

**Perceptions of nursing students towards caring for  
people living with HIV/AIDS: A qualitative study  
spanning multiple cultural contexts**

A thesis submitted in fulfilment of the requirements for the award  
of Doctor of Philosophy

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## ***Abstract***

Since HIV and AIDS were first identified in the early 1980's the global epidemic has claimed the lives of more than 25 million people. The number of people living with HIV/AIDS (PLWA) has been variously estimated at between 35 and 42 million. Throughout this epidemic, and worldwide, nurses have played a leading role in providing care to PLWA. However, research studies have shown that some nurses and nursing students have negative perceptions of PLWA. These studies indicated a reluctance to provide care to PLWA, resulting in less than optimum quality nursing support being provided. It is essential for the nursing profession to understand and work towards overcoming negative perceptions of PLWA to ensure the provision of high quality nursing support.

Research has suggested that perceptions are strongly influenced by prevailing socio-cultural values. An appreciation of these values is necessary in developing an understanding of the perceptions shaped by them. Such an understanding should be a precursor to developing strategies to reshape negative perceptions. This study has explored socio-cultural influences on perceptions held by nursing students from a number of countries toward caring for PLWA. The aim was to develop a deep understanding and appreciation of these perceptions in order to inform and influence nursing curriculum development. Based on the foundations of social constructionism and situated in the interpretive paradigm, this qualitative descriptive study has been informed by the concept of stigma and aspects of stigma theory.

The study was conducted at a university in Australia, with data being collected via semi-structured interviews and vignettes to elicit the thoughts, feelings and perceptions of the participants towards PLWA. Recorded interviews were transcribed and interpreted using a process of thematic content analysis to identify themes in the data. Three major themes emerged, each with a number of associated sub-themes. These three themes were named: Blame; Othering; Values.

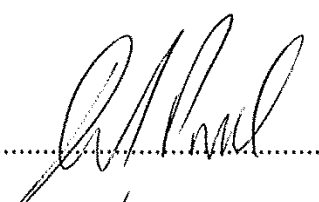
Some study participants held PLWA responsible for behaviour perceived to have resulted in infection with the HIV virus, this concept of blaming the victim has been explored through the theme: Blame. The labelling of PLWA by some study participants as being different from main-stream society was the focus of the theme: Othering. Culturally construed perceptions of homosexuality and drug use were assigned to PLWA thereby 'othering' them. In contrast to the negatively construed concepts of the themes: Blame; Othering, the focus of the third theme: Values, was placed on positive values described by participants in this study. Participants indicated a strong sense of what was expected of them in their future professional capacity of Registered Nurses, and of the professional nursing values expected of them. Some disparity became apparent between these professional values and participants socially and culturally construed perceptions of PLWA.

The study findings have been interpreted and appraised in relation to appropriate theory and literature. This discussion highlighted contrasts between study participants and their culturally informed perceptions of

PLWA. Following the interpretation, appraisal and discussion of the study findings, recommendations have been made in three main areas: nursing student education; clinical practice; further research.

## ***Declaration***

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text

David Pickles: .....

Date 8<sup>th</sup> December 2015

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Finally I would like to thank the undergraduate nursing students who volunteered to participate in this study, without their cooperation this project could not have taken place.

## ***Glossary of Key Terms***

|       |   |
|-------|---|
| AHPRA | <p>Australian Health Practitioner Regulation Agency</p> <p>National body operating in partnership with and providing administrative support to 14 National Boards of health care practice in Australia, including the Nursing and Midwifery Board of Australia</p>  |
| AIDS  | <p>Acquired immune deficiency syndrome</p> <p>In the later stages of infection with the human immunodeficiency virus (HIV), AIDS may develop. This is a life threatening condition resulting in severe dysfunction of the immune system, and for which there is currently no cure</p>   |
| ANMF  | <p>Australian Nursing &amp; Midwifery Federation</p> <p>The ANMF is a national professional organisation representing nurses and midwives in Australia, membership being voluntary. At the time of writing the ANMF had over 240,000 members</p>  |
| HIV   | <p>Human immunodeficiency virus</p> <p>HIV is an infection in which cells essential to the immune system of the human body become infected resulting in the person being more susceptible to secondary infections. Untreated the disease progresses to AIDS, there is currently no cure, however treatment slows the progression of the illness</p> |
| PLWA  | <p>People living with HIV/AIDS</p> <p>There are a variety of acronyms commonly used when referring to people who are infected with the HIV virus or have developed AIDS, these include: PHA; PLHIV; PLWA; PLWHA; PLWHIA. Throughout this thesis, the acronym PLWA has used when referring to people living with HIV/AIDS.</p>                       |

# Chapter 1 – Introduction and Background

## *Introduction*

When addressing the United Nations General Assembly HIV/AIDS Review in 2009, Secretary-General Ban Ki-moon emphasised that ‘The fight against AIDS also requires us to attack diseases of the human spirit – prejudice, discrimination, stigma’ (Ki-moon 2009). Dr Peter Poit, United Nations AIDS (UNAIDS) Task Force Executive Director, informed us that, ‘Misinformation about the disease and stigma against PLWA still hamper prevention, care and treatment efforts everywhere’ (UNAIDS 2006, p. 3).

For many years a diagnosis of HIV/AIDS was considered a death sentence, a terminal illness, whereas in recent years the status of the illness has become that of a chronic illness for many PLWA in developed nations. Nevertheless, the stigma that surrounds PLWA has shown little sign of abating and negative perceptions of PLWA still persist. Research evidence, together with the researcher’s own experience as a Registered Nurse providing nursing care to PLWA, has highlighted that these negative perceptions of PLWA also exist in the nursing profession. Negative perceptions result in PLWA being treated unequally and receiving a lesser quality of nursing support afforded people living with other chronic illnesses. Inequality in care is a significant issue that needs to be addressed by the nursing profession, underlining the importance of identifying where negative perceptions come from in caring for PLWA, and is the key focus of this study.

While HIV/AIDS is a disease to be challenged and one day defeated, in this study the centre of my attention has been on nursing care for people living their lives with HIV and AIDS. A desire to address the misinformation and contribute to overcoming the stigma associated with HIV, particularly in relation to the provision of nursing support to PLWA, provided the inspiration and determination to conduct this research study.

Australia is a multicultural society and has a significant intake of international students to universities each year. International students accounted for around 35% of nursing student enrolments at the university where this project was conducted. In this study I sought to investigate nursing student experiences and perceptions of PLWA. The study cohort were nursing students studying in Australia who came from a range of different socio-cultural contexts, a cohort familiar to me through working in an educational role with undergraduate nursing students.

The study placed the nursing students in a cultural context, and has implications for nursing education and clinical nursing practice in a multicultural society with a multicultural nursing and student population. As will be highlighted throughout this thesis, in much of the world, including Australia, PLWA are vulnerable and marginalised by society. While the goal of this study has been to enhance the nursing support provided to PLWA, there are potentially wider implications stemming from the study in relation to the nursing care of other marginalised groups of people in society.



The purpose of this introductory chapter is to introduce the researcher and bring the issues which inspired this study into focus. This chapter provides some background information to the study, specifically in relation to PLWA; how the researcher became interested in this field; the aim, objectives and research question. The chapter is drawn to a close with a brief outline of the overall structure of the chapters in this thesis.

### **Global perspective of PLWA**

Acquired immune deficiency syndrome (AIDS) is a life limiting condition which develops subsequent to infection with human immunodeficiency virus (HIV). Following infection with this virus, cells essential to the body's immune response become infected and eventually die (Craft, Gordon & Tiziani 2010; Martini 2004). The result is severe dysfunction to the immune systems of PLWA, leaving them highly susceptible to other life threatening infections (Craft, Gordon & Tiziani 2010; Green 2007; Lemone et al. 2011). According to a United nations AIDS taskforce (UNAIDS), world-wide, some 1800 children are born with HIV every day and over 570,000 children under 15 years of age die of AIDS each year, 90% of these children live in sub-Saharan Africa (UNAIDS 2006). While the number of PLWA continues to increase, there are indications that the epidemic is slowing, with the number of new infections decreasing, and fewer people are now dying from AIDS (UNAIDS 2010). It should be noted that these are world-wide trends and in some countries and regions there continues to be an increase in deaths and new infections, particularly in Eastern Europe, Central Asia, and the Indian sub-continent (UNAIDS 2010).

Despite the high number of PLWA worldwide, declining death rates in many Western countries ‘may be creating a false sense of public complacency concerning the disease’ (Kelly & Kalichman 2002). The incidence of PLWA in Australia remains reasonably static with little change since the early 1990’s. The Australian Bureau of Statistics (ABS) reports approximately 800 new cases of HIV per year (ABS 2006, 2010). According to the latest UNAIDS country progress report, there had been approximately 35,287 cases of HIV reported in Australia, with around 26,800 people living with infection at the time of the report (UNAIDS 2015). The majority of people contracting HIV in Australia have done so via male homosexual contact, 71% in 2013, with 13% via heterosexual contact, and only 3% via IV drug use (UNAIDS 2015).

The reported incidence varies greatly in different parts of the world. In South Africa for example, the adult prevalence rate of PLWA is almost 20%, while in some South African provinces as many as 33% of the population are infected (UNAIDS 2013; Uys 2003). In comparison China has one of the lowest reported rates of infection with an estimate of less than 0.1% of the population being PLWA (UNAIDS 2012), yet due to its enormous population HIV looms as a major health issue for China in the future (Pan & Wu 2009; Williams et al. 2006; Zhang, Gray & Wilson 2012). Meanwhile the world wide epidemic continues, with an estimated 42 million PLWA globally, and there remains no known cure (Craft, Gordon & Tiziani 2010; Green 2007; Lemone et al. 2011).

## **Expectations of nurses providing care for PLWA**

Since HIV and AIDS were first identified, literature has consistently shown that health care professionals and society at large tend to have negative feelings and perceptions towards PLWA (Akansel et al. 2012; Cornelius 2006; Lohrmann et al. 2000; Ngan et al. 2000). Ever since the first cases of HIV/AIDS were diagnosed, nurses have been at the forefront of providing care to PLWA (Barbour 1995; Newmann et al. 2013; Vance & Denham 2008; Williams et al. 2006). Caring has long been seen as the essence of nursing (Kozier et al. 2012; Leininger & McFarland 2006; McCarthy & Landers 2010; Wilkes & Wallis 1998) and nursing care ‘involves fundamental values ... and ethical concerns’ (Austgard 2008, p. 318). Regardless of personal preferences, nurses continue to be individually accountable for the nursing care given to each patient (Kozier et al. 2012; Maze 2005). Nevertheless, the perceptions of nurses and nursing students towards PLWA have been under scrutiny since early in the HIV/AIDS epidemic. Providing nursing care to members of disenfranchised groups, such as PLWA, ‘instils fear at some level in nurses who are working with these individuals’ (Maze 2005, p. 546).

Previous studies have demonstrated reluctance on the part of some nurses and nursing students to provide care for PLWA due to their fear of being infected with the virus (Goldenberg & Laschinger 1991; Robinson 1998; Tierney 1995). How this care is provided and the willingness of the nurse to provide care depends on how the nurse perceives each patient and their illness. More recent studies have consistently found that negative perceptions towards PLWA continue to persist among some nursing students throughout the

world (Bektas & Kulakac 2007; Earl & Penny 2003; Madumo & Peu 2006; Petro-Nustas, Kulwicki & Zumout 2002; Rondahl, Innala & Carlsson 2003). According to a United Nations AIDS taskforce report (UNAIDS 2006) negative perceptions and reluctance to provide care results in a poorer quality of care being provided to PLWA, this finding should be of great concern to all in the nursing profession. Nursing students become the practicing nurses of the future, hence the focus on nursing students in this study. It is essential that the nursing profession, and nurse educators, play a major role in formulating strategies to better comprehend and reshape any negative perceptions that nursing students may have.

With continual technological advances there is an ever increasing technical emphasis in the provision of health care. While technology is to be embraced, nursing education must nevertheless avoid pressures to adopt a skills-orientated culture at the expense of the ethos of nursing. Nurse educators need to maintain a focus on ‘what it can mean to care for vulnerable people in increasingly pressured health care environments where economic constraints drive the demand for increased efficiency with limited resources’ (Drummond & Standish 2007, p. 2). Nurses provide care for many vulnerable individuals, including PLWA. Nursing education must prepare them to provide this care without prejudice, discrimination or ignorance, and in the context of a world where ‘stigma, discrimination, and bad laws continue to place roadblocks for people living with HIV’ (UNAIDS 2010, p. 5).

Nursing care is multifaceted and includes ‘the nurture, the physical care, and the emotional support provided by nurses to preserve the human face of medicine and the dignity of the patient’ (Kuhse 1997, p. 47). According to Funnell, Koutoukidis and Lawrence (2009), nursing is much more than one person simply undertaking activities for another person. In fact the ‘nurse and client enter a relationship of respect, concern and support’ (Funnell, Koutoukidis & Lawrence 2009, p. 25). Factors such as nursing students having negative perceptions towards a particular group of people, are likely to disrupt this nurse-client relationship. As today’s nursing students become tomorrow’s practicing nurses, the ultimate result of negative perceptions among nursing students is that people will potentially receive poorer quality nursing care in the future.

### **The nursing role in caring for PLWA in Australia**

Nurses of all classifications in Australia, and in all nursing contexts, are likely to have a role in providing nursing care for PLWA. Unlike some nations, Australia does not attempt to isolate PLWA when providing health care. While specific HIV/AIDS treatments are often instigated in hospital infectious diseases wards, PLWA are nevertheless integrated within the general patient population. Increasingly PLWA receive HIV/AIDS treatment through hospital out-patient services and community based health care services. As with most people in Australia, the primary source of health care for PLWA are community based general medical practitioners. Nurses work in all areas of health care in Australia, caring for PLWA may be a primary role or an occasional role, regardless of the context, nurses must be appropriately prepared to provide such care.

However, since the first cases of HIV and AIDS were diagnosed in Australia over 30 years ago, HIV related stigma has presented as a barrier to the provision of unprejudiced health care to PLWA (Donohoe & Tart 2012). In the mid 1990's a study of beliefs and perceptions of doctors and nurses at several Australian hospitals found significant levels of blame attributed to homosexual men and injecting drug users who were HIV positive. These perceptions of blame led to reluctance on the part of some clinicians to provide care to PLWA (McCann & Sharkey 1998). This mirrored general community perceptions towards PLWA in Australia at the time (Mameli 2001). A more recent Australian study found 77% of PLWA were reluctant to disclose their status due to the stigma they feared they would experience from such disclosure (Slavin 2012). Limited research studies have been published that examine the stigma associated with HIV/AIDS in the context of nursing in Australia. A study among Australian nursing students did find perceptions of homosexuality and IV drug use underlay the stigma associated with HIV/AIDS (Pickles, King & Belan 2012). These findings were similar to those of studies in other western nations (Relf et al. 2009; Rondahl, Innala & Carlsson 2003; Rutledge et al. 2011; Stewart 1999).

The nursing profession and nursing education in Australia are highly regulated by government legislation. Any recommendations to enhance the nursing profession or nursing education must be mindful of the context in which nursing functions in Australia. To legally practice in Australia, nurses must be registered with the Nursing and Midwifery Board of Australia via the

Australian Health Practitioner Regulation Agency (AHPRA). This is a national body responsible for providing administrative support to various health practitioner boards in Australia. AHPRA operates in partnership to support 14 National Boards of health care practice, including the Nursing and Midwifery Board of Australia. The Nursing and Midwifery Board of Australia is a national body which regulates the nursing profession in Australia. State and Territory Boards support the work of the National Board. The National Board is responsible for setting policy, developing professional standards and codes for nursing and midwifery practice, accrediting courses of study, as well as registering nursing and midwifery practitioners and students. The scope of practice of nurses in Australia is bound by a set of Competency Standards, Code of Ethics and Code of Conduct established by the National Board (ANMC 2006b, 2008a, 2008b, 2014). All nurses in Australia are expected to practice within this regulatory framework of standards and codes regardless of the context they work in, or the clients for whom they are providing nursing support, including marginalised people such as PLWA.

A Bachelor of Nursing degree is pre-requisite to apply for registration with the regulatory authority to be a Registered Nurse. Within the Australian nursing profession, in addition to the Registered Nurse classification, there are two other classifications, Registered Midwife and Enrolled Nurse. The Registered Midwife requires a university degree qualification, whereas the Enrolled Nurse requires a non-university diploma level educational qualification. Educational institutions which provide nursing education in

Australia that leads to registration with AHPRA, must structure their nursing programs towards ensuring students understand their obligations and meet the requirements of the appropriate codes and standards. Nursing students are also required to be registered with the National Board.

The total number of registrations for all classifications of Nurse and Midwife with the Nursing and Midwifery Board of Australia was 356,071 as at September 2014, the majority being 318,866 general practicing nurses (ANMC 2014). In 2012 there were 17,790 commencing enrolments for students undertaking programs of study required for initial registration as a Registered Nurse, 2406 (16%) of these students being international students (Health Workforce Australia 2014). However there was considerable variation between university undergraduate nursing programs in the proportion of international students enrolled, ranging from approximately 2% to over 30% (Crawford & Candlin 2013; Gaynor et al. 2007; Health Workforce Australia 2013; Jeong et al. 2011). The proportion of international students enrolled at the university where the study reported in this thesis was conducted, was at the top end of this range.

### **Socio-cultural influences on nurse perceptions of PLWA**

Due to the continuing shortage of nurses in Australia, there has been a policy of actively recruiting nurses and nursing students from overseas countries by governments, health care providers and universities throughout Australia. This multicultural cohort of nurses and nursing students bring with them a diversity of socio-cultural beliefs, values and practices which enrich Australian society. They also bring a diversity of culturally construed



perceptions of PLWA. Research, discussed throughout Chapter 2 of this thesis, indicated that negative perceptions in relation to caring for PLWA persist among nurses and nursing students throughout the world. While recommendations have been made to improve these perceptions through targeted educational programs, there is limited evidence as to the success of such programs.

Sociological Determinism presents the point of view 'that people's behaviour and beliefs are entirely shaped or determined by the social structures or social processes' (Germov & Poole 2007, p. 13). Few sociological theorists subscribe to this view, most believe human behaviour is determined by a combination of factors, including social and cultural structures (Germov 2014). However, research does suggest that the perceptions of nurses and nursing students are strongly influenced by prevailing moral, social and cultural values in the community (Leininger & McFarland 2006; Petros et al. 2006; Rondahl, Innala & Carlsson 2003; Sovran 2013).

An appreciation of these socio-cultural values is necessary in developing an understanding of the perceptions that are shaped by them. Such an understanding should be a precursor to developing strategies to reshape negative perceptions. There is an obligation on nurse educators to ensure that nursing curricula sufficiently prepare students to enable them to provide stigma free, safe, high quality and compassionate care to all their patients, including PLWA. All patients should have the right to expect the same

quality of nursing support regardless of who they are or the condition they are receiving care for.

Negative perceptions lead to a reluctance to provide nursing care with a consequential poorer quality of nursing support being provided. This experience has been described by many PLWA when interacting with the health care system in Australia, and throughout the world, a situation that should be unacceptable to the nursing profession. It is hoped the findings of this study will make a contribution toward understanding, and subsequently overcoming, negative perceptions of PLWA, so that high quality nursing care is delivered to all. Hence the significance of this study is to achieve this goal through investigation of potential social and cultural influences leading to negative perceptions toward providing nursing care to PLWA. What sparked the researcher's interest in the quality of nursing care provided to PLWA, and inspired this study, is expanded upon below.

### ***Researcher's interest in PLWA***

As a Registered Nurse, I was employed in the infectious diseases ward of a major Australian metropolitan teaching hospital during the years 2005 and 2006. While patients with a wide variety of illnesses received treatment on this ward, the major specialisation was the treatment of PLWA. Prior to working on this infectious diseases ward, I had minimal contact with PLWA. When providing nursing care to people with HIV, on a number of occasions, patients verbally expressed concerns to me about the negative perceptions displayed towards them by some health professionals. In addition, I witnessed instances of discriminatory behaviour towards PLWA by health

care and ancillary staff. For example, many ancillary staff insisted on wearing protective gloves when removing meal trays from patients with HIV/AIDS. The implication being that they felt they risked being infected with HIV by touching a plastic tray. Another example I witnessed was of a Medical Officer who insisted on providing treatment last to someone with HIV. His comment was 'they are going to die anyway'.

Nurses were not immune from expressing negative perceptions for on a number of occasions I overheard nurses commenting on how PLWA 'only had themselves to blame'. I found these experiences disquieting and this stimulated my interest in the disease itself, and more specifically in the perceptions nurses and other health care personnel have towards PLWA. In turn, this led to a strong commitment to investigate these issues further, through a formal research process, with the intention of being able to make recommendations to enhance the nursing care of PLWA in the future.

In 2007 I undertook a research study (Pickles 2007) which formed the basis for meeting the requirements of the degree of Bachelor of Nursing (Honours) Degree. The research study was entitled, 'Undergraduate nursing students' attitudes towards caring for PLWA', the published findings from this study are included as Appendix 1 (Pickles, King & Belan 2012). This quantitative study was conducted among second year nursing students at an Australian university. Among the study sample ( $n=396$ ), 28 different countries of citizenship were identified.

Overall the sample students had very positive attitudes towards caring for PLWA. Using the AIDS Attitude Scale (Froman, Owen & Daisy 1992), the study ascertained that only 4.3% of participants recorded negative scores which indicated negative attitudes. The variables of: gender; age group; previous HIV/AIDS education; previous nursing experience; experience of providing care for someone with HIV/AIDS, were all determined to have had no statistically significant influence on participants AIDS attitude scores. However, the variable, country/region of citizenship, was found to have a statistically significant influence on AIDS attitude score, a finding clearly warranting further investigations, and leading to further research questions. The research question posed for the study reported in this thesis, along with the aim and specific objectives of the study, are stated below to clearly indicate what I set out to accomplish (Cooper 2011; Polit & Beck 2004; Richardson-Tench et al. 2011).

### ***Aim, objectives and research question***

The broad aim of this study was to develop a deep understanding and appreciation of the perceptions held by nursing students from different countries towards PLWA, and of the experiences that underpinned these perceptions in order to inform and influence curriculum development. Thus the specific objectives of the study were to:

- Understand the cultural context of nursing students studying in Australia
- Develop a deep insight into the experiences and perceptions of nursing students about homosexuality, IV drug use and PLWA, and

how these views had been influenced by family, community and government

- Contrast similarities and differences in perceptions within and between socio-cultural groups of students
- Explore the role stigma played in nursing student perceptions of PLWA
- Examine the influence living and studying in Australia has had on students' perceptions

The ultimate goal in conducting this study was to improve the quality of nursing care provided to PLWA. Through the development of greater understanding and knowledge of the socio-cultural contexts informing the perceptions of nursing students towards PLWA, greater understanding of these contexts could be gained and shared. This enriched understanding and knowledge was then able to be utilised to make recommendations to inform and enhance nursing education programs. To meet the stated aim and objectives, the main research question for this study was:

What are the experiences and perceptions of nursing students studying in Australia, from a range of different socio-cultural contexts, of PLWA?

### ***This thesis***

The thesis consists of nine chapters, with this opening chapter providing an overview of this research study. This first chapter also establishes the context and significance of the study, why it is important to the nursing profession, and why it is important for PLWA. In the next chapter a comprehensive

review of the literature is presented to position the study and place it within a global context. Research studies from around the world relating to nursing students perceptions of HIV/AIDS, and perceptions of providing nursing care for PLWA, have been critically appraised and the emergent major themes presented. The pervasiveness of the stigma associated with HIV/AIDS is evident throughout these themes, highlighting the impact of stigma in caring for marginalised and vulnerable groups.

Chapter 3 discusses the theoretical concepts of stigma and socio-cultural influences on the formation of perceptions. These concepts were fundamental to achieving the aim of this research study especially in relation to the provision of health care. Chapter 4 outlines the research approach taken in this study and comprehensively describes methodological choices, decisions and procedures undertaken in the design of the study, the collection of data and the analysis of it to draw rigorous findings that will inform nursing education in the future. This study is positioned in the interpretive paradigm, and while stigma theory has provided the theoretical basis for the study, social constructionism provided the philosophical foundations. The chapter concludes by describing the emergence of three major themes from analysis of the study data. These three themes, along with a number of sub-themes, are presented in chapters 5, 6 and 7.

Chapter 5 presents the theme of 'Blame' and explores how some study participants held PLWA responsible for engaging in behaviour which resulted in them being infected with HIV. The second theme, 'Othering', is

presented in chapter 6 and describes how the practice of 'othering' sets people apart from main-stream society, so that they are perceived negatively and ostracised for being different. Chapter 7 focuses on positive values and qualities which emerged and highlights the positive values of the nursing student participants. This chapter describes how students are challenged to reconcile conflicts that occur between their personal beliefs and their developing professional nursing values.

Chapter 8 provides discussion of the most significant aspects of these findings, which are related to relevant theoretical and research based literature. This discussion chapter leads into the final chapter of this thesis where eleven recommendations are made for: nursing student education; clinical nursing practice; future research.

## **Chapter 2 – Literature review: Nursing student perceptions of PLWA**

### ***Introduction***

With the research question in mind, an extensive review of research literature relating to the perceptions of nursing students towards caring for PLWA was undertaken. The purpose of undertaking a literature review as part of a research project is to ensure the researcher has a comprehensive awareness of the current body of knowledge on the topic. This allows the researcher to be ‘aware of what is known and what questions need to be answered’ (Taylor, Kermode & Roberts 2007, p. 73). By developing and answering relevant questions, the researcher is able to contribute to and expand the body of knowledge on a particular topic. As discussed in Chapter 1, there has been considerable scrutiny of the perceptions nurses and nursing students have towards caring for PLWA. Studies in the past have shown that some nursing students were reluctant to provide care for PLWA. The aim of this literature review was to examine the findings of recent research studies into the perceptions and beliefs nursing students have towards caring for PLWA.

### ***Search and retrieval of research studies for review***

A number of electronic data-bases were searched including: MEDLINE; ScienceDirect; GALE; Web of Science; CINAHL; Informit. These electronic data-bases were selected because of their global reach and relevance to this review as they encompass major health discipline specific databases, as well as more general scientific and social science databases. The following key words were used to search data-bases: HIV/AIDS and nursing; HIV and



nursing perceptions; HIV and nursing student perceptions; HIV and nursing care; HIV/AIDS and nursing students.

A number of criteria were used for selecting articles for review. The primary focus of each article needed to be the perceptions of nursing students towards caring for PLWA. Further criteria were that all articles be primary research studies, published in the English language in peer reviewed journals. While the search was extensive, it was not exhaustive. Further studies, particularly in languages other than English, which fit the selection criteria, have been published, but were not accessible to the researcher who is only literate in the English language. In deciding how far back in time to search the literature for this review, initially the position of Roberts and Taylor (2002, p. 48) who suggested, '10 years is a reasonable period to search', was adopted.

Therefore, the original search performed in 2008 included studies published during or later than 1997. Further searches of the literature were performed regularly throughout the study to keep the researcher abreast with current research, relevant studies were then included in this review. Hence the review presented in this chapter includes studies published between 1997 and 2014.

Initial electronic data-base searches using the above search terms identified 497 studies. To ascertain relevance to this review, the title and abstract of each of these studies was read, 403 studies were deemed to not be relevant to the review and were therefore discarded. The remaining 94 identified studies were assessed in relation to the inclusion and exclusion criteria. Studies determined to be not fulfilling the criteria were discarded, leaving 28 studies

for appraisal and potential inclusion in this review. Following the initial database search, further searches, using the same criteria, were conducted in 2010, 2012 and 2014. These searches resulted in a further 12 studies being identified for inclusion, hence a total of 40 studies are included in this review. To maintain consistency, the original search terms and selection criteria remain unchanged throughout.

### ***Critical appraisal of reviewed studies***

Each study was critiqued to determine the rigour of the study to justify its inclusion in this literature review. The critiquing of research studies needs to be approached in a structured manner, a five step strategy proposed by Langford (2001), was followed. These five steps were:

1. First read the article to get a general feel for it
2. A more detailed reading to form an understanding of the article
3. Read the article critically
4. Make an evaluation of the strengths and weaknesses of the study
5. Considering how the study results can be applied to nursing practice

Langford (2001 p. 174-175)

The strengths and weaknesses of each study included in this literature review were evaluated using a set of critical review guidelines proposed by Schneider (2004). These guidelines (see Appendix 2) are extensive asking over 30 questions regarding each research study to evaluate its merits, thus allowing the inclusion of studies considered to be conducted with a high quality of rigour. Not every included study met all the criteria specified in the guidelines, some weaknesses could be identified in every study. However

these weaknesses were not considered to be sufficient to disqualify them for inclusion in this review. Research studies, from around the world, examining the perceptions of nursing students towards caring for PLWA were reviewed and major themes identified. See Appendix 3 for the published findings of the original review conducted in 2008 (Pickles, King & Belan 2009).

### ***Analysis framework of the review***

A manual thematic analysis of the included studies was performed, a process informed by the work of Braun and Clarke (2006), Roberts and Taylor (2002), Leininger (1985) and Strauss (1987). Each study was read several times with connected ideas being grouped together. The groups were then reduced as far as possible ensuring that meaning was not lost in the process, the specific themes were then identified (Braun & Clarke 2006; Leininger 1985; Roberts & Taylor 2002; Schneider et al. 2007; Strauss 1987). While the body of relevant literature relating to nursing students is not extensive, the reviewed studies highlighted the international scope of this issue (Pickles, King & Belan 2009). A total of 40 studies spanning 22 countries have been included in the following literature review. Of these studies, eight were located in Europe, seven in North America, six in Africa, six in East or South-East Asia, six in the Middle East, four in the Indian sub-continent, and one each in Australia, the South Pacific, and South America. With only one study conducted in Australia meeting the criteria for inclusion in this review, the need for further research in the Australian context became more evident.

### ***Emergent themes from findings of reviewed studies***

Five significant themes were identified, these themes were: education and knowledge of PLWA; fear of contracting HIV/AIDS from PLWA; homophobia in the context of caring for PLWA; reluctance to care for PLWA; stigma associated with PLWA. Each of these themes is briefly discussed below. Appendix 4 summarises the included studies for this literature review in the form of a table.

### **Education and knowledge of PLWA**

Among nursing students in the USA, one of the major causes of fear, negative perceptions and reluctance to care for PLWA was identified as a lack of HIV/AIDS education and poor knowledge of PLWA (All & Sullivan 1997; Carney, Werth & Martin 1999; Cornelius 2006; Earl & Penny 2003; Valois et al. 2001). Similar findings were made in Europe. Researchers in Sweden concluded that nursing education should also include broader cultural and ethical issues surrounding HIV/AIDS and PLWA (Rondahl, Innala & Carlsson 2003). These findings were supported by Stewart (1999), Peate et al. (2002) and Veeramah, Bruneau and McNaught (2008). These three studies, conducted in the UK, emphasised HIV/AIDS education as a means of overcoming fear of the disease, of promoting positive perceptions of PLWA, and fostering a non-judgemental approach among nursing students towards PLWA. Recommendations which were also supported by researchers who conducted a multinational study in the three nations of Finland, Estonia and Lithuania (Suominen et al. 2009).

In contrast, a study conducted in Nigeria (Uwakwe 2000) found that education did little to reduce fear. However, Uwakwe (2000) did recommend

more comprehensive nursing student education of HIV/AIDS as the study concluded that education promoted more positive perceptions and reduced the reluctance to care for PLWA. Researchers in Turkey also recommended increased HIV/AIDS education for nursing students (Akansel et al. 2012; Akin et al. 2013; Bektas & Kulakac 2007; Özakgöl et al. 2014). Whilst finding that education increased knowledge, one of these studies concluded that education did not change the perceptions nursing students had of PLWA (Akansel et al. 2012). A study in India also found little correlation between knowledge and perceptions, although increased HIV/AIDS education was recommended to dispel misconceptions of the disease and of PLWA (Balpande et al. 2014). Similarly researchers in China found that education only had a short term impact on reducing stigmatising perceptions of PLWA by nursing students (Yiu et al. 2010).

Regardless of the impact education has on stigmatising perceptions, a study in Thailand concluded that more education was necessary to help overcome nursing students' fears of contracting HIV during routine nursing care of PLWA (Earl 2010). While the latter conclusion conflicted with the findings of Uwakwe (2000), there was common agreement on the importance of enhanced HIV/AIDS education for nursing students as a means of promoting positive perceptions of PLWA. The conflict lay over the potential benefits of this education in different contexts.

A further study in Nigeria (Atulomah & Oladepo 2002) found that nursing students had less than what was considered to be an adequate knowledge of

HIV/AIDS and PLWA; the need for improved education was again stressed. Similarly, researchers in Nepal found large gaps in HIV/AIDS knowledge among nursing students (Mahat & Eller 2009). Although researchers in India found nursing students generally had good knowledge of HIV/AIDS (Balpande et al. 2014; Sachdeva et al. 2011), there were nevertheless some widely held misconceptions about the disease and about PLWA. For example, one Indian study found 50% of nursing students believed that smoking was a risk factor for acquiring HIV (Sachdeva et al. 2011). While in Papua New Guinea researchers found 48% of tertiary students in a study believed that PLWA had contracted the disease as a 'punishment from God' (Jose et al. 2011, p. 59). The researchers found that when it came to this belief, there was no difference between nursing students and the general tertiary student body (Jose et al. 2011).

A retrospective study in Brazil found there had actually been a decrease in HIV/AIDS knowledge among nursing students between 1998/9 and 2010 (Praca, De Freitas & Kimura 2013), highlighting the ongoing need for enhanced HIV/AIDS education. The importance of HIV/AIDS education and the promotion of understanding of PLWA was also emphasised by researchers in a number of other countries, including: Cameroon (Diesel, Ercole & Taliaferro 2013; Rosenburg, Taliaferro & Ercole 2012); China (Li, Scott & Li 2008; Qu et al. 2010); South Africa (Madumo & Peu 2006); Turkey (Akansel et al. 2012; Akin et al. 2013).

## **Fear of contracting HIV/AIDS from PLWA**

A study of Nigerian nursing students' attitudes towards caring for PLWA, (Uwakwe 2000), found 80% of participants feared being infected with HIV if required to provide nursing care for PLWA. In addition to fearing self-infection, 55% of the nursing students in this study also feared infecting members of their own family. Similarly, South African nursing students were fearful of contracting HIV from PLWA when they were undertaking student placement in the hospital environment and providing nursing care for PLWA (Madumo & Peu 2006). Several studies in Turkey concurred (Akansel et al. 2012; Akin et al. 2013; Bektas & Kulakac 2007; Nazik et al. 2012), finding high levels of fear of contagion from PLWA among nursing students. One of these studies from Turkey reported 67% of nursing students were afraid they would contract HIV when providing nursing care to PLWA (Akansel et al. 2012).

In Singapore, 48% of nursing students participating in a study (Ngan et al. 2000) were found to be concerned that they might contract HIV when performing basic nursing tasks with PLWA. Comparable findings were made in Thailand with 41% of nursing students being scared of contracting HIV from the patients they cared for if those patients were known to be PLWA (Earl 2010). According to a study conducted in China, these fears were also shared by Chinese nursing students (Li, Scott & Li 2008).

Considerable fear was also found among North American nursing students of contracting HIV/AIDS from patients they cared for who were PLWA, these studies all linked lower levels of fear with increased HIV/AIDS education

(All & Sullivan 1997; Earl & Penny 2003; Petro-Nustas, Kulwicki & Zumout 2002). While education might not eliminate fear of PLWA, it 'is only through education that people will become comfortable with their own fears' (All & Sullivan 1997, p. 802). Similarly, in Sweden, Rondahl et al (2003) found that 26% of the participating nursing students did not want to care for PLWA. Fear of contracting HIV/AIDS being cited as the main reason for this attitude with 33% of the nursing students being fearful of contagion from PLWA (Rondahl, Innala & Carlsson 2003). However, not all studies found high levels of fear among nursing students, one study in the UK found low levels of fear of contagion among participating nursing students (Veeramah, Bruneau & McNaught 2008).

### **Homophobia in the context of caring for PLWA**

A Swedish study reported that HIV/AIDS had been presented in the media as the 'gay plague' (Rondahl, Innala & Carlsson 2003, p. 455), this study reported that 36% of the nursing student participants would refrain from providing nursing care to homosexual patients if they were given the option to do so. North American studies found high levels of homophobia among nursing students (Cornelius 2006; Earl & Penny 2003; Grossman, Wheeler & Lippman 1998). This was particularly the case with students from rural and remote regions of the USA, they showed little compassion towards PLWA unless the disease was contracted via blood transfusion (Earl & Penny 2003). Ngan et al's (2000) Singaporean study found 24% of nursing students felt 'negatively towards gays because of their association with AIDS' (Ngan et al. 2000, p. 28). Those Singaporean nursing students with high levels of homophobia were also found to be less willing to provide care for PLWA



(Ngan et al. 2000). The homophobia of many nursing students in Turkey was manifested through the anger they directed at homosexual men who were blamed for increasing the risk of AIDS in Turkish society (Akansel et al. 2012; Nazik et al. 2012).

In a study into nursing students' attitudes towards PLWA in Finland, Estonia and Lithuania (Suominen et al. 2009), older nursing students and those with more work experience showed more negative attitudes towards homosexual patients than their younger and less experienced student peers. There was considerable variation between the three nations examined in this study with nursing students in Finland having 'significantly more positive attitudes towards homosexually oriented patients than did students in Estonia and Lithuania' (Suominen et al. 2009, p. 287).

Elsewhere in Europe, German nursing students were found to have a low level of homophobia and positive attitudes towards PLWA (Lohrmann et al. 2000). Similarly, a study of British nursing students by Stewart (1999) concluded that 'homosexuality no longer plays such an important role in the negative evaluation of AIDS' (Stewart 1999, p. 746). These findings from the UK were supported by a more recent study which also found low levels of homophobia among British nursing students (Veeramah, Bruneau & McNaught 2008). The above findings suggest that, while perceptions and attitudes towards homosexuality do vary in different parts of the world, homophobia among some nursing students remains commonplace throughout

many regions of the world, with an associated reluctance to provide nursing care to PLWA.

