest.com
ADT (Australian Digital Thesis program)	http://www.caul.edu.au/
Academic Search Complete	EBSCO http://web.ebscohost.com
Health Source – Nursing/Academic Edition	EBSCO http://web.ebscohost.com
Health Collection	Informit http://search.informit.com.au
The Joanna Briggs Institute ConNECT+	http://connect.jbiconnectplus.org
ProQuest Health & Medical Complete	ProQuest http://search.proquest.com

Table 2.3 Electronic data searches and retrieved articles

SI	EARCH TERMS						
Concept 1 (Subject)	Concept 2 (Nursing) Synonyms and Free text	CINAHL	Medline	PQDT	GHO	World Bank	PubMed
History of TB	Background of TB; TB in Australia; TB in Malawi; TB records	10	93	9	5520	0	352
Global statistics of TB	Number of TB patients, trends in TB, developed world, undeveloped 'world'	10	1	2	7040	14	38
Incidence of TB in Malawi	Prevalence, frequency, risks, contributing factors	8	620	0	1170	4	31
Incidence of TB in Australia	Prevalence, frequency, risks, contributing factors	19	4828	0	1510	2	32
Nursing management & TB	Ward, community, care, challenges of TB care	3	3	0	2910	4	5
Nursing care of TB patients	Physical care, emotional care, psychological care, nursing presence, nursing availability	3	2	1	1940	0	25
TB and isolation	Physical, emotional, family, spouses, healthcare workers, nurses, community	7	532	1	1680	0	2794
TB and nursing	Hospital, inpatient wards, outpatient wards, community TB nursing	22	113	1	2690	4	340
Perception of TB	Self, family, spouses, society, community, nurses, healthcare workers	2	3	3	1780	6	142
Attitudes towards TB patients	Society, family, spouses, nurses, healthcare workers, community	313	3	1	1940	2	26

The critique of available literature that follows was reviewed in four broad areas and is outlined in Figure 2.1. These areas are: risk factors; knowledge and delayed diagnosis; attitudes and perceptions towards TB patients and nurses' role and management in the current care of illness in Australia and Malawi. The review will discuss how these studies impact on nursing care of TB patients and whether any identified barriers could be eliminated, reduced or adjusted to change

the outcomes of these patients. The researcher has examined studies from different regions of the world in order to present a globally representative picture of the identified problem.

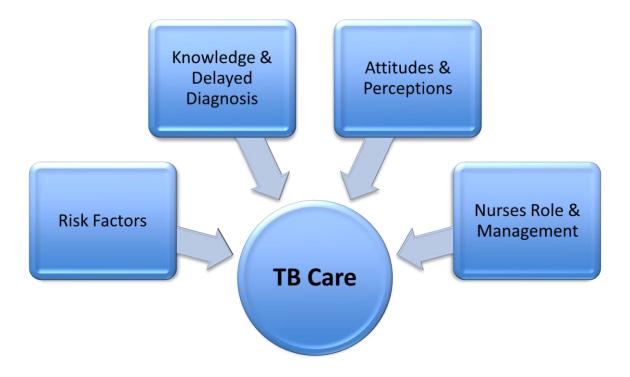


Figure 2.1: Components of reviewed literature

2.3 Review findings

Increasingly throughout the world there are more studies being conducted on TB and these studies are focused on a particular perspective such as, anthropological (Scott, 2009); public health (Zahir, 2011; Asamenew, 2011; Finnie et al., 2011) or nursing (Zvavamwe, 2006; Saadeh, 2010). The majority of literature investigating interventions on TB care has focused on health service systems, such as direct observed therapies (DOTs) (Garner, 2003; Heller, 2006; Okuonghae, 2007; Hu et al., 2008; Xu et al., 2009; Moonan, 2011). Furthermore, the literature on care is primarily perceived as biological, therefore, the focus is on the physiological aspects while neglecting psychosocial, emotional and spiritual domains of care. Of greatest significance, it was found that most of these studies have shifted the responsibility of TB care to the individual sufferer, identifying the patient as the 'cause of the problem'. Despite this, the TB

patient has little input into care and, therefore, has limited negotiation within the convoluted systems of care.

Most of the studies previously conducted were quantitative and focused on a medical issue within TB care and/or management. There was a paucity of qualitative research and also mixed method research studies on TB care. It was also evident that there were minimal TB studies that included a nursing focus. These review findings contibutes to the importance of conducting this particular study. The following addresses the retrieved literature on TB.

2.4 Literature on TB

TB is a global catastrophe that is continuing to spiral upwards. If the disease is diagnosed late or left untreated, TB affects the person and the community with dire consequences such as high morbidity rates and even preventable deaths. Perkins, Roscigno and Zumla (2006), claimed that late diagnosis impedes the management of TB patients and disease control. They further argued that where TB is most prevalent, the services fail both the individual and the community.

2.4.1 Risk factors of TB

The available literature on risk factors was focused on the impact of poverty, overcrowding and isolation as the main contributing factors to TB.

2.4.1.1 Poverty, overcrowding and isolation

The literature search identified poverty as a major risk factor for TB. However, none of the literature actually defined poverty. Poverty is multi-dimensional and relies on many indicators as opposed to one specific indicator (Bourguignon & Chakravarty, 2003). Nevertheless, income per capita remains the major indicator of poverty (Bourguignon & Chakravarty, 2003; Foster, 2007). While the income-based indicator is limiting, it is reported to be extremely useful in practice as it can be adjusted to account for individual situations and variations. However, it is stated that monetary indicators alone are inadequate to describe poverty, hence the degree of deprivation one may be experiencing (Betti & Vijay, 2008; Betti, Lemmi, Verma, (2009). Madden (2000) discussed that individuals experience poverty in different forms such as lack of housing, acquisition of assets, education and nutrition which all impact on health and illness. Poverty, in

whatever form, is unhealthy in that it impacts on mortality from cardiovascular disease and homicide (Cohen, Farley & Mason, 2003). The researcher argues that poverty also contributes to higher morbidity and mortality rates from many other diseases, and TB is no exception.

Murray (2006) argued that poverty and health are strongly intertwined, that extreme poverty undermines human capabilities, possibilities and opportunities and widens the gap in social disparities. Sachs and McArthur, (2005) maintain that health is central if poverty is to be reduced and if socio-economic advancement is to occur. "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1946, p.100). While this has been the operational definition since 1948 (p.1), it is argued that the WHO definition of health needs to be revised because health also encompasses spiritual and economic well-being. Bircher (2005) extended the WHO's definition of health and added that health is "a dynamic state of wellbeing characterised by a physical, mental and social potential, which satisfies the demands of a life commensurate with age, culture, personal responsibility." (p.335). It is strongly argued that richer patients have greater access to specialised health care than poorer patients (Doorslaer, Masseria & Koolman, 2006). The researcher asserts that these health inequalities are not isolated from TB patients. As such, the researcher argues that there is a link between TB and poverty and in order to fight TB, the issue of poverty cannot be overlooked.

The following studies will discuss poverty, social and economic factors and examine their relationship to TB. A Canadian study by Clark, Riben and Nowgesic (2007) identified links between housing density, isolation and TB prevalence in First Nation Communities, which refers to indigenous, or native Canadians (Battiste, 2002). Data included 602 community records which were collected and analysed between 1997 and 1999. These data included the number of people occupying one room, the type of isolation experienced, average household income, population (of the community) and the number of TB cases. Two multiple regression models were developed to analyse the association between: the number of people occupying one room, isolation, income and population, with the occurrence of TB cases in a community.

The study found that there were high rates of TB among First Nations Communities. Specifically, with a 95% confidence interval, the results found the TB incidence rate of in communities with an average of 0.4-0.6 ppr; 113.0 per 100,000 (95% CI: 95.4 – 130.5) in communities with 1.0-1.2 ppr. Other findings were that an increase of 0.1 people per room in a community was associated with a 40% increase of TB cases occurring; isolation within the community was associated with a TB increase of 2.5 times and a \$10,000 increase in income in a community household was associated with 0.25 increased risk, with increased income, the risk is less than other associated factors, such as the number of people per room or isolation.

The study concluded that there was a significant relationship between household density, isolation, income levels and TB. It was stipulated that overcrowded housing and isolation from health services are likely to increase the likelihood of TB. These findings are consistent with other studies on TB that poverty, overcrowding, malnutrition, poor hygiene and inadequate clinical care aggravate TB (Singh et al., 2002; van Lettow et al., 2005; Muniyandi et al., 2007; Gracey & King, 2009; Meeting of the International Task Force for Disease Eradication, 2010). It is important to note this study took place only in Canada. The researcher strongly argues that this research should be replicated in other First Nations in order for the results to be generalisable to other populations.

Boccia et al. (2009) researched the association between household economic status and TB infection in urban areas of Zambia. The study was conducted in two Zambian communities located within Lusaka Province, rural with approximately 13,000 residents and urban with approximately 11,000 residents. The aim was to assess the impact of household socio-economic position (SEP) on the risk of prevalent tuberculosis. This was a cross-sectional investigation, nested within a larger case control study of a previous population-based HIV-TB prevalence survey (n =106 cases; controls = 318).

Data was collected from respondents' homes using two differently structured questionnaires. One assessed individual socio-demographic characteristics: age, gender, education and occupation; and known risk factors for TB infection and disease: HIV status, contact with TB cases, smoking, alcohol, migration and past disease history. The other questionnaire assessed

the household socio-economic position in terms of socio-economic variables status measured in terms of aggregated data on human resources, availability of food, ownership of assets, household quality and access to services and infrastructures. The strength of these variables and their correlation with each other was analysed with household groups labelled as: very poor, poor and less poor.

The control subjects were matched to the cases by age group and area of residence; rural and urban. The prevalence of TB was estimated to be 650 per 100,000 (95% confidence interval (CI), 360–940 per 100,000 in rural areas and 750–1640 per 100,000 (95% CI) in urban areas. With probability (p = 0.05), the results indicated that infection status was not associated with any other aforementioned socio-demographic factors: gender (probability [p] = 0.6) and age (p = 0.9). Among the risk factors investigated, only people having more than two meals containing proteins per week were more likely to be TB infected (p = 0.04). There was a weak association of TB infection with increased crowding (p = 0.09).

Whereas historically there has been an association between TB and deprivation, this study disputed those findings. On the contrary, the study found that TB infection is more prevalent in individuals who were less poor and had relatively higher socio-economic position. These findings concur with a previous study by Harling, Ehrlich and Myer (2008). The authors, (Boccia et al., 2009) however, acknowledged that while the factors traditionally associated with TB infection showed little evidence in this study, the explanation why that was the case was unclear. They conceded that, while in the 19th century urbanisation was linked to increases in TB and death in Europe, the modern-day developing countries and wealthier conditions maybe contributing factors to increases in TB. The authors also stated that living in better-equipped households and living in houses with more solid material are markers of wealth. However, this may also mean poor air quality and inadequate ventilation. Such living areas, being modern, may also be characterised by greater population density and higher chance of interaction and, therefore, transmission of TB. The researcher argues that this reasoning is strongly associated with the historical argument, that TB is associated with urbanisation and overcrowding (Jackson,

Sleigh, Wang & Liu, 2006; Harling, Ehrlich & Myer, 2008; Corbett, et al., 2009; Hoa et al., 2010; Oblitas et al., 2010; Bloss et al., 2011; Oren et al. 2011).

Table 2.4 summarises the literature on risk factors of TB. Specific authors confirmed the researcher's belief that this present research is warranted. The research of Oblitas et al. (2010) which addresses nurses' roles in TB care, and the studies conducted by Corbert et al. (2009) and Jackson et al. (2006) are the most relevant to the study. The latter two authors address factors that impact on TB care and control. While these are not necessarily nurse-related, they bring insight into the factors that enhance or hinder TB care and control, which resonates with the aims of this study.

Overall, the findings of the studies addressed above disputed each other. Whereas Clark et al. (2007) found a strong relationship between overcrowding, isolation and increased income with increased incidence of TB, Boccia et al. (2009) found a weak association with the stated variables and incidence of TB. It is argued that the studies could be replicated in those settings using similar methodological rigour and matching the study populations in order to objectively compare and contrast the findings. Table 2.4 points out other literature investigating contributing factors that impact on TB.

Table 2.4 Summary of studies on risk factors of TB

AUTHOR/S, YEAR, STUDY	METHODOLOGY & SAMPLE	MAIN FINDINGS
Bloss et al. (2011). Analysis of US National Surveillance system <i>Origin: USA</i>	-Longitudinal: 2003- 2008	-TB rates 5-13x for Indigenous people; ↑ than non-Hispanic white people
Oren et al. (2011). Investigating TB incidence rates & characteristic of patients with TB in 48 large US cities. Origin: USA	-Longitudinal: 2000-2007 -CDC & National Tuberculosis Surveillance System data-48 cities - 42,448 patients	-Average incidence rate larger than other US cities -Patient characteristic non-conclusive
Oblitas et al. (2010). Latin America: Nursing's Role in TB Control: a discussion from the perspective of equity Origin: Vietnam	-Literature review -Nurses' role in regional TB control through review of intergovernmental agency reports	-Social inequalities in receiving TB care exist; Poverty and social disadvantage compound the problem
Hoa, et al. (2010). Household expenditure and tuberculosis prevalence in Vietnam: prediction by a set of indicators Origin: Vietnam	-Cross-sectional survey Sept. 2006 to July 2007 - Nationwide cluster sampling (urban, rural & remote areas) -94,179 adults (aged 个15 years).	-TB prevalence 307/100,000 population- \uparrow Prevalence = associated with \downarrow household expenditure level = 2.5x > for lowest household expenditure quintile

AUTHOR/S, YEAR, STUDY	METHODOLOGY & SAMPLE	MAIN FINDINGS
Boccia et al. (2009). Association between household economic status & TB. Origin: Zambia	-Cross-sectional investigation -106 cases, 318 controls	-Weak association between overcrowding & TB infection; TB 个in people with 个socioeconomic status
Corbett et al. (2009). Prevalent infectious TB in Harare, Zimbabwe: burden, risk factors and implications for control Origin: Zimbabwe	Quantitative; random selection of registered patients -10,092 participants	-Population 33%; male sex 40%; overcrowding 34%; infectiousness period = 18 weeks in HIV+ & approx. 1 year in HIV- patients
Harling, Ehrlich & Myer (2008). The social epidemiology of TB in South Africa: a multilevel analysis Origin: South Africa	-1998 cross-sectional survey -1996 South African National census -13,043 respondents	-Risk factors of TB: cigarette smoking, alcohol, ↓body mass index, ↓education, ↓household wealth & unemployment; ↑levels of community income = ↑risk of TB
Clark, Riben and Nowgesic (2007). Association between housing density, isolation & TB prevalence. Origin: Canada	-Quantitative -602 community records	-High rates of TB among First Nations communities; -Overcrowding, isolation & ↓ income = ↑ incidence of TB
Jackson, Sleigh, Wang & Liu (2006). Poverty and the economic effects of TB in rural China Origin: China KEY: ↓ = Decrease/d or less ↑ = Incr	-Longitudinal (2002–2004) -160 new smear + pulmonary TB (PTB) cases; 320 controls ease/d or more X = times & = and	-Poverty =↑risk incidence /adverse outcomes of TB; out-of pocket expenses = 55.5% of annual household income; households heavily in debt for Rx of TB >= equal or greater than

This section has presented a critique of the international and regional studies available on social and economic factors which impact on prevalence of TB. The majority of these study findings concur that TB is associated with poverty, poor nutrition, poor access to health facilities, urbanisation as well as overcrowding and excessive alcohol or drug use. The following section pinpoints identified gaps of the above-mentioned studies.

2.4.1.2 Significance and identified gaps of the research studies

These studies highlight that TB is still a major public health problem and many areas of the world do not show decreasing incident rates. The studies identified homelessness, excessive drug use, poverty, poor access to health services, overcrowding, male gender, HIV infection and minority groups as the major social factors that contribute to high incidence of TB. The critiques provide insight into the social and economic determinants of TB in both the developed and developing world settings. They highlighted an increased need to address these determinants and the significance of ongoing poverty reduction schemes that incorporate TB reduction. The need for health services to be tailored to specific needs of individuals is also stressed in the analysis of these studies.

While the strengths of these research findings have been identified, further studies on city-level variations in migration, social and economic status to improve urban TB control are needed. There is also a need to identify flexible TB-control strategies that incorporate social determinants of health specifically tailored to needs of indigenous populations or minority groups and vulnerable groups such as homeless populations. Other identified gaps relate to inadequate educational preparation for nurses to deal with TB. In addition, the impact of income inequality on TB disease requires further investigation.

It should be noted that in all these identified studies, only one approached TB from a nursing perspective (Oblitas et al., 2010); asserting that there is inadequate educational preparation for nurses to deal with TB. Nurses are in a position to intervene for TB patients politically, economically and socially, in local and international contexts, yet there is significant paucity of studies that address their contribution to TB care. This drives home the need to investigate the factors that impact on nursing management of TB patients from both patients and nurses perspectives; which is the essence of this study.

2.4.2 Knowledge and delayed diagnosis

This section presents an appraisal of literature that argues a lack of knowledge of the illness by patients, healthcare providers and the community and that delayed diagnosis of TB are contributing factors to TB. As with the previous section, international, national and regional literature is reviewed.

A Norwegian study by Storla, Yimer and Bjune (2008) conducted a systematic review of 58 studies that investigated delays in diagnosis and treatment of TB. Through searching databases and contacting individual researchers in the field of TB, the authors selected observational studies only with patients receiving treatment for active pulmonary TB with at least the median and mean delay in treatment included. The review found that there were delays of up to 12 weeks before patients were diagnosed. The analysis discovered the possible factors for delay in diagnosis is diverse. It outlined that some of the findings were contradictory. For example, the risk factor that increased delay in one study was a risk factor that decreased delay in another study. In relation to HIV, the systematic review reports that findings of one study stated that HIV

increased delays while three other studies elaborated that HIV decreased TB diagnostic delays. Overall, there was general consensus that diagnostic delays were attributed to: history of immigration, geographical isolation such as being in remote areas with limited health services; clinical characteristics such as HIV; socio-economic factors such as low income and poverty (Eastwood & Hill, 2004) and socio-demographic factors, for example, old age and being female (Gosoniu et al., 2008).

Other causes were socio-psychological factors, such as stigma attached to the illness (Gosoniu et al. 2008), low educational levels and seeking care from traditional or unqualified practitioners; beliefs and attitudes which state that TB is incurable and caused by evil spirits and, finally, the repeated visitations to low-level healthcare facilities, general practitioners or traditional healers (Harries et al. 2003); all contributed to diagnostic delays. Kiwuwa, Karangi and Mayanga (2005) emphasised that delay is prolonged at referral centres, therefore, health-service delay significantly contributes to overall delays in diagnosis and commencement of treatment. These delays posed a significant risk to both the individual sufferer and at the community level. The researcher critically reviewed most of the studies outlined in this systematic review and discovered that none of these had a nursing focus, which signifies the importance of the current study on factors that impact on nursing care of TB patients.

A cross-sectional study by Maamari (2008) examined delays in case-finding, diagnosis and commencement of TB treatment expressed in Syrian Arab Republic. The study was conducted in all National TB Control Program centres in the country that implemented DOTS. This study investigated factors that delay between the experience of symptoms, making a diagnosis and commencement of TB therapy. A structured questionnaire was utilised for data collection on health-seeking behaviours. There were 800 new smear-positive pulmonary TB patients aged above 15 years who were also interviewed on factors they perceived influenced health-seeking behaviour and accessibility to timely health care.

The study found that, on the part of the patient, lack of knowledge about the illness, seeking care at a non-specialised health provider, living very far from a health facility and overcoming stigma to obtaining healthcare were key factors that delayed diagnosis and treatment of TB. On

the part of the healthcare provider, these factors include lack of clinical suspicion of TB. It is argued that patient-related diagnostic delay was the major contributing factor to the total delay of treatment (66%), contrasting delays in diagnosis and treatment (34%). Studies in seven countries in the Middle East, in Pakistan and in Ethiopia (Bassili et al., 2008; Saqib et al., 2011; Belay, Bjune, Ameni & Abebe, 2012), presented similar findings. These findings echoed the importance of increasing awareness of signs and symptoms of TB and increasing close collaboration between the general public and healthcare providers about the importance of early diagnosis and treatment of TB. The study also highlighted the significance of improving referral systems within the healthcare sector; improving accessibility to faster diagnosis and treatment of TB thereby minimising transmission of the illness.

Identified limitations of this study relate to the inability to define the time onset of symptoms in all patients in the study. Another limitation concerned unavailability of medical records of patients who had visited private physicians. This may have underestimated the delays in this group of patients. The other limitation is that there could have been recall bias regarding TB symptoms prior to the diagnosis of the illness; since interviews were conducted after patients had begun treatment. In addition, it can be difficult to determine if a delay was caused by the patient or the health-care system. For example, when a patient's appointment was delayed by the healthcare provider, the delay may have been classified as a patient delay, even though the patient had sought healthcare at the appropriate time.

Godfrey-Fausset et al. 2002 examined why patients delayed seeking care in two urban health centres (Chipata and Kanyama) in Lusaka, Zambia. These centres are densely populated and they each notify approximately 10% of the TB caseload for Lusaka. The centres were conveniently sampled. Power analysis assessed the required number of participants (416), and 427 participants were recruited. A health system approach was utilised, which adapted modules developed by WHO Health System research project for Southern Africa. Health care workers from district health services were involved in interviewing the 427 patients. The results showed that 35% were found to have delayed seeking medical care for more than one month since experiencing TB symptoms. The study identified that the main factors associated with the delays

were older age, severe underlying illness, poor outlook or perception of health services, knowledge about TB, financial constraints as well as distance from the clinic (geographical isolation). However, the authors alleged that they were confident to conclude that perception of health services is a more significant factor for delays in presentation to a health facility than knowledge of TB.

It was also found that there was no association between delay and knowledge of illness, education, socio-economic level or gender. This disputes other studies (Hoa, Thorson, Long & Diwan, 2008; Maamari, 2008); that alleged the previously mentioned factors to be causes of delay for seeking TB care. Nevertheless, the delays in presentation result in delays in diagnosis as well as treatment, posing danger to the patient as well as the general community. The study signifies that if urban tuberculosis control is to improve, then the reception and care given to TB patients at health centres needs to improve as well. Likewise, efforts must be made to improve accessibility for the more disadvantaged members of the community such as the elderly and the more severely ill. Further studies could be carried out to assess whether patients' perceptions have changed and delays shortened.

Delays in hospital treatment could also be attributed to seeking alternative therapy, for example, consulting traditional healers. In one study in Malawi, Banerjee, Harries, Nyirenda and Salaniponi (2000), discussed the role of traditional healers in TB management. The authors reported that there is a National Traditional Healers Association in Ntcheu district in Malawi, where their study took place. One hundred and eight traditional healers were reported to be registered with the Association but the majority were not registered. Unregistered healers were approached through village headsmen for collection of quantitative data. In-depth interviews were conducted with ten traditional healers at their work place by district medical officers (DMOs) or district health education officers (DHEOs). Data were also collected from two-hundred and seventy six traditional healers through structured questionnaires. Other qualitative data were collected through focus group discussions with TB patients and their guardians.

The study found that traditional healers managed a variety of diseases, including TB and they were visited by approximately 4,600 patients per week. They recognised four major causes of

diseases: (1) diseases caused by spirits (ancestral or demonic); mainly epilepsy and psychiatric disorders; (2) bewitchment performed for different purposes such as with intention to harm someone of whom one is jealous; to protect oneself or to try to gain material wealth; (3) careless sexual behaviour. This can involve extra-marital sexual behaviours which might lead to manifestations such as urethral discharge or which cause cough, chest pain and weight loss either for the patient or for a member of the family and (4) diseases inflicted upon someone by God or through bad luck.

This study reported twenty-four per cent of patients seen by traditional healers had a cough, including patients with TB. The healers identified several diseases, such as TB, AIDS, and other local conditions that cause a cough. They asserted that these diseases are acquired for the four aforesaid reasons and traditional healers are convinced western medical treatment would not cure such illnesses; except for such diseases caused by 'God's will or bad luck'. TB was classified in the category where it can also be acquired due to bad luck or God's will, in which case western treatment would be appropriate. It is reported that approximately 40% of pulmonary TB patients in a central hospital in Malawi had reportedly seen a traditional healer before being diagnosed with TB and that most of these patients that looked for these alternative treatments were mainly told why they were sick rather than what the illness was (Banerjee et al., 2000). Traditional healers believe they can cure TB therefore they have been briefed on the infectious form of TB (smear-positive cases).

Considering the large number of patients that these traditional healers see on weekly basis, the feasibility of including traditional healers in early diagnosis is imperative. This study further highlights that to aim for positive outcomes, the involvement of local people is deemed crucial; a sentiment echoed by Salaniponi (2002), that "we decided to do it the Malawian way... People like the system because it is user-friendly, sociable, cheaper and culturally acceptable" (p.3). This was achieved by incorporating both the traditional healers and the patients as well as by collecting both qualitative and quantitative data. However, the study was only conducted in one district (Ntcheu) that has its own traditional customs and beliefs, which might not be representative of the whole country. A similar study replicated in a few more districts would

provide increased generalisability. It should be emphasised that the data was collected in 1997 and could be outdated, therefore the findings may not be representative of current trends. New studies would provide more updated information on current trends.

With regard to China, Gai et al. (2008) claimed that China had the second highest incidence of TB consequently village doctors played a pivotal role in managing these patients. The authors concurred with Salaniponi (2002) that the engagement of local people is paramount if the country is to cater for the health needs of TB patients. However, while most of the doctors in China underwent a training program for TB, their knowledge was insufficient to meet the demands of their responsibilities. Peltzer, Mngqundan and Petros (2006) also confirmed the significant role that traditional healers play in South Africa and postulated that many South African patients consult traditional healers as the first contact in an effort to remedy or eradicate ailments, including TB. From these claims, it is argued that while there is a need to involve local people, it is also crucial that these local practitioners are provided with sufficient, practical and feasible educational and training programs in order to regulate their practices and adequately provide the needed services for TB patients.

A summary of the studies discussed, knowledge and delayed diagnosis, is presented in Table 2.5.

Table 2.5 summarised the contributors to the research on knowledge and delayed diagnosis of TB. However, the authors who were most significant to the development of this study were Wang et al. (2008) whose research was a comparative study with a mixed methods approach. The study by Yimer et al. (2008) was also critical in relation to the similarities of the settings of the study and the research design. Godfrey-Fausset et al. (2002) study was relevant because this study used a similar research design. Studies by Banerjee et al. (2000) and Salaniponi (2000) were pivitol because they are Malawian studies and, as such, are significant to this research in terms of location and cultural practices. Bernejee et al. (2000) study was also important because the researchers used a mixed methods approach in the investigation of health-seeking behaviours of TB patients before they present to a health facility.

Table 2.5 Summary of studies on knowledge and delayed diagnosis

AUTHOR/S, YEAR, STUDY	METHODOLOGY/ SAMPLE SIZE	MAIN FINDINGS
Storla, Yimer and Bjune (2008). Delays in diagnosis and treatment of TB <i>Origin: Norway</i>	-Systematic review -58 studies	-Delays of up to 12 weeks before diagnosis -Causes: history of immigration, geographical isolation, HIV; low income and poverty; old age & female gender.
Maamari (2008). Delays in case-finding, diagnosis & commencement of TB Rx Origin: Syrian Arab Republic	-Cross-sectional -800 smear + pulmonary TB patients	-Patient-related delays; ↓ TB knowledge, geographical isolation, seeking care from non-specialised health providers -System-related: Lack of clinical suspicion of TB
Wang, Long, Liu, Tolhurst & Tang (2008). Tx seeking for symptoms suggestive of TB: Comparison between migrants & permanent urban residents in Chongqing, China Origin: China	-Mixed methods -Quantitative = questionnaire -Qualitative = Focus groups &semi- structured interviews	- Patient & system/provider factors → diagnostic delays
Okur et al. (2006). Patterns of delays in diagnosis amongst patients with smear-positive pulmonary TB at a teaching hospital in Turkey Origin: Turkey	-Quantitative - questionnaire -Review of clinic records-151 smear- positive pulmonary TB patients selected	-Mean age = 30.4 years; -Mean time delay = 46.4 days; Mean referral delay = 28.9 days; Mean delay in diagnosis = 2.4 days; -Mean delay in treatment initiation = 0.8 days
Yimer, Bjune & Alene, (2005). Diagnostic and treatment delay among pulmonary TB patients in Ethiopia: a cross sectional study Origin: Ethiopia	-Cross-sectional study -Randomly selected TB management units (TBMUs) -384 Smear positive pulmonary TB patients	-Median total delay = 80 days; Median health-seeking period & health providers' delays = 15 and 61 days respectively; Median patients' & health systems' delays: 30 & 21 days respectively
Odusanya & Babafemi, (2004). Patterns of delays amongst pulmonary tuberculosis patients in Lagos, Nigeria Origin: Nigeria	-Longitudinal -141 patients (63% males, 37% females) - Semi- structured questionnaires & interviews	-117 (83%) delayed in seeking help from health facilities > 1 month; - median patient delay =8 weeks; doctor delay = 1 week; Rx delay = 1 week - Patient delay = most frequent & major contributor to overall total delay
Hoa, Thorson, Long & Diwan (2003). Knowledge of TB & associated health- seeking behaviour among rural Vietnamese adults with a cough for at least three weeks Origin: Vietnam	-Population-based survey of a surveillance site in Viet Nam -35,832 newly diagnosed smear + TB subjects -Interviews	-1.6% (559) people =coughing for ≥ three weeks - Mean total delay = 7.5 weeks; 63% patient delay
Godfrey-Fausset et al. (2002). Delay in seeking care <i>Origin: Zambia</i>	-Quantitative: health system approach -427 participants	-Patient delays: patients' recall of symptoms of when cough first started.
Banerjee, Harries, Nyirenda & Salaniponi (2000). Role of traditional healers in TB management Origin: Malawi	-Mixed methods -Qualitative: In-depth interviews with 10 traditional healers; Focus groups with patients & guardians Quantitative: 276 questionnaires	-Approx. 40% of pulmonary TB patients consulted traditional healers before being diagnosed with TB

AUTHOR/S, YEAR, STUDY	METHODOLOGY/ SAMPLE SIZE	MAIN FINDINGS	
Salaniponi et al. (2000). Care seeking	-Quantitative study	-Median delay between onset of cough	
behaviour and diagnostic processes in	-Survey with smear-positive PTB patients	and Dx = 8 weeks	
patients with smear-positive pulmonary tuberculosis in Malawi	-1,099 interviews in 5 hospitals	Diagnosis = 8 weeks	
Origin: Malawi			
KEY : ψ = Decrease/d or less approx. = approximately Rx = treatment \uparrow = Increase/d or more			
& = and + = positive Dx = diagnosis \Rightarrow = greater than \Rightarrow = leading to			

While the studies lacked a nursing focus, they nevertheless provided a foundation for the development of this research project in understanding factors that contribute to delays in diagnosis using mixed methods.

In summary, the studies outlined above have a general consensus that there are significant delays in presentation of TB patients to healthcare facilities with minimum delay periods equal to, or more than one month. The lack of knowledge and delays in diagnosis contribute and exacerbate TB disease to individuals and the general community. However, study results differed on factors that cause delays — a factor that caused delay in one study was a factor that decreased delay in another. Patient-related diagnostic delays were a major contributing factor to total diagnostic and treatment delay. Perception of health services was found to be a more significant factor in causing delays than lack of knowledge about TB disease. The researcher argues that the inclusion and education of private practitioners and the involvement of local people, such as traditional healers, is imperative in early diagnosis and treatment of TB.

Other studies highlighted in Table 2.5 present an analysis of international and national studies, emphasising that lack of knowledge, delays and diagnosis of TB impacts on the patient. These studies provide a representative picture of delay of presentation of symptoms through to diagnosis and treatment of TB. The delays are shown to be due to poor health-care provision from the health-care sector and by the patient's lack of access to health-care facilities, lack of perceptions of disease and symptoms of TB, seeking alternative traditional health-care and financial constraints.

Harries, Nyirenda, Godfrey-Fausett, Salaniponi (2003), presented a summary on how early patients are diagnosed of TB in Malawi in comparison to the other parts of Africa. The authors report median time from onset of symptoms to diagnosis and/or treatment has been reported to be eight weeks in Malawi and Gambia, nine weeks in Zambia, ten weeks in rural South Africa, twelve weeks in Botswana, six weeks in rural Tanzania and two months in Ghana. Perkins et al. (2006), reinforced that in some places where TB is endemic, diagnosis has taken weeks or even months of waiting, consequently increasing costs to individuals and the society. Sadly, "many patients are never diagnosed and contribute to the astonishing number of yearly deaths from tuberculosis worldwide" (p.942).

2.4.2.1 Significance and identified gaps of the research studies

These studies have highlighted significant gender inequalities between men and women in regards to knowledge and access to healthcare; men being more knowledgeable than women. It was also found that people from rural areas had less knowledge of TB and were less able to understand their rights to healthcare and, therefore, remained untreated for a longer period than their urban counterparts. In their study regarding gender and community views of stigma and Tuberculosis in rural Maharashtra, India, Atre et al. (2011) concluded both men and women were disadvantaged in relation to access and knowledge about TB; women being at a greater disadvantage than men. As such, the untreated TB cases contributed to the rates of ongoing TB transmission.

Whereas the studies found delays were contributing to late diagnosis of TB, thereby delaying treatment, it was found that patients sought healthcare relatively early, however, doctor delay was significant and institutional delay was the most important component of doctor delay. Health providers and health systems delays in initiation of treatment contributed to a significant portion of total delay. These delays consequently increase the risk of disease transmission in the community, and where the patient is institutionalised, a prolonged period of infectivity for health-care personnel.

The studies highlighted the need to access a simple and rapid diagnostic test for TB at the lowest level of health care facility. In addition, dialogue among all health providers is a crucial

intervention and need to be encouraged. The studies also emphasised the need for health education about the symptoms of tuberculosis and the importance of early medical treatment and the need for more collaboration between the TB program units and other stakeholders such as private general practitioners (GPs), traditional healers, village headsmen, school teachers and patients who are responding well to treatment in the health sector in order to minimise delays.

Some identified gaps are that the outcome measure of delay and duration of symptoms tended to be self-reported and based on patients' recall and interpretation, which could be tampered by recall bias. Knowledge gaps on rights of rural to urban patients regarding free TB services were also identified. Some studies used small study samples and most patients were from government health care facilities. Mission hospitals, private hospitals, private practitioners such as traditional healers, general curative health facilities, village health stations and county hospitals where most TB cases are diagnosed were not included, making it difficult to generalise the results to all smear-positive pulmonary TB patients. Some village stations and private centres do not offer free services and the impact of such facilities on patients need further investigation. Other delay factors such as ethnic minorities, geographic isolation, middle age and female gender also require further analysis. In addition, some data collection for some studies was conducted over a decade ago and the findings may not be representative of current trends.

The studies discussed above emphasise the importance of education in the recognition of symptoms of TB disease, which would consequently minimise delays in diagnosis and commencement of treatment. In all studies outlined, no Australian studies were found, in addition, the studies analysed lack a nursing focus, highlighting the importance of this project's research into factors that impact on nursing management of TB patients approached from the developed and developing world and addressing nurse and patient perspectives.

2.4.3 The societal, health carers and patients attitudes and perceptions towards TB

This section examines societal, health carers and patients attitudes towards TB as factors that contribute to or exacerbate TB In addition, this section examines how these influence

behaviours of both patients and health care providers. As in the previous sections, the critique will present international, regional, and where possible, national literature.

Weiss and Ramakrishna (2001) asserted that stigma has many associations and is both a historical and social framework with social science and public health implications. They reiterated that stigma has a strong influence on health policy and clinical practice as it contributes to the suffering of patients in ways that they may delay appropriate self-seeking behaviours or may terminate treatment due to reduced self-esteem. They added, "for diseases and disorders that are highly stigmatised, the impact and meaning of the disease may be as great or a greater source of suffering than symptoms of a disease" (p.3). The following studies examine the impact of attitudes and stigma associated with TB and how these influence health-seeking behaviours.

A study conducted by Dodor, Kelly and Neil (2009), examined causes, manifestations and results of TB stigma in an urban district in Ghana. The study investigated how health professionals, not specifically nurses, viewed TB patients and how their attitude impacted on the community and TB sufferers. In addition, it explored feelings and experiences of TB patients and how stigmatisation impacts on case finding and treatment. This was a grounded theory qualitative study that interviewed one hundred and twenty-one individual participants. In addition, the study collected data from twenty-eight focus groups, consisting of members of the community, TB sufferers and health-care workers.

Dodor and Neil (2009) identified eleven core causes of TB stigma: fear of infection; physical frailty of TB patients; association of TB with HIV/AIDS; perceived causes and spread of TB; outdated societal practices about TB; public health practice and discourse; attitudes of healthcare workers towards TB patients; health staff's own fear of TB; self-stigmatisation by TB patients; judgement, blaming and shaming TB patients; and past experiences with TB. Stigmatisation led to isolation and exclusion from activities of people who were infected and negative behaviours of health professionals towards TB patients. The study found that health managers located TB wards in isolated sites of the hospital and failed to adequately provide

equipment and supervision for quality care of the patients. Patients' food was also reported to be improperly handled by hospital staff and deceased TB patients were denied full burial rites.

These behaviours led those experiencing symptoms which may be indicative of TB to not disclose their feelings, not go to a health facility and to contemplate suicide. Most were psychologically isolated from friends and family, which consequently led to late presentation at a health facility and at times contributed to poor compliance to treatment. The authors cite that, unfortunately, this is the case among many TB patients in Ghana. The study signifies the need for increased awareness, education and sensitisation of the illness to the community, healthcare professionals and patients to dispel the myths associated with the disease. This might help in reducing stigmatisation therefore patients would seek health care much earlier, which would alleviate morbidity and mortality from the disease.

A limitation of the study was that it is reported to have incorporated 'health workers'. However, the study does not identify the 'health workers' therefore it is difficult to assess the nursing involvement. Nevertheless, this study draws lessons for nursing staff and provides a benchmark for this research into factors that impact on nursing care.

Bond and Nyblade (2006) endorsed similar experiences in Zambia, where people with TB often suffer from discrimination and stigma, rejection and social isolation. They reported that it is not uncommon for a man to leave his wife if she develops TB and if she is not already married, the stigma attached to TB might prevent a woman from finding a husband. This may cause considerable delay in the diagnosis and case finding of TB. These behaviours may undeniably result in huge costs to the individuals, to the society and ironically, added costs of TB in terms of longer hospital stays associated with late diagnosis. Kemp, Mann, Simwaka, Salanponi and Squires (2007), reported that, in Malawi, "the poor spent 244% of their total monthly income on TB diagnosis, compared with 129% for the non-poor. It is estimated that the poor must work for 2.5 months to recover the costs of seeking a TB diagnosis" (p.582). Campbell and Deacon (2006) confirmed that this is the case in most parts of Zambia and Africa at large. Regular in-service education for health professionals in TB control and management, and addressing the fear of

infection to health professionals in their work settings are some strategies identified to conquer this stigma.

Dodor and Kelly (2009) reported on a study in Ghana where attitudes and behaviours of community members towards TB patients were analysed. Data were collected in nine communities where participants were purposefully selected. Individual in-depth interviews and focus groups were held with sixteen focus groups and sixty-six members of the community. The generated data were analysed using grounded theory techniques and procedures.

The core theme found among the participants was the fear of infection. While they understood that TB was a highly infectious disease that is airborne, they also were ill-advised of other ways of transmission, for instance, physical contact with a person with TB. Some respondents believed that a TB patient should "sit quietly, not dance among the crowd or be shouting and talking like others" (Dodor & Kelly, 2009, p.3). This naturally results in social isolation. Social isolation was also evident when the participants indicated that they would not contemplate themselves or their relative marrying a TB patient. Community members were also of the view that TB sufferers should not "sell in the community" (p.4), causing social isolation, in addition to being financially disadvantaged. The majority of community members also believed TB patients should not be engaged in any official capacity. When it came to close proximity in a situation which was unavoidable, for example, at a funeral gathering (with a TB patient), the participants indicated that they would cover their mouth with a handkerchief, turn their head or sit in the opposite direction of the wind from the patient so that they would not contract the disease.

The study should in a cultural context, and, therefore, may not be applicable to all cultures in Ghana. Nevertheless, it reinforced that communities discriminate against people with TB and isolate them as outcasts of society. Baral, Karki and Newell (2007) reported that TB carries stereotypical views and patients do not disclose the illness for they would transmit TB to others, therefore preferred to not disclose the illness. Patients also did not disclose in order to avoid gossip and discrimination. This may impact on the choices the patient may make, whether to disclose or not disclose the problem; whether to seek or not seek treatment. These

stereotypical views therefore contribute to negative health choices, hence negative outcomes for the patient.

Knowledge, attitudes, practices and choices of communication about TB were also examined in a rural community in Vietnam. Hoa, Chuc and Thorson (2008), selected a randomised sample of 12,143 adults who completed a survey. More than 50% of respondents believed that TB is hereditary. Like the study by Zhang et al. (2006), it was found that a large proportion of the general population had limited knowledge about TB, women less than men. Traditional beliefs also influenced the way participants understood the disease, for example, that the disease is hereditary and, as such, one can do nothing about it. Significant also is the fact that occupation, economic status, education and sources of information played a major role in people's knowledge about the disease. The authors reinforce that 64.6% of the sample population had obtained information about TB via television (TV), whereas 42.7% said that friends and relatives were the main sources of information. It was concluded that TV and loudspeakers were good ways to transfer information. This study is consistent with all the other reported studies, that recognition of symptoms, individual knowledge, attitudes, socio-cultural practices, socio-economical factors as well as social stigma are all determinants of whether a TB patient seeks healthcare or not.