### **Reluctance to care for PLWA**

North American studies have linked reluctance to care for PLWA with fear of contagion and high levels of homophobia among the nursing students participating in those studies (Cornelius 2006; Earl & Penny 2003; Grossman, Wheeler & Lippman 1998). A study of Turkish nursing students found fear of contagion to be a major factor in the reluctance of participants to care for PLWA. However this study did find that students with previous experience of HIV/AIDS showed less reluctance to provide nursing care to PLWA (Bektas & Kulakac 2007). Two other Turkish studies found that 35.2% (Akansel et al. 2012) and 40.8% (Nazik et al. 2012) of nursing students would prefer to not work with PLWA if given the choice. The Akansel et al (2012) study examined the impact of a HIV/AIDS educational program for nursing students, the percentage (35.2%) who preferred to not work with PLWA remained unchanged, both before and after the education. A finding which calls into question the impact education alone has on nursing student perceptions of PLWA.

Chinese nursing students were found to be reluctant to provide a full range of nursing care to PLWA. For example, a study found that participating nursing students were comfortable taking vital signs but reluctant to clean up following urination or defecation. This reluctance was due to the fear of contracting HIV from PLWA through performing these basic nursing tasks (Li, Scott & Li 2008). In Singapore, Ngan et al (2000) found 24% of nursing

students were reluctant to hold hands with PLWA. Furthermore, 11% of the sample nursing students in this study would leave nursing altogether if they had to care for PLWA on a regular basis. Such findings indicated considerable reluctance among these nursing students to provide care to PLWA. Strong feelings were also demonstrated by Thai nursing students with 27% of participants in one study (Earl 2010) indicating that they would not provide nursing care for patients who were PLWA.

### **Stigma associated with PLWA**

In the USA, a positive correlation between stigmatisation of PLWA and avoidance of association with PLWA was found when researchers were validating an instrument designed to measure stigma among health care providers; the instrument was pilot tested on a sample of nursing students (Rutledge et al. 2011). The stigmatisation was associated with the stereotyping and labelling of PLWA as being homosexual, intravenous drug user, or having multiple sex partners (Rutledge et al. 2011). High levels of stigma associated with HIV/AIDS were also found by Relf et al (2009) in their study involving nursing students in both South Africa and the USA. In contravention of ethical principles and patient confidentiality, the nursing students strongly favoured patients who were PLWA being clearly identified and labelled as such. This was due to their fear of contracting HIV from PLWA and the 'societal stigma associated with the disease' (Relf et al. 2009, p. 1454). Societal stigma, along with a lack of HIV/AIDS knowledge, was also a factor in the stigmatising perceptions of nursing students towards PLWA found in China (Li, Scott & Li 2008; Yiu et al. 2010), Nepal (Mahat & Eller 2009), and Turkey (Akansel et al. 2012; Nazik et al. 2012).

European studies found nursing students reacted negatively towards PLWA who also identified as being homosexual or an intravenous drug user. Overall the studies indicated a strong link between stigma and homophobia (Rondahl, Innala & Carlsson 2003; Stewart 1999). Rondahl et al (2003) found that PLWA who also identified as homosexual experienced a double stigma, resulting in the quality of care received being placed in jeopardy. In contrast, homosexuality and intravenous drug use did not figure significantly in a study among nursing students in Cameroon into HIV-related stigma (Rosenburg, Taliaferro & Ercole 2012). Although the students stigmatised PLWA, it was more from a lack of knowledge about HIV/AIDS, and also due to the stigma the nursing students themselves experienced as people providing nursing care to PLWA. Family, friends and acquaintances feared the students would spread the disease following involvement in nursing care of PLWA (Rosenburg, Taliaferro & Ercole 2012).

Stigmatisation of PLWA was also found to be a significant barrier in the provision of patient care in Thailand although homophobia did not play a major role (Chan, Stoove, et al. 2007). In a study among Thai nursing students, the relationships between HIV/AIDS stigma and the co-stigmas of commercial sex and injecting drug use were analysed (Chan, Stoove, et al. 2007). The study found injecting drug use carried a greater stigma than having HIV/AIDS. Having the co-stigmas of HIV/AIDS and injecting drug use significantly increased the stigmatisation directed towards this group of PLWA. In contrast, the co-stigmas of HIV/AIDS and commercial sex did not

increase stigmatisation significantly higher than having HIV/AIDS alone. Chan et al (2007) attributed these findings to the socio-cultural context in Thailand where injecting drug use was highly stigmatised but commercial sex widely tolerated (Chan, KY, Stooove, et al. 2007).

### ***Discussion***

This review of research literature pertaining to nursing student perceptions towards caring for PLWA found five main themes from analysis of the reviewed studies. There were two common threads running throughout these themes and across nursing student populations. First, many nursing students had unfounded fears of contracting HIV when providing nursing care to PLWA. The reviewed literature clearly indicated a lack of knowledge of HIV/AIDS and a lack of understanding of PLWA, both contributed to nursing students unfounded fears of contracting the disease from PLWA. In some cases the fear was extended to having a fear of infecting their own family through having provided nursing care to PLWA. While education alone might not be successful in overcoming such fears among nursing students, there was general agreement in the literature that more comprehensive education was necessary and important to promoting more positive perceptions of PLWA. Fear was found to be a major factor in the reluctance by some nursing students to provide nursing support to PLWA.

The second common thread running throughout the emergent themes from the reviewed literature was that PLWA were perceived to be different from the rest of society. PLWA were stigmatised and labelled as belonging to socially undesirable minority groups. With homophobia remaining

commonplace, and illicit drug use highly stigmatised throughout the world, PLWA were doubly stigmatised, from the disease and from the association with homosexuality and illicit drug use. These negative perceptions were also found to exist among some nursing students. The reviewed literature suggested that stigmatising and labelling of PLWA to be widespread and evident among nursing students around the world, thereby contributing to a reluctance to provide nursing support to PLWA.

All patients, regardless of their illness or disability, have the right to expect the same high quality of nursing support delivered with care, compassion and without judgement. Consequently there is an obligation upon the nursing profession to develop strategies to understand and overcome negative perceptions such as revealed during the course of this literature review. While the review highlighted the international scope of these issues, limited research was available from most regions of the world, including Australia. We live in a world of complex cultural systems and many nations, such as Australia, have culturally diverse populations. Cultural influences play an important role in how people perceive PLWA and in social constructs such as stigma, with the reviewed research studies indicating that stigma has become synonymous with HIV/AIDS around the world.

We cannot gain an understanding of how nursing students' perceptions of PLWA are formulated without an appreciation of the wider culture and society that shape these perceptions. This literature review has highlighted how the concepts of culture and stigma are central to how PLWA are

perceived. These concepts are very much qualitative in nature, giving further support to the decision to take a qualitative approach in this study. To assist in developing a clearer appreciation of how socio-cultural factors influence perceptions, these concepts and various theories of culture, are the focus of discussion in Chapter 3 of this thesis.

## **Chapter 3 – Concepts and theory informing the study**

### ***Introduction***

As discussed in Chapter 1, the aim of this study has been to gain a greater understanding and knowledge of the experiences of and perceptions held by nursing students from different countries towards people living with HIV/AIDS. Personal observation and experience on the part of the researcher, along with analysis of the research studies reviewed in Chapter 2, suggested that prevailing cultural and social values in the community construct the stigma associated with PLWA. These socio-cultural constructions of stigma influence perceptions of HIV/AIDS and of PLWA. Hence, knowledge of the concepts of socio-cultural influences and stigma emerged as important in relation to the care of PLWA, they have informed the researcher and the findings of this research study.

These two important concepts are the focus of this chapter. First, the concept of socio-cultural influences on perceptions in relation to PLWA has been explored. The concepts of society, culture and stigma each have theoretical foundations. While models of social theory, cultural theory and stigma theory can all be applied to perceptions of PLWA, various theorists have more closely and directly applied stigma theory to HIV/AIDS and PLWA. Hence the researcher chose to pursue the concept of stigma further, and ultimately made the decision to utilise stigma theory as the theoretical basis for this study (rather than social or cultural theory). In addition, research literature reviewed in Chapter 2 demonstrated that the association between stigma and PLWA has been ongoing, thus making stigma theory a logical and



appropriate theoretical underpinning for the study presented in this thesis. Following the initial discussion of sociocultural influences on perceptions, the remainder of the chapter has been devoted to an exploration of the concept of stigma and stigma theory. The chapter is concluded with contextualisation of the concepts and theory that inform the study presented in this thesis.

### ***Socio-cultural influences on perceptions***

So as to develop a deeper understanding of socio-cultural influences on the formation of perceptions, relevant scholarly literature has been explored.

Commencing with a general discussion on the relationship between society, culture and perceptions, the focus of the discussion then becomes more specific in relation to socio-cultural influences on perceptions of PLWA.

Culture provides societies, or groups of individuals with shared perspectives of the world around them; culture helps to shape the beliefs and perspectives of us all. While there are many definitions of culture, that provided by Madeleine Leininger, who first theorised about transcultural nursing (Vandenberg 2010, p. 241), appeared to be the most pertinent to this study:

Culture refers to patterned lifeways, values, beliefs, norms, symbols, and practices of individuals, groups, or institutions that are learned, shared, and usually transmitted intergenerationally over time

(Leininger & McFarland 2002, p. 83)

Human behaviour has been immensely influenced by culture, it ‘provides the framework for a society’s way of life; it influences the way social life is regulated and guides interactions between members of a social group’ (Stein-

Parbury 2009, p. 91). Within the great diversity of human culture, each culture has its own beliefs, values and behaviour patterns. Due to the wide variety of human cultures, people from one culture often have difficulty in understanding the perspectives of other cultures (Giddens 1997; Jeon & Chenoweth 2007; Jeong et al. 2011; Leininger & McFarland 2002). According to Atlani and Rousseau (2000), socio-cultural systems are complex systems which constantly change and evolve. Furthermore, 'culture exists in a complex relation to economic and environmental circumstances within which people make their livings and negotiate their identities' (Atlani & Rousseau 2000, p. 439).

There are many dimensions to culture, with each dimension influenced at various levels, from the individual, the family, community, and regional levels (Dupre & Goodgold 2007; Leininger & McFarland 2002). Cultural influences at the individual level include, socialization, coping mechanisms, values and beliefs. The social and cultural context of each individual largely determines their own set of personal moral values. Moral values are developed passively from birth, then more actively with the development of critical thinking abilities through into adult life (Aalberts, Koster & Boschhuizen 2012; Atkins, Britton & de Lacey 2011; Holma 2011). These values, which are not static, guide our interactions with each other, with society at large, and with groups in society, groups such as PLWA.

Since HIV/AIDS was first identified it has been culturally construed. Human behaviour in relation to HIV/AIDS and towards PLWA was, and has

continued to be, strongly influenced by our socio-cultural systems and beliefs. HIV/AIDS developed into more than a medical term for a physical dysfunction; it came to represent a broader social construct associated with fear, stigma, and helplessness within society (Deacon, Stephney & Prosalendis 2005; Liamputtong, Haritavorn & Kiatying-Angsulee 2009; Pisal et al. 2007). AIDS became a modern day example of illness as stigma, similar to how leprosy was perceived in Europe during the Middle Ages, and has continued to be perceived until recently in parts of the world (Cannon Poindexter 2013; Giddens 1997; Shamos, Hartwig & Zindela 2009). Various theoretical perspectives of stigma are discussed in some detail later in this chapter.

As discussed in Chapter 2, the stigma associated with HIV/AIDS significantly influenced the perceptions of nursing students towards caring for PLWA. The influence of HIV stigma can be even more significant in the wider community. For example, in China, there have been many reports of PLWA being denied access to health care. Children from families with a member living with HIV have been prevented from attending school, and cases have been reported of vegetables grown by someone with HIV being unable to be sold in markets (Lieber et al. 2006). Similarly in India, PLWA have been denied health care and newspapers have reported, almost on a daily basis, cases of PLWA being thrown out of their villages (Charles et al. 2012; Kalasagar, Sivapathasundharam & Einstein 2006). There have been cases in India of entire families committing suicide as a consequence of one member of the family being diagnosed with HIV (Sivaram et al. 2009).

Discrimination toward PLWA has continued throughout the world, and has not been confined to any one group in society. In Canada, for example, refugees living with HIV were reported to be facing ‘systemic discrimination’ (Mah, H & Ives 2010, p. 76) in addition to the many other challenges they faced.

These injustices of HIV stigma go beyond those people who have been diagnosed with the illness. People perceived to be at high risk of contracting HIV, specifically homosexual men, sex workers or intravenous drug users, have experienced similar stigma (Berry et al. 2013; Deng et al. 2007; Goodman & Ley 2012; Herek 2002; Lieber et al. 2006). Community norms regarding such stigma have varied over time and between different societies and cultures. For example, in parts of China HIV has been associated with so called deviant sexual behaviour (such as promiscuity and homosexuality). To avoid the stigma and the label of being deviant, there are reported cases in China of people with sexually transmitted diseases refusing ‘to seek treatment and/or to notify their sex partners (including spouses) about their health status’ (Zhou 2007, p. 286). HIV and AIDS have long been social justice issues. The concept of social justice draws our attention to how ‘justice and injustices are sustained through social institutions and social relationships’ (Kirkham & Browne 2006, p. 325).

According to Young (1990) social justice can be characterised in terms of oppression and domination. For us to understand oppression, we must locate individuals in groups, such as PLWA, because people tend to be oppressed as

members of social groups (Goodman 2011; Warner, Wohl & Branscombe 2014; Young 1990). These social groups then need to be perceived as part of the wider society, as part of the culture in which they exist. People not of the dominant group in society are considered to be 'other' and frequently subjected to stigma and discrimination (Daftary 2012; Germov 2014; Jensen 2011).

Guerin (2004) presented the view that 'to analyse social behaviour it must be looked at from many perspectives' (Guerin 2004, p. 13). He went on to suggest five main contexts to be considered when analysing social behaviour, namely: social contexts; economic contexts; environmental contexts; cultural contexts; historical contexts (Guerin 2004). These five perspectives, or socio-cultural contexts, have formed the basis for developing an understanding, through this study, of the socio-cultural influences which shaped the beliefs and perceptions of nursing students towards PLWA. To gain an understanding of how perceptions towards people with HIV have been formulated, each society can be examined in terms of these five contexts.

### **Social Context**

The social context can be analysed by talking to people; by asking them about their feelings and perceptions towards PLWA; by asking about the feelings and perceptions of their peers and their family; by listening to their stories; by listening to the silences in their stories.

### **Economic Context**

Different economic systems can influence the behaviour and attitudes of individuals and groups. For example, in a public health study conducted in

Bangladesh, the researchers found that 31% of women living in slum areas, 'did not even know the name of a disease called AIDS' (Khan & Kraemer 2008, p. 261).

### **Environmental Context**

Close links have been found between the environmental context and the economic context. A study among poor city dwellers in India found 20% of males and 11% of females had not heard of AIDS (Kalasagar, Sivapathasundharam & Einstein 2006). Of the study participants who were aware of AIDS, only 55% of females and 67% of males 'were aware of the sexual mode of transmission' (Kalasagar, Sivapathasundharam & Einstein 2006, p.67).

### **Cultural Context**

While culture has been conceptualised in a variety of ways, one important dimension of cultural variability is the individualism-collectivism continuum (Gudykunst 2003). Behaviour and perceptions are influenced significantly by whether a person lives in an individualistic society (such as Australia) or a collectivist society (such as Japan) (Gudykunst 2003). However, such systems of categorisation should be employed with caution as they can tend to assign unvarying characteristics to the members of any particular cultural group (Dutta 2007).

### **Historical Context**

How HIV/AIDS and PLWA have been historically conceptualised has varied between countries and over time. In Ghana, for example, prevention campaigns in the early days of AIDS emphasized the relationship between HIV and prostitution. In a country where prostitution was highly stigmatised,

these early messages meant that AIDS was also highly stigmatised. It has now been widely recognised that these early prevention campaigns contributed to people not disclosing their HIV status, and for caregivers of PLWA providing care to their relatives in absolute secrecy (Mwinituo & Mill 2006).

In conducting the study reported herein, the researcher has subscribed to the philosophy linking beliefs, perceptions and behaviour. Study participants, and their social/cultural backgrounds have been examined in relation to the perspectives proposed by Guerin (2004) to determine the factors informing their beliefs and perceptions. These five perspectives, which provide a framework for understanding socio-cultural influences on perceptions, have been collectively referred to as socio-cultural contexts in this study. The study has predominantly focused on the social and cultural contexts of nursing students, and to a lesser extent, the influence that the historical context has had on these other contexts. While economic and environmental contexts were considered to be beyond the scope of this study, their significance should not be overlooked, with further research into these contexts highly recommended.

The preceding discussion has focused on AIDS related stigma in society and the importance of gaining an appreciation of the wider culture and society that has influenced and shaped the perceptions of nursing students towards PLWA. While there are many dimensions to these issues, the perception society has of nurses' warrants particular mention in the context of this study.

In most Western nations, including Australia, nurses are highly regarded and trusted. As a result, many people in Western societies have become accustomed to the nursing profession being ‘held in the highest esteem by the community’ (Crisp & Taylor 2005, p. 2). However, such a view has by no means been universal. In Bangladesh for example, nursing has often been equated with commercial sex work. A study by Hadley et al (2007) in Bangladesh found ‘negative views of nursing were so strong that the profession was often associated with prostitution’ (Hadley et al. 2007, p. 1170). The influence that such a background may have on nursing students has highlighted the importance of taking individual contexts into consideration when examining their perceptions of PLWA.

How nursing students perceive PLWA has clearly been strongly influenced by the social and cultural background of the students, and by the unique context of each individual. The preceding discussion has demonstrated the importance the concept of socio-cultural influences has on perceptions of PLWA, and has established the relevance of the concept to this study. The concept of stigma and the relationship between stigma and PLWA will now be explored.

### ***Conceptualisation of stigma***

Stigma has been described as a social construct with a person singled out by virtue of a physical or social trait. It results in negative social reactions such as discrimination and avoidance, along with the stigmatised person being discredited and labelled as an outsider and not normal (Anleu 2006; Germov 2014; Herek 2002; While & Clark 2010). Stigma has become a symbol



signifying social disgrace due to deviance from an accepted norm of society. When a person has been labelled this way, they suffer a loss of status in their society and are likely to have experienced some form of overt or subtle discrimination, avoidance or exclusion (Link et al. 2004; Pescosolido et al. 2008; Yang et al. 2007).

People not part of the dominant social group in any given society, those 'others' in society, come to be perceived as outsiders and the possessors of social strangeness. The concept of 'othering' is a socially constructed process whereby people are identified as being different from or inferior to the dominant group in society, they are perceived as not belonging to mainstream society (Jensen 2011; Johnson et al. 2004; Liamputtong, Haritavorn & Kiatying-Angsulee 2009). These people, identified as 'other', can then be at risk of being ostracised or marginalised by society. Throughout the brief history of HIV/AIDS, PLWA have been ostracised and labelled as being deviant, they have been 'othered' by society. The 'othering' of PLWA became a theme explored in detail through the findings of this study.

As well as being alienated from mainstream society, the stigmatised person may experience feelings of fear, anger, humiliation, shame, guilt or embarrassment (Link et al. 2004; Scambler 2009; Yang et al. 2007).

'Othering' can be manifested in many ways, such as through racism, homophobia, sexism, violence, lack of opportunity, or domination, to name but a few. Not only are perceived differences emphasised by the individuals or group that perpetrated the 'othering', but the victims would often construct

their own identities around being 'other' (Johnson et al. 2004; Sandelowski, Lambe & Barroso 2004).

Stigma can and does exist at a number of different levels, not only affecting the person possessing the negatively perceived trait, but also those around them. The concept of courtesy stigma was introduced by Goffman (1963) and referred to how stigma spread from the stigmatised person to people closely associated with them, such as family members (Denny & Earle 2009; Goffman 1963). Many people living with stigmatised conditions, such as a mental illness, constantly have to work to reduce the effects of stigma on themselves and their family. When examining the stigma experienced by women living with HIV, Sandelowski and colleagues (2004) described this working to reduce the impact of stigma as stigma management. Women living with HIV have to work hard at stigma management to counteract perceptions of them as being bad, disease bearing people, they have to work to maintain their 'identities as good, vital, and normal women' (Sandelowski, Lambe & Barroso 2004, p. 126). Stigma management has become a constant battle for the stigmatised person.

In societies throughout the world PLWA have been characterised in terms of their 'otherness'. Not only because they live with HIV/AIDS, but also because they are perceived to be part of a marginalised or ostracised group in society such as IV drug user or homosexual. 'Othering' takes place throughout society, including within the health care system and by health care professionals. Within the health care environment, 'othering' can result

in nurses and other health care professionals failing to give culturally sensitive care to their clients. The stigma associated with HIV has not been confined to homosexuality and drug use, there has long been a tendency to blame all PLWA and focus on their perceived 'otherness'.

### ***Stigma theory***

Stigma, and how it has been conceptualised in relation to HIV/AIDS and PLWA, was not only an important theoretical concept which informed this study, it has also provided a theoretical foundation for the study. Hence the remainder of this chapter discusses stigma theory in some detail. Identifying and articulating the philosophical research orientation and theoretical positioning of the researcher has been an essential component of this study from its inception. This not only provided a theoretical and ideological basis to the study, it also helped to place the researcher in context and orientate the reader in relation to the findings of the study.

### **Goffman and stigma**

While early conceptualisations of stigma evolved through the work of a variety of stigma theorists and models of stigma, the conceptualisation of stigma applied in this study has been largely based on the work of Deacon, Stephney and Prosalendis (2005) which specifically focused on HIV/AIDS stigma. However, the current research study has also been influenced by the work of earlier theorists in the field of stigma. This included Erving Goffman and his work during the 1960s (Goffman 1961, 1963), the later work by Edward Jones and colleagues (Jones et al. 1984), as well as Bruce Link, Jo Phelan and colleagues with their more recent conceptualizations of stigma (Link & Phelan 2001, 2006; Phelan, Link & Dovidio 2008; Yang et al. 2007).

The work of contemporary researchers in relation to stigma and HIV/AIDS has also been used to inform this study.

Current stigma theory has largely evolved from the work of Goffman in the 1960s. Goffman described stigma as an ‘attribute that is deeply discrediting’ (Goffman 1963, p. 2), used where someone has an undesirable attribute perceived to be ‘incongruous with our own stereotype of what a given type of individual should be’ (Goffman 1963, p. 3). This then led to the concepts of virtual and actual social identity, introduced by Goffman. According to Goffman, people tend to make assumptions about ‘what the individual before us ought to be’ (Goffman 1963, p. 2). These assumptions can then be used to assign certain traits and attributes to the individual, this characterisation would then become their virtual social identity. In contrast, the traits and attributes that the person really does have can be described as their actual social identity. Goffman described stigma as being a special kind of discrepancy between the virtual social identity and the actual social identity, as a ‘special kind of relationship between attribute and stereotype’ (Goffman 1963, p. 4).

Goffman categorised stigma into three distinct categories. He described these stigma categories as: physical characteristics of the body such as disfigurement, handicap or deformity; blemishes of character related to personality or behaviour; tribal stigma related to race, nationality and religion (Dawes 1998; Denny & Earle 2009; Goffman 1963). The era and context in which Canadian born Goffman mainly lived and wrote in was the USA of the

1950's and 1960's. Hence he directed his attention to the major stigmas of the day, physical deformity, mental illness and race. While he did much work on developing social theory relating to stigma in a general context, Goffman devoted considerable time focusing on mental illness and the institutions surrounding mental illness. Nevertheless, his work has continued to have great relevance today and to more recent stigmas such as that experienced by PLWA.

When discussing stigma, Goffman described how society tended to have the perception that 'the person with a stigma is not quite human' (Goffman 1963, p. 5). Although this was written 20 years before HIV/AIDS appeared, it was prophetic of how PLWA came to be perceived. When he focused on disease stigma, Goffman referred to how some diseases, such as leprosy, were highly stigmatised at that time. Goffman and contemporary scholars postulated that diseases which were subject to the highest degree of stigma have three common characteristics. Highly stigmatised diseases were: progressive and incurable; not well understood by the general public; diseases with symptoms that are not readily concealed (Gilbert & Walker 2010).

Since the early 1980s, and throughout much of the world, HIV/AIDS became the new leprosy, meeting the three characteristics of a highly stigmatised disease described above. Negative perceptions and attitudes, along with avoidance behaviour and blame, were commonplace throughout societies around the world during the evolution of the response to HIV/AIDS. Such perceptions not only existed among the general population, but also among

many health care professionals, including nurses, and they can still be observed to this day. HIV/AIDS and PLWA have continued to remain highly stigmatised even though the three characteristics of a highly stigmatised disease, as described above, may no longer be completely met.

But stigma is not just about categories of people, the so called normal and the stigmatised, it is a complex social process where the roles of the groups blur and overlap. In fact Goffman described the normal and the stigmatised as being 'not persons but rather perspectives' (Goffman 1963, pp. 137-138). Perspectives can be subject to change, they are time and context dependent. Hence the emphasis placed in this study on context when presenting and discussing the perspectives of study participants in relation to HIV/AIDS and PLWA.

Researchers in the field have variously defined stigma, with some definitions being quite vague, whereas others have refined and built on Goffman's more explicit definition. As Link and Phelan (2001) pointed out, definitions of stigma have varied considerably as stigma has been conceptualised and applied in a wide variety of situations. As each situation is different, then researchers have conceptualised stigma somewhat differently to suit the circumstances. Additionally, researchers of stigma have come from a wide variety of disciplines bringing their discipline specific conceptualisations of stigma with them. While Goffman's seminal treatise on stigma has informed a generation, his work has since been built upon and broadened by a number

of sociological theorists (Scambler 2009), several of whom are briefly discussed below.

### **Post Goffman perspectives**

Jones and colleagues (1984) built on Goffman's earlier work and developed their own conceptual model of stigma. They observed that social stigma is all around us and can involve anyone who deviates 'noticeably from norms of appearance or behaviour' (Jones et al. 1984, p. 4). The person who has deviated from the norm is then distinguished from the so-called normal person by bearing a "mark" that defined their deviance. The mark did not have to be a physical characteristic, it could be a behaviour or membership of a particular group. It was this characteristic that defined the person as 'deviant, flawed, limited, spoiled, or generally undesirable' (Jones et al. 1984, p. 6). If the mark were visible to society then the person would be liable to be stigmatised due to their association with the undesirable, discrediting characteristic symbolised by the mark (Jones et al. 1984; Link et al. 2004).

Six key dimensions of stigma were identified by Jones and colleagues (1984), these dimensions provided the basis for understanding the effects of marks and the stigmatising processes associated with them. Briefly, the six dimensions were: *concealability*, the degree to which the characteristic was visible and whether it could be hidden; *course*, was the condition reversible or irreversible, did it change over time; *disruptiveness*, did the mark inhibit or disrupt interpersonal relationships; *aesthetic qualities*, was the possessor of the mark made unattractive or repellent; *origin*, how did the condition

originate, was the possessor perceived as being responsible for the condition; *peril*, was the mark perceived to pose a threat or danger to others, did it induce feelings of vulnerability (Jones et al. 1984; Link et al. 2004).

More recently, Link and Phelan (1999, 2001) developed a conceptualisation of stigma which also built on Goffman's earlier work, as well as on the work of Jones and colleagues. Goffman described stigma as a relationship between attribute and stereotype, Link and Phelan (2001) expanded this and conceptualised stigma as requiring five interrelated components. These five components were: the distinguishing and labelling of difference; the association of human difference with negative attributes; the separation of "us" from "them"; status loss and discrimination; the dependence of stigma on power (Link & Phelan 2001). Link and Phelan (2001) defined stigma as the co-occurrence or convergence of these interrelated components. While there was a degree of complexity in this definition, particularly in comparison to other more succinct definitions, it did reflect the complexity of the stigma concept.

Stigma has been extensively researched and undergone various re-conceptualisations since Goffman's early work in the 1960s. Regardless of how stigma has been conceptualised, researchers have agreed, and consistently demonstrated, that stigma has a considerably negative impact on the lives of people who have been stigmatised. Link and Phelan characterised stigma as having 'strong and pervasive consequences' (Link & Phelan 1999, p. 491) which they described in terms of a person's life chances, including



aspects of life such as: employment, housing, personal relationships and health (Link & Phelan 2001). The negative impact of being stigmatised generally impinged on all these, and other, aspects of life for the stigmatised individual or group. When the negative impact on all of these aspects of life chances were considered collectively, the enormous influence and social harm that stigma has on people's lives could be readily seen (Cluver & Orkin 2009; Link & Phelan 2006; Phelan, Link & Dovidio 2008).

While exploring conceptual models of stigma and prejudice looking for commonality and distinction, Phelan and colleagues (2008) proposed a three function typology of stigma and prejudice. While the focus of the current study has been directed towards stigma rather than prejudice, this three function typology has helped to conceptualise and reinforce the abovementioned negative impact stigma has on the stigmatised. These three functions of stigma and prejudice were described as: exploitation and domination (also referred to as keeping people down); enforcement of social norms (keeping people in); avoidance of disease (keeping people away) (Phelan, Link & Dovidio 2008). This built on the earlier work of Link and Phelan (2001) where they stressed the importance of power in relation to stigma, 'it takes power to stigmatise' (Link & Phelan 2001, p. 375).

People who are members of certain groups in society enjoy a high status by virtue of being perceived as being part of a high status group. Examples include doctors, lawyers and politicians who are generally people with a high status and occupy positions of power. They are not as readily stigmatised as

relatively powerless groups of people, which include low status groups such as the unemployed or people with a disability. So if the same negative trait were assigned to people of both a low status and a high status group, the ability to stigmatise becomes quite different. For example, if lawyers and the unemployed were both described as being lazy, this label would really only hurt the relatively powerless and low status unemployed, the higher status lawyer could shrug it off (Corrigan & Shapiro 2010). Clearly stigma has a dependence on social, economic and political power differentials, a concept central to the existence and understanding of stigma in society (Link & Phelan 2001; Phelan, Link & Dovidio 2008).

The focus of researchers has tended to be very much on how stigma has influenced the individual, whereas a focus on the wider societal implications of stigma presents another dimension. The above definitions and conceptualisations of stigma have clearly demonstrated stigma to be a social process very much dependent on social/cultural/power contexts for existence. It has been in relation to aspects of these social, cultural and power contexts that this research study aimed to make a contribution to the body of research knowledge. While stigma has been increasingly conceptualised as a social process, another conceptualisation would be to consider stigma as a moral issue. The concept of moral experience could then be added to stigma theory to provide new interpretations and understandings of stigma, the stigmatised and stigmatisers (Yang et al. 2007). This became an important dimension of stigma that was kept in focus when analysing and interpreting data from this study.

Researchers in the social sciences bring their own particular focus on stigma, and their primary area of interest may not be stigma. For example, the focus of Miller and Kaiser (2001) was on stress and coping. They conceptualised stigma as a stressor which should be considered in terms of the stress and coping mechanisms of the stigmatised person (Miller & Kaiser 2001). People have various physiological and psychological responses to stress. An example that Miller and Kaiser (2001) gave was that of someone who was stigmatised due to their race. This person might respond with anger, anxiety and fear, all of which could increase cardiovascular function (Miller & Kaiser 2001). Such physiological responses to stigma should not be ignored by social researchers. Living with the stress of being stigmatised has real physical as well as psychological impacts on the persons' health and well-being. Thus, yet another dimension has been added to the many conceptualisations of stigma.

As discussed above, the work of Goffman on stigma theory has been built upon by a number of social researchers and theorists, including: Jones and colleagues; Link and Phelan. In addition to the conceptual models of stigma proposed by these and other theorists, the above discussion also indicated that stigma can be considered from a wide range of perspectives. The current study has been informed and enriched by considering a variety of perspectives and conceptualisations of stigma. These have all contributed to the theoretical foundations of the study.

## **Stigma in health care**

Individuals and groups of people are stigmatised because they possess, or are thought to possess, certain negatively perceived attributes. In relation to stigma, Goffman (1963) made the distinction between easily visible attributes and less visible attributes. The visible attributes, referred to by Goffman as discrediting attributes, were immediately stigmatised. These contrasted with the less visible or less discreditable attributes which have the potential to be stigmatised, particularly if they become public knowledge. These concepts were particularly relevant in the health care arena when it came to people who suffered from a disability or a chronic disease, either of which could have varying degrees of visibility.

A person living with a visible or readily apparent physical or intellectual disability would be highly likely to be immediately stigmatised due to the visible, discrediting attribute of the condition. They would be stigmatised by virtue of being different, of having a mark/attribute negatively valued by society and which isolated them (Stuber, Meyer & Link 2008; Vickers 2012; While & Clark 2010). In contrast to more visible conditions, a chronic health condition may or may not be visible. Therefore the potential for the person with a chronic disease to be stigmatised would depend on who knew about the person's condition (visibility), and the nature of the discreditable attribute itself (Denny & Earle 2009). Some discreditable attributes are stigmatised more than others, mental illness, for instance, has long been highly stigmatised as a discreditable attribute. An additional consideration being that there may not be a clear distinction between a physical disability or deformity and a chronic condition. For example, obesity, a highly visible condition,

could be considered to be a chronic condition and a physical disability, it has also continued to be a highly stigmatised condition (Sikorski et al. 2012).

According to Scambler (2009), 'Many conditions and symptoms from nervous ticks and stuttering to tuberculosis and leprosy carry stigmatising connotations' (Scambler 2009, p. 445). Yet people with conditions such as these have generally not been considered to have personal responsibility for having the condition. When a chronic disease or condition has been perceived to be the result of a person's own behaviour or lifestyle, the condition would be more highly stigmatised than conditions where blame were not so easily attributed to the victim (Denny & Earle 2009; Gollust & Lantz 2009; Stuber, Meyer & Link 2008). Examples of conditions that have readily attracted blame include: HIV/AIDS; obesity; lung cancer. The point being, diseases, disabilities and deformities are not all stigmatised in the same way or to the same degree, thus highlighting the need for greater understanding of the diverse socio-cultural contexts which contribute to the varied constructions of stigma.

Chronic conditions have always been highly visible to health care professionals by virtue of the position these professionals occupy. They would generally have full access to their client's confidential medical records, regardless of the presenting condition for which the client was receiving care. So the health care professional would rapidly become aware of a person's previous history of, for example, mental illness, even if this had no direct relevance to the condition with which they have presented. The

condition might be hidden from others, but it would become visible to the health care professional, opening the door to potential stigmatisation of the person. Therefore the health care professional has been placed in a position of power, not just because they are the deliverer of health care, but also as the possessor of knowledge about their client. Knowledge is power (Burr 2003; Fairclough 2005; Foucault, Michel 1976) and power is needed to stigmatise both individuals and groups (Link & Phelan 2001; Phelan, Link & Dovidio 2008).

The health care system and health care professionals have the capacity to provide protection and advocate for the reduction of the stigma suffered by people with chronic conditions. However, they can also do the opposite. The system can enact policies and public health campaigns which have the result of promoting stigma (Guttman & Salmon 2004; Herek, Capitanio & Widaman 2003). Some anti-obesity campaigns for example, have stigmatised people who may be considered to be overweight or obese. Similarly, health care professionals can hold stigmatising beliefs and, in some cases, enact and perpetuate stigmatising behaviour. For instance, studies have shown that health care professionals working in the area of mental health were among the most stigmatising group when it came to people with mental illness (Corrigan & Shapiro 2010).

While the above example of health care professionals stigmatising mental illness can certainly be considered a morally indefensible position, less clear cut are some public health campaigns. As well as the obesity example

mentioned above, another example of a campaign of questionable moral defensibility were the anti-smoking campaigns in which health authorities deliberately stigmatised people who smoked through a shame and blame approach. Bayer (2008) asked us to consider if such campaigns could be considered morally defensible (Bayer 2008). While shame and blame campaigns might reduce the prevalence of smoking, they may ethically be at odds with the ethos of public health due to the suffering of the stigmatised. This would particularly be the case for those who continued to smoke as they tended to be the poor, already a socially vulnerable group in society, and the burden of stigmatisation would fall mainly on them (Bayer & Stuber 2006).

Not only are people liable to be stigmatised by society in general for health conditions suffered by them, the health care system itself and the health care professionals working in that system can promote and/or enact stigmatising behaviour. As HIV/AIDS has continued to be a stigmatised (chronic) health condition, it is therefore important to have an understanding of the relationship between stigma and health care, hence the above discussion.

While many examples of stigma in health care have been found, the focus of this study is on PLWA. The following section of this chapter has concentrated more specifically on the stigma of living with HIV/AIDS.

### **Stigma and PLWA**

As presented in chapter 2 of this thesis, studies from throughout the world demonstrated that some nursing students have negative perceptions of PLWA. Such perceptions can lead to stigmatising behaviour and PLWA having the quality of the health care they receive diminished. Of course

nursing students with such perceptions are not alone, PLWA have long been singled out for avoidance and stigmatised by society in general, and by some members of the health care professions. These perceptions have continued to persist among health care providers around the world (Ahsan Ullah 2011; Chan, Stoove & Redpath 2008; Lekganyane & du Plessis 2012; Li et al. 2012; Machine, Ross & McCurdy 2011). And as Feyissa and colleagues (2012) observed when conducting a study into stigma by health care providers in Ethiopia, health care providers shared the ‘stigma and discrimination present in their communities’ (Feyissa et al. 2012, p. 532). The findings of this study have therefore highlighted the importance of exploring how communities perceive HIV/AIDS and PLWA.

Within Western societies PLWA have been frequently labelled as homosexual or drug user, or both, which has emphasised their behaviour as being deviant from a perceived norm (Goodman & Ley 2012; Herek 2002). Despite a gradual shift in perceptions since the 1980’s, these two groups have remained highly stigmatised in Western societies (Goodman & Ley 2012; Simmonds & Coomber 2009). In the context of sub-Saharan Africa, PLWA have been stigmatised for different reasons, they were generally greatly feared and discriminated against. The disease in the African context has been characterised in terms sexual taboos, prostitution, myths, gossip and rumour (Chiu et al. 2008; Ogunmefun, Gilbert & Schatz 2011; Zeelen et al. 2010), all of which has contributed to PLWA being highly stigmatised.



Two decades into the AIDS epidemic, Herek (2002) wrote that after such a time the stigma associated with HIV/AIDS might have been expected to have lessened considerably. This was not the case and he observed that ‘the sorts of beliefs and opinions that provide a foundation for AIDS stigma continue to be widespread’ (Herek 2002, p. 596). According to Herek (2002), the persistence and degree of HIV/AIDS stigma was due to the perception of the disease as being: contracted through avoidable and voluntary behaviour; incurable; presenting a risk to others. Such perceptions continued into the third decade of the AIDS epidemic. In 2004, one of the key findings, by Sandelowski and colleagues, through a metasynthesis of qualitative studies relating to stigma in HIV-positive women was the ‘pervasiveness of both felt and enacted stigma’ (Sandelowski, Lambe & Barroso 2004, p. 124).

Although HIV and AIDS remain incurable, current treatments mean that for many PLWA the disease has become a chronic condition rather than an automatic death sentence. This change has done little to reduce the stigma of HIV/AIDS throughout the world. There have been campaigns throughout the world that have attempted to reduce the stigma of living with HIV/AIDS. Despite these numerous campaigns over the past 30 years, ‘stigmatisation remains a core feature of the patient experience of HIV/AIDS’ (Gilbert & Walker 2010, p. 144). While the Gilbert and Walker (2010) study was conducted in the context of South Africa, similar findings have been made by studies worldwide (Campbell et al. 2011; Feyissa et al. 2012; Hosseinzadeh & Hossain 2011; Jimenez et al. 2012; Lekas, Siegel & Leider 2011; Li et al. 2010; Liamputtong, Haritavorn & Kiatying-Angsulee 2009). Not only do

these findings call into question the effectiveness of stigma reduction programs, it can be argued that some programs have actually disempowered PLWA (Scambler 2009) and thereby perpetuated stigmatisation. They have disempowered by adopting a top-down approach, by trying to impose on people, including PLWA, how they should think, feel and behave.

Moving the discussion now from the above observations on stigma and HIV/AIDS and returning to focus again on stigma theory. Specifically looking at the work on stigma theory by Deacon, Stephney and Prosalendis (2005), where the conceptualisation of stigma has been more explicitly focused on HIV/AIDS and PLWA than the conceptualisations discussed earlier in this chapter. When defining stigma many theorists have conceptualised stigma and discrimination as being almost interchangeable (Deacon, Stephney & Prosalendis 2005). This can be seen in the above discussion where discrimination was one of the five required components postulated by Link and Phelan (2001) to conceptualise stigma. In contrast, Deacon, Stephney and Prosalendis (2005) working in the field of disease stigma, separated the two concepts of stigma and discrimination.

Stigma is about what people believe, whereas discrimination is about what people do (or say they will do). While they have often been linked, there is not a one-to-one correlation between them. Stigmatising beliefs can and have led to discrimination, but this may not always be the outcome. A person could have stigmatising beliefs but then never act upon those beliefs. Similarly, discrimination could exist without stigma being present, for

example, gender is not a stigmatised condition but has clearly resulted in discrimination (Deacon, Stephney & Prosalendis 2005).

The point of difference between stigma and discrimination, as highlighted in the preceding paragraph, became important in the context of this study where the researcher has explored what people (nursing students) have said they believe, and what they have said they might do. The study has not looked into actions that may have occurred, so the focus has been more specifically on stigma rather than on discrimination. Deacon, Stephney and Prosalendis (2005) have viewed stigma, and particularly disease stigma, as a problem of fear and blame. They have described disease stigma as a social process, and defined it as ‘an ideology that claims that people with a specific disease are different from ‘normal’ society, more than simply through their infection’ (Deacon, Stephney & Prosalendis 2005, p. 19). Disease stigma has been closely related to other forms of stigma and prejudice that exist in each society. The stigmatisation of PLWA has been heavily dependent on local prejudices and stereotyping, which in turn were influenced by social, cultural, political and historical factors that exist in a society. These factors combined to produce the fear and blame that became disease stigma.

Fear and blame have long been synonymous with PLWA, and the Deacon, Stephney and Prosalendis (2005) definition of stigma is in accordance with how this researcher conceptualised stigma when the study reported herein was commenced. Fear can be related to the threat posed by the stigmatised disease and those inflicted with the disease. Blame can be related to those

with the disease being held personally responsible for contracting the disease due to having engaged in deviant, risky behaviour. Hence the blame model of stigma was developed. This model has furthered understanding of the construction of stigma, and has emphasised that ‘stigmatisation is a fundamentally social process’ (Deacon, Stephney & Prosalendis 2005, p. 23).

### **Application of stigma theory in this study**

Within the blame model of stigma, the threats posed by the disease can be perceived as being either tangible or intangible. The model considered tangible threats to be those which posed a direct threat to life or safety. In regards to HIV/AIDS, an example would be the fear a nurse might have of contracting HIV from a needle stick injury. Such an injury would pose a real, tangible threat to health and welfare. In contrast, intangible threats are more abstract, more of a symbolic threat rather than a real direct threat. There are people who have perceived HIV/AIDS to be a threat to the moral fabric of society, this would be an example of an intangible threat. The perceived threat could stem directly from PLWA, or be associated with behaviour deemed to be deviant or immoral. What constitutes such behaviour has varied between societies, depending on prevailing social and cultural norms. Whether due to tangible or intangible threats, the fear and blame associated with HIV/AIDS has tended to be pervasive in all socio-cultural contexts.

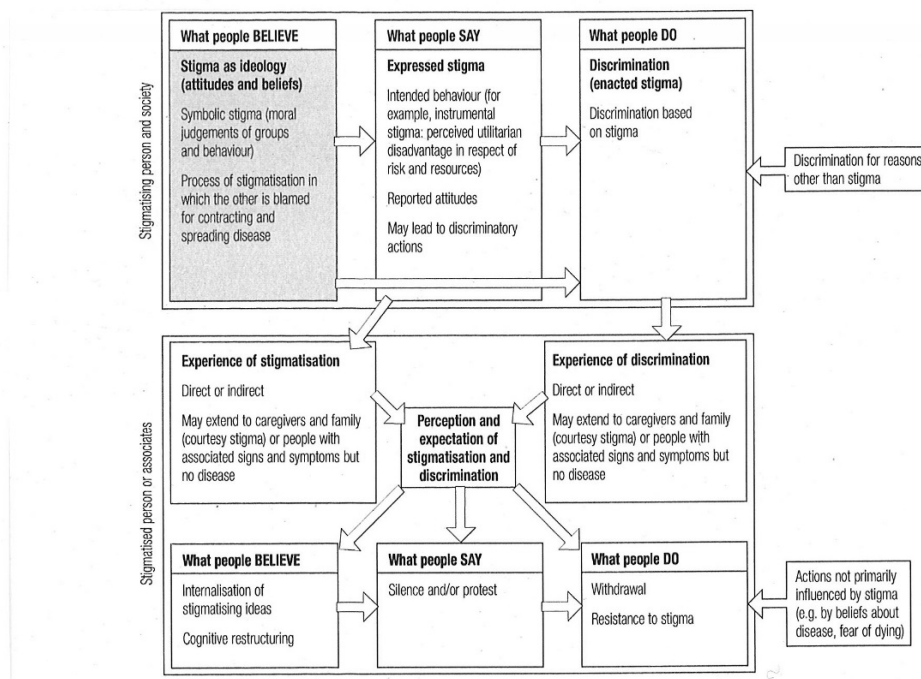
The previously introduced concept of ‘othering’ has presented another dimension to the fear and blame surrounding PLWA. The ‘othering’ of PLWA adds to the health inequalities that have existed between HIV positive and HIV negative people in society. It has built on existing prejudices

relating to deviance and the social inequality that went with belonging to a perceived morally deficient minority. As previously discussed, the possession of power has been demonstrated as being fundamental to being able to stigmatise others (Link & Phelan 2001). The dominant group in society is the one with the power to 'other' minority groups in society.

According to Deacon, Stephney and Prosalendis (2005), in western society the 'othering' of PLWA revolved around existing prejudices of sexism, racism, and homophobia. As a western nation, this characterisation of prejudice could certainly be applied to Australia. However, the prejudice and stigma associated with homosexuality and illicit drug use have tended to be the major influence on the 'othering' of PLWA in the Australian context. The prejudices which form the basis for the 'othering' of PLWA have remained varied throughout the world. Nevertheless, regardless of the context, living with 'othering' and social inequality became part of what it has meant to be living with HIV/AIDS.

The above concepts led Deacon, Stephney and Prosalendis (2005) to explain disease stigmatisation as a social process with four main steps. People in the dominant group distance themselves from the risk of being contaminated by the diseased minority by: constructing the disease as being preventable or controllable; finding that the disease was caused by immoral behaviour; associating the immoral behaviour with carriers of the disease in other groups; assigning blame to people for being infected with the disease, thereby allowing for them to be punished (Deacon, Stephney & Prosalendis 2005).

When articulating their theory of disease stigma Deacon, Stephney and Prosalendis (2005) used a diagrammatic illustration to show where their theory fits in the wider picture of stigma and discrimination. Their diagram has been reproduced below as Figure 1. This study explored the issues from the perspective of the stigmatising person (the top row of the diagram) and focused on what people believed and what they said. What people (nursing students) actually did or would do was not covered by the current study; thus presenting a focus for future research.



**Figure 1 – How different kinds of stigma and discrimination relate to each other - from: (Deacon, Stephney & Prosalendis 2005, p. 20)**

As well as needing a theoretical foundation for conducting a research study, qualitative researchers also have to choose from a wide variety of techniques for communicating their findings. These findings are ‘the sum of an irreplicable sociocultural performance involving researcher and subject’

(Sandelowski & Barroso 2002, p. 215). From the outset, the objective of this study has been to enhance understanding by presenting a richer, more complete representation of data than would have been achieved by simply describing the data. It was important to place the findings data in a relevant and significant theoretical context, in this case, the context of the stigma surrounding HIV/AIDS and PLWA.

The concepts of blame, of tangible and intangible threats posed by HIV/AIDS, along with the social inequality and 'othering' of PLWA, provided a framework for this study and for the presentation of the findings derived from analysis of data gathered in this study. In addition, the stigma theory promoted by Deacon, Stephney and Prosalendis (2005) has been specifically relevant to HIV/AIDS stigma. The above were all factors that influenced the decision to structure this study, and base the analysis and interpretation of the findings on the Deacon, Stephney and Prosalendis (2005) conceptualisation of stigma.

### ***Contextualising the concepts and theory to this study***

We live in a world of complex cultural systems and many nations, such as Australia, have culturally diverse populations. Society and culture have a significant influence on the perceptions, beliefs, and behaviour of people. Hence, the importance of appreciating the significance of socio-cultural influences on nursing student perceptions of PLWA has been highlighted in this chapter. An appreciation of the wider culture and society that has been dominant in the life of the nursing student is necessary to better understand how their personal perceptions of HIV/AIDS and PLWA were shaped. The

concept of socio-cultural influences on the formation of perceptions of PLWA was central to addressing the research question that this study set out to answer.

A common thread running throughout this chapter and linking the themes of the previous chapter has been the stigma surrounding PLWA. The concept of stigma and how it related to PLWA was also fundamental to understanding perceptions nursing students have of PLWA, and to addressing the research question. The disease itself, the people living with the disease, people associated with PLWA, and people perceived to be in high risk groups for contracting HIV, have all been stigmatised by society throughout the world. Cultural influences play a significant role in social constructs such as stigma, and stigma has become synonymous with HIV/AIDS, with stigmatisation of PLWA widespread. Thus, not only was stigma a concept central to the context of this study, stigma theory became a logical choice as the theoretical basis for the study.

The decision to utilise stigma theory as the theoretical foundation for this study stemmed from the overwhelming stigma that surrounds HIV/AIDS and PLWA. While various theoretical perspectives of stigma exist, the stigma theory primarily utilised in this study has been largely based on the work of Deacon Stephney and Prosalendis (2005) with their focus on stigma and PLWA. The aspects of this theoretical perspective of stigma specifically relating to this study were: the blame model of stigma; tangible and intangible threats; ‘othering’; power and social inequality. These have formed



the basis for the presentation of the findings of this study around the major themes that emerged from analysis of data collected via interviews with nursing students participating in the study. The stigmatisation that has continued to characterise PLWA can be seen throughout the findings chapters of this thesis.

While stigma theory provided the theoretical basis for this study, the underlying philosophical foundations of the study have stemmed from social constructionism. The researcher has also firmly positioned the study within the interpretive research paradigm. These concepts are discussed further in the following chapter, along with the research methods employed in conducting the study.

## **Chapter 4 – Research Methodology and Methods**

### ***Introduction***

As discussed in the previous chapter, stigma theory has provided the major theoretical underpinnings for this study. While stigma theory provided the theoretical basis for the study, social constructionism and the interpretive research paradigm have provided the philosophical foundations for the study. This chapter commences with a discussion of these two philosophical tenets before stigma theory is revisited to place in context with the overall research methodology. There is then a brief discussion relating to various methodologies that were considered and rejected as being suitable for utilising in this study, leading to the decision by the researcher to adopt a descriptive qualitative interpretive approach, informed by social constructionism. Important issues relating to rigor and ethics in the study are also discussed.

Following these philosophical and methodological considerations, the processes of data collection and data analysis are presented. In relation to data collection, the discussion includes a description of the recruitment methods, the study sample, and details of the interview processes employed for data collection. Moving on from data collection issues, the formulation of a data analysis strategy is highlighted and the adopted approach of content thematic analysis presented. The chapter concludes by introducing the findings from data analysis, namely the major themes and sub-themes. These themes and sub-themes are presented in three findings chapters, Chapters 5, 6 and 7.

Before proceeding, the aim and objective of the study are re-stated here so as to assist in placing the research methodology and methods in context with them.

**Aim:**

To develop a deep understanding and appreciation of the perceptions held by nursing students from different countries towards PLWA, and of the experiences that underpinned these perceptions in order to inform and influence curriculum development.

**Objectives:**

- Understand the cultural context of nursing students studying in Australia
- Develop a deep insight into the experiences and perceptions of nursing students about homosexuality, IV drug use and PLWA, and how these views had been influenced by family, community and government
- Contrast similarities and differences in perceptions within and between socio-cultural groups of students
- Explore the role stigma played in nursing student perceptions of PLWA
- Examine the influence living and studying in Australia has had on students' perceptions

## ***Positioning the Study***

### **Philosophical Positioning**

#### **Social Constructionism and the Interpretive Paradigm**

Social constructionism and the interpretive paradigm established the philosophical foundations of this research study; they also assisted in placing the philosophical perspectives of the researcher in context. Articulating the philosophical underpinnings of a research study is essential as it provides a foundation and justification for the methods and methodological processes employed in the study (McGregor & Murnane 2010; Morehouse 2012; Schneider & Whitehead 2013). The intention of the researcher has been to make a contribution to our understanding of the world in relation to the study issues by exploring and interpreting their meaning from the perspectives and contexts of the study participants. By developing such understandings, recommendations were able to be made with the aim of effecting positive change through enhanced nursing student educational programs. The philosophical perspectives provided by social constructionism and the interpretive paradigm were congruent with the intentions of the researcher. There has also been congruence between the philosophical positioning and the data collection/analysis strategies and methodology employed in the study.

Cultural beliefs, social practices and institutions define and construct the reality of human life. Reality is socially constructed rather than being inevitable or objective fact (Gergen 2009; Prinz 2012). Each of our perceptions of reality is a consequence of ‘shared understandings, conventions, negotiations, and power-based relations that produce and are

produced by a discursive context' (Gemignani & Pena 2007, p. 278). These philosophical concepts are at the core of social constructionism. According to Lupton (2003), social constructionism is 'an approach which questions claims to the existence of essential truths' (Lupton 2003, p. 12). There can be multiple versions of truth and if we view the world through the lens of social constructionism, we accept that there is no undying, constant standard by which truth can be known, and we appreciate that truth has multiple perspectives (Burr 2003; Gergen 2009; Guba & Lincoln 2005).

What is truth, what is reality, and what is meaning are questions raised by many theorists and philosophers, not just social constructionists. Various ideologies, such as Marxism, raise questions about truth, reality and meaning. Reality, truth and meaning are subject to change and are products of our ever changing social practices and social structures. Consequently our social structures are defined by our knowledge, and what we perceive as knowledge and truth are constantly changing (Cruickshank 2012; Fairclough 2002; Holloway & Wheeler 2010; Kim 2011; Paley 2010). Hence knowledge 'is not seen as a universal, independent reality but as a participant in the construction of reality' (Lupton 2003, p. 12). Knowledge is relative rather than absolute and scepticism about knowledge claims is central to social constructionism (Burr 2003; Cruickshank 2012); knowledge is context-bound or culture-specific, and often subject to multiple meanings. Hunt (2004) stated this in straightforward terms when she wrote about seeking solutions to problems in society, 'life is complex, people's lives and experiences are complex, there are no simple solutions' (Hunt 2004, p. 8). This perspective

also emphasised the individual, each person is an individual with their own experiences and context in the world.

Social constructionism questions the nature of knowledge, truth and reality. Knowledge, truth and reality in relation to any phenomena being studied are context bound and a product of our continually evolving social structures (Gergen 2009; Prinz 2012). Researchers posited in the interpretive paradigm seek to develop an understanding of how people make sense of the world around them. What are knowledge, truth and reality in the unique context of an individual, how do they find meaning in the phenomena experienced in their lives (Jackson & Borbasi 2008; Westerman & Yanchar 2011).

Understanding this meaning is the purpose of interpretive research. A fundamental philosophical presupposition of the interpretivist approach is that research findings result from 'intersubjective, meaning-focused processes that themselves interact with and potentially shape the worlds we study' (Schwartz-Shea & Yanow 2012, p. 40).

The interpretive research approach developed out of the hermeneutic and phenomenological traditions where human agency, experience, culture and context are privileged (Morehouse 2012; Schwandt 2003; Scotland 2012).

Our social practices are 'inherently reflexive' (Fairclough 2003, p. 22).

People do things and interact with each other, we then represent our actions to others, which, in turn, then further shapes our actions. Our actions are the product of a multitude of interactions with the people in the world around us.

Trying to understand and find meaning in the ever changing nature of our

social world is inherent to the interpretive paradigm, and is the essence of social constructionism (Cunliffe 2008; Fairclough 2003; Lock & Strong 2010).

From a social constructionist perspective, knowledge is not seen as ‘something that a person has or doesn’t have, but as something that people do together’ (Burr 2003, p. 9). Burr asserted that knowledge, regardless of its source, is always historically and culturally specific. It is ‘derived from looking at the world from some perspective or other, and is in the service of some interests rather than others’ (Burr 2003, p. 6). Interpretive research studies human action and the influence context, events, culture, and society have on the individual (Jackson & Borbasi 2008; Morehouse 2012; Scotland 2012). Therefore the focus of our research should be directed towards the interactions between people and the social practices informing these interactions, and how meaning is shaped by these interactions. The focus of the research study presented in this thesis has been on people, their interactions with others, the social context in which they live, and the socio-cultural influences which shaped their beliefs and perceptions. There has been alignment between this study and the philosophical concepts of social constructionism and the interpretive paradigm, thus their appropriateness as the philosophical foundations for the study has been established.

An interpretivist stance is not only one of generating understanding and explaining society, it is also about being critically reflective (Morehouse 2012; Schwandt 2003). Hence interpretive research has the potential to raise

awareness of injustices in society and highlight where change is needed (Schneider & Whitehead 2013). Addressing some of the injustices surrounding HIV/AIDS (Levy & Sidel 2013; Rosenthal 2006) helped to provide motivation and justification for this study. The justice aimed for through this research was to reduce the stigma of HIV and AIDS, to recommend strategies for overcoming the negative perceptions shown by some nursing students towards PLWA, and with the ultimate goal of improved patient care.

There is coherence between interpretive and social constructionist perspectives; taken together they can lead to a variety of theoretical approaches in exploring our social structures and social groups. Building on the foundations of social constructionism and the interpretivist paradigm, aspects of stigma theory have been applied to this study. Since the acronyms of HIV and AIDS came into existence they have been synonymous with stigma. The stigma surrounding PLWA has continued to be pervasive, hence the appropriateness of utilizing stigma theory to inform this study.

## **Methodological Positioning**

### **Evolving Research Design**

The methodological approach taken during the course of this study evolved and changed focus over time. From the outset there was a determination to conduct the study from a qualitative research perspective, thereby enabling an exploration and illumination of the experiences, contexts and subjectivity of the study participants. The aim was to adopt a humanistic approach to a topic that has, at times, become somewhat dehumanised in the world around us



(Jarlais, Arasteh & Hagan 2008; Ray 2005; Tomaselli 2009). Choosing a qualitative interpretive research methodology to inform this research study was not a straightforward process. As Denzin and Lincoln observed, qualitative research 'privileges no single methodological practice over another' (Denzin & Lincoln 2005, p. 6). Every approach has merit if it contributes to our understanding and comprehension; thus every approach, in the context within which it takes place, contributes to the totality of our body of knowledge (Belsey 2002, p. 26; Schneider & Whitehead 2013, pp. 28-29).

A number of conventional qualitative methodological approaches were explored and considered for this study. Each was carefully examined and ultimately rejected as being unsuitable to achieve the aim and objectives of the study in the context in which it was to be conducted. Two such examples were ethnography and phenomenology. The use of ethnography did not fit well with the purpose of this study or with the proposed data collection approach. Whereas the 'end purpose of ethnography is the development of cultural theories' (Nieswiadomy 2008, p. 174), the purpose of this study was to gain an understanding of how the individual's beliefs and perceptions were socially and culturally constructed. Data for an ethnographical study is usually collected in the field, via participant observation and in-depth interviews (Nieswiadomy 2008; Robson 2011; Schneider & Whitehead 2013). The participants in the current study were nursing students, very few had any prior opportunity to provide care for PLWA, so there was no prospect of observing them in the field.

Similarly, a phenomenological approach was found to be unsuitable for this study. Phenomenological researchers examine people's experiences as described and perceived by the people themselves (Holstein & Gubrium 2008; Nieswiadomy 2008). These experiences are referred to as lived experiences, and 'the goal of phenomenological inquiry is to fully describe lived experience' (Polit & Beck 2004, p. 253). A phenomenological approach was not considered appropriate for this study as the focus was on beliefs and perceptions rather than personal experience. It was considered highly likely (and later demonstrated during participant interviews) that the vast majority of the nursing student subjects in the study would have no experiences involving PLWA, but they would have perceptions and beliefs.

The decision was made to adopt a qualitative descriptive approach, informed by social constructionism, and fashioned around stigma theory. After careful consideration, much reflection, and recognition of the merits of more conventional approaches, a qualitative descriptive approach was deemed by the researcher as being the most appropriate for the study. It provided the best fit with the purposes of the study, the context in which the study was to be conducted, as well as taking into consideration factors such as sampling, data collection and data analysis.

### **Qualitative Description**

While qualitative description is a useful qualitative research method (Neergaard et al. 2009), Sandelowski (2000) observed that 'there is no comprehensive description of qualitative description as a distinctive method' (Sandelowski 2000, p. 335). This is not to suggest that qualitative

description, as a research approach, has no form or structure. But, like all research approaches, it has been an evolving entity that each researcher builds upon and interprets depending on the research context, ‘all methods become what they are in the hands of users’ (Sandelowski 2010, p. 78). It should be stressed that a qualitative descriptive research approach needs to be as well conceived, structured and conducted with the same rigor as any other research approach (Neergaard et al. 2009; Sandelowski 2010).

Qualitative descriptive studies are a ‘reasonable and well considered combination of sampling, and data collection, analysis, and re-presentational techniques’ (Sandelowski 2000, p. 337). The choice of a qualitative descriptive approach for this study met with these recommendations made by Sandelowski (2000). Considerable thought, time and effort were expended before concluding qualitative description was a reasonable and appropriate approach to pursue. This effort involved carefully considering the overall research process, from sampling through to the presentation of the findings. A number of different approaches were not only considered for the study, but were actively pursued until their suitability, for various reasons, came into question. Establishing a cohesive overall research approach appropriate to the aim, objectives and context of the study was a challenge to the researcher, qualitative description was a fitting approach.

## **Theoretical Positioning**

### **Stigma Theory**

The interpretive paradigm and social constructionism provided the philosophical foundations for this study, and stigma theory provided the

theoretical basis to the study. While stigma theory has been discussed in some detail in Chapter 3, it is briefly mentioned again here so as to place it in the overall context of the research methodology of the study. Although the chapter on stigma theory preceded this chapter, the philosophical positioning of the researcher and that taken in this study were in place from when the study was first conceived. As the study evolved it became important to structure it around a theoretical position which would link it to and build upon the existing knowledge base (Longo & Dunphy 2012; Polit & Beck 2008; Schneider & Whitehead 2013). The stigma associated with PLWA made the use of stigma theory an appropriate choice, especially considering the substantial body of work throughout the social and medical sciences relating to stigma. In the context of this study, the work of Deacon, Stephney and Prosalendis (2005) was determined to be the most directly identified with the issues under focus.

### **Summary – Positioning the Study**

This research study has been posited in the interpretive paradigm and social constructionism has provided the methodological foundations for the study, the focus being on the interactions between people and the contextual social world in which they live. Flowing from these foundations, and in the context of the ongoing stigmatisation of PLWA, stigma theory was determined to be a highly relevant and suitable theoretical basis to underpin this study. Before moving to elaborate on the research methods employed in this study, a brief discussion on issues of rigour and ethics will now follow.

## ***Rigor***

This chapter now moves on to discuss, in relation to the study, the issue of rigor, essential in establishing the credibility and trustworthiness of this study (Whittemore, Chase & Mandle 2001). Rigor is about ensuring research is conducted with the utmost propriety and honesty, it involves discipline, scrupulous devotion to detail, and maintaining the highest degree of accuracy (Burns & Grove 2005; Taylor, Kermode & Roberts 2007). According to Nixon and Power (2007), qualitative researchers often have difficulty in ‘articulating clearly what constitutes credibility in qualitative report’ (Nixon & Power 2007, p. 73), yet it is the responsibility of the researcher to demonstrate to the reader that rigor has been established (Porter 2007; Whiteley 2012).

There are a number ways to establish rigor in qualitative research, one such approach has been presented by Lincoln and Guba (1985) who asserted that rigor in qualitative research can be established by addressing four key measures: credibility; transferability; dependability; confirmability (Lincoln & Guba 1985). Sandelowski proposed alternative criteria of: true value; applicability; consistency; neutrality (Sandelowski 1986; 1998). These four measures have been re-stated as: credibility; fittingness; auditability; confirmability (Taylor, Kermode & Roberts 2007). According to Whittemore and colleagues (2001), the primary criteria for conceptualising rigor in qualitative research are: credibility; authenticity; criticality; integrity (Milne & Oberle 2005; Whittemore, Chase & Mandle 2001). The criteria recommended by Lincoln and Guba (1985) have mainly been used to guide

considerations of rigor in this study, while also being informed by other scholars.

In striving to achieve excellence in this study, meticulous attention has been paid to the detail and accuracy of each step in the research process. Without accuracy of data, research would be unethical and findings valueless, the importance of accuracy was highlighted by Christians (2008) who stated, 'Ensuring that data are accurate is a cardinal principle in social science' (Christians 2008, p. 194). The accurate representation of the lived experiences of study participants is the ultimate goal of rigor (Streubert 2011b). Ensuring that the research has been conducted with rigor while remaining true to the methodology, and in an ethical manner, was and continues to be of paramount importance to the researcher. How this was achieved is discussed below.

Without credibility, there can be no dependability of the findings (Lincoln & Guba 1985). Establishing credibility refers to activities undertaken as part of a study that ensure the study findings are perceived as being credible and achieve the purpose of the study. It is essential that study participants have the ability to provide information relevant to the purpose of the study (Streubert 2011a), they must be free to speak and their voices must be heard (Milne & Oberle 2005). The study participants, details of whom are provided later in this chapter, were nursing students able to share their experiences and perceptions on the phenomena being studied. Thus they were appropriate informants to participate in the study. Interviews with them were designed to

maximise their ability to speak freely and with confidence that their privacy and anonymity would be protected, please see page 103 for further details. The researcher consciously and actively listened to their voices during the interviews and throughout the transcription and interpretation of the interview data.

Credibility was also enhanced through the researcher having sustained engagement with the phenomena being studied (Milne & Oberle 2005; Streubert 2011b). At the time of writing, the researcher had engaged with the subject matter for over a period of approximately ten years. In addition, the researcher's immersion in the collected study data extended over three years, repeatedly re-reading transcripts and re-listening to interview recordings.

Transferability of findings to other settings is not the principle aim of qualitative research, the focus is on small groups of people in specific contexts (Koch, Niesz & Mccarthy 2014; Polit & Beck 2010). Whether the findings can be generalised or transferred to another context is for the reader of the qualitative research report who is familiar with that particular context, it is for the writer of the report to provide sufficient detail for the reader to make this determination (Sandelowski & Leeman 2012). The researcher has described in considerable detail each step of the current study so as to enable the reader to draw conclusions about the transferability of the findings to other contexts (Lincoln & Guba 1985).

To assist in achieving credibility and dependability, the analytical and decision making processes have been documented and were discussed with the researcher's supervisors, who also had access to all interview transcripts (Whiteley 2012; Woodward, Webb & Prowse 2007). Throughout the research study, a reflective log was kept, thus an audit trail was established which assisted demonstration of the dependability of the findings (Lincoln & Guba 1985; Ryan - Nicholls & Will 2009). Auditability is a primary mechanism for the establishment of rigor in qualitative research (Locsin et al. 2003; Whiteley 2012).

The audit trail has assisted in establishing that the data is real and the interpretations made in the findings come from the data itself and not from the researcher's imagination (Ryan - Nicholls & Will 2009; Tobin & Begley 2004). However, no matter how impartial the researcher tries to be, their own biases inevitably have an influence on the study. Qualitative research produces highly contextualised data and 'interpretations of this data involve subjective individual constructions' (Scotland 2012, p. 12). Understanding and overtly reflecting on the potential biases and researcher subjectivity enhanced the confirmability of the current study. Throughout this thesis and throughout the research process itself, the context of the researcher has been openly and explicitly portrayed, thereby demonstrating the researcher's self-reflection processes to the reader (Whiteley 2012). This assisted in demonstrating the credibility of the study findings, although it can be argued that only the original researcher, who has been immersed in the study,



collecting and analysing the data, can confirm the findings (Sandelowski 1998).

As a final reflection on rigor, there is also a need to establish that each step in the research process (sampling, data collection/analysis/presentation) is well-thought-out and a reasonable fit with the research methodology employed by the researcher (Sandelowski 2000, 2010; Whiteley 2012). As articulated earlier in this chapter, there is no prescriptive way to go about a qualitative descriptive research approach (Sandelowski 2000), however Sandelowski (2000) does make a number of recommendations. Sampling needs to be appropriate to satisfy the purposes of the study and provide a rich variety of information relevant to the phenomena being studied. In the current study, this was achieved through purposeful sampling to elicit the perceptions of nursing students from a wide diversity of backgrounds. Data were collected in moderately structured interviews designed to encourage participants to freely share their thoughts, beliefs and experiences with the researcher. Content thematic analysis was the strategy employed to code, organise, interpret and present the data in this study, this was an appropriate strategy for a qualitative descriptive study (Sandelowski 2000).

### ***Ethics***

For nursing research to be ethical it must protect the rights of participants and guarantee they will suffer no harm, it must also demonstrate the validity of the research findings (Schneider & Whitehead 2013; Taylor, Kermode & Roberts 2007). Approval to conduct this study was sought from the University's Social and Behavioural Research Ethics Committee (details of

the institution have been provided in the following section). The committee approved the study in July 2009 (see Appendix 5). A request to modify the study by conducting follow up interviews was approved by the ethics committee in July 2011 (see Appendix 6), and a change to the project title approved in November 2012 (see Appendix 7).

All students invited to participate in the study were free to decline to participate and to withdraw from participation at any time. All potential participants were given an information sheet outlining the study and explaining their participation was entirely voluntary and their confidentiality and anonymity would be protected (Robson 2011). This information was provided to potential participants at least several days prior to making an appointment for interview. Thus, volunteers were given ample opportunity to reflect on and re-consider their participation in the study. Maintaining the rights of study participants' was of paramount importance to the researcher, pseudonyms have been used throughout so individual participants cannot be identified. All participants were asked to give their informed consent prior to the commencement of interview, and all were competent to give that consent (Schneider & Whitehead 2013).

Interview recordings and transcripts have been held securely and in confidence at the University's School of Nursing & Midwifery without any information that could identify participants. Interview recordings were transcribed by the researcher and a professional transcription service provider who gave an assurance of complete confidentiality. Several participants

mentioned their real names during their interview, these names were removed and replaced with pseudonyms when the recordings were transcribed. Apart from the researcher, the only persons with access to the original interview recordings were the researcher's supervisors.

In any research study there can be potential to cause harm to participants, this harm could be physical, psychological, economic, or any combination of these. It is essential for the researcher to protect participants by minimising the risk of harm and discomfort (Polit & Beck 2004; Whiteley 2012). The researcher acknowledged that there were some slight risks involved in the study. It was possible some students might feel embarrassed about discussing certain issues during the interview process due to their moral, cultural or religious beliefs. Others may have found it distressing if they had personally experienced or witnessed negative reactions towards PLWA, or perhaps someone close to them had died from this illness. The sample group of nursing students all had a choice to not participate. The voluntary nature of participation was repeatedly stressed. In recognition that some students might have found the study and the issues involved distressing or stressful, the information sheet provided details of appropriate counselling services available, as recommended by Polit and Beck (2004).

### ***Research Methods***

Having presented and discussed the philosophical and theoretical underpinnings of this study, the next step describes the actual research processes. This includes a description of the setting, sample, and the

processes of collecting and analysing data that have been utilised in the study.

### **Setting**

In determining the study setting, the research question, aim and objectives were re-examined. This was done with a view to deciding what setting would best answer these questions (Taylor, Kermode & Roberts 2007) while maintaining the feasibility and practicality of the study with the time and resources available. The study was undertaken as the researcher's PhD research project, and as such there were time and resource constraints on the researcher. There not only needed to be time for planning the study, collecting and analysing data, but also time for reflection (Holloway & Wheeler 2010). Hence the decision was made to conduct the study in one location, in the city where the researcher was undertaking the PhD candidature. The study was conducted at a university in the city of Adelaide, South Australia. At the time of the study, there were three major public universities in South Australia, with the university where the study was conducted having approximately 2,000 undergraduate nursing students.

### **Sample**

The sample from which study participants were drawn consisted of undergraduate nursing students studying at the university described above. Study participants were required from two distinct groups of students within the total body of undergraduate nursing students at the university. One group consisted of students with a country of citizenship other than Australia, known as international nursing students. Approximately 35% of nursing

students studying at the study university at the time were international students and had a country of citizenship other than Australia. The second group were local nursing students with Australia as their country of citizenship.

The intention was to have a sample that spanned the rich cultural mix of nursing students, without allowing the study sample to be dominated by the majority of local Australian citizen students. There was a deliberate attempt to especially encourage international students to volunteer so as to gain a wider cultural perspective in the study. However, this was not reflected in the inclusion/exclusion criteria, the encouragement was verbal when a personal address was made to the students calling for volunteers. To be eligible for selection into the study, potential participants were required to be: undergraduate nursing students studying internally in the School of Nursing & Midwifery at the university where the study was conducted; over 18 years of age; able to give informed consent. There were no other inclusion criteria. The only exclusion criteria applied to students personally known to the researcher through enrolment in classes taught by the researcher. These students were not accepted into the study for ethical reasons.

When seeking participants for the study there was an awareness of the potential difficulties involved in obtaining suitable volunteers. It was anticipated that this process might prove to be particularly difficult in relation to obtaining volunteers from the international student body due to a range of cultural factors. With these thoughts in mind, and with due consideration to

ethical issues, a three pronged approach to recruiting participants for the study was devised. This consisted of: printed advertisements placed on notice boards throughout the Campus of the School of Nursing and Midwifery at the study university; an email to all potential student participants with a letter of introduction and detailed information sheet attached; a brief personal address to nursing students during a scheduled lecture in which the researcher and the study were introduced.

When the initial cohort of volunteers was exhausted, a copy of the recruitment email was again sent to the nursing students to elicit further volunteers. The initial approach to students inviting them to volunteer to participate was made during July 2009. When the list of volunteers from that approach was exhausted, a second approach was made during October 2009. Students were asked to contact the researcher to indicate their willingness to be involved in the project. They had the choice of making contact via email, telephone or in person. The initial address to students and recruitment email only targeted second year nursing students, however the recruitment poster was accessible to all. This approach was adopted as second year nursing students could be regarded as typifying all undergraduate nursing students at the university. Addressing multiple student lectures and emailing all nursing students was considered unnecessary if sufficient volunteers were found from the initial approach.

Selection of volunteers was not influenced by demographic characteristics such as age or gender, however, as previously mentioned, an emphasis was

made to encourage international nursing students to volunteer. There were four students who volunteered but were excluded from the study. One was a postgraduate nursing student, and one a student of a discipline other than nursing, neither met the eligibility criteria. The remaining two exclusions were nursing students who were personally known to the researcher, and were thus excluded for ethical reasons and to reduce perceptions of researcher bias.

### **The participants**

Of the 25 students who volunteered to participate in the study, four were excluded on the above grounds, and the remaining 21 were interviewed by the researcher. The countries from which nursing student participants were drawn from included Australia and eight other nations. This selection was determined by the students who volunteered to participate and their countries of citizenship. An Australian nursing student was regarded as someone holding Australian citizenship, this included dual citizenship holders. International nursing students were defined as people who have a country of citizenship other than Australia. The participants' countries of citizenship have been summarised in Table 1, and presented in greater detail in Appendix 8.