A study by Ottmani, Obermeyer, Bencheikh and Mahjour (2008) further explored knowledge, attitudes and beliefs about TB in urban Morocco. Using passive case finding (where patients present themselves to health facilities for diagnosis and treatment), Morocco is reported to have met and exceeded the international targets for case detection and treatment success rates (WHO, 2006). This study investigated factors that encourage or discourage patients to seek care. Three-hundred and one participants were selected from two Moroccan cities (three community health centres with one government health centre specialising in management of TB and thoracic diseases) respectively. This population consisted of confirmed TB patients, TB suspects and a group of patients deemed to represent the general population in that they presented to the same health facilities but had illnesses other than TB. TB patients were given an open-ended questionnaire, which aimed to understand their views of the illness and any issues they may

have faced. Non-patients were given a closed questionnaire, which intended to investigate popular views about TB.

It was found that only 20% of patients indicated that they were suffering from TB. 40% of the TB population delayed in seeking treatment for one month or more. However, 98% of these patients were committed to finishing their treatment, though only 38% were aware of how long the treatment regime would take. Only 9% of non-patients understood that TB is an infectious disease. TV, radio and newspapers were found to be the main sources of information (43%). 42% knew about TB from word-of- mouth. 85% of TB suspects indicated that they had received no education from the health services.

Findings of this study suggested that lack of knowledge is paramount in making decisions about whether to seek healthcare or not. The study also highlighted that there were significant issues of stigma and prejudice against TB patients, with only 27% of non-patients stating that the larger community does not accept TB patients, 32% believing that they should avoid TB patients altogether. Again, women tended to be most affected, with 54% of non-patients stating that a woman with TB should not marry and 18% believed that if a woman is married and has been found to have TB, she should be divorced by her husband. The researcher asserts that while this study affirms that knowledge, stigma and utilisation of health services are essential factors that impact on health outcomes of TB patients, it should be noted that the population sample was small. While the study has allocated the participants into three groups, i.e. (patients, TB suspects and non-patients), it does not explain how many participants represented each group. Different tools utilised for the different groups (i.e., open-ended and closed questionnaires for patients and non-patients respectively) was also seen as a limitation of the study.

Zhang, Liu, Bromley and Tang (2006) explored perceptions and health-care seeking behaviours among poor rural communities in Mongolia. This was a mixed methods study. Participants included one hundred and five farmers, twenty focus groups and six-hundred and fourteen randomly selected participants who completed a questionnaire. Data was collected in three poor counties which had high prevalence of TB. The study found that there was significant lack of knowledge among participants, especially women, young people, low-income groups and

those with less education. Participants were misinformed about the transmission of TB and only 40% understood that close interaction with TB patients is a risk of transmission of the illness. 70% of the participants indicated that they could not afford the cost of TB treatment therefore they could not either start or complete treatment.

It was found that TB carried heavy social stigma, for instance, it impeded the prospects of marriage. All farmers reported to have commenced on some self-initiated treatment or sought treatment from less qualified village healthcare providers. This study, yet again, highlights the significance of knowledge which, in the end, influences health-seeking behaviours — where patients might opt to seek treatment earlier if they were well informed about the disease. Again, this contributes to the type of outcomes for the patients.

An ethnographic investigation by Joseph, Waldman, Rawls, Wilce and Shrestha-Kuwahara (2008) discovers perceptions of TB among Mexicans living in the United States of America (USA). As pointed out earlier, TB cases in the USA have been decreasing and 54% of new cases are foreign-born (CDC, 2004). Structured, in-depth, open-ended interviews were conducted in the Spanish language by bicultural and bilingual researchers. Fifty Mexicans were recruited from two cities, Atlanta and Denver, from TB clinics and surrounding communities. The choice of these cities was based on local epidemiology, large concentration of foreign-born persons, local and national need for TB-specific cultural information and the willingness to participate. The study aimed to elicit attitudes, behaviours, beliefs and experiences of TB patients. The sample included half male and half female participants aged over eighteen years of age. Half the sample had resided in the US for less than five years and the other half for more than five years.

It was found that 66% of the participants correctly identified that TB is transmitted from person to person even though some incorrect mechanisms were identified, for example, kissing or sharing food utensils. More participants from Denver identified incorrect mechanisms than the ones from Atlanta. Participants who were not English-literate and not conversant in English believed that they were at lower risk of contracting the illness than their English-speaking counterparts. Almost all respondents acknowledged that they would see a medical doctor if they thought they had TB and about 64% indicated that they would combine traditional (herbal)

medicines with Western therapies. Almost all participants affirmed that having TB would change how a person was treated by others and over half believed they would change how they felt about themselves if they had TB because the disease is associated with personal shame.

Whereas the participants had received education about TB, almost all (96%) wanted more information on TB pathology, transmission and access to treatment and services. The study expresses that TB knowledge varied across the participants, perception of risk of infection and transmission was low. Nevertheless, the study concludes that Mexicans are not isolated in their perceptions and understanding of TB. On the part of healthcare workers, missed opportunities for patient education during screening were apparent, with 63% of those screened receiving TB information. It is noted, however, that the study sample was small and not randomised therefore the results cannot be generalised.

As has already been stipulated, TB disease carries many stereotypes within many communities. As such, while a person may experience signs and symptoms of the illness, they may not disclose these for fear of discrimination or isolation. A study by Zolowere, Manda, Panulo and Muula (2008), examined the experience of self-disclosure among TB patients in rural Malawi. After an in-depth interview of thirty-two patients aged between 22 and 49 years, it was found that the majority of the patients disclosed their status to only close family members such as spouses and parents; people who they deemed to be supportive. Interestingly, only few of them revealed their illness to their children.

The study concluded that patients felt they could not disclose their diagnosis as it brought a lot of stigma, as the disease is associated with HIV infection. Non-disclosure potentially exacerbates the problem of disease transmission and prevents "informed decision-making regarding patient management and support" (Zolowere et al., 2008, p.2). Zolowere et al. affirmed that if patients felt they were supported and not stigmatised, they would be more inclined to disclose their illness and hence receive the help they need much earlier. Atre et al. (2011) reinforced that stigma associated with TB is a strong barrier to health-seeking behaviours and a cause of suffering for patients. It is further argued that TB patients conceal the illness because of fear of losing social status and avoidance of hurtful behavior by the community. Community views

acknowledged that TB sufferers share a psychological burden of unfulfilled social responsibilities and experience unjustified social distance and isolation (Atre et al.). Cramm, Finkenflügel, Møller and Nieboer (2010) elaborated that stigma influences TB patients' decision in health-seeking behavior and adherence to TB treatment. Table 2.6 provides a synopsis of studies on attitudes and perceptions towards TB as discussed above.

Table 2.6: Summary of studies on attitudes and perceptions towards TB

AUTHOR/S, YEAR, STUDY	METHODOLOGY/SAMPLE	MAIN FINDINGS
-Dodor, Kelly and Neil (2009). Causes, manifestations & results of TB stigma in an urban district in Ghana. <i>Origin: Ghana</i>	-Qualitative, Grounded theory -Interviews with 121 participants; 28 focus groups	-Infected people adversely stigmatised and isolated; denied access to adequate equipment and supervision; their food improperly handled & deceased TB patients denied full burial rites
-Dodor and Kelly (2009). Attitudes& behaviours of community members towards TB patients. <i>Origin: Ghana</i>	-Qualitative, Grounded Theory -In-depth interviews with 66 community members; 16 focus groups	- Fear of infection; Social isolation -Financially disadvantaged: TB sufferers not to sell in the community -Not engage in official duties or in Marriage with TB sufferers
Ottmani, Obermeyer, Bencheikh and Mahjour (2008). Knowledge, attitudes and beliefs about TB in urban Morocco Origin: Morocco	-Quantitative; open- ended questionnaire; Non-patients - a closed questionnaire -301 participants	-Lack of knowledge of TB -98% of participants found television (TV), radio and newspapers as major sources of information -TB held negative stereotypes
Zolowere, Manda, Panulo and Muula (2008). Experience of self- disclosure among TB patients in rural Malawi Origin: Malawi	-Qualitative -In-depth interviews -32 patients	-Patients could not disclose their diagnosis stigma, as the disease is associated with HIV infection - Majority of patients disclosed their status to only close family members such as spouses and parents; not their children
-Joseph, Waldman, Rawls, Wilce and Shrestha-Kuwahara (2008). Perceptions of TB among Mexicans living in the United States of America (USA) Origin: USA	-Qualitative: Ethnography -Structured, in-depth, open- ended interviews -50 Mexicans	-66% had correct knowledge of TB transmission ->More participants Denver identified incorrect mechanisms than ones from AtlantaNon-English speaking: believed they had lower risk of TB than English-speaking Almost all participants: would treat a person differently if they had TB - >50% would change how they felt about themselves if they had TB
-Zhang, Liu, Bromley and Tang (2006). Perceptions and health-care seeking behaviours among poor rural communities in Mongolia Origin: Mongolia KEY: >= greater than	-Mixed methods -Twenty focus groups (105 farmers) -Questionnaires- 614 randomly selected participants	- Lack of TB knowledge -Social stigma was paramount -70% could not afford cost of treatment -Sought alternative treatment (traditional)

While the above studies outlined attitudes and knowledge about TB, Dodor et al. (2009) and Zhang et al. (2006) were more influential to this study. Dodor addresses traditional beliefs that are congruent with the Malawian culture whereas Zhang et al. investigated perceptions and

health-seeking behaviours of TB patients. These were congruent with the current investigation, therefore, the studies provided a platform for further enquiry.

In summary, this section has presented a number of studies on attitudes and perceptions towards TB by the patients, healthcare workers and the general community. It has explored the significance of knowledge of TB transmission and symptoms to decrease the spread of the disease; education to change perceptions and social stigma associated with TB and the need to make TB services affordable and accessible; especially targeting disadvantaged populations such as people in rural areas, low-income groups, those with less education, women, the frail and elderly in the communities. This could be done through health promotion expansion of the DOTS strategy (Chemtob et al., 2003; Zhang, Liu, Bromley & Tang, 2006; Dodor & Kelly, 2009).

Rundi (2010) argued that TB is still a stigmatising disease and affects patients in different aspects: physical, psychosocial, financial and life practices. Rundi reinforced that most public reactions to TB patients are based on lack of knowledge and misconceptions about TB, therefore, health education is imperative to both patients and the general community. Studies in this section negate nursing focus, as did studies analysed in earlier sections of this thesis. Therefore, the need to investigate factors that impact on nursing management of TB patients-the essence of this research – is reinforced. Figure 2.2 (below) summarises the discussion on the impact of attitudes and perceptions towards TB on patients.

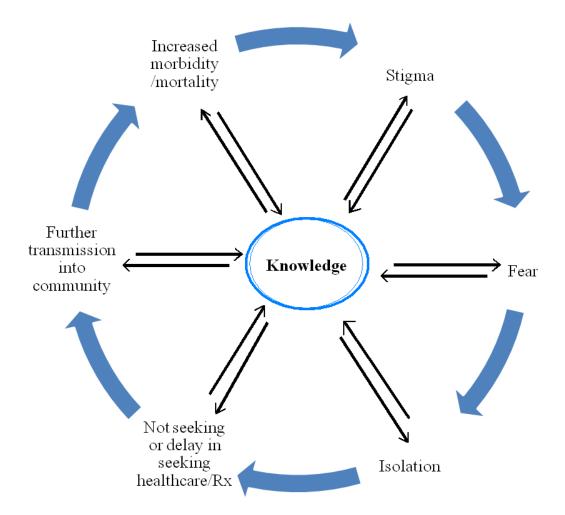


Figure 2.2: Summary of themes identified on attitudes and perceptions towards TB

This figure highlights that knowledge is central to fighting TB on a personal, community, national and international level. Lack of knowledge of TB regarding transmission and care and treatment leads to stigma for the sufferer. In turn, stigma leads to fear and isolation which delays patients from presenting themselves for healthcare, consequently exacerbating symptoms and causing further infections in the community. In the next section, the analysis will explore the nurses' roles and management in the care of TB patients.

2.4.4 Nurses roles and nursing management of TB in Australia and Malawi

This section scrutinises the various roles that nurses' play in the care of TB patients in light of the research questions 3: Are there significant relationships between patients and nurses characteristics and their perception of nursing care in Australia and Malawi? This question will be examined in chapter four as the researcher found no literature to review this question in this chapter. 4: What are the characteristics, qualifications and experiences of nurses caring for TB patients in Australia and Malawi and 5: What are nurses and patients perceptions about: (i) care given and received / provided in these facilities; (ii) impact of nursing care on patients' well-being; (iii) availability and access to resources to improve quality of care and (iv) changes needed to improve quality of care of TB patients in these facilities?

Nurses' roles differ according to work settings. Nurses are usually the first contacts of care and have the most frequent patient contact and responsibility for ongoing monitoring of patients. They play a pivotal role in recognising and responding to clinical changes in patients (Liaw, Scherpbier, Yobas & Rethans, 2011). Nurses are identified as: caregivers/care providers, teachers, counselors, change agents, advocates, managers and researchers. Caring is deemed to be the very heart of nursing (Royal College of Nursing, 2008). Within the healthcare team, nurses significantly contribute to the patients' recovery and maintenance of health and where recovery fails, they comfort and support the dying and their families. Nurses' roles include health promotion and chronic disease management, in addition to providing ongoing care to the sick (American Association of Colleges of Nursing [AACN], 2007).

Sibbald, Shen and McBride (2004), identified two models working in the provision of nursing care. These were identified as substitution and supplementation. Substitution is explained in terms of a nurse replacing a doctor; for example, nurses in remote areas have long acted outside the boundaries of the nurse's role, such as prescribing medications or ordering pathological tests. This may be regarded as substitution. Supplementation is defined as nurses working with doctors as part of a team. In the application of either models i.e., substitution or supplementation, teamwork is crucial to the improvement of patients' health outcomes, as reinforced by Mittman (2001), who endorse that teamwork is necessary for optimising quality and safety in the care of hospitalised patients. The researcher asserts that this does not only relate to hospitalised patients, but to patients in all settings.

Teamwork is no different in the care of TB patients. Nurses are a major part of the healthcare team in the care of this group of patients. Their roles include primary health care, where nurses are involved in case detection in different settings such as within families and communities; chronic disease management where they are involved with follow-up of individuals to ensure compliance with drug therapy and providing ongoing care in education about control of transmission of the disease to families and to the community.

A registered nurse elaborated on the role of the TB nurse (presented verbatim to capture the essence of the meaning):

Nurses trained in general hospital and unfamiliar with the care of TB, will find that a little practical knowledge from the field of psychology is of greatest value when caring for such cases, and the nurse has real difficulty in appreciating [the patient's] viewpoint, unless she grasps his mental attitude.

In the first place the nurse must take into consideration the fact that the patient has been through a period of severe mental suffering after being informed of his condition. The outcome of which is irritability, depression, a very self-centred state of mind and a feeling that he has been cut right off life. Therefore, he is very much in need of cheerful encouragement.

The nurse must interest herself in the patients' welfare, gain his confidence and try to overcome his habit of letting his mind dwell continually on his symptoms by arousing interest in the surroundings, and outside affairs. [And,] minimise visitors but encourage visitation. It is absolutely essential that he be kept free from worry and anxiety if possible; mental rest as well as physical being necessary to build up his resistance.

It may appear to the nurse who is accustomed to caring for patients with acute illnesses and not consulting the about treatment, that the tuberculosis patient is dictatorial in suggesting changes. She should realise that most TB patients are well-informed by doctors regarding their condition consequently that attitude is not unreasonable and, if the nurse is willing to cooperate in small matters which are not vital, things should adjust themselves harmoniously (Kelshaw, 1930, pp. 12-13).

Kelshaw wrote those words over eighty years ago in her appeal for nurses in general practice to reform TB nursing care. Perhaps their most staggering revelation is that despite the essence of the traditional role of 'caring' for general nurses, they have difficulty in appreciating the 'viewpoint' of TB patients. Kelshaw therefore highlighted the enormity of the responsibilities that general nurses have in order to understand the intense psychological demands of TB patients. It is only through this understanding that nurses can provide optimal care to TB

patients. From this argument, it is apparent that while physical needs are just as vital in the care of TB patients, psychological support from the nurse is paramount in the provision of quality of care to TB sufferers. This, undoubtedly, may be taxing on the nurse's time, especially in areas with shortage of staff, such as Malawi.

It was discussed in chapter one that Australian nurses have many opportunities to choose a nursing specialty after undergraduate study. However, because of the low incidence of TB, academic institutions in Australia do not offer specialisation in TB care. Consequently, general nurses provide TB care and learn 'on the job' through practice and in-service educational sessions. Similarly, because of the shortage of nurses and lack of specialty training in TB care in Malawi, general nurses provide TB care on the wards. Nevertheless, Australian nurses utilise the supplementation model (Laurant, Reeves, Hermens, Braspenning, Grol & Sibbald, 2007), where nurses work with doctors as part of the team. In contrast, substitution – nurses taking the role of a doctor – is the usual practice in Malawi due to lack of medical staff. The researcher contends that these nurses would not have appropriate qualifications to carry out medical duties, thereby posing a risk to both the patients and the general community.

The care of TB patients is facilitated by many other factors that can hinder or enhance effective nursing care. These factors are systemic, physical and resource-dependant. The major challenge in Malawi was associated with inadequate resources; human or material. The infrastructure related to ward layout, inadequate beds and lack of isolation rooms, which were major barriers to effective nursing care. The wards were a Nightingale-style and beds separated by curtains, if any, (which did not provide privacy). The rooms were mainly overcrowded with some patients sleeping on the floor, posing a major risk of nosocomial infections. There were inadequate supplies of personal protective gear such as masks and gowns, which exposed staff and the community to occupational health risks and the risk of contracting TB. Norr et al. (2006), reinforced that *health system barriers* such as inadequate workers, supplies, training as well as *personal barriers* such as risky occupational and personal behaviours all contribute to ineffective health care delivery (p.318). This scenario was more applicable in Malawi than in Australia.

Another barrier to effective TB nursing care relates to the stigma and discrimination towards TB patients, which is reportedly among the greatest barriers to preventing more infections, providing adequate care, support and treatment (Advocacy, Communication and Social Mobilisation [ASCM], n.d.). This situation is applicable to both Australia and Malawi, as elaborated in chapter one, that TB patients were isolated, which was the major factor which led to the development of this project. Another identified hindrance in Malawi was the lack of policies, poor regulation and administration regarding infection control practices for example, some patients being nursed on the floor because of shortage of beds.

A lack of clear policies and guidelines for TB patient care in healthcare institutions was discussed earlier in this thesis. A shortage of doctors, nurses and laboratory technicians, such as is experienced in Malawi, means TB patients stay in hospital for excessive periods before a diagnosis is made. As a result, hospital staff experience an increased workload and patients needs are not addressed in a timely manner. In Australia, a shortage of community nurses results in increased stress and less time spent with patients, and in consequence their needs are not adequately addressed.

Dodor & Kelly (2009) commented that TB patients understand the illness from the biomedical model and perceive themselves as disease carriers. As such, they isolate themselves and become secretive about their illness resulting in more psychological isolation yet healthcare workers view this behavior as non-compliance. It is therefore critical that nurses caring for TB patients focus and address the psychological needs of the patients as this may have an impact on compliance with treatment, resulting in negative outcomes of the patients. Thakkar (2007) argues that management of pulmonary TB requires "holistic care, motivated patients, dedicated healthcare workers and regular monitoring" (p.2). Being the crucial component of that teamwork, nurses need to provide support, motivate patient and encourage them to adhere to TB management strategies for better health outcomes for all – the patient and the community at large.

It is apparent, after discussing the research literature, that the acuity levels of TB are increasing due to factors such as HIV/AIDS, multi-drug resistant TB and extensive drug-resistant TB and,

therefore, medical management needs to be greater. As previously noted, there have been many studies on the medical management of TB patients. However, the reality of nursing involvement in the management of this group of patients is unclear.

In the United States of America (USA), it was reported that with the erosion of the public health systems, many larger cities replaced public health nurses with outreach workers, responsible to follow-up patients with TB. This eliminated the clinical case management model (which combines in-hospital education and Direct Observation Therapy (DOTS) strategy. This model was deemed to be effective in the improvement and compliance of tuberculosis patients thereby in the control of tuberculosis-epidemic situations (Hsieh et al., 2007).

With the resurgence of TB, however, the decline of TB programs severely limit the ability to safely monitor TB patients during the six to twelve months of chemotherapy. Echoing the sentiment was Mulholland (2004), who stated "the current numbers of TB clinical nurse specialists also fall dramatically short of the (BTS) Joint Tuberculosis Committee recommendations that there should be one nurse for every 40 TB patients. Unless the numbers of TB nurses are increased, we will continue to see an inexorable rise in TB in London" (p.1).

Another given example is New York City, where outreach workers replaced public health nurses (American Nurses Association [ANA], 2004). This city reported that 89% of patients discharged from hospitals were lost to follow-up and failed to complete therapy. Conversely, in Boston, where a nursing care management model is used in TB control with the assistance of outreach workers, rates of completion of therapy are frequently above 90% and TB cases are beginning to decrease (ANA). The care management model is collaborative between managers and clients in order to identify and facilitate options and services catered for individual needs. This, in turn, minimises duplication and fragmentation of care, which results in better and cost-effective clinical outcomes (White & Hall, 2006).

While it is acknowledged that Boston may have had success in management of TB patients, there is limited information as to what degree the nursing model is successful in the delivery of care, in comparison to the outreach workers. The number of patients who were investigated in both cities and the duration of the investigation is indistinct. It is not clear whether all public

nurses in New York were replaced by outreach workers, or only by a certain percentage. A replicated investigation in other cities could provide more insight into the impact of nursing on TB care. These arguments reinforce the reason for this study into factors that impact on nursing care of TB patients from both nurses and patients perspectives.

The previous paragraphs have addressed the historical roles of the nurse and further elaborated on how this role can be specifically incorporated into TB care. It has pronounced that provision of holistic care is paramount if nurses are to be agents of change in reducing morbidity and mortality rates from TB. Following is a brief discussion on management of TB.

2.4.5 Management of TB

A number of studies have investigated the medical management of TB patients. These studies are mainly focused on multi-drug resistant TB (MDR-TB) and HIV/AIDS co-infection with TB, how TB is diagnosed, and the effectiveness of chemotherapy as set by the World Health Organisation through the implementation of direct observed treatment – short course strategy (DOTS), in areas with high incidence of TB. The WHO, at its assembly in Geneva in 2000, set targets for case detection of infectious TB at 70% and treatment success rate at 85% by 2005. However, it is reported that while the treatment is successful at 82%, the case detection is very low, at 45% globally (Xu, Diwan & Bogg, 2007). Case detection being so low means more patients are in the community without treatment, which makes the spread of TB a self-perpetuating problem.

In 2000, the United Nations Summit stipulated Millennium Development Goals (MDGs) with these frameworks: (1) eradication of extreme poverty; (2) promotion of gender equality and empowerment of women; (3) reduction of child mortality; (4) improvement of maternal health; (5) combat HIV/AIDS, malaria and other diseases; (6) ensure environmental sustainability and (7) develop a global partnership for development (UN Summit on Millennium Development Goals, 2000). Malawi concurs with these goals and added one more i.e., achieving universal primary education. Whereas all these goals are essential, it is the fifth target (combat HIV/AIDS, malaria and other diseases), that is of great interest to this discussion as, within this target is the management of TB using Directly Observed Treatments - Short Course (DOTS) to control TB world-wide. The expansion of this is that the DOTS policy has five pillars: political will; diagnosis

of TB by sputum; availability of TB treatment all the time; record and report and direct observed therapy (UN Summit on MDGs). In its report of 2010, the Ministry of Development Planning and Cooperation (MDPC) in Malawi stated that the country is set to achieve its MDGs target number five by 2015, as the proportion of TB cases under DOTS is currently at 86%. Arguably, this is deemed to be very successful as the targets for the WHO are at equal or greater than 85% (Frieden & Sbarbaro, 2002).

The DOTS strategy has been applied in both Malawi and Australia, with Australia acknowledging that there have been "suitable modifications for a low incidence industrialised country" (Communicable Disease Network Australia, 2002). Lawn, Bekker, Middelkoop, Myer and Wood (2006) discuss that while Africa has 11% of the world's population, it accounts for 27% of global incidence of TB and 30% mortality rate. Whereas the DOTS strategy was effective in the past, it alone is failing to contain the African epidemic and there is a need for complimentary strategies. Like Australia, Malawi, in adopting the DOTS strategy, needs to 'modify' it according to the specific needs of the country. The authors suggest age-specific interventions, such as prevention of mother-to-child transmissions, voluntary counseling and HIV testing in prenatal clinics, administration of anti-retroviral therapy to infected pregnant women and prophylactic administration of isoniazid to household contacts of adults with TB. While these interventions were specifically for South Africa, Malawi is as badly affected with the TB epidemic, therefore, could benefit by adopting the same proposal.

A retrospective study of TB registers by Salaniponi, Nyirenda, Kemp, Squire, Godfrey-Faussett and Harries (2003) discussed the management outcomes for patients with recurrent TB under routine program conditions in Malawi. The authors reported that "we are unaware of national studies on the management and outcome of patients with recurrent smear-positive pulmonary (PTB) from high HIV-prevalent areas in Sub-Saharan Africa" (p.948). Malawi is currently experiencing a devastating epidemic of HIV / AIDS, complicated with an epidemic of TB.

Though falling short of the 85% target rate as set by the WHO, Malawi is a leader in TB treatment in Sub-Saharan Africa with cure rate of 73%, reported to be a real achievement, taking into account the big challenge of HIV (Salaniponi et al., 2004). Mortality rates are

reported to have reduced by 1% due to decentralisation of the system. Bed-occupying rates have reduced from 400% to 60%. Decentralisation of the system also brought the costs down from USD\$100 to USD\$25 per patient (Salaniponi, Nyirenda, Godfrey-Faussett & Harries, 2003). Salaniponi stated that this is attributed to the fact that "we made it clear that we are going to be bent on operational research" (2002, p.1). At that time the cure rate was 60% and with technical assistance, it rose to 65%. This current study developed out of these achievements as the researcher was curious to discover how Malawi, with very limited resource systems, became a leader in TB treatment.

Australia and Malawi are united with the rest of the world to fight the catastrophic outcomes of TB. In the quest to working towards achieving the Millennium goals, it must be pointed out that nursing contribution to these efforts and successes has very little documentation. This justifies the need to further explore the factors that either contribute to, or hinder the management of TB patients from the perspective of nurses and patients, from the developed and developing world; the very essence of this study.

2.5 Summary

The literature review has presented four major areas in TB care: Risk factors, knowledge and delayed diagnosis, attitudes and perceptions towards TB patients, and nurses' roles and management in TB. Factors that contribute to delays in the diagnosis thereby delaying commencement of treatment for TB have been emphasised as a major issue. Factors such as lack of knowledge or awareness about the illness, geographical isolation, financial constraints and traditional beliefs that individuals may hold, are patient related. Other factors are related to healthcare facilities that lack human resources, lack of knowledge and expertise related to disease symptoms and time delays between diagnosis and commencement of treatment.

In addition, this chapter has examined the stereotypical views portrayed by healthcare professionals, which contribute to delays in diagnosis thereby delays in commencement of treatment with consequent negative health outcomes for TB patient and the general community. As demonstrated by the few studies outlined in this chapter, it is apparent that TB

has very huge impact on individual sufferers, their families, societies and the world at large not only in a physical sense, but also socially, psychologically, economically and even spiritually. Most of the studies neglect the involvement of the individual sufferer and allow little negotiation within the convoluted systems of care. In this sense, it is evident in the literature that this negates the fact that healthcare is multi-faceted and, as such, it is vital that efforts are made to investigate and submit shared knowledge and care plans which incorporate the social and cultural focus on TB care as well as in the global arena of the developed and developing worlds.

Orr (2011) reiterated that many studies addressing adherence to TB care are grounded in the opinion that the problem rests with the patient. The author argues that adherence is unlikely to improve unless there is an integrated approach to healthcare; the individual being the centre. TB care requires multi-sectorial and interdisciplinary interventions. While there have been a few studies addressing TB care, and after an extensive and critical analysis of the literature has been exhausted, key points and knowledge gaps in the factors that impact on nursing care of TB patients were pronounced; providing justification for the conduct of this research. It is apparent that nurses, being at the forefront of healthcare, are placed in a unique position to strongly advocate, educate and assist patients in the fight against TB.

CHAPTER THREE: METHODOLOGY, METHODS	S AND PROCESSES

SECTION A: Methodology

3.1 Introduction

In this chapter, an exploration of the conceptual framework and theoretical principles for the research will be put forward. The methodological framework chosen for the study was critical paradigm, embedded within principles of primary health care (PHC) and utilising a mixed methods approach. The lens of critical paradigm allowed for a deep focus on patients with TB who are often marginalised by their condition and socio-political circumstances. Furthermore, as the theoretical constructs of this paradigm are centred on acknowledging and validating the voice(s) of all participants, deep listening to their experiences was important to the study. The chapter will further explore the decision to incorporate PHC principles and the relevance of mixed methods in the investigation. Specifically, the discussion will focus on this research design, providing a deeper understanding of the factors that enhance or hinder the care or management of TB patients from both the patients' and nurses' perspectives. What follows are the paradigmatic and methodological decisions for this research project.

The chapter is divided into two sections. The first section is the methodology and the latter section explores the methods and processes. Firstly, the chapter will present an overview on the development of research knowledge in order to contribute to the understanding of the methodological framework.

3.2 The development of research knowledge: An overview

In generating knowledge, researchers use methods from different paradigms. All quantitative and qualitative research is based on underlying assumptions regarding what constitutes 'valid' research and which research methods are deemed appropriate to a study (Richardson & Robinson, 2007). Irrespective of the type of study, the following are fundamental issues to be considered: the purpose of the research and questions; the nature of problems or issues to be investigated; what is likely to provide 'best fit' for research process and outcomes; the knowledge and experience of the researcher and the need or not, for generalisability (Schneider

et al. 2007, p. 22). All these points are critical for the researcher in their determination of an appropriate conceptual framework and the development of research questions.

In this research study, the purpose and development of the research questions were guided by the principles of PHC which include health promotion and partnership, in addition to the aim of empowering a marginalised group of TB patients. To explore the social reality of TB for patients and nurses, the research questions were devised and the conceptual framework was identified. The nature of the problems to be investigated involved both an objective and subjective interpretation of the social world of the participants. This research utilised a quantitative and several qualitative methods. In this study, the qualitative methods enriched the quantitative method and the design was intentionally triangulated to highlight the strength in each approach.

The researcher's clinical experience and knowledge with TB patients contributed to the development of the conceptual framework and research questions. Specifically, as a TB nurse, the researcher's personal and professional experiences as well as the literature reviewed in chapter 2 confirmed that TB patients are marginalised and isolated. Therefore, what was likely to be 'best fit' was research embedded in a critical emancipatory paradigm. The researcher was strongly aware that transformation and positive change of patients and nurses was pivotal and also possible from the devised research questions. Consequently, understanding of both patients' and nurses' experiences of their social world was crucial if emancipation was to occur (Rose & Glass, 2008).

3.3 Conceptual framework

A conceptual framework is described as a set of broad ideas and principles taken from different and relevant fields of study and used to construct knowledge about a particular topic (Smyth, 2004). However, it needs to be emphasised that:

 a framework is the construction of knowledge bound by the life-world experiences of a person, therefore, should not be attributed power that it does not deserve;

- the nature of the framework means that it consciously, or unconsciously informs thought and practice by increasing personal sensitivity to notice particular occurrences so must be accounted for;
- no researcher can expect that all data will be analysed utilising the framework without the risk of limiting the results from the investigation (Mason, 2002).

The researcher took all the above-mentioned recommendations and suggestions into consideration in that she did not allow her 'life-world' experiences to mask those of the participants. She considered her view of the social world and endeavoured to remain open, sensitive and non-judgmental to experiences of the participants — allowing the nurses' and patients' social position to be explored. This notwithstanding, she was aware of her own experiences, knowledge and inherent subjectivity and its potential and actual role within the research process. For instance, she believed in subjectivity and declaring her own beliefs as a means to sustain trust with participants (Elmir, Schmied, Jackson & Wilkes, 2011).

Methodology contributes further to overall research design and how the researcher explores and investigates 'knowledge' (Minichiello, Sullivan, Greenwood, & Axford, 2003). Methodology is defined as the "research approaches with theoretical assumptions underlying the choice of methods and processes in generating and validating a particular form of knowledge" (Taylor, Kermode & Roberts 2006, p.395). The three concepts together form a paradigm or conceptual framework; a position or the way one understands and acts in the social world. Paradigms encompass philosophical assumptions which are decisions made using values and principles that derive from background knowledge of a subject; the most significant assumptions being those which relate to the underlying epistemology which guides the research (Vasilachis de Gialdino, 2009). Below is a diagrammatic summary of the three concepts (adapted from Schneider, Elliot & LoBiondo-Wood, 2003; Glass, 2000).

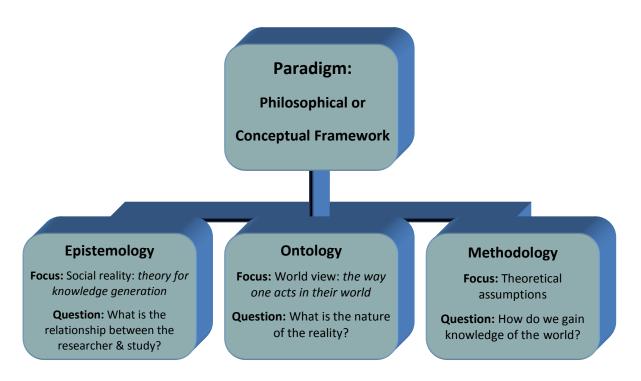


Figure 3.1: Focus and questions of the concepts

In summary, the diagram above elaborates on the focus and questions one needs to ask in the application of the concepts of epistemology, ontology and methodology, which is the 'umbrella' of the paradigm. The following section discusses the different research paradigms and philosophical approaches as well as the justification of the choice of a paradigm applied for this study.

3.4 Approaches to research

It is pointed out that "every philosopher will say they know what are philosophical problems, although, like biologists trying to define 'species', they do not agree on a singular solution" and they concur that "it is really hard to describe, let alone define, philosophy" (Wilkins, 2011, p.3). However, the two broad categories of philosophical frameworks are positivism, referred to as quantitative, and qualitative. These have shaped research inquiry since the nineteenth century (Little, 2009). The quantitative philosophical approach is deductive and objective. Whereas the

qualitative philosophical approach is inductive and subjective in the creation of knowledge. It explores subjective human experiences (Minichiello, 2004; Taylor, 2006).

3.4.1 Positivist and post-positivist theories

Guba and Lincoln (1994) put forward four paradigms or frameworks for research: positivism, post-positivism, critical theory and constructivism. However, Schneider et al. (2007) proposed three categories, which originate from the principal research epistemology: positivist, interpretive and critical approaches. For the purposes of the thesis discussion and research application, the latter will be applied.

Table 3.1 below (adapted from Smith, 2005; Schneider et al., 2007) outlines the differences between positivist (quantitative) and post-positivist (qualitative) approaches in terms of key concepts, methodologies and methods. Under the post-positivist arena are interpretive and critical/emancipatory frameworks. This section expands on these two concepts and the choice, rationale and application of critical theory (post-positivist) to this current study will be discussed.

Table 3.1 Research paradigms: Key concepts, methodology and methods

V5V 60116555		POST-POSITIVIST		
KEY CONCEPTS	POSITIVIST	Interpretive	Critical (Emancipatory)	
Assumptions	Reality: objective, measurable and & predictive	Reality: Only through social constructions e.g., language, consciousness & shared meanings	Reality: Historically constituted and that it is produced and reproduced by social, cultural, economical and political circumstances	
Methodology	Experimental, quasi- experimental, Correlational	Phenomenology, grounded theory, exploratory/descriptive, case study, historical.	Feminist research, action research, critical ethnology, critical ethnography.	
Data collection	Experiments, closed surveys & interviews	Open observations or interviews, focus groups	Open observations, individual interviews, focus groups	
Researcher position	Distant	Close	Close	
Aim/s	Test theory; attempt to increase the predictive, understanding of phenomena	-Describe, explore, understand and generate meaning	-Emancipation, empowerment & equality of participants →change social structures	

Smith (2005) pointed out that positivist research theory is congruent with quantitative research where reality is predicted, objective and measurable. It is deductive and examines cause and effect relationships. This method of inquiry has been widely used in scientific, medical and health research (Bryman, 2006). Because this approach is deductive, it does not explore the complexities and subjectiveness of human experiences (Sale, Lohfeld & Brazil, 2002). As such, qualitative approaches can complement quantitative research and provide a greater understanding of human behaviours.

Contrary to the positivist theory, post-positivists address reality through social construction rather than the objective view. This reality is subjective and investigated through meticulous approaches (e.g., grounded theory), which aims at having a deeper understanding of human behaviours (Ryan, 2006). This is in line with the qualitative inquiries. Post-positivists paradigms consist of interpretive and critical approaches which will be discussed below.

3.4.2 Interpretive theory

Interpretive approaches can also be referred to as naturalistic or constructivist paradigms. They aim to describe, understand and generate meaning within a social or practice context (Schneider et al., 2007; Smith, 2005). They often focus on lived experiences and explore a phenomenon (Taylor, Kermode & Roberts, 2006). McQueen and Zimmerman (2006) stated that interpretive research is a research design based in the social sciences and is guided more by the researcher than the participant using pre-planned series of questions on a topic. Denzin and Lincoln (2003) also argued that in interpretive paradigms, the researcher is urged to ask questions as well as make interpretations of a situation. In other words, interpretive researchers are interested to learn how individuals engage in their social environment and make sense of this interaction. Schneider et al. (2007) stated that the interpretive approach is not fixed and is made of natural events occurring within the environment. They elaborated further that the interpretive approach is sensitive to context, uses a variety of methods to understand social life and is more concerned with achieving an empathic understanding of feelings and world views than with testing laws of human behaviour (Schneider et al., 2007). In essence, interpretive

approaches seek to examine and learn how individuals interact with their social world. This emphasises the subjectivity of this research paradigm.

3.4.3 Critical theory

Critical theory, also termed emancipatory, assumes that reality is constituted, produced and reproduced by social, cultural, economical and political circumstances (Yolles, 2006). It stems from a history of social oppression due to economic, gender or ethnic identities (Turris, 2005). Consequently, it aims to bring about change to groups of oppressed or marginalised people (Rose & Glass, 2008; Glass & Davis, 1998). Its focus is to enable "empowerment, emancipation and equality for research participants and to challenge and change social structures" (Schneider et al., 2007). Like interpretive theory, critical theorists investigate and/or explore research questions within a social context. Whereas interpretive theorists aim to describe, understand and generate meaning within a social or practice context, critical theorists go further and question the socio-political experiences of people and their experiences of marginalisation (Rose & Glass, 2008; Williamson & Prosser, 2002). In essence, critical theorists investigate inequalities of marginalised groups in order to raise awareness of their oppression. Once that is realised, emancipatory conclusions should occur. Jackson and Borbasi (2008) discussed that critical theorists are enthusiastic to address peoples' experiences and empower them to alter their status quo in material or immaterial sense, or both. Critical theorists are therefore catalysts for positive change in marginalised or oppressed groups. Figure 3.2 below highlights the goals of the critical paradigm approach.

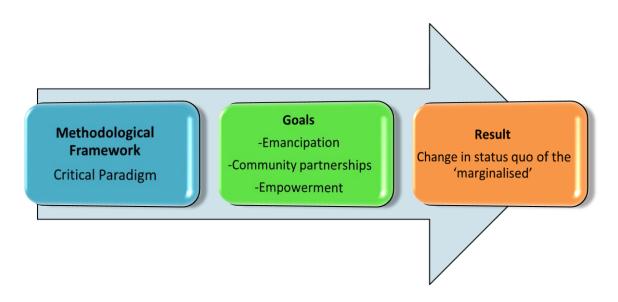


Figure 3.2: Summary of Critical Paradigm

In summary, while both the interpretive and critical theorists investigate social knowledge, interpretive researchers aim to understand and generate meaning; whereas, while critical theorists incorporate those aims, by focusing on experiences of being marginalised, further aims are to explicitly bring awareness and change in the status quo.

3.4.4 Application of methodological approaches for this research

This research study was emancipatory and utilised critical ethnology to explore the participants' experiences of TB care in health facilities. In line with Table 3.1, data were collected through open observations, interviews, field notes and photographs. In addition, Taylor (2006), emphasised that the choice of a paradigm is also dependent on the researcher's intentions and what they hope to achieve through research i.e., how one intends to answer the research questions. This determined the choice of the critical paradigm for this research study.

As discussed in chapter 2, the influence of the social, political, cultural and economic domains on the care or management of TB were scrutinised and the impact of these variables on TB patients was outlined. Healthcare workers play a dominant role over TB patients where patients feel overpowered and a sense of isolation and stigmatisation exists. In addition, healthcare systems contribute to this domination in delays and diagnosis, and thereby treatment of TB. In this regard, patients are voiceless. Turris (2005) stated that critical paradigm researchers seek

understanding, derive meanings and bring about social change in understanding the experiences of participants, more specifically, the oppressed.

In line with the critical paradigm, the current study investigated a marginalised group of TB patients attempted to understand nurses and patients views on factors that hinder or enhance the care of TB patients. While critical theory also generates meaning, the overall aim is to empower and better the lives of the marginalised, the weak and the oppressed, at the same time, to potentially bring about change in nursing care and socio-political views on this group of patients. Consequently, this understanding would give voice and empower this 'marginalised' group of patients with an anticipated change in their status quo. Accordingly, critical theory resonates with this research study.

The theoretical perspective that framed this research was blended with philosophical concepts from other disciplines such as PHC and health promotion. While critical paradigm was the overriding paradigm for this study, the conceptual framework incorporates the principles of PHC and health promotion, which are embedded within concepts of empowerment, emancipation, community partnerships and social determinants of health, which are intrinsic in the philosophy of PHC and health promotion. MDGs were also incorporated as they are closely aligned with these principles. In the literature review (chapter 2), health education/health promotion, such as the expansion of DOTS, educating TB patients, nurses, healthcare professionals and all first-line contacts for TB patients, such as traditional healers were all highlighted as part of PHC. In addition, TB patients were identified as marginalised, stigmatised and 'oppressed'. As critical paradigm aims to bring about social change of the participants, specifically the oppressed, it was chosen as the most appropriate paradigm for this study. Figure 3.3 (adapted from Doran, 2010) below outlines the key principles that fortify the conceptual framework for this research study.

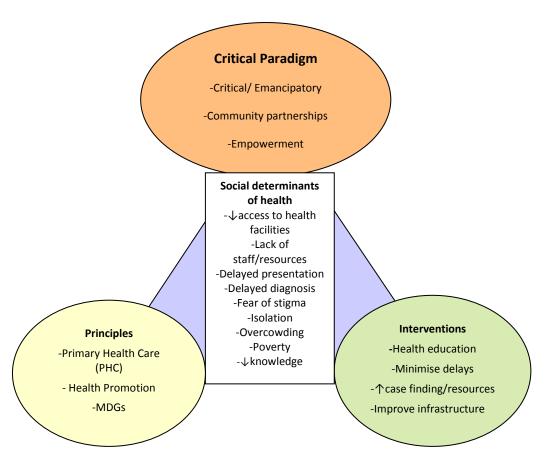


Figure 3.3: The conceptual framework of this research

The principles in the above diagram were integrated and synchronised with the epistemological and ontological views of the researcher in the application of the critical paradigm and the use of mixed methods to answer the research questions. The quantitative and qualitative data as well as the implications for health promotion were guided by these concepts. While this study used surveys for quantitative data such as demographic tendencies, the qualitative aspect was explored by open-ended questions, which allowed the subjective elaboration of the patient and nurse participants' experiences. An overall aim was to bring about change for TB patients by the development of a TB nursing care model. This model of care will potentially change nursing practice of TB patients and thereby change the social position of these 'marginalised' groups of patients.

As TB health care is closely aligned with PHC and health promotion, these principles will be further explored in the chapter however quantitative and qualitative methods and mixed methods will be addressed firstly.

3.5 Quantitative and qualitative methodological approaches

Over many decades, there has been much debate about two broad research paradigms – the quantitative and the qualitative. Rooted in positivism, quantitative research is scientific in nature. Bernard (2011) affirmed that quantitative research applies to studies whereby the variables of interest are measurable and the results are quantified, coded and presented as numerical data. Quantitative research is therefore objective, in that it addresses the research questions by investigating cause and effect relationships.

It is argued that quantitative research is deductive (Macnee & McCabe, 2008) because it focuses and investigates only the phenomena of interest in detail, which aims to provide answers to research questions by testing hypothesis as well as explaining variability between individuals, groups and specific conditions. Bernard (2011) elaborated further that deductive research begins from common sense, observation or literature that results in either confirming or falsifying a hypothesis. Quantitative research targets a large sample to answer research questions but researchers tend to have a brief contact with these participants.

Minichiello et al. (2004) stated that quantitative research is crucial when health professionals endeavour to find answers regarding effectiveness of service provision. In addition, they might want to investigate other possible options, which are useful in treating people with a particular health condition hence quantitative research is paramount in clinical decision-making. Results are in numerical form and are generalised to similar groups. McLeod (2008) explained that findings of quantitative approaches are context-bound and are a manifestation of the assumptions that the researcher brings to the investigation.

Under the umbrella of quantitative research design are three subtypes: observational (non-experimental where the researcher aims to build a picture of people or events as they occur in their natural environments); quasi-experimental (where the researcher administers treatment but may lack a control group or randomisation) and experimental (which determines whether a treatment causes a change or not) (Schneider et al., 2007). In essence, the true experiment is regarded as the only one that can answer the cause and effect relationship (Field, 2009), as it applies all the three principles of having a control group, participants are randomised and a

treatment is administered. Of the three groups, the researcher in this study applied the observational design with the sub-categories of descriptive and correlational arenas. Observational design was chosen as the researcher wanted to understand and construct a picture of events, patients and nurses and associated situations as they occurred in their natural environments. The correlational domain analysed the relationships between dependent and independent variables and a comparison between groups (Pallant, 2005).

In contrast to quantitative research, it is stated "if people define situations as real, then they are real in their consequences" (Thomas & Thomas, 1928. p.26). This seminal statement encapsulates qualitative research. Qualitative research takes the view that there is more than one truth or no truth to human experiences. Jackson & Borbasi (2008) explained that qualitative research explores a range of human experiences rather that a single objective reality. As such, qualitative research aims at understanding and exploring the subjectiveness of human existence (Macnee & McCabe, 2008). It appreciates the fact that human beings are influenced by many factors in their surroundings. Qualitative research therefore targets a few people but at the same time, attempts to have an in-depth knowledge of the participants.

It is argued that qualitative research is holistic in nature because it is inductive, that is, it takes all aspects of human existence into consideration (Myers, 2000; Hall, 2006). Induction also searches for patterns from observations to develop explanations or theories that are tested, modified and retested until a point of saturation occurs (Bernard, 2011). Macnee and McCabe confirmed that qualitative research is not static but rather, is expected to be ever-changing as people and their environments also change. Analyses are interpretive and results are presented in themes and categories and present the unique experiences of the participants.

In summary, Table 3.2 below (adapted from Punch 2005; Schneider, 2007, p.25) summarises the contrasts between quantitative and qualitative research approaches.

Table 3.2: Comparisons between quantitative and qualitative research approaches

CONCEPTS	QUANTITATIVE	QUALITATIVE
Origins	Search for truth in an objective, controlled manner	Search for meaning, interactive approach
Beliefs	Biopsychosocial beings with measurable components	Complex beings with multiple realities
Truth	Objective reality	Subjective with multiple realities
Basis of knowing	Cause and effect relationship	Meaning, discovery
Focus	Concise and narrow	Complex and broad
Level	Reductionist	Holistic
Reasoning	Logistic, deductive	Dialectic, inductive
Setting	Investigator seeks experimental control of the setting	Occurs in uncontrolled, naturalistic settings
Purpose	Tests hypotheses and theories by control and observation	Develops theory by exploring meaning and describing relationships
Sample	People in a group are called samples; referred to as subjects, cases or respondents	People in sample referred to as participants; in ethnography called informants
Researcher position	Passive. Uses measuring instruments or tools e.g., questionnaires	Active and interactive participant; immersed in the setting
Data elements	Numerical form (numbers)	Written form (words)
Analyses	Statistical analyses using software to facilitate examination of quantitative data	Interpretive; undertaken manually or using software that orders and categorises data
Outcomes	Measurable and reported in numerical terms	Thematic and conceptual, not quantifiable
Clinical application	Findings able to be generalised to similar groups	Exploration of unique experiences by individuals

The abovementioned table highlights the different methodological approaches to conducting research. While the differences are apparent, it should be emphasised that whatever approach is chosen, it must be systematic and rigorous in design (Taylor, Kermode & Roberts, 2006). Again, while these guide the direction of the research, it is argued that "no single paradigm or framework alone can address the disciplines of nursing and midwifery; nor is any superior to another therefore, theoretical pluralism exists" (Schneider et al., 2007, p.22). This emphasises that both qualitative and quantitative approaches are complementary rather than being competitive. The fundamental reasoning for the development of research questions is based on the paradigm that the researcher chooses. It must also be stressed that the researcher chooses

apt approaches and methods depending on the question/s that meet the epistemological and ontological perspectives of the researcher (Hall, 2006; Schneider et al., 2007). The elicited knowledge can be then evaluated based on methodological clarity and transparency and consequently applied to better practice.

The following section discusses the merging of the different approaches of qualitative and quantitative research for this research study. The principles of health promotion and PHC introduced above and outlined in Figure 3.3 (Conceptual Framework) will be comprehensively discussed below.

3.6 Mixed methods research

Traditionally there has been a tendency for nursing and midwifery research to shift towards qualitative research in contrast to medicine, which predominantly veered towards quantitative research (Stewart et al., 2003; Borrell-Carrió, Suchman & Epstein, 2004). Of recent times has been the advent of mixed methods, which is the culmination of qualitative and quantitative approaches to research. Mixed methods are regarded as a third methodological paradigm or research methodology, which makes inferences to both quantitative and qualitative approaches (Baum, 2002; Creswell & Plano Clark, 2007). Schneider et al. (2007) described mixed methods as a "more reasoned and enlightened approach to health-related research that now includes research collaboration between all disciplines" (p.26). The genesis of mixed methods, as a research methodology as well as methods, was devised in order to compensate for the weaknesses that are seen in the application of the quantitative or qualitative methodologies alone. It is therefore suggested that health professional researchers, regardless of the discipline, should engage in a wide range of research activities that integrate both paradigms in order to address increasingly complex clinical issues (Polit & Tatano Beck, 2008).

This study aims to investigate characteristics and factors that impact on patient outcomes of TB patients from the perspective of patients and nurses alike, using mixed methods. Both quantitative and qualitative methodologies are integrated in this study in order to answer research questions. Tashakkori and Teddlie (2003) reinforced that mixed methods are research

designs using qualitative and quantitative data collection and analysis techniques. Creswell and Plano Clark (2007) reiterated that mixed methods are "philosophical assumptions as well as methods of inquiry" (p.5) thus, mixed methods is a methodology as well as methods which direct the researcher in multiple ways of answering research questions. This research approach recognises the significance of the natural and physical world; the integration of the social and the psychological world that integrates languages, cultures, institutions as well as the subjectivity of human beings (Johnston & Onwuegbuzie, 2004). Mixed methods is, therefore, a way of collecting, analysing and interpreting data to provide a broader understanding of events and enrich the interpretation of experiences by combining the quantitative and qualitative approaches.

Many researchers have argued over which research methodology is better than the other. This thesis takes the view that neither paradigm is better than the other but rather, it depends on what research questions one has and how one intends to answer those questions. Mindful of this fact, the researcher took the view that the quantitative and qualitative methods can complement each other (Punch, 2005; Teddlie & Tashakkori, 2009), and are, therefore, able to explore the objective as well as the subjective views of participants in order to answer the research questions.

It must be acknowledged that no single method can answer all questions (Katsirikou & Skiadas, 2010). Bryman (2004) suggested that qualitative and quantitative approaches should be combined because they yield the 'best of both worlds'. In this regard, mixed methods provides strength in that it offsets the weaknesses of both quantitative and qualitative research and helps answer questions that cannot be answered by quantitative or qualitative methods alone (Creswell, 2009). This, it is believed, gives much stronger arguments and addresses the multifactorial angles of answering research questions and understanding of experiences. Giddings (2006) affirmed that mixed methods approach is holistic because of its ability to be inclusive in multiple approaches, providing more certain results. It is argued that mixed methods are appropriate for health and health care research for the depth of insight that can be obtained (Annells, 2007).

Recent literature refers to mixed methods as being transformative as the approach can be aligned with the principles of social justice and human rights. Researchers who adopt 'transformative methods' recognize the importance of critical frames of reference and incorporate their social justice beliefs throughout the methodology as well as the mixed methods. Therefore as with this study, community involvement and particularly individual's voices are imperative to research design and outcomes (Mertens, 2009). Therefore transformative methodologies acknowledge experiences are contextual and culturally dervived and as such, challenge power differences in the research context as well as the general community (Mertens, Bledsoe, Sullivan & Wilson, 2010). Mertens (2007) emphasised that the transformative paradigm addresses "the inequality and injustice in society using culturally-competent, mixed methods strategies" (p.348). In essence, transformative mixed methodological approaches are of great significance for research with minority groups and the intentions and actions are emancipatory.

While there are apparent advantages to using mixed methods, this paradigm has also been criticised. It is postulated that mixed methods lack philosophical underpinnings and "there has also been some work in the area of integrated mixed methods data analysis although this work has not yet covered into a widely accepted framework of set of ideas" (Greene, 2008, p.14). Mixed methods have also been discredited with the argument that two paradigms that are incompatible with each other cannot be mixed. In addition, it is postulated that mixed methods are not clear on what and how it is being mixed is disputable therefore rigour is compromised (Creswell, 2007; Hesse-Biber, 2010). Schneider et al. (2007) also argued that mixed methods demands a lot of time and resources and the collection and analysis of data is more complex than that of a single paradigm. There are three major purposes for using mixed methods being:

- corroboration: where there may be two studies that are independent of each other,
 often with no new perspectives. This seeks to converge the studies through triangulation
 of methods;
- initiation: usually provocative, this seeks paradox and contradiction which leads to change in perspective;

• expansion: which aims to enrich and expand issues raised by participants.

Mixed methods encourages the understanding of phenomena, using different perspectives (Creswell, 2003, p.16).

It could be argued that there are two independent groups being studied, i.e., patients and nurses therefore corroboration is applicable to this study. However, because the same variables are being studied from two different perspectives rather than two separate studies, corroboration does not fit well into this study. Initiation challenges results obtained through one research method and stimulates new research questions and as this is not the case with this study, initiation is not applicable. As such, "expansion" has been chosen as the most applicable angle as the qualitative findings open up and explain the quantitative findings of the study. It provides the subjective interpretation and enriches the objective data.

There are four different ways in which qualitative and quantitative data can be integrated. Creswell and Plano Clark (2007) identify these as the Embedded Design, the Explanatory Design and the Exploratory Design and the Triangulation Design. The Embedded Design, also referred to as nested model, is entrenched within the predominant method. This may be used to address a different question than that/those being examined in the main design or, as Creswell puts forward, the Design helps to "gain a broader perspective as a result of using the different methods as opposed to using the predominant one alone" (2003, p.218). This seeks information from a different level.

The Explanatory Design addresses quantitative data collection and quantitative data analysis initially, followed by qualitative data collection and data analysis. This aims to explore the quantitative findings in more detail. The Exploratory Design aims to obtain themes and statements from individuals that are then used to create scales and items in a questionnaire. It commences with qualitative data collection, qualitative data analysis as initial phases followed by quantitative data collection then data analysis and interpretation of entire data results. This aims at quantifying the qualitative findings (Tashakkori & Teddlie, 2003).

Triangulation design is claimed to be the most commonly used. The emergence of triangulation dates back to Campbell and Fiskel who, in 1959, invented the term "multiple operationism" (Jick, 1979, p.602). Their argument was based on the premise that more than one method is essential in the validation process in order to confirm that variances reflected are not as a result of the approach or methods taken but rather, they should reflect on the trait. In other words, the conformity between the two methods "... enhances our belief that the results are valid and not a methodological artifact" (Bouchard, 1976, p.268). The quantitative and qualitative methods as well as the contrasts and comparisons were carried out within the same timeframe and complemented each other.

The design is used to compare and contrast quantitative statistical results with qualitative findings consequently expanding and validating data. This is considered as a one-phase design where quantitative and qualitative methods are carried out within the same timeframe. The Triangulation Design was chosen as the most appropriate design for this study as this design seeks "to directly compare and contrast quantitative statistical results with qualitative findings or to validate or expand quantitative results with qualitative data" (Tashakkori & Teddlie, 2003, p.62).

Creswell and Plano Clark (2007) recommend that capital letters be used to highlight the major focus of the research methods and approach used in a study. Conversely, the use of smaller letters identifies that that methodology is supporting the main one. This study had a quantitative focus therefore capital letters "QUAN" indicate the main focus of the study is quantitative in nature. Whereas, "qual" signifies that the qualitative aspect of the study is utilised to support and expand on the quantitative findings. Figure 3.4 below reinforces the aspects discussed.

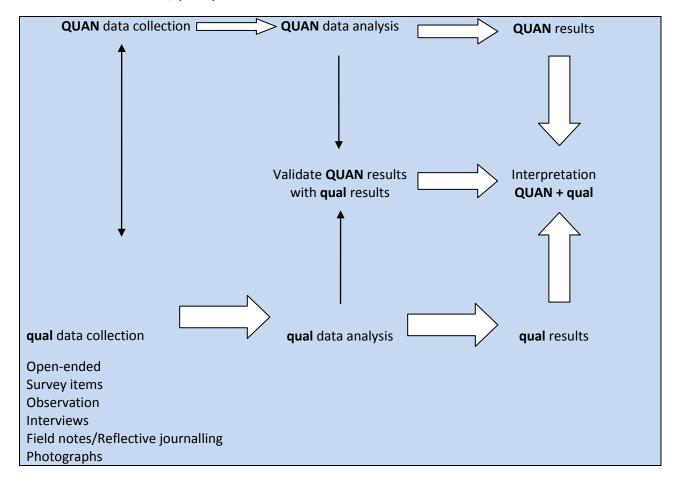


Figure 3.4: Triangulation design: Validating quantitative data

Figure 3.4 above demonstrates the quantitative and qualitative data collection occurring simultaneously using a survey questionnaire which contained several open-ended questions. This is referred to as data triangulation, where a variety of data sources in a study are capitalised (Creswell & Plano Clark, 2007). Primarily, the quantitative foundation is set through responses to closed-ended questions and the qualitative data is used to gather and provide more in-depth information related to responses to closed-ended items in the survey. Qualitatively, the researcher collected more information from open-ended questions that were part of the questionnaire. Qualitative data were also collected through observations, interviews, diary entries and photographs. This allowed the data obtained from the statistical analyses (quantified numerical data) to be reinforced and enriched by information about the participants experiences and explanations.

3.7 Application and justification of mixed methods to this research study

Mills (1958) avowed, "drop the liberal rhetoric and conservative default; they are new parts of one and the same official line; transcend that line" (p.183). The researcher concurs with this seminal statement, that while the debate regarding qualitative and quantitative research continues, one needs to transcend beyond the mere debate and appreciate their contribution to research. As no one methodology alone can answer all research questions, mixed methods therefore transcends that 'line' and appreciates and integrates the quantitative and qualitative approaches to provide a deeper and richer understanding of the questions under investigation. This researcher therefore takes this stance. The research questions guided the choice of the design of the study and mixed methods allowed a broad and flexible approach to answering the research questions (Bryman, 2004; Creswell, 2009).

In summary, this section has outlined the differences in research paradigms: quantitative, qualitative and mixed methods and their application to the current research. The section has addressed advantages and disadvantages of each paradigm and their contribution to generating knowledge. The section has also addressed the rationale for choosing mixed methods for the current research project. The following section will elaborate on the principles of PHC, health promotion and MDGs. To appreciate these concepts, social determinants of health will be addressed first.

3.8 Integration of the conceptual framework, methodological framework and methodology

3.8.1 Social determinants of health

Marmot and Wilkinson (2006) stated that as long as statistics have shown, or as long as one has cared to look, health continues to follow a health gradient. That is, the higher the social position one has, the better the health. As such, social determinants of health relate to how one's social status, circumstances or behaviours influence health and disease. The WHO (2012) describes social determinants of health as conditions in which people are born, grow, live, work and age,

including the health system. Social determinants are concerned with the impact of economic and social policies on health and, as such, they inform public health.

Marton (2005) argued that there are gross inequalities in health between and within countries; between the most and least disadvantaged communities. To grasp the extent at which social determinants of health operate and how they can be changed, the WHO set up an Independent Commission on Social Determinants of Health with the mission to discuss problems and inequalities and how those can be addressed. These social determinants that impact on the individual's health include political, economical, environmental, cultural and educational factors; hence the incorporation of political involvement of nurses in the nursing care model which will be addressed in chapter 5. These factors can be adjusted and altered to create social justice and health equity between the advantaged and disadvantaged in communities around the world. The WHO (2012) stated that health inequalities are avoidable and that social and economic conditions impact on peoples' lives and determine their risk of illness. As discussed in Chapter 2, it has been discovered that TB patients are not immune from social injustice, hence the significant impact on their health and illness.

In 1978 the WHO adopted the primary health care approach as the basis and a model for global health policy and effective delivery of health services which aims at promoting health and preventing illness. However, the WHO (2008) asserted that there is no uniform, applicable definition of PHC and elaborated that PHC means different things in different settings. For example, PHC is understood to be the first level of care in the high to medium income countries. In low-income countries where there are significant challenges, PHC is viewed as system-wide strategy. Nevertheless, the WHO (2008) define the PHC approach as both a philosophy of health care and a model for providing health services. As stated at Alma Ata Conference:

Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination (WHO, 1978, p.1).

PHC should not be confused with primary care as the latter represents the biomedical model of care provided within institutions (McMurray, 2007). This model of care is based on treating an already existing problem/illness whereas PHC is focused on preventing the problem in the first instance. While the biomedical model of healthcare remains a dominant aspect of healthcare, it must be pointed out that PHC is more diverse and is based on a social justice system, therefore it encompasses the social, economic, political and cultural aspects of care. As such, PHC is founded on the following five principles:

- accessibility making health services available to all despite their geographical location;
- public participation clients being active participants in decision-making about their health;
- health promotion health education, nutrition, sanitation, maternal and child care, immunisations and control of endemic diseases;
- appropriate skills and technology importance of adjusting to new and innovative models of health care through research, ongoing capacity building and professional development;
- inter-sectoral cooperation recognition that health and well-being are associated with both economic and social policy (WHO, 1986; Marmot, Friel, Bel, Houweling & Taylor, 2008).

However, PHC and the biomedical model of primary care need to be integrated in order to understand and address one's epistemological and ontological views. This current study examines health promotion programs that are receptive to the needs of TB patients. The abovementioned principles aim at empowering clients to be active participants and managers of their health (Adeleye & Ngozi Ofili, 2010), congruent with the critical paradigm. This onus also rests with the healthcare workers on how to enable and empower people to make healthy choices.

According to Magnussen, Ehiri and Jolly (2004), there are two levels to PHC, which are: i) comprehensive PHC and ii) selective PHC. As the name implies, comprehensive PHC addresses a diverse range of social and environmental factors, which are detrimental to good health. Comprehensive PHC also involves activities that promote good health such as engaging in

exercise activities (Keleher, 2001; Wakerman & Davey, 2008). The comprehensive PHC targets individuals and populations as well as the intersectoral and intrasectoral collaboration.

The selective PHC was developed a year after Alma Ata Conference with the argument that the comprehensive PHC is unrealistic. Selective primary health care was regarded as an "interim" (Carrin, Buse, Heggenhougen, 2009, p.65) strategy to begin the process of primary health care implementation. They proposed that the best way to improve health was to fight disease based on cost-effective medical interventions. Although they acknowledged that the goal set at Alma Ata was "above reproach," (Stuckler & Siegal, 2012, p.98), they contended that its scope and resource constraints made it unattainable. As such, the selective PHC was instituted and is closely aligned with primary care (biomedical); with a focus on the medical interventions by health workers such as nurses.

3.8.2 Primary care and TB

Whereas there is an obvious need to apply PHC principles for TB care or management, the reality is that most TB patients seek care from health professionals such as general practitioners. As such, TB patients utilise primary care where the focus is on medical interventions with health practitioners taking opportunities for health education (Jones et al., 2005). After diagnosis is made, patients have medical follow-up and monitoring by nursing staff. Following discharge, patients have follow-up with outpatients clinics – set by appointments until patients recover (set within a six-month timeframe). This resonates with principles of primary care/primary medical care.

In this model, the participant is rather a passive recipient of care and health carers/ professionals dominate this model of care (Bowman & Spicer, 2007). In PHC, the client is a partner. The researcher argues that medical care should include principles of empowerment as in the PHC approach in order to give a voice and bring about a change in the status quo of patients. TB patients are not an exception. In essence, the principles of health promotion as suggested by the PHC approach significantly contributed to the framing of this research (refer to Figure 3.3).

In the following section, the relationship between PHC and health promotion as well as the application of both to the current study will be addressed.

3.9 The new public health movement: The Ottawa Charter for Health Promotion

Central to PHC is the principle of health promotion, which is described as the process of enabling people to increase control over and to improve their health (WHO, 1986). In 1986, an international conference for Health Promotion was held and presented a CHARTER for action with the aim of achieving "health for all by the year 2000 and beyond" (WHO, 1986, p.1). This was regarded as the beginning of a new public health movement that reinforced the already existing philosophy of PHC which was heralded as a model for providing health services (Alma Ata Conference, 1978; Hall & Taylor, 2003). Culminated with research into social determinants of health, the Declaration of Primary Health Care at Alma-Ata, the World Health Organisation's Targets for Health for All document and debate at the World Health Assembly on Intersectoral action for Health – all defined a new global new public health movement (WHO, 1986; Baum, 2008).

The Ottawa Charter was primarily developed in recognition of the needs of industrialised countries. However, it also addressed similar concerns in other regions of the globe (Carrin, Buse & Heggenhuegen, 2009). This was in response to the limitations of other approaches that were rampant in the 1980s and, at the same time, as a commitment to PHC and health promotion (Marya, 2011). The charter emphasised that health is a resource for everyday life and a positive concept emphasising social and personal resources as well as physical capabilities (Carrin et al., 2009). Consequently, the Charter reinforces that health promotion is not solely the responsibility of health sectors but is rather multisectoral. It incorporates the individual within the political, social, economical, cultural and environmental aspects. It is therefore indisputable that the PHC and Ottawa Charter goals are inseparable. Figure 3.5 below shows the promotional emblem representing the principles of the Ottawa Charter.

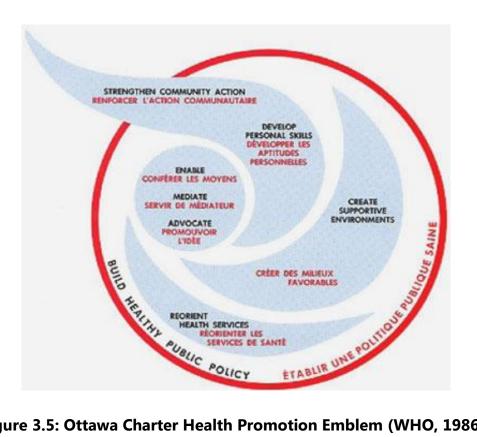


Figure 3.5: Ottawa Charter Health Promotion Emblem (WHO, 1986).

The aim of the Ottawa Charter was to build healthy public policy (the outer circle) through the five principles pointed out within the circle.

- Strengthen community actions: The core of this motto is the empowerment of communities to be masters of their own health. It draws the available human and material resources to enhance self-help health behaviours and encourages social support (WHO, 1986; Laverack & Mohammadi, 2011).
- Develop personal skills: This can be achieved through the empowerment of personal and social development, education for health and enhancing life skills (Reports of the subplenary sessions, 1986; WHO, 1986). An investigation into factors that hinder or enhance nursing care of TB patients, the quest to understand patients' and nurses' perspectives were linked to giving patients a voice therefore empowering them to take charge of their own health. The long-term follow-up with TB patients during and after admission is an opportunity for nurses to give health education/promotion to TB patients.

- Enable, mediate and advocate: As pointed out in Figure 3.4, the Charter encourages political, economic, social cultural, physical and environmental factors to work together to achieve optimal health. This commands healthcare workers to mediate and advocate thereby enabling individuals to develop personal skills in order to manage their own health (WHO, 1986). Health promotion also aims at equal distribution of resources to enable people to achieve the maximum health potential. This could be achieved by equal access to information and providing educational skills for making healthy choices.
- Create supportive environments: Recognises that there are indisputable links between people and their environments and these are the formations for socioecological approach to health (Sundsvall Statement on Supportive Environments for Health (WHO, 1986). TB care requires a supportive environment, empowered individuals and community, building on personal skills as well as collaboration between the individual, the community and the health sector. This research sought to explore the health promotion role of nurses who supported TB patients.

Reorient health services: Recognises the shared responsibilities among individuals, community groups, health professionals, health service institutions and governments (Yeatman & Nove, 2002). The Ottawa Charter reinforces the collaboration between individuals, communities and the health systems to promote health (WHO, 1986). The charter encourages a holistic approach to health promotion. Through the experiences of TB patients and nurses, this research highlights the need for health carers to give health education thereby enabling the individual.

The above-mentioned principles are significant for health promotion and they framed this research study. These principles are congruent with the United Nations Millennium Declaration (discussed in chapter 1) where the resolution of the General Assembly reaffirmed the Charter in 2000. The researcher puts forward a particular emphasis is on *protecting the vulnerable* and, in this case, TB patients. Again, this reinforces the application of critical paradigm to this study. Another goal is *meeting the needs of Africa* with a highlight on helping Africa build up its capacity to tackle the spread of HIV/AIDS pandemic and other infectious diseases (Moore &

Pubantz, 2008). In essence, the UN declaration reaffirmed the principles of PHC, primary health and health promotion.

3.10 Measuring outcomes of primary health care and health promotion

The preceding sections have examined the concepts of PHC, primary care and health promotion as stipulated by the Ottawa Charter. It has been highlighted that the critical focus of health promotion is the empowerment of individuals to take control of their health. In essence, this is congruent with the choice of the critical paradigm; which promotes and addresses the needs of the oppressed to bring about social change. This section discusses how the attainment of goals of health promotion is achieved and measured.

Nutbeam (1998) and de Salazar, Jackson, Shiell, and Rice (2007), stated that assessing the effectiveness of and value of a health promotion programme is complex and challenging. They argue that among many interpretations in literature, the significant populations are the beneficiaries of health promotion action. They value how the programme was conducted, whether or not it was participatory and whether or not it addressed the needs of the community, just as the organisers of a programme need to assess whether they met the objectives of a project or not and need to take constructive criticism about their project. Table 3.3 below, adapted from Nutbeam (1998) outlines a health promotion outcome model that is utilised in this research.

From Table 3.3, it can be seen that there are four levels of assessing outcomes. The researcher proposes that health and social outcomes target the individual; intermediate health outcomes extend from the individual to the wider community; health promotion outcomes assess the individual and the systems e.g., governments and the fourth, health promotion actions integrates all the fore-mentioned levels.

Table 3.3: An outcome model for health promotion

Health and Social Outcomes	Quality of life						
	Functional independence						
	Equity						
	Mortality						
	Disability						
Intermediate Health Outcomes	Healthy	Effective health	Healthy				
	Lifestyles	Services	Environments				
Health Promotion Outcomes	Health	Social influence	Healthy public policy				
	Literacy	and action	and organisational				
			practice				
Health Promotion Outcomes	Education	Facilitation	Advocacy				

Like Nutbeam, Richardson (1998) identified four levels of measurements:

- elimination of disease or Ill-health and the restoration of 'normal' health;
- promotion of individual well-being or healthiness above and beyond the elimination of disease, narrowly defined, but where benefits are attributable to changes in the individual health states;
- promotion of 'social welfare' whereby well-being is achieved not only through the promotion of health, but also by the creation of a health system incorporating desired attributes: social justice, equity and respect for autonomy and
- systemic change where all of the above objectives are pursued by a community wide change in attitudes, relationships and the modification of social institutions to achieve, for example, a more collectivist or more individual based responsibility for health and welfare (p.9).

In essence, the success of a health promotional programme should be reflected by the physical, social, economical, psychological and environmental adjustments beginning with the individuals who are the building blocks of the communities.

McKenzie, Neiger and Smeltzer (2005), emphasised that the effectiveness of health promotion is reflected in the targeted individual. This is reflected in health literacy, knowledge, empowerment, attitudes and involvement in health promotional programmes. However, this

measure of literacy assumes that the targeted individual has been given relevant information by the relevant assessor and health professional. The provision of education to TB patients by health professionals, more especially nurses, about the risks of disease transmission; recognising TB symptoms (among both TB patients and healthcare workers, especially nurses); the need for early presentation for diagnosis and management of the illness were all analysed in this research study.

3.11 Summary

This section has presented an overview of the development of research knowledge. Key concepts of epistemology and ontology have been explored and their relevance to this study have been addressed. The section has further explored the conceptual framework, which is embedded with concepts of PHC, health promotion and MDGs. In addition, the positivist and post-positivist approaches have been examined. Critical research is the methodological framework planned for this research using a mixed methods approach to answer the research questions. TB is viewed within the PHC and health promotion arenas. Strategies to achieve health promotion, which are embedded within the Ottawa Charter as well as MDGs were explored.

In line with critical theorists, this research aimed at the development of a model of nursing care in order to bring about social change especially in the status quo of TB patients. The study investigates approaches to promoting the wellbeing of TB patients and interventions influencing patients' health outcomes and addressed nursing systems. The information obtained will allow key issues to be identified, and consequently used in the identification of strategies and development of a model to improve the nursing care of TB patients hence their status quo. This important data will guide staff knowledge and performance in this highly specialist area thus, better prepare them in the care that they provide to this group of patients.

Section B of this chapter follows and discusses methods and processes used in the research study and addresses the ethical considerations for this research.

SECTION B: METHODS and PROCESSES

This section builds on the methodology discussed earlier in the chapter. The application of mixed methods in relation to the research questions, the methodological framework and the advantages of using mixed methods for this study were explored. The following section further elaborates on the stages of the research, the sampling and recruitment of participants, development of the research tools, data collection and analyses are explored. Ethical considerations and associated issues of translating and validating the tool are also discussed. Data collection and data management processes will also be presented.

3.12 Methods

There were four methods utilised in the study. These comprised one quantitative: a survey questionnaire tool and four qualitative: open ended comments on the questionnaire, selected interviews; field notes and collection of photographs. Together these triangulated the data to have four focal points for the qualitative lens and one survey questionnaire. Both the quantitative and qualitative data were collected simultaneously.

3.12.1 Participants: Sample size calculation

This study compared Australian and Malawian patients and Australian and Malawian nurses. A survey that assessed patient satisfaction with medical care across Australia showed that 25% of acute patients were dissatisfied with the hospital services that also included nursing care (Pearse, 2005). In contrast, dissatisfaction with medical services was much less common among Malawian patients (5%) as reported by Changole et al. (2010). Using a two-sided alpha (α) of 0.05, power of 0.8, ratio of Malawian to Australian patients of 3:1, and the proportions of dissatisfaction as described above, 35 Australian and 104 Malawian patients were required (based on Fleiss test with continuity correction factor). These numbers were exceeded in this current study as described in the following Results Chapter.

A similar approach was adopted to calculate the nurses sample size. The outcome measure was set as "job satisfaction" since this is argued to be directly linked to provision of nursing care (McHugh et al., 2011, p.202). This study found that 25% of nurses providing direct patient care,

24 percent of hospital nurses and 27 percent of nursing home nurses reported dissatisfaction in their current jobs. This contrasts with 13% of nurses working in other settings. While this was an American study, a study of five developed countries including Australia, (Aiken et al., 2001), reported that 30 to 40% of nurses are dissatisfied with their job. In Malawi, around 40% of nurses are dissatisfied with their job (McAuliffe, 2009). Using a ratio of Malawian to Australian nurses of 5:1, a total of 12 nurses were required for the study. This number was exceeded.

3.12.2 Procedure: Participant selection and recruitment

Both patient and nurse participants were recruited from the inpatient and outpatient wards in Australia and Malawi. The eligibility criteria was that patients had to be adult males or females of consenting age, suffering from pulmonary TB and if outpatients they would have experienced a period of hospitalisation and respiratory isolation. The nurses were required to be classified as either registered nurses division 1 (RN1) or registered nurses division 2 (RN2). They were also required to either be looking after pulmonary TB patients or have previously cared for patients with pulmonary TB. If participants satisfied the eligibility criteria, they were recruited for the study. Following initial classification and screening, one hundred and ninety-four (194) patients were recruited (44 Australian and 150 Malawian patients) and forty-six (46) nurses (26 Australian and 20 Malawian nurses). A summary the selection process for patients and nurses alike in presented in Table 3.4 below.

The aforementioned table summarises how the participants (patients and nurses alike) were recruited in both Australia and Malawi. The response rates are further discussed in chapter 4. The research design now follows.

Table 3.4: Summary of the selection and recruitment process

PARTICIPANTS	RECRUITMENT PROCESS					
Australian patients	Contact made with heads of departments/ward managers					
	Study explained					
	Permission sought					
	Researcher visited inpatient and outpatient wards					
	Mainly on Wednesdays and Fridays for a period of 2½ years. These were outpatient clinic days in					
	the two Australian Hospitals (HA and HB).					
	Recruited patients of ≥18 years of age (consenting legal age in Australia)					
Malawian patients	Contact made with Directors of Hospitals and ward matrons					
	Study explained to managers					
	Study explained to patients					
	Researcher visited inpatient wards					
	Permission sought					
	Recruited Mondays to Fridays over 4 months					
	Recruited patients of ≥21 years of age (consenting legal age in Malawi)					
Australian nurses: (RN1	Contact made with heads of departments/ward managers					
or RN2)	Study explained to nurses					
Nursing or nursed TB	Permission sought					
patients	Researcher visited inpatient and outpatient wards					
	Mainly on Wednesdays and Fridays for a period of 2½ years					
	Contact made with directors of hospitals and ward matrons					
Malawian nurses: (RN1	Study explained					
or RN2)	Researcher visited inpatient wards					
Nursing or nursed TB	Permission sought					
patients	Recruited Mondays to Fridays over 4 months					

3.12.3 Study design

A cross-sectional one phase study design was utilised for this research study. In cross-sectional studies variables of interest in a sample of subjects are assayed once and the relationships between them are determined (Taylor, Kermode & Roberts, 2006). Convenient sampling was used. TB patients in Australia were placed in Infectious Diseases or Respiratory Diseases wards. This meant that not all patients on these respective wards were positive for TB therefore the researcher was required to screen for potential participants. Unlike in Australia, Malawian patients were located in 'TB wards' therefore all patients were either positive for TB and/or TB/HIV/AIDS. It was therefore easier to identify the Malawian patients.

3.12.3.1 Choice of the countries

The researcher resides in Australia, however she is a native of Malawi. Therefore accessibility to both countries was straight forward and there was a strong familiarity with each country. The major reason however, for selecting Malawi is based on report/s by the World Health Organisation (WHO, 2003), that this country has very high rates of TB yet has limited resources. This notwithstanding, Malawi is reportedly a leader in Sub-Saharan Africa in achieving TB health goals as set by WHO. The researcher was therefore keen to investigate how this success has being achieved and was interested in examining nurses' positions in this regard. The researcher also believed she would easily identify with the people as she is a native of the country and, therefore, access to the study sample would be easier.

In Australia, the researcher had worked on an Infectious Diseases ward, where TB was managed, the researcher therefore had an insider's view of how TB was managed. As such, she identified some shortfalls, such as the isolation of TB patients in nursing care, which led to the development of the specific research questions (explained in detail in chapter 1, section 1.3).

3.12.3.2 Choice of the hospitals

TB patients in Australia were chosen from two major TB centres in Melbourne, located in the northern and the western areas of Melbourne because these institutions were major TB referral centres. Ethics approval was also sought from a hospital in the southern area of Melbourne but it was not granted. The particular hospitals were chosen because it is believed that these would capture people of different backgrounds and different socio-demographic factors, thereby minimising bias due to demographic characteristics of participants in the study. The researcher also chose these sites as she had worked in one of the hospitals and was therefore familiar with the structure of the organisation. The researcher believed that this would provide easier access to the participants.

As in Australia, the hospitals in Malawi were chosen as these were the major treating and referral centres for TB care. Geographically, these TB centres are dispersed to capture the populations from the central and the southern regions of the country. It was believed that this

selection criteria would capture a diverse range of participants, therefore the sample would be more inclusive and representative.

3.12.4 Study tools

This section discusses the process that was utilised in choosing items and designing the questionnaire that was used in this study. Data were collected using a self-administered questionnaire. David and Sutton (2004) reported that self-complete surveys are relatively cheap, they are not influenced by the researcher and respondents are able to complete them in their own time. The survey questions were adapted from quality of life studies (QoL) (RAND, 2004) and from the field exercise conducted in Malawi by the World Health Organisation (WHO, 2003), which are both validated instruments that have been used in many studies.

The 36-item Health Survey RAND-36 was developed as part of the Medical Outcomes Study which were observational studies into different practising styles of physicians and the resulting patient outcomes in different health-care systems. Ware (2000); Hays and Morales (2001) pointed out that the RAND is the most widely used measure of health-related quality of life tool today. This tool has been used in numerous studies addressing different chronic illnesses such as hypertension, HIV/AIDS, diabetes, depression, epilepsy, cancers – the list is not exhaustive. The outcomes may be summarised as addressing nine (9) domains of health namely: physical functioning, role functional/physical, role functional/emotional, energy/fatigue, emotional wellbeing, social well-being, pain, general health and health change. The reliability of these variables are summarised in a table (see Appendix 3a). As demonstrated by the table, the reliability of the Health Survey is strong, with α value greater than 0.70, where value of less that 0.70 is considered too low (Pallant, 2005).

The RAND 36-Item Health Survey (Version 1.0) gives permission for researchers to use the tool on the basis that:

Changes to the Health Survey may be made without written permission of RAND. However, all those changes need to be clearly identified as having been made by the recipient. This permission also stipulates that the user of the Health Survey needs to accept full responsibility and holds RAND harmless for any accuracy in translations of the

Health Survey into another language and for any errors, omissions, misinterpretations or consequences thereof (RAND Health, 2004, p.3).

In view of the above statements, the researcher modified some of the questions to meet the objectives of the study. Not all questions of the RAND Health Survey were adapted for the questionnaire for this study.