Three of the participants were male while 18 were female, a gender ratio reflecting the overall nursing student population at the university with 85% being female and 15% male. This is similar to the gender ratio of practicing nurses in Australia (92.8% female, 7.2% male) and comparable Western nations such as: Canada (94.9% female, 5.1% male); USA (95% female, 5%

male): UK (90% female, 10% male); Norway (92.5% female, 7.5% male)  
(Speedy 2010).

| <b>Country of Citizenship</b> | <b>Number of Participants</b> |
|-------------------------------|-------------------------------|
| Australia                     | 7                             |
| China                         | 5                             |
| South Korea                   | 2                             |
| Hong Kong                     | 2                             |
| England                       | 1                             |
| Nigeria                       | 1                             |
| Tanzania                      | 1                             |
| Iran                          | 1                             |
| Japan                         | 1                             |

**Table 1 – Participant Nationalities**

Participants were in one of three age ranges, with six in the 18-24 year age range, eleven in the 25-34 year age range and four in the 35-44 year age range, none of the participants were aged greater than 45 years. Nineteen of the students were studying in the 2<sup>nd</sup> year of the Bachelor of Nursing program, one participant was in 1<sup>st</sup> year, and one in the 3<sup>rd</sup> year of the program. The Bachelor of Nursing program, leading to the professional Registered Nurse qualification, was a three year full time course of study at the study university. At the time of the study, this was typical of pre-registration Bachelor of Nursing programs at Australian universities, and met the national accreditation requirements (ANMC 2009). However some participants were undertaking a shorter program of study due to being awarded credit for previous academic achievement and/or previous nursing experience.



## **Data Collection**

Participants were undergraduate nursing students who volunteered to participate in the study, and they were interviewed by the researcher. These semi-structured interviews were designed to elicit the thoughts, feelings and beliefs of the participants towards PLWA. By listening to their stories, by listening to the silences in their stories and guiding the conversations, not only did the participants share their own beliefs, feelings and experiences, but also those of their peers and family. While the interviews have been described as semi-structured, there was, nevertheless, a general framework to assist in encouraging participants to tell their stories. A number of questions were formulated to be used as cues to assist in this story telling (see Appendix 9).

## **Development of scenarios/vignettes**

During the interviews, to assist in exploring the participants' beliefs and perceptions about HIV/AIDS and PLWA, the students were presented with four scenarios or vignettes (see Appendix 10). The vignette is a short story which presents fictional characters in a hypothetical situation (Clare et al. 2012; Gourlay et al. 2014). It is a useful approach to aid in data collection when interviews are employed in qualitative research to explore sensitive topics which interviewees might otherwise be hesitant to discuss (Clare et al. 2012). These scenarios were developed prior to the interview/data collection phase of the study. Encouraging interviewees to comment on each scenario and how they might interact with the fictional characters allowed them to indirectly express personal views which they might be reluctant to express through direct questioning (Gourlay et al. 2014). The researcher's own

experiences of nursing PLWA were used to develop the four scenarios. Although these scenarios were based upon real people and situations, they were modified sufficiently to de-identify the people involved. The scenarios were a tool used to assist the participants to indicate how they characterised, comprehended and constructed their world view of PLWA. They facilitated the expression of personal perceptions and beliefs (Mah et al. 2014). By loosely structuring the interviews around the scenarios, the interviews became conversations which explored what the students had to say about their own lived in world (Gourlay et al. 2014; Kvale 2007).

When developing the scenarios, input and guidance was received from an experienced and respected clinician who was employed as a HIV Liaison Officer at a major public teaching hospital in South Australia. The intention was to use the scenarios as an aid to stimulate discussion during the interviews. With this in mind, the scenarios were developed so as to be somewhat confronting for participants. However there was an acute awareness that by presenting scenarios which, although factual, might be considered to be extreme, there was a risk of reinforcing stereotypical perceptions the nursing students may have already had of PLWA. Therefore the consultations with the experienced HIV liaison officer was to strike a balance between making the scenarios stimulating and realistic, without perpetuating negative stereotyping.

### **The interviews in context**

Commencing in August 2009, initial interviews with volunteer participants took place at irregular intervals over a three month time span. The length of

time of each interview varied, and ranged from 24 minutes to 61 minutes, with an average length of 38 minutes. All the interviews were conducted by the researcher and took place within the University campus of the School of Nursing & Midwifery. While the location for the interviews varied slightly, most were conducted in a private meeting room while some were in private offices, the venues were all similar and ensured discretion and privacy were maintained. The anonymity and confidentiality of the participants and data from their interviews was, and continues to be, scrupulously preserved throughout the entire process.

### **Follow-up interviews**

Following the initial interviews with participant nursing students, a lengthy process of interview transcribing and immersion by the researcher in the interview data took place. As this process evolved it became apparent that the study would be enriched and strengthened if follow-up interviews were conducted with some participants, specifically with the international student participants. This group of participants had generally been less forthcoming during the initial interviews, and most of the shorter duration interviews were with international students. These issues have been discussed in more detail in the Data Analysis section later in this chapter.

Commencing in July 2011 and continuing sporadically until October 2011, six of the original participants were re-interviewed. Difficulties in contacting the original participants and being able to arrange for interview at mutually convenient times resulted in the follow-up interviews being spread over a three month time interval. Many of the original interviewees, in particular

those from overseas, were unable to be contacted. All the original considerations to safeguard the anonymity and confidentiality of participants were extended to these follow-up interviews. The locations and other environmental contexts of these follow-up interviews were as near as identical as possible to the original interviews. Details of the follow-up interviews, which ranged in duration from 33 to 55 minutes, are included in Appendix 8.

### **The interviews – asymmetries of power and experience**

Before proceeding to discuss the processes of data analysis, it is important, for ethical reasons, to spend some time reflecting on the power asymmetries that existed during the interviews with study participants. There are a number of reasons for this, including: the interviews and the transcribed interview data are better contextualised; the reader is made more aware of the researcher's context and of how that may have unintentionally biased the data; it adds to the transparency of the research process.

According to Kvale and Brinkmann (2009) research interviews have 'a clear power asymmetry between the researcher and the subject' (Kvale & Brinkmann 2009, p. 33). While attempting to minimise the influence of such power asymmetries during the interviews, that power cannot be eliminated as it is inherent in all human interaction. Recognising and acknowledging that such power asymmetry existed was essential for the researcher and crucial 'to reflect on the role of power in the production of interview knowledge' (Kvale & Brinkmann 2009, p. 34). There were a variety of potential asymmetries relating to such factors as: role; age; gender; language; culture; experience.

These issues, which have been discussed in more detail below, did not invalidate the knowledge generated. They became part of the context of the interviews and relevant to the interpretations of data surrounding the perceptions of participants towards HIV/AIDS and PLWA.

The roles of the interviewer included that of “teacher”, “interviewer” and “researcher”, whereas the roles of study participants included “student”, “interviewee” and “subject”. Although students who were in classes taught by the researcher were excluded from the study, the researcher did nevertheless have the role of “teacher” and all the participants were aware of that and they were all “students”. Therefore, not only were some pre-interview power relationships inevitable, but a power asymmetry due to role was noticeably present, to a greater or lesser extent, during all of the interviews. This was further influenced by cultural factors in that there were differences between cultures in the teacher-student roles.

An age imbalance existed between the researcher and all of the study participants. At the time of the study the researcher was between 10 and 35 years older than the study participants. Deference to one’s seniors was very much the cultural norm in some societies, but less so in others. The age asymmetry was perceived to be of significance with some participants but not with others.

There was the potential for power asymmetry due to gender – the researcher as male and the majority of participants being female. Many participants had

been brought up in male dominated societies. While no asymmetry due to gender was apparent during any of the interviews, it was important to reflect on the supposition that what was not apparent to the researcher may have still existed.

Most participants had no previous experience of partaking in a research interview, whereas the researcher had prior experience both as interviewee and interviewer. Although all the interviews were conducted at the School of Nursing & Midwifery, they took place in a private office area that was unfamiliar to most of the undergraduate nursing students. This was an environment with which the researcher was familiar, but potentially intimidating to participants. All of the interviews were conducted in English, however, for 13 of the 21 participants, English was a second language (a number of participants were fluent in multiple languages). Adjusting to a new culture was also a significant challenge for the international students, one participant, for example, had only been in Australia for seven months (her first time outside of South Korea). These were all factors that could have contributed to power asymmetries during the interviews and have therefore been worthy of reflection during data interpretation and reporting.

There were also asymmetries in relation to experience of HIV/AIDS and of contact with PLWA. Over half of the participants had no direct experience of HIV or AIDS, whereas the researcher had a number of years of experience in nursing PLWA. However, five participants had some experience of nursing PLWA during a student nursing clinical placement, three had illicit drug use

experience and knew of someone with HIV, and two were from Africa where they had lived with the devastation of AIDS. The variation in experience of HIV/AIDS that existed between the researcher and the participants was considerable, as was the variation between the participants themselves. Such experience has been demonstrated to play a role in how HIV/AIDS and PLWA can be perceived.

### **Data Analysis**

Following data collection, the next sequential step in the research process is generally data analysis. In reality, the qualitative research process is not sequential, steps overlap. For example, data analysis informs data collection and vice versa. According to Streubert (2011), the process of data analysis in qualitative research ‘actually begins when data collection begins’ (Streubert 2011b, p. 46), it has also been suggested that data analysis occurs continuously throughout the study. Regardless of perceptions of when data analysis commences, the ‘goal of data analysis is to illuminate the experiences of those who have lived them by sharing the richness of lived experiences and cultures’ (Streubert 2011b, p. 47). The data tells a story, the role of the researcher, through data analysis, is to identify that story and tell it to an audience (Ziebland & McPherson 2006).

In this study, a manual thematic analysis was performed on the transcribed interview data. Each transcript was read repeatedly, systematically analysed, coded and categorised. Then the categories were reduced to identify, classify and extract sub-themes from the data. From these sub-themes three major themes were constructed which have formed the basis of answering the

research question. Prior to presenting the thematic analysis approach adopted in this study, some data transcription issues are discussed, as is the strategy used to formulate the data analysis approach.

### **Transcription issues**

Before formal analysis of interview data can commence, interview recordings must be transcribed. This process of transforming oral interview data into a written transcript is an interpretive process. There will be variations in a transcript when the same interview is transcribed by different people, each transcriber has their own style and there can also be discrepancies due to mishearing and misinterpretation (Kvale & Brinkmann 2009). The researcher had an obligation to not only be aware of such transcription issues, but to minimise their influence in relation to the interpretation of the data.

Although the interviews took place over an extended period of time, particularly in relation to the follow-up interviews, the same transcription service was employed throughout. However the interviews were transcribed by a number of different transcribing staff employed by this service, some of whom had difficulty fully understanding the accents of some study participants. To enhance consistency and reliability, the researcher repeatedly listened to all the original recordings and compared them with the written transcripts. In doing so corrections were made as well as filling in blanks where the transcriber had inserted (unable to understand) or (recording unclear). This task was performed by the researcher to ensure a consistent approach, and as the original interviewer, the researcher was in the best position to make any necessary interpretations.



In analysing the written text, the researcher repeatedly returned to re-listen to the original recordings, heeding the following comments: ‘transcripts are impoverished, decontextualized renderings of live interview conversations’ (Kvale & Brinkmann 2009, p. 178). Frequently returning to the actual interview recordings was to see beyond the transcripts and analyse them with the words of the interviewees and the interview contexts kept in focus. Meaning is produced within language rather than being reflected by language. Written text is not an exact representation of language or thought, but it is a major unit of currency when searching for meaning. However, our critical analysis of text can only ever reveal a limited selection of the vast number of potential meanings. These are the meanings which are intelligible to the analyst or perceived to be of value by the analyst (Belsey 2002).

Having addressed matters of transcription reliability and validity, it is important to make a final comment on ethical issues relating to transcription. As described earlier, the professional transcription service employed gave assurances of confidentiality and all copies of interview recordings and transcripts were either destroyed or returned to the researcher, this applied to both the original interviews and to the follow-up interviews. Copies of the recordings have continued to be kept in secured storage within the University’s School of Nursing, and no unauthorised access to them has been permitted.

### **Formulating a strategy**

Analysis is the process of moving from collected data to an overall account of what is found from this process. The stages of describing, classifying and connecting lead us from one to the other. However, this process of analysis is not really sequential, rather 'analysis is iterative and is better represented by a spiral than a straight line' (Dey 1993, p. 53). The analysis process involves the researcher developing an intimate knowledge of the data they have collected, this is commonly referred to as becoming immersed in the data. While this is an ongoing process, 'an extended period of immersion occurs at the conclusion of data collection' (Streubert 2011b, p. 46). Following the initial interviews for this study there was a period of some twelve months of intimate association and immersion with the data by the researcher. Then at a later stage, when a number of follow-up interviews were conducted, all the data were revisited and reappraised in the context of data from the follow-up interviews.

Many different approaches can be taken in analysing qualitative data. In their study and discussion of qualitative data analysis techniques, Leech and Onwuegbuzie (2008) identified and presented 18 qualitative data analysis techniques. These techniques ranged from the more traditional techniques such as: constant comparison analysis (Glaser & Strauss 1967); domain, taxonomic, and componential analysis (Spradley 1979), to more contemporary techniques such as: secondary data analysis (Heaton 2004); text mining (Powis & Cairns 2003), these are just some of the available techniques (Leech & Onwuegbuzie 2008).

Data can come in many forms, and for the purposes of analysis, it has generally been reduced to written text format. Taped interviews must be transcribed for analysis, even though these transcripts cannot fully capture the interviewee – interviewer interaction or the context of that interaction. To become intimate with the collected data, the researcher must, obviously, read the data. As we read the data we need to be annotating at the same time. This is essential because we ‘need to record our observations and ideas about the data in order to prepare the ground for further analysis’ (Dey 1993, p. 88). A key concept here is that the process of analysis should be systematic, suggesting the need for a strategy of some nature. To analyse data it must be classified in some way as this ‘lays the conceptual foundations upon which interpretation and explanation are based’ (Dey 1993, p. 40).

Clearly a systematic data analysis strategy was essential if the aim of the study was to be achieved and the merit of the conclusions demonstrated. An open, consistent and systematic approach to data analysis was essential to demonstrate the rigor or trustworthiness of the process and of the findings. In analysing the data it is important that the interviewer should not impose any preconceived interpretations on what the interviewee has said but rather ‘identify the ways in which participants themselves actively construct and employ categories in their talk’ (Wood & Kroger 2000, p. 29). Discovering these categories was an essential component of data analysis. However, when creating these categories, the researcher was acutely aware of the need to keep in mind that categories ‘should not be imposed upon the data arbitrarily; the categories adopted should reflect the data’ (Dey 1993, p. 98).

### **Thematic Analysis**

The approach chosen to organise and analyse the textual data collected in the course of this study was informed by the previously discussed philosophical and theoretical positioning of the study, along with the original aim and objectives of the study. The approach needed to be able to not only describe the data, but also provide a mechanism for interpreting and understanding the data. The general approach of constant comparison analysis, developed by Glaser and Strauss (1967) as a strategy to be used in their grounded theory approach, provided the basis for the data analysis approach. Thematic analysis is one of a number of methods that utilise the constant comparison approach to ‘develop ways of understanding human phenomena within the context in which they are experienced’ (Thorne 2000, p. 69). This led to the decision that conducting a thematic analysis would be an appropriate mechanism for exploring and interpreting the textual data arising from the interviews conducted with participants in this study.

When analysing data, the approach of many qualitative researchers is to group similar data into clusters, these are commonly referred to as themes. Themes are ‘structural meaning units of data ... themes emerge from the data; they are not superimposed on them’ (Streubert 2011b, p. 46). Thematic analysis is a method used to identify patterns, concepts or themes in the text of data being analysed. A systematic analysis of the data is undertaken to divide data into labelled components commonly referred to as codes (Braun & Clarke 2006; Richardson-Tench et al. 2011; Schneider et al. 2007). Like codes are then tentatively linked which results in connected ideas and

concepts being brought together into groups or categories. These groups or categories are then further grouped and reduced as far as possible by the researcher while maintaining the meaning of each group or category.

The end result of this analysis and grouping process are the explicit and implicit themes found in the data. The researcher discovers what they perceive as the themes emerging from the data, and gives these themes names or labels. These names or labels are often in the form of short statements which highlight the beliefs and perceptions of the people and the culture being studied. Themes help us to form a deep ‘understanding of a person, persons, or culture’ (McMurray, Pace & Scott 2004, p. 252). Thematic analysis offers great flexibility and although it is often used as a tool in various methodological approaches, such as grounded theory, thematic analysis ‘should be considered a method in its own right’ (Braun & Clarke 2006, p. 78).

### **Developing a Data Analysis Approach**

There is no set formula for undertaking a thematic analysis (Braun & Clarke 2006; Ryan & Bernard 2003; Taylor, Kermode & Roberts 2007), thus necessitating the development of a systematic approach to data analysis guided by a number of different theorists. The approach taken in this study involved exploring data using a process of content thematic analysis. The process of content thematic analysis involves searching for themes across the entire data set, across all the interview transcripts, based on the content of what participants said (Simons, Lathlean & Squire 2008). It is necessary to

make this distinction as other forms of thematic analysis exist, including other forms of content analysis.

In conducting a thematic analysis of qualitative data, themes and categories can be developed inductively or deductively. An inductive approach involves developing themes gradually from the data as analysis proceeds, whereas in a deductive approach themes are developed at the beginning or early in the analysis (Pope, Ziebland & Mays 2000). The approach adopted in this study was inductive, it involved a five step strategy designed to guide data analysis so as to reveal themes and categories in the data in a rigorous manner. The first step was to develop a deep familiarisation with the data, a deep immersion in the data. Next, initial codes of key concepts in the data were generated. This was followed by a process of searching for and identifying themes. In the fourth step, the themes were reviewed, refined and mapped to reflect the data. Finally, the explicit themes found in the data were defined, named and their story articulated. This five step strategy was developed from and informed by the work of: Braun and Clarke (2006); Taylor, Kermode and Roberts (2007); Pope, Ziebland and Mays (2000); Rose and Webb (1998). Based around this approach and strategy, a multilevel analysis approach was developed. Developing, employing and articulating the approach has assisted in demonstrating the trustworthiness and confirmability of the process.

### **A multi-level approach to data analysis**

A multilevel data analysis approach was adopted. Assigning levels to the strategy provided structure and enabled analysis to proceed in a systematic manner (Rose & Webb 1998). This was an evolving process that progressed

through as many levels as was necessary, ultimately analysis progressed through five levels. Figure 2 (see page 117) is a diagrammatic representation showing the connection between the five step strategy described above, and the five levels of analysis which were required in the study. The five levels will now be described in detail.

### **Data Analysis – Level 1**

1. Beginning the process of self-immersion in the data, repeated reading and re-reading of the texts
2. Verifying the transcripts:
  - checking for accuracy in content and expression

Although the interview recordings were transcribed by a professional transcribing service, there were some errors and omissions in the transcripts. The first formal step of analysis was to verify that the transcripts were true representations of the interview recordings. This involved repeatedly replaying the interview recordings, checking them against the transcripts, and correcting mistakes and omissions, which resulted in the final, corrected, transcripts being faithful and true accounts of the original recordings.

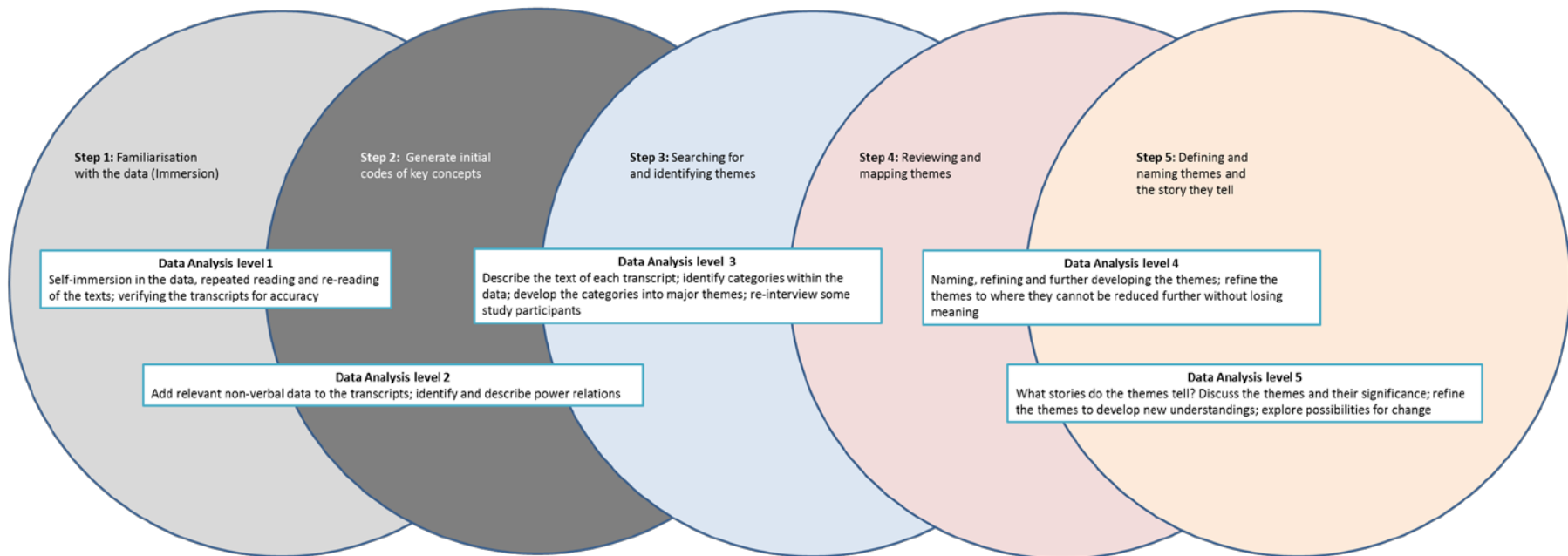
This stage of data analysis and immersion in the data was the beginning process of identifying categories within the data, and developing awareness of what was omitted from the data. It was essential to develop such a systematic approach to classification and analysis of data. This approach 'lays the conceptual foundations upon which interpretation and explanation are based' (Dey 1993, p. 40). This Level 1 of data analysis encompassed the beginnings of steps 1 and 2 of the thematic analysis strategy described above.

## **Data Analysis – Level 2**

1. Add relevant non-verbal data to the transcripts
  - the person
  - the context
2. Identify and describe power relations between the interviewer and the interviewees

Level 2 of data analysis continued steps 1 and 2 of the thematic analysis strategy. All study participants were assigned pseudonyms which were added to the transcripts. Relevant, but non-identifying, data about each participant was appended to each transcript. Included were details of participants: age range; year of study in the undergraduate nursing program; gender; country of citizenship; duration of interview. Notes taken during and immediately after interviews were added to each transcript. These notes related to the context of each interview, interactions between interviewer and interviewee, and any other information that might be significant or relevant to the data. In addition to the notes taken during and immediately after the interviews, copious notes and annotations on the transcripts were made during the first two levels of data analysis. These aided in the construction of a “map” of the data, linking like categories of data and concepts together.





**Figure 2:** Diagrammatic representation of the five step/five level data analysis process

This information formed an important part of the data analysis process as it helped to position and contextualise the interview, interviewer and interviewee. An important aspect of this contextualisation was to identify and describe the power relations between the study participants and the researcher. Notes of the significance of these power issues were added to each interview transcript with the intention of maintaining an awareness of how they might have influenced the interviewee. In addition, maintaining an awareness of power issues assisted in striving for impartiality when categorising data and identifying themes during the subsequent levels of analysis.

### **Data Analysis – Level 3**

1. Describe the text of each transcript
  - what structure does the text have
  - how can the data be categorised
  - what is being said on the surface
  - look for what is below the surface
2. Identify categories within the data
3. Develop the categories into major themes
4. Re-interview some of the original study participants and bring that data into the analysis

During the first 2 levels of analysis a deep familiarity with the data was developed and patterns and categories started to emerge. In the Level 3 phase, this started to become more formalised as categories were assigned codes and tentatively connected to each other. Although this process was undertaken

manually, using a number coding system, it was computer assisted for the storage of codes and categories. Codes were linked together and from them, categories and themes started to develop from the data. Working through all the transcripts systematically, equal attention was paid to each component of the data and assigned one or more codes to each (Braun & Clarke 2006). In the five step thematic analysis strategy being followed, this Level 3 of analysis involved a shifting of emphasis from steps 1 and 2, to step 3, the identification of themes.

During this process a conscious effort was made to ensure the categories were developed from the data, rather than the data made to fit the developing categories. As Simons et al (2008) pointed out, how the researcher categorises the data is influenced by many factors. In this case, the researcher's personal values, experience and cultural background, along with knowledge of the literature, all had the potential to contribute to how the data was categorised. Maintaining an awareness of these influences helped to maintain researcher objectivity and ensured the categories and themes stemmed from the data.

As this level of analysis progressed, it became apparent that it would strengthen the research process and enriched the findings if some participants were re-interviewed. Specifically, follow-up interviews would help to meet the research objective of examining the influence living and studying in Australia had on students' perceptions. During the initial interviews with

study participants, many of the international students were reticent to disclose their own thoughts and personal opinions in relation to the topics discussed. There were a range of social and cultural influences behind this reticence by the international nursing students, these issues are made clearer from the participants own words as they are presented in the following chapters. While these issues combined to considerably delay the research project, it was perceived there would be value in observing if this reticence had changed in the period of time that had elapsed since the original interviews.

The follow-up interviews took place approximately two years after the original interviews and therefore the students had that additional time of being exposed to the Australian socio-cultural contexts. Attempts were made to contact all of the former international nursing student participants and invite them to be re-interviewed. Unfortunately it was only possible to establish contact with eight of them as the contact details for the others were no longer valid. One of these participants declined to be re-interviewed stating they had nothing to add to their original comments, another was busy and unable to find the time to be interviewed again. This left six of the original participants to be re-interviewed.

The follow-up interviews were conducted under the same circumstances as the original interviews, and this data was integrated into the following findings chapters. At the time of the follow-up interviews, all the participants who were re-interviewed were no longer students. They had all successfully

graduated from the Bachelor of Nursing program although they were not all working as Registered Nurses. Some were still struggling to meet the English language requirements for registration with the Australian Health Practitioner Regulation Agency, such registration being a legal requirement to practice as a Registered Nurse in Australia.

#### **Data Analysis – Level 4**

1. Naming, refining and further developing the themes across all the texts based on the deeper understanding developed from previous levels of analysis
2. Refine the themes to a point where they cannot be reduced further without losing meaning

As analysis moved from step 3 into steps 4 and 5 of the thematic analysis strategy, the themes started to solidify. A combination of explicit and implicit themes had been identified, mapped and brought together. This was very much a reflective phase of the process. It occupied considerable time as categories of data did not always neatly merge into themes; there was an overlapping and shifting of categories from one theme to another. Common themes were merged and named, in some cases sub-themes were identified and also assigned names. This level of analysis was revisited on a number of occasions until the themes and sub-themes accurately reflected and flowed from the data, and came together ‘to its steady state’ (Richardson-Tench et al. 2011, p. 181).

### **Data Analysis – Level 5**

1. The interpretive part of the process, what stories do the themes tell
2. Development of the following chapters which present and discuss the themes and their significance
3. Refine the themes to develop new understandings and explore possibilities for change

At some point the researcher must decide that the data analysis process must be brought to completion and the findings from the analysis interpreted and presented. Although analysis and interpretation tend to be iterative and overlap a great deal (Richardson-Tench et al. 2011), they are distinct phases in a research project. Once the identified themes could not be reduced further without losing meaning, the reporting phase of the project began in earnest.

### **Presenting and Interpreting the Findings from Analysis**

In analysing the participant interview data, making sense of the multitude of disparate views and perceptions presented a considerable challenge. Further reading of the interview transcripts and further listening to the interview recordings could have revealed alternative perspectives on the themes already identified. Inevitably a halt had to be called to the process of analysis. The data and interpretations from analysis of data need to be presented in an ordered manner, and the aim and objectives of the research study realised.

The approach adopted was to consider several conceptual themes that arose from analysis of data. These themes were a way of interpreting the text to explore and develop insights, understandings and meanings. Although they

were by no means exhaustive, they do however present one version of truth and meaning to the data collected from the nursing student participants. As data analysis progressed through levels 1 to 4, data were contextualised and interpreted around three major themes which, in turn, were constructed of seven sub-themes. The three major themes, and their associated sub-themes, are presented in the following three chapters. Table 2 below provides an overview of the three findings chapters, along with the themes and sub-themes presented in them.

| <b>Findings Chapters</b>              | <b>Major Themes</b> | <b>Sub-themes</b>   |
|---------------------------------------|---------------------|---|
| Chapter 5:<br>First Findings Chapter  | Blame               | <ul style="list-style-type: none"> <li>▪ Responsibility<br/>Sub headings: <ul style="list-style-type: none"> <li>○ Being responsible</li> <li>○ Taking responsibility</li> </ul> </li> <li>▪ Fear of catching HIV<br/>Sub headings: <ul style="list-style-type: none"> <li>○ Characterisations of PLWA</li> <li>○ Cultural taboos</li> </ul> </li> <li>▪ Myths and misconceptions<br/>Sub headings: <ul style="list-style-type: none"> <li>○ Cultural context</li> <li>○ Knowledge</li> </ul> </li> </ul> |
| Chapter 6:<br>Second Findings Chapter | Othering            | <ul style="list-style-type: none"> <li>▪ Homosexuality &amp; drug use<br/>Sub headings <ul style="list-style-type: none"> <li>○ Homosexuality</li> <li>○ Illicit drug use</li> </ul> </li> <li>▪ Power and influence of authority</li> </ul>  |
| Chapter 7:<br>Third Findings Chapter  | Values              | <ul style="list-style-type: none"> <li>▪ Disparity</li> <li>▪ Professional values</li> </ul>  |

**Table 2 – Findings chapters: themes and sub-themes**

The systematic approach to data analysis described above determined how the major themes were constructed from sub-themes and how they have been presented in Chapters 5, 6 and 7. However, there was a degree of arbitrariness

and subjectivity involved in this process as the sub-themes cross boundaries between each other and between major themes. The words of participants can often “fit” in a number of themes and sub-themes simultaneously. Ultimately, it has been the researcher who has had to make decisions as to how the data has been presented. In doing so, every attempt has been made to ensure the data presented is representative and presented without bias (Ryan - Nicholls & Will 2009; Tobin & Begley 2004). Reducing the risk of researcher bias was assisted by critical and impartial feedback from the researcher’s PhD supervisors. This helped to maintain researcher objectivity throughout the research project.

### ***Chapter Summary***

Posited in the interpretive paradigm and based on the foundations of social constructionism, the study has been structured around the concept of stigma and utilises aspects of stigma theory. The methodological approach adopted by the researcher was a qualitative descriptive approach, informed by social constructionism. Before arriving at this choice of methodology a number of alternatives were considered and found to be less suitable to achieving the aim of the study considering the context of both the data and the study. How the study met the challenges of establishing rigor has been illustrated. Ethical issues were highlighted, protecting the rights and welfare of the participants was paramount throughout the study. Addressing each of the above issues has formed the basis for establishing the trustworthiness and ethical integrity of this study.



Issues of method, including an overview of how volunteers for the study were recruited and how data was collected, have been presented in this chapter.

The mechanism for collecting data from study participants was through semi-structured interviews. The benefits of returning to some of the participants after a considerable period of time and reinterviewing them were discussed. It was essential to have a systematic approach to data analysis. A multi-level approach was developed which then continued to evolve as analysis progressed. This detailed analysis of the interview texts revealed three major themes and seven sub-themes in relation to the study issues. These themes, the findings of the study, are presented in the following three chapters.

## **Chapter 5 – First Findings Chapter: Blame**

### ***Introduction***

This chapter presents data from the nursing student interviews which led to the development of the major theme of Blame. Assigning blame to people for having HIV/AIDS, showing avoidance behaviour towards them, and/or wanting to punish people for having HIV/AIDS, are all strong indicators of stigmatising perceptions of PLWA. Blame, how it was constructed, and the associated stigmatisation, was one of the three major themes which emerged from analysis of the nursing student interview data. As indicated in Table 2, Chapter 4, this theme consists of three sub-themes which became evident during analysis of the interview transcripts and the stories they told. These sub-themes are: Responsibility; Fear of catching HIV; Myths and misconceptions.

For many of the nursing student study participants, PLWA were responsible for their own infection and to be blamed for the spread of the disease. There was some fear of HIV/AIDS and of PLWA due to the perceived threat they represented, irrespective of the actual risk of transmitting HIV/AIDS that they posed to the students. As well as perpetuating fear, such perceptions resulted in students stigmatising PLWA by labelling and blaming them, as well as characterising PLWA as ‘bad people’. Myths and misconceptions about the disease and PLWA reinforced and perpetuated long standing stigmatising beliefs, perceptions and blame. The three sub-themes have assisted in developing a picture of how the varied and contrasting social context of each

participant has been constructed. These social contexts influenced and informed the nursing students' perceptions of PLWA, and their constructions of blame. As an aid to clarity of presentation, a number of sub-headings have been used when presenting the following sub-themes.

### ***Theme: Blame***

#### **Sub-theme: Responsibility**

There was evidence of blame and responsibility being assigned to PLWA for their own infection and the spread of HIV/AIDS, this has been manifested throughout the world and across all cultures (Brown, Hanefeld & Welsh 2009; Larsen 2008; Petros et al. 2006). While the nursing students in the study presented here represented many national and cultural groups, the overall sample was small as befitting an in-depth qualitative research approach. Such a small participant group makes it inappropriate to attempt to make direct comparisons between the participants in relation to blame and responsibility based on the data collected in this study. Rather, the data indicated that these issues were evident in all the cultural groups represented by the study sample. However, contrasts between and within the cultural groups did emerge and this becomes evident in the excerpt of student interviews presented below.

Student interview data indicated that responsibility and blame when it came to PLWA had two main foci. On the one hand, PLWA were blamed because they were held responsible for their own actions which resulted in them contracting HIV. On the other hand, PLWA were blamed for not always

taking socially acceptable responsibility for their own actions, thereby leading to the infection of others with HIV. The two foci have been used as sub-headings below to separate the discussion of two different conceptualisations of responsibility and blame. These conceptualisations helped to construct the social context of each nursing student, which in turn informed their degree of empathy and perceptions of PLWA.

### **Being Responsible**

Janet, an Australian nursing student aged in her early 20s, indicated that she understood HIV was not confined to any one group of people, and at first she did not directly assign blame to the person with HIV/AIDS. However she then went on to comment that:

*Well it's like you do wonder [how a person has contracted HIV] whether it's because of their use of drugs and that sort of stuff – at first I was thinking it doesn't really matter because it's their decision to do drugs and it's only affecting them, but then you read about the kids, that's when you realise it doesn't just affect them, it affects other people*

(Janet 6<sup>th</sup> August 2009)

The association was being made by Janet between the disease and the use of drugs, as well as “that sort of stuff”, the implication being that PLWA can be assumed to be drug users. Wondering how someone has contracted HIV, and jumping to the conclusion that drugs must be involved, is holding the person responsible for contracting HIV due to their own actions, in this case, taking

drugs. Holding the person responsible for their own HIV infection suggests the inclination to assign blame is not far away. The person is labelled and stigmatised as ‘drug user’. This label has negative connotations in most, if not all, societies throughout the world (Latkin et al. 2013; Simmonds & Coomber 2009; Wolfe, Carrieri & Shepard 2010).

As the interview with Janet progressed, she adopted a stronger tone and position on drug use. When discussing the scenario of an IV drug using woman dying of AIDS (see Appendix 10), she blamed the woman for her plight, although she was prepared to temper that blame if the woman was remorseful, there appeared to be degrees of stigma associated with drug use:

*Like you'd want to say a little bit like you're an idiot because of how it affected her children – like I'd almost want to say to her, you know, like it's your fault because of how it affected your children. But you can't change it – if she regrets it then that's different but she might be happy that happened or something, you don't really know*

(Janet 6<sup>th</sup> August 2009)

A similar characterisation of responsibility and blame was made by Susan in relation to the same scenario, although unsafe sex and prostitution, as well as drug use, were included as behaviour a person has control and responsibility over. When asked how she felt about the situation described in the scenario, Susan, in her late 20's and also an Australian student, replied:

*Well I don't know, just that, well that she's got HIV and that she's dying and that she got it because she probably had unsafe sex from prostituting and the injection of heroin – I was sort of, you know, oh that's a bit sad, but I don't know really – nothing dramatic is really passing through me, I wouldn't like to be in her shoes but maybe she might have liked what she was doing*

(Susan 24<sup>th</sup> August 2009)

Contrasting with Janet and Susan, students who had some exposure to illicit drug use, showed more empathy towards drug users and towards PLWA who had contracted the disease that way. Alice, aged around 40 years at the time of interview, demonstrated a much greater awareness that societal factors play a role in drug use. As well as being older than Janet and Susan, Alice believed that drug use was much more likely in lower socio-economic areas. She grew up in what she described as a densely populated low socio-economic area in northern England:

*It's different, while we have low socio-economic areas here [in Australia] they're not as densely populated as in the UK, because of the dense population in England, and the economic conditions – you're much more likely to find the IV drug user in the UK, I would have thought*

(Alice 10<sup>th</sup> August 2009)

When presented with the scenario of a female patient about to die from AIDS, Alice showed compassion and empathy for the woman even though she was a long time drug user:

*Obviously compassion, yeah, she's had a horrible life, she's had no life and it was taken over by drugs at such a young age, and you wonder what was the catalyst to start injecting at that age, it's very very sad – just have complete compassion for her, it's very very sad*

(Alice 10<sup>th</sup> August 2009)

Alice's age, along with her childhood and teenage experiences, appeared to lead to a more tolerant and empathetic perception of drug users, and by association, PLWA. However for most of the nursing students, individual agency was still perceived to have greater significance than societal factors when it came to the use of illicit drugs. For these students, people who contracted HIV through drug use were responsible for their own behaviour and to blame for it. In addition, there were clear contrasts in empathy among the Australian nursing students for PLWA who contracted the disease via illicit drug use.