Other items in the questionnaire consisted of questions that were adapted from the field exercise conducted in Malawi by the World Health Organisation (WHO, 2003). This was a training module on management of TB for health care staff in different healthcare settings. The module was prepared by a section of the World Health Organisation referred to as the *Stop TB Department*. The main objectives of the module was to identify TB suspects, ask the staff at the health facility about the steps that they perform in regards to the detection and treatment of TB, to observe staff on how they carry out steps of case detection and treatment of TB and lastly, where applicable, to visit a laboratory that conducted sputum examinations. These objectives were not relevant to the patients' questionnaire so they were not used. However, some questions were adapted and used in the questionnaire for the nurses. Nevertheless, not all the sections addressed in the module were relevant for nurses therefore the researcher chose those questions that were deemed applicable to the study. Whereas the module required the participants to record answers as notes, the researcher quantified these and asked participants to choose the best answer on a Likert scale or ranking in order of priority.

Both the patients and nurses questionnaires asked questions, which were categorised into four domains as characteristics of the (a) individual (b) disease and treatment regime (c) clinical setting or range of services in the clinical environment and (d) patient-provider relationship. However, the patients' questionnaire included a fifth domain, where they answered questions on how they perceived their quality of life, such as their physical and emotional well-being.

3.12.5 Final version of the questionnaire

As discussed, the RAND Health Survey contained 36 items that examined the physical and emotional experiences of patients over a period of four weeks whereas the field exercise was to examine the experiences of health workers regarding TB services. Questions deemed relevant

for the study from these two tools were combined to extract both the patients and nurses perspectives into the understanding of TB and the perceptions of how this illness is managed.

The final version of the patients' questionnaire contained 33 questions divided into personal characteristics, medical history, understanding of TB and its management, the physical and emotional experiences of the patients, the patients' views on clinical accessibility and services provided and finally, their perceptions of the nursing care received (see appendix 10a). Conversely, the final version of the nurses questionnaire had 23 questions because some of the questions that were asked of patients, for example, the type of work they do, the symptoms they experienced and their understanding of TB medication therapy; were not relevant for nurses. As the patients questionnaire, the tool examined individual attributes, qualifications and experiences of nurses, their understanding of TB, their perceptions of the characteristics of the care systems i.e., the health facilities in which they work and the range of services available to TB patients, workloads, accessibility, the nurses' understanding of TB and its management; concluding with the perceptions of the care that nurses provide to TB patients (refer to Appendix 4b).

3.12.6 Translation of the questionnaire

To minimise bias regarding the type of participants that would participate in this study, the patients' questionnaire was translated from English into Chichewa, the native Malawian Language (see appendix 4c). This was to ensure that all participants had an equal chance of being involved in the study. As the researcher is bilingual, the questionnaire did not need to be back-translated. This was incongruent with usual translation rules regarding a further translation by another translator with subsequent translations (Wild, Grove, Mona, Eremenco, McElroy, Verjee-Lorenz & Erikson, 2005). However, while the questionnaire was not back-translated to the original language, the researcher did all the data entry as she reads and fluently speaks Chichewa as well as English. Therefore, the essence of the meaning outlined in both languages was maintained. The nurses' questionnaire was not translated because both the Australian and Malawian nurses' education is in English. The decision was therefore based on the fact that all nurses would be able to answer the questionnaire in English.

Venuti (2004) pointed out that being involved in a communication activity, the translator is a crucial link in the communication chain because they need to be conscious of delivering the message of the original text. In essence, a good translation should not lose the concepts and ideas of the original text, as well as the structural and cultural features (Abdellah, 2002). The translators are therefore required to have credentials and be recognised as certified translators. The patients' questionnaire was translated by certified staff who were bilingual and were appointed by the National TB Services of Malawi. The staff also reviewed the paper and because they knew the subject of interest i.e., TB, they pilot-tested the questionnaire, ensuring face validity (explained further under processes). The final version of the questionnaire included the independent and dependent variables are outlined in figure 3.6 below:

3.13 Stages of the research

Data collection took place over a period of four months in Malawi (July to October, 2005) and two and a half years in Australia (January 2006 to June 2008). This time span is attributed to the fact that many patients were not willing to participate and that only a small number of TB patients presented to the selected hospitals. Most of the patients that presented in the outpatients' clinics were mainly those that the researcher had already met in the inpatients wards. Whilst the researcher distributed and collected questionnaires from the hospital institutions, she also spent time observing, questioning, documenting and interacting with participants in the study. This section therefore narrates the data collection process.

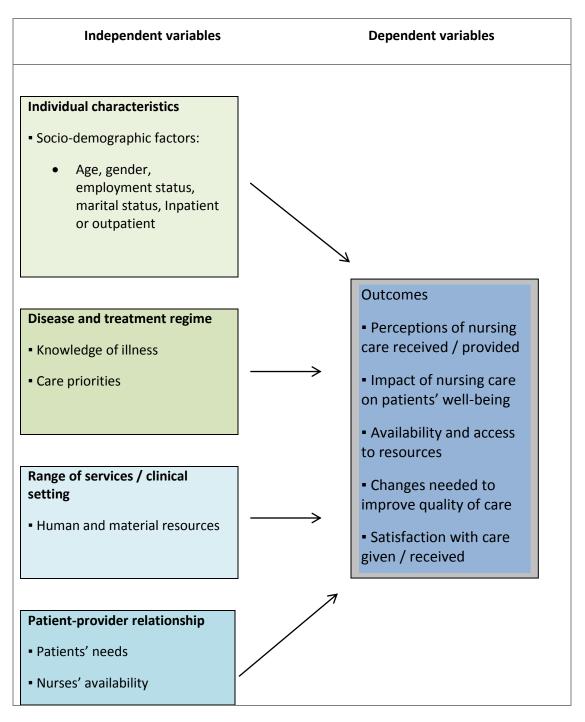


Figure 3.6: A diagrammatic representation of variables in the questionnaire

3.13.1 Data collection

Survey data were collected through the use of the questionnaire. The data collection process involved gathering information on the personal and situational variables related to TB, using questionnaires which had some open-ended questions. The open-ended approach allowed some flexibility and some rapport-building with the participants. The interviews allowed the patients the opportunity to recall their experiences of TB and TB care. The interviews were audio-taped and transcribed verbatim.

In both Australia and Malawi, the researcher collected data only during the day shifts on TB wards (inpatient and outpatient wards). In Malawi, there were only two shifts in the twenty-four hour period. The morning shift started at 0700hrs and finishing at 1700hrs and night shifts starting from 1700hrs to 0700hrs. The researcher was usually on the wards in the mornings because that is when the wards were busiest and a lot of interaction between staff and patients took place during this time. For example, nurses would administer medications, ward rounds would take place and families would assist their loved ones with activities of daily living. On occasions, the researcher would be at the hospital for the whole day to observe significant events that related to TB patients' care. For example, some educational forums for TB patients were conducted in the afternoon and the researcher would be present for such.

In Australia, the wards from where data were collected had three shifts. The morning shift commenced at 0700hrs to 1530hrs; afternoon shift commenced at 1300hrs to 2130hrs and night shifts started from 2100hrs to 0700hrs. However, the researcher was mainly on the wards in the mornings. As in Malawi, there was a lot of activity during this time. The researcher also collected data from the outpatient clinics, which run from 0900hrs to 1200hrs, and therefore visited these clinics during this time. Part of the afternoon was spent on the inpatient wards, recruiting participants. Field notes were being collected during this time in both countries.

3.13.2 Observation

As indicated earlier, the researcher had previously worked on Infectious Diseases ward in Australia and therefore was familiar with the work environment and terminology applicable to TB care. A few members of staff were also familiar to her therefore rapport was quickly

established and sustained. The participants under observation had consented to be observed during the time the researcher spent on the wards.

The experience was different in Malawi. Apart from being familiar with the terminology, the researcher was not familiar with the working environment therefore she had to build a working relationship with staff and patients alike. This was achieved by showing interest in what was taking place on the wards, showing positive body language, not intimidating staff, being honest, giving space and not being intrusive to the staff on the ward. The researcher worked close to the nurses' station and resisted from obstructing any activities on the ward. She endeavoured to eliminate any preconceived ideas so that they would not mar or influence participants' experiences. Bowling and Ebrahim described this as "refraining from judgment" (2005, p. 227). In this sense, the researcher neither denies nor confirms the experience of the participants, allowing their life-world to surface. As a non-participant observer, therefore, there was no risk to patients and nurses alike.

Field notes and associated reflective journaling was undertaken during the observations. Minichiello et al. (2003) suggested that field notes are not necessarily written in the field, despite the name. In most circumstances, it is not possible to make a detailed account of one's observations in the field. The authors suggest that the best one can do is to document key points as they take place and afterwards expand to a more detailed account once one leaves the field. While the researcher adhered to this recommendation she extended her field notes to incorporate her own reflections on her progress with the research and interaction with participants.

In relation to the field notes in particular, this involved more than the theoretical orientations. Rather, it involved watching, listening, examining material, being there, taking notes and any activity or observation that took place to address the research objectives. Alder and Alder (2000) emphasised that qualitative observations "consist of gathering impressions of the surrounding world through the relevant human faculties" (p.378). In that sense, field notes consisted of observations of the ward environment and all senses were applied: smell, sight, touch, hearing as well as detailed accounts of the researcher's feelings. Included in field notes

were photographs, reflective diary, personal feelings and views as well as anything that was deemed to be useful for the study. Schneider et al. (2003) point out that not all qualitative studies involve oral interviews or observations only. Rather, there are other sources of data such as literary and artistic media, photographs, paintings and literature. All these observations were recorded in the notebook, as suggested by O'Reilly (2009) that it is useful for recording events that trigger memory such as names, data and anything else that is considered useful for a study.

3.13.3 Interviews

Data were also collected through interviews. These interviews were conducted by the researcher with patients only. The interviews were intended for patients to provide a detailed account of their experiences with TB in their own words. Schneider et al. (2003), reiterated that qualitative research methods require a direct relationship with participants, unlike quantitative research, therefore interviews are integral in that encounter. According to Doran (2010), good questions are critical to the effectiveness of focus groups. The researcher contends that this is applicable to all types of interviews. The interviews in this study were one-to-one, between the researcher and the participant.

Minichiello et al. (2003) suggested three methods of interviewing. First is the concept of funnelling, where the interview begins with broad and general questions. The second is story-telling, where questions are targeted to encourage the participant to 'tell a story' or to open-up. The final stage is regarded as probing, where the interviewer seeks more information and clarification from the participant. The overall aim of the interview was to gain an in-depth understanding and capture the essence and perspectives of the interviewees' world in their own words (Baum, 2008). These three steps were applied to the interview process in this study.

The interview were planned to be conducted in the native languages, in order to facilitate patients' in-depth expression of their experiences without being deterred by language. Welch and Piekkari (2006) supported the notion that conducting interviews in the participant's language is more successful than another language because they express their feelings in greater details without reservation. They argued that qualitative interviewing has largely been

dominated by "monolingual – English" (p.1) and they propose that foreign language is crucial in the interview process. Though the authors discuss this in relation to a business sense, the same can be applied to nursing practice.

The interviews were audio-taped and supplemented by data from field notes which included verbal and non-verbal behaviours of participants prior, during and after the interviews. As suggested by Minichiello et al. (2003), the researcher, at times, used props such as "please tell me about..." Due to the researcher's experience with TB care, it was at times difficult to separate personal feelings, thoughts and assumptions associated with TB. Therefore, the researcher endeavoured to avoid comment on the patients' narration regarding their experiences. The questions were conveyed and related to the participants in a way that encouraged them to focus on their own experiences, for example, "tell me what it means to you to have TB". The researcher was sensitive to the fact that patients might not necessarily feel comfortable with narrating their experiences because of associated stereotypes of TB and/or TB/HIV.

Data was planned to be transcribed verbatim by the researcher, as suggested by Bailey (2008), who confirmed that transcription involves close observation of data and requires the transcriber to listen carefully. She continued to state that this familiarity with data can enhance the realisation of emerging ideas or themes during the analysis. This process was crucial and helpful to the researcher as she became familiar with the data and made the thematic analysis easier and achievable. Transcripts were scrutinised and profound words and statements were highlighted. The formulated meanings were then clustered into themes and gaps were identified.

3.13.4 Photography

Qualitative data were also collected through photography. This data was mainly about the infrastructure of the TB wards in both Australia and Malawi. Photography substantiated other data, such as interviews and observations.

3.13.5 Data management and data analysis

Two files were created which combined all the patients (Australian patients and Malawian patients) as one group and all the nurses (Australian and Malawian) as another group. Variable indicators identifying which country the participants were from were also created. Demographic comparisons such as age, gender, educational level of samples for patients and nurses were done. For nurses, their level of education, training, specialty and years of experience were also considered. For patients, multivariable logistic regression analyses were constructed to assess predictors of dissatisfaction from nursing care among patients (see Appendix 4a, question 31).

New variables were created for the nurses' questionnaire, the sum of all "Yes" responses (question 9 and 14, see Appendix 4b). A total scale score for all the other questions was added (adding the scores for each of the items), for example, total scores of knowledge of TB patients were added. Scale reliability for items in patient and nursing services was performed. The nurses' and patients' quantitative demographic data were analysed and their perceptions of nursing care received were evaluated. Qualitative data were contextualised and the following research questions examined:

Research question one: What is the patients and nurses level of knowledge about TB and its management?

Research question two: What are nurses and patients perceptions of nursing care received/ provided in these facilities; impact of nursing care on patients' well-being; availability and access to resources to improve quality of care and changes needed to improve quality of care of TB patients in these facilities?

Research question three: Are there significant relationships between patients' and nurses' demographic characteristics and their perception of nursing care in Australia and in Malawi?

Research question four: What is the cultural, social and medical history of TB patients who present to inpatient and outpatient facilities in Australia and Malawi?

Research question five: What are the characteristics, qualifications and experiences of nurses caring for TB patients in Australia and Malawi?

The quantitative data were analysed using SPSS software, version 15.0. Qualitative data were manually coded and grouped into themes and sub-themes, following guidelines by Roberts and Taylor (2002) which involves identification of themes, coding and grouping emerging patterns of data. Bazeley (2007) pointed out that data management has been made easier by use of computers, scanners, audiotapes and videotapes. Other software packages are no different. These were effective ways of coding, storage, retrieval and analysis of data. However, Bazeley also argued that using computer-based software is very daunting as much as is the manual way. This was the experience of the researcher.

Baseline characteristics were summarised using descriptive statistics. Assuming random data, normal distributions, and independence between the observations, Pearson chi-square and Fisher exact tests were used to compare groups of interests (for categorical variables). For continuous variables with a normal distribution, the mean differences between the various groups were evaluated using Student's t-test. The non-parametric Mann-Whitney test was used for variables that did not show a normal distribution. Statistical significance was set at a P-value of \leq 0.05 (two-sided). Dissatisfaction was modeled for each of 15 questions that the patients were asked to answer using a multivariable logistic regression that adjusted for age, gender, ethnicity, marital status, employment status, inpatient versus outpatient status, first versus recurrent episode of TB, severity of acute TB symptoms, physical and mental wellbeing, and the patient-reported general health.

The qualitative data (explanations in the questionnaires, interviews, reflective journal entries, photographs) opened up and explained the objective findings of the study was intended to enrich and expand on issues raised by participants which would encourage the understanding of variables from different perspectives. In order to identify themes from the qualitative data the researcher listened to the interviews several times. She then read the open-ended survey responses, interview transcriptions and reflections several times. The processes of listening, reading and also viewing the photographs led to data immersion and subsequent identification of the themes.

Table 3.5 Summary of data collection and analysis methods

DATA COLLECTION	DATA ANALYSIS	
Quantitative and qualitative data occurring concurrently	Quantitative data analysis (SPSS 15)	
Stage 1a: Quantitative data collection: Survey Stage 1b: Qualitative data collection: Open-ended questions in survey, observations, interviews, reflective journaling, photographs	Thematic analysis	
Stage 2: Qualitative in-depth interviews with one Australian and one Malawian TB patients using semi-structured questions	Thematic analysis	

The following section outlines the research processes undertaken for this study. Ethical considerations will address the issues of rigour, credibility and reliability.

3.14 Processes

3.14.1 Ethical considerations

3.14.1.1 Ethics approval

Jamrozik (2004) emphasised that, for any study, ethics approval is necessary in order to eliminate or minimise hazards associated with the research. This study was no different. Ethics approval was granted from Australian catholic University (ACU) (approval number V200405_53), see appendix 5). Thereafter ethics approval was obtained from all data collection sites in Australia and Malawi. Data collection commenced in Malawi first. For all participants, screening involved informing them of the aims and questions of the study both verbally and with patient's information sheet. Participants were screened for eligibility and if willing to participate, further explanation of the study was provided. The participants were informed that participation was strictly voluntary, all information from the research would remain anonymous and any personally- identifying information they provided would only be available to the researcher.

After the ethics application was lodged with this department, the researcher contacted the hospitals and an approval to enter the site was granted. For all participants, screening involved informing them of the aims and questions of the study both verbally and with patient's information sheet. Participants were screened for eligibility and if willing to participate, further explanation of the study was provided. The participants were informed that participation was

strictly voluntary, all information from the research would remain anonymous and any personally-identifying information they provided would only be available to the researcher.

3.14.1.2 Confidentiality

All subjects were assured and informed that all study details supplied by them were strictly confidential. Only the researcher had access to their files and was the only one liaising with the participants' physician, nurses and their records. The researcher treated all information with confidentiality. The hard copies of the questionnaire were coded and did not identify any of the participants. The copies are stored under lock and key in a filing cabinet at the student researcher's office at ACU, Melbourne Campus. This cupboard is only accessible to the researcher involved in this project. All electronic data is stored in a password-protected database. At the end of the project, all data will be compressed and will be stored at the ACU Research Centre. The security of storage devices of data e.g., USB disks was of prime importance and the researcher kept these pieces of equipment in a locked briefcase during travel. The researcher had the briefcase with her at all times.

3.14.3 Withdrawal and care of participants in the event of adverse effects of the study

The well-being of these subjects was of paramount importance in this study. There were no adverse events witnessed during the data collection period of the study. However, had there been any adverse event related to the study e.g., distress, the participants would have been counselled and referred to appropriate services as required. The participant/s would have been withdrawn from the study for a period of time as requested by the subject, or withdrawn totally if desired. The participant might have elected to continue in the study at a later date if they chose to do so. In the event where a "true" physical emergency develops, for example, an acute illness, the participant would have been referred to the treating physician. However, no emergencies or adverse events occurred during the data collection period.

Participants were informed that had they decided to no longer continue with the study, they were in no way obliged to do so. At each instance, eligible participants of the study were given a participant information sheet (see Appendix 6) to read, in which the aims, risks, methods and

potential benefits of the study were explained. Phone numbers, e-mail and contact details of the researchers were included should clarification of the study be needed. Completed questionnaires were collected on the spot, some were returned to the researchers via mail. Stamped self-addressed envelopes were provided to the subjects. Participation in the study was voluntary and participants were also reassured that their involvement would in no way jeopardise their care or their relationship with the researchers or the TB nurses.

Issues of rigour, credibility and reliability are addressed after the discussion of the study tool, which is presented next.

3.14.4 Validity, reliability and pilot-testing the questionnaire

To establish face validity, the questionnaires were pilot-tested on both patients and nurses. Fifteen patient and four nurse questionnaires were piloted across the three hospitals from which data were being collected in Malawi. Five patients and five nurses working on TB wards in Australia reviewed the paper in order to make any suggestions and recommendations. Because of the small group of TB patients in Australia and being widely dispersed in the community, only a small number could be found for pilot-testing. These participants were not included in the study.

The researcher also altered the questionnaires after the suggestions and recommendations made by research academics who were present at the probational presentation of the study, before full candidature was granted. Cronbach's alpha was utilised to establish internal consistency. Reliability and validity of patients' and nurses' questionnaires is presented in appendices 3b and 3c respectively. The fifteen items yielded alpha (α) value of 0.963, that is, confirmed that the items in the tool were actually measuring what they were meant to measure, rendering the tool to be very reliable (Pallant, 2005). Using a validated survey added credibility to the research instruments used.

3.14.5 Rigour in qualitative research

In both quantitative and qualitative research methods, errors can be introduced which may render the results a study invalid or not applicable to nursing practice. As such, research needs to be evaluated and the quality and presentation of data needs to be scrutinised. With quantitative research designs, the reliability and validity of data evaluates the consistency of the research (discussed in section 3.14.4). With qualitative methods, rigor examines the consistency of data analysis and interpretation. Macnee and McCabe (2008) define rigor as a strict process of data collection and analysis which examines the quality of the qualitative process. It is an evaluation criteria which is paramount to assessing the quality of a study. Originally identified by Lincoln and Cuba (1989), there are four criteria that are used to discuss issues or rigor in this study. These are credibility (confidence), confirmability (auditability) transferability, and trustworthiness (dependability).

Credibility refers to the confidence that the researcher and consumers of the research can have in the findings of the study. It answers critical questions that, in essence gives validity to answers applicable in nursing care. Macnee and McCabe argue that one way of establishing credibility of a study is through "member checks" (2008, p.172). This refers to the process where findings are brought back to the participants to seek their input about the accuracy, consistency and interpretation of the data. In this study, the researcher consistently clarified with the participants about some information which may not have been clear by asking questions such as: "what do you mean by that? Please elaborate...". Credibility was also ensured by involving more than one key informant about the same topic. In this case, the same questions were applied for both interviews in Australia and Malawi.

The second aspect in evaluating qualitative research is the concept of confirmability, also called auditability. This refers to the ability for another investigator to follow the decision trail. Schneider et al. (2007) explain it as "the adequacy of information leading the reader from the research question and raw data through to various aspects of analysis to the interpretation of findings"(p.139). In this study, confirmability was enhanced by providing an in-depth explanation on the background of study, the research questions and how the researcher intended to answer the questions. In the qualitative findings, more often than not the researcher directly quoted the participants so the uniqueness of their experiences could surface, thereby reinforcing the confirmability of the study.

Transferability or fittingness is another aspect of evaluating qualitative research. Koch (2006), p.92) denotes that:

...a study meets the criteria of fittingness when its findings can 'fit' into contexts outside the study and when its audience can view its findings as meaningful and applicable in terms of their own experiences.

Lincoln and Guba (1989) elaborated that transferability refers to what extent findings are applicable to other groups or settings. In other words, people who have experienced a similar situation recognise the descriptions as 'fitting' their own experiences. Macnee and McCabe (2008) suggest that transferability can be achieved by describing themes that have been identified in one sample to a group of similar participants who were not part of the initial data collection in order to assess whether the second group agrees with the themes or not. In this sense, the findings of the study from TB wards from one country need to be compared and contrasted with the findings from the other TB wards in another country.

The other way of assessing rigour in qualitative research is trustworthiness or dependability, which refers to the stability and honesty of data collected from or about participants over a time and under different conditions (Shenton, 2004; Lewis, 2009). This is achieved by establishing a positive relationship between the researcher and the participant. Trustworthiness can also be achieved by being consistent with data collection. While having a protocol for qualitative data collection could be counter-productive, Macnee and McCabe (2008) considered it to be useful as it gives a framework for data collection in terms of providing similar settings and interactions. In this study, trustworthiness was achieved by the researcher having meaningful relationships with the participants; the collection and transcription of data done by the researcher only and by the use of semi-structured questions for the interviews allowed consistency.

3.15 Summary

The chapter has explored the conceptual framework and theoretical principles of this study. It has addressed the methodological framework of the critical paradigm which is embedded within the principles of PHC. Critical paradigm allowed an investigation of the marginalised group of TB

patients. The research design, research methods and processes undertaken and the rationales associated with the choice of these methods were also investigated. The chapter has also examined how participants were recruited, the methods of data collection, data management and data analysis. Ethical considerations and issues of validity and reliability have also been analysed.

Combining quantitative and qualitative methods was the most appropriate approach to investigate factors that hinder or enhance the provision of nursing care to TB patients. The information obtained will allow key issues to be identified and consequently used in the identification of strategies and development of a model to improve the nursing care of TB patients, and hence their status quo. This important data will guide staff knowledge and performance in this highly specialist area thus, better prepare them in the care that they provide to this group of patients. The following chapter will present quantitative, qualitative and the discussion of the results of the study in relationship to the research questions.

The chapter is divided into three sections. The first section will present patients' results, the second section will address the nurses' results and the final section will discuss these findings. The TB nursing care model will also be presented.

CHAPTER FOUR: RESULTS

4.1 Introduction

This chapter will discuss the quantitative and qualitative results of the study in light of the research aims and questions. It narrates the comparisons and contrasts between the patients' and nurses' groups; the similarities and differences between the Australian and Malawian patients as well as between hospitals within the respective countries. The discussion will follow the presentation of the results.

The results from all the hospitals in both countries were merged into three core categories. For patients, these were: the nurses; resources; and, the system or ward environment. Subcategories then emerged from these categories. Like the patients' data, there were three categories for the nurses' findings, these were: the patient; resources; and the system or ward environment; from which sub-categories also emerged. Confidentiality was maintained by removing any names or identity numbers provided to the patients by the hospitals, Nurses and all hospital data collections were also coded.

4.2 Survey return rates

A total of 161 questionnaires were distributed to Australian patients. Of these patients, 44 were recruited, indicating a response rate of 27.3%. In Malawi 345 questionnaires were distributed and 150 patients were recruited, indicating a response rate of 43.5%. There were more outpatients' responses in the Australian sample. All respondents in the Malawian sample were inpatients.

A total of 122 questionnaires were distributed to the nurse participants. Of these 26 were recruited indicating a response rate of 21.3%). In Malawi, 56 questionnaires were distributed to the nurse participants. Of these 20 were recruited indicating a response rate of 30.8%. It is clearly evident that the response rates were much higher in Malawi for both the patients and nurses groups. The outpatients' responses were more difficult to follow because they had one clinical day a month. If they did not complete the questionnaire immediately, they were requested to complete and post to the researcher. A self-addressed, stamped envelope was

provided. More often than not, the participants did not send the completed questionnaires. In Malawi, some patients did not respond because they were too sick; one patient was discharged to another hospital and another had died. Others did not respond because they had reported that a lot of research has been done but they 'never' get any benefit from it therefore these patients declined to participate. These figures are illustrated in Table 4.1 below.

Table 4.1 Survey return rates for patients and nurses

AUSTRALIAN PARTICIPANTS				MALAWIAN PARTICIPANTS					
Institution	Patients		Nurses		Institution	Pa	tients	Nurses	
	Handed	Completed	Handed	Completed		Handed out	Completed	Handed	Completed
	out	(%)	Out	(%)			(%)	Out	(%)
'HA'	85	27 (31.7)	50	15 (30)	'HC'	112	36 (32.1)	30	3 (10)
'HB'	76	17 (22.4)	42	8 (19)	'HD	120	57 (37.5)	35	11 (31.4)
'HS'	-	-	30	3 (10)	'HE'	113	51 (28.7)		6 (24)
					Hospital Not indicated		6 (1.7)	-	-

SECTION A: Quantitative research findings

Descriptive analyses were conducted in order to identify broad demographic characteristics of the patient and nurse population. Below are the demographic findings and comparisons for Australian and Malawian patients, answering these research questions:

Will there be significant relationships between patients and nurses' demographic characteristics and their perception of nursing care in Australia and in Malawi?

What is the nature and history of TB patients who present to inpatient and outpatient facilities in Malawi and Australia?

4.3: Results for Australian and Malawian Patients

4.3.1 Patients characteristics

This section displays patients' characteristics by race (Australia and Malawi) in the table below. Table 4.2 also identifies the severity of disease and whether or not the illness affected the patients' physical and mental health.

No statistical significant differences were observed between the groups in terms of age, gender, marital status and employment. However, Malawian patients were significantly sicker and were more likely to be inpatients. While the acute TB illness interfered with their physical and mental wellbeing, the Malawian patients were significantly less likely to report that their general health was poor. Table 4.2 below illustrates these findings.

Table 4.2: Patient characteristics by race

VARIABLES	MALAWI (N=150) %	australia (n=44) %	P VALUE	
Age categories				
18-24	27.3	27.3		
25-34	36.7	29.6		
35-44	20.0	15.9		
45 +	16.0	27.3	0.373	
Male gender	60.1	52.3	0.353	
Married	48.7	43.2	0.522	
Employed (full-time, part-time, casual)	76.0	70.5	0.457	
Inpatient	78.7	43.2	<0.001	
First episode	50.7	81.8	<0.001	
Severity of TB symptoms				
Mild	41.3	59.1		
Moderate	15.3	31.8		
Severe	43.3	9.1	<0.001	
Acute TB interfered in physical wellbeing	76.0	43.2	<0.001	
Acute TB interfered in mental wellbeing	70.7	25.0	<0.001	
Patient-reported poor general health	8.7	20.5	0.030	

4.3.2 Symptoms experienced by patients

Table 4.3 below outlines the results of the general symptoms that patients experienced before they were diagnosed with TB. The symptoms are listed according to race.

Table 4.3: Symptoms of illness by race

Symptom	Australia (N=44) %	Malawi (N=150) %	P VALUE
1. Long-term cough	25.0	60.0	0.001
2. Recent chest infections	29.5	47.3	0.353
3. Coughing up blood-stained sputum	22.7	38.0	0.036
4. Fevers and night sweats	43.2	53.3	0.431
5. Loss of weight	45.5	39.3	0.294
6. Feeling generally unwell	36.4	61.3	0.003
7. Pain in chest	25.0	47.3	0.008
8. HIV/AIDS	0.0	22.7	0.001

4.3.3 Timeframe for seeking treatment

The timeframe from the presentation of the symptoms to the time of diagnosis was also investigated. The results indicated there were noted significant differences in symptoms of 1) long-term cough 3) coughing up blood-stained sputum; 6) feeling generally unwell 7) pain in chest and 8) HIV/AIDS. Highlighted in the analysis is the fact that 22.7% of Malawian patients were co-infected with HIV/AIDS (p = 0.001).

Further analysis using standard chi-squared test (Pearson) of independence, showed there was no evidence of association between gender and HIV status (χ^2 (2) = 6.357, p = 0.32). The patients who were also HIV positive were of child-bearing age. The findings indicated that there was strong association between age and HIV status (p=0.003) and employment status and HIV (p=0.041). The younger adults and the employed were more likely to be HIV positive. Results of the findings are presented in Table 4.4 below, and in Table 4.5, which shows timeframes in relation to gender.

Table 4.4: Timeframe for seeking treatment

LENGTH OF TIME	AUSTRALIA (N=44)	MALAWI (N=150)	P VALUE
Sought alternative treatment %	59.1	33.3	0.008
Length from symptoms to diagnosis of TB %			
1-2 weeks	31.8	26.0	
3-4 weeks	22.7	30.7	
1-2 months	-	1.3	
2-3 months	15.9	21.3	
4-6 months or >	29.5	20.7	<0.001

Table 4.5: Gender and timeframe of seeking treatment

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TIMEFRAME	MALE	FEMALE	P VALUE
1-2 weeks	22.8%	28.2%	
3-4 weeks	38.0%	25.5%	
1-2 months	-	1.8%	
2-3 months	21.5%	20.9%	
>4 months or >	17.8%	23.7%	0.429

There was a statistically significant difference in patients seeking alternative treatment before the hospital presentations. More APs (59.1%) sought alternative treatment than MPs (33.3%), (p=0.008). Again, with the length of time from experiencing symptoms to diagnosis, there was a statistically significant difference (p=<0.001). There was no statistically significant difference with gender (p=0.429).

4.3.4 Transport to a health facility

It was noted that 36 (81%) of Australian participants usually travelled to the health facility using private transport, compared to 69 (38%) of the Malawian participants. For most of the Malawian patients, transport consisted of public transport rather than privately owned vehicles. There were more patients who walked to the health facility among the Malawian patients than did the Australian participants. In summary, more Australian patients used private transport means to get to health facilities than the Malawian participants, who used other transport means such as public transport, bicycles or walking to the health facilities.

4.3.5 Knowledge of TB

This section analyses the research question, 'What is the patients' and nurses' level of knowledge about TB and its management?'

There were statistically significant differences in the understanding that TB is passed from one person to another (4.7% Australian patients, 19.0% Malawian patients, p = 0.017); Medicines used to treat TB have side-effects (84.4% Australian patients, 43.8% Malawian patients , p = 0.001); Medicines used to treat TB can be taken any time of the day (74.4% Australian patients 32.4% Malawian patients, p = 0.001); Medicines used to treat TB are taken over a long period of time (90.7% Australian patients, 69.3% Malawian patients, p = 0.012); there is no need to follow-up care of TB once out of the hospital (9.3% Australian patients, 24.3% Malawian patients, p = 0.001). More Malawian patients showed lack of knowledge in the 'medicine to treat TB' arena than the Australian patients. Table 4.6 outlines these findings.

Table 4.6: Knowledge of TB

UNDERSTANDING	AUSTRALIA % (N=44)	MALAWI % (N=150)	P VALUE
TB is infectious	100	88.7	0.69
TB can be prevented by vaccination	51.2	41.6	0.78
TB is passed on from one human to another through touch	4.7	19.0	0.017
TB can be cured if medical treatment is sought	93.0	85.1	0.390
Spreading of TB can be prevented by taking medicine	86.0	74.6	0.157
Spreading of TB can be prevented by avoiding contact with anyone	16.3	18.1	0.388
Sharing of utensils is one way to prevent TB	23.3	20.1	0.84
Medicines used to treat TB have side-effects	84.4	43.8	<0.001
Medicines used to treat TB can be taken at any time of the day	74.4	32.8	<0.001
Medicines used to treat TB are taken over a long period of time	90.7	69.3	0.012
TB can be prevented by wearing gloves	39.5	32.4	0.230
Spreading of TB can be prevented by wearing masks	69.8	58.3	0.085
Someone with TB should stay on their own	51.2	17.4	<0.001
There is no need to follow-up care of TB once out of the hospital	9.3	24.3	<0.001

4.3.6 Patients perceptions of nursing care

Perception of nursing care that TB patients received (from the nurses' perspectives) addressed the following research questions:

What are nurses' and patients' perceptions about:

- perceptions of nursing care received / provided in these facilities;
- impact of nursing care on patients' well-being;
- availability and access to resources to improve quality of care;
- changes needed to improve quality of care of TB patients in these facilities?

In the multivariable logistic regression models, the outcome was whether patients were satisfied with nursing care or not (Yes = satisfied; No = dissatisfied). Each question that assessed satisfaction was modeled alone. All those who answered that they were "quite a bit dissatisfied" or "extremely dissatisfied" were grouped together versus all other responses, and this was the study outcome in each of the questions.

Multivariable logistic regression analysis models were constructed to assess predictors of dissatisfaction nursing care for patients. These were adjusted for age, gender, marital status, employment status, severity of disease, physical and mental wellbeing, inpatient status and the self-reported general health. Table 4.7 illustrates the findings.

In each of the questions in table 4.7, the model was adjusted for age, gender, marital status, employment status, severity of disease, physical and mental wellbeing, inpatient status and the self-reported general health.

The multiple regression analyses indicated that Australian patients were more likely to be dissatisfied with nursing care across all asked questions (results not shown). The severity of illness and patient-rated general health were one of the stronger predictors of dissatisfaction. Patients who rated their health as "poor" were more likely to be satisfied from "spending enough time with nurse" and "being aware of side effects of medications". Those who were moderately ill were significantly more likely to be satisfied from "nurses being courteous and respectful", "follow-up care by special nurse", "confidentiality assured by nurse", and "being

supported by nurse". Inpatients were significantly more likely to be dissatisfied from "follow-up nursing care".

Table 4.7: Dissatisfaction from nursing care: multivariable logistic regression analyses

QUESTION	PREDICTORS		95% CI	P VALUE
Staff are courteous and respectful	Male gender	2.3	1.0 - 5.2	0.044
	Mildly ill (ref)	1.0		
	Moderately ill	0.2	0.1-0.7	0.007
	Severely ill	0.8	0.3 – 2.0	0.690
Enough time to spend with nurses	Patient-rated poor general health	0.2	0.1 – 0.5	0.003
Follow-up care by special nurse	Inpatient	2.6	1.2-5.7	0.018
	Mildly ill (ref)	1.0		
	Moderately ill	0.3	0.1 - 0.8	0.010
	Severely ill	0.8	0.4 – 1.7	0.623
Medication on time	Employed	2.7	1.1 – 6.6	0.028
Aware of side effects of medications	Patient-rated poor general health	0.3	0.1 - 0.9	0.033
Comfortable to ask nurse questions	Married	2.1	1.0 – 4.3	0.047
Confidentiality assured by nurse	Mildly ill (ref)	1.0		
	Moderately ill	0.2	0.1 – 0.6	0.002
	Severely ill	0.6	0.3 – 1.4	0.267
	Illness disturbed mental wellbeing	3.2	1.2 - 8.6	0.020
Supported by nurse	Mildly ill (ref)	1.0		
	Moderately ill	0.4	0.2 - 0.9	0.047
	Severely ill	0.9	0.4 – 2.1	0.900
	Married	0.2	1.1- 4.6	0.027

4.3.7 Patients suggestions to improve nursing care

Patients were asked if there were aspects of nursing care that needed improvement. Table 4.8 below presents the results.

Table 4.8 Patients suggestions

IMPROVE CARE	AUSTRALIA (N=44)	MALAWI (N=150)	P VALUE
Aspects of nursing care that need improvement, %	10.3	35.3	0.010

The results demonstrated there were statistical significant differences in whether nursing care needed to be improved (10.3% APs, 35.3% MPs, p = 0.010). Despite Australian patients indicating that they were dissatisfied with many aspects of nursing care identified above, the response here is in contrast to that – the majority replying "no" to the fact that there were other aspects of nursing care that needed improvement.

4.4 Summary of quantitative findings for patients

This section has presented the quantitative results for Australian and Malawian patients. The differences between each patient group has been addressed. Specifically, the demographic findings of the patients, severity of symptoms, knowledge about TB and differences between males and females in terms of delays in presentation and range of services. Multivariable logistic regression analysis predicted patients' dissatisfaction with nursing services.

4.5 Results for Australian and Malawian nurses

4.5.1 Nurses data

Descriptive analysis was conducted to identify broad demographic trends of the nurse population. Table 4.9 below shows the demographic findings and comparisons for Australian and Malawian nurses, according to the research questions:

- Are there significant relationships between patients' and nurses' demographic characteristics and their perception of nursing care in Australia and in Malawi?
- What are the characteristics, qualifications and experiences of nurses caring for TB patients in Australia and Malawi?

This section also reveals the demographic results of the nurses.

Table 4.9: Australian and Malawian nurses' demographic findings

VARIABLE	AUSTRALIA (N=26) %		P VALUE
Age categories			
18-24	7.7	15.0	
25-34	46.2	45.0	
35-44	30.8	30.0	
45 +	15.4	10.0	0.341
Female gender	88.5	80.0	0.363
Specialty			
General medical	23.1	45.0	
Surgical	0.0	10.0	
Respiratory Medical	3.8	0.0	
Infectious Diseases	65.4	15.0	
Other	7.0	30.0	0.001
Qualifications			
Hospital certificate	19.2	21.4	
University Diploma	19.2	0.0	
Bachelor Degree	46.2	21.4	
Graduate certificate	7.7	57.1	
Graduate Diploma	3.8	0.0	
Other	3.8	0.0	0.015

The results indicated that of twenty-six nurses recruited from Australian hospitals and twenty nurses recruited from Malawi. There were no significant statistical differences in terms of age and gender. However, there were statistical significant differences in terms of specialty (p=0.001). More Australian nurses worked in infectious diseases (65.4%) in comparison to 15.0% of Malawian nurses.

It was found that more Australian nurses (36.2%) had a University Bachelor's Degree in Nursing compared to 15% MNs. Conversely, more Malawian nurses (57.1%) reported to have graduate certificate than Australian nurses (7.7%). Overall, there was a statistically significant difference in qualification between Australian and Malawian nurses (p = 0.015).

4.5.2 Comparing years of experience and various aspects of nursing care

Nurse perspectives were investigated in regards to aspects of nursing care. It was found that differences and similarities were evident. Nurses rated the degree of importance to certain domains of care, for example, whether they would rate "changing bed-linen" as important or not important in the care of TB patients. There were five levels of importance: Not very important, not important, undecided, important and very important. The responses were dichotomised. Negative responses "not very important, not important and undecided" were grouped as one response = (not important). These were not reported in the table below. "Very important and important" were also regarded as one response = (important); which are the values indicated in Table 4.10 below.

As is noted in table 4.10, there were no statistically significant differences in terms of management of TB. However, there was a statistically significant difference in the way Australian nurses viewed the need to provide special crockery as a means of preventing the spread of infection (86.6% Australian nurses, 20.0% Malawian nurses, p=<0.001). Further analyses showed that nurses who were in the middle of their practice (4 - 8 years) and the experienced (>9 years) had a tendency to report that the aspects of care (as stated in the table) were not important.

Table 4.10: Years of practice and aspects of nursing care

	AUSTRALIAN PATIENTS	TOTAL N%	MALAWIAN PATIENTS	TOTAL N %	TOTAL N %
Years	Isolation of patients				
	VI I U NI NVI	n = 26	VI I U NI NVI	n = 17	n = 43
0-4	11 1 2	14 (53.8)	6 3 1	10 (58.8)	24 (55.8)
5-8	5 - 1	6 (23.1)	2	2 (11.8)	8 (18.6)
9-12	3 1	4 (15.4)	4 4	4 (23.5)	8 (18.6)
13-16	- 1	1 (3.8)	1	1 (5.9)	2 (4.7)
>16	1	1(3.8)		-	1 (2.3)
	Views of medication				
	VI I U NI NVI	n = 26	VI I U NI NVI	n = 17	n = 43
0-4	12 2	14 (53.8)	9 1	10 (58.8)	24 (55.8)
5-8	5 1	6 (23.1)	2	2 (11.8)	8 (18.6)
9-12	4	4 (15.4)	3 1	4 (23.5)	8 (18.6)
13-16	1	1 (3.8)	1	1 (5.9)	2 (4.7)
>16	1	1 (3.8)		-	1 (2.3)
	Protective equipment				
	VI I U NI NVI	n = 26	VI I U NI NVI	n = 17	n = 43
0-4	13 1	14 (53.8)	5 4 1	10 (58.8)	24 (58.8)
5-8	4 2	6 (23.1)	2	2 (11.8)	8 (18.6)
9-12	4	4 (15.4)	3 1	4 (23.5)	8 (18.6)
13-16	1	1 (3.8)	1	1 (5.9)	2 (4.7)
>16	1	1 (3.8)		-	1 (2.3)

0-4 11 3 - - 14 (53.8) 9 5-8 5 1 - - 6 (23.1) 2 9-12 3 1 - - 4 (15.4) 3	/ U N NV 	n = 17 10 (58.8) 2 (11.8)	n = 43 24 (55.8)
5-8 5 1 6 (23.1) 2 9-12 3 1 4 (15.4) 3	2		24 (55.8)
9-12 3 1 4 (15.4) 3	-	2 (11.8)	
) 1		8 (18.6)
13-16 1 1 (3.8)) 1	4 (23.5)	8 (18.6)
	1	1 (5.9)	2 (4.7)
>16 1 1 (3.8)		-	1 (2.3)
Changing bed-linen/crockery			
VI I U NI NVI n = 25 V	/I I U NI NVI	n = 16	n = 41
0-4 2 5 1 1 5 14 (53.8) 3	3 4 1 - 2	10 (58.8)	24 (55.8)
5-8 1 2 1 1 - 5 (19.2) 1	1	1 (5.9)	6 (35.3)
9-12 1 1 - 2 - 4 (15.4) 2	2 1 1	4 (23.5)	8 (18.6)
13-16 1 - 1 (3.8)	1	1 (5.9)	2 (4.7)
>16 1 - 1 (3.8)		-	1 (2.3)
Standard precautions			
VI I U NI NVI n = 28 V	/I I U NI NVI	n = 17	n = 45
0-4 2 6 6 14 (53.8) 2	2 3 3 1 1	10 (58.8)	24 (55.8)
5-8 2 2 - 4 - 8 (30.8) -	- 1 1 -	2 (11.8)	10 (23.3)
9-12 3 1 4 (15.4) 1	1 1 2	4 (23.5)	8 (18.6)
13-16 1 - 1 (3.8)	- 1	1(5.9)	2 (4.7)
>16 1 - 1 (3.8)		-	1 (2.3)

4.5.3 Australian and Malawian nurses' differences

Similarly to the patients, Independent t-tests were used to compare the mean scores and examine any significant differences between the Australian and Malawian nurses based on the services in the table above. Levene's test highlighted whether or not the variation of two groups is the same. Again, utilising guidelines outlined by Pallant, if significant value (p) is greater than 0.5, then the first line i.e., "Equal variances assumed" should be used whereas if significant values are less than 0.5, it is recommended that "Equal variance not assumed" be applied. The

rows that are bolded and italicised in Table 4.11b highlight the variances applicable to the respective domains; signifying that p = > 0.5. The column labelled Sig. (2-tailed) indicates the significant differences between two groups, the Australian and Malawian nurses. Once again like the patients, the magnitude of the differences between the groups were Eta squared to analyse the effect size. Cohen (1988), proposed guidelines for interpreting effect size values. He points out that .01 = small effect; .06 = moderate effect and .13 = large effect. These recommendations are therefore applied in the interpretation of the presented results. Eta squared values for t-tests were calculated by using this formula:

Eta squared =
$$\frac{t^2}{t^2 + (N1 + N2 - 2)}$$

The appropriate values were therefore replaced in the formula to yield the magnitude of the differences.

Table 4.11: Group Statistics

DOMAIN	GROUP (NURSES)	N	Mean	Std. Deviation	Std. Error Mean
Range of services Total of 'Yes' responses	Malawian Australian	20 26	13.20 16.92	3.862 3.907	1.087 .962
Management of newly diagnosed	Malawian	20	28.75	2.268	.507
TB: Total responses	Australian	26	31.23	2.717	.533
How nurses can help: Total responses	Malawian Australian	20 26	20.30	5.986 3.188	1.338 .625

An independent-samples t-test was conducted to compare scores on views of range of services between Malawian and Australian nurses. It was found that there was no statistically significant difference in scores between the mean scores on the 'range of services' and in 'how nurse can help' TB patients between the Australian and Malawian nurses. However, there was a statistically significant difference in scores for the understanding of 'management of newly diagnosed' TB. (p=<0.001). Nevertheless, magnitude of the differences was again very small (eta squared of 0.005). See Table 4.12 below.

Table 4.12 Independent Samples Test

	Levene's T Equality of		es	t-test for Equality of Means								
DOMAIN	F		Sig.	t	df	Sig. (2- tailed)	Mean Difference	Std. Error Difference	95% CI of the D	95% CI of the Difference		95% CI of the Difference
									Lower	Upper	Lower	Upper
Range of services Total of 'Yes' responses	Equal variances assumed	.101	.753	- 1.873	33	.068	-2.723	1.353	- 5.653	.207	- 5.653	.207
	Equal variances not assumed			- 1.876	31.207	.068	-2.723	1.352	- 5.655	.209	- 5.655	.209
Management of newly diagnosed	Equal variances assumed	1.139	.292	- 3.078	32	.000	-2.953	.723	- 3.313	- 1.392	- 3.313	-1.392
TB: Total responses	Equal variances not assumed			- 3.321	31.703	.000	-2.953	.668	- 3.301	- 1.605	- 3.301	-1.605
How nurses can help: Total responses	Equal variances assumed	3.909	.053	.151	33	.880	.208	1.371	- 2.555	2.971	- 2.555	2.971
	Equal variances not assumed			.131	27.210	.889	.208	1.377	- 2.822	3.238	- 2.822	3.238

4.5.4 Range of services: human and material resources

Nurses were also asked how they viewed the range of facilities available in their institutions for TB care and whether or not they perceived those to be adequate as shown in Table 4.13 below.

Table 4.13 Views on range of services

Services	Australia (N=26) %	Malawi (N=20) %	P value
All services within the facility: Chest X-ray, Mantoux testing, BCG Vaccination, Sputum collection, Blood collection, Pharmacy	88.5	42.9	0.004
Signs at entrance indicate location of TB testing services	26.9	73.7	0.010

The table above highlights that there were significant differences in the way nurses viewed the range of services available for TB care. More Australian nurses (88.5%) reported that they had all services within the facility than Malawian nurses (42.9%), p = 0.004. Again, there was a statistically significant difference in the responses regarding the location of TB services where more Malawian nurses (73.7%) said that testing services were easier to find than Australian nurses (26.9%), p = 0.010.

4.5.5 Perception of care

For data in ordinal scale, Mann Whitney was used as a non-parametric alternative to test the differences between the independent nurse groups in an attempt to determine whether Australian and Malawian nurses differ in their perception of management of TB patients. Whereas t-tests compare means of two groups, Mann Whitney U test compares medians by converting scores to ranks. Wilcoxon Signed Rank Test is regarded to be the same as repeated measure t-test, when subjects are measured on two occasions or under two different conditions (Pallant, 2005). This test is not applicable for this study. The results of these tests are presented in Table 4.14 below.

In this analysis, the Z value is critical. At Z value of -3.395 and the significance level: (Asymp. Sig. 2-tailed) p = .001 indicates that there was a significant difference between the understanding of management of TB between Australian nurses and Malawian nurses.

Table 4.14: Ranks and test statistics

	GROUP	N	Mean Rank	Sum of Ranks		
Management of newly diagnosed TB: Total responses	Malawian Nurses	20	15.95	319.00		
	Australian Nurses	26	29.31	762.00		
Total		46				
Test Statistics						
		Management of newly diagnosed				
		TB: Total responses				
Mann-Whitney U		109.000				
Wilcoxon W		319.000				
Z		-3.395				
Asymp. Sig. (2-tailed)		.001				

4.6 Summary of quantitative findings for nurses

This section has presented the quantitative results for Australian and Malawian nurses. The differences between each nurses' group has been addressed. Demographic variables and educational qualifications of the nurses have been explored. Nurses' knowledge about TB and the care thereof has been addressed. In addition, nurses' views on range of services, management and how they can best help TB patients have been explored. Overall, the results showed that there were no significant differences in demographic variables of the nurses. However, there were significant differences in their understating of TB and how they perceived they could care for this group of patients.

SECTION B: Qualitative research findings

4.7 Introduction

The section will address the findings from the patients and then the findings from the nurses. The patient data is grouped into three sections: the nurses; the resources; the ward and/or the health care system. Similarly, the nurses' data is grouped into three sections: the patient; the resources and, the ward and/or the health care system.

It must be pointed out that there was a need for the researcher to be accompanied during travel throughout the data collection period in Malawi. This was because she was in possession of equipment such as a laptop and some data collection tools such as USBs, mini-recorder and other electronic devices. These could easily put the researcher in physical danger as 'bag-snatching' was common in Malawi. As such, the researcher's brother escorted her to all the health facilities in the three districts from where the data were collected. While he was 'there' for physical security, he had no influence or no involvement in the data collection. He would sit at a distance and observe the interaction between the researcher and the participants.

The qualitative data begins with the researcher's entry into the field.

4.8 Entry to the field

The researcher was anxious to commence the data collection because of anticipated insider/outsider challenges that could possibly be encountered. Herewith are some reflections:

I was reluctant to start because, while I could presumably be seen as an insider (Malawi being my country of birth), I was also aware that I could be perceived as an intruder. I was uncomfortable with that thought. Here I was, returning to my homeland as a researcher representing two opposite worlds – the western and the developing – and I feared resentment.

As I entered the ward, I was greeted with smells, noises of people passing by and hospital bells ringing to signify the beginning of morning visiting hours. I arrived on the TB ward at Hospital A the following day, introducing myself to a nursing staff member who was finishing night duty. I soon learned that she was the only nurse on duty overnight, on a ward of 68 TB patients in a 71-bed ward: 20 males and 48 females.

The Matron (Nurse Unit Manager – NUM) was unavailable that day. I was referred to the District TB Officer (DTO) and my knock at his door was met by an unfriendly, "come in". Reluctantly I entered and told him who I was and what I was there for. He told me that I could not go ahead with my research on the ward. I tried to reason with him that the project had been approved by the NHRSC and, if he had any objections, to contact my supervisor. At the mention of the supervisor's name, the DTO's whole demeanour and attitude towards me changed. He referred me to the Nurses' Office where I met two nurses who had taken over for a morning shift: a Registered Nurse Division 1 [RN1] and an Auxiliary Nurse (equivalent of RN Division 2 [RN2] in Australia). These, again, were the only nurses on duty for the 68 patients. I was in a state of disbelief.

The researcher knew she needed to 'fit in' if the research with the progress in Malawi. Glass and Ogle (2012) argued that if interpersonal engagement with the participants is to occur, researchers need to demedicalise environments and intentionally create positive environments (p.72). Therefore it was intentional to attempt to be part of the patients' environment. However, it was not without inner conflict and contention, as expressed in this excerpt:

Guardians sat by the bedside. We [my brother and I] walked in with our masks on and strangely, we were the only ones in the room wearing masks! I felt very awkward even though I was fully aware of the rationale behind my actions. I felt I didn't belong. Everybody seemed to look at us as if to say, "who and what are you?" The RN1 introduced us to all the patients at once and then left. She herself was not wearing a mask. I felt confused about what I should really be doing. I knew that if I had to reach these people, I needed to 'fit in'. Against my better judgment, I stopped wearing masks during my subsequent visits. What was the use anyway? Doors and windows were wide open. Families and visitors walked in and out without masks. Should I be the educator about the importance of wearing masks? Who would supply them? This was one of the many ethical and moral dilemmas I came across. I felt defeated (see appendix 8c).

However, the patients were receptive to the researcher and were willing to share their experiences. The following encapsulates the experience:

As we were leaving the ward, one patient who looked so ill and could barely sit up, called out, 'I know you want us to complete the questionnaire. You want us to tell you what you want to know. How about we tell you our story and you hear what is really happening with us?' I asked if he would be willing to tell us his story and if we could record it. 'No problem', he replied. I could not believe that someone so sick, who looked as if he was on his 'death-bed', was willing to share his experiences. While as a nurse I had all good intentions and wanted to recruit [this patient] for my study, the patient pulled me aside and alerted me to the realisation that as a nurse, I needed to know and allow the 'who' in that patient to

surface...He challenged me to look beyond the statistical number, calling me to realise that, despite the frail body lying there, there was a 'who' still in existence.

After 'traumatic' experiences with the data collection exercise in Malawi, the researcher was too anxious to commence data collection in Australia. Herewith are some reflections:

Every day I went to the hospital that week, there was a death on the ward either from TB alone, or as a co-infection with HIV/AIDS. Sadly, that was to be my experience throughout the rest of the three months. I was physically and emotionally drained. I heard the cries, I saw the pain and I even witnessed a patient convulse to his death. I felt helpless; it was not my environment and I could do nothing, or could I? (Field notes, 16th September 2005).

While aware that Australia and Malawi were two different environments, the researcher could not help but re-live the Malawi experience. However, the realisation that data were collected over a short period of time in Malawi (4 months), the researcher was encouraged to resume the data collection in Australia. This excerpt frames the field entry into the Australian wards for data collection:

I came back to Australia with my world more divided than ever. Had I achieved my goals for the trip? Who am I? Which world do I represent? It took five months after my return to gather the courage go to the TB wards here to commence the next phase of my study, which is data collection in Australia. I still see those faces, hear those cries, listen to those requests and ask myself, 'What can I do to make a difference?' (Dulanya et al., 2007).

Despite these experiences, the familiar environment of the Australian wards made it easier to resume data collection. Rapport was quickly established with staff at Hospital A and this had a positive influence and empowered the researcher to approach the ward environment at Hospital B. However, while the medical staff were more welcoming, the researcher experienced 'lack of acceptance' from the nursing staff at this hospital. The qualitative findings of the study are presented below.

4.9 Overview of findings: Patients and nurses

The predominant theme regarding patients and nurses perception of TB care provision in both countries was dissatisfaction. Dissatisfaction has four embedded components, these were insensitivity and judgemental attitudes, inadequate resources, lack of knowledge and experience and nurses as victims. Dissatisfaction strongly correlated with the quantitative

findings. Interestingly there was a second theme, albeit minor which was satisfaction experienced by a minority of patients and nurses. Figure 4.1 below illustrates these findings.

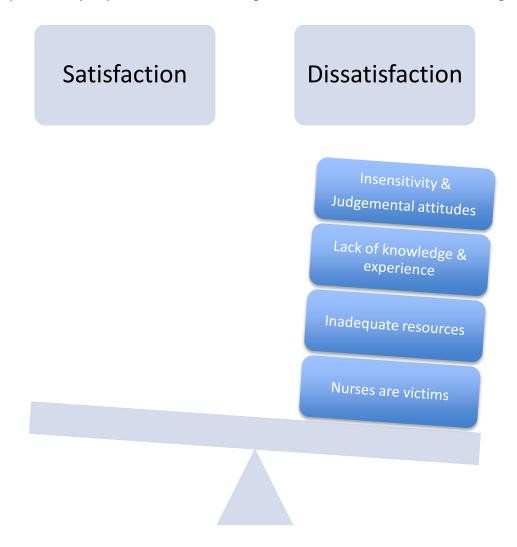


Figure 4.1: Thematic representation of patients and nurses perceptions of TB Care

4.10 Patients perceptions

4.10.1 Insensitivity and judgemental attitudes

Patients perceived nurses to be task-oriented in 'care' and lacking sensitivity to their needs. Their interactions were consistently characterised by rudeness. Highlighting this aspect were patients' comments:

There are some nurses who are rude and don't take notice of patients concerns when expressed to them. They take their time and don't hurry to help.

These nurses need to be advised that they need to be very tolerant and mindful of patients' needs. We need their patience.

There are different ways of receiving patients. Sometimes they [nurses] are extremely rude in the way they speak to patients. Some nurses are very rude when a patient brings a complaint to them.

Some nurses are extremely cruel to the sick. If the patient drops some tablets the nurses tell them off instead of speaking to them politely. Some of us are receiving injections and they don't care how they inject and it can be very painful.

Some nurses are extremely rude to the patients and they just don't care. Some do not even touch the patients and, in turn, the patients are not free to express their concerns about how they are actually feeling.

Some nurses dispense medication on time whereas others don't, some like to look after patients, some don't. 'Food services' [personnel] are extremely rude especially when it is a good meal. Sometimes they don't even give those meals to patients.

Patients often reflected on the ineffective communication and it was evident they were considerably marginalised. They did not feel able to speak with the nurses about their interaction because the nurses did not appear to listen to their concerns. For instance one patient reflected:

If you tell nurses what you need, it takes a long time before you have any help from them. I think they need to be educated that when patients express concerns, they need to act quickly.

Yet it was clear that patients lamented the lack of respect shown to them by the nurses, evident with comments:

Maybe nurses could be sensitive to individual needs of the patient.

I wish to see change in the way nurses speak to patients. They really do not care about the patients. They work because they love money so they get paid at the end of the month but we, as TB patients, we lack care.

Some nurses do not care about patients. They seem to be bitter and I don't understand why they chose this work.

Noted also was the fact that patients felt stigmatised and isolated after they were diagnosed with TB. The following comments explained this issue:

The main issue I have about my diagnosis of TB is the social stigma attached to it and the reaction of other people to my disease rather than my own reaction. I am just relieved that a diagnosis has been found for my illness and that I am now receiving treatment.

Whilst the stigma is certainly acknowledged, I feel more can be done to educate people more e.g., spread the same way as a cold, especially to contain cultural groups who may tend to ostracise TB patients to a greater extent. For example, point out how isolating and demeaning such behavior is.

Not only were the patients isolated by the general population, but by hospital staff as well, including nurses. The researcher reflected:

I am about to enter the isolation room at 1100hrs. Outside of the room is a medicine cupboard. A breakfast tray sits there with food that has not been touched at all. I put on the mask, knock at the door and am allowed in the room. I ask the patient if we could have a chat and he replies "really"? He elaborates that nurses just come and drop off medicines and have no time for a chat. I ask him if he would like to have his breakfast first and he welcomes the idea. He explains that meals are often left outside and sometimes he misses them (Field notes, 17th September 2006).

This was reflective of many times that the researcher observed how the kitchen staff and many other people handled TB patients. They would not enter the room and patients felt the physical and mental isolation. At the second interview conducted with a patient, she explained:

Look, let me be honest with you: probably you are the only person who has chatted with me for this long. People come here and see, don't get me wrong, they are nice but they don't stay. I guess they are scared...Who knows? Maybe they are busy? Mmmmh, perhaps they are scared they will catch TB too. Ooooh, it's hard. You are in this room day and night. Sometimes you cry but sometimes it's okay. I am confused.

Sometimes patient were also isolated from their families:

You know, my brother asked me for money and I told him I am not working at the moment because I am sick. You know, Centrelink is paying for my rent now but I don't know for how long they can do that. It was sad that my brother thought I am lying to him. He thinks I am pretending to be sick so I don't give him the money. I feel very sad about this. I have always supported him and how can he think like that now? [Patient cries].

Some patients seemed confused with the nurses' behavior and wondered whether they were too busy to have time for the patients, or because they were afraid they would catch TB themselves, as noted by the following comment:

Everybody, the nurses come and leave the medication on the table. If they find you are in the bathroom, they just leave the medication and they go. Some will find out how you are and some just go...

Asked how the patient felt about this experience, they replied:

See, you are in this alone, you don't know what's happening to you. How would that make you feel? It is more than isolating Jean. It makes you feel dirty, it's like you are an outcast, a leper. Don't get me wrong, I appreciate what everyone is doing. I know they are also busy but three weeks is a long time on your own, I mean, in a place like this.

4.10.2 Lack of knowledge and experience

While the researcher observed that most nurses had general knowledge rather than specialising in TB care their lack of specialty knowledge and experience was also evident in the patients' comments. Patients expressed that nurses lacked specific knowledge in the care of TB. The researcher observed that lack of knowledge was evident in that nursing staff would use one pair of gloves for different patients. Patients expressed their observations as such:

More self-discipline is required. More knowledge in the nursing profession of TB is necessary.

Young nurses need more training [and] lots of experience.

Patients also expressed concerns about doctors. They commented that most doctors were trainees therefore lacked experience in the care of TB. The following quotations explain:

Three-quarters of all doctors that come here are trainees...

Those trainee doctors, you know, they work and somewhat has set us back because they, of course, haven't been working for long therefore lack experience. For example, if one happens to be found with TB, it takes them time to initiate therapy. They delay with other investigations, perhaps with blood tests, referring you to MACRO [Malawi AIDS Counseling Resource Organisation].

Sometimes it may appear that one has TB and they would start receiving treatment for TB. Then it maybe that the person is suffering from something else, for example, severe vomiting. The problem here lies that they delay to assist.

4.10.3 Inadequate human and material resources

Patients expressed frustration due to shortage of services and nursing staff. Noted also in Malawian ward settings was the lack of personal protective equipment for both staff and guardians.

As discussed earlier in the chapter, it was noted that the Malawian nurses had very high patient ratios as opposed to the Australian nurses. This may have contributed to the nursing care that patients received. Whereas this may have been the case, it was observed that nurses did seem to sit in the office for a long period (refer to appendix 8d – [nurses' office]). These were some of the observations by the researcher:

At one hospital, a Registered Nurse on duty essentially sat in the office and dispensed medications to inpatients, which were dutifully collected by family members who queued outside the office. She had a few intramuscular injections of Streptomycin to administer to some patients and she went to the bedside to do so. Streptomycin is normally given to TB patients on short-course regime, those on re-treatment regime or patients with new TB Meningitis. Other than that, she appeared to have had no other reasons to go to the bedside.

This could be because family members or guardians were the ones who mainly assist patients with activities of daily living such as bathing, eating or even tidying their beds. There were times when patients reported that they did not even have nurses on duty. They expressed their frustrations:

We don't have enough services, especially at night. Sometimes we have no nurse on duty and it is very difficult to have that help if there is no one to give it.

We wish we could have more help; we receive very little help.

The government should employ more people. There are not enough nursing staff.

It was observed that there was lack of privacy in many aspects. Poor infrastructure and/or lack of space resulted in overcrowding in the Malawian wards. Because of lack of beds, some

patients were placed on a mattress on the floor; some even under other patient's beds. The researcher noted:

I guess this is something I must get used to, I don't know how. I see people everywhere on the ward; patients placed under each others' bed; some dragging their mattresses from the floor to give way. All these patients obviously need treatment and rest. This is not the way but, how else can these patients be accommodated? (Field notes, 2nd August 2005).

Despite the wards being overcrowded, more TB patients are admitted because these hospitals are the major and central hospitals for treating TB. Many of the smaller hospitals in the districts do not have resources for diagnosis and management of TB.

The Nightingale ward styles did little to provide physical privacy for patients and their families (see appendix 8e). There were some beds that had no curtains around them. At times a temporary mobile curtain was used to facilitate privacy when working with the patient (refer to appendix 8f). Nevertheless, it was very difficult to engage in private conversations unless one whispered. These are some of the researcher's experiences:

At one point, while I was conducting an interview with a patient, there was a patient across the room who was very ill and was having serious convulsions. The nurse on duty had gone to the office to contact the doctor. Unfortunately there were no more staff members on the ward. Whilst the nurse was waiting for the doctor to come, she came to the bedside and tried to work with the patient. Being a nurse myself, it was very difficult for me not to go to assist but I also have to be a 'researcher'. I don't know which should have come first in this instance. Unfortunately the patient convulsed to his death. I feel so terrible for doing nothing to assist, being the researcher and not the carer in that environment. Patients and guardians witnessed the death as well.

This lack of privacy would also be echoed in the fact that, once confirmed a TB suspect, the patient's contacts need to be traced. Whereas the health-carers may endeavour to identify TB suspects and at the same time maintain privacy and confidentiality of the patient, this sometimes might not be the possible. The following excerpts support this notion:

Given the need to test contacts, there is very little in the say of privacy, hence the reaction of others need to be addressed.

I feel that my privacy has not been fully protected as it could have been done. This is primarily the action of my workplace and not my TB nurse.

Another issue with inadequate resources is treatment delays. Patients expressed concerns that there was a delay from the time of diagnosis to commencement of treatment. At one interview, a patient presented concerns that most TB sufferers were experiencing delays. This delay was attributed to all health professionals and also, some patients indicate, other patients did not take responsibility for their care. For instance one patient stated:

I was admitted about a month ago. It took three weeks to have a diagnosis of TB. Yes, three weeks just waiting. I hadn't had my sputum sample taken, hadn't had any X-ray, for three weeks.

Of course, we cannot totally blame the hospitals. Patients are also responsible by the fact that they seek help much later than they should have. When I see some people arriving, I do think, "oh no, he/she has come too late for help". I can see such things as I lie here. I look at these people, but then the hospital delays even further and does not start treatment right away. Such things - not good for the people. We people suffering from TB are dying in masses; we are finished really...

The patient participants were also dissatisfied with their treatment regime. The standard TB treatment regime consists of chemotherapy drugs: isoniazid, rifampicin, pyrazinamide and ethambutol and all drugs are administered orally. However, Malawian patients receive streptomycin as part of this therapy instead of ethambutol and this is administered intramuscularly. Nevertheless, some patients preferred having an injection to oral medication. They stated:

It would be better if every TB patient received an injection because I think the tablets don't work as well.

It would be nice if we could receive an injection rather than tablets; it's just easier.

I used to have my follow-up in another town. I used to chat with TB officers in Ntcheu [another town in Malawi]. I told them they had a problem; all those people that are dying from TB is because they are not doing their job properly. Of course they denied the accusation saying, "no, it can't be true". They naturally had to deny that but I didn't back down. I told them they had a problem in the way they administered their medication. It was not right. I told them that administration was better in Blantyre.

Firmly believing that the medication does not work, some patients exclaimed:

I really see no change. Sometimes I have horrible mornings and I feel awful. I ask the nurse if there is some medication for that particular complaint but none of them really help.

Yes, there are some changes that need to happen especially in the way medication is administered. They tend to administer medication when one is really weak and please, tell the nurses that this should not be the case as from today.

Other concerns expressed by patients involved lack of follow-up by TB carers in the community. Patients complained:

One is supposed to take those tablets maybe three or four times a day. However, one could also stop taking the medication. Oh, people escape just like that. No-one would follow them up. So, I left, I went to Lilongwe. I used to attend the clinic and receive the medication there.

I mean, the health-care workers in Ntcheu and Lilongwe did not seem to care about the patients' whereabouts. I noticed Blantyre is different.

Yes, like that, just like that. Let's get the main point of the interview. The main point of the interview is that there are many people dying here. People are dying in very traumatic ways. Quite sad really. Starting from this very hospital [HE], extending to many hospitals in all the districts, I tell you what; a lot of people are dying from TB. But you know, it's not the fault of those dying patients. It really hurts...

Other patients complained about how the medication was administered. Some explained that this was not their first episode of TB and, from their previous experience with TB treatment, drug administration could be done better. While acknowledging that some hospitals practised better than others, patients expressed:

Maybe nurses could change in the way they administer the medication. Sometimes they hand them out an hour after breakfast and I think it's not the best time then, because many of us don't feel well after taking the medication.

I once again observed how they were administering the medication. I told them that "no, you really are doing so much harm to the patients." They asked me, "what do you mean?" I told them, "no, you can't keep going like this. You are hurting many people." I told them that they should adhere to the guidelines for administering the TB medication because this was not my first time. I had taken the medication before and I am still taking it. I told them they were giving wrong advice to people. I personally kept following the treatment regime from Blantyre.

4.10.4 Nurses are victims

Whereas the patients desire to see more nursing services provided to them, patients also recognised that nurses are victims of the system they work under. These anecdotes reinforce their feelings:

There is a need to increase the number of staff nurses as well as their pay so that their work continues to excel.

Here in Africa the nurse-patient care is very low in standards. Reasons being they complain they are not paid enough, their working conditions are not good. I think the whole system needs a total change. The nurses should enjoy what they do than just the money.

There needs to be a few attractions that would stimulate nurses to do their jobs well, with enthusiasm.

They have very heavy workloads. It would be nice if more staff members were added in the hospitals.

Not only were there inadequate services. It was disheartening to hear patients complain about the lack of basics of survival, such as food. Herewith are excerpts supporting this notion:

We need to be provided with adequate food. Thank you. God bless you.

There is not enough food and we have bad cleaning services.

...sure, the TB medication that I am taking does have side-effects. They make me feel hungry. This side effect, you know. I wake up in the middle of the night, I roll in bed because I am too hungry to sleep. About, round about...you know, about...I don't know what to really say; the very early hours of the morning, I have terrible hunger pangs. I wake up and toss and turn, touching here and there and there's nothing to eat that time of the night. The drugs make me really hungry. In the morning we have very watery porridge for breakfast; you look at it and think, "this really won't do much for me". How on earth can the medication work with the body lacking essential nutrients? You know, things like that...

Aaah, I think for the nurses, let me not beat about the bush; we need food. It would be helpful if the nurses would campaign for that. I suffer so much during the early hours of the morning. I even dread going to sleep. I do suffer greatly. You'll notice that in the early hours of the morning, so many patients are awake, turning, tossing, moaning because they are too hungry to sleep. Sometimes we receive some milk, a small cup of milk and that's after so long...A really small cup which doesn't go far. You get to the

point that you say, "there's nothing more I can do", like that...Things like that...I think the nurses can help us that way.

These comments explain how dire the Malawian situation can be.

4.10.5 Patients' satisfaction

As indicated above patient satisfaction was minimal and it was reported mainly from patients in Malawi. Yet the comments were not extensive and while stated as satisfaction the patients indicated the nurses were psychologically distant in their interactions.

I know that nurses are very busy. I am pleasant to them and they are pleasant to me.

Others said:

Keep up the good work.

I am very happy with nursing care.

I do not have any more comments because I am satisfied with the assistance that nurses are giving me.

I thank the hospital for the TB clinic. They help a lot.

It was also observed that some patients, while not satisfied with TB care, did perceive they had a role in speaking out. The researcher explored this with the patient participants. During one of the hospital visits, there was a meeting held by the senior District TB Officer (DTO) at HD where all patients had come together in the male ward. On request, the DTO welcomed the researcher to attend the meeting. Most of the people were seated on the hard floor. This was an open forum where patients discussed how they were coping with their respective illnesses. One particular lady, who was also a TB patient, talked about how she contracted HIV/AIDS through her husband's infidelity. She expressed how angry she was when she was first told of the diagnosis. "I could have killed him but the disease took him first", she added. Now, with the husband gone, she decided she would seek help and try to 'live' as much as she could. She expressed that she had at least two years of 'quality' life since she started taking her antiretroviral medications. This, she attributed to the fact that she came forward and sought help. These meetings were reported to take place once a week.

Patients also portrayed some knowledge on self-help behaviours that would prevent illnesses or exacerbation of their illnesses. A few patients explained that they received education on these behaviours:

Someone may have a drinking problem. We are discouraged from alcohol consumption and from smoking cigarettes. We need to minimise or stop alcohol intake or stop smoking cigarettes.

Nurses are involved in educating TB patients on how to take their medication; to avoid taking any type of alcohol, smoking cigarettes, or any chili and even avoiding promiscuity.

... I don't mean that everybody is compliant with the therapy here, no, far from it. But let me put it this way. When you get sick, you yourself know that you need to do the right thing to get better and if you are coming to the hospital, you are simply saying that you want to get better and you need to comply with the treatment.

Some of us have suffered a lot from TB but for those that have never been ill from it, you know; we will and I will get better, I know that. You understand?

It was remarkable to discover that, despite most of all the negative experiences with TB, some patients missions were to make sure that other people are spared from these experiences. The following statements imply that patients were determined to address the discrimination against TB:

I speak because I would like people to know. They may think all is okay in our hospitals but it's not. I am not dreaming about all this, it's a reality.

How can I be of any help in this regard that no one else experiences this pain? I have really suffered so much as a result of TB, how do you think I can help my friends not to experience this? What do you think?

Therefore it is acknowledged that some patients were empowered by their experiences even though they were often characterised by injustice. They wanted to make a change, to transform and to 'speak up' against injustices experienced through their illness. It was evident in the interactions with the researcher at least, they had a voice.

4.11 Nurses' perceptions

Arguably, nurses play major roles in the health-care of patients and their families. Regardless of work settings, nurses have the traditional and the most important role of caregivers to patients and their families. They provide comfort for the sick and the dying, they are regarded as educators, counsellors, change-agents who initiate and assist clients to make lifestyle modifications; they are advocates for patients and their families; managers who coordinate and make decisions about resources and researchers who participate by bringing change through identifiable and researchable problems (Bonsall & Cheater, 2008). TB care in Australia and Malawi requires the same role, and this was typified by the nurse participants in this study, who were recruited from different settings: inpatient wards, outpatient clinics and TB community nurses in both Australia and Malawi.

The Australian wards from which the study was conducted were rather quiet. Patients did not have next of kin looking after their day-to-day activities, unless a patient was critically ill. The hospitals serviced catchment areas. For example, participants who lived in the western suburbs of Melbourne were likely to be admitted to a hospital in the West. Visiting hours were long, ranging from 1400 to 2000hrs but these hours were flexible. As normal routine, nurses in Australia are responsible for total-patient care, which includes responsibility for admitting patients to the ward, administering medications, managing patients and nurses alike, coordinating allied health services and, at times, they preceptor new staff and students.

The day was divided into three shifts. Morning shift started at 0700hrs and finished at 1530hrs, afternoon shift from 1300hrs to 2130hrs and night duty beginning from 2100hrs to 0730hrs; the first two shifts being eight hours each and ten hours for night duty. The nurse-in-charge of the morning and afternoon shifts had no patient allocation because they manage staff, patients and all administration of human and material resources. There was also a ward clerk during the morning shift and part of the afternoon, who was responsible for clerical duties. Ward assistants were also available to transport patients for tests, deliver laboratory samples for pathological tests and move patients within the ward or to and from other wards. On night duty, the nurse-in-charge had a patient allocation, though less than all the other nurses on the ward as she/he

not only managed the staff on duty, but had responsibility for running the ward. Ward assistants were also on duty during the night shift.

Contrasting Australia were the Malawian wards. As discussed previously, except for one ward, the TB wards in Malawi were overcrowded as opposed to those in Australia. One was greeted with various noise and sounds on approaching the entrance to the TB ward; noises of people, equipment, hospital bells, telephones. As the researcher experienced a patient death within the Malawian hospitals on a daily basis, it was not unusual to hear the sounds of a grieving family—crying and wailing. At times people singing accompanied these noises. Some patients in Malawian wards travelled great distances to get to the hospitals, in which instances, they are allowed to have their next of kin looking after them therefore wards could be full not only with patients, but their family members or friends. More crowded were visiting hours, which extended from breakfast time: 0700 to 0730hrs, lunch hour from1200 to 1300hrs and dinner time from 1700 to 1800hrs. Being a religious country, these visiting hours would also accommodate pastoral services, sometimes with choirs performing. Some wards needed repair, for instance, some floors had some potholes. These factors may have contributed to the level of care that the nurses provided.

Malawian nurses in the respective hospitals worked two shifts only. Morning shift, which started at 0700hrs to 1700hrs, and night duty, which began at 1600hrs and finished at 0730hrs. The overlapping times in both in Australia and Malawi allowed for a handover to take place between the nurses finishing duty and those beginning a shift. In as much as the traditional roles have been mentioned, it was observed that Malawian nurses were mainly responsible for medication administration and minor procedures, for instance, wound dressing. The activities of daily living were either carried out by the patients themselves or patients were assisted by their family members or friends. Only at critical stages would the nurses in Malawi assist with these activities.

During the day shift, the RN1 in Malawi was accompanied by a nursing assistant or, rarely, another RN1. There was also a matron [nurse-in-charge], who did not have a patient allocation. The matrons were responsible for overseeing the management of the ward, however, it was

observed that the matrons were on the wards infrequently and were said to be attending meetings. As previously discussed, Australian nurses working during the morning and afternoon shifts had four patients and six to seven patients during night shifts, in contrast to Malawian nurses, who would look after the whole ward. While the Australian patient load is a lot lower than that of Malawian nurses (four patients to one nurse and fifty plus patients to one nurse in Australia and Malawi respectively); nurses in Australia appeared to be busier than in Malawi.

4.12 Dissatisfaction

Similarly to the patient data, dissatisfaction was a major thread in this data. The task rather than a holistic approach to care resulted in nurses not being able to have quality interactions with patients.

It was observed that nurses in both Australia and Malawi were task-oriented. Generally Australian nurses on a morning shift would receive a handover, give medications, attend to hygienic needs of the patients, measure vital signs, take blood sugar levels for diabetic patients and prepare to handover to afternoon staff. During the shift there might be admissions and discharges. In this case, the nurse would be responsible for coordination of allied health services, such as physiotherapists, social work services, occupational therapists, pastoral services or other services as assessed for these patients. On the whole, the shift would follow a predictable sequence. Apart from the Nurse Unit Manager (NUM) or, at times, the nurse-incharge, it was not often that ward nurses accompanied doctors on a medical round. No difference was observed in the Malawian experience. Nurses concentrated on the tasks at hand and had very little time with patients at the bedside. These were some of the observations:

As soon as the handover is done everybody seems to be rushing to get patients' folders. These contain medical and observation charts. Nurses are absorbed in giving the medication and moving on to provide ADLs. Except for the charge nurse, I have not seen any other nurse on a medical round. They are very busy trying to complete tasks for the day (Field notes, 18th August 2006).

The dispensing of drugs appeared to be easier on the Australian wards as most of the patients have medication drawers by the bedside. In a situation where medication was missing from the

bedside drawer, medication was taken from an imprest of drugs on the ward. If the imprest had no stock, the nurse dispensing the drugs would be responsible for order more from the hospital pharmacy. A ward assistant would collect the drugs from the pharmacy.

Contrary to this setting, there were different ways of dispensing drugs on Malawian wards (see appendix 8d). One option was for the nurse on duty to take the medication trolley and go from patient to patient. It was observed that nurses took a long time to complete a drug round because of a large workload. Another option was for either the patient or their relation to queue outside the nurses office and wait for their turn to receive medication. Insensitivity and judgemental attitudes were quite clear in the nurses behaviours and actions. As an example, the researcher observed:

The RN1 essentially sat in the office and dispensed medications to inpatients. She had a few intramuscular injections of Streptomycin to administer to some patients. Streptomycin is normally given to TB patients on short-course regime, those on retreatment regime or patients with new TB Meningitis. Other than that, she appeared to have had no other reasons to go to the bedside. Family members dutifully queued for the medications outside the office. A patient came and asked the nurse, "can I please have some Panadol, my legs have been very sore overnight?" The nurse replied, "we don't have any, go and buy some..." There was no compassion in her voice. She sounded abrupt and the patient appeared as if he was afraid of her. The patient walked away without a word.

4.12.1 Lack of knowledge and education

The majority on nurses acknowledged that the care of TB patients is heavily impacted by lack of education from many health-care providers. There was a consensus that many nurses as well as the general public are not well informed about the etiology and transmission of TB leading to bias and stigmatisation of TB sufferers. The following nurse statements exemplify the need for better education:

Better education about TB, its impact on patients and consistent management practices is needed for everybody. Through civic education on the spread and compliance to the community.

Better education for these people re: signs and symptoms of TB; therefore earlier detection.

It would be ideal to have more resources available. Certainly educate staff and patients about TB.

Information pamphlets in many languages or a day where an interpreter can come in and translate for doctors. Maybe a video - with pictures (cartoon); that could be understood by most people would be helpful.

More education for nursing staff and reinforcement of initial education is necessary. Civic education should not be overlooked.

Educating the community to seek care as quickly as possible whenever they have a cough for any more than two weeks. Have posters about TB, education awareness, health talks as well as guardians and patients to be taught more about TB.

Need to train all staff in TB cases.

4.12.2 Inadequate resources

Nurses, as did the patients, expressed dissatisfaction at the lack of material resources on the wards and units, and also at the lack human resources. In Australia, these dissatisfactions were mainly related to nurses working in the community setting, whereas in Malawi, the dissatisfaction applied to the wards as well and more broadly, the hospitals. The excerpts below illustrate these findings:

There is no liaison nurse at the hospital. TB Liaison nurses in public hospitals are a great help re: patient attendance. In fact, this position is essential and assists with informed patient care.

We need an increased number of health assistants as well as lab techs [laboratory technicians] to do sputum tests. We simply need more employees working at the TB lab.

The number of staff needs to be increased.

Community nurses in both Australia and Malawi expressed that they also had increased workloads and reduced staff numbers. Compounded with this was the following:

Increase of traffic on the road, which makes it difficult regarding travel time which has increased exponentially over the years due to traffic numbers on the road.

Shortage of staff and costs were also attributed to the delay of sputum examinations, especially over the weekend in Australia.

A service for AFB testing of sputum that provided weekend runs to cut down on inpatient length of stays.

Nurses also expressed dissatisfaction on the lack of communication between themselves and the medical team. They stated that often they would find a change of patient care documented in the progress notes or medication chart but the information was not communicated immediately to the nurse:

If medical staff communicated with us more readily when treatment changes occur, this would be an asset to a public health nurse. Find that the [A] Hospital is the best hospital re: communicating treatment and attendance at outpatient clinics.

The [B] Hospital is the worst regarding communication. Care of patients should be a partnership between patient, treating physician, hospital and public health nurse.

There was however, an acknowledgement that some hospitals do perform better than others in communication. These hospitals were regarded as benchmarks therefore one nurse elaborated:

The A is the best hospital re: communication and attendance at the outpatient clinic.

This collaboration between the medical team, nurses and patients was reported to have made nurses' work much easier as the plan of care becomes clear.