While Janet, Susan and Alice were associating drug use with HIV, nursing students from other countries had different perceptions. When 30 year old Sang was asked how she recalled people with HIV being portrayed in the media of her native South Korea, she commented that the portrayal was very negative and people with HIV were:

*You know, the people who have very enjoyable sex life and very irresponsible people, yeah, yeah very negative image – people who is not responsible for their sexual behaviour, yeah bad people who are portrayed as people who are going somewhere to enjoy their sexual life*

(Sang 21<sup>st</sup> November 2009)

The association for Sang was between sexual activity and HIV, contrasting with Janet, Susan and Alice. Sang was blaming people who contract HIV through sexual activity for engaging in irresponsible behaviour, for not taking responsibility for their own actions, she showed little empathy towards them. According to Kim, this position was reflecting South Korean society. At the time of interview Kim was in her late 30's and had only arrived in Australia to commence her nursing studies a few months earlier:

*My culture is very – has a very negative attitude towards those people with HIV because we have some prejudice that HIV and AIDS are usually through the sexual intercourse – we are very closed minded towards those stuff*

(Kim 4<sup>th</sup> August 2009)

In this case the stigmatised behaviour was sexual intercourse, perhaps promiscuity, or sex in what Sang might consider to be an irresponsible manner. According to Sang, the majority of PLWA in South Korea contracted HIV through heterosexual sex, whereas drug use or homosexual sex as modes



of transmission hardly rated a mention. So although the behaviour Sang and Kim were assigning responsibility for differed from Janet, Susan and Alice, the resultant blame was the same.

According to Heng, there were similarities and differences in the commonly perceived and stigmatised modes of HIV transmission in his native Hong Kong to that of the South Korean context. In Heng's opinion homosexuality was the behaviour PLWA were being held responsible for:

*The drug use problem, it's getting more serious in Hong Kong yeah, but it's not commonly associated with AIDS. In Hong Kong HIV is associated with the sexual activities, especially homosexuality – yeah the stigma is really high*

(Heng 2<sup>nd</sup> November 2009)

Although drug use might not be commonly linked with AIDS in Hong Kong, homosexuality certainly was as far as Heng was concerned. This provided considerable contrast with Australia, England and South Korea as characterised by Janet, Susan, Alice, Sang and Kim. In the context of blame, homosexuality did not figure prominently during the nursing student interviews. However it did figure more prominently in the context of the fear of contracting HIV, discussed later in this chapter, and the role of homophobia in the 'othering' of PLWA is explored in Chapter 6.

In the context of blame, the perceptions of the two nursing students participating in the study who were from Africa were somewhat at variance

with their fellow students. They took exception to the characterisation of PLWA as having personal responsibility and blame for their infection. Mari took a completely different perspective on blame from that of the students discussed above, hers was an anti-blame message which showed considerable empathy with PLWA. In her late 30's, Mari was a nursing student from the African nation of Tanzania, she decried what she perceived as being a culture in Australia of blaming people for having HIV, particularly blaming them for being homosexual. Mari was surprised at the level of stigmatisation of homosexuality, and dismayed by the attitude of many local students in Australia towards homosexuality:

*The attitude of the local students it was shocking to me a little bit here [in Australia] that they blame just a group of people – homosexuals, just imagine, yeah it's terrible – because he's a homosexual and to think it was deserved, it's not a good attitude, it's sick*

(Mari 4<sup>th</sup> August 2009)

According to Mari, the major mode of HIV transmission in Tanzania was via heterosexual intercourse, whereas homosexuality and intravenous drug use were not common modes of transmission in Tanzania.

Pearl, in her early 20s, had grown up in Nigeria with the spectre of HIV/AIDS omnipresent. Since graduating, becoming a Registered Nurse, and working in an Australian hospital, Pearl had come across a small number of

patients living with HIV/AIDS. She found a culture of blame among her nursing colleagues in Australia:

*Oh there was lots of talk among the nurses. There was – people would say things like, being gay, oh he should have used protection. He shouldn't – people blaming and just being – not really being sympathetic, so they would just talk about him, I felt like he was being judged all the time – I mean as nurses we should take care of people, at least not judge them*

(Pearl 27<sup>th</sup> July 2011)

Both Mari and Pearl perceived that people who were homosexual bore the brunt of blame and responsibility for the spread of HIV in Australia. However this did not correlate with the observations made above in relation to Janet, Susan and Alice. This point will be revisited in Chapter 6 where perceptions of homosexuality are discussed further.

### **Taking Responsibility**

Strong feelings were evoked among the participants when presented with the scenario of “Paul”, a man who knew that he was HIV positive but continued to have unprotected sex with women without informing them of his HIV status. There was certainly a feeling that this person was not taking responsibility for his actions and should be held accountable. Another Australian nursing student in her late 20s, Fiona, felt very strongly about this issue:

*I'd be disturbed by that definitely – personally I think he should be prosecuted because it's almost manslaughter,*

*intent, his intent but obviously he's got some sort of mental issue going on there because he doesn't seem to think his HIV is threatening or doesn't seem to understand the implications of his HIV – I wouldn't have any empathy for Paul*

(Fiona 3<sup>rd</sup> August 2009)

Concurring with Fiona was Jiao, who was of the opinion that someone like Paul should be put in prison. Jiao, from China, was also in her late 20s and recounted a similar story which she recalled had received considerable media attention in China:

*This man, and he's a gay, and he has HIV and he knows that exactly, but he still have sex with a lot of people – there were a lot of people get infection, it's so horrible. He was put in prison but a lot of people's life was destroyed, I think he should be responsible*

(Jiao 8<sup>th</sup> October 2009)

Similar sentiments were expressed by Lee who was also from China. She recalled discussing with her friends a case reported in the Australian media of a man knowingly and recklessly passing HIV to several sexual partners. Lee and her friends thought the person should be locked up. They also questioned whether he might have a mental illness as a way of trying to explain his lack of responsibility for his actions:

*He knew he had it and just had sex anyway – you know, no condom or anything. Yeah, I remember we talked about that a bit, how selfish can someone be – we all thought he should be locked up, maybe he has some mental illness thing going in his head, maybe that would explain it*

(Lee 6<sup>th</sup> September 2011)

There was little in the way of dissent from the other participants regardless of age or social context. Lee and Yue from China were both in their early 20s, whereas Sang, from South Korea, was older, they all agreed that Paul was not a good person. Yue showed no empathy for him, saying that he should be punished, not only for his actions but also for talking about them (see Appendix 10 for scenario details):

*Yeah, even punishment for saying that, he doesn't respect nurse or other people or women – generally women I think, so yeah I will report it – he doesn't a good person*

(Yue 21<sup>st</sup> November 2009)

There was no sign of empathy from Sang either, she was so angry with Paul that she felt he deserved to die:

*That man, he doesn't have any responsibility for his disease and he's showing intention to spread his disease to other person just for fun, yes, so he deserves to die – I'm very angry against him, he's not a mature person*

(Sang 2<sup>nd</sup> November 2009)

Rachel was of a similar age to Alice and had similar experiences during her teenage years growing up in Australia. She adopted a more conciliatory tone in relation to Paul than did Fiona, Jiao, Lee, Yue or Sang. Rachel tried to find some empathy with Paul:

*It would be very hard to talk to somebody like that and to be able to give them the same amount of care as other people. I would try and have a chat with him to see where he's coming from – ask him why he doesn't like women, what has someone done to him to make him feel that way? I would hope he wasn't instantly dislikeable, you know, "Oh that bloody guy" but I would hope that wouldn't overpower my ability to talk to him*

(Rachel 30<sup>th</sup> September 2009)

**Summary – Sub-theme: Responsibility**

To summarize, drug use, homosexuality and promiscuous heterosexuality were stigmatised behaviours many of the nursing students associated with PLWA. These were behaviours that the students generally perceived people to be personally responsible for. The association between behavioural responsibility and HIV can lead to the perception of HIV being what might be described as a lifestyle disease, perceptions that potentially result in stigmatisation and victim blaming. PLWA were blamed for their own infection due to being responsible for engaging in behaviour that led to them contracting the disease. However, some of the students showed considerable

empathy for illicit drug users, with cultural background, social context and age appearing to influence the contrasting perceptions. Additionally, PLWA were also blamed if they were perceived to not be taking responsibility for their own actions and putting others at risk of infection. These perceptions did not involve drug use, rather it was reckless sexual activity that people were responsible and blamed for.

### **Sub-theme: Fear of catching HIV**

While drug use was a behaviour closely associated with responsibility and blame directed towards PLWA, the fear associated with contracting HIV extended very much to include sexual transmission. In Western nations, since HIV and AIDS were first identified, the male homosexual has been demonised and linked to contagion, they soon became seen to be 'carriers of a new plague' (Holmes & Federman 2010, p. 69). Therefore they were perceived to be dangerous, shunned by society, and blamed for the spread of HIV/AIDS. In Asian nations AIDS was commonly characterised as being a Western disease caused by perceived immoral behaviour such as drug use and homosexuality. Many Asian leaders were so confident of the morality of their society they denied HIV/AIDS posed a threat to the health of the population. According to Nepal (2007), 'Asian AIDS denial is a reflection of lamentation about the perceived deterioration of traditional moral orders and weakening hold on new generations' (Nepal 2007, p. 139).

A culture of fear and blame has continued to be perpetuated in many societies around the world, and the fear of contracting HIV influenced the perceptions

of many of the nursing student participants in the study reported here. The historical characterisation of PLWA, and traditional cultural taboos against discussing sexual matters that exists in many parts of the world, contributed to help define this fear. Hence the following two sub-headings used to explore these concepts and the contrasting social context of participants. Perceptions of PLWA are informed by a person's social context and their willingness to embrace cultural change.

### **Characterisations of PLWA**

Anne was in her early 30s at the time of interview, she was old enough to remember some of the early AIDS awareness campaigns in Australia, campaigns she described as being “crap”. Growing up in Australia, she had a clear picture of the traditional, historical perceptions society had at that time of PLWA:

*Yeah, the junky AIDS carrier, they're going to blame that person, he's a homosexual HIV or a drug addict HIV, like it's all his fault – like as if someone has committed a crime – so the grim reaper, the scare tactics and that sort of crap they put out during the 80's and 90's*

(Anne 3<sup>rd</sup> August 2009)

Anne did not subscribe to that historical perception of PLWA. Her own experiences relating to drug use and knowing people who had contracted HIV appeared to give her more tolerant perceptions:

*... had a lot of friends that were IV drug addicts ...*



(Anne 3<sup>rd</sup> August 2009)

She talked about a friend who contracted HIV through drug use becoming very unwell and dying:

*... he'd had a very difficult life and spent time in jail and that sort of thing, so he'd had it a bit rough ... but he was quite sick, yeah quite sick but then he died. After I met him it was only about two years later then he died*

(Anne 3<sup>rd</sup> August 2009)

Anne had seen HIV/AIDS lead to the death of a friend, so it was something to be feared. Yet she empathised with him and had willingly abandoned the societal perceptions of PLWA that she had grown up with.

Coming from South Korea, Kim's perceptions and characterisation of PLWA were quite different to those of Anne. While Kim had no experience with HIV/AIDS she did have a clear image in her own mind about PLWA:

*They are very sick and they are very lonely and they are quite isolated from friends, even family, and people usually pretend to not discriminate to them, but actually they discriminate to these people so they are – they usually – I'm sure that the patients or people with HIV or AIDS are very psychologically ill as well as physically ill, and living a horrible life – so I feel some – how do you say – sympathy for them*

(Kim 4<sup>th</sup> August 2009)

This was a dark picture described by Kim, one of loneliness, isolation and discrimination, certainly a horrible life to be feared. Kim discussed how HIV/AIDS was perceived by people of her generation in South Korea as a Western disease, something:

*Very far from our culture in Korea*

(Kim 4<sup>th</sup> August 2009)

So although her historical image of PLWA could be viewed as being more sympathetic than Anne's description of the "junky AIDS carrier", it was nevertheless a dark image tinged by the historical perception of HIV/AIDS being alien to South Korea. Kim continued with her dark characterisation when she described the picture she had in her mind of a woman living with AIDS:

*She's suffering from HIV I think, I can picture her as so very horrible – not horrible, just a miserable, sorrowful woman, you know, in a dark room in the hospital, she has no friends. I don't think, she doesn't like – I don't think she likes turning the light on – maybe she prefers a dark room, that's just a personal opinion*

(Kim 4<sup>th</sup> August 2009)

Unlike Kim, Jiao did not describe having an image of a PLWA although she had similar perceptions of HIV/AIDS being a foreign disease. Jiao grew up

with the perception that HIV was something that only happened elsewhere. She talked about growing up in a medium size city of 2 million people in China:

*In China I was growing up in a medium size city and all the people, especially the older generation, I mean my parents, my grandparents, they think HIV is so far from our life – it's something really unfamiliar to them – I think that most of the time the people are scared or something because they don't know, they are scared they will get the infection just because of touching hands – you know*

(Jiao 8<sup>th</sup> October 2009)

This appeared to be a common perception in China. As Jiao indicated, HIV/AIDS was something little known, yet something to be feared. The historical perception of HIV/AIDS in China meant that Ying, in her late 20s, could not conceive of knowing someone living with HIV/AIDS in China. According to Ying, only 'bad people' have AIDS, and contact with them must be avoided:

*I want to tell you, yeah, in China, you know China's a traditional country, if I know you have AIDS, yes I can't have contact with you, I never make friends with you, I think you are bad people because, you know, the main way for transmission is from the sex and also the drugs*

(Ying 25<sup>th</sup> August 2009)

The concept of PLWA being ‘bad people’ is significant and further elaborated upon in Chapter 6. There has been a history of fear relating to PLWA in China, according to Ying:

*In my country, if you heard some people have AIDS, most people scared because they nearly died. If you have AIDS you have to be sent to the special hospital – and you have to tell the government, like the police, if you know some people have HIV. Why don't you do that here [Australia] – why don't you tell some people like the police, or like have special hospitals to monitor them?*

(Ying 25<sup>th</sup> August 2009)

While for Jiao, HIV was something far away that should be feared, Ying did at least recognise the disease existed in China. For Ying it was also to be feared and presented such a perceived threat that, in her opinion, PLWA should be isolated, physically and psychologically.

In a similar way, the existence of HIV/AIDS was barely acknowledged in Japan up until recent times. According to Mieko it was only within the previous five years that there started to become any public focus on HIV, when she went to high school in the late 1980s there was:

*No education about HIV, not at all – it was not really a big issue about HIV because it like involved sex quite often so they don't want to really talk about the HIV thing – yes, so they*

*don't really mention about how to protect yourself or what is safety to contact with HIV people or HIV – they don't really mention about that*

(Mieko 13<sup>th</sup> October 2009)

There was a vast difference between the Japanese context and that of the participating nursing students from Africa. For them AIDS immediately conjured images of death and darkness, very much to be feared. Mari stressed the significance of context when a diagnosis of HIV was made, in Africa such a diagnosis was immediately viewed as a death sentence. She made the contrast between Australia and Africa in following terms:

*When you're in this part of the world [Australia] it's like if you find you have HIV, you could sort of carry on and run your life like normal – where on the other side of the world [Africa], if you find you're HIV positive, it's like somebody has just announced your death, just like that, they're die within a year, two years max maybe*

(Mari 04<sup>th</sup> August 2009)

Such perceptions persist despite more recent advances in anti-retroviral treatments which are gradually becoming available in Africa. HIV and AIDS have decimated societies throughout Africa. Multiple deaths in the extended family are commonplace, as are attempts to keep infection and death hidden from neighbours. As Pearl pointed out, in Nigeria:

*In Africa most people will hide it [being diagnosed with HIV] because there's still lots and lots of intimidation, the main problem that I've seen is that we are not really educated about accepting these people, it's really hard, it's not as good as it should be – I think it's the society*

(Pearl 10<sup>th</sup> September 2009)

### **Cultural taboos**

Historically much of Japanese society is traditional and conservative with a reluctance to acknowledge the issues of HIV/AIDS in society. This description aptly described Mieko's parents who would never have considered talking about sexual matters with their children. Consequently anything to do with HIV/AIDS was also taboo and became something of an unknown and feared entity. Mieko felt that her mother would have liked to ask her daughter to protect herself from HIV but tradition and culture prevented her from doing so:

*My parents are really conservative parents and quite traditional parents they don't really talk about sexual things. I think my mother wanted ask me to protect myself – even though she was thinking that, she never mentioned it*

(Mieko 23<sup>rd</sup> August 2011)

Mieko was describing what she perceived to be a conflict on the part of her parents between discussing traditionally taboo subjects in Japan, and the fear

of their daughter contracting HIV. For her parents, tradition and culture were more powerful than their fears. Living in Australia for a number of years had influenced Mieko's perceptions, and she indicated a willingness to change in response to her changing social context. She expressed a determination to be different from her parents and openly discuss sex, drugs and other previously unmentionable topics with her own children:

*Yes, absolutely, I think in my age we are more free to talk with children about many things, like my parents didn't do in the old times – I discussed with my friends and they think they want to discuss with their children about sexual disease or any kind of conversation which we used to avoid*

(Mieko 13<sup>th</sup> October 2009)

*The younger people they are trying to like be more aware about HIV – more than middle aged or older aged people, yes – maybe because they have education overseas*

(Mieko 23<sup>rd</sup> August 2011)

The traditional cultural taboos against parents discussing sexual and related matters that Mieko experienced as she grew up in Japan were mirrored in the experiences of students from China and South Korea. As Fan, a nursing student in her early 20's from China commented in relation to sex and HIV:

*Actually my parents would never discuss with me, because of different culture in China, like different generation, different*

*education, different opinion – we don't learn much about this disease at home*

(Fan 4<sup>th</sup> August 2009)

Kim was surprised to be asked if her parents in South Korea had ever discussed HIV with her, the very thought of this occurring made her laugh as she answered:

*No – never, this is very far from our culture*

(Kim 4<sup>th</sup> August 2009)

The similarity in family cultural taboos between South Korea, China, and Japan did not extend to society at large. Whereas public discussion of HIV/AIDS was slow to happen in Japan and South Korea, in China the mass media was the main source of HIV/AIDS information for people:

*From my parents no, and from high school no I don't think so but we've got lots of information about HIV and how it is transmitted, how do we take some precautions, out of the mass media, like TV, newspaper*

(Fan 4<sup>th</sup> August 2009)

While Mieko indicated a willingness to change her perceptions from those dictated by Japanese culture, she did so in the context of having lived in Australia for two and a half years at the time of interview. Her social context had changed over that time influencing her perceptions. In contrast, Fan and Kim had only been in Australia for a short time and they were struggling to



comprehend different cultural perspectives. Their social context had barely had chance to change so there was no indication as to their willingness to embrace different perspectives.

However this was not the case with Ying who was in stark contrast to Mieko with regards to willingness to change. Ying was determined to maintain the cultural beliefs and practices she had grown up with even though she had become familiar with, and was living in a different social and cultural context. During a follow-up interview with Ying, two years after the original interview, she was quite adamant that her views would not change even though she had been in Australia for two and a half years by then. Ying adopted a strong position, PLWA were still to be feared and blamed:

*The culture is already in my mind, I still have the same idea and discrimination as in China – if I know somebody has HIV I think I should deliberately just keep away from them. No I will not change, because you know why I will not change, once the person has HIV or AIDS he or she must have some behaviour badly – like intravenous drug use or like the prostitution – that's the problem, cause of HIV*

(Ying 25<sup>th</sup> August 2011)

As Alice was in her early 40's, she grew up in an era where similar taboos still existed in most Western nations to those discussed above in China, South

Korea and Japan. When asked if her parents talked about sex or warned her about the dangers of HIV, she replied:

*Oh God no – what I learnt about AIDS I learnt through the media not through any formal education or from my parents. So no, sex wasn't a thing you ever talked about at home – you got pregnant from kissing someone according to my Mum!*

(Alice 10<sup>th</sup> August 2009)

Rachel had similar experiences to Alice during her teenage years but willingly adopted a different stance to that of her parents. At the time of interview she had teenage children of her own and encouraged family discussion of sexual issues and the dangers of HIV.

*Absolutely, yeah, yeah, not just specifically about AIDS but what you can get if you have unprotected sex, or if you share needles, or – so, yeah*

(Rachel 30<sup>th</sup> September 2009)

This generational change had generally occurred earlier in Western nations compared with many Asian nations where the historical taboos were still strong. Nevertheless, there was a common fear of HIV/AIDS along with continued stigmatisation and blame of PLWA.

**Summary – Sub-theme: Fear of catching HIV**

The nursing students had clear perceptions of who they believed PLWA were, and some had vivid images of how they perceived them to be. These perceptions and images were largely based on the stereotypical characterisations of PLWA that they grew up with. Such images stigmatised and labelled PLWA, as well as generating fear of the disease disproportionate to the risks of contracting it. Compounding these perceptions were strong cultural taboos against discussing sexual issues and behaviours. Historically, in much of the world, there were cultural taboos against parents discussing sexual matters with their children. Such taboos can inhibit HIV/AIDS awareness and education, as well as perpetuating the ignorance, fear and stigma associated with the disease.

This situation has changed somewhat in many Western societies with parents encouraged to discuss sexual matters with their children and sex education commonplace in schools. Whether this has changed perceptions of fear of HIV/AIDS and blame of PLWA is questionable. Changing the historical taboos in Asian nations is taking place more slowly than in the West.

Although rates of infection are increasing, many people still see HIV as a Western disease, nevertheless change is occurring both at an individual level and a societal level. However, not all study participants were willingly embracing cultural change. The individual social context of each nursing student influenced that willingness and also their perceptions and fear of PLWA.

### **Sub-theme: Myths and misconceptions**

With the ever increasing number of people infected with HIV/AIDS throughout the world, nurses and nursing students must have a good knowledge of the disease and its treatment. Poor knowledge, misconceptions and myths about HIV/AIDS and PLWA can lead to unnecessary fear and stigma. An example of one of the more extreme misconceptions and myths surrounding HIV/AIDS found in various disparate parts of the world, are so called virgin cleansing rituals (Richter 2003; Zeelen et al. 2010). This is the belief that HIV/AIDS can be cured through intercourse with a virgin. In parts of Africa there are 'sex cleansing rituals' perpetuated on widows of men who have died of AIDS. Some believe that having sex with a village cleanser will rid the widow of any sexually transmitted disease and make them fit to be remarried (Kastenbaum 2009; Mwanga et al. 2011). Such practices are inherently assigning blame and stigmatising the victim.

While there is no suggestion that any of the nursing students in the current study gave such myths any credence, growing up in a country where extreme and bizarre beliefs and practices existed has the potential to influence perceptions, either positively or negatively. Pearl and Mari, from Nigeria and Tanzania, were brought up in societies where some of these beliefs and practices existed. Consequently making them all the more determined to try and achieve change and justice for PLWA in Africa, particularly for women and children. All the study participants had grown up in societies where myths and misconceptions in relation to HIV/AIDS were widespread,

although not as extreme as those experienced by the African nursing students. The cultural background, experience and knowledge of each participant formed the basis for their social context as nursing students in Australia, and shaped their perceptions of PLWA. Cultural context and knowledge are used as sub-headings below to better understand the nursing students' social contexts. Social context is also contrasted with tolerance towards others who have differing or, what some might perceive, less socially acceptable lifestyles.

### **Cultural context**

In many nations the submissive role of women is a deep rooted cultural practice, women 'belong' to their fathers when unmarried and then 'belong' to their husbands when married (Mbonu, Van den Borne & De Vries 2010; Mwanga et al. 2011; Owen 2002). One such nation is Nigeria and this subservience was evident when Pearl described how she was expected to greet her parents, and particularly her father:

*It was really different, the cultures, the way it is in Australia, like the way we relate to our parents, the way we were brought up it's really different – like different respect and things like that, so, yeah, in the morning I have to be on my knees when I greet my parents, it's really strict and you have to respect people that are older than you, things like that, so yeah that was the sort of upbringing that I had*

(Pearl 10<sup>th</sup> September 2009)

Both Pearl and Mari showed great compassion for a woman who was drug addicted and dying from AIDS as portrayed in one of the scenarios presented to them. Both students were influenced by the social status of women in Africa and the way they had seen society treat women living with HIV/AIDS in Africa. As Sandelowski and colleagues (2004) described it, women infected with HIV have to live with the ‘fear and the hurtful effects of stigmatisation, including social rejection, discrimination, and even violence, in relations with children, partners, relatives, friends and acquaintances, employers and co-workers, and health care providers’ (Sandelowski, Lambe & Barroso 2004, p. 124). Mari demonstrated her tolerance and empathy as she concurred with these views regardless of how the woman had contracted HIV:

*I really sympathize with her about she had a problem with drugs and she got AIDS ... I think especially for them [women] it's quite difficult because you lose your friends, the society, the way they look at you – most of them, they have few people who are with them, I think they just need those professional nurses to be there for them, be there for them the whole way*

(Mari 4<sup>th</sup> August 2009)

Widow abuse and the denial of basic human rights has not been confined to Africa, similar widespread abuse has been reported from Asia, the Americas

and Europe (de Souza 2010; Groce & Trasi 2004; Kastenbaum 2009). While these myths and practices are extreme, they highlight the exclusion practices perpetuated on PLWA. At the other end of the spectrum, myths such as smoking being a risk factor for acquiring HIV somewhat pale in comparison. Nevertheless, even these more trivial myths and misconception, highlighted in chapter 2, serve to exclude PLWA and emphasise their ‘otherness’. For example, Fan demonstrated irrational fears when asked how she would respond if her patient with AIDS asked her to hold her hand:

*It's kind of dilemma, I really try to help her, but I feel uncomfortable, maybe I try to wear gloves and hold her hand, but if I wear gloves it's not respectful to her, so it's really hard – I would probably say no to hold her hand, it's like my psychological fear, to be with her or sit with her is OK, but no to hold her hand*

(Fan 04<sup>th</sup> August 2009)

Deng and Lee shared Fan's reluctance to hold the patient's hand but were not quit as fearful as Fan. Deng was a little tentative but after some consideration he concluded:

*Hold her – yeah I think it's okay, hold hands, I think I can fulfil this desire, this request*

(Deng 12<sup>th</sup> October 2009)

Initially Lee indicated no hesitation at all about holding hands with the patient but said so in the context of declaring she was not afraid of dying.

Later Lee described how she had irrational fears and wanted to keep washing her hands after touching someone living with HIV/AIDS. It was Lee who made this association between holding hands and death:

*I don't mind because I don't afraid to die, like that's fine, I think it should be fine for me ...*

(Lee 2<sup>nd</sup> October 2009)

*... even like HIV I know is like transferred from blood and, like when you have sex, but when you shower them or ... I always think it's dangerous, I don't know why I think I'll get sick, I keep washing my hands after I touched the patient – kept washing my hands, yeah, I don't know*

(Lee 2<sup>nd</sup> October 2009)

Fan, Deng and Lee were all of a similar age and shared similar cultural backgrounds, although there were differences in their social contexts. Fan was from a more traditional region in central China whereas Deng and Lee were from quite Westernised cities on the East coast of China. Lee also had strong religious convictions, hence her not fearing death. Nevertheless, they all struggled to overcome their fears of touching PLWA.

There appeared to be less in the way of irrational fear among the Australian nursing students, possibly reflecting a culture where greater understanding and tolerance for homosexuality and drug use had become more socially acceptable. Melanie certainly indicated her understanding and tolerance



towards drug use. When discussing the scenario of a patient living with AIDS contracted via IV drug use and who was on the verge of death, Melanie commented:

*I felt sorry for her, so, I mean people start taking drugs for any number of reasons you know*

(Melanie 10<sup>th</sup> September 2009)

Melanie was in her late 20s and had no qualms about holding the hand of the patient to comfort her as death approached. Neither did Sandra who was also an Australian student of a similar age and social context:

*Yeah, sure, that's fine – I'm not concerned about catching HIV from holding her hand*

(Sandra 3<sup>rd</sup> September 2009)

### **Knowledge**

The complex link between knowledge, culture and social context was highlighted by Mieko. Prior to studying in Australia she had little understanding of homosexuality, indicating that she had relied on second hand knowledge about homosexuality in the past. Later, she became more knowledgeable as she discovered Australian society was more open towards homosexuality than Japanese society:

*I talked with my friends sometimes because one of my friend's friends was a gay ... here in Australia it's much more open than in Japan*

(Mieko 13<sup>th</sup> October 2009)

After living in Australia for several more years, and as Mieko became more accepting and more knowledgeable about homosexuality, she relied less on gossip and myths. However, this was said in the context of Mieko living in Australia, she admitted that if she were to return to live in Japan her perspectives might need to change again:

*Japan is very conservative, but my perspective has changed since living in Australia ... the gay is not some weird thing anymore ... if I'm in Australia I have a different feeling but if I go back to Japan maybe I'm – my perception goes back to my Japanese way. So if I was in Japan maybe I will still said I don't like gay people as well, but here in Australia I am happy to say it's okay, and for them to get married in the future*

(Mieko 23<sup>rd</sup> August 2011)

Mieko could see the contradictions in what she was saying but she felt she would not be strong enough to oppose the dominant culture if she were in Japan. Similarly, several of the Chinese participants showed a lack of understanding and knowledge concerning homosexuality. When knowledge is lacking there is always a risk of intolerance, and where myths or misconceptions might become accepted as fact. As indicated earlier, Ying was not open to changing her perceptions, even though her social context had changed. This contrasted with Mieko who was prepared to adopt a more tolerant and understanding stance, at least when she was in Australia. Jiao

knew little about homosexuality prior to coming to study in Australia, however she had more exposure to homosexuality since studying in Australia:

*I don't know why but since I am here, I heard a lot of stories about the homosexual gay and lesbians, about that, and now some of my friends are gay – yeah, I can understand them, but not completely, yeah*

(Jiao 8<sup>th</sup> October 2009)

There was little evidence of overt homophobia during Jiao's interview, just a lack of knowledge and a willingness to listen to stories and gossip in relation to homosexuality, which contributed to her existing misconceptions. Her compatriot, Yue, also indicated that her knowledge of homosexuality came from gossip. When discussing homosexual men being at a higher risk group for contracting HIV than homosexual women, Yue had not considered that this might be due, in part, to the practice of anal intercourse among some homosexual men. Although Yue had lived in Australia for five years at the time of a follow-up interview with her, she was still of the opinion that:

*The reason why the male homosexual are more like, tend to get AIDS rather than the female homosexual is because the male, the relationship is quite unstable, so they have to change [partner] every day or so, they don't have stable relationships.*

(Yue 3<sup>rd</sup> October 2011)

There was no apparent basis for Yue's perceptions other than these were long standing misconceptions that she believed in and showed little inclination to consider the validity of them. This indicated a lack of tolerance to new or differing perceptions (Scully 2012; Warriner, Nagoshi & Nagoshi 2013), thereby informing her perceptions of homosexuality. Such negative perceptions of people who are homosexual tend to heighten the stigmatisation and blame afforded PLWA.

Some participants demonstrated misconceptions and a lack of knowledge in relation to illicit drug use, particularly such use in Australia. Fan had gained the impression that illicit drug use was so widespread in Australia perhaps there were no laws against it. In relation to a woman who was addicted to heroin, Fan also asked the following question:

*Okay so if she went to hospital and said, oh I feel uncomfortable I need treatment – can the doctor order some heroin for her?*

(Fan 4<sup>th</sup> August 2009)

This was quite a reasonable question as some countries do allow doctors to prescribe heroin in certain circumstances, however the question did show an absence of understanding concerning the law in Australia where no legal use of heroin is permitted. Fan further showed her lack of knowledge in relation to illicit drugs when she asked about heroin:

*Oh, is this drug addictive, is it like morphine addictive? ...*

*I just wonder if it is legal to have to take this drug – to take  
drugs like this in Australia?*

(Fan 4<sup>th</sup> August 2009)

A low level of accurate knowledge about significant social issues, such as illicit drug use, creates an environment where myths and misconceptions can flourish. In this context lack of understanding and lack of tolerance can enhance perceptions of blame directed towards PLWA due to their association with homosexuality and drug use.

The greater knowledge and tolerance by Sandra and Melanie of drug use has already been observed, and this was, at least in part, a product of the cultural context they grew up in. Rachel and Alice were older and grew up in a slightly different cultural context. Rachel talked openly about her lack of knowledge about HIV during her teenage years and some of the popular beliefs among her peers at that time. She remembered not having any clear idea about the meaning of the acronym HIV, and with regards to the transmission of HIV:

*Not very knowledgeable, actually I remember when it first sort  
of hit the news – but of course there was the, you know, oh  
well, they got it from monkeys, you know people rooting  
monkeys and things, you know, like it's a gay disease and that  
sort of thing is what I remember first off and seeing in the*

*media, and of course kids pick up on that and add their own lovely bits to it, don't they!*

(rooting is Australian vernacular for having sexual intercourse)

(Rachel 30<sup>th</sup> September 2009)

Similarly, Alice admitted that she had long held misconceptions of which she had only recently become aware of, she commented:

*I suppose the only knowledge I got [about HIV/AIDS] I'd gained through the media like most people, I definitely had some wrong ideas – I didn't realise that HIV positive women could have children and things like that, so yeah, my knowledge was exceptionally limited*

(Alice 10<sup>th</sup> August 2009)

Rachel and Alice grew up listening to myths such as people contracting HIV from monkeys. When they were younger they were quite open to such ideas and had a lack of tolerance in their perceptions of PLWA. They were the two oldest study participants and with maturity, increased knowledge and experience, they became far more tolerant in their perceptions of PLWA. However, not all the Australian students were as tolerant. As discussed earlier in this chapter, Janet and Susan both perceived PLWA as being responsible and to blame for their own infection.

Despite the widespread myths and misconceptions about HIV/AIDS in Africa referred to earlier, Mari and Pearl both indicated they had good knowledge of the disease. The tolerance and empathy for PLWA that these two nursing students from Africa demonstrated was not clouded by any perceptions they had about homosexuality and drug use. Homosexual sex and drug use were not commonly associated with HIV/AIDS transmission in Africa according to Pearl:

*I think it's mostly heterosexual, yeah mostly heterosexual because there's really no, there's homosexuals as well but it's really, really a minority, but mostly what I know of is heterosexual people*

(Pearl 10<sup>th</sup> September 2009)

**Summary – Sub-theme: Myths and misconceptions**

Many of the nursing students in this study grew up surrounded by myths and misconceptions about HIV/AIDS and PLWA. There was a commonality across cultures and societies that these myths and misconceptions existed, although there were differences in the details of these. Among the Australian participants there was a general understanding and tolerance towards homosexuality and drug use, although there were exceptions to this. The older Australian nursing students showed considerable self-awareness of the misconceptions they had held when they were younger. The African students had good knowledge of HIV/AIDS which they did not associate with homosexuality or drug use. Poor knowledge appeared to contribute to some

of the lack of understanding and misconceptions that nursing students from Asian nations had about PLWA, homosexuality and illicit drug use. Lack of knowledge is closely associated with myths and misconceptions, which in turn are inextricably linked to the intolerance and blame afforded PLWA.

### ***Conclusion – Theme: Blame***

Constructing the major theme of Blame were three sub-themes which have been explored in this chapter. Drug use and sexual activity, both heterosexual and homosexual, were the main issues behind the nursing student participants perceptions of blame presented in the first sub-theme: Responsibility.

Although some participants showed empathy for PLWA who had contracted the disease from engaging in such activities, others had little empathy and perceived PLWA to be responsible for their own infection. The contrasts in the degree of empathy were related to the individual social context of each nursing student. When it came to PLWA who recklessly or intentionally risked infecting others, for not taking responsibility for their actions, there was no empathy at all.

Closely associated was the next sub-theme presented: Fear of catching HIV. Most of the students had clear images of who PLWA were and how they perceived them to be. These perceptions were largely based on the stereotypical images they grew up with which tended to stigmatise and label PLWA. Compounding these perceptions were strong cultural taboos against discussing sexual issues and behaviours. These characterisations of PLWA



and cultural taboos combined to help create the social context of each participant, and contributed to irrational fears of contracting HIV/AIDS. Some participants showed a willingness to embrace new or different perspectives, to not be bound by tradition or cultural taboos. However there were other participants who had no such willingness.

The culturally construed role of being a woman, along with myths and misconceptions surrounding homosexuality and illicit drug use, fashioned the sub-theme: Myths and misconceptions. The traditional role of women in some cultures, along with various myths about HIV/AIDS, created contexts where woman living with HIV/AIDS carry a greater burden of blame and stigma than do men. Participants who had seen this first hand showed tolerance and considerable empathy for women living with HIV/AIDS, although this did not always allay fear. The nursing students demonstrated degrees of tolerance towards homosexuality and drug use which was linked to their knowledge and misconceptions. Intolerance of homosexuality and drug use reinforced the stigma and blame directed towards PLWA.

Collectively the three sub-themes presented in this chapter illustrate the complex and interrelated factors that constructed the nursing student participants' perceptions of PLWA. These perceptions were underscored with the prevailing culturally construed blame associated with HIV/AIDS and directed towards PLWA. Throughout the world, much of the brief history of HIV/AIDS has been defined by blame and fear. PLWA have historically been

assumed to be either: homosexual, IV drug user, or heterosexually promiscuous. These assumptions, along with the fear of AIDS, have resulted in much of the stigma associated with HIV/AIDS. Such beliefs and perceptions have continued to exist as evidenced by the comment from more than one of the nursing students that, 'bad people' get HIV. These 'bad people' were perceived as presenting a threat to the safety of the nursing students. Following on from this first finding chapter, is the second findings chapter which focuses on the theme of Othering.

## **Chapter 6 – Second Findings Chapter: Othering**

### ***Introduction***

The concept of ‘othering’ has previously been defined and discussed in Chapter 3. Nursing students participating in this study tended to perceive and label PLWA as being ‘other’, people likely to be ostracised or marginalised by society. An undercurrent of prejudice was perceptible among a number of participants in the study. While this did not present itself in any overt manner, the stigma associated with HIV and stereotyping of PLWA became apparent through the labels some participants assigned to PLWA. The major theme of Othering, presented in this chapter, consists of two sub-themes stemming from analysis of the nursing student interview data. These sub-themes are: Homophobia & drug use; Power and influence of authority. Stigmatising perceptions of PLWA were a common feature of these two sub-themes, perceptions which perpetuated existing prejudices, stereotypes and the ‘othering’ associated with PLWA.