Most nurses were dissatisfied with screening and particularly the inadequate resourcing of such and expressed concerns related to the delay in the diagnosis and, therefore, in treatment of TB patients. This delay was attributed to late presentation and a lack of understanding of TB on the part of the medical team regarding the presentation of TB. The following comments typify this issue:

Better "screening" by non-VIDS doctors in Emergency Department is important. This will include more education.

Early identification of disease should not be ruled out. TB should be considered as a possible diagnosis at admission; considering patient demographics, country of birth; assessing prevalence of TB. Early case detection is vital.

Ensure all respiratory patients have a detail history in emergency and CXR. Many respiratory patients are sent to 5SW Respiratory Unit only to discover 3 days later that

they maybe TB positive, by that time staff and patients may be infected. Early treatment should eliminate some of these problems.

Patients are often already on the ward before TB is considered as the diagnosis and put in isolation. Can this sometimes be considered earlier given patients' sex and social history?

Some delays occurred due to, once again, lack of communication and poor administration. The following comments were noted:

Informing Infection Control as soon as suspect cases are identified to ensure patients are risk managed as soon as they are identified. Better education and its impact on patients and consistent management practices are essential.

Consider community outreach for screening of citizens in high risk groups.

Proper Sputum specimen / examination can mean a lot to the patient.

Proper filling of lab forms for sputum specimens.

Insensitivity also encompassed the issue of follow up from the health facilities. Most people in Malawi use post office box numbers for receiving letters. It was also discovered that, some patients in both Australia and Malawi, despite having a physical address, were not comfortable providing such because of related social stigma. Whereas the post office address would function well for communication purposes, it was identified as a problem in regards to following-up the patient as well as tracing contacts.

Physical address needs to be taken in case of a follow-up.

On screening patients' documentation, it was discovered that a number of people from overseas who had been tested for TB on entry to Australia were found to have active TB some months later. It was not clear how people from high-risk countries were followed up after entering Australia. Nurses recommended the following actions:

Maybe some follow-up could be done on all people entering Australia from high risk countries some months after arrival.

Ensuring that all follow-up is free of charge.

Home visiting for case detection, encourage DOT method.

Tracing contacts. Following-up cases at their homes to see who they have come in contact with.

Testing of all suspected individuals.

4.12.3 Nurses are victims

Unlike the patients, nurses did not verbalise that they were 'victims' of the system. While they might not have stated such, the researcher observed that indeed, nurses' reactions and behaviours were possible reaction to the 'system' they worked under. For example, some nurses did not seem to care how they communicated with patients. As pointed out by the patients, nurses were 'rude'. The researcher reflected:

I arrived on the TB ward at Hospital A the following day, introducing myself to a nursing staff member who was finishing night duty. I soon learned that she was the only nurse on duty overnight, on a ward of 68 TB patients in a 71-bed ward.... I met two nurses who had taken over for a morning shift: a Registered Nurse Division 1 [RN1] and an Auxiliary Nurse (equivalent of RN Division 2 [RN2] in Australia). These, again, were the only nurses on duty for the 68 patients. I was in a state of disbelief.

I sat aside observing, until a patient came and asked the nurse, 'Can I please have some Panadol; my legs have been very sore overnight?' The nurse replied, 'We don't have any. Go and buy some.' The patient appeared as if he was afraid of her and he walked away without a word. I felt very sorry for him, obviously in pain but probably with no money to buy it. 'Panadol, of all things,' I sighed.

While the workloads were high, nurses were also exposed to occupational and health hazards due to lack of resources such as personal protective equipment. However, they did not voice any concerns regarding these situations.

4.13 Satisfaction

The nurses were asked whether they regarded patient outcomes as successful or not. The majority of nurses in both Australia and Malawi responded that treatment outcomes of TB patients in their facility was very successful. In other words, nurses were satisfied with the care that they delivered to TB patients. In addition, nurses were given the opportunity to suggest any improvements that would be needed to provide better care of TB patients. It was found that the majority of nurses made no further comments in this regard. Overall, while the majority of

patients were dissatisfied with nursing care received, the majority of nurses were satisfied with the care given.

4.14 Summary

This section has presented the results of data collected through observations, reflective journalling, interviews, and patients and nurses open ended questionnaire comments on perceived factors of TB care. These issues have been discussed according to the major theme of care dissatisfaction and the minor theme of satisfaction. Within the theme of dissatisfaction, the four sub themes of: insensitivity and judgemental attitudes; lack of knowledge and education; inadequate resources; and nurses are victims were addressed.

The demographic and social barriers that participants identified as impinging on effective TB care have emerged throughout the subthemes of dissatisfaction. The findings suggest a strong need to improve TB care for patients from both countries. It is evident that collaborative strategies from health care teams are necessary to: address more effective interpersonal communication; improve knowledge and education of health care providers; rectify inadequate material and human resources, particularly in Malawi; improve patients' knowledge level regarding TB; and, eliminate the victim status of nurses in their care of patients with TB.

SECTION C: Discussion

4.15 Introduction

This section is focused on a discussion of both the quantitative and qualitative findings in light of current literature. The overall healthcare system results are discussed firstly followed by patients' and nurses' results.

4.16 The healthcare system

In chapter one, an overview of the public and private healthcare systems for both Australia and Malawi were presented. This was intentional to provide an overview of both. However, in the research most TB patients in both Australia and Malawi were cared for in the public sector.

The Australian hospitals from which the study was conducted comprised multi-storey buildings with the TB wards located upstairs and not easily identifiable. For example, at one hospital the ward was labelled 'Infectious Diseases', the other was 'Respiratory'. However, each hospital had a reception service to assist in giving clear directions to the wards. In each ward there were patients with other infectious diseases and/or other respiratory disorders. Whereas the wards were different in their layouts, they generally shared basic similar characteristics. They were generally quiet, clean and well serviced (see appendix 8c), for example, they had isolation rooms with negative pressure, personal protective equipment and adequate personnel to attend to patients.

Apparent in the Australian hospitals was the shortage of TB community nurses and translators. As do the TB officers in Malawi, community nurses in Australia follow-up outpatients to ensure they attend their appointments and are not defaulting from therapy. Most of the TB patients in Australia were migrants and were not conversant in English therefore translators were required for TB care. While the nurse-patient ratio is much lower than in Malawi, patients indicated their dissatisfaction with the lack of resources for translators. Patients also continually stated that nurses spent limited time in patient interactions, other than performing essential tasks, such as administering medications. This could be due to two main factors which was also a finding in

previous research: nurses have very high workloads in relation to the acuity of patients in their care. In addition, the attached stigma associated with a diagnosis of TB which results in restricted patient contact (Hendrich, Chow, Skierczynski & Lu, 2008; Dodor & Kelly, 2009). In contrast to the high nurse-patient ratios in the data from Malawi, the Australian nurse-patient ration remains at 5 to 20 (Gerdtz & Nelson, 2006). In addition, Patient Dependent Systems (PDSs) are in place to anticipate emergency and short-term resource demands (Gerdtz & Nelson). Never-the-less, irrespective of the amount of time nurses were involved in patient interactions in each country, patients perceived the communication was restricted.

As indicated in chapter one, the hospitals in Malawi are managed by the Ministry of Health (MOH). The MOH lacks clear policies and guidelines regarding services that should be provided at central level and this was evident in this research. One major issue that caused considerable dissatisfaction was inadequate resources that resulted in overcrowding. This confirmed early research by Cripps & Shehata, (2000). As TB care is centralised and not all public hospitals can care for TB patients, those that do are extremely overcrowded and under-resourced. The lack of adequate human resources, particularly, doctors and nurses compounds the problem.

The Malawian hospitals where the data was collected, were single-storey buildings with TB wards located on the outskirts of the buildings. One hospital had clear directions to the wards. As the wards were solely dedicated to TB patients and/or TB/HIV patients, they were known as "TB Wards". Only one hospital had isolation rooms mainly available for the very sick or for private-paying patients. The wards were a Nightingale-style with beds closely parallel and opposite each other (see Appendix 8e). One particular TB ward had pot-holes in the floor and as such, needed repair and of most significance, revealed an occupational health and safety issue for patients and staff. There were no patient call-bell systems in place. Family members known as guardians would attend to patients needs such as calling the nurse when necessary and assisting with activities of daily living (ADLs) (see appendix 8g). It was not unusual to see some patients lying on the floor or on the verandah as there were not enough beds for all of the inpatients.

Complicated by the fact that these hospitals form the major TB treatment centres, the wards were therefore extremely congested (appendix 8h), with bed occupancy rates exceeding 100% (Harries et al., 2003) due to poor planning and an uncontrolled admission system. Other noted differences were lack of resources, including personal protective equipment such as antiseptic hand gels, masks, gowns. Additionally, a lack of human resources was noted. The Malawian patient-to-nurse ratios were much larger than the Australian ratios. Senior (2010) argued that there are 17 nurses for 100,000 people in Malawi.

In this research, nurses remained influenced by the biomedical model, they had a limited voice, and as patients indicated, they were victims in the health care systems. Earlier findings mirror the issues of medical doctor dominance. May and Fleming (1997) commented that whereas nursing is diverting from medicine, there still remains medical control in health-care decisions. Mulhall (1998) argued that, while there is an increasing overlap between nursing and medicine through interprofessional training and multidisciplinary working, nurses have been encouraged to adopt as their own some tasks traditionally undertaken by doctors, creating a division between the two professions. Indeed, in their operation, practice and culture, nursing and nurses are said to be quite different with the notion that doctors "cure" or "treat" and that nurses "care". Coombs and Ersser (2004) reinforced this line of thinking, stating that while nurses play a pivotal role in clinical decision-making, they are still dominated by medicine and remain devalued and unacknowledged. This research extends the existing literature by indicating that nurses are not only dominated by medicine, but that they are also 'victims' of the systems they work under.

For instance, a case described earlier was that of a nurse in Malawi who was unable to assist a patient until the doctor arrived and the patient convulsed to his death. Arguably, apart from the doctors acting as ultimate decision-makers, inadequate material and human resources and limited knowledge of staff has significantly compromised care. In the case above, the ward did not have a defibrillator for patient resuscitation, there was one RN and one nursing aide on duty to care for over fifty patients. Even without the defibrillator, it was noted that first aid measures, such as cardiopulmonary resuscitation, were not performed.

4.17 Patients

4.17.1 Recruitment

This study found that the majority of TB patients recruited in both countries were male. This is attributed to finding that males are not proactive regarding their health and therefore have late presentations. This finding was confirmed in earlier research, (Banks, 2001; Leppert & Peipert, 2003). However, while earlier research indicated the reason for late health check is based on males' difficulty with acting on fears about their health, this was not discussed in this research (Banks, 2001; Leppert & Peipert, 2003). Contradicting the findings of the study is Juel & Christensten (2005) who suggest that, at all ages, women have higher rates of contacts with general practitioners than men and they also have higher rates of hospital admissions. The results of this study suggest otherwise.

Most patients in Australia were recruited from the outpatient clinics as opposed to inpatients in Malawi. It could be argued that as there is a low incidence of TB in Australia – in the State of Victoria there are 250 – 300 cases per year (Lumb, Bastian, Carter, Jelfs, Keehner &Sievers, 2011) – there are only a few admissions with TB and when the patients are deemed to be no longer infectious, they are discharged from the isolation wards and continue their therapy at home, followed by outpatient services.

The DHS TB Control unit strictly monitors outpatient attendance at the clinic; reminding patients of their appointments with the hospital, making home visits and tracing new contacts. These activities discourage patients from defaulting from treatment. The majority of patients in Australia were, therefore, recruited from outpatients' clinics in contrast to inpatients in Malawi. Another possibility for more outpatients in Australia could be the fact that the majority of TB patients in Australia were presenting for treatment of their first episode of TB. Unlike subsequent episodes, the first TB episode is easier to treat, therefore, most of the patients are treated through the outpatient clinic.

Contrasting the Australian pattern, more inpatients than outpatients were recruited in Malawi. Almost half of the Malawian patients indicated that this experience of TB was not their first episode. A plausible reason for this is the decreased compliance and high rates of treatment

interruptions. The combination of drug-resistant TB and HIV epidemic which have resulted in Multi-Drug Resistant TB (MDR-TB) and Extensive Drug Resistant TB (XDR-TB), could also be a factor (Singh, Upsur & Padayatchi, 2007). Inappropriate treatment regimes such as irregular drug supply, choice of drugs, duration of treatment, dosage, incompetent health professional, in addition to patient factors, such as decreased compliance are all factors that increase the risk of MDR-TB and XDR-TB (Singh, Upsur & Padayatchi). These, unlike the first episode, are much harder to treat, therefore patients tended to be exposed to longer institutionalisation. Almost half (49.3%) of the Malawian patients reported this episode of TB as a second or subsequent one. This could also explain the higher number of inpatients in the Malawian population as opposed to the Australian group.

4.17.2 Delayed diagnosis

A large proportion of patients in both countries sought alternative treatment before a hospital presentation and a diagnosis of TB. This contributed to delayed diagnosis and commencement of appropriate treatment. There were diagnostic delays of up to three weeks for hospitalised patients and up to six months between the first presentation of symptoms to diagnosis. This study has supported the previous reports by Wang et al. (2008); Yimer et al. (2008); Godfrey-Fausett et al. (2002) and Banerjee et al. (2000) who reported major delays in presentations and commencement of treatment. Findings of this study has concurred with previous findings that lack of knowledge of TB and its symptoms by both the healthcare workers and patients contributed to delays in presentation to TB centres. Salaniponi et al. (2000), highlighted average delays of eight weeks between onset of cough and diagnosis.

Soliman (2004) stated that 66% of delays are patient-related factors and 34% are systemic. Contrasting this is Meintjes et al. (2008) study who found there was a median delay of 30 days by the provider and 14 days by the patient. This was attributed to male gender, first visit with the public health clinic and not to private institutions. The major contributing factors to the delay were lack of awareness of TB symptoms. Meintjes et al. (2008) argued that most of the patients are aware of TB and/or HIV. However, they do not personalise the symptoms and consequently present late for diagnosis and treatment.

Other delays were attributed to poor diagnosis by local medical officers or low-level healthcare facilities who would initiate a drug therapy to which the patient would not respond, visits with private practitioners, traditional healers, geographical isolation or some beliefs and social stigma (Hoa, Thorson, Long & Diwan, 2003; Oblitas et al., 2010). Consistent with these findings are some studies that reiterate the major problem in diagnosis and commencement of TB treatment is the vicious cycle of endless visits at the very same healthcare level which often results in nonspecific antibiotic treatment and failure to commence specific TB treatment (Storla, Yimer & Bjunel (2008); Enwuru Idigbe, Ezeobi & Otegbeye, 2002). Meintjes et al. (2008) in their study, claim that delays in TB diagnosis are more attributed to provider than patient delay and provider delay is associated with high mortality. Patients in this study had an average of three visits to different care providers before they were diagnosed with TB. Even whilst in hospital, there were delays; one patient stated that it took up to three weeks to have a TB diagnosis made.

In Malawi delay was also associated with traditional healers and witchcraft (Wandwalo & Morkve, 2000). It is reported that TB patients in Malawi usually consult traditional healers before visiting formal services. On presentation to a health facility, health staff were not responsive to patients' needs. At the same time, there were delays of up to six weeks from the time the patient is tested to receiving results. There are also reports that further diagnostic results are returned after the patient has died (Dunn, n.d.). Patients could also delay in presenting to a health facility due to fear and also the stigma attached to the illness. Because of very high correlation between TB and HIV/AIDS in Malawi, women feel, and are more stigmatised than me therefore they are reluctant to discuss their illness and seek medical care (Dunn, year). Lack of financial means compounds the problem. Oblitas et al. (2010) elaborated that social inequalities in receiving TB care exist. Poverty and social disadvantage, such as being elderly and being a woman compounds the problem. This could explain why there were more male than female patients in both the Australian and Malawian groups.

4.17.3 Age of patients

Of interest was the fact that the Australian group had a tendency to have older patients than in Malawi. It was also reported that there is a direct association between increasing age and disability. In 2009, 40% of Australians aged between 65-69 years had a disability; 88% of 90 years or older also had a disability (ABS, 2008). Co-morbidities such as cancer and diabetes mellitus (DM), most prevalent in the elderly, make it difficult for this age group to ward off illness. It is stated that people with diabetes mellitus, especially with chronic hyperglycaemia, are more prone to be immune-compromised, which enhances progression to active TB (Restrepo et al., 2008). The combination of increased longevity and comorbidities could explain why there are more elderly patients with TB in the Australian group. Another reason could be because the life expectancy of Australians at birth was reported in 2011 to be at 85 years for females and 80 years for males (Central Intelligence Agency, 2012). Contrary to this is the life expectancy in Malawi in 2011, being 51.5 years for males and 53.13 years for females (Central Intelligence Agency, 2012). This could explain why the Australian group had more elderly patients than Malawi.

4.17.4 Co-morbidities

The Malawian group had a large percentage (22.7%) of TB patients who were also HIV seropositive. This supports the previous studies that suggest that there is a strong correlation between TB and HIV. It is reported that it is quite common to have a co-infection of HIV and TB, especially in the developing world (Lawn, Bekker, Middelkoop, Myer & Wood, 2011; Mardani, 2007; Lemos, 2008). It is emphasised that TB is the commonest co-infection in HIV-positive individuals, who are at increased risk of both reactivation of latent infection and acquisition of new infection (Mardani, 2007). As the degree of immune-suppression increases, the risks of developing TB disease also increase.

In this study, the majority of the patients with HIV co-infection were of child-bearing age; between eighteen and thirty-five years of age and most of them were employed. The WHO (2007) argued that the socio-economic implications of TB patients are profound, not only to the sufferer but to the community at large. It is argued that if people in employment are affected by TB, they experience the loss of productivity. It is estimated that up to three months of work is

lost as a result of TB; approximately 30% of potential annual household income is lost (WHO, 2011). This applies to one admission only. Most of the participants in this study were employed and considering the fact that some of the group had multiple admissions, the socioeconomic impact and losses is insurmountable.

4.17.5 Marital status

The researcher also enquired about marital status in order to contribute to the determination of the social impact of the illness on participants as well as the community at large. The majority of the patients were single or married and of child-bearing ages. While in this study the participants were aged from 18 years, other citings indicate TB prevalence to be higher from the age of 15 to 29 years (Pettifor et al., 2005; Hall, Byers, Ling & Espinoza, 2007). In their study, Lawn et al. (2006) argued that most of the increasing cases and burden of TB occur in the 20 to 49 year-old age groups. Indisputable is the fact that TB is most prevalent in productive age groups; which has tremendous impact on the socioeconomic outlook for the individual sufferer, their families and the greater community.

4.18 Barriers to TB care – Patients' perspectives

As indicated in the qualitative findings, there was widespread dissatisfaction with TB care. Compounding this were specific barriers to care. This study identified that most Australian patients had private transport to travel to the health facility unlike Malawian patients who either walked or used public transport. It is been argued that accessibility to transport and geographical location are the major factors that impact on patients behaviour in seeking healthcare (Gulliford, Figueroa-Munoz, Morgan, Hughes, Gibson, Beech, Hudson & MGulliford, 2002). Inadequate access to health care is attributed to be the cause of premature deaths in 100 million "missing" women worldwide. Affordability, physical accessibility, organisational, social and cultural barriers all impact on behaviour in seeking healthcare (Gulliford et al., 2002). As patients need continued follow-up with the TB outpatient clinic, having access to private transport could help prevent patients defaulting from treatment.

It is stated that in Malawi, economic reasons such as travel costs, guardian costs, cost of food and other medical expenses beyond the free DOTS treatment are one of the major causes of patients not accessing health facilities or defaulting from treatment (Dunn, n.d.). This may have contributed to some of the delays in presentation at a health facility after noticing symptoms. In addition to the above-mentioned factors, the study found that lack of human resources, such as nurses and poor working conditions, such as very heavy workloads, psychosocial isolation, poor communication between healthcare providers and patients as well as stigma and the reaction of people (including nurses) towards TB patients and lack of food are all barriers to seeking and receiving TB care. This is the unfortunate experience of many patients in the developing world; lacking the very resources, such as good nutrition, that would assist them in the fight against TB.

4.19 Outcome: Perceptions and dissatisfaction of care

As indicated in the findings, the Australian hospital wards had greater facilities than those in Malawi. However Australia did experience specific resource issues related to lack of translators. This in turn resulted in care that was perceived as insensitive. Despite having reasonably adequate resources in Australia, patients in both countries continually emphasized that they did not have a positive relationship with the nurses. They experienced judgemental attitudes and overall ineffective communication. This silenced patients in both countries. Merkouris, Papathanassoglou & Lemonidou (2004) point out that interpersonal relationships with nurses are central to patients well-being.

Patients were asked to comment on the nursing care that they received by stating: 'strongly agree', 'agree', 'undecided', 'disagree' and 'trongly disagree' with different aspects of care such as nurses knowledge on TB, whether nurses are courteous and respectful, caring, confidential, discuss care with patients, give medication on time, spend enough time with patients and whether patients feel comfortable with nursing staff or not. The majority of Australian patients were dissatisfied with the care they received. This was evident in both the quantitative and qualitative findings. Patients stated that nurses were rude, discourteous and disrespectful. They also stated that nurses were negligent about patient care. Patients continually stated lack of

unavailability, lack of knowledge or education about TB, delay in responsiveness to patients' requests and lack of empathy from nurses.

Özbe, (2001) highlight areas of reliability, tangibles, responsiveness, assurance and empathy as often lacking in the delivery of nursing care and that they need to be improved. However, it is known that patient satisfaction is lower if nurses are dissatisfied with working conditions or are burnt out (McHugh, 2011). In that sense, delivery of quality of care suffers and, in turn, leads to more patient dissatisfaction. Highlighted was the fact that the majority of the Australian participants were dissatisfied with all aspects of nursing care; most of these were employed. Contrasting this was the Malawian group that either agreed or strongly agreed that they were satisfied with nursing care received. This could be attributed to different expectations of 'care' by the patients.

Al-Mailam (2005) argued that patient satisfaction is directly linked to quality nursing care. He goes on to state that quality nursing care depends on the leadership of the institution and claims that transformational leadership yields nurse satisfaction which in turn empowers and motivates nurses to work effectively to the benefit of the patient who, in the end, is the recipient of quality nursing care. Bratt, Broome, Kelber and Lostocco (2000); Montoro-Rodrigue & Small (2006) reinforced the importance of leadership, stating that there is a direct link between the satisfaction of care recipients and caregivers. It is argued that a cordial relationship between patients and healthcare staff is the main factor for completion of treatment; financial difficulty being the main reason for defaulting from treatment (Donor & Afenyadu, 2005; CDC, 2006; WHO, 2006). This could have been the case with the Malawian group.

There is limited literature that describes quality nursing care in TB, though there is an abundance of literature about quality nursing care generally. Burhans (2008) asserted that quality nursing care is about meeting human needs through "caring, empathetic, respectful interactions within which responsibility, intentionality and advocacy form an essential integral foundation" (p.151). Lundberg and Boonprasabhai (2001) put good nursing care into the following categories: compassion, creation, courage, competency, comfort and communication. These are central to patient care. The findings of this study point to the fact that Australian

patients identified their nurses as lacking in the above-mentioned domains, unlike their Malawian counterparts. The Department of Foreign affairs and Trade (DFAT) (2008), stated that Australia, like many countries, faces ever-increasing pressure on healthcare attributed to technological challenges, increasing patient expectations and, to some degree, due to an ageing population. The developed world may have easier access to information and are therefore able to question aspects of care that are deemed to be inadequate.

Some studies (Eysenbach, 2000; Horton, 2000; Navarro, 2001; Smith, 2003; Odutola, 2003) indicated the inequalities regarding access to health information between the developed and developing world. They argued that the developed world has much more access to health information and communication technologies. This empowers and gives choices to users to access information in their own time and place. Consequently, people in the developed world view health as a 'right', in contrast to the developing world which generally does not question healthcare. Health care in these settings is therefore perceived to be a 'privilege'. Edejer (2000) claimed that the current digital divide is more dramatic than any other inequity in health or income. He also emphasised that knowledge is power and, more so, users of that knowledge are not passive recipients of care. It is in light of this that people in the developed world might raise questions about aspects of care. Of interest is the notion that, despite the Australian patients being overall dissatisfied with the nursing care received, most of them stated that there were no aspects of care that needed to be improved. The researcher postulates that this could be because patients felt that even if they expressed their concerns, their voices would not be heard.

4.20 Nurses

4.20.1 Trends and demographics

Demographic analysis discovered that there were no significant differences in age and gender of nurses between Australia and Malawi. The majority of the nurses were aged between 25-34 years, seconded by 35-44 years in both countries. It is claimed that nursing is an ageing workforce, with the majority of nurses being over 45 years of age (Palumbo, McIntosh, Rambur

& Naud, 2009). Senior 2010 reinforced the notion that the majority of nurses fall within the age range of 40 years or older. Most of the nurses were females in both countries. Kleinman (2004) asserts that nursing is a female-dominated profession and men represent a small minority in this profession. Cross and Bagilhole (2002) claimed that men in nursing are in a non-traditional occupation. The findings of this study support the notion.

4.20.2 Qualifications

It was noted that the majority of nurses in Australia had access to education at an undergraduate degree level, unlike the Malawian nurses. However, the Malawian nurses claimed to have obtained a graduate certificate qualification. While this may be true and is obtainable in Australia, it should be noted that the Malawian nursing educational system does not provide graduate certificate level. It could be explained that the questioning of this item was either ambiguous or misinterpreted hence the responses given. To the researcher's knowledge, the Kamuzu College of Nursing is the only institution in the country that offers Bachelor of Nursing and Midwifery Degree, Masters programmes and a Certificate in Midwifery. To date the researcher is not aware of the graduate certificate level being offered in Malawi. Nevertheless, the study found that that educational level was not directly correlational to the care delivered.

4.20.3 Years of experience and aspects of care

It was discovered that almost an equal percentage of Australian nurses and Malawian nurses agreed that isolation of patients is important in the care of patients. However, lack of knowledge was evident as most nurses, irrespective of country, did not perceive 'respiratory isolation' and other infection control practices such as standard precautions as important in the care of TB patients. More alarming was the fact that the majority of these nurses were experienced in their practice. This was no different to the issue of the importance of medication. These findings are attributed to nurses' complacency.

While nurses in Australia were more equipped with resources to aid in infection control practices, they displayed a greater deficit in knowledge of safe practices, contrasting with the Malawian nurses who had limited resources. These findings indicated that the longer one is in practice, the more complacent one becomes. Henriksen and Dayton (2006) confirmed this issue

of complacency, they referred to it as a hidden trap that awaits the most competent nurses in all settings. This is when nurses feel self-satisfied and content, the result of which is procrastination. The authors claimed that complacency affects the most experienced nurses rather than beginners – as the RN who is learning a new role is often too afraid to be satisfied or content within their practice. Castledine (2006) concurred with this notion and highlighted that automaticity results from complacency and senior nurses have a tendency to attribute poor practice to junior nurses; viewing themselves as less vulnerable. This could explain why the majority of nurses who displayed more knowledge about most aspects of care were beginners in practice because they were more vigilant than experienced nurses.

Complacency is not only attributed to nurses, it is also the situation in governments. Kelly (1999) argued that, in the developed world, societal complacency about low incidence of TB leads to decreased public funding of TB control programs, resulting in increased number of patients who are inadequately treated. Another reason could be the fact that nurses tend to label patients as being non-compliant and as such blame the patient for their condition. Again this raises the issue of the judgemental attitudes to which patients were subjected. It is argued that nurses have a tendency to label TB patients as non-compliant which leads to negative interventions towards the patients (Kelly, 1999), with nurses only attending to patients basic needs, such as drug administration.

4.20.4 Human and material resources

The study found that there was a shortage of nurses on the Malawi wards. Despite high patient numbers and the acuity of patients, the number of staff on the ward was the same. At times, as one patient reported, there were no nursing staff on the ward, especially at night. This was unlike the Australian nursing staff numbers on the ward. The nurse-patient ratio in Australia is 1:4, contrasting Malawian ratios of one nurse to over fifty patients. However, Australia experienced a shortage of community staff nurses; responsible for following-up TB patients in the community. The nurses expressed that they had very high workloads and found it challenging to adequately follow-up all the patients. Due to the increased workloads, nurses focused on routine care such as giving medications and not addressing patients' other concerns.

There is a direct link between shortage of nurses and quality nursing care. In their study on the impact of shortage of nurses on patient care, Buerhas et al. (2007), argued that nursing shortages impact negatively on communication, nurse-patient relationships, timeliness of care and overall efficiency. These areas were of concern for the patients in this study and nurses attributed this to increased workloads. It is also argued that shortages of nurses result in higher levels of poor patient outcomes (Stanton 2004). He cites pneumonia, cardiac arrest, failure to rescue, urinary tract infections and longer hospital stays as some of the adverse effects of low staffing levels.

With increased workloads nursing was task-oriented in both countries. It could be argued that nurses were focused on the tasks rather than individual needs of the patients because they worked to just 'survive the shift'. Van der Walt and Swartz (2002) emphasised that task-oriented nursing stems back to the traditional hospital ward and organisational practice which originated from the colonial history of nursing. While nurses in this study focused on tasks as a necessity due to staff shortages, it is claimed that this form of practice is socially-structured and engraved in nursing. Medical dominance is attributed to some of the nursing routines as they are perceived as overriding nurses' autonomy (Mills & Hallinan, 2009). Mills & Hallinan (2009) asserted that nurses and nursing has traditionally been viewed as an oppressed feminine entity whereas medicine is a dominant masculinised group. This division is apparent in the distribution of labour and the influence of decision-making. It was noted that nurses in the study were task-oriented and not in a position to influence key decision-making as they were not accepted as part of the team for medical rounds. Again this is an example of nurses being victims in health care structures.

Another noted aspect was the use and lack of personal protective equipment (PPE) such as gloves, gowns, face-masks for infection control in Malawi. The use of PPE is historical, stemming back to as early as 1700 BC. Finger and wrist guards were worn by Bronze Age Archers and these represented early PPE. In the 1st Century AD, veils were worn to cover the face as part of PPE (Goshfeld, 2005). Indeed, the recognition of occupational diseases, their mode of transmission as well as preventative measures are not a new concept. If PPE were available, it was noticed

that they were not applied on properly or were used spasmodically in order to reduce costs. Considering the Malawian ward environments where guardians, visitors and even healthcare personnel would entered TB wards without masks, the researcher found herself in the same boat which contradicted her moral, ethical and professional stance. This was an attempt to demedicalise and 'fit-in' with the participants. Glass and Ogle (2012, p.72), emphasised that "demedicalized environments of familiarity" should be "intentionally created" if effective and positive interactions between patients and nurses is to occur.

From the researcher's knowledge and experience, current nursing education emphasises the importance of infection control measures. Even though this is stated in theory there was a practice 'misjunction'. While this is the case, the researcher observed that even though PPE was available on the Australian wards, some nurses used them inappropriately. For example, while having a mask on to enter the isolation wards, the mask would not be secured properly. When coming out of the room, some nurses would have the mask around their neck and not dispose of it immediately after leaving the room. In some cases, some nurse reused the masks; yet an unsafe practice. While antiseptic hand gels were placed within the rooms and immediately outside the rooms, once again, nurses would not use these appropriately.

4.20.5 Communication

Another area of concern expressed by the nurses was lack of communication by doctors. Whereas the majority of doctors communicated through the progress notes, nurses were dissatisfied with this type of the communication as they claimed it lacked detail and any connection with themselves and the patients. They preferred verbal to written communication. It is claimed that lack of, or poor communication results in more medical errors, delays in treatment, wrong-site surgeries, and even fatal falls (O'Daniel & Rosenstein, 2008). In contrast, effective communication improves the flow of information, yields more effective interventions, improves patient safety and increases staff morale and patient satisfaction. Overall, it reduces the length of hospital stays (Propp, et al., 2010). In all this, the patient becomes the beneficiary of quality care.

It is clearly evident in this research that communication with TB patients, and of equal importance those who have yet to be diagnosed, requires a more structured and humane approach from governments, health care organisations and health care providers. If this were to occur insensitivity and judgemental attitudes should be minimized and care would be considerably improved. Sarkar and Sealway (2005, p.9) argued:

Our failure to respond to TB is largely a communication failure. People suffering from TB symptoms often think they just have a cough rather than TB. Likewise, those affected, and their care-givers, often do not know where to find help. National political and health programming leaders continue to devote insufficient attention and resources to tackling this curable illness. The media and civil society largely leave the problem of TB to the medical community, and take no action to mobilise funds or force TB onto the public agenda. An increasingly networked, informed and globalised civil society has led to international social movements on poverty, gender and specific health issues such as HIV/AIDS. Yet few campaigners on these issues make the connection with TB, meaning that the fight against the disease fails to benefit from broader and more creative public engagement.

Reinforcing the argument above, ASCM (n.d.), confirmed that surmounting TB challenges cannot be achieved without "far greater prioritisation and improvement in TB-related communication activities" (p.12). One example originates from Peru, where it was stated that the TB problem needs to be approached in a comprehensive way and constant dialogue with patients and their organisation should be encouraged. They further stated that in the fight against TB it is vital to understand that the problem originates in poverty and any strategy that does not take this into account will "surely fail" (p.19). This needs to be addressed at a national and global level.

4.20.6 Nurses' knowledge and experience with TB

The majority of nurses in this study received formal nursing education at an undergraduate level and a few postgraduate certificates. In Malawi, this training involves the fields of nursing and midwifery as one course whereas in Australia, the nursing and midwifery courses are separate. However, apart from the experience acquired through working on TB wards over a long period of time, most nurses did not have a specialty in TB care. Moreover, there are limited opportunities to specialise in TB care in both Australia and Malawi as courses do not run often

in Australia, and In Malawi, to the researcher's knowledge, these specialty courses are not offered.

In earlier chapters, it was discussed that the role of the nurse in TB care is more psychological due to the stresses patients encounter through isolation, social stigma, physical pain and socioeconomic loss. It is stated, and this study confirmed the findings that that the majority of TB patients in the developed world are foreign-born. In Australia, it is claimed that 85% of TB sufferers were born overseas (DHS, 2008). These patients come with different concepts of health and illness and tend to be isolated by culture, language and the stigma associated with the illness. While it is not possible to understand the diverse needs of all cultures, it is imperative that nurses are open-minded and willing to cater for the individual needs of these patients.

Mangan et al. (2008) emphasised that the role of the nurse in a cultural context is to bracket stereotypes and provide the best possible care in the way that is most acceptable to the patient. This involves a greater understanding and insight into cultural behaviours that impact on patients' health. Kelshaw stipulated (1930), that nurses working with TB patients need to learn from the field of psychology as the patients' behaviours are often a result of psychological stresses caused by TB. In this case, specialisation in TB care is crucial.

While it is acknowledged that specialisation in TB care could assist nurses to manage TB patients better, it should also be mentioned that the shortage of nurses in Malawi could limit them from specialisation. Rather, general knowledge allows the nurses to be deployed in different ward settings, as the situation demands. Beginners in nursing practice therefore gain TB knowledge through modeling senior nurses.

4.20.7 Barriers to TB management – nurses' perspectives

One of the barriers identified as hindering nursing care is poor infrastructure. Infrastructure, in this study, implies to the physical nature of the ward environment: the ward layout, number of beds and bed occupancy rates. For the purpose of this discussion, infrastructure does not relate to the administrative, managerial or leadership structure.

Lack of beds and isolation rooms in Malawi were significant barriers to nursing care. As already stated, bed occupancy rates exceeded 100% on the wards. In some wards, patients were being 'cared for' underneath other patient's beds. Incorporating guardians, these wards were noisy and overcrowded. One Malawian nurse expressed, "we need bigger and better TB wards". The lack of call-bell systems made it difficult for patients to communicate with nurses from the bedside; especially those patients without a guardian. Poor lighting and other items on the floor pose safety concerns to all: the patients, nurses, other healthcare workers and guardians. While there is a paucity of research-based material to support this argument, it is unquestionable that this type of working environment would not be conducive to effective delivery of nursing care.

Another barrier to delivery of nursing care to this group of patients is lack of human and material resources. It has already been highlighted that the shortage of diagnostic equipment add to diagnostic delays; lack of PPE exposes staff to contracting the illness; shortage of staff such as nurses and laboratory technicians (a problem on weekends in Australia) and shortage of district health officers in Malawi and community nurses in Australia result in increased workloads thereby hindering the quality of care given (Buerhals et al., 2007; Van der Walt & Swartz, 2007).

Lack of knowledge of TB care was identified as another barrier to TB care. This is not isolated to nursing staff, but also involves doctors from different work-settings such as the local medical doctors, private doctors, emergency department doctors; allied health staff, supporting staff as well as the community at large (Aoatwala & Al-Absi, 2004; Storla, Yimer & Bjunel, 2008). Nurses also expressed the lack of communication with the medical team as another barrier to TB management as this hinders continuity of care and compromises patient safety (Propp et al., 2002). Community nurses in Australia had a major concern that the treating doctors did not communicate with them and they stated, "care of patients should be a partnership between patient, treating physician, hospital and public health nurse". Whereas patients voiced that they felt stigmatised by other people including nurses, nurses themselves did not identify this as a barrier to the delivery of healthcare to TB patients.

4.21 Outcome: Nurses' perceptions and dissatisfaction of care

Despite all patients highlighting that they were dissatisfied with nursing care provided, ironically nurses stated they were satisfied with their care delivery. Yet, there were significant differences between nursing groups in the way they viewed priorities in the provision of care to TB patients and how best they perceived they could care for patients. In contrast, there were no significant differences in the way these groups viewed the range of services provided.

A study by Chiari et al. (2008) examined the perception of health care workers in acute and post-acute wards. It showed that nurses showed satisfaction in nursing care delivered based on positive changes that they see in clinical symptoms of patients or in managerial outcomes, such as short length of hospital stays, decreased numbers of falls and increased numbers of hospital discharges. Rosenstein (2002) also pointed out that the nurse-physician relationship is important for the satisfactory and effective delivery of care. Further literature states that team nursing, work allocation, communication and management (Robinson, n.d.) are essential to nurse satisfaction therefore delivery of care which in turn, leads to patient satisfaction with care.

While the Malawian patients were less dissatisfied with nursing care received, overall, as observed by the researcher, a lot of negative outcomes on TB wards in Malawi were noted. There was at least one death per day due to TB and TB/AIDS. Patients appeared to be sicker, they stated that they had poor nutrition and reported that nurses were 'rude'. Patients in Malawi also had lengthened hospital stays due to the need to have streptomycin injections as part of TB treatment. Found in the study, the lengthened hospital stays could also be associated with MDR-TB. Australian patients also showed dissatisfaction in nursing care received. Despite these factors, both the Australian and Malawian nurses perceived that they were satisfied with the nursing care given.

4.22 Recommendation: The development of a nursing care model

This section draws together the results and discussion by proposing the development of a nursing care model for TB care. In addition, the model will be based on health promotion

principles, MDGs and outreach and educational activities occurring internationally to improve TB care.

In the United States of America, a model of TB care, named the 'Boston model' was developed. This model involved collaboration between managers and clients with the assistance of outreach workers, which proved essential in identifying and facilitating individual needs (White & Hall, 2006). The outreach workers replaced public health nurses (Position Statement, 2004). This city, which had 89% of patients discharged from hospitals lost to follow-up and failed to complete therapy, later reported a success rate of above 90% on completion of therapy. In addition, TB cases were reported to be decreasing. The involvement of laypersons in monitoring patients on TB therapy was attributed to positive outcomes for TB patients.

Another example is from the Philippines, where it is reported that the majority of TB patients are predominantly poor and are not aware of their civil rights and often feel stigmatised. This potentially isolates patients and they often hesitate to participate in their care. The Philippines now practises a Participatory Health Model which involves patient participation and community mobilisation (Sixth Meeting of the Working Group on MDR TB partnership, 2007). It is reported that this has empowered the local communities and has enabled early diagnosis of disease therefore has encouraged early commencement of TB treatment. The rates of completion of therapy have also been reported to be increasing (Sixth Meeting of the Working Group on MDR TB). In Namibia and Indonesia, where there is a lack of human resources, as is also the case in Malawi, it is reported that volunteers meet patients who are at risk of failing treatment in an informal setting and motivate them to continue treatment.

In the town of Zomba, Malawi, TB Officers established centres in rural areas where they collect sputum samples over a three week period from people with extensive coughing to assess if they are positive or not for TB. This active case-finding assists people who are geographically isolated from the treating centres to have a much earlier diagnosis, and therefore early treatment. This consequently reduces morbidity and minimises the risk of transmission to the local community. While no documentation has been found on how successful this programme has been, other authors acknowledge that active case finding encourages early detection of TB in the

community and the challenge is to follow-up these cases to completion of therapy (Golub, Mohan, Comstock, & Chaisson, 2005; Becerra et al. 2005; Getahun & Raviglione, 2010). A coalition between America and KwaZulu Natal Department of Health in South Africa collaborated in the development of a programme where patients are treated in their homes; injection teams visit, monitor, encourage and support patients through the treatment programme. This has reportedly reduced the burden on hospital beds and is essentially more humane and cost effective (Margo, 2011).

Popay and Noyes (2007), reported a systematic review on improving TB services. While the review was primarily focused on the DOTs strategy, this research study resonates with the overall findings of the meta-synthesis. The authors identified socio-economic circumstances, material resources and individual agency; explanatory models and knowledge systems in relation to tuberculosis and its treatment; the experience of stigma and public discourses around tuberculosis; sanctions, incentives and support, the social organisation and social relationships of care to have impacted on the social relationships of care (p.227).