### ***Theme: Othering***

PLWA were not only stigmatised for having HIV/AIDS, but are also frequently assigned one or both of the co-stigmas of being homosexual or an IV drug user, as detailed in the following sub-theme: Homophobia & drug use. Being perceived as different, or ‘other’, and socially ostracised from mainstream society is a direct consequence of these stigmas. This stereotyping and negative portrayal of PLWA served to ‘other’ them as individuals, setting them apart from mainstream society. Study participants perceived PLWA as being outsiders, deviating from the norm, as belonging to

social or cultural groups separate or different from their own. Reinforcing these perceptions were three powerful institutions in society, each of which had a varying degree of influence on the nursing student participants. These institutions were: government; family; church. Their influence is presented under the second sub-theme: Power and influence of authority.

### **Sub-theme: Homophobia and drug use**

There was a common characterisation and labelling of PLWA as being homosexual, drug user or both, this emerged as a significant sub-theme from analysis of the nursing student interviews. This labelling of PLWA contributed greatly to the 'othering' of them. While the stigmatisation associated with homosexuality may have lessened in some parts of the world, homophobic attitudes and perceptions have changed little in many countries. The 'heteronormative' nature of legal institutions such as marriage remains unchanged in much of the world (Bernstein & Naples 2010; Elder 2007), with people frequently still regarding homosexuality as deviant behaviour. In Australia, for example, the Federal Government recently (2013) mounted a successful High Court challenge to overturn legislation in the Australian Capital Territory that had a few months earlier legalised gay marriage (Wilson 2013). Legal challenges have also occurred in India where the Supreme Court in December 2013 reversed a decision of a lower court that had decriminalizing homosexuality (Harris 2013). While these are just two examples, they serve to highlight the influence that conservative forces exert in many societies when it comes to maintaining the status quo regarding homosexuality.

Joining the early recognised and continued presence of stigma associated with male homosexuality was the stigma associated with illicit drug use, particularly intravenous drug use. In many countries intravenous drug use is highly stigmatised and also regarded as deviant behaviour (Chan et al. 2007; Simmonds & Coomber 2009; Wolfe, Carrieri & Shepard 2010). Some people experience double or even treble stigma, being an intravenous drug user and homosexual and living with HIV/AIDS. Nurses are not immune from such stigmatising perceptions, nor are nursing students, as indicated by excerpts of interviews with study participants presented below.

While there was general commonality among the study participants in characterising PLWA as homosexual or drug user, there were exceptions to these characterisations. There were also culturally and socially construed contrasts between how the nursing students perceived each of the two characterised groups of people. These perceptions were influenced by the level of acceptance of the 'deviant' behaviour. A lower level of acceptance was associated with greater 'othering', whereas greater acceptance was associated with less 'othering'. There were contrasts in study participants' perceptions of homosexuality and drug use, therefore the sub-theme of homophobia and drug use is discussed using the two sub-headings of homosexuality and illicit drug use.

## **Homosexuality**

Presented first, homosexuality is one of the two aspects of the sub-theme: homophobia and drug use. Fiona articulated her perception that homosexuality and HIV go hand in hand:

*Well I mainly thought it was something that affected homosexual men and I sort of had this preconceived like visual in my mind about just a gay man in a hospital bed – everyone has their own opinion on homosexuality and I don't know – not really sure if my image is – like matches reality*

(Fiona 3<sup>rd</sup> August 2009)

While this was Fiona's image of PLWA, she went on to demonstrate her compassion and acceptance of homosexuality. When discussing the scenario of a patient (Steve) living with AIDS who was being judged due to his sexuality:

*I think it is very sad about Steve because he is being criticised for his sexual orientation*

(Fiona 3<sup>rd</sup> August 2009)

Although Fiona was not expressing homophobia, she was nevertheless labelling and categorising PLWA as being homosexual. Even though she indicated an understanding and acceptance of homosexuality, there was still an 'othering' of PLWA who are homosexual. Similarly, Alice grew up associating HIV/AIDS with homosexuality:

*... the gay community is where the epidemic is here in Australia, that's how we all believed it. Oh, it's a gay persons' disease, it's not going to affect us, you know!*

(Alice 10<sup>th</sup> August 2009)

Thus PLWA were being ‘othered’ for deviating from the acceptable heterosexual norm. Such perceptions were not confined to the Australian participants, as Japanese Mieko observed:

*I think when I was a student at high school [in Japan] they portray it , HIV, in a sexual way – the image, my image of HIV is that, I’m sorry to say, it is a gays disease – but I don’t know about Australian ways of thinking about this, maybe it is different from Japan*

(Mieko 23<sup>rd</sup> October 2009)

A later interview with Mieko indicated that, over time, her perceptions had somewhat changed. After living for several more years in Australian society, she had become more accepting of homosexuality. Mieko also became more aware of how her earlier image of HIV being a ‘gay disease’ was still being reinforced in Australia:

*I had a chance to watch a movie about HIV a couple of months ago – the main character who has HIV was a gay, and when he finds he has HIV he had to discuss with his family and with his partner as well – but I think my perspective has also changed – now I know it’s not only a disease between gays*

(Mieko 23<sup>rd</sup> August 2011)

However the image that Fiona, Alice and Mieko had was not universal. As Pearl observed, in Africa HIV had been predominantly spread through

heterosexual sex, therefore homosexuality was not something given much prominence:

*I think it's mostly spread through heterosexual people because there's really no – well there's homosexuals as well but it's a really only a minority, but yeah, mostly what I know of is it's through heterosexual people*

(Pearl 10<sup>th</sup> September 2009)

Mari's dismay at the blame she had seen in Australia being directed towards homosexual PLWA has been documented in Chapter 5 (see page 132).

However she did indicate that there was still 'othering' of PLWA in Africa, however it was not in relation to homosexuality:

*... people [living with HIV/AIDS] still have stigma and they're discriminated against ...*

(Mari 4<sup>th</sup> August 2009)

This is not to say that homosexuality was any more accepted or less stigmatised in Africa than in the rest of the world. Rather it did not figure largely in the thinking of Pearl and Mari in relation to HIV/AIDS in the African context, nor were PLWA being 'othered' because of their sexual orientation. This is a notable difference in perspective by the African participants in contrast to their peers from other nations.

While Fiona, Alice and Mieke tended to 'other' PLWA who were homosexual, they nevertheless indicated willingness to accept homosexuality. There was no sign of such acceptance on the part of Sang who found even the concept of homosexuality difficult to cope with. As described in Chapter 5,



Sang indicated little association in the South Korean context between homosexuality and PLWA, a similar position to that of the African participants. Yet Sang's response to homosexuality was quite different to that of the African students. When presented with a scenario in which she (as a nurse) was to interact with a male homosexual patient in relation to aspects of his behaviour, Sang responded with:

*Oh, very difficult case – I can't handle this situation – I might just ignore that case. I don't know, in my culture it's really hard to say something that people don't want to hear. We normally just accumulate the feeling inside ...*

(Sang 21<sup>st</sup> November 2009)

Yet Sang was a compassionate person who believed in fairness and equal treatment for everyone:

*I think everyone should be respected, yes, regardless of how their life was terrible or not – and should get proper treatment, we should act for patient care all the time*

(Sang 21<sup>st</sup> November 2009)

There was conflict between Sang's sense of what is right and her culturally ingrained perceptions of homosexuality, her response was to try and ignore or avoid the situation. Sang made no outright expression of homophobia but found homosexuality difficult to accept. The thought of interacting with a homosexual patient, someone who was so 'other' to her, was almost too difficult for Sang to contemplate.

Often homophobia is not expressed overtly; in fact a discriminatory homophobic dialog is frequently prefaced with phrases such as the following from Mark:

*I've got no problem against gay people but ...*

(Mark 2<sup>nd</sup> October 2009)

Mark, in his early 20s at the time of interview, was a nursing student from Iran and he freely talked about his friends being homophobic but considered himself to be more understanding:

*I don't know, I've got a lot of homophobic mates as well and I'm trying to talk to them about it but – well like I said before I've got gay friends, and but see, I'm more understanding about it all but there are a lot of people that just got that narrow mind about it*

(Mark 2<sup>nd</sup> October 2009)

Mark was professing to not be homophobic yet there were inconsistencies and contradictions in what he was saying. If most of his friends were homophobic then it is difficult to see how he managed to fit into that power structure of friendship if he had such opposing views. Similarly there was no mention of inner conflict or being uncomfortable associating with people who express such prejudice. Mark also made frequent use of the word 'but', this is an example of a ubiquitous disclaimer being used in relation to a negative portrayal of a minority group (Augoustinos & Every 2007), in this case, homosexual men. A similar situation could be seen when Janet stated:

*Well they're in the shower together, we don't know what they're doing – but even if they were gay, it would be no*

*different technically if it was a husband and wife – it's not like the gay people are more tending to do that sort of stuff*

(Janet 6<sup>th</sup> August 2009)

The inclusion of the word 'technically' by Janet contradicted and immediately prejudiced what she was saying and reinforced the subtle undercurrent of discrimination and 'othering'. Janet was discussing the scenario of a gay patient being assisted to shower by his partner, and the suggestion that sexual activity (described as 'that sort of stuff' by Janet above) might be taking place at the same time. She went on to comment further about homosexuality:

*He's being stereotyped because he's gay when he might not really be a bad person or hasn't done anything to really deserve it – other than that, it's sort of part of life, you can't avoid those things*

(Janet 6<sup>th</sup> August 2009)

Janet recognised that being gay did not, per se, make someone a bad person. The concept of describing PLWA as 'bad people', previously introduced in chapter 5, is significant in relation to the theme of Othering, and is explored further later in this chapter. Negative representations and evaluations of minorities are commonly preceded by ubiquitous disclaimers such as: 'I'm not racist but ...'; 'I've got nothing against ...' or, as Mark might say, 'I'm not homophobic but ...'

When discussing the same situation described above, Lee used a similar opener and then qualified the conflict in her position by ascribing it to the position of being a nurse, she observed:

*I don't against gays, I don't against it, but – because I think as a nurse you can't be against anything because it's not like – we have to treat them the same, like the gay person they – I think like his partner is kind of like his wife, and in the hospital the wife's always going to help her husband shower, so yeah, that's why in this situation I will let his partner do it [assist with the shower] and I don't think they would actually do it [have sex] in the bathroom*

(Lee 2<sup>nd</sup> October 2009)

Lee went on to contrast the relative openness and acceptance of homosexuality in Australia compared to what she had experienced growing up in Hong Kong. She was confused about the conflicting cultural perceptions of homosexuality, even though there were similarities. Lee's own confusion about homosexuality was also evident as indicated in the following interview excerpt:

*I know some people who is gay – in Hong Kong they, I think they still feel shy, they don't want to let people know about it, that's why they won't do it like in public, they just do it at home or in the bar, the gay bar, yeah – it's the culture, the parents is so against it if their daughter or son is gay or lesbian, here in Australia they are still against it but I think it's a little bit better here – I don't even know what I think*

(Lee 2<sup>nd</sup> October 2009)

The ambiguity and confusion that Lee showed towards homosexuality was also apparent in Heng, another nursing student participant from Hong Kong. During interview, 28 year old Heng revealed his own homosexuality, something he had divulged to only a few of his fellow students in Australia. He was of the opinion that HIV/AIDS related stigma was much greater in Hong Kong than in Australia, nevertheless he was still careful to whom he disclosed his sexuality, even in Australia. Heng showed his indignation about the association made in Hong Kong between HIV and homosexuality when he asserted:

*Actually many people in Hong Kong think – perceive that HIV is associated with the sexual activities, so in Hong Kong they don't accept that – yeah pretty much they think that, oh if you've got HIV then you are the homosexual, but that's just totally wrong!*

(Heng 2<sup>nd</sup> November 2009)

According to Heng, there was little acceptance of homosexuality in Hong Kong and it was very much a taboo subject for discussion within the family. He emphasised the cultural differences between Hong Kong and Australia in relation to sexual matters, both heterosexual and homosexual:

*But that's why Australia is different, in Hong Kong not much people talk about that, because of the culture difference, yeah in Hong Kong parents don't talk about sex with their children, so talk about homosexuality – never!*

(Heng 2<sup>nd</sup> November 2009)

Although Heng professed his homosexuality he also demonstrated a degree of confusion about his own sexuality and he even made what could be considered to be homophobic comments. In relation to overt displays of homosexuality:

*Yeah, that's their business, they can do it at home actually, but not here, not in a public place like the hospital – that's disgusting, they have to respect the other patients*

(Heng 2<sup>nd</sup> November 2009)

Heng by and large made the choice to keep his homosexuality secret, certainly from his family in Hong Kong, he knew they would not be accepting of his sexual orientation. He had similar concerns about being stigmatised and how he would be perceived by some of his nursing student peers in Australia if he were to openly make his sexual orientation known.

There generally appeared to be greater acceptance of homosexuality among the Australian participants than among the Asian participants who were influenced by strong cultural perceptions of homosexuality. PLWA who are homosexual were 'othered', to a greater or lesser extent, due to their sexual orientation by all the participants with the exception of the African students. Although one participant introduced the label of 'bad person' in relation to homosexuality, this label was generally not applied to people who are homosexual. This contrasts with how illicit drug users were perceived by many of the study participants.

### **Illicit drug use**

The second aspect to the sub-theme: homophobia and drug use, is illicit drug use. Along with homophobia, the stigmatisation and ‘othering’ of people who are illicit drug users is widespread and considered to be deviant behaviour that is socially unacceptable (Ahern, Stuber & Galea 2007; Ha et al. 2012). Similarly, stigmatisation of people who have contracted HIV through such drug use is common place (Chan, Stoove, et al. 2007; Chan, Yang, et al. 2007; Latkin et al. 2013). Many of the nursing students had little knowledge or experience of drug use. In South Korea the spread of HIV via intravenous drug use accounted for less than one percent of infections (UNAIDS 2008). This was supported by Sang who observed that illicit drug use was not widespread in South Korea, she perceived drug abuse to be an Australian (or Western society) issue:

*I heard that now-a-days using drugs is very – a high issue in Australia, like in night clubs and something like that, but drug abuse, it’s rare in Korea – it is really hard to get drugs in Korea so it’s not common among normal people*

(Sang 21<sup>st</sup> November 2009)

This comment implied that people who use illicit drugs are not normal people. So while Sang may not have deliberately stigmatised drug users, she was ‘othering’ them through her perceptions that they were not normal people. Kim expressed similar views, also in relation to South Korea:

*I never meet any person with the history of drug abuse. To be honest, if I meet her in Korea I would never – I don’t think I can see her, I mean because in my culture we quite think this kind of people [drug users] deserves to get this kind of thing*

*[AIDS] because those disastrous results, it always comes from what they've done in the past, I don't think I can go along with this kind of person*

(Kim 4th August 2009)

Sang and Kim had little direct experience or knowledge about illicit drug use. They concurred with what they believed to be the general view held in Korean society, that drug users were somehow different or 'other' from everyone else and deserved their fate. Even when that fate was HIV/AIDS, it was perceived as being due to engaging in socially unacceptable and deviant behaviour. There was no conflict between the perceptions Sang and Kim had of drug users and those of Korean society which 'othered' drug users. By the time Kim had lived in Australia for several years, graduating with a Bachelor of Nursing and working as a registered nurse, she had gained more experience and knowledge about illicit drug use. However this had done little to change her perceptions of drug users who contracted HIV/AIDS and labelled them as 'bad people':

*Well, of course now I have more experience I feel sorry for them if they got AIDS, but bad consequences come from if we do bad things – everyone knows taking drugs is wrong, it's like – I'm sorry but my culture says they are bad people, so it's their fault*

(Kim 22<sup>nd</sup> September 2011)



This was in stark contrast with the perceptions of Anne and her experiences as a teenager growing up in Australia where she had considerable experience of drug use at that time in her life. These experiences not only gave her more knowledge than Kim or Sang had about drugs, they appeared to give her more understanding and acceptance towards drug use and drug users. So although she might still be ‘othering’ drug users, she was not labelling them as ‘bad people’:

*I was at a horrible, horrible age, I was awful and then got with the wrong crowd, and then, you know, had a lot of friends that were IV drug addicts so there's been a bit of exposure to certain things that I've had these, so information wise and what I've seen and all that side of things, so that's where my education came from I think*

(Anne 3<sup>rd</sup> August 2009)

Another Australian nursing student, Melanie, had similar familiarity with illicit drug use. Melanie showed considerable compassion for PLWA and great understanding for people with a drug addiction, something she had firsthand experience of. The greater acceptance of drug users by Anne and Melanie reflected their own experiences during their teenage years. For them, drug use was not so much of a deviant behaviour. When discussing a scenario of a woman dying of AIDS who had been an intravenous drug user, Melanie commented:

*I feel sorry for her, I mean people start taking drugs for any number of reasons you know, so yeah how her life ended up ... I've been around people with drugs, probably not heroin, I*

*removed myself from people that were starting to take heroin at a young age, but yeah, around people that regularly take drugs*

(Melanie 10<sup>th</sup> September 2009)

These comments from Anne and Melanie differed considerably to those made by Sang and Kim with their minimal experience of drug use. This suggests that direct experience of illicit drug use can foster greater understanding of the behaviour. These two Korean students were not alone in lacking experience of drug use. In addition to little direct experience, Fan, from China, showed a real lack of knowledge in relation to illicit drugs. This was demonstrated by her questions asking if heroin is addictive and if it was an illegal drug in Australia, previously discussed in Chapter 5. Another nursing student from China, Ying, also showed a lack of accurate knowledge about illicit drugs. When discussing needle exchange programs operating in Australia, Ying not only found such programs unacceptable, she also believed they did not exist in China, asserting:

*I disagree with it [needle exchange programs for intravenous drug users] because if we offer the syringe to the people doing illegal drug use that's part of encouraging them, if you give a syringe they will do it more and more people get HIV – that's why in China we don't give syringes*

(Ying 25<sup>th</sup> August 2011)

This was despite the fact that needle exchange programs had been operating in China since 2002 (Zhang et al. 2011). Ying had six years of experience as

a nurse in China before going to Australia to further her nursing career. In light of her apparent lack of accurate knowledge about the situation in China, it would be unwise to assume that nursing students have accurate knowledge in relation to HIV/AIDS in their home countries, regardless of their previous nursing experience.

Mieko also found the concept of needle exchange programs a little difficult to comprehend, as far as she was aware such programs did not exist in Japan. She also believed that the injection of illicit drugs was uncommon in Japan, and not a significant issue. When discussing harm minimisation programs in Australia, she observed that:

*I was so surprised, the injecting drug issue is very, very big in Australia – the way of taking drugs in Japan is not similar to Australia, they don't use injection – I don't think there are needle exchange programs in Japan, and I've never seen the needle disposal containers there, yeah, but here I see everywhere – the yellow containers in toilet, I was so surprised!*

(Mieko 23<sup>rd</sup> August 2011)

While the accuracy of Mieko's knowledge of drug use in Japan was questionable, she did recognise there were gaps in her knowledge. She left the interview expressing a desire to learn more and with the stated intention of searching for research studies on the effectiveness of needle exchange programs in reducing the spread of HIV. Fan and Ying's poor knowledge in

relation to illicit drug use may well have contributed to their lack of acceptance of drug users, as indicated by Ying:

*I want to tell you, yeah – in China, you know China's a traditional country, if I know you have AIDS, yes I never make friends with you, I think you are bad people, you are a bad person*

(Ying 25<sup>th</sup> August 2009)

AIDS is seen by some as being Karma or a just retribution for deviance, for sinful or bad behaviour. As indicated by Ying's words quoted above, PLWA are often perceived as 'bad people'. The stigmatisation, labelling, group portrayal or 'othering' of PLWA also became evident during interviews with several other Chinese nursing student participants. Yue expressed similar sentiments and used similar labels in her 'othering' of PLWA, although not all were considered 'bad people':

*Well tons of people they get infected because they do drugs, they use the same needles and this is their route for getting HIV – these people are called bad people. But some people like children get because their parents get AIDS, so we need to support them, the children they're good people, but the parents that's bad people*

(Yue 21<sup>st</sup> November 2009)

While Kim had directly labelled PLWA who had used illicit drugs as 'bad people', her Korean compatriot, Sang, did not directly use the 'bad people' label, rather the label was 'not a good person'. When Sang was presented

with a scenario of a woman with AIDS who was about to die, during discussion Sang commented:

*Yeah because – actually she’s the one who’s responsible for her tragic destiny, so she can’t be described as a good person obviously, maybe her background was really bad, like her parents abused her or her friends are not good people, things like that, but I don’t think the media in South Korea will describe her as a good person*

(Sang 2<sup>nd</sup> November 2009)

There was a common perception and labelling of PLWA as ‘bad people’ who are to blame for their illness, particularly if they were illicit drug users. Leading on from this lack of acceptance was the suggestion that it could result in a real reluctance to provide nursing care. The idea was openly canvassed by Fan when discussing the scenario of a patient who was being unashamedly reckless about spreading HIV:

*I can’t deny no people want to take care of this kind of person, but as a registered nurse I can’t deny to nurse him – personally I prefer not to take care of him, he’s not worthy to take care of even though he got his human right to appropriate treatment as a human being – but personally I thought he’s not worthy to nurse*

(Fan 4<sup>th</sup> August 2009)

Ying, Yue, and Fan quoted above, were from China and all described how someone with HIV would be barrier nursed in China. That is, nurses would wear masks, gloves and gowns for all interactions with a person infected with HIV or AIDS. These patients would then be immediately transferred to a specialist infectious diseases hospital (Chen et al. 2010; Zhao 2010). Such nursing practices being compulsory and they perpetuate irrational fears of contracting HIV from just being in proximity of someone with the disease. These well-established health care practices or norms unintentionally tend to propagate a culture that ‘others’ PLWA. They are a form of stigmatisation and ‘othering’ that has become entrenched in the Chinese health care system, and reinforces perceptions about the deviance of PLWA. Studies suggest that institutional norms become assimilated by health care professionals working within the institution. Acceptance of and conformity to the norms is generally necessary for an individual to succeed within the institution, whereas non-conformity can result in exclusion and less likelihood of personal success (Roberts, et al. 2010). The desire to succeed and conform can therefore reinforce the institutional norms.

Deng described how people with AIDS in China were afraid to expose their status, he also tended to label PLWA and portrayed them as different, emphasising their ‘otherness’, not only as ‘bad people’ but also as having little education:

*In my opinion, I think – yes, I think most of the patients in China with HIV are living in a different world from us, they’re afraid to expose they have HIV – the majority of them I think*

*is not very good persons, not very high educated persons I think*

(Deng 12<sup>th</sup> October 2009)

So while the government in China might be actively working towards reducing discrimination towards PLWA (see pages 189-192), it is apparent that some deep-seated perceptions and fears remained to be overcome. Similar fears and perceptions were noted by Pearl when she described how people in Africa were reluctant to disclose their HIV status:

*Yeah, most people will hide it [being diagnosed with HIV] because there's still lots and lots of intimidation, the main problem that I've seen is that we are not really educated about accepting these people*

(Pearl 10<sup>th</sup> September 2009)

However neither Pearl nor Mari used the label of 'bad person' when referring to PLWA. Both showed greater acceptance of PLWA than most of their peers in the study, regardless of how it was contracted. When talking about her experiences of PLWA in her home country of Tanzania, Mari pointed out that illicit drug use was only a minor problem and the vast majority of PLWA in Tanzania contract HIV through heterosexual-sexual intercourse. Although Mari had little experience of intravenous drug use, she still demonstrated great empathy for PLWA who had contracted the virus through intravenous drug use. Mari did go on to point out that in Tanzania there would be less stigma associated with contracting HIV through drug use than if it were via

sex as a prostitute. Throughout the world, women living with HIV are commonly stigmatised and labelled as being prostitutes (Sandelowski 2004). Mari's acceptance regardless of how HIV was contracted can be seen when she observed:

*I really sympathise with her [the woman dying of AIDS contracted through intravenous drug use] about she had a problem with drugs then she got AIDS and now she needs someone to be there and I think I would do that for her without doubt – but I think in my country if you got HIV through drug using you might be better off than if you were a prostitute, yeah, to some degree, you know what I mean*

(Mari 4<sup>th</sup> August 2009)

**Summary – Sub-theme: Homosexuality and drug use**

With the exception of students from Africa, there was considerable commonality between the nationalities represented by the participants on how homosexuality was perceived and associated with HIV/AIDS. This association labelled and 'othered' PLWA, with the students generally demonstrating limited understanding and acceptance of homosexuality. Perceptions were culturally and contextually construed, with the Australian students showing a greater acceptance of homosexuality than the other students. In relation to illicit drug use, some of the Australian students demonstrated a degree of acceptance towards and affinity with people who contracted HIV through intravenous drug use. Nevertheless these PLWA were still considered outsiders and 'othered' in a similar manner as were homosexual men. Many of the participants were much less accepting and



characterised drug users, and PLWA who had contracted the disease via drug use, as ‘bad people’. This contrasted with PLWA who were homosexual (and not drug users), they were not afforded the ‘bad people’ label.

### **Sub-theme: Power and influence of authority**

As discussed in Chapter 4, our social structures are defined by our

knowledge, although what we know as knowledge and truth are in a state of constant change. The individual who possesses knowledge can use that knowledge to exercise power. This is fundamental to the Foucauldian concept that power and knowledge are intertwined, where there is knowledge, there is power. Fairclough (2005) stressed the central role that power plays within the organisational structures of society, with particular emphasis on the ‘power relations between groups of social agents’ (Fairclough 2005, p. 931). The relative power and authority possessed by agents determines their ability to control, influence and change the structures of society. These agents of power can be individuals, groups or institutions, with the power of the state at the centre of these multiple power structures. Foucault (1976) viewed the state as being the superstructure of our power networks.

When it comes to state institutions, such as the police force or the department of health, they certainly exercise power and they also control and direct the institution’s version of ‘truth’ which then tends to be dominant in society. Therefore truth and power sustain each other (Foucault 1976). Institutions have the power to influence and to help shape the culture of society, including perceptions of HIV/AIDS and of PLWA. Analysis of participant interview data suggested their beliefs to be culturally embedded, hence the

connection between participants' perceptions of HIV/AIDS and PLWA, and the institutions of society. However, it was not only the power of the state which appeared to be influencing the culturally construed perceptions of participants, but also the power of another two institutions, namely, organised religion and the family. Government, religion and family are all part of, and help to construct, our culture and society.

Culture itself has power, the power to construct our realities and belief systems, and the power of culture resists changes to these constructions. We tend to be intolerant towards challenges to the dominant culture, intolerant to changes in our cultural construction of reality because 'they introduce unacceptable levels of uncertainty and doubt' (Marsella 2005, p. 653). The power of culture has previously been illustrated by an excerpt from interview with Sang, in relation to Korean culture:

*I don't know, in my culture it's really hard to say something that people don't want to hear ... even when we really should talk about it*

(Sang 21<sup>st</sup> November 2009)

Sang was recognising there was a conflict between her cultural values and what she believed was the right thing to do. This dichotomy is explored further in Chapter 7 within the theme of Values. When the institutions of society inform people's perceptions of PLWA, they have the power to do so in ways that can serve to include or exclude PLWA from mainstream society. While there may not be a deliberate intent to be exclusive of PLWA, many institutional and cultural policies and practices result in the 'othering' of

PLWA. However this influence is not uniform as people are individuals who process and integrate information in their own individual manner. They are swayed by many factors such as their personal experiences and beliefs, along with their pre-existing perceptions. The concept of attitude polarisation is a mechanism by which the individuals' pre-existing perceptions can become even stronger despite receiving evidence to contradict those perceptions (Boysen & Vogel 2008; Wojcieszak 2011; Zimper & Ludwig 2009). Hence the messages from society's institutions may or may not achieve their desired intention.

Several of the Chinese participants have been previously quoted as describing IV drug users as 'bad people'. They were associating HIV/AIDS with drug use, thereby labelling PLWA as 'bad people' which served to 'other' them. These perceptions may well have been a reflection of the uncompromising stance taken over many years by the Chinese Government in relation to drug use (Hammett et al. 2007). However, in more recent years the Chinese Government incorporated HIV prevention and harm reduction strategies into its policies (Hammett et al. 2007).

When being interviewed, the Chinese students in this study appeared to be echoing the policies of the Chinese Government. For example, Jiao introduced several stories she recalled from the state controlled media in China about HIV. One of the stories she recalled was about a number of

people in a small Chinese village contracting HIV via blood transfusion. The story was to dispel perceptions that only people who are in some way different from everyone else in society contract HIV, and to emphasise that PLWA have feelings and a life in the same way as everyone else. This was an example of government, through the media, attempting to reduce the degree of exclusion from society of PLWA. As Jiao recounted:

*I can remember a story – yeah, in the newspaper, like people discussing whether or not patient with HIV should have children or not – yeah, something like that. And you know, in China there's a little village, a lot of people get HIV there, because of the blood transfusion, because of that. So the story's about the people's life and how they're feeling, and like the normal people what they are thinking about their children, or something like that, to let people have some knowledge about this – yeah, I think most of the time the people are scared or something because they don't know, they are scared they may get the infection*

(Jiao 8<sup>th</sup> October 2009)

The media in China assists the government to use its authority to influence public opinion through storytelling, but also through reporting of direct action by high profile figures. Ying stated that she firmly believed Government has a responsibility to protect its citizens and described how the then Chinese President and General Secretary of the Politburo showed his concern for PLWA by personally setting an example:

*On World AIDS day, Hu Jintao, he concerned about HIV patients, he shake hands with all the HIV patients in order to encourage the public to be without discrimination*

(Ying 25<sup>th</sup> August 2009)

While the above are examples of government attempting to be inclusive of PLWA, at the same time there were stories which did the opposite by reinforcing perceptions that ‘bad people’ get AIDS. Ying recounted a ‘news’ story reported on a Chinese web site of a young man who had committed suicide by jumping from a high building. His girlfriend was devastated and could not understand why he would do such a thing until it was revealed he had contracted AIDS by having sexual intercourse with another girl. So the young man was portrayed as a ‘bad person’, whereas the girlfriend, who had not had sexual intercourse with her boyfriend, was portrayed as a ‘good girl’. The messages of morality, right and wrong, are obvious in the story so far, but the story continued. The girlfriend then used hundreds of dollars of her own money trying to track down the girl who had transmitted AIDS to her boyfriend, with the aim of preventing her from infecting anyone else. This girl was so civic minded, according to Ying, the Chinese people said:

*Oh this girl she is such a good girl, she use her own money to assist and protect the other people.*

(Ying 25<sup>th</sup> August 2009)

For Ying the story carried the twin messages of morality and working for the good of the nation. While these may well be admirable messages and are

evidently intended to be positive, they do nevertheless label and 'other' PLWA in the process. The State, through its influence over the media, had the power to exert influence over the cultural beliefs and practices of society. Of course governments throughout the world influence public opinion through the various popular media. This use of the media is not something restricted to China by any means. However media organisations in Australia, for example, can claim a greater degree of independence from state influence than the media in China. Nevertheless, apart from two Australian students, only the Chinese nursing students recounted such stories during interviews with them, these stories remained etched prominently in their psyche.

Governments certainly have a legitimate role in attempting to influence the health of the population through public health policy and health promotion, this was emphasised by the 1986 Ottawa Charter for Health Promotion (WHO 1986). How governments choose to exercise this role has varied over time and between nations. The State attempting to influence perceptions of HIV/AIDS and PLWA was most perceptible during interviews with the Chinese students, however it was also apparent among some of the Australian students, particularly those aged in their 30's or older. These older Australian students could recall and were still influenced by government HIV/AIDS educational campaigns conducted 20 years earlier. In contrast, the younger Australian students did not disclose similar influences, thus suggesting a perceptible change in the role of the state in Australia with regards to HIV/AIDS.

Rachel's earliest memories of having an awareness of HIV and AIDS dated back to 1987 with the Australian Government's powerful but controversial 'Grim Reaper' advertising campaign. The aim of this public health campaign was to raise public awareness about AIDS and the advertisements used images of the 'grim reaper' mowing down women and children portrayed as AIDS victims. The grim reaper in the advertisements became popularly associated with gay men (not the intention of the advertisements). This resulted in the campaign having the unintended consequence of demonising homosexual men, heightening their exclusion and their 'otherness'. In fact Rachel did not fully understand the advertisements at the time, and they gave her the impression that they were really just targeting the male homosexual community:

*I think the first advert I saw was the grim reaper ads, they're the ones I sort of remember. And I'm thinking, the grim reaper with the bowling ball, you know, like it doesn't make sense, you know, like I understood the it's not who you've slept with it's who've they've slept with, and it shows the beds going back and back and back, and that was quite good, but I didn't really understand – why is it like, just about gay men?*

(Rachel 30<sup>th</sup> September 2009)

This was a clear example of the Australian Government using its power to influence public behaviour through a public health campaign. Many years after the campaign, the images described by Rachel remained firmly imprinted in her mind, in a similar way to the stories the Chinese students

remembered so well. Alice, almost the same age as Rachel, also clearly recalled the same advertisements:

*I think everybody growing up as a teenager in the 80s – it really hit you because that's when all the ad campaigns came out, you know, the grim reaper ad still sticks with me*

(Alice 10<sup>th</sup> August 2009)

However the rest of the Australian students were too young to remember that particular campaign. They did not recall any more recent campaigns in the media, only news stories that were:

*Generally negative because you hear about like the ones where, like, the people get raped or, like with a person cheating on their wife and find out they've got HIV ...*

(Janet 6<sup>th</sup> August 2009)

Indications are that Australian Governments of the mid to late 1980's had a greater willingness to take an active and highly visible role in HIV/AIDS prevention strategies than more recent governments have been willing to undertake. The early government campaigns were controversial at the time and could be seen as being 'risky' politically for the then government, a willingness to take such political risks in the name of HIV/AIDS prevention has appeared to be absent in more recent Australian Governments. Yet, with hindsight, these early campaigns in Australia served to highlight the existing stigma of homosexuality, and defined HIV/AIDS as a disease to be feared and PLWA to be excluded and 'othered'.



Power can be exercised in many ways, the words of the stories described by the Chinese students above were being used in attempt to ‘normalise’ PLWA, to portray them as normal people with children and aspirations the same as everyone else. The effectiveness of this approach is questionable. With respect to Jiao, the approach would appear to be effective and had helped to shape her perceptions. However, perceptions that all PLWA are ‘bad people’ and very different from everyone else continue to be prevalent in many nations, including China. As noted earlier, both Ying and Yue used the ‘bad people’ label to stigmatise PLWA, contrasting with Jiao’s position. Power can be used in positive and negative ways, the above were examples of power being exercised to try and overcome existing exclusion practices towards PLWA. Yet this very process tends to exclude by highlighting the ‘otherness’ of PLWA.

Governments are not the only institutions to exercise power. Previously, in Chapter 5, the power and influence of the traditional patriarchal family was demonstrated when Pearl described greeting her father on her knees. According to Foucault the power of the father in the family is interrelated with the power of the state, they provide a plurality of patriarchy (Foucault 1978). Throughout Pearl’s upbringing, her parents, who exercised considerable power over her, had stressed that the way to avoid HIV was sexual abstinence before marriage:

*It’s sort of the way we’ve been educated about the disease,  
HIV, no sex at all, yeah it’s safer with no sex, its other than*

*teach about protection – the main thing they preached was no sex before marriage, yeah.*

(Pearl 10<sup>th</sup> September 2009)

While Heng was happy to declare his homosexuality during the safety of a confidential interview (as discussed earlier in this chapter), the traditional patriarchal nature of the Chinese family influenced him to keep his homosexuality secret from his family in Hong Kong. As head of the family, his father exercised considerable power and perhaps generated a degree of fear. Heng could not entertain the thought of raising the issue of his sexuality with his father, any discussion or even mention of sex was not permitted in the family:

*Oh no, they didn't talk about anything like that, nothing at all – it's a cultural difference, yeah, in Hong Kong parents don't talk about sex with their children*

(Heng 2<sup>nd</sup> November 2009)

The experiences of both Pearl and Heng demonstrated the power of the family, specifically the father, in perpetuating traditional cultural norms, prejudices and taboos. However, along with the similarities, there were differences in that Pearl was living with her family in Australia so the power was immediate. In contrast, Heng's family was in Hong Kong and so the power had become more indirect as long as he remained in Australia, nevertheless the influence was still strong. Power and influence exercised at a distance was also apparent with Ying. When in China, Ying's family would

not conceive of allowing her to be friends with anyone other than someone from a similar family with the same cultural beliefs and practices. Although Ying was living in Australia when interviewed, she still followed the family's practices when choosing her friends, and that would certainly be the case if she discovered a friend had HIV:

*My idea is same in Australia, if I know somebody, even my friend, he or she had HIV I think I would deliberately just keep away from them – it's my culture from when I was born ... it's hard to change you know*

(Ying 25<sup>th</sup> August 2011)

In many cultures the family exercises considerable power and influence. This influence extended to perceptions of perceived threats such as homosexuality, and, by association, PLWA, thereby leading to exclusion practices that 'other' PLWA. Another powerful institution in many parts of the world is the 'Church', or religious institutions of all faiths and beliefs. The only religion that was referred to by participants of this study was Christianity, although the researcher did not directly raise the issue of religion during the interviews. There was little evidence of the power of religion arising from the interviews, with the exception of the two nursing students from Africa. In many parts of Africa the Christian Church wields considerable power and influence and this was apparent in talking with the African students. The message and influence of the Church paralleled that of the family. They tended to reinforce each other and both were committed to conservatism and determined to resist

change. HIV/AIDS presents a threat to the status quo, hence the people held responsible for this threat, PLWA, are to be excluded and ‘othered’ for being a threat.

Throughout Africa, and in some other parts of the world, women are considerably more likely to be infected with HIV than are men. Many women in Africa have little idea of how HIV/AIDS is transmitted or of how to protect themselves (Zeelen et al. 2010). Even if they have such knowledge it may be of little benefit to them as sexual exploitation and abuse by men is common (de Souza 2010; Metz 2008; Mwanga et al. 2011). Not only do many African cultures discourage discussion of sex, but this is also reinforced through the power of the Church. In Nigeria the Christian Church takes a very active role in relation to social issues such as the spread of HIV/AIDS. According to Pearl the message from the church echoed that of her family, in relation to HIV education:

*Yeah, they do educate people about protection, but it's just that they sort of try and scare you with no sex – it's more of no sex and that is the education, but it's still huge, cos' people will still do it – but yeah, there's education but that's what they teach us*

(Pearl 10<sup>th</sup> September 2009)

The power and role of the Church varies around the world and is very much contextual. Since living in Australia Pearl had continued to be part of the same Christian Church that she followed in Nigeria. She noted the different perspective of the Church in Australia regarding HIV/AIDS:

*Yeah it's different, it's different, it's more – it's not so rigid or as traditional here, it's quite flexible and you know – open minded. But here we don't even hear about HIV in Church, it's not a big deal I think for the Church here, so yeah, there's charities that they support and everything with HIV and stuff but it's not like a big deal here, it's just not in the Church here – back home it's like such a big deal, but not here*

(Pearl 27<sup>th</sup> July 2011)

**Summary – Sub-theme: Power and influence of authority**

Culture has the power to influence whether society is inclusive or exclusive of particular individuals or groups of individuals. As indicated above, it is generally minorities, such as PLWA, that tend to be excluded from mainstream society. Change comes slowly to traditional cultures which are committed to maintaining the status quo. Similarly, individuals and institutions such as government, family and church, exercise powers of inclusion and exclusion, they all tend to emphasise the threat posed by HIV/AIDS and of PLWA. The actions of governments, as seen from the perspectives of study participants, tend to emphasise the 'otherness' of PLWA, even if that was not the intention. The family was seen to have a particularly strong influence on the perceptions of both the Asian and African participants, with the African students also having their perceptions moulded by the Christian Church. Both institutions emphasised traditional cultural taboos which have tended to exclude and 'other' PLWA.

### ***Conclusion – Theme: Othering***

Throughout the history of HIV/AIDS there has been a portrayal of PLWA as having personal responsibility for contracting the disease. This characterisation has resulted in the labelling of PLWA, a process that was continued by most of the nursing students participating in this study. Categorisation and labelling are fundamental aspects to the concept of ‘othering’ which was one of the major themes developed from analysis of the nursing student interview data. The labels predominantly given to PLWA were homosexual and/or drug user. These labels served to continue the ‘othering’ of PLWA and reinforce the stigmatising perceptions held by many people, including nursing students participating in this study. Cultural factors served to construct the ‘othering’ of PLWA. In contrast, personal experience and positive contact with stigmatised minorities fostered acceptance, lessening both ‘othering’ and stigmatising behaviour.

The degree of acceptance of homosexuality and drug use by the participants contributed to how they ‘othered’ PLWA. There were contrasts between how the two stigmatised groups (homosexuals and drug users) were perceived by the nursing students. The Asian students in particular had strong perceptions of drug users being ‘bad people’, whereas homosexuals were not afforded such a negative label. For these participants, homosexuality generated feelings of discomfort rather than the strong negative perceptions that drug use generated. Cultural taboos relating to sexual issues were strong among the Asian students resulting in the feelings of discomfort homosexuality generated for them. Similarly, cultural factors contributed to the ‘bad people’ label given to drug users.

In contrast, the African participants, with their greater personal experience of HIV/AIDS, were more accepting of all PLWA and condemned the labelling of people or the allocation of blame. The Australian participants were generally quite accepting of both homosexuality and drug use. While they still 'othered' PLWA who were homosexual, there was little evidence of overt homophobia. When it came to drug use, many of the Australian students had personal experience of using drugs or of knowing people who did so. This direct experience appeared to contribute to their greater acceptance of drug use.

Some of the powerful institutions of society, government, family and church, helped to form and reinforce negative perceptions of PLWA. These institutions tended to foster perceptions that exclude PLWA from mainstream society, this exclusion further served to 'other' PLWA. The influence these institutions had on perceptions varied among the study participants.

Government and family appeared to strongly influence the perceptions of the Asian students. Contrasting with the African students for whom family and church had the greatest influence. Only the older Australian participants indicated their government had contributed to perceptions of PLWA.

Chapters 5 and 6 have explored the themes of Blame and Othering, along with associated sub-themes. In Chapter 7, the final findings chapter, the focus changes to explore the theme of Values. This theme provides considerable contrast with the previous two themes.

## Chapter 7 – Third Findings Chapter: Values

### ***Introduction***

Chapters 5 and 6 explored the study participants' perceptions of PLWA in relation to the blame and 'othering' of PLWA. Social and cultural influences and context helped to shape these perceptions which tended to revolve around perceptions of homosexuality and illicit drug use. Varying degrees of acceptance, empathy and tolerance towards people engaging in these 'deviant' behaviours influenced the perceptions the nursing student participants' had of PLWA. Blame and 'othering' are negative concepts and generate negative perceptions of people who are the targets of the blame and 'othering'. Contrasting, and at times conflicting with these negative perceptions, the participants showed they also held many very positive values. These values are the basis for the third major theme constructed from analysis of interview data from the participants, and presented in this final findings chapter. Values are desirable goals that serve as a set of standards or guiding principles for how individuals and groups are expected to behave in society, they are part of our identity and regulate our behaviour (Longest, Hitlin & Vaisey 2013; Talbot & Verrinder 2010; Welzel & Inglehart 2010). There are positive values, defining what is good and desirable, and negative values, defining what is not good and undesirable (Talbot & Verrinder 2010).

The theme of Values is comprised of two sub-themes: Disparity; Professional values. Contrasting with perceptions of blame and 'othering', the sub-theme of Disparity placed the participants in a moral context where they expressed a strong sense of doing what is 'right', and indignation at the injustices in the



world. In order to present a balanced picture of the nursing students, it is important to present this contrasting image arising from analysis of participant interview data. All contributed to the identity of each individual participant and the values they stand for. The final sub-theme, Professional values, has briefly highlighted some of the contrasts between the nursing students' developing professional nursing values and their culturally informed personal beliefs, a source of conflict for many participants.

### ***Theme: Values***

#### **Sub-theme: Disparity**

The disparity that exists around the world in access to health care and other basic services caused concern among many of the study participant nursing students. There was recognition by the nursing students that there was great disparity throughout the world when it came to PLWA, and a sense of outrage that more was not being done to combat HIV/AIDS around the world. The nursing students did recognise the social inequalities that surround diseases such as HIV/AIDS, there was also frustration that not enough was being done to alleviate this and other social issues in relation to HIV/AIDS.

Although the pall of despair caused by HIV/AIDS that continues to hang over parts of the world, and in particular sub-Saharan Africa, can appear to be omnipresent, there is also cause for hope. Many of the participants talked about their ideals and goals of being able to contribute, as healthcare professionals, to world society beyond their own nations. Deng had previously (as a nurse in China) wanted to go to Africa to play a role in fighting disease. In relation to HIV he commented:

*This disease is global so try to minimise – to try to reduce the numbers, it's not just for one country, it's for the whole world because it can benefit for the whole world to help other countries as much as they can – I applied [in China] to go to Africa to help some people with disease, most with HIV, but because of my experience, they needed more years work experience than me*

(Deng 12<sup>th</sup> October 2009)

Lack of nursing experience prevented Deng from going to Africa in the past, but the desire to do so in the future was still within him. Similarly, Lee and Heng both professed the ambition to join an international aid organisation such as Médecins Sans Frontières (MSF) in the future so that they could use their nursing skills to help people in less affluent countries:

*... for me in my, like my future, I really want to go to some poor country to volunteer, like I know some of the team – I can't remember the organisation, MSF I think ...*

(Lee 2<sup>nd</sup> October 2009)

*Yeah I would like to do that ... to help these people ... if you go there you experience a lot*

(Heng 2<sup>nd</sup> November 2009)

South Korean Kim was very much in support of wealthier countries providing assistance to poorer countries in the fight against AIDS:

*Yes of course, a lot of medication that is effective in dealing with those HIV or AIDs disease, those drugs are too expensive for the African people or the poor people in poor countries. I think the rich countries – this is not an obligation, but ethically, they have some responsibilities to share that problem and they should provide them with those drugs, this is humanity, right?*

(Kim 4<sup>th</sup> August 2009)

Susan concurred with these sentiments and was of the opinion that education was the key to overcoming HIV/AIDS in the future. She believed that the focus of foreign aid should be targeted towards educational programs designed to limit the spread of HIV:

*I think with proper education, not just – not so much just giving money, but just educating people in the poorer countries about HIV and the effects of it and how it gets transmitted to people, I think in that way we should be helping out a lot*

(Susan 24<sup>th</sup> August 2009)

The assumption by Susan appeared to be that people in poorer countries were not aware of how HIV is transmitted, that education was all that was needed. Such assumptions have the tendency to ignore the wider social determinants of health and the spread of HIV. Nevertheless, Susan's belief that help should be given to those in need was clear.

Jiao's perspective was slightly different, she believed there should be greater corporate citizenship or responsibility towards providing aid. In Jiao's opinion, the fight against AIDS, and other injustices in the world, should not just be the responsibility of individuals and governments. Big business and the corporate world should be playing a role as well:

*Yeah, and I don't think it should just be governments responsibility to help them, a lot of countries do and that's really good thing, you know, yeah – but like a big organisation, some big companies, if they can – if they can afford to do it, they should do it, they should help as well!*

(Jiao 8<sup>th</sup> October 2009)

There was criticism from some participants of the level of assistance provided by wealthier nations to their less fortunate counterparts. This criticism demonstrated their values and indicated a strong sense of compassion and morality on the part of the nursing students, and there was hope that more would be done in the future. Heng's comments were typical:

*I think the richest countries, such as USA, should provide more education, medicine, that kind of program – it's still not doing sufficient, it's our responsibility – these people are suffering too much!*

(Heng 2<sup>nd</sup> November 2009)

Why wealthier countries, such as Australia, should be doing more to help their less fortunate neighbours was articulated by Rachel:

*Like I say, we're a lucky country – people go to work to earn the money to live in the big houses and play the Playstations and drive the huge 4-wheel drives, and they never go on holidays because they are too busy working to pay for the house and the car. Do you know what I mean? Like, we need to get back to helping. Helping's good. Helping gives you more than you think, helping makes you rich!*

(Rachel 30<sup>th</sup> September 2009)

Rachel's words echoed the ethos of nursing around the world, and articulated her concept of self, her values, and her own role and identity as a nurse. The personal experiences of some of the students also led to confidence and optimism about the nursing care they would provide to PLWA. Anne felt that her past association with illicit drug use in Australia would help her to empathise with PLWA, even if the disease was not contracted through drug use. As Anne commented:

*I think probably coming from where I've come from I'd be able to empathise more with them and be able to say "I know what you're going through, I know what you're feeling" – so not just I've read it in the book, I do know what you're on about*

(Anne 3<sup>rd</sup> August 2009)

Mark also had previous and ongoing contact with the illicit drug culture in Australia, and this appeared to have enhanced his understanding and compassion for PLWA. He didn't assign blame to illicit drug users, just empathy and compassion for those whose life had been devastated through drug use:

*It's not uncommon either, like a lot of people do start injecting and things like at a young age, and just the life they go through just from there is horrible, because I've got a few mates that have been involved in drugs and I've just seen it ruin lives basically, and it's scary*

(Mark 2<sup>nd</sup> October 2009)

While a cure remains elusive, the development of more effective treatments means that PLWA in many Western countries are now surviving for long periods of time. In stark contrast, throughout Africa it is impossible to avoid the spectre of HIV/AIDS and life expectancy remains poor for PLWA. As Mari observed:

*The reality of it is massive so really there is no way you wouldn't know about it because it's affecting everybody, everywhere, all aspects of life, so it's really a thing you grow up with, and yeah, it's devastating sometimes – unless you've been there, there's no way you can explain the situation – it's quite sad, especially if you saw the small children, their parents dead, there are just grandparents then, and they can't*

*do much of anything, so now it's going to be really plus plus  
poverty, there's going to be crime, there's no teachers, there's  
nothing there and we just wait and see*

(Mari 4<sup>th</sup> August 2009)

The sheer magnitude of the HIV/AIDS catastrophe in Africa is difficult to comprehend when observed from afar, there is a tendency for the human toll to become represented by numbers rather than countless individual stories of tragedy. During the interview with Mari, she never blamed the Western world for a lack of understanding of events in Africa, nor for the disparity between richer and poorer nations. Mari's sadness was apparent and the words 'unless you've been there' were oft repeated. Nevertheless Mari still managed to remain positive, she was training to be a nurse so that one day she would be able to return to Africa to help her people:

*Well I always have maybe this fantasy, I'll go back and really  
I'm so much challenged by HIV to do something, somewhere,  
somehow – if you can save even one, just one life, I think it's  
worth trying instead of just giving up*

(Mari 4<sup>th</sup> August 2009)

Contrasting with all the other participants, an undercurrent of sadness was evident during the interviews with both Mari and Pearl, the two nursing students from Africa. Sadness about the human toll that is the reality of

HIV/AIDS, and that there was no end in sight to the misery caused by AIDS in Africa. However such expressions of sadness were not entirely confined to the African students. Many of the other students concurred and also showed frustration at how foreign aid was being delivered to developing nations.

Pearl was exasperated that foreign aid to African nations to assist in combating HIV/AIDS was still not getting through to the people in most need:

*What I think it's just not getting to the right people, yeah sometimes it doesn't go to, it stops somewhere, it's available in some places and it's not in the other places – I think countries should do more of making sure it gets to where it should because sometimes it doesn't get there*

(Pearl 10<sup>th</sup> September 2009)

This view was echoed by Mari who bemoaned the lack of aid and how little gets to where it is intended, she had firsthand experience in Tanzania of seeing those in most need missing out on aid intended for them:

*Yeah, that's really, really making me sad*

(Mari 4<sup>th</sup> August 2009)

Those concerns that aid was not reaching its intended target were shared by other participants. Melanie had previously experienced being a volunteer on an aid project in a rural region of South East Asia. Upon returning to the



country's capital, she was outraged to see the number of expensive cars on the road, she commented:

*I mean I found it hard, I know from my own experience going in to the capital and it was a first time in three months that I'd seen any cars besides the standard utes [Australian slang for pickup truck] and stuff you see throughout South East Asia and was looking at Ferraris and Hummers all owned by the NGO's, and you just sort of think, well where's that money coming from?*

(Melanie 10<sup>th</sup> September 2009)

Many of the students felt that the wealthier nations of the world, such as Australia, should be doing more to help poorer nations fight the spread of HIV/AIDS. Mieko felt that her government in Japan should be providing more assistance to combat HIV/AIDS around the world. However, she appeared to be somewhat pessimistic about whether it would actually make any difference in reducing the spread of HIV:

*Yes we can do more to help – we can do more to help more poor countries, like, of course medication is important, but education and hygiene also – but it's really hard to prevent more expansion of HIV, so I wonder can we reach that – someday can we achieve that?*

(Mieko 13<sup>th</sup> October 2009)

Mieko also showed exasperation with the slow rate of change in Japanese society and what she saw as a lack of international engagement by the Japanese Government on issues such as HIV/AIDS. There was a perception by Mieko that large sections of Japanese society still favoured an isolationist policy and encouraged the belief that HIV/AIDS was predominantly a Western disease:

*Japan is like an island, a very small island and although we can get any information we want by internet, but I think it is like we are still in the war – it's hard for Japan to be influenced by other countries like Europe or America, it's simply not connected, yes isolated*

(Mieko 23<sup>rd</sup> August 2011)

Yue was certainly in favour of wealthier nations providing more support for poorer nations, and she was very concerned about the increasing disparity between countries:

*I think we should probably do more to support them – so I think that the rich countries like Western countries should do more stuff to help them, not just in AIDS control but in other situations as well – but I think in the world the richer country becomes richer and the poorer country becomes poorer*

(Yue 21<sup>st</sup> November 2009)

**Summary – Sub-theme: Disparity**

There were concerns expressed by many of the nursing students that much of the aid to the developing world was not getting through to the people who really were in the greatest need. This was a common perception and contributed to the disquiet expressed by many of the students at the disparity between richer and poorer nations. Many of the participants expressed the desire to one day be able to work in developing nations to directly contribute to helping some of the most disadvantaged people in the world. The students showed their awareness and concern at the social inequalities, and injustices in general, that exist in the world, and for some of the students, specifically in the context of HIV/AIDS. All served to demonstrate the values held by the participants, their morality and strong sense of right and wrong, along with the belief that more should be done to alleviate disparity and inequities in the world.

**Sub-theme: Professional values**

The concerns, beliefs and ideals of the study participants presented in the above sub-theme demonstrated some of what was important to them, their concern for others, their moral values. Being incorporated into this value system was a set of professional nursing values that the nursing student participants were developing. The concepts and traits of care, compassion and duty are part of the professional values expected of nurses. There is an expectation that nurses will not only provide care to their patients, but that this will be ‘humanly sensitive care’ (Galvin & Todres 2011, p. 523). This developing professionalism became apparent during the nursing student interviews and is demonstrated below by interview excerpts. Yet these

professional values at times conflicted with personal beliefs associated with blame and ‘othering’, as highlighted in previous chapters. Reconciling this conflict, or cognitive dissonance, presented a personal challenge to the nursing students. People use different strategies to reduce or reconcile their cognitive dissonance, some study participants were able to do so more readily than others. The concept of cognitive dissonance was defined by Festinger (1957) and is the state where a person is experiencing mental stress or disturbance due to holding two or more contradictory beliefs, ideas, or values at the same time (Festinger 1957; Fontenot, Hawkins & Weiss 2012; Kneer, Glock & Rieger 2012; Yousaf & Gobet 2013). Cognitive dissonance theory is a central concept in social psychology (Cooper, 2007; Metin & Camgoz 2011; Visser & Cooper 2003).

A great deal of idealism and enthusiasm for the nursing profession was evident among the study participants. Sang showed some of her moral values and compassion when she described the ideal she was striving for as a nurse, as the interview excerpt below demonstrates. However this needs to be contrasted with Sang’s previously quoted description of PLWA as ‘bad people’ and her suggesting that the person recklessly spreading HIV ‘deserves to die’ (see Chapter 5, pages 129 & 135). Sang commented:

*As a nurse, for me I have an image of Angel, like Nightingale or something like that, so I want to be like that sort of nurse – rather than one who is just working like a machine – and I think everyone should be respected ...*

(Sang 21<sup>st</sup> November 2009)

Sang had commenced the nursing program at university in Australia only a few months before being interviewed. Although Sang was a graduate entry student, she had no nursing background (her previous degree and profession were in commerce), and had come to Australia to pursue her dream, her idealism and her humanity, by becoming a nurse. The strong professional values demonstrated by Sang contrasted with her personal beliefs which blamed, stigmatised and 'othered' PLWA.

The same compassion, professional traits and idealism demonstrated by Sang were shared by Fan who had also only been in Australia for a few months at the time of interview. She advocated for fairness and equality in health care for everyone:

*No matter who's male or female, how old is he or she, where he's from, his or her religion, it doesn't matter, he's got his own right to get a proper treatment, no matter if he's HIV or something – you can't treat some with any discrimination out there*

(Fan 4<sup>th</sup> August 2009)

However, this somewhat contrasted with the fears of providing care to PLWA that Fan had, as demonstrated by the following excerpt previously quoted in Chapter 5:

*It's kind of dilemma, I really try to help her, but I feel uncomfortable, maybe I try to wear gloves and hold her hand, but if I wear gloves it's not respectful to her, so it's really hard – I would probably say no to hold her hand, it's like my*

*psychological fear, to be with her or sit with her is OK, but no  
to hold her hand*

(Fan 04<sup>th</sup> August 2009)

Jiao had similar fears to Fan (see Chapter 5, page 141), yet she wanted to do the best she could to care for the HIV positive patient in one of the scenarios presented to her, she carefully thought about her role and the care she wanted to give:

*Yeah, I think I would – at first I would give him some  
psychological support and let him know – make him feel better  
and let him feel he does not have to face it by himself, a lot of  
people can help him – give some help to him – some people  
have no love in their hearts so if more people can help him,  
then things will be better*

(Jiao 8<sup>th</sup> October 2009)

Australian nursing students echoed the caring and compassionate views of Sang, Fan and Jiao. For example, Fiona commented:

*In my opinion, it doesn't really matter – HIV as well –  
someone's on their death bed, then it doesn't really matter  
how they die, you want to provide the best care that you can,  
or in any case – not just on their death bed, but in any  
situation*

(Fiona 3<sup>rd</sup> August 2009)

However Fiona indicated her care would be influenced by her peers. She struggled to reconcile the conflict between wanting to provide the best care that she could, with wanting to conform to her peers:

*I think the main issue for me would be – cause you'd get a lot of attitudes from other nurses around the nursing station where you work – it does, sort of, influence how you sort of care for patients to an extent, for sure, yeah, that would be for me the main thing*

(Fiona 3<sup>rd</sup> August 2009)

Learning to reconcile such inner conflicts was part of the professional nursing values that were still developing in the nursing students. While Deng had previously worked as a Registered Nurse for three years in China before coming to Australia, he had to adjust his practices and professional values to suit the Australian context. In relation to the scenario of a female patient about to die from AIDS, Deng showed his compassion by indicating his willingness to sit and hold her hand to provide comfort as her life ended. While he indicated his willingness to hold the dying woman's hand, this was not something he had ever done as a nurse working in China, in fact he had not considered it part of his role as a nurse in China. According to Deng:

*Hold her – yeah I think it's okay, hold hands, I think I can fulfil this desire, this request. But if this is in China – basically in China, when a patient is going to die, it's almost – their family will accompany them. Most nurses don't be with her –*

*stay with her, I think it's mostly the family's job – that's very different here [in Australia]*

(Deng 12<sup>th</sup> October 2009)

The concept of someone dying in hospital without family beside them was alien to Deng, so although he was compassionate and felt sadness for the dying woman, he also felt a sense of duty to fulfil the role he would normally expect of the family. There was a perceived link between AIDS, loneliness and dying alone, AIDS was seen as a lonely death away from the traditional care and comfort of the family.

While Jiao was a little uncertain about the differences between the health care systems in China and Australia, the needs of the patient were paramount in either context. Jiao was clear about her role and identity as a future nurse, she showed her compassion when she stated:

*I think probably the first step for a nurse or doctor – you know whatever we do is to try and do some things better for patients – is to do the best for the patient because we have to think about the whole therapy or care of the patient*

(Jiao 8<sup>th</sup> October 2009)

The sense of social responsibility and awareness of family was strong among the Chinese nursing students, and this was informing their developing professional nursing values. There was compassion and a sense of duty to the family, and a sense of duty as a nurse, to act when the family was missing.



Lee talked about her sense of duty when discussing the same scenario as Deng referred to above:

*In my mind, I think the nurses have the job or the duty like, for me, I think we should [stay with the patient] we have to make the patient feel comfortable, although like she's dying like – because she's dying that's why I want to do this but I'm not sure, is it a job for the nurse, but for me I would do it because I'm comforting her and try to imagine if she is you and when you're dying you want someone to be with you, and then you're not alone. And in her situation she doesn't have family, so yeah, I think she's scared, that's why I think the nurse should stay with her – if they can do it*

(Lee 2<sup>nd</sup> October 2009)

Mieko was also touched by the thought of someone dying alone. Her compassion was obvious when she recounted a personal experience from her recent student nursing clinical placement in which she developed a bond with a dying woman she was caring for:

*... so the last day of my placement I said thank you to her, I went to her room and I said thank you to her and I said I wish that you could be better and she cried a lot, yes – she didn't have any visitors so she felt very lonely – I was so emotional when I see her tears*

(Mieko 13<sup>th</sup> October 2009)

There was no open criticism by Deng, Lee or Mieko of Australian society where people can die alone without family being with them. However all three students showed a sense of duty to assume the obligations of family, and compassion towards the person dying without their family alongside them. This was a strong part of their identity and it helped them to reconcile conflicts with personal beliefs which contributed to their fears of nursing PLWA. However none questioned why the person with AIDS was dying alone, there appeared to be an acceptance that AIDS created a lonely death.

While all but one Australian nursing student showed great compassion, noticeably absent were concepts of duty and of family obligations. Melanie was more than happy to sit with the dying woman provided it did not interfere with her other duties:

*Yeah I would, yeah I mean as time permitting and that, yeah  
I would sit there and talk to her and whatever she wanted*

(Melanie 10<sup>th</sup> September 2009)

But Melanie's compassion stemmed more out of sympathy and her empathy with someone who had contracted HIV through illicit drug use, rather than a sense of compassion because the person was dying without their family around them. Melanie's involvement with illicit drugs has been previously mentioned. In a similar fashion, Alice indicated enormous sympathy for the dying woman, she felt:

*Obviously compassion, yeah, she's had a horrible life, she's  
had no life and it was taken over by drugs at such a young*

*age, and you wonder what was the catalyst to start injecting at that age, it's very very sad – just have complete compassion for her, it's very very sad*

(Alice 10<sup>th</sup> August 2009)

As well as having empathy with illicit drug users, Alice also indicated her compassion was, as least in part, related to her knowledge and empathy for women working as prostitutes (also part of the same scenario presented to the students). Alice had no hesitation about holding hands with the dying woman. She had no doubts about her personal values and role as a nurse, and no doubts whatsoever that:

*I know I'm not going to catch HIV from holding her hand – and yes, holding her hand, that's a very important part of the nursing role*

(Alice 10<sup>th</sup> August 2009)

Rachel, concurring with Melanie and Alice, also had great compassion for the dying woman:

*I feel that would be part of my job to be there, to sit there and hold her hand, absolutely. I'd lay down with her and give her a cuddle if she wanted to – I've got no hesitation, no problems whatsoever, it doesn't matter what the circumstances are, in my head if somebody's dying and they're scared, or even if they're not dying, but if they're scared and alone, then they*

*need someone to comfort them, well then, that's what you do really!*

(Rachel 30<sup>th</sup> September 2009)

Providing care in such a manner was something Rachel considered to be an important part of a nurses' job, and an important part of the professional values of the Registered Nurse. Rachel talked freely about her empathy for people who had, as she described them, 'a chequered past'. The life experiences of Melanie, Alice and Rachel, and their socio-cultural backgrounds, had helped to mould their perceptions and values. They generally showed less in the way of conflict between their personal beliefs and professional values than did their Asian peers.

Participants, who were interviewed twice, with a two year interval between interviews, demonstrated that their developing professional values were becoming better reconciled with conflicting personal beliefs. Pearl's compassion for someone with AIDS dying alone had evolved and changed over time as her knowledge about the disease increased. She contrasted the actions she would have taken when living in Nigeria in the past, with what she would have currently done in Australia at the time of interview. In relation to the same scenario discussed above, Pearl, when asked if she would sit and hold hands with the dying woman, replied:

*When I read it now, with what I know now I will sit with her, but if it was back when I was in Nigeria, they don't have enough education about this I wouldn't sit with her, back*

*then – I was not scared of dying but scared of HIV, but now I have more knowledge, so yeah, I will sit with her*

(Pearl 10<sup>th</sup> September 2009)

Two years later this changed perception was again very apparent during a follow-up interview with Pearl. Having more knowledge was partly responsible, but it was also a contextual and cultural change as well. Moving from one country to another had helped to change Pearl's perceptions, and helped to form her professional nursing values:

*Yeah, so I've been really, really scared if I'm still there [in Africa], it's still scary there. But here, now, I think coming here [to Australia] has sort of changed my perspective because I'm here now, I feel like – if I'm in Africa I think I'd still be really, really scared to death*

(Pearl 27<sup>th</sup> July 2011)

Many of the students felt a strong sense of duty towards their patients; this was part of the professional nursing values they were coming to embrace. In fact some participants indicated that their actions would be determined more by this sense of duty, rather than an intrinsic sense of compassion. Chinese Ying showed a strong sense of duty towards her patients. She perceived this duty as her job, part of the professional role of being a nurse, yet there was a degree of detachment associated with this sense of duty. When considering the scenario relating to a woman dying of AIDS as discussed above, Ying felt that it was her professional duty to put aside her fears and provide care to her

patient, but with little involvement either. This was another aspect of her values, raising the question as to whether her sense of professional duty and her professional values correlated. Ying commented:

*Yes, I'm her nurse, I have responsibility to take care of her, this is my shift I have to do everything about her – that's my responsibility for taking care of her so I'm not scared. If this patient was in my country, I think – how to say – probably I have no idea to talk with her – she is a patient, I am a nurse, I just take care of her because I am professional*

(Ying 25<sup>th</sup> August 2009)

While Ying would provide professional nursing care to the person dying from AIDS in any context, she did perceive there would be some differences in her care between the Chinese and Australian context. When discussing this further with Ying during a follow-up interview, she stated that her personal beliefs were unchanged by the context. However, she did recognise the context did place different expectations on her when nursing PLWA. Ying has been previously quoted (see Chapter 5, page 142) as believing PLWA were 'bad people' who should be placed in special hospitals to monitor them. These views or beliefs did not appear to cause any conflict for Ying with her professional nursing values. She had reconciled them by adopting a professional but detached nursing persona. Whether this would allow her to provide the same high quality of nursing care to PLWA as to her other (non-stigmatised) patients is debatable.

Ying also explained that although she had a sense of duty and responsibility to care for all her patients, how they contracted HIV did influence the care she would provide:

*I'm a nurse and if I have to look after people who have HIV because of blood transfusion, because the people didn't want to be infected, so I feel sorry for them, I will be kind to them. But if I look after people who suffer HIV from illegal reasons, because it's hard to know the reason they did that – you just do what you can for the patient*

(Ying 25<sup>th</sup> August 2011)

Yue's perceptions were a little different. When talking about showing care and compassion to PLWA, Yue observed that duty only went so far. She appeared to be indicating that nurses should be able to choose to put their personal beliefs ahead of their professional values when it came to providing nursing care to PLWA:

*I think the nurse – the job of the nurse to just care for people, and it's sort of part of the job – but if the nurse don't want to do it – I think they don't need to do it*

(Yue 21<sup>st</sup> November 2009)

Reconciling confusion and conflict between the nursing role and personal beliefs presented a challenge to Yue. Nursing students are often confused about their role (Hjalmskult 2009), therefore part of their learning is to develop strategies for how to reconcile conflicts between personal beliefs, professional values and expectations of the nursing role.

During the interview, students were most emphatic about ‘that’s not my job’ when considering issues that challenged their personal beliefs. Discussing sexuality and sexual practices, HIV status, or interacting with people who are homosexual or drug users, were all issues that many participants found challenging. Traditional cultural beliefs and taboos were particularly strong with the African and Asian students, less so with the Australian participants.

The issues the students generally struggled to discuss were all issues commonly associated with HIV/AIDS and PLWA. When asked if she would be comfortable about discussing such issues with her patients, Pearl was quite emphatic:

*No, that’s not my job, I will not discuss these issues – but, I’ll just walk away from this situation and maybe come back later, and probably tell maybe a doctor or someone else*

(Pearl 10<sup>th</sup> September 2009)

The expectation of the nursing role in this situation proved too much of a conflict with Pearl’s culturally informed beliefs. Pearl was not alone in this, and students responded in a variety of ways, often by assigning responsibility to someone else. Most commonly the ‘someone else’ was a doctor, ‘it’s not our job’, ‘I can’t handle it’ and ‘the doctor has responsibility’, were mechanisms used by participants to respond to conflicting values. Another tactic a number of students wanted to employ was to ignore anything that challenged their values too much. That was how Yue responded in relation to



a patient talking about issues she was uncomfortable with. She described her attitude as being part of her culture:

*As Chinese people we are traditional so basically we ignore him, I just finish my job and he says what he likes, I just ignore him and other issues that arise – but if he talks more about me – like if he says if you want to have sex with me and then blah, blah, I will probably report him*

(Yue 21<sup>st</sup> November 2009)

However, in some cases education and experience did appear to have reshaped student perceptions. After Pearl had graduated and been working in a large Australian acute hospital for six months, she expressed greater confidence in being able to raise these issues, although she still preferred someone else to do it:

*If they want education about what they will need to do, how they need to take care of themselves, I think I can do that. I do feel better about doing it now although I would prefer if there's a senior nurse to do it, if I was left with it, I think I would still be alright to do it*

(Pearl 27<sup>th</sup> July 2011)

Similarly, Yue's position shifted somewhat over time although she also still preferred someone else to tackle the issues:

*We don't have time to provide actual – we don't have time to provide sort of education, but ideally we should do that. I mean, I don't have professional training like a psychologist, counsellor or social worker – the government should put money into helping them do it rather than it be the nurses' job*

(Yue 3<sup>rd</sup> October 2011)

**Summary – Sub-theme: Professional values**

Coexisting with the personal beliefs of the study participants was a sense of idealism and a striving to uphold the professional values expected of the Registered Nurse role. The nursing culture of compassion and social responsibility was common across all the nations and cultures represented by the nursing students. In tandem with the compassion shown by almost all the participants, a sense of duty was particularly evident among the Asian nursing students. Reconciling conflict between the professional values the students were striving for and their personal beliefs and values, presented challenges for many of the nursing students, with some placing greater emphasis on personal beliefs than on professional values.

**Conclusion – Theme: Values**

Contrasting with previously discussed perceptions of blame and 'othering', the nursing students participating in this study demonstrated positive and strong moral values in the way they perceived health disparities around the world. There was general acknowledgement among the participants that HIV/AIDS is a global epidemic and recognition of the social inequalities endured by PLWA throughout the world. National and cultural boundaries

were transcended when it came to wanting wealthier countries to provide more aid and assistance to poorer countries in the fight to contain the spread of HIV/AIDS and reduce the global disparity in availability of treatment for PLWA. Many of the nursing student participants expressed a strong desire to go to developing nations at some point in the future to directly assist in tackling the health challenges faced by disadvantaged populations.

The perceptions of the nursing students towards the people portrayed in the scenarios they were presented with generally showed considerable compassion along with a sense of duty to their patients. These are all very positive attributes which help to define nursing and the professional values of the nursing profession. The students were all in various stages of finding ways to reconcile any differences between their culturally informed beliefs and perceptions, and their developing professional nursing persona and values. Some appeared to have resolved these conflicts, and were successfully synthesising their personal beliefs and values with their developing professional nursing values. However this was not always in a way that would ensure high quality nursing care, free of stigmatising behaviours, to all patients, including PLWA. Other participants were still struggling to achieve some reconciliation between their personal beliefs and professional values.

Values, the third and final findings chapter has generally focused on positive attributes and perceptions study participants demonstrated towards PLWA, presenting a counterbalance to the first two chapters of Blame and Othering.

The values of the nursing students were multifaceted and in a constant state of change. These values were, in part, a product of culturally construed personal beliefs and developing professional nursing values. Gaining an insight into the students' views and perceptions through the major themes and the sub-themes presented in the findings chapters, helped to contextualise the students and provide insight into their characterisation of issues such as homosexuality, IV drug use, HIV/AIDS, and PLWA. The following discussion chapter interprets these findings, in the context of relevant literature, and discusses their implications.

## Chapter 8 – Discussion

### ***Introduction***

This study set out to answer a research question: ‘What are the experiences and perceptions of nursing students studying in Australia, from a range of different socio-cultural contexts, of PLWA?’ The broad aim of the study was thus stated as, ‘to develop a deep understanding and appreciation of the perceptions held by nursing students from different countries towards PLWA, and of the experiences that underpinned these perceptions in order to inform and influence curriculum development’. Stigma theory, which has provided the theoretical framework underpinning the study, also informed the following discussion.

To answer the above question and address the aim, this chapter discusses what the researcher considers to be the four most significant aspects of the findings from the study. Each of these four aspects is headed by a statement which summarise the nature of the findings for discussion. While presented as discrete sections for discussion, they are interrelated and there is overlap between them. The four statements are:

1. A well-developed understanding of culturally construed beliefs and perceptions is essential before nursing students can address stigma impacting on PLWA
2. Nursing students struggle to correlate and reconcile personal beliefs and perceptions of HIV/AIDS and PLWA, with the professional nursing standards and values expected of the Registered Nurse

3. Professional values of nursing students can be at odds with the blame and 'othering' of PLWA stemming from their culturally construed perceptions of homosexuality and drug use
4. The co-existence of blame and 'othering' of PLWA, with indignation at injustice and aspiring to nursing students' professional values, demonstrates the need for a widening of traditional conceptualisations of stigma

Within each of the above aspects, the findings have been discussed in relation to relevant theoretical and research based literature, which have then led to the recommendations and conclusions of the study. The relationship between these elements is depicted in Figure 3. This illustration is a diagrammatic representation of how the researcher has conceptually related the study findings to theory and research literature, to answer the research question, and identify recommendations that emerged from the study.