Drawing from the findings of the study, the examples and models presented above and the Malawi experience where the TB Officer conducted meetings in an informal setting with TB patients at HD, the researcher developed a new nursing model for TB care. The model reinforces the principles of PHC, health promotion and MDGs as stipulated by the WHO in the Ottawa Charter discussed in chapter 3. From the literature and the findings of this study, it is apparent that health promotion is not solely the responsibility of the health sector but rather, it is multisectorial. This emphasises the need to incorporate the model within these multifaceted boundaries. The individual patient is, therefore, incorporated within the social, political, economical and environmental arenas and the nursing care model addresses the patient within these premises. In line with the critical paradigm, the patient is empowered and is given a voice. Transformation and change in status quo follows. From the study findings and incorporating other key aspects for improved care, the nursing model of TB care was developed and is presented in Figure 4.2 below. The model is termed 'Kennieth' model of TB care. Kennieth is

representative of all of the people who have suffered an untimely early death and, therefore, by naming the model as such, the people of Malawi are strongly recognised and valued.

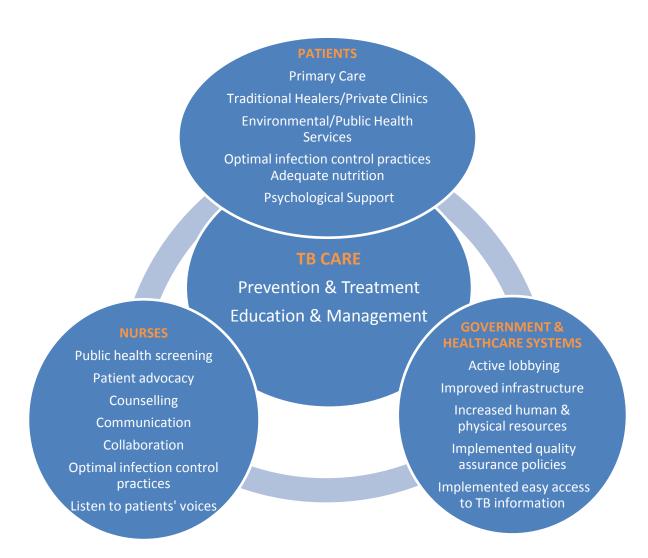


Figure 4.2: The Kennieth TB model of care

4.23 Discussion of the TB model

From the literature review and the results of the study, the findings were approached from the positions of the health-care system, patients and nurses. Consistently throughout the results it can be seen that patients were dissatisfied with their care, and as such, care interventions need to be addressed from three focal points.

4.23.1 The healthcare system

In this study, it was found that the healthcare system contributed to some of the problems associated with accessing TB healthcare. Pronounced is the centralisation of TB care, which means there are only a few centres that manage TB patients. Some patients were geographically isolated. As a result, accessibility to TB treating centres is not convenient or not possible for everyone. The majority of the centres were in urban areas therefore disadvantageous to people from rural areas. This situation was applicable in both Australia and Malawi. The expenses associated with travel, maintaining the patient – especially in Malawi where there is inadequate food supplied to the patient, let alone the guardian –, all become barriers in accessing healthcare.

Other infrastructure related to the ward situation: ward layout, inadequate beds and lack of isolation rooms. Again, this situation was more applicable in Malawi than in Australia. Another barrier related to the stigma and discrimination towards TB patients, which is reportedly among the greatest barriers to preventing more infections, providing adequate care, support and treatment (Advocacy, Communication and Social Mobilisation [ASCM], n.d.).

Other identified hindrances were the lack of policies, poor regulation and administration regarding infection control practices. As discussed before, even the Ministry of Health lacked clear policies and guidelines about the distribution of patients to different healthcare institutions. Shortage of staff such as nurses, doctors and laboratory technicians as in Malawi made it difficult to care for these patients. Patients stayed in the hospital longer before a TB diagnosis was made. Increased workloads puts pressure on staff therefore patients' needs were not addressed promptly. Shortage of community nurses in Australia added to increased stress therefore less time was spent with the patients. Lack of material resources, for example,

diagnostic equipment such as X-ray machines, personal protective gear such as masks and gowns exposed staff and the community to occupational health risks and the risk of contracting TB. Poor diet exacerbated the illness. Reduced staff numbers on the weekend and the fact that no sputum examination was done on the weekends in Australia resulted in some delays in diagnosis and commencement of treatment.

Some suggestions for addressing problems with the system are improving accessibility and infrastructure to allow easy access to health facilities and provision of more health facilities especially in rural areas is also important. It is also recommended that the government invests in more diagnostic equipment to minimise delays. Governments also need to provide more funding for basic necessities in health-care institutions, such as good nutrition, and personal protective equipment, such as gloves

There is also a need to employ more personnel to reduce workloads. Lobbying governments for better working conditions which are not detrimental to patients care is crucial. This could attract, motivate and retain health-care workers. It is also essential that policies and procedures are reinforced and adhered to, for example, ensure the provision of ongoing in-service education for all healthcare professionals. Other necessary interventions would be to enable the community to access health information easily through, for example, schools and mass media. Local medical officers and traditional healers can also be instrumental advocates and educators of communities on TB and symptoms as they have been identified as first contacts of care.

4.23.2 The patients

Cultural and traditional beliefs such as the focus of the disease being attributed to heredity or witchcraft caused delays in presentations to health facilities and consequent delays in diagnosis and commencement of treatment. In Australia, alternative treatment was sought from local medical doctors. This delay also exposed the community to dangers of potentially acquiring the illness. Delays were also attributed to a lack of knowledge about TB and its symptoms. Patients also felt stigmatised and isolated therefore delayed in presentation to a health facility for TB care. Geographical isolation and transport costs also presented some difficulty in accessing TB services. These, again, compounded these delays. Lack of support from health-care workers as

well as the general community left patients feeling isolated. Other issues related to the patients themselves, for instance, in terms of failure to comply with treatment.

It is therefore proposed that nurses or healthcare workers encourage or educate patients and the community in passive case finding and early presentation to a health facility. Through civic education, nurses can also educate patients on effective infection control measures. It is also essential that patients are afforded good nutrition. Furthermore, it is crucial that nurses and all healthcare professionals provide psychological support to patients to minimise the impact of marginalisation and isolation of this minority group.

4.23.3 The nurses

The findings indicated that nurses were task-oriented rather than engaged in holistic work in the provision of TB care. Lack of communication/collaboration between patients, nurses, doctors, allied health professionals and other healthcare staff, such as kitchen staff, was identified as another factor that fragmented nursing care. Lack of knowledge and education on TB care, as nurses did not have specialised orientation to TB also contributed to the care that nurses provided. In addition, negative attitudes and stigmatisation of the illness and TB patients left patients feeling more isolated and marginalised. Poor infection-control practices such as standard precautions were lacking. These issues could have been compounded by increased workload due to staff shortages or, due to complacency.

It is therefore proposed that nurses be involved in active case finding by screening of high risk communities. Advocating for patients by lobbying and representing their needs to other professionals, the hospital system and to governments is suggested. Counselling these marginalised groups would also be beneficial in addressing stereotypes and empowering the patients. Nurses themselves are encouraged to eliminate negative behaviours and stereotypes towards the patients in order to facilitate positive relationships. This could minimise the sense of isolation experienced by the patients. It is also recommended that nurses encourage patients to actively participate and collaborate in their care, not only with the nurses, but with other health professionals. Again, it is vital that nurses eliminate complacency and adhere to effective infection-control practices. Finally, nurses are encouraged to participate in ongoing education

regarding TB care and its management. The need to train nurses and supporting staff in Infectious diseases and specifically in TB care should not be overlooked.

4.24 Overall recommendations

It is important that the community at large is sensitised regarding TB and its symptoms through TB education and awareness, such as identification of presenting symptoms. This could be achieved through popular media such as television, radio and loud-speakers in the village settings (Hoa, Chic & Thorson, 2008). Schools and churches could also be utilised in rural areas where people may not have access to newspapers, radios or modern technological devices such as television, it is imperative to advise patients and educate the community to immediately seek advice at a nearby health facility when symptoms present. While not all health facilities have capabilities to diagnose or treat those with TB, they could act as referral centres for TB sufferers.

It would be helpful if more drop-off stations for sputum samples which are collected by TB Officers are set up in Malawi. It is also important to dispel some traditional beliefs about TB such as that it is hereditary and the focus on 'who' caused the disease rather than 'what' is the disease and how the disease is spread, such as sharing utensils (Zhang, Liu, Bromley & Tang, 2006).

Avoid and address stigma, discrimination, social, emotional and psychological isolation of sufferers. This could be achieved through sensitising the community about the presenting symptoms for the disease and that it is curable through early presentation, early diagnosis and early commencement of treatment. Utilise traditional healers, village healthcare providers and local medical officers as educators and advocators by providing them with basic training on TB symptoms and management. Emphasis should also be placed on the necessity for traditional healers and local medical officers to refer patients to TB treatment centres. Encourage participation of TB patients in their care (similar to the social mobilisation in the Philippines).

Encourage collaboration between patients and healthcare workers by having open dialogue regarding each other's roles and needs in achieving positive outcomes. It is also suggested that

past TB sufferers be involved as advocates and counselors through sharing their experiences. As is the case in Malawi where informal gatherings with patients and the TB Officer were conducted, ex-TB patients could be invited to address and motivate others on how to deal with the illness and its associated consequences. Support of the patient as well as their carers by listening to their concerns is also vital.

4.25 Summary

This chapter has discussed the patients and nurses results. Literature pertinent to the findings has also been highlighted. Highlighted in the chapter are factors that impact on nursing care identified by both groups of patients and nurses. The findings suggest the need for collaborative strategies. These should incorporate i) the healthcare system, such as improving the infrastructure and access-related problems such as geographical isolation; decreasing staff workloads; ii) the patients, such as increasing TB awareness and self-help behaviours in seeking advice for early diagnosis and iii) healthcare workers, including nurses. Strategies such as increasing TB knowledge and education in related to TB care; changing attitudes towards TB and TB sufferers to aid the early detection, diagnosis and treatment of these patients could result in patients' satisfaction of care with consequent outcomes of decreased morbidity, disability and mortality. Based on these analyses, a nursing model of TB care has been developed.

The following chapter will present the implications, limitations and conclusion of the study.

CHAPTER FIVE: CONCLUSION

5.1 Introduction

This chapter revisits the intentions of the study. The research questions are revisited and the key findings are outlined. The overall highlights of the study are put forward as are the clinical implications and limitations. The chapter concludes with recommendations for further study.

The main study aim was to investigate the factors that enhance and/or impinge on the provision of nursing care to TB patients from the perspectives of patients and nurses. The study also investigated whether any identified barriers can be eliminated, minimised or adjusted to improve the outcomes of patient care. As such a secondary aim was to develop a model of care to improve TB care.

The following research questions formed the premises of the investigation.

- What is the patients' and nurses' level of knowledge about TB and its management?
- What are the patients' and nurses' perceptions regarding:
 - provision of nursing care;
 - impact of nursing care on patients' wellbeing;
 - availability and access to resources to improve quality of care;
 - changes needed to improve quality of care of TB patients in these facilities?
- What are the characteristics and history of TB patients who present to inpatient and outpatient facilities in Australia and Malawi?
- What are the characteristics, qualifications and experiences of nurses caring for TB patients in Australia and Malawi?
- What are the relationships between patients' and nurses' demographic characteristics and their perception of nursing care in Australia and Malawi?

The findings revealed that there were no statistically significant differences in demographic variables between the patients' and nurses' groups in Australia and Malawi. Patients' differences were in terms of the severity of the illness and being an inpatient. The nurses' differences were regarding their educational status and qualifications. The overall quantitative and qualitative results were closely aligned and revealed that the predominant theme

regarding patients' and nurses' perceptions of TB care provision in both countries was dissatisfaction. Dissatisfaction had four embedded components, these were insensitivity and judgemental attitudes, inadequate resources, lack of knowledge and experience and nurses are victims. The results also revealed a second minor theme of satisfaction experienced by a minority of patients and nurses primarily in Malawi.

5.2 Highlights of the study

To the researcher's knowledge, this is the first comparative nursing study that has taken place between the developing and the developed world; two settings that are not only geographically separated, but also socially, culturally, economically and even spiritually. It is also the only study that has addressed perceptions of both patients and nurses that impact on nursing care using two research methods; quantitative and qualitative. This has highlighted some of the patients' and nurses' concerns and has provided some insight into the needs of each group respectively; which sets the study apart as a benchmark for further inquiry. Furthermore, the study was that it had greater than 80% power therefore the researcher was confidently able to detect differences when they existed in the quantitative analyses.

The research was embedded in the conceptual framework of PHC, health promotion and MDGs and critical paradigm was the overriding methodological framework. As such, equality, empowerment and giving voice to participants was central to the thesis. The study has confirmed previous findings that TB patients' voices are not heard and reinforced what is already known about stigma attached to this illness. Consequently, TB patients feel marginalised and isolated. This was highlighted in the interview with a patient who stated that they have TB medications but what use is it on a hungry body? Regrettably, healthcare professionals, including nurses, contribute acutely to these experiences and patients' are therefore dissatisfied with the nursing care they receive. In light of these findings, a TB model of nursing care was developed which enveloped the principles of PHC health promotion in an effort to attain the MDGs. The findings also revealed that there is a need for healthcare workers to listen to the needs of the people, not to give them only what is thought best for them, and challenges the nurse to exercise that traditional role of 'caring.'

At the commencement of the project, the researcher assumed that the developed world was the pinnacle of healthcare from which the developing world could learn. However, this study has identified that the developed world can draw lessons from the developing world. Some of the highlights concerned basic hygiene standards in the application of standard precautions in TB care. Whereas it could be assumed that with better education and resources then better performance would ensue, however, that was not the case with some aspects of nursing care with Australian nurses. It is stated that:

Poor countries make the best teachers. It is not what we spend on health but how we spend it. We will meet in the developing world the level of will, skill and constancy that may put ours to shame. We may find ourselves not the teachers we thought we were, but students of those who work under circumstances that would have stooped us long ago (Editorial of BMJ, 2004).

The study therefore provides a platform for collaboration in the care of TB between the developed and developing countries, as well as within the countries.

Another finding has highlighted that novice nurses were more vigilant with TB patients and provided better care than experienced nurses. Another considerable finding was the fact that even though the developed world has greater available material and human resources, Australian patients were more dissatisfied with nursing care received than patients in the developing world who have limited resources.

The study also highlighted that TB is not an illness of an individual, rather, it is a community problem in terms of diagnosis and management. The sufferer belongs to a larger social network and is a crucial part of this web. There are many healthcare providers involved in frontline diagnosis, care and management, most specifically, local general practitioners, traditional and alternative healers, emergency department staff ward staff and community and/or district carers. The community has a crucial role in identifying and referring suspected TB patients for further investigation and/or treatment. This emphasises the importance of continual ongoing education in TB care for healthcare workers and the wider community. Such education would minimise delays and rates of transmission within communities.

Another finding was the historical shift in the epidemiology of the disease. Whereas historically there were more TB patients of 60 years of age and older, today the burden of this disease falls among the youth; 20 to 49-year old population (Lawn et al., 2006). The study findings indicated the age bracket of 18 to 44 years as the most vulnerable. Possible explanations could be the impact of HIV/AIDS which is much higher in the younger age-groups than the older generation. In addition, the impact of HIV/AIDS has been highlighted as having a tremendous impact on the epidemiology of TB.

Highlighted also are the differences in the way cultures deal with illness. It was observed that the Malawian group added a spiritual component in the way they dealt with sickness and death. There were choirs on the wards and preachers from different dominations visiting the patients. This was not the case in the Australian hospitals. Whereas there are pastoral services available at the Australian hospitals, these were only provided at the request of the patient. It has been documented the spiritual wellbeing and meditation is important in enhancing the psychological health of individuals as well as positively altering the brain and immune function, the cardiovascular and neuroendocrine systems (Seeman, Dubin & Seeman, 2003; Davidson et al., 2003; Matchin & Armer, 2007). Koenig (2007) also asserted:

If religious people have a world view that gives hope and meaning in the face of stress and loss, if they have social support from other members of the religious community and if they have lived healthier lifestyles by smoking less, drinking less and making more conservative, less risky decisions in marriage, workplace and recreational activities; there is good reason to expect they will have better physical health as well (p.545).

Echoing these sentiments is Eckersley (2007); who emphasised that religious people have similar benefits as described above.

The study also highlighted that patients themselves are the best counselors of people suffering from TB. Patients in Malawi had very high regard for the informal meetings conducted by the TB District Health Officers where patients had a forum to share their experiences of TB and how they dealt with the illness. Patients could therefore learn from each other and, once again, this minimised the impact of isolation.

5.3 Clinical implications of the study

From the findings of the study, it is clear that there is a need for understanding the needs of TB, which, if not treated, is one of the most deadly diseases of the 21st century especially in the developing world. Whereas the responsibility to understand the preventative measures and management of the illness lies with the society as a whole, healthcare professionals, be it medical staff, counselors, allied health, psychologists, traditional healers or nurses need more insight into the disease. This could assist patients to deal with the illness and complications associated with TB. The descriptive analysis gives some insight into the thoughts, fears, emotions, difficulties and stresses that TB patients experience. One of the highlighted facts is the lack of participation that some patients felt. Empowering patients to be involved in their care is essential as it may encourage compliance with treatment. This places nurses in a unique role of collaborating with these patients, their families and communities for better outcomes of all.

The findings redirect nurses to the basic principles of infection control. Whereas the practice of standard precautions may be neglected, it is the core of primary prevention in breaking the chain of infection transmission. Nurses therefore need to be mindful of this practice in order to avoid further transmission of TB. The findings also challenge nurses, more especially the experienced, not to be complacent in their work but to be vigilant, like novices in nursing practice.

The findings have identified that poor nursing care in the developing world is a result of increased workloads due to shortages of staff, lack of diagnostic equipment and personal protective equipment. Despite this, patients are satisfied with nursing care received. Opposed to this is the developed world, where human as well as material resources for TB care are considered adequate nevertheless, patients reported to be dissatisfied with the nursing care received. This was attributed to more accessibility to health information for the developing world, thereby increasing patients' expectations. Cultural differences were also highlighted as contributing factors. Considering all these facts, there is a need for more staff: doctors, nurses, pathologists, radiologists, radiographers and all the supporting personnel which would reduce

workloads therefore speed the diagnostic process and commencement of treatment. It is recommended that the government improves services and infrastructure such as roads (Malawi) so people can access health facilities without any delays. Specialised education in TB care could also be beneficial as most of the nurses in this study had only general training. It is also imperative that culturally-appropriate care is provided to these patients.

Through family and community assessment and screening, nurses are charged with an essential role in health promotion by collaborating with the patients. This could be achieved by listening to patients concerns and identifying their needs for referral to other health professionals and agencies. The study challenges nurses to be more available to TB patients to minimise the effects of isolation associated with the illness, whether physical or psychological. The study also points out that even though the incidence of TB is very high in the developing world, both worlds form a global village therefore TB is a shared responsibility for both the developing and developed world. It has been argued that immigration, or people born outside Australia, contribute to the highest percentage of TB in Australia. It is therefore apparent that this problem cannot be ignored.

Among many other roles nurses play is the important role of educator. Nurses can only be resourceful in the role if they themselves 'understand' the needs of TB patients. Similarly to TB Officers at HD in Malawi holding educational sessions, nurses could hold educational sessions between themselves in order to promote awareness of TB. This would be an important resource for the patients and their families. Inservice educational sessions related to health promotion programs and activities that could be helpful in either preventing or dealing with the disease would also be helpful.

Another implication is that there needs to be some age-specific interventions in addressing the TB epidemic, especially in Africa and, more specifically, Malawi. As the illness is more prevalent in the productive age socio-economically (20-49 years), it has a tremendous impact on the outcomes of the society at large. It is suggested that education should start from adolescence through mass media, schools, churches and work places; which could be beneficial in addressing the wider community in combating TB. The elderly and children are also vulnerable

and therefore are an essential educational target. As HIV/AIDS is attributed as a co-infection to TB, sex education can and should not be overlooked.

It is also suggested that, while the DOTS therapy has been a successful policy and is central to the management and control of TB, it alone is inadequate for the changing epidemiology in the Sub-Saharan Africa. Some complementary strategies have been suggested such as the participatory model and the involvement of laypeople. Tarder (1957), elaborated:

By temperament and by habit, administrators are fond of buildings and physical structures which demonstrate investment; but without basic objective knowledge of the people, of the spirit and structure of the society to which they belong, the buildings may remain deserted, and costly physical structures with such niceties of modern science may be inadequate. That knowledge today is within our reach (p.345).

It is with this understanding that to aim for positive outcomes, the involvement of the local community and health-care practitioners is crucial. As the first points of contact for patients, local medical officers or traditional healers need to be provided with TB education as, with TB knowledge, they can be utilised as referral points for TB patients to the central treating centres. Through education, there could potentially be minimal delays in presentation to a health facility therefore decreasing rates of transmission and reducing morbidity, disability and even mortality. It is also imperative that the global community continues their efforts in joint research, surveillance and treatment targets in combating the diseases that are compounding each other – HIV/AIDS and TB.

Nurses at the community level should be supported as they are primary carers of TB patients. They are involved in providing follow-up, education, screening TB contacts and promoting self-seeking behaviours such as reducing substance abuse. In the acute settings, nurses are required to provide more psychological health which might be achieved by distracting patients and encouraging them to engage in positive activities.

It is therefore apparent that there is a need to appreciate what it means to be a TB sufferer. It is through this understanding that nurses would exercise sympathy, empathy and compassion in dealing with TB patients and their families as well as demonstrating consideration, respect and an understanding that all patients' needs are unique.

5.4 Limitations of the study

There are some limitations of the study. In terms of site locations, one limitation of this project is that while the study took place in major referral TB/Infectious Diseases centres, these were located in urban areas, and therefore the samples are not representative of the whole Australian or Malawian population. In Malawi the study took place in three cities, and in Australia the study was conducted in two hospitals in one state (Victoria). The results cannot be generalised to all the Australian States and Territories and to all the districts in Malawi. However, these findings can be genaralised to urban Victoria and the urban districts in Malawi where the study took place. The study gives scope for further inquiry into the nursing care of TB patients from both the patients and nurses perspective.

In terms of research design, the study was cross-sectional. Such studies seek to identify possible predictors of outcome and are useful for studying rare diseases or outcomes. This was the case with this study. While cross-sectional studies are relatively efficient regarding data collection, they compare groups retrospectively and do not permit distinction between cause and effect (Mann, 2003). Therefore, such research methods rely on patients recalling the history of their illness and health-seeking behaviours rather than reviewing specific documented records.

In relation to participant selection, nurses and patients were hesitant to consent to the study. This was most marked in Australia, consequently the data collection period was prolonged to over two years in Australia, whereas it took four months in Malawi. The challenge in Malawi was to find a reasonably adequate nursing sample as the number of nurses per ward were few. Another limitation is that the researcher lacked experience and the study was ambitious. The project was large for a novice researcher and therefore very challenging.

There were several costs related to the study. A major financial burden was travel expenditure as the data were collected from geographically distant areas – three cities and two hospitals, in Malawi and Australia respectively. This financial consideration prohibited further data collection from other sites. In Malawi, the researcher was required to provide her own personal protective equipment. A further expense was the emotional impact of data collection in Malawi. The researcher was emotionally traumatised during the data collection period because

she was constantly confronted by death from TB and TB/AIDS. As a result there was a delay before the commencement of data collection in Australia.

5.5 Recommendations for future study

The study has explored the factors that impact on nursing management of TB patients in Australia and Malawi; addressing these from both the patients and nurses perspectives. The quantitative and descriptive accounts of patients and nurses make it clear that nurses need greater insight into the needs of TB patients, which would be useful in minimising the negative outcomes of TB sufferers such as increased disability, morbidity and mortality. To enhance and enrich this study are the following recommendations:

The TB model of nursing care highlights the multi-disciplinary approach that can be useful to plan and deliver effective nursing care to TB patients. Emphasised is the need for reinforcement of PHC and health promotion principles to patients, nurses and the healthcare sectors as well as the general community. The study could also be conducted in rural areas in both Australia and Malawi as well as in more states in Australia, to give a more representative picture for both countries. More participants for interviews would provide a deeper insight into the perceptions and needs of TB patients.

5.6 Conclusion

From the findings of the study, it is apparent that TB patients experience many physical, psychological, social and economic losses which may not be apparent to the general population. Feelings of isolation and powerlessness resulting from societal attitudes and stigma associated with TB compound these losses. Regrettably, healthcare workers such as nurses contribute to the negative experiences for the patients. In some cases, lack of involvement in their care leaves patients even more isolated and lost.

Shortages of medical personnel, nurses and other healthcare workers that are crucial in the management of TB often results in increased workloads, leaving little time to address the psychological needs of the patients. Due to factors such as geographical isolation from main

treating centres, lack of knowledge of TB symptoms on the part of the patient and the health professionals to whom TB patients first present themselves, there are associated delays in diagnosis and commencement of treatment. These delays often result in more transmissions into the community, increasing morbidity and mortality rates. Combined with HIV/AIDS, TB has become a catastrophe, especially in the developing world.

Despite the gloomy outlook, there are tremendous efforts being made by governments and organisations to minimise the impact of the disease on a national level as well as on a global scale. The Director of WHO calls for action, urging that "African leaders must focus even more attention on TB as it is not only the major killer of HIV-infected people but a disease that is out of control on the African Continent" (Raviglione, 2004, p.165). It is imperative that, while there is geographical, cultural and economical separation between the developed and the developing world, Australia and Malawi; the common goal of reducing human suffering to patients and communities due to TB remains the focus; though we cannot deny the fact that these countries are worlds apart.

The Researcher's epilogue

"A journey of a thousand miles begins with one step". I wonder whether I have actually reached the final step, or is it a dream? But then, I was told never to stop dreaming. If anyone told me in 2004 that I would still be writing a PhD thesis in 2012, I would not have taken them seriously. Yes, it has been that long since I started this project. However, I am not complaining. I have had more ups than downs in the process. I was not sure if I would be a permanent employee as a Lecturer at the Australian Catholic University, in the School of Nursing, Midwifery and Paramedicine had I not undertaken my PhD. My PhD has been a major step in my nursing career. It has enriched me and I have grown both academically and personally.

Oh, within the seven years I met the love of my life, Kasozi, and got married; God blessing us with Kito Iris Mukasa, the "precious child". While it has been an incredible experience to care for a little child as well as to complete my studies, I would not have done it any other way. I am thankful for Kito's presence in my life. This long journey does not come without its hurdles; relocation from Australia to Uganda, though an exciting adventure, has been a challenge: the illnesses, the sleepless nights while writing the project as well as being a mother and a wife. As I reflect, I am thankful for those obstacles as they have made me stronger and more resilient.

Where to from here? Knowing where I have been and where I am at, I cannot be afraid of what is before me now and will not stop looking up as I hold on to these words, "the sky is limitless".

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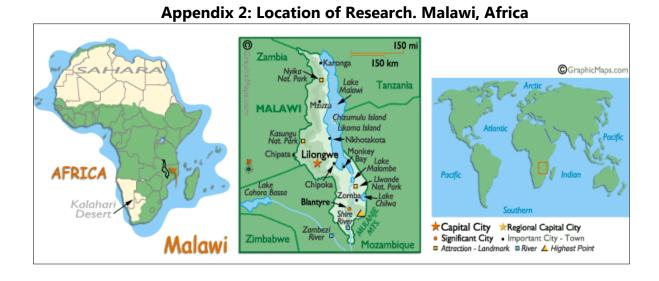
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Appendices





Appendix 3: Reliability scales

3a: Reliability, central tendency and variability of scales in the medical outcomes study

Adapted from the Medical Outcomes Study (N = 2471), except for the Health Change, which was obtained one year later (RAND, 2004).

Scale	Items	Alpha (α)	Mean	Standard deviation(SD)
Physical functioning	10	0.93	70.61	27.42
Role functioning/physical	4	0.84	52.97	40.78
Role functioning/emotional	3	0.83	65.78	40.71
Energy/fatigue	4	0.86	52.15	22.39
Emotional well-being	5	0.90	70.38	21.97
Social functioning	2	0.85	78.77	25.43
Pain	2	0.78	70.77	25.46
General health	5	0.78	56.99	21.11
Health change	1	-	59.14	23.12

3b: Reliability and validity of final questionnaire for patientsItem Statistics

Scale	Mean	Std. Deviation	N
Nurses' knowledge of TB	4.17	1.167	167
Respect for patients	3.92	1.282	167
Care for patients	3.87	1.315	167
Care for patients	3.60	1.481	167
Meeting patients' needs	3.68	1.428	167
Availability of interpreters	3.75	1.532	167
Availability of nurses	3.65	1.393	167
Primary nursing – case manager	3.52	1.480	167
Timely drug administration	4.01	1.280	167
Understanding of drugs by patients	3.82	1.286	167
Timely nursing care	3.75	1.346	167
Patients feeling comfortable to express needs	3.86	1.357	167
Speaking with patients clearly	3.90	1.300	167
Maintaining confidentiality	3.66	1.400	167
Patients feeling supported	3.69	1.447	167

3c: Reliability and validity of final questionnaire for nurses Total item statistics

Scale	Scale Mean if item deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Nurses' knowledge of TB	52.69	253.481	.688	.963
Respect for patients	52.95	244.810	.846	.960
Care for patients	52.99	244.548	.830	.961
Care for patients	53.26	242.783	.768	.962
Meeting patients' needs	53.19	243.742	.776	.962
Availability of interpreters	53.11	245.113	.687	.964
Availability of nurses	53.22	242.712	.823	.961
Primary nursing – case manager	53.34	246.419	.684	.964
Timely drug administration	52.85	248.212	.757	.962
Understanding of drugs by patients	53.04	246.077	.810	.961
Timely nursing care	53.11	242.916	.850	.960
Patients feeling comfortable to express needs	53.00	243.663	.823	.961
Speaking with patients clearly	52.96	244.354	.845	.960
Maintaining confidentiality	53.20	242.175	.832	.961
Patients feeling supported	53.17	242.285	.800	.961

Reliability Statistics

Cronbach's Alpha	N of Items
.964	15

Appendix 4: Patient and nurse questionnaires

4a: Patients questionnaire



SCHOOL OF NURSING (Victoria) ST PATRICK'S CAMPUS

PATIENT QUESTIONNAIRE

PLEASE	TICK	BOX/BOXES	THAT	ARE	APPLICABLE	TO	YOU	FOR	THE	FOLLOWING
QUESTIC	NS:									

QUE	3110N3:			
1	AGE			
	□ 18 – 24		45 - 54	
	□ 25 – 34		55 - 64	
	□ 35 – 44		65 and over	
2	GENDER			
	MALE 🗆	FEMA	ALE 🗆	
				_
3	RACE			_
	 Aboriginal / Torres Islander 		European	
	□ Anglo-Saxon		Asian	
	□ African		Other (please specify)	
	□ African American			
				_
4	Please indicate your country of origin			
				_
	Which hasnital do you attend for your	comicos?		_
5	Which hospital do you attend for your	ser vices:		
3				
				_
6	Are you: Inpatient □	Outpat	ient □	_
	r			_
7	MARITAL STATUS			
	□ Single			
	□ Married			
	□ Separated/Divorced			
	□ Widowed			
	□ Other (please specify)			
	Q			

8	EMPLOYMENT TYPE							
	TYPE OF WORK							
	LENGTH OF TIME IN THIS POSITION							
	STATUS							
	□ Part-time □ Disabled							
	□ Full-time □ Unemployed							
	□ Casual □ Retired							
	□ Other (please specify)							
_								
9	MEDICAL HISTORY (Please tick as many boxes as applicable)							
	□ Long-term cough							
	□ Recent chest infections							
	□ Coughing up blood-stained sputum							
	☐ Fevers and night sweats							
	□ Loss of weight							
	□ Feeling generally unwell							
	□ Pain in the chest							
	□ HIV/AIDS							
	□ Other (please specify)							
	Allergies? Yes \square No \square Unsure \square							
4.0	TATE . C I. I TOTO CECL)							
10	What year were you first diagnosed with TB (If known)							
		П						
10	What year were you first diagnosed with TB (If known) Is this your first episode of TB? Yes No Unsure							
	Is this your first episode of TB? Yes \square No \square Unsure	□ ES	NO	NOT				
11	Is this your first episode of TB? Yes \square No \square Unsure		NO	NOT SURE				
11	Is this your first episode of TB? Yes \square No \square Unsure What is your understanding of TB? (Please tick the most YI		NO					
11	Is this your first episode of TB? Yes No Unsure What is your understanding of TB? (Please tick the most YI applicable answer to you?		NO					
11	Is this your first episode of TB? Yes No Unsure What is your understanding of TB? (Please tick the most YI applicable answer to you? TB is infectious		NO					
11	Is this your first episode of TB? Yes No Unsure What is your understanding of TB? (Please tick the most YI applicable answer to you? TB is infectious TB can be prevented by vaccination		NO					
11	Is this your first episode of TB? Yes		NO					
11	Is this your first episode of TB? Yes		NO					
11	Is this your first episode of TB? Yes		NO					
11	Is this your first episode of TB? Yes No Unsure What is your understanding of TB? (Please tick the most YI applicable answer to you? TB is infectious TB can be prevented by vaccination TB is passed on from one human to another through touch TB can be cured if medical treatment is sought Spreading of TB can be prevented by taking medicine Spreading of TB can be prevented by avoiding contact with		NO					
11	Is this your first episode of TB? Yes No Unsure What is your understanding of TB? (Please tick the most YI applicable answer to you? TB is infectious TB can be prevented by vaccination TB is passed on from one human to another through touch TB can be cured if medical treatment is sought Spreading of TB can be prevented by taking medicine Spreading of TB can be prevented by avoiding contact with anyone		NO					
11	Is this your first episode of TB? Yes No Unsure What is your understanding of TB? (Please tick the most YI applicable answer to you? TB is infectious TB can be prevented by vaccination TB is passed on from one human to another through touch TB can be cured if medical treatment is sought Spreading of TB can be prevented by taking medicine Spreading of TB can be prevented by avoiding contact with anyone Sharing of utensils is one way to prevent TB		NO					
11	Is this your first episode of TB? Yes No Unsure What is your understanding of TB? (Please tick the most YI applicable answer to you? TB is infectious TB can be prevented by vaccination TB is passed on from one human to another through touch TB can be cured if medical treatment is sought Spreading of TB can be prevented by taking medicine Spreading of TB can be prevented by avoiding contact with anyone Sharing of utensils is one way to prevent TB Medicines used to treat TB have side-effects		NO					
11	Is this your first episode of TB? Yes		NO					
11	Is this your first episode of TB? Yes No Unsure What is your understanding of TB? (Please tick the most ylapplicable answer to you? TB is infectious TB can be prevented by vaccination TB is passed on from one human to another through touch TB can be cured if medical treatment is sought Spreading of TB can be prevented by taking medicine Spreading of TB can be prevented by avoiding contact with anyone Sharing of utensils is one way to prevent TB Medicines used to treat TB have side-effects Medicines used to treat TB can be taken at any time of the day Medicines used to treat TB are taken over a long period of time		NO					
11	Is this your first episode of TB? Yes No Unsure What is your understanding of TB? (Please tick the most yield applicable answer to you? TB is infectious TB can be prevented by vaccination TB is passed on from one human to another through touch TB can be cured if medical treatment is sought Spreading of TB can be prevented by taking medicine Spreading of TB can be prevented by avoiding contact with anyone Sharing of utensils is one way to prevent TB Medicines used to treat TB have side-effects Medicines used to treat TB can be taken at any time of the day Medicines used to treat TB are taken over a long period of time TB can be prevented by wearing gloves		NO					

13	What symptoms did you experience before you were diagnosed? (Tick as many boxes as applicable)									
					□ Los	s of we	ight	I	<u> </u>	
					□ Pai	n in che	est			
					□ Cou	ghing				
					□ Cou	ghing l	olood-stair	ied spu	ıtum	
					□ Ger	erally f	feeling unv	vell		
					□ Fev	ers and	l night swe	eats		
	□ Other (please specify)									
14	How long did you have the symptoms before your first visit to your doctor or health facility?									
	□ 1 – 2 weeks □ 2 –3 months □ 3 – 4 weeks □ 4 – 6 months □ Other (please specify)									
15	How long o	lid it ta	ke from th	e time	of those sy	mptom	s to the di	agnosis	s of TB?	
	□ 1 - 3	2 week	S			2	- 3 month			
		4 week er (ple:	s ase specify	·)		4	-6 months			
16	Did you ha	ve any	alternative		nent before No	e being			ital? i't know	
	□ Yes				NO			ווטע	I KIIOW	
17	If yes, pleas	se com	ment on th	e type	of treatme	nt you l	had			
	e answer the									u:
On a	scale of 1 to	5, pleas	e indicate h	ow you	felt when y			f the dia	agnosis:	
Not u	pset	Least l	Jpset	Undec	ided	Moder Upset	ately	Very U	Jpset	
	1		2		3		4		5	
18B	On a scale	of 1 to	5, please in	dicate h	ow you feel	now				
	Not upset		Least Ups		Undecided		Moderatel Upset	у	Very Up	set

19	Are you currently taking any medication for TB?									
	□ Yes □	No	□ Not sure							
	Please list the medications you are currently taking for TB and how often you are									
20	taking these? (If known).									
	MEDICATION	HOW OFTEN DO YOU TAKE THE MEDICATION								
21	Have the symptoms you experienced b	efore subsided since vo	u have been on medication?							

22	Using the scale of 1 to 5, 1 being the highest score, please circle what answer is applicable to you in the following two questions:						
		Excellent	Very good	Undecided	Good	Poor	
i	In general, how is your physical health at present?	1	2	3	4	5	
ii	Comparing now with the time you were diagnosed, how would you rate your health in general?	1	2	3	4	5	

No

Not sure

Please tick answer applicable to you for the following three questions:

23	Before diagnosis, did the way you felt about yourself interfere with your daily activities such as:					
		Yes	No			
i	Cutting down on the amount of time you spent on work and other					
1	activities.					
ii	Accomplishing less than you would like.					
iii	Not doing work or other activities as carefully as usual					

Please circle one answer for this question:

Yes

24		Excellent	Very good	Undecided	Good	Poor
	Currently, how would you rate the way you feel about yourself?	1	2	3	4	5

Please circle one number for the following two questions:

25		Not at all	Slightly	Undecided	Quite a bit	Extremely
		1	2	3	4	5
i	Since you have felt unwell, to what extent has your physical well-being interfered with your normal social activities with family, friends, neighbours or groups?					
ii	Since you have felt unwell, to what extent has your mental well-being interfered with your normal social activities with family, friends, neighbours or groups?					

On a scale of 1 to 5, with 5 being very severe pain, please circle the answer most applicable to you:

26		Very mild	Mild	Undecided	Moderate	Severe
	How much physical pain have you had since diagnosis?	1	2	3	4	5

How TRUE or FALSE is each of the following statements for you (Please tick appropriate box)

27		Definitely	Mostly	Don't	Mostly	Definitely
27		disagree	disagree	Know	agree	agree
,	I seem to get sick a little					
1	easier than other people					
ii	I am as healthy as					
111	anybody I know					
iii	I expect my health to get					
111	worse in the future					
iv	My health is excellent					

28	RANGE OF SERVICES/ CLINICAL ENVIRONMENT	YES	NO
i	Location of TB services easy to find for patients		
	All services are done within the facility:		
	•Chest X-ray		
	Mantoux testing		
ii	BCG Vaccination		
	Sputum collection		
	Blood collection		
	Pharmacy/Chemist		
iii	Medical consultation is available when needed		
iv	Signs at entrance indicate location of TB testing services		
v	Culturally appropriate care is provided		
	Patient information regarding clinic hours, costs and		
Vi	services is available		
vii	Examination rooms clean and private		
viii	Waiting areas are clean and ventilated		
ix	Sufficient medication is available at the facility		
Com	ments:		

The following questions relate to the TB Clinic structure. Please tick appropriate box.

29		YES	NO
i	Clinic hours sufficient to meet my needs		
ii	Services are free		
iii	Services are set at a minimal cost or at a reasonable cost		
iv	Services are too expensive		
Com	ments:		

30		TRANSPORT TO THE HEALTH FACILITY					
	•	applicable box using this scale):					
	1 = Never	2 = Sometimes 3 = Often					
	4 = Very often	5 = Always					
			1	2	3	4	5
	Walking						
	Bicycle						
	Vehicle (bus/car)						
	Other						
	I				1	1	
		CES AVAILABLE AT YOUR HEALTH FACILITY					
31		wer most applicable to you using this scale):					
		e 2 = Agree 3 = Undecided					
	4 = Disagree	5 = Strongly disagree					
			1	2	3	4	5
i		ledgeable about my illness					
ii		courteous and respectful					
iii	Nursing staff are	<u> </u>					
iv	Nursing staff disc	cuss my care with me					
V	Nurses are sensit	ive to my cultural needs					
vi	Interpreter servi	ces are available to me					
vii	I have enough tin	ne to spend with my nurse/s					
viii	I am assigned to a	a special nurse for my follow-up care					
ix	My nurse gives m	e my medication on time					
X	I am aware of the	side-effects of the medication I take					
xi	I receive all the n	ursing care I need in a timely manner					
xii	1	e asking my nurse any questions					
xiii	1	to me in a clear manner					
xiv		me of confidentiality					
XV	I feel supported b	•					
Com	iments:						
In yo	our words, please o	comment on:					
32	What aspects of r	nursing care you received were done well?					
	•	<u> </u>					

In yo	our opinion, what influenc	ced this typ	pe of care you	received from	the nurses?	
33	_					
1						
34	In your opinion, are ther	e any othe	er aspects of n	nursing care tha	t need improvem	ent?
34	In your opinion, are ther Yes	re any othe	er aspects of n	nursing care tha	t need improvem Not sure	ent?
34	□ Yes	ſ				ent?
34		ſ				ent?
34	□ Yes	ſ				ent?
34	□ Yes	ſ				ent?
34	□ Yes	ſ				ent?
34	□ Yes	ſ				ent?
34	□ Yes	ſ				ent?

THANK YOU FOR YOUR TIME.

4b: Patients' questionnaire translated to Chichewa



SCHOOL OF NURSING (Victoria)

Tikukupemphani kuti mutiyankheko mafunso ali m'musiwa

Chonde lembani chizindikiro chilichonse mutimabokosi tomwe tili m'musimu

1		Muli mugulu liti la zaka ?		
		18 – 24		45 - 54
		25 – 34		55 - 64
		35 – 44		65 kapena kupitilira
	-			
2	Ndine			
		Mwamuna 🗆		Mkazi 🗆
3		Mtundu wanu ndinu a ku:		
		Aborijino / Torres Islander		Amerika
		Mangalande		Asia
		Afrika		Ulay
		Ngati si muli mu magulu a mtundu	omw	e ali pamwambawa lembani mtundu
	wanu	pansipa		
4	Chond	le lembani dziko lomwe munabadwir	a:	
	Ndi ch	inatala shiti shamuza mumanita kuks	landir	a shithandiga multadurala?
5	Nui Cii	lipatala chiti chomwe mumapita kuka	ilallull	a cilitilaliuizo iliukauwala?
) 				
	Muma	gonera pa chipatala pompano	Mum	ayendera□
6	Traina		Main	ay chacra
	ı		1	
7	BANJA	1		
		akwatire 🗆		
		wokwatira 🗆		
		siyana ndi akazi/amuna anu 🏻		
		,	٦	
		ani gulu lomwe muli pa mzere uli pan	_	gati simuli m'magulu omwe ali
		rambawa	isipa II	5au Jiman in magura omwe dii
	Parry	uiibuvu		

8	NTCHITO:									
	Mumagwira ntchito yanji?									
	Mwakhala nthawi yaitali bwanji muli pa ntchito imeneyi?									
	NTHAWI YOMWE MUMAGWIRA NTCHITO:	NTHAWI YOMWE MUMAGWIRA NTCHITO:								
	Mumagwira tsiku lonse									
	Simugwira tsiku lonse									
	Mumagwira ntchito ikapezeka pa nthawiyo									
	Sankhani yankho limodzi m'musimu									
	Ndinu olumala									
	Simuli pa ntchito									
	Munapuma pa ntchito									
	Lembani pansipa ngati mumagwira ntchito mwambapa	mosiyana	ndi	momwe	talembera	pa				
9	i. Kodi mukudwala kapena munadwalapo mater	nda omwe	talem	ıba m'mus	siwa					
4.0										
10	(Lembani chizindikiro pa matenda omwe muk	udwala ka _l	pena	munadwa	alapo)					
	□ kukhosomola nthawi yaitali									
	□ Kumva kusakhala bwino m'mthupi									
	□ Matenda aliwonse a m'chifuwa									
	□ Kupweteka mchifuwa									
	□ Kukhosomola ndi kutulutsa makhololo o	sakanikira	ına no	di magazi						
	□ Kutenthedwa ndi kutuluka thukuta usiki	u								
	□ kuwonda									
	□ HIV/AIDS									
	Thupi lanu limagwirizana ndi makhwala aliwon	ise?								
	□ Inde □ Ayi □	Sindikud	lziwa							
	Lembani pansipa ngati pali matenda ena omwe	munadwa	lapo/	mukudwa	ala omwe					
	sanalembedwe									
11	Ndi chaka chiti chomwe munapezedwa ndi chif	uwa chach	ikulu	(TB)						
12	2 Kodi ndi koyamba kudwala matenda a chifuwa	chachikul	uchi	(TB)?						
			,		J ·					
	Inde □ Ayi □			Sindiki	udziwa 🗆					

Pa mulingo wa 1 mpaka 5 sankhani sakhani nambala yogwirizana ndi manvedwe a ululu:

Ta maningo wa 1 mpaka o samkilam sakham hambala yogwi izana har manveawe a arata.							
13		Ululu wa	Ululu wa	Sindikudziwa	Ululu	Ululu	
		pang'ono	pang'ono	Siliuikuuziwa	wocheperako	wambiri	
		zedi					
	Mwamva ululu wotani kuyambira pamene anakuyezani za matenda a TB?	1	2	3	4	5	

14	Umadziwa zotani pa zamatenda a TB (sankhani yankho loyenera).	Inde	Ayi	Sindikudziwa
	TB ndi matenda opatsirana			
	Tikhoza kupewa TB polandira katemera			
	Munthu akhoza kutenga TB kuchokera kwa munthu wina pokhudzana			
	TB ikhoza kuchiritsika ngati ulandila mankhwala			
	TB siingafale ngati odwala amwa mankhwala ake			
	TB siingafale ngati tipewa kukhudzana ndi anthu			
	Kubwerekana ziwiya za pa nyumba ndi njira imodzi yopewera TB			
	Mankhwala a TB amayambitsa zizindikiro zosakhala bwino kwa munthu			
	Mankhwala a TB akhoza kumwedwa nthawi iliyonse			
	Munthu amakhala akumwa mankhwala a TB nthawi yaitali			
	Tikhoza kupewa TB povala ma gulovu (gloves)			
	Tikhoza kupewa TB povala zozitetezera popuma ku			
	nkhope yathu			
	Munthu wodwala TB ayenera adzikhala payekha			
	Munthu wodwala TB akachoka kuchipatala safunanso			
	thandizo lililonse lochokera kuchipatala			

15	Ndizizindikiro ziti zomwe mumazimva asanakuyezeni TB?				
	Kuwonda				
	kupweteka m'chifuwa				
	kukhosomola				
	kukhosomola makhololo osakanikirana ndi magazi				
	kusamva bwino mthupi				
	kutentha thupi komanso kutuluka thukuta usiku				
	ngati panali zizindikiro zina, lembani pa nsipa				

16		enga nthawi yaitali bw ikiro zili pamwambapo	anji kuti mupite kuchipatala o?	mutamva kapena kuwona
		ıbata zosaposera ziwiri ıbata 3 – 4	(Milungu 1- 2)	
		iyezi 2 -3		
		iyezi 4 – 6		
	□Ku	pitilira miyezi 6		
	Zir	na (chonde fotokozani)		
17			biri bwanji pamene munazir	ndikila kuti mukudwala ndi
	pame	ne munauzidwa kuti m	uli ndi matenda a TB?	
	Ш	Masabata 1 – 2		
		Masabata 3 – 4		
		Miyezi 2 – 3		
		Miyezi 4-6		
		Kupitilira miyezi 6		
		Zina (chonde fotokoza	ani)	
40	77 11	1 1.1		
18	Kodi kuchi	munasaka chithand patala?	izo china musanabwere	kudzayang'ana chithandizo
		Inde	☐ Ayi	Sindikudziwa
	Ngati	mwavomela, chonde n	enani chithandizo chomwe r	nunalandila.

CHONDE YANKHANI MAFUNSO AWIRI (2) OTSATILAWA POCHONGA NAMBALA YOMWE MUKUONA KUTI NDI YOYENELETSETSA KWA INU:

19 (i)	Pakati pa 1 ndi 5, chonde nenani momwe munamvela poyamba pemene munauzidwa za matenda anu:									
	Sindinadandaule		Ndinadandaula pang'ono		Sindikudziwa		Ndinadandaula kwambiri		kwai	andaula nbiri thu
	1	2			3		4		Ţ	5
19 (ii)	Pakati pa 1 ndi 5, c	honde ne	nani mo	mwe	mukumve	la pan	opa z	a maten	ıda anu?	,
	Sindikudandaule		dandaul ıg'ono	Si	ndikudziw a	Ndikudandaul a kwambiri			a kw	dandaul ambiri ithu
	1		2		3		4			5
OTS	NDE CHONGANI ATILAWA:	YANKHO	LIRI	LOY	ENERA K	ζWΑ	INU	PAMA	FUNSO	ATATU
20	Pakali pano mukula	alndira ma	ankhwal	a ali	onse a TB?					
	☐ Inde ☐ Ayi			Ayi	ri Sindikudziwa				a	
21	Chonde lembani ma mukutengela mank						mom	we ndi 1	nthawi y	romwe
	MANKHWALA				NTHAWI Y	OMWI	E NDI	KUMW	A	
										
22	Chiyambila kumwa	mankhwa	alawo, m	ıuku	ona kusintl	ha kuli	i kons	e mthu	pi mwar	nu?
	☐ Inde			Avi				Sind	ikudziw	a

23	Pakati pa 1 ndi 5, 1 kukhala nambala yokhonza kwambiri, chonde sankhani yankho lomwe mukuona kuti mukugwilizana nalo pamafunso ali mmusimu:						
	Bwino kwambiri ndithu Bwino kwambiri Sindikudziwa Bwino bwin						
i	Panopa mukupeza bwanji mthupi mwanu?	1	2	3	4	5	
ii	Kufanizila ndi momwe anakupezani ndi matendawa ndi panopa, mungati thanzi lanu liri pati?	1	2	3	4	5	

CHONDE CHONGANI YANKHO LIRI LOYENERA KWA INU PAMAFUNSO ATATU OTSATILAWA:

24	Asanakupezeni ndi matendawa, ndi momwe mumazionela inuyo, zinakupangitsani kuti mutele:				
		Inde	Ayi		
i	Kuchepetsa nthawi youmwe inuyo mumagwila ntchito kapena zochita-chita zina?				
ii	Kuchita zochepa mosayenela momwe inu mumafunila?				
iii	Kugwila ntchito kapena zinthu zina mopanda dongosolo momwe mumapangila nthawi zonse		-		

CHONDE CHONGANI YANKHO LIMODZI PAFUNSO AWIRI LIRI MMUSIMU

25		Bwino kwambiri ndithu	Bwino kwambiri	Sindikudziwa	Bwino	Sindili bwino
	Pakali panopo		2	3	4	5
	mukumva bwanji mumtima mwanu?					

CHONDE CHONGANI YANKHO LIMODZI PAMAFUNSO AWIRI ALI MMUSIMU

26		Ngakhale pang'ono pomwe	Pang'ono	Sindikudziwa	Kwambiri	Kwambiri ndithu
i	Chiyambile kusapeza bwino, momwe mukumvela mthupi mwanu mwakhala mukusokoneza momwe mumachezela kapena momwe mumachitila ndi abale, anzanu, a nebala kapena magulu ena?	1	2	3	4	5
ii	Chiyambile kusapeza bwino, momwe mukumvela mmaganizo anu mwakhala mukusokoneza momwe mumachezela kapena momwe mumachitila ndi abale, anzanu, a nebala kapena magulu ena?	1	2	3	4	5

CHONDE CHONGANI YANKHO LIRI LOYENERA KWA INU PAMAFUNSO ANAYI OTSATILAWA

27		Ndikugwir izana nazo kwambiri	Ndikugwiriza na nazo	Sindik udziwa	Sindikugwilizana nazo kwenikweni	Sindikugwirilizana nazo
i	Ndimadwala					
	pafupi-pafupi					
	kusiyana ndi					
	anthu ena					
ii	Ndiri ndi nthanzi					
	ngati anthu onse					
	omwe					
	ndikuadziwa					
iii	Ndikuyembekeza					
	kuti thanzi langa					
	likhala lofooka					
	mtsogolomu					
iv	Ndiri ndi nthanzi					
	kwambiri					

28	Zofunika za TB (Chonde chogani yankho liri loyenela kwa inu).	Inde	Ayi
i	Zofunuka zonse za TB ziri posavuta kupeza kwa odwala		
ii	Izi zones zimachitika pachilapata chimodzi:		
	•X-ray ya pachifuwa		
	•Koyeza TB ndi Mantoux jakisoni		
	- Za katemela wa BCG		
	•Kutenga makhololo		
	•Kutenga magazi		
	•Kotenga /kogula mankhwala (ku famase)		
iii	Chithandizo cha madotolo chilipo chokwanila chikafunika		
iv	Pali zikwangwani zoonetsa komwe amayeza TB		
V	Ndimalandila chisamaliro momnga mwa chikhaliro chathu		
vi	Odwala amadziwitsidwa nthawi yomwe amatsegula ma kiliniki, malipilo ake, ndi chithandizo chomwe tingalandile kumeneko		
vii	Zipinda zoyezela ndizosamaliridwa bwino ndiponso zopatsa ulemu		
viii	Malo odikira ndi osamalirika ndiponso opita mphepo yabwino		
ix	Mankhwala aliko okwanila kuchipatalako		

Ndemanga:	

Mafunso akubwelawa ndi mimwe chipatala cha TB chilili. Chonde chongani yankho liri loyenera kwa inu.

29		Inde	Ayi
i	Nthawi yotiona odwalafe ndi yokwanila kwa ine		
ii	Chithandizo ndi chaulere		
iii	Chithandizo sichodula kwambiri		
iv	Chithandizo ndi chodula kwambiri		

Nde	manga:					
	Momwe ndipapitila kuchipatala nhtawi zambiri (Chonde chongani					
30	yankho liri loyenera kwa inu)					
	1 = Mwakanthawl 2 = Nthawi zina 3 = Sindikudziwa					
	4 = Nthawi zambiri 5 = Nthawi zonse	1				
	17 1	1	2	3	4	5
	Kuyenda					-
	Njinga				-	-
	Galimoto kapena basi					-
	Zina					
24	77:1 1: : MUCHIDAMALA CHIMEM INH MILL		1		Т	
31	Zithandizo za manamwino KUCHIPATALA CHIMEM INU MULI					
	(Chonde chongani yankho liri loyenera kwa inu) 1 = Ndikuvomela kwambiri 2 = ndikuvomera 3 = sindikudziwa					
	4 = sindikuvomera 5 = Sindikuvomeletsetsa					
	4 – Silidikuvoineta 3 – Silidikuvoinetetsetsa	1	2	3	4	5
i	Manamwino amadziwa za matenda Amene ine ndikudwala	1		3	4	3
ii	Manamwino ndi a ulemu ndipo amatilemekeza					\vdash
iii	Manamwino ndo osamala					-
iv	Manamwino amandiuza zomwe zikuchitika za kasamalidwe anga					\vdash
	+					\vdash
v vi	Manamwino amatisamala monga mwa miyambo yathu Othandiza kutitanthauzira chinanala amanazaka ndikawafuna					-
vii	Othandiza kutitanthauzira chinenelo amapezeka ndikawafuna Manamwino amakhala nane nthawi yokwanira					-
viii					-	\vdash
	Ndiri ndi namwino amene amatsatila za umoyo wanga				-	\vdash
ix	Manamwino amandipatsa mankhwala munthawi yake Ndikudziwa zotsatila za mankhwala amene ndikumwa					\vdash
X						\vdash
xi	Ndimalandila zithandizo zones munthawi yake kuchokera kwa a namwino					
	Sindimamangika kuti ndifunse funso lina liri lonse kwa a namwino					-
xii	Anamwino amandilankhula momveka					-
xiii	Anamwino amanditsimikitsila za chinsisi za matenda anga				-	\vdash
xiv	Ndimaona kuti anamwino amandisalalira bwino					-
XV	Numaona kuu anamwino amanuisalama bwino					
Ndo	manga:					
Nuc						

32	Mumaganizo anu mukuganiza kuti anamwino anagwila ntchito bwino mumbali iti?		
Mumaganizo anu, mukuona kuti chinapangitsa ndi chain kuti mulandile thandizo			
	loteleli kuchikela kwa anamwino?		
34	Mumaganizo anu, chilipo china chomwe ndichofunika kusintha ndimomwe anamwino amagwilira ntchito?		
	☐ Inde ☐ Ayi ☐ Sindikudziwa		
	Ngati mwavomela kuti 'inde', chonde fotokozani:		

ZIKOMO KWAMBIRI POYANKHA MAFUNSO AWA

4c: Nurses' questionnaire



NURSES QUESTIONNAIRE

DEMOGRAPHICS:

Please tick which box appropriate to you for the following six questions				
1	AGE			
	□ 18 - 24	☐ 45 – 54		
	□ 25 – 34	□ 55 − 64		
	35 – 44	65 and over		
2	GENDER			
	MALE	FEMALE		
3	NUMBER OF YEARS OF NURSING EXPERIENCE / PRACTICE AS A QUALIFIED NURSE year/s			
4	NUMBER OF YEARS OF TRAINING			
	year/s			
_	CAMPROON	ADDA ODVAODY		
5	CATEGORY	AREA OF WORK		
	Australian RN (Division 1)	☐ Inpatient hospital ward		
	Australian RN (Division 2, EN)	☐ Outpatient clinic		
	☐ Malawian RN	Other (please specify)		

6	PLEASE TICK THE MOST APPLICABLE AREA OF YOUR SPECIALTY		
		General Medical Nursing	
		Surgical Nursing	
		Respiratory Medical Nursing	
		Infectious Diseases Nursing	
		Other (please specify)	
	LENG	TH OF TIME WORKING IN THIS SPECIALTY	
		year/s	
7	PLEAS	SE TICK YOUR HIGHEST QUALIFICATION	
		Hospital Certificate of Nursing	
		University Diploma of Nursing	
		University Bachelor of Nursing	
		Honours Degree	
		University Graduate Certificate in Nursing	
		University Graduate Diploma in Nursing	
		Masters Degree	
		Doctorate Degree	
		Other (please specify)	

Which of the following best describes the demographics of patients that you see. Please rank in order from the most prevalent to least prevalent category in your community/health facility.

8	The race of patients who utilise your TB services:					
			nal / Torres Is			
		Anglo-S	axon			
		African				
		African-	-American			
		Asian				
		European				
		Other (please specify)				
9	Age group of your clients (Tick one or more boxes):					
		1-10		41-50		
		11-20		51-60		
		21-30		61-70		
		31-40		71 and over		
10	The r	najority	of patients are	e:		
	Male		Female 🗆	Don't know		
	A GE ===	OV 455) DDI A # 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	TOD WITE TOT -	01111110 70117	VIDOM ONG
	1				OWING FOUR Q	UESTIONS , the age / gender) of the
11			TB patients y		ics (ioi example	, the age / genuer) or the
		YES		NO		Don't know

	ng a scale of 1 to 5, p nmunity/health facili		tegories belo	w for prevale	ence of TB in y	our .
COII		1	2	3	4	5
12		Not at all prevalent	Not Prevalent	Undecided	Prevalent	Very Prevalen
i	Foreign born					
ii	Homeless					
iii	Drug use					
iv	HIV/AIDS					
V	Heterosexual communities					
vi	Homosexual communities					
vii	Other (please specify)					
Plea	ase explain your ansv	wer:				
	ase answer the follov lity/facilities.	ving question ba	sed on your u	ınderstandinş	g of your heal	th
13	On average, how m	any active cases	of TB would y	our health fa	cility see per	year?
	Has this changed fr	om when you fir	st started wo	rking with th	ese patients?	
	Yes	No		Do	on't know	
	If yes, how has this	shangad2 (Dlaga	o ovmloin).			

The following four questions are about accessibility and clinical services available in your health facility. Please tick box applicable.

14	RANGE OF SERVICES/ CLINICAL ENVIRONMENT	YES	NO	DON'T KNOW
I	Location of TB services easy to find for patients			
ii	All services are done within the facility: Chest X-ray Mantoux testing BCG Vaccination Sputum collection Blood collection Pharmacy/Chemist			
iii	Adequate medical consultation is available when needed			
iv	Signs at entrance indicate location of TB testing services			
V	Culturally appropriate care is provided			
vi	Patient information regarding clinic hours, costs and services is available			
vii	Examination rooms clean and private			
viii	Waiting areas are clean and ventilated			
ix	Sufficient medication is available at the facility			
X	I have enough time to spend with my patients			
xi	My nurse to patient ration is adequate for my patients' needs			
xii	I have access to adequate personal protective equipment is provided (e.g., masks, gloves)			
xiii	Sufficient medication is available at the facility			
xiv	Isolation rooms are adequate			
XV	Diagnostic equipment is adequate			
xvi	Adequate personnel e.g., medical, nursing staff, interpreters			
Pleas	se explain your answer:			

15	What are the most common languages spoken in your facility with patients?

16	Do you have medical interpreter services in your health facility?							
	yes \square	NO 🗆	Don't	kno	W			
	If no, please explain why:							
17	In your opinion, are these	a corvições adoquatos						
1/	in your opinion, are these	services adequate.						
YES		NO	Don't know					
	If no, please explain why	:						
	First stans in the manager	ment of newly diagnosed TB are	a to					
		f infection. In your opinion, fro						
	to most important factor,							
18	Key:	2 - Not important 2-IInd	a ai d a d					
	1=Not very important 4=Important	2 = Not important 3=Undo 5 = Very important	eciaea					
	1 Important	o very important						
				1	2	3	4	5
	Isolation							
	Medication							
	Personal protective equip							
	Explanation of the disease							
	Changing bed-linen at lea							
	Providing special crocker	•						
	Standard (universal) precautions for infection control							

		portant how nurses can help patients					
1.0	with TB.						
19	Key:	2 N					
	1=Not very important	2 =Not important 3=Undecided					
	4=Important	5 = Very important	4		_		_
			1	2	3	4	5
	Educating regarding spread						
	Tracing family and other co						
	Immunizing contacts with						
	Encouraging compliance w						
	Explaining importance of n	otification of TB					
20		lems do you observe at your health facility	that	: hin	ıder	•	
	effective management of yo	our TB patients?					
21	What factors contribute to	these problems?					
22	What could be done to assis problems?	st you with providing TB care and treatmen	it to	im	prov	ve tl	ne
23	List some ways that case defacility.	etection and treatment can be improved at	you	r he	alth	1	
	-						

24	In general, how wou		reatment outco	mes of your TB p	atients (Please
tick appropriate box)					
	1	2	3	4	5
	Not very	Not	Undecided	Successful	Vory cuccoccful
	successful	successful	Ondecided	Successiui	Very successful

THANK YOU FOR YOUR TIME.

Appendix 5: ACU Human Research Ethics Committee (HREC) Approval

Human Research Ethics Committee

Australian Catholic University Brisbane Sydney Canberra Ballarat

Committee Approval Form



Principal Investigator/Supervisor: Dr Michelle Campbell Melbourne Campus

Co-Investigators: Dr Maria Cynthia Leigh Nth Sydney Campus **Student Researcher:** Ms Jean Dulanya Melbourne Campus

Ethics approval has been granted for the following project:

Factors that impact on nursing management of Tuberculosis (TB) patients in Australia and Malawi.

for the period: 20.07.05 to 20.07.06

Human Research Ethics Committee (HREC) Register Number: V200405 53

The following <u>standard</u> conditions as stipulated in the *National Statement on Ethical Conduct in Research Involving Humans* (1999) apply:

- (i) that Principal Investigators / Supervisors provide, on the form supplied by the Human Research Ethics Committee, annual reports on matters such as:
 - security of records
 - compliance with approved consent procedures and documentation
 - · compliance with special conditions, and
- (ii) that researchers report to the HREC immediately any matter that might affect the ethical acceptability of the protocol, such as:
 - · proposed changes to the protocol
 - unforeseen circumstances or events
 - adverse effects on participants

The HREC will conduct an audit each year of all projects deemed to be of more than minimum risk. There will also be random audits of a sample of projects considered to be of minimum risk on all campuses each year.

Within one month of the conclusion of the project, researchers are required to complete a *Final Report Form* and submit it to the local Research Services Officer.

If the project continues for more than one year, researchers are required to complete an *Annual Progress Report Form* and submit it to the local Research Services Officer within one month of the anniversary date of the ethics approval.

Signed:	 Date:
	 ;)

Appendix 6: Information letters to participants

6a: Information Letter to patients



SCHOOL OF NURSING (Victoria) ST PATRICK'S CAMPUS

PARTICIPANT INFORMATION AND CONSENT FORM - PATIENTS

Full Project Title: Factors that Impact on Nursing Management of Tuberculosis (TB) Patients in Australia and Malawi

Principal Researcher: Dr. Michelle Campbell

Associate Researcher: Dr. Cindy Leigh Student Researcher: Miss Jean Dulanya

THIS PARTICIPANT INFORMATION AND CONSENT FORM IS 3 PAGES LONG.

Dear Participant,

You are invited to take part in this research project. This Participant Information Sheet contains detailed information about the research project. Its purpose is to explain to you as openly and as clearly as possible all the procedures involved in this project before you decide whether to or not to take part in it.

Please read the Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative, friend or your local health worker. Please feel free to do so.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign a Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in this research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

Purpose and Background

The purpose of this project is to investigate factors that affect nursing delivery of care to TB patients. A total number of 480 people will participate in this project. Two groups are invited to take part in the study; nurses and patients over 18 years of age, male or female.

Previous experience has shown that a lot of attention is on medical management of TB patients, for example how TB is managed using drugs. While these services are important, the reality of how nurses contribute or hinder the recovery of TB patients is unclear. It is therefore the aim of this study to investigate the needs of TB patients in regards to nursing services, thereby assisting nurses deliver maximal care of TB patients. The information from the study may also help stimulate further research on this subject.

You are invited to participate in this project because your participation will contribute to the knowledge of what is done well and what needs to be improved for better nursing care

of TB patients. The results of this research may be used to help the student researcher, Jean Dulanya, obtain a Doctor of Philosophy Degree in Nursing.

Procedures

Participation in this project will involve you to complete a questionnaire, which covers questions about your understanding of TB and your thoughts on how nurses manage TB. The questionnaire will take about 30 minutes to complete.

Possible Benefits

We cannot guarantee or promise that you will receive any benefits from this project. However, it is hoped that findings from this study will assist nurses and other health professionals gain some insight into the needs of TB patients, for better care of future TB patients.

Possible Risks

There are no possible risks, side effects and discomfort that will result from completing the questionnaire.

Privacy, Confidentiality and Disclosure of Information

Any information obtained in connection with this project that can potentially identify you will remain confidential. Access to this information will only be by the researchers. It will only be disclosed with your permission, except as required by law. Completed questionnaires will be given codes, which will de-identify you will be kept in a locked filing cabinet at the Australian Catholic University Research Centre for a period of 7 years. Afterwards, all hard copies will de shredded and disposed of in a confidential bin, all disks will be erased. Reports of this study will be published in the form of a thesis and information will be provided in a way that you cannot be identified.

New Information Arising During the Project

During the research project, new information about the risks and benefits of the project may become known by the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs and medical condition.

Results of the Project

Results of the project will be placed at the Australian Catholic University Libraries and the libraries of participating hospitals in Australia and Malawi, if requested. A copy will also be given to the National TB Control Centre in Malawi.

Further Information or Any Problems

If you require further information or if you have any problems concerning this project, you can contact the principal researcher, Dr. Michelle Campbell at: School of Nursing, Australian Catholic University, St. Patrick's Campus, 115 Victoria Parade, FITZROY VIC 3065, E-mail: m.campbell@patrick.acu.edu.au, Phone number: 0011 61 3 9953 3184, Fax: 0011 61 3 9963

3355. You may also contact Dr. Maria Cynthia Leigh on c.leigh@mackillop.acu.edu.au, Phone Number: 0011 61 2 9739 2075; Fax: 0011 61 2 9739 2075.

Participation is Voluntary

Participation in any research is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not, or to take part and later withdraw, will not affect your relationship with the hospital or the researcher and the Australian Catholic University.

Before you make your decision, a member of the research team will be available to answer any questions you have about the project. You can ask for any information you want. Please sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

Ethical Guidelines

This project will be carried out according to *National Statement on Ethical Conduct in Research Involving Humans* (June 1999), produced by the National Health and Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

Reimbursement for your costs

You will not be paid for your participation in this project.

Participant Information Sheet, Version 2, 6th December 2004 (Patients)

6b: Patients' Information letter translated to Chichewa



SCHOOL OF NURSING (Victoria)
ST PATRICK'S CAMPUS

Zikomo bambo/mayi

Tikukupemphani kuti mutenge nawo mbali pa kafukufuku. Werengani bwino lomwe m'musimu momwe tikulongosola zolinga za kafukufukuyu. Mukatenga nawo mbali, mukhala mu gulu la anthu omwe angathandize kusintha kwa zinthu zina zokhuza chithandizo chomwe chimaperedwa ndi a namwino kwa anthu onse odwala matenda a TB ngati kungafunikire.

Kafukufukuyu ndi mbalinso imodzi ya maphunziro omwe Jean Dulanya akupanga malinga ndi m'mene sukulu yomwe akuphunzirako ikufunira. Werengani zonse zomwe zalembedwa m'musimu bwino lomwe. Mukhale omasuka kufunsa mafunso aliwonse okhudzana ndi kafukufukuyu. Muli ndi ufulu wokambirana ndi banja lanu, abale anu komanso anzanu poyankha mafunsowa. Dzina lanu silidzalembedwa pena paliponse.

Ndondomeko

Muyenera kuyankha mafunso onse otsatirawa amene akufuna kudziwa zambiri zokhudza chisamaliro ndi chithandizo cha a namwino ndi anthu ena a za umoyo kwa odwala TB. Simudzalandira china chilichonse potenga nawo mbali pakafukufukuyu.

Zovuta zina

Palibe vuto lina lilonse lomwe mudzakumane nalo mukayankha mafunsowa.

Muli ndi ufulu wofunsa zina ndi zina zokhudza kafukufukuyu kwa anthu awa mwapadera. Staff Supervisors:

Dr. Michelle Campbell at: School of Nursing, Australian Catholic University, St. Patrick's Campus, 115 Victoria Parade, FITZROY VIC 3065, E-mail: m.campbell@patrick.acu.edu.au, Phone number: 0011 61 3 9953 3184, Fax: 0011 61 3 9963 3355. You may also contact Dr. Maria Cynthia Leigh on c.leigh@mackillop.acu.edu.au, Phone Number: 0011 61 2 9739 2075; Fax: 0011 61 2 9739 2075.

Kafukufukuyu ndi wovomerezedwa ndi bungwe loyang'anira kafukufuku m'dziko la Australia. Ngati mungakumanepo ndi mavuto ena aliwonse m'mene mumatenga mbali mukafukufukuyu, muli ndi ufulu wolembera ku:

Chair, Human Research Ethics Committee C/O Research Services Australian Catholic University Locked Bag 4115 FITZROY VIC 3065 Phone (61) 3 9953 3157 Fax (61) 3 9953 3315 Dandaulo lanu lidzasungidwa mwachinsinsi ndipo mudzalandira yankho loyenera. Sayinani pa pepala lovomereza kutenga nawo mbali pa kafukufukuyu. Musayine mapepala onse awiri, lina atenge okuyang'anirani ndipo linalo likhale ndi inu.

Zikomo kwambiri.

Appendix 7: Consent forms

7a: Consent form (to submit)



SCHOOL OF NURSING (Victoria)
ST PATRICK'S CAMPUS

CONSENT FORM (TO SUBMIT)

Full Project Title: Factors that impact on Nursing Management of Tuberculosis (TB) patients in Australia and Malawi

I have read and I understand the Participant Information and Consent Form, Version 1, dated 22^{nd} November 2004. I freely agree to participate in this project according to the conditions in the Participant Information and Consent Form.

I will be given a copy of the Participant Information and Consent Form to keep. The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant's Name (printed)	
	Date
Name of Witness to Participant's S	ignature (printed)
•	Date
Researcher's Name (printed)	
	Date
- 0	

Consent Form (to submit), Version 2, 6th December 2004 (Patients)

7b: Consent form to keep



SCHOOL OF NURSING (Victoria) ST PATRICK'S CAMPUS

CONSENT FORM (TO KEEP)

I have read and I understand the Participant Information version 2, dated 6th December 2004.

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep. The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Signature:	Date:
Name of Witness to Participant's	signature (printed)
Signature:	Date:
Researcher's Name (printed):	
	Date:

Consent Form (to keep), Version 2, 6th December 2004 (Patients)

7c: Revocation of consent form



SCHOOL OF NURSING (Victoria) ST PATRICK'S CAMPUS

REVOCATION OF CONSENT FORM

Full Project Title: Factors that impact on Nursing Management of Tuberculosis (TB) patients in Australia and Malawi

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with the Researcher and the Hospital.

Participant's Name (printed)	
Signature	Date

7d: Revocation of consent (Patients)

Revocation of Consent (Patients), Version 2, 6th December 2004 (Patients)



SCHOOL OF NURSING (Victoria)

KU MALAWI: FOMU YOVOMEREZA KUTENGA NAWO MBALI PA KAFUKUFUKU (SUNGANI FOMUYI)

Mutu wa kafukufuku:

Kafukufuku wofuna kupeza m'mene chithandizo cha ma Nurse chimaperekedwera kwa onse odwala matenda a TB ku Malawi ndi ku Australia.
Oyang'anira: Dr. Michelle Campbell Dr. Cindy Leigh Wopanga Kafukufuku: Jean Dulanya
Ndine
Ndikuvomeranso kuti mayankho onse omwe ndipereke pano ndiowona ndipo akhoza kugwiritsidwa ntchito ina iliyonse ndi munthu wina aliyense kutsogoloku.
Dzina
Dzina (Ochita kafukufuku):
Oyang'anira (1): Signature: Date:
Oyang'anira (2): Signature:
Oyang'anira (3): Signature: Date:



SCHOOL OF NURSING (Victoria)

Oyang'anira (2):...... Signature:

Oyang'anira (3):...... Signature:....

Ku Malawi: <u>FOMU YOVOMEREZA KUTENGA NAWO MBALI PA KAFUKUFUKU (PEREKANI</u> FOMUYI)

Mutu wa kafukufuku: Kafufuku wofuna kupeza m'mene chithandizo cha ma Nurse chimaperekedwera kwa onse odwala matenda a TB ku Malawi ndi ku Australia.

Oyang'anira: Dr. Michelle Campbell School of Nursing and Midwifery Australian Catholic University, St. Patrick's Campus 115 Victoria Parade, FITZROY VIC 3065 E-mail: m.campbell@patrick.acu.edu.au Phone number: 0011 61 39953 3184, Fax: 0011 61 39963 3355 Dr. Maria Cynthia Leigh on: E-mail: c.leigh@mackillop.acu.edu.au, Phone Number: 0011 61 2739 2075; Fax: 0011 61 29739 2075 Wopanga Kafukufuku: Jean Dulanya Ndine...... ndipo ndili ndi zaka zoposera 18. Ndawerenga momveka bwino zonse zofunikira kuti munthu utenge nawo mbali pa kafukufukuyu. Mwakufuna kwanga ndavomera kutenga nawo mbali poyankha mafunso onse koma ndili ndi ufulu wosiyira panjira kuyankha mafunsowa nthawi ina iliyonse ngati nditafuna kutero. Ndikuvomeranso kuti mayankho onse omwe ndipereke pano ndo oona ndipo akhoza kugwiritsidwa ntchito ina iliyonse ndi munthu wina aliyense kutsogoloku. Dzina Phone Signature......Date......Date Dzina (Ochita kafukufuku):..... Signature:..... Date: Oyang'anira (1):..... Signature: Date:

Date:

Date:

7e: Participant information and consent form - registered nurses



SCHOOL OF NURSING (Victoria) ST PATRICK'S CAMPUS

PARTICIPANT INFORMATION AND CONSENT FORM - REGISTERED NURSES

Full Project Title: Factors that Impact on Nursing Management of Tuberculosis

(TB) Patients in Australia and Malawi

Principal Researcher: Dr. Michelle Campbell

Associate Researcher: Dr. Cindy Leigh Student Researcher: Miss Jean Dulanya

Dear Participant,

You are invited to take part in this research project. This Participant Information Sheet contains detailed information about the research project. Its purpose is to explain to you as openly and as clearly as possible all the procedures involved in this project before you decide whether to or not to take part in it.

Please read the Participant Information carefully. Feel free to ask questions about any information in the document. Once you understand what the project is about and if you agree to take part in it, you will be asked to sign a Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in this research project. You will be given a copy of the Participant Information and Consent Form to keep as a record.

Purpose and Background

The purpose of this project is to investigate factors that affect nursing delivery of care to TB patients. A total number of 270 people will participate in this project. Two groups are invited to take part in the study; nurses and patients over 18 years of age, male or female. Previous experience has shown that a lot of attention is on medical management of TB patients. While these services are important, the reality of nursing management of TB patients is unclear. It is therefore the aim of this study to investigate the needs of TB patients in regards to nursing services, thereby assisting nurses deliver better care of TB patients. The information from the study may also help stimulate further research on this subject.

You are invited to participate in this project because you are a nurse working with TB patients and your participation will contribute to the knowledge of what is done well and what needs to be improved for better nursing management of TB patients. The results of this research may be used to help the student researcher, Jean Dulanya, obtain a Doctor of Philosophy Degree in Nursing.

Procedures

Participation in this project will involve your completing a questionnaire, which covers questions about your understanding of TB and your thoughts on how nurses manage TB. The questionnaire will take about 30 minutes to complete.

Possible Benefits

We cannot guarantee or promise that you will receive any benefits from this project. However, it is hoped that findings from this study will assist nurses and other health professionals gain some insight into the needs of TB patients, for better care of future TB patients.

Possible Risks

We do not anticipate that there will be any risks, side effects and discomforts that will caused by completing the questionnaire.

Privacy, Confidentiality and Disclosure of Information

Any information obtained in connection with this project will not identify you in any way. Completed questionnaires will be given codes, which will de-identify you will be kept in a locked filing cabinet at the Australian Catholic University Research Centre for a period of 7 years. Afterwards, all hard copies will de shredded and disposed of in a confidential bin, all disks will be erased. Reports of this study will be published in the form of a thesis and information will be provided in a way that you cannot be identified. In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access the information with which you disagree be corrected. Please contact one of the researchers named below if you would like to access your information.

Results of the Project

Results of the project will be placed at the Australian Catholic University Library and the libraries of participating hospitals in Australia. Letters will be sent to individual subjects informing them of the results at the end of the project. For participants in Malawi, results will be given to the National TB Control Centre as it may not be possible to reach each individual participant.

Further Information or Any Problems

If you require further information or if you have any problems concerning this project, you can contact the principal researcher, Dr. Michelle Campbell at:

School of Nursing and Midwifery

Australian Catholic University, St. Patrick's Campus

115 Victoria Parade, FITZROY VIC 3065

E-mail: m.campbell@patrick.acu.edu.au

Phone number: 0011 61 39953 3184, Fax: 0011 61 39963 3355

Or you may contact Dr. Maria Cynthia Leigh on:

E-mail: c.leigh@mackillop.acu.edu.au,

Phone Number: 0011 61 2739 2075; Fax: 0011 61 29739 2075

Or Jean Dulanya at: School of Nursing and Midwifery Australian Catholic University, St. Patrick's Campus 115 Victoria Parade, FITZROY VIC 3065

E-mail: <u>j.dulanya@patrick.acu.edu.au</u>

Phone number: 0011 61 39953 3188, Fax: 0011 6139963 3355.

Other Issues

If you have any complaints about any aspect of the project, the way it has been conducted or any questions about your rights as a research participant, then you may contact: Dr. Angela Watt, The Secretary, Human Research Ethics Committee, The Royal Melbourne Hospital, Grattan Street, PARKVILLE VIC 3050.

Participation is Voluntary

Participation in any research is voluntary. If you do not wish to take part you are not obliged to. Your decision whether to take part or not, or to take part and later withdraw, will not affect your relationship with the Royal Melbourne Hospital/ Western Hospital and Australian Catholic University.

Before you make your decision, a member of the research team will be available to answer any questions you have about the project. You can ask for any information you want. Please sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers. You may decide to withdraw at any time, without any consequences to you.

Ethical Guidelines

This project will be carried out according to *National Statement on Ethical Conduct in Research Involving Humans* (June 1999), produced by the National Health and Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of the Australian Catholic University and the Human Research Ethics Committee of the Royal Melbourne and Western Hospitals.

Reimbursement for your costs

You will not be paid for your participation in this project.

Participant Information Sheet, Version 2, 6th December 2004 (Registered Nurses)



SCHOOL OF NURSING (Victoria) ST PATRICK'S CAMPUS

CONSENT FORM (TO SUBMIT)

Full Project Title: Factors that Impact on Nursing Management of Tuberculosis (TB) Patients in Australia and Malawi

I have read and I understand the Participant Information and Consent Form, Version 2, dated 6th December 2004.

I freely agree to participate in this project according to the conditions in the Participant Information and Consent Form.

I will be given a copy of the Participant Information and Consent Form to keep. The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

	Date
•	Signature (printed) Date
	Date

Consent Form (to submit), Version 2, 6th December 2004 (Registered Nurses)



SCHOOL OF NURSING (Victoria) ST PATRICK'S CAMPUS

CONSENT FORM (TO KEEP)

Sites: Hospital A and Hospital B

Full Project Title: Factors that Impact on Nursing Management of Tuberculosis (TB) Patients in Australia and Malawi

I have read and I understand the Participant Information and Consent Form, Version 2, dated 6th December 2004.

I freely agree to participate in this project according to the conditions in the Participant Information and Consent Form.

I will be given a copy of the Participant Information and Consent Form to keep. The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

	Date
_	Signature (printed) Date
7.	Date

Consent Form (to keep), Version 2, 6t December 2004 (Registered Nurses)

7f: Revocation of consent



REVOCATION OF CONSENT FORM

Full Project Title: Factors that Impact on Nursing Management of Tuberculosis (TB) Patients in Australia and Malawi

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise my relationship with the Royal Melbourne Hospital, Western Hospital and Australian Catholic University.

Participant's Name (printed)	
Signature:	Date:

Revocation of Consent Form, Version 2, 6th December 2004 (Registered Nurses)

Appendix 8: TB / Infectious diseases wards

8a. Infectious Diseases Ward – Respiratory isolation room, Hospital A, Australia.



8b: TB Ward (Male section), Hospital E, Malawi



8c: TB Ward, windows open, patient sitting outside



8d: Nurses' office and preparation room



8e: Nightingale ward layout



8f: Mobile curtain for facilitating privacy



8g: Guardians' possessions



8h: Overcrowded ward