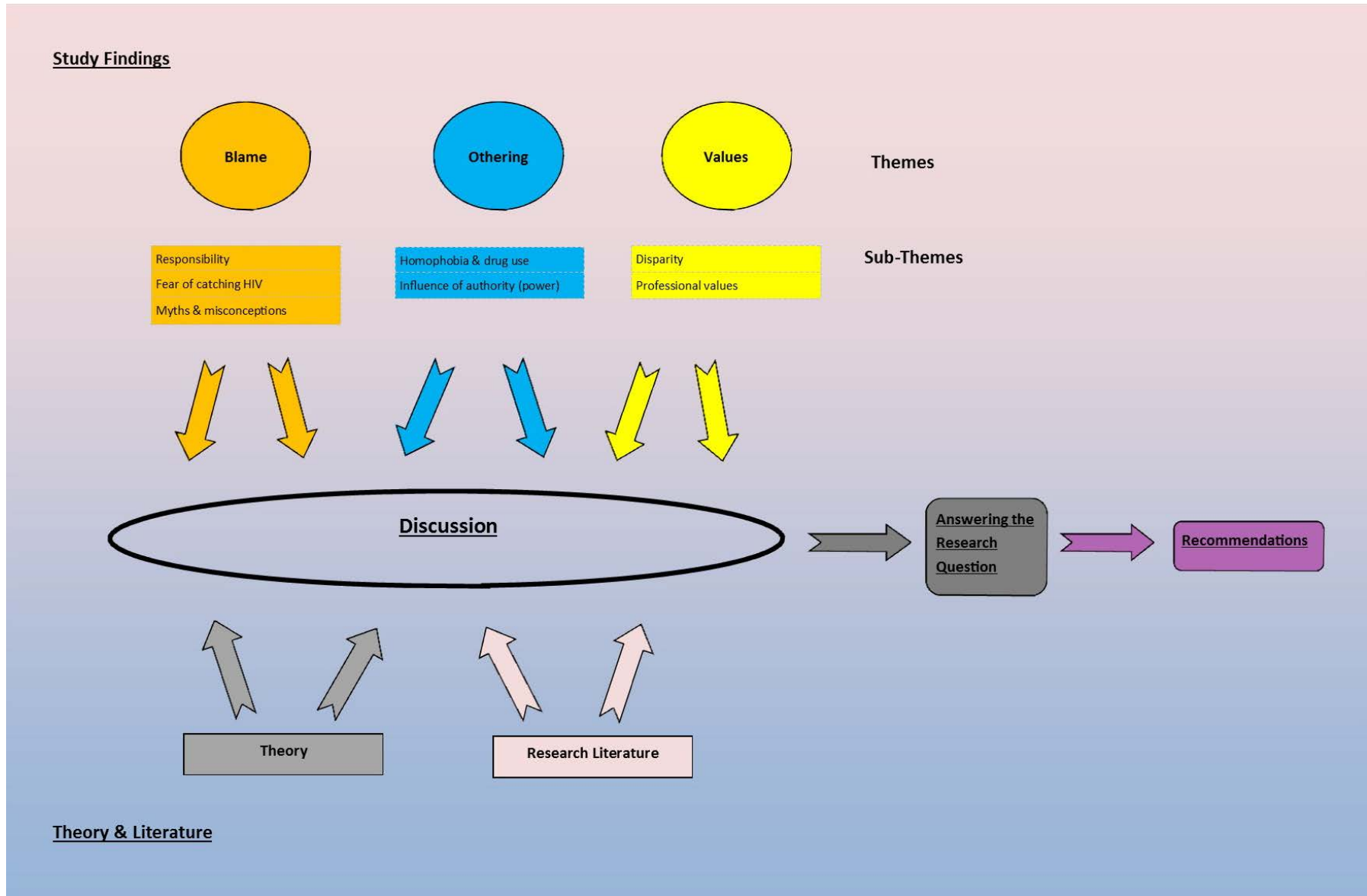


Figure 3: Illustration of relationship between findings, relevant literature, discussion and recommendations

## ***Discussion***

Each of the four main aspects of the findings will be discussed in detail throughout the remainder of Chapter 8. The recommendations will be presented in Chapter 9.

### **1. A well-developed understanding of culturally construed beliefs and perceptions is essential before nursing students can address stigma impacting on PLWA**

The culturally construed stigma and blame surrounding HIV/AIDS, the labelling of PLWA, and its impact on nursing student thinking, are the main focus of this aspect of the findings. Viewed through the lens of social constructionism, knowledge and understanding are developed in a social context (Cruickshank 2012; Holloway & Wheeler 2010). Similarly, truth, meaning and reality are socially construed, they evolve from cultural beliefs, perceptions and social practices. These beliefs, perceptions and social practices do not remain static. What is understood as truth and reality, and how meaning is attributed, are all a consequence of social practices, structures, cultural beliefs and perceptions (Cruickshank 2012; Fairclough 2002; Holloway & Wheeler 2010; Kim 2011; Paley 2010). Culture and context are central to interpreting phenomena in the world, hence culture and context must be considered if HIV/AIDS stigma is to be addressed.

Literature has clearly demonstrated the fear and blame associated with HIV/AIDS, and also the stigma that surrounds both the disease and PLWA (Akansel et al. 2012; Brener et al. 2013; Chan & Stooove, et al. 2007; Land & Linsk 2013; Li, Scott & Li 2008; Relf et al. 2009; Winskell, Hill &



Obyerodhyambo 2011). Additionally, literature has indicated that PLWA are not only stigmatised for having HIV/AIDS, but are also are often assigned one or more co-stigmas of being homosexual or an IV drug user. Being perceived as different, or 'other', and socially ostracised from mainstream society is a direct consequence of these stigmas. The nursing students participating in this study brought with them the dominant cultural beliefs of their society to their nursing studies in Australia, including their culturally construed perceptions of people who are homosexual, drug users, or PLWA. The blame and 'othering' found to be major themes in this study concurs with and supports the findings reported in previous research literature (Patterson 2010; Relf et al. 2009; Välimäki et al. 2010; Winskell, Hill & Obyerodhyambo 2011). In addition, what the current study has demonstrated is how deep seated these cultural beliefs and perceptions are, and, in the context of a multicultural nursing student cohort, the considerable diversity in the characterisation of PLWA. While this finding is supported by literature (Patterson 2010; Relf et al. 2009; Välimäki et al. 2010; Winskell, Hill & Obyerodhyambo 2011), these, and most other studies contrasting cultural differences, have contrasted people living in different countries. This is distinct from the study reported here in which the study cohort have different cultural backgrounds but also have the common context of living and studying in Australia to become Registered Nurses in Australia.

In many instances culturally construed perceptions and beliefs caused the students to see PLWA as being a threat, and to overlook many of the social inequalities associated with HIV/AIDS. The existence of such beliefs and

perceptions was highlighted by the comment from more than one of the nursing students participating in this study that, 'bad people' get HIV. These 'bad people' were perceived as presenting a tangible threat to the individual safety of the nursing students, even though the fear of contracting HIV vastly outweighed the risk for most people. Nevertheless, the current study demonstrated that these fears can result in a reluctance to provide care or nursing support for PLWA in the same manner as would be provided for other recipients of nursing support. This finding concurs with those of previous studies (Bektas & Kulakac 2007; Cornelius 2006; Juan et al. 2004; Mahat & Eller 2009; Nazik et al. 2012; Välimäki et al. 2010). Perceiving PLWA as being 'bad people' creates a barrier to the provision of high quality nursing support to them. Underlying the 'bad people' label were beliefs and perceptions of homosexuality and illicit drug use, how these were associated with PLWA is discussed further throughout this chapter.

While some of the Australian students demonstrated a degree of affinity towards people who contracted HIV through illicit drug use, the latter were still considered outsiders in a similar manner as were homosexual men. Within this established antagonistic cultural positioning towards drug users and homosexuals, a diagnosis of HIV/AIDS labelled a person as being deviant (Brener et al. 2013; McKay et al. 2011; Medina 2009; Sovran 2013), bringing an almost automatic disassociation from the dominant mainstream culture. This was evident in the current study through the 'bad people' label being assigned to PLWA, and in the way participants articulated their perceptions of homosexuality and drug use. The positioning and labelling of

PLWA as outsiders demonstrated the stigma associated with HIV/AIDS, which then created obstacles to the delivery of quality nursing care to PLWA.

Somewhat in contrast, and taking a strong moral stance, there was universal condemnation among the nursing students of anyone who knowingly spread HIV either through intent, indifference or ignorance. Although only the African students had firsthand experience of this phenomenon, there was a common outrage among all the students at any suggestion of the deliberate or apathetic spread of HIV/AIDS. While this was a moral and ethical stance that would reasonably be expected of nursing students regardless of their nationality or culture, it did however, serve to strengthen perceptions of blame and 'othering' towards PLWA.

Such behaviour, of recklessly spreading HIV, was perceived as being almost entirely behaviour made by individual choice. The exception to this perception, for some students, was if the PLWA was also suffering from a mental illness. Otherwise there was little conception that society might play a role in such behaviour. Blame and individual agency/choice went hand in hand for most of the nursing students, although there were culturally inspired differences. For example, Sang blamed people for having an enjoyable sex life, whereas Heng perceived society to be attributing homosexual sex as carrying most of the blame for HIV/AIDS. This overall perception spanned cultures with the exception of the African students who, although strongly condemning such behaviour, showed an understanding of context and the role played by society. Overall, there was a definite lack of appreciation of

wider social influences and determinants that contribute to behaviour which can increase the risk of HIV infection (Skovdal & Belton 2014; Sutherland 2011; Underwood et al. 2011). There is limited research available with which to appraise this conclusion, particularly in the multicultural Australian context.

The beliefs and perceptions of many of the nursing students were significantly influenced by government actions. Typically government messages have been focused on the tangible threat posed by HIV/AIDS and on behaviour seen as increasing the risk of contracting the disease. The Chinese Government, for example, actively and openly used its power to demonise illegal drug use, it also endeavoured to humanise PLWA in an attempt to decrease stigma and limit the spread of HIV infection. Governments can play an important role to influence culturally construed beliefs and perceptions of PLWA and of HIV/AIDS.

The Chinese nursing students recounted stories that had appeared in the State media of individuals with HIV or AIDS, stories designed to inform and educate the population as to the risks and dangers of HIV/AIDS. The students clearly supported the role their government was taking in relation to HIV/AIDS, and were appreciative of the moral leadership of their government. However, analysis of Chinese media indicated that PLWA continued to be stigmatised, even when the media was attempting to present an anti-stigma message (Ren, Hust & Zhang 2010). According to Zheng (2009) the Chinese media has created an 'environment of hostile public

opinion to AIDS patients' (Zheng 2009, p. 56). The mixed messages from the Chinese Government and Chinese media were reflected by the Chinese nursing student participants. This was demonstrated in the contrast between Ying's strong support for Chinese Government attempts to humanise PLWA, and her characterisation of PLWA as being 'bad people'.

The role of powerful institutions such as governments in shaping beliefs and perceptions should not be underestimated. They must be taken into consideration with attempts to reshape deeply held beliefs and perceptions in relation to important social issues such as HIV/AIDS. There continue to be governments around the world that demonise homosexuality. In Russia, for example, at the time of writing, there was ongoing hostility and intolerance towards homosexuality among large sections of the population, including at the top levels of government (Anderson 2013; Cassidy 2014; Holzacker 2013; Kon 2010). Nevertheless, the position of governments are not static in relation to social issues, they do change over time, as does the degree of influence they have on their peoples' beliefs and perceptions (in this case, the beliefs and perceptions of nursing students).

This could be seen in Australia where the older Australian nursing students remembered earlier highly visible government campaigns to prevent the spread of HIV/AIDS, campaigns which had the effect of demonising homosexual men. However, in more recent years the Australian Government has played a less prominent role in combatting HIV/AIDS. This diminishing role of the Australian government was one the younger Australian students

demonstrated no awareness of. The focus and priorities of all governments change over time, with recent Australian Government HIV education and prevention campaigns not targeting the wider Australian population (Cameron 2014; McKay et al. 2011; Persson & Newman 2008). Currently there appears to be considerable contrast between the Australian Government and the Chinese Government in the role they adopt in fighting the spread of HIV/AIDS. These contrasts are mirrored in society, and in the study participants. Again, only a few of the students showed an appreciation of how society, and the institutions of society, can and did contribute to people engaging in so-called 'bad behaviour', and how this behaviour was perceived.

This study has demonstrated the existence of deep seated culturally construed beliefs and perceptions of PLWA among the study participants. While research literature supports this finding, the context of the current study presents a different perspective to previous research. Conceptualisations of homosexuality and illicit drug use, along with the associated stigma, fear and blame, are fundamental to perceptions of PLWA. Similarly, beliefs relating to behaviour attributed to PLWA, and government influences on these beliefs, also contributed to the students' perceptions of HIV/AIDS and to the stigmatisation of PLWA. Having an appreciation of these varied culturally construed beliefs and perceptions, as well as having an understanding of influences on them, is essential to the development of successful strategies to address the stigmas nursing students associate with PLWA.

## **2. Nursing students struggle to correlate and reconcile personal beliefs and perceptions of HIV/AIDS and PLWA, with the professional nursing standards and values expected of the Registered Nurse**

Nurses in Australia practice under the auspices of a regulatory body (the Australian Health Practitioner Regulation Agency). Furthermore, nurses remain bound by a set of Competency Standards, Code of Ethics and Code of Conduct (ANMC 2006b, 2008a, 2008b) within that practice. Nursing students must adhere to the Codes and work towards achieving the Competency Standards prior to becoming a Registered Nurse. A degree of incongruity could be seen between these expectations and the personal beliefs and perceptions articulated by the nursing students that participated in this study. For example, Value Statement 4 of the Code of Ethics for Nurses in Australia, states, in part, that nurses 'seek to eliminate prejudicial attitudes concerning personal characteristics such as race, ethnicity, culture, gender, sexuality, religion, spirituality, disability, age and economic, social or health status' (ANMC 2008a, p. 4). Some incongruity is apparent between this aim, and the blame and 'othering' of PLWA demonstrated by many of the nursing students participating in this study.

All the study participants were in a state of transition as they were moving from the role of nursing student to that of qualified practicing Registered Nurse. For many of the students this transition challenged their culturally construed personal values. As they were transitioning they sought to incorporate the professional nursing values expected of them in the context of

Australian society with, for some, its unfamiliar cultural norms and taboos. The nursing student interview data demonstrated that the students were working towards establishing a professional nursing identity for themselves. This required some degree of reconciliation of their personal beliefs and perceptions, with the professional nursing values expected of the Registered Nurse.

A number of qualities and values were articulated by participants as being requisite for a Registered Nurse, these included: respect for others; a belief that everyone has the right to receive treatment; the desire to provide the best possible care; a duty to one's patients. These correlate with the sweeping value statements made in the Code of Ethics for Nurses in Australia. One of the stated purposes of the code was to 'provide nurses with a reference point from which to reflect on the conduct of themselves and others' (ANMC 2008a, p. 1). Whether this process of reflection was actually consciously taking place among study participants was questionable. The interview data showed little evidence of awareness by participants of discrepancies between their personal values and the professional values they were striving for. HIV/AIDS was characterised by a number of the study participants as a feared Western disease associated with homosexuality, drug use, and permissive sexual activity. There were similar fears and characterisations among students from other parts of the world, albeit without the association of being a Western disease.



Powerful institutions such as government, religion and the family have frequently reinforced these characterisations of HIV/AIDS and PLWA. These perceptions, heard throughout this study, especially in relation to sexuality, were at odds with the expectation that nursing care be delivered without prejudicial attitudes, and meet the requirements of the Code of Ethics for Nurses in Australia (ANMC 2008a). Studies have shown that, depending on the patient's illness, negative perceptions and prejudicial attitudes can be found among some nurses throughout the world (Nash, Stuart-Hamilton & Mayer 2014; Rondahl, Innala & Carlsson 2003; Rosenburg, Taliaferro & Ercole 2012; Williams, N 2009). The current study has supported these findings among nursing students in Australia, more specifically in relation to negative perceptions of HIV/AIDS and of PLWA. Thereby demonstrating that some nursing students are at risk of not fulfilling their obligations under the Code of Ethics for Nurses in Australia (ANMC 2008a).

The Asian students had a definitive perception of nursing values with a strong sense of respect, responsibility and duty. In contrast the Australian students were more esoteric with a general commitment to ideals of providing the best compassionate care they could offer. However, the Asian students showed greater confusion about actually adopting the role of a professional practicing Registered Nurse and wanting explicit boundaries placed on their practice. This need was demonstrated when they became quite confused in the absence of clear demarcation between the roles of Nurse and Doctor when it was necessary for issues of sexuality and sexual practices to be discussed with patients. The nurses' role varies between countries, aspects

of the role in Australia are not part of the role in other nations, including how nurses and doctors interact professionally (Hearnden 2008; O'Neill 2011; Wright 2009). All participants expressed their intention of being able to use their role as a professional practitioner to help people, for the good of humanity. The African students, for example, showed a burning desire to do something for the people of Africa. Yet there was some incongruity between these esoteric intentions and participants' personal beliefs and perceptions of homosexuality, drug use, HIV/AIDS, and PLWA.

While the study participants were generally indignant about the social inequalities in the world, not all recognised or had considered the inequalities in relation to PLWA. At times they were torn between what they believed to be right, and their fears and perceptions which contributed to the stigmatisation of PLWA. Among the participants, the international nursing students experienced conflict between their developing professional nursing values as nursing students in Australia, and their personal values in the context of their native country. This conflict in values, found to be very much a part of the construction of the students' perceptions of HIV/AIDS and PLWA, has implications which need to be addressed by the nursing profession.

Conflict could also be seen between aspects of the nursing role and the personal beliefs and perceptions of study participants. One of the more challenging issues facing the nursing students was to discuss HIV/AIDS and interact with PLWA. The challenges ranged from social and cultural taboos

of discussing sex, sexuality and related issues, to inexperience and the lack of self-confidence felt by a number of participants. There was a noticeable reluctance among many of the students to discuss or confront issues with their patients that might in some way relate to sex or sexuality. Strong cultural influences underscored this reluctance, particularly for the students from Africa and Asia, with several indicating they felt that it was 'not my job' to do so. This concurred with Peiffer and Boussalis (2010) who found the 'stigmas associated with the disease [HIV/AIDS] are mired in cultural taboos' (Peiffer & Boussalis 2010, p. 570).

While there was recognition by the nursing students that an educational role is one of the responsibilities and requirements of a Registered Nurse in Australia (ANMC 2006b), cultural influences were a barrier to actually performing this role for a number of study participants. The need for nursing curricula to address the difficulties that nursing students have discussing issues of sex and sexuality with their patients has been highlighted by Washington and Pereira (2012) who describe these issues as 'closed door topics' (Washington & Pereira 2012, p. 64). This concurs with the findings of previous research over a considerable time span (Haboubi & Lincoln 2003; Herson et al. 1999; Magnan, Reynolds & Galvin 2005; Ussher et al. 2013; Weerakoon, Sitharthan & Skowronski 2008), and with the findings of the study reported herein, thereby suggesting that nursing curricula continue to struggle to successfully address this issue.

Research literature, from English speaking nations, exploring communication difficulties nurses from non-English speaking backgrounds have when becoming a nurse in an English speaking nation, tend to focus on language skills, local jargon and shyness in communicating with peers and other health care professionals (Bland et al. 2011; Crawford & Candlin 2013; O'Neill 2011; Wright 2009). Cultural barriers to effective nurse-patient interactions have been extensively documented, and given rise to the concept of transcultural nursing (Leininger 1991; Leininger & McFarland 2002; Leininger & McFarland 2006), yet there is a scarcity of literature focusing on the issue of culture contributing to reluctance by some nurses to fulfil the patient education role that is a requirement of the profession in Australia (ANMC 2006b), and in many nations around the world.

Cultural influences were not the only factors involved. A number of participants cited a lack of proficiency and confidence in using English language with their patients for this reluctance. Although they were sufficiently proficient in English to gain entry to the Bachelor of Nursing course at university, they lacked confidence in their own English language ability to discuss sensitive issues with patients. The level of language proficiency required to confidently and sensitively discuss highly personal and emotive issues with patients, was greater than required in the ordinary course of undertaking a Bachelor of Nursing Degree at an Australian university.

This conclusion correlates with studies which have explored the experiences in Australia of overseas qualified nurses, and the communication problems facing those from non-English speaking backgrounds (Brunero, Smith & Bates 2008; Jeon & Chenoweth 2007; Jeong et al. 2011; Omeri & Atkins 2002). As observed by Jeon and Chenoweth (2007, p. 18), 'communicating in a language different to one's mother tongue is not a skill that is easily mastered through study alone'. For many participants, language skills were an issue that compounded strong cultural taboos to discussing sex and sexuality issues. They found pressure to do so confronting as it challenged them to cross strong emotional and cultural boundaries. Thus, the important interrelationship between culture, language and communication skills has been highlighted. For many of the international nursing students, these issues presented a barrier to them developing the requisite skills to fully perform the Registered Nurse role.

Some of the Asian nursing students, Mieko for example, did express greater confidence and willingness to discuss sensitive issues after they had graduated with a Bachelor of Nursing degree and become more familiar with Australian society. However it should also be noted that some nursing students may make a conscious decision to maintain their adherence to the cultural norms and beliefs that they grew up with. Even after living in Australia for a number of years, Ying was adamant her views would not change because, as she put it, the 'culture is already in my mind'. This was not just about maintaining cultural heritage, it was also about choice and where the nursing students decided to position themselves in society. This

sense of culture and personal values they embodied could be in conflict with meeting the professional standards and values expected of the Registered Nurse in Australia. The nursing profession, including educational institutions and regulatory authorities, need to understand that providing knowledge and fostering tolerance and acceptance of difference may not necessarily lead to desired perceptual change in the individual, or desired outcomes in nursing practice (Jeon & Chenoweth 2007; Jeong et al. 2011; Stankiewicz & O'Connor 2014).

Nursing regulatory authorities in Australia set standards and codes which practicing nurses in Australia are mandated to adhere to. Educational institutions which provide nursing education in Australia, leading to registration with the Australian Health Practitioner Regulation Agency, structure their nursing programs towards ensuring their students understand their obligations and meet the requirements of the various codes and standards. However, evidence from this study indicated that nursing students, particularly international students, were struggling to meet some of these statutory obligations. It would appear that educational institutions need to work towards enhancing strategies that assist nursing students to address these issues, and ensure all requirements under the Competency Standards for the Registered Nurse are met before graduation.

### **3. Professional nursing values are at odds with the blame and ‘othering’ of PLWA stemming from culturally construed perceptions of homosexuality and drug use**

The portrayal of HIV/AIDS as the ‘gay plague’ (Rondahl, Innala & Carlsson 2003, p. 455) was previously highlighted in Chapter 2. While this was a more overt expression of homophobia, it was nevertheless typical of portrayals, attitudes and perceptions in the early days of the HIV epidemic, and the stigma surrounding homosexuality. Blaming male homosexuals for the spread of HIV and AIDS was the norm during the early history of the epidemic (Cornelius 2006; Earl & Penny 2003; Grossman, Wheeler & Lippman 1998; Ngan et al. 2000). Discourses of blame abounded, and the avoidance of contact with homosexual men was widespread as they were perceived as being a threat to health and wellbeing. The continued stigmatisation of homosexuality was evident among study participants. In Australia, the decriminalisation of male homosexual acts began in the state of South Australia in 1972 (Mindel & Kippax 2013). However the national decriminalisation process progressed slowly and was not complete throughout Australia until 1997 when the state of Tasmania repealed its laws criminalising male homosexual behaviour (Johnson 2008). Hence, all study participants who were born in Australia, were born in an era where laws still existed in parts of Australia criminalising male homosexual acts.

A 1987 report described AIDS as ‘a fatal disease that strikes at homosexuals ... with a catastrophic vengeance ... society has tended to blame the victim ... made to feel that they have deserved it’ (Ward & Papadakis 1987, p.

1136). In Australia, even more than 25 years after this report, the perception of HIV/AIDS as being a self-inflicted disease contracted predominantly by homosexual men has remained prevalent, including among participants in the current study. With the exception of the students from Africa, there was considerable commonality and similarity between the nationalities represented in this study on how homosexuality was perceived and stigmatised. Participants demonstrated limited acceptance of homosexuality, which was seen as deviance, and their perceptions continued the 'othering' and stigmatisation of anyone who was homosexual. The Australian students were more knowledgeable in relation to homosexuality than other participants, and this translated into greater empathy and understanding. However, perceptions associated with stigmatising behaviour persisted. There were indications of homophobia and reluctance by the students to question their own perceptions.

Homophobia in nursing is the fear of homosexuality which may result in the homosexual patient not receiving comprehensive, quality, holistic and compassionate care (Campo-Arias, Herazo & Cogollo 2010; Christensen 2005). Any risk to the provision of quality nursing care for all patients should be of concern to the nursing profession and something to be confronted. Although one of the nursing students declared his homosexuality during interview, he also characterised the male homosexual as being a stigmatised outsider. Again, there was considerable commonality among study participants with this characterisation and 'othering' of homosexual men.



This 'otherness' meant that homosexual men were people who were not able to be accepted as part of the cultural majority, their perceived deviance leading to social inequality. As perceptions and beliefs about homosexuality were central to the stigma directed towards PLWA, addressing these deep seated perceptions is essential if the stigma associated with PLWA is to be combatted. With regards to study participants, such perceptions were at odds with the professional nursing values expected of them as students working towards becoming Registered Nurses in Australia.

The nursing students from Africa, Mari and Pearl, commented on what they perceived as a subtle but overarching culture of blame in Australian society towards PLWA, where PLWA were blamed for contracting the disease. This surprised and saddened them as it was not something they had expected to find in what they perceived as a tolerant Western society. Their knowledge in that regard was lacking as blaming PLWA was almost the norm throughout much of the Western world (Brener et al. 2013; Foster & Gaskins 2009; Rogers & Mapp 2011; Seacat, Hirschman & Mickelson 2007). According to Mari the Australian students generally blamed PLWA for being homosexual, yet this was not entirely borne out by the interview data. Several of the Australian students, Janet and Susan for example, were quick to attribute blame to PLWA for drug use rather than to homosexual activity. However what was evident was a tendency among all the participants to blame and 'other' people who were homosexual.

Homosexual activity and drug use were perceived as threats and created fear among many of the nursing students, there was an inextricable association between HIV/AIDS, homosexuality and drug use. There were exceptions to this, Melanie and Anne both had firsthand exposure to illicit drug use, they were much less inclined than other students to blame or 'other' PLWA who were drug users. While the Australian students indicated a much greater understanding and empathy towards drug users than did their peers from other nations, they still tended to hold drug users responsible for their behaviour. Having personal experience or exposure appeared to significantly influence perceptions to be more empathetic towards drug use and drug users. This finding concurs with the findings of previous research (Duan et al. 2009; Francis 2011; Järvinen & Østergaard 2011; Scull, Kupersmidt & Erausquin 2014), and should be taken into consideration by nurse educators when developing HIV/AIDS educational programs.

However, while direct personal experience with drug use or drug users by study participants certainly moderated the blame assigned to people who contracted HIV via drug use (Rudolph et al. 2012), such experience did not eliminate perceptions of blame altogether. The implication being that drug users only have themselves to blame for contracting HIV as this was a logical and obvious consequence of IV drug use. Studies from around the world have consistently supported this characterisation of PLWA, where PLWA are blamed and held personally responsible for their own infection (Bogart et al. 2013; Fuster-Ruizdeapodaca et al. 2014; Lawson, Bayly & Cey 2013; Visser et al. 2009). While some of the nursing students did recognise that societal

factors played a role in illicit drug use, others did not. The Asian students in particular showed a lack of awareness of social factors, their perceptions of individual agency and blame were strong. In the case of the Chinese students, mirroring the stigmatising messages given, often unintentionally, by the Chinese Government and media over the previous decade (Gao et al. 2013; Ren, Hust & Zhang 2010; Sun et al. 2010).

The study identified that perceptions of blame varied among participants and tended to be associated with the most commonly perceived mode of HIV transmission in the student's home country. In contrast to the Australian students, the Korean students, for example, blamed PLWA for having permissive sexual attitudes and behaviour which presumably led to them contracting HIV, the Japanese student had similar perceptions. In both of these countries the students were of the opinion that HIV was predominantly transmitted via heterosexual sex, by irresponsible people who had a 'very enjoyable sex life', according to Sang. These people were perceived to present a tangible threat to the students, more so at a personal level, rather than in their nursing role. Socio-cultural factors influenced the nature of the perceived threat presented by PLWA, yet there was a commonality in the perception that a threat existed. These variations in perceptions of blame based on personal behaviour emerged as being important to recognise when developing strategies to reduce HIV/AIDS stigma, as well as closing the gap between professional nursing values and personal beliefs held by nursing students.

The African students associated AIDS with death as families throughout Africa were affected in some way by the experience of death from AIDS (Ansell et al. 2012; Boon et al. 2010; Iwelunmor & Airhihenbuwa 2012). The Asian students not only associated AIDS with death, but also with loneliness and dying alone. The perception of people with AIDS dying alone can be connected to the 'bad people' image evident among the Asian students. That is, 'bad people' might be expected to not have any friends or family therefore they die alone. This does not suggest that the 'bad people' image was not evident among the Australian nursing students, some certainly perceived PLWA in that way. Associating PLWA with death and loneliness, or labelling them as 'bad people', does not sit well with the attributes expected of a Registered Nurse. Although the Australian students made the association between AIDS and death, they did not make the same connection with being lonely or dying alone as described by the Asian students. Cultural perceptions of the role of the family perhaps contributed to such differences.

Nevertheless, with regards to HIV/AIDS, the threat posed by death and for some, loneliness, was perceived by most of the nursing students. Such perceptions are common in society, for many people 'HIV is a lonely person's disease' (Edwards, Irving & Hawkins 2011, p. 1369), and facing death from AIDS or an AIDS relate illness is a lonely experience (Habib & Rahman 2010; Ogunmefun, Gilbert & Schatz 2011; Trainor & Ezer 2000).

In addition to the more obvious homosexual/drug user labels given to PLWA, the nursing students also placed them in categories of being lonely and isolated people, miserable people, and people with whom there was an

automatic association with death. Labelling of this nature 'others' people and can be detrimental to the nursing care being provided, and the care provided may be based on the perceived needs of each category a person has been characterised as belonging to. Assumptions and labelling can hinder the individualisation of health care to best meet the needs of each and every client, something all nurses, and nursing students, should be striving to achieve. Personal beliefs and perceptions do intersect with professional nursing values, the challenge is to make this a positive coming together, rather than a continued discordant collision.

#### **4. The co-existence of blame and 'othering' of PLWA, with indignation at injustice and aspiring to professional nursing values, demonstrates the need for a widening of traditional conceptualisations of stigma**

When considering the conceptualisation of stigma for this study, stigma theory espoused by Deacon, Stephney and Prosalendis (2005) was used. Stigma can be perceived as an ideology revolving around perceptions of fear and blame. 'HIV/AIDS stigmatisation relies heavily on existing prejudice and social stereotypes' (Deacon, Stephney & Prosalendis 2005, p. 25). This stereotyping and negative portrayal of PLWA serves to 'other' them, to set them apart from mainstream society, to create an environment of social inequality. The social inequality associated with HIV/AIDS results from the blame and 'othering' of PLWA. However, the findings of this study have demonstrated that, in addition to the stigma associated with blame and 'othering', participants also demonstrated a strong sense of moral outrage and righteousness, while at the same time struggling to reconcile their personal

beliefs and perceptions with the professional nursing values expected of them.

Hence, to develop a deeper understanding of nursing student perceptions towards HIV/AIDS and of PLWA, it is necessary to look beyond the more traditional, narrow, blame and 'othering' focus of stigma theory, and to embrace a wider conceptualization of stigma. A conceptualization where stigmatising personal beliefs and perceptions can and do co-exist, in a constant state of flux, with indignation at injustice and professional values defining what is 'right'.

The AIDS epidemic in Africa has been described as 'a humanitarian disaster of millennial proportions' (Young 2005. p. 460). Only Mari and Pearl had witnessed firsthand the impact of HIV/AIDS as the disease devastated their home countries in Africa. There was a strong perception on their part that, no matter how well meaning, the rest of the world could not really comprehend the enormity of the calamity that HIV/AIDS brought to Sub-Saharan Africa. This was aptly summed up in Mari's lament, 'unless you've been there'. While the nursing students from elsewhere did recognise that Africa was particularly hard hit by HIV/AIDS, there appeared to be a general lack of real consciousness of what this actually meant for the people of Africa.

Nevertheless, national and cultural boundaries were transcended when it came to wanting wealthier countries to provide more aid and assistance to poorer countries in the fight to contain the spread of HIV/AIDS. This

provided a real contrast with perceptions of blame and ‘othering’, highlighting the coexistence of a strong sense of morality and positive values along with the negative perceptions. The nursing profession has accepted norms of ethical behaviour which are embedded in the professional values expected of study participants (ANMC 2006a, 2008a). These positive professional values and strong sense of morality are at odds with the major conceptualisations of stigma which revolve around blame and ‘othering’.

As has been discussed throughout this chapter, reconciling personal beliefs and perceptions with professional values and morality presented challenges, both for the individual, and the underlying theory. In his seminal work during the early 1960’s, Melvin Lerner theorised that people have a need to believe in a world where good behaviour or attitudes are rewarded and bad behaviour or attitudes are punished. The basic assumption being that it is necessary for people to believe the world or environment they live in is just and fair (Hayes, Lorenz & Bell 2013; Lerner & Lichtman 1968; Lerner & Miller 1978; Miller 1977). Lerner further theorised that the consequences of behaviour are predictable and socially construed. Although the consequences of behaviour may not be immediate, eventually ‘people generally get what they deserve’ (Lerner & Miller 1978, p. 1030). Clearly evidence can be seen, on a daily basis, of injustices in the world, hence people use various strategies to reconcile these injustices. Believing in a just-world gives people a sense of safety by making the world appear more predictable and controllable (Hayes, Lorenz & Bell 2013; Lucas et al. 2009). It provides

people with 'psychological buffers against the harsh realities of the world as well as personal control over one's own destiny' (Furnham 2003, p. 796).

When people see an injustice in the world, they attempt to re-establish justice through a variety of approaches. In some cases they may attempt to intervene to right the injustice or to alleviate suffering by demonstrating empathy and trying to engage in helping behaviour (Furnham 2003; Lerner & Miller 1978). This concept was demonstrated by the study participants wanting more aid and assistance provided to fight the spread of HIV/AIDS. Many of the students expressed the desire to volunteer to go to Africa at some stage in their future nursing career in an attempt to contribute to improving the health of some of the most disadvantaged people in the world. Among the Asian students there were expressions of the desire to go and assist in poorer Asian nations, Cambodia and Laos were mentioned, as well as helping in Africa. This strong sense of values, along with social and political will, was shared by most of the nursing students, as typified by Rachel's observation that 'helping makes you rich'.

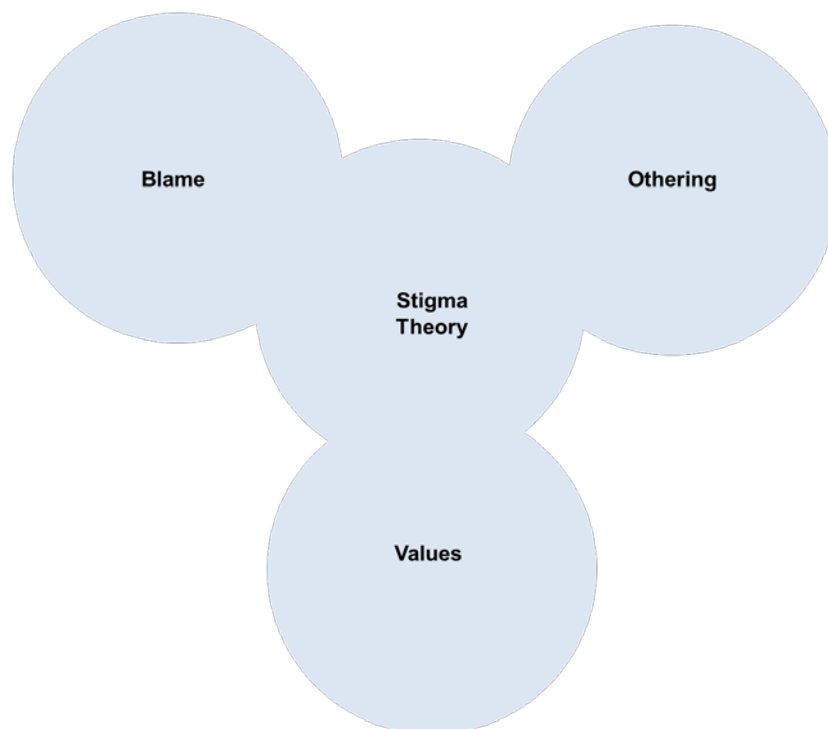
In stark contrast to wanting to right injustices, people can take quite a different approach in an attempt to re-establish their own sense of justice. One such way is to derogate the victims of injustice. People are held personally responsible for their own fate, which is then perceived as a direct consequence of their own behaviour. This is the process of victimisation or victim blaming (Bizer, Hart & Jekogian 2012; Furnham 2003; Hayes, Lorenz & Bell 2013; Miller 1977), and has been widely discussed in relation to study



participants during chapters 5 and 6 of this thesis. There are obvious parallels between the work of Lerner and that of his contemporary, Erving Goffman, in relation to stigma theory, especially between the concept of people getting what they deserve and victim blaming. As previously discussed (see page 239), study participants demonstrated a deficiency in awareness of the wider social influences that can contribute to risk taking behaviour which increases the risk of HIV infection. A lack of appreciation of the wider social determinants of health can contribute to victim blaming and the stigmatisation of PLWA. In re-evaluating conceptualisations of stigma, knowledge and understanding of the role of the social determinants of health, and how this potentially contributes to victim blaming, needs to be taken into consideration.

The blame and ‘othering’ displayed by study participants has correlated with the blame and ‘othering’ conceptualisation of stigma theory. However, not correlating with this conceptualisation of stigma theory, were the strong and positive moral values expressed by study participants in relation to the injustices suffered by victims of HIV/AIDS. This sense of positive moral values co-existed with their blame and ‘othering’ of PLWA, a coexistence which was not necessarily in harmony. Along with personal beliefs, perceptions, and values, how people identified themselves also influenced how they interacted with PLWA. This conflict applied to the nursing students in the study described here, and many experienced variance between their personal beliefs and the professional nursing values they were trying to identify with as aspiring Registered Nurses. Clearly, the traditional blame and

'othering' conceptualisation of stigma does not alone account for the conflict experienced by study participants, hence the need for a widened re-conceptualisation of stigma. Figure 4 on page 262 diagrammatically represents the need for stigma theory to encompass blame, othering and values.



**Figure 4 – Diagrammatic representation of the need for stigma theory to encompass blame, othering and values**

### ***Closing observations***

Before proceeding to the final chapter of this thesis where recommendations based on the findings and discussion are made, there are several points it would be remiss of the researcher to not mention. To make the findings and recommendations of this study available to a wider audience it is intended to present them at conferences and to submit them for publication in peer reviewed journals. At least three papers are planned or have been published

based on this thesis. One paper related to the literature review has been published (Pickles, King & Belan 2009), papers on the findings and recommendations, and relating to data collection issues with a multicultural study sample, are planned. By disseminating the findings widely, it is hoped to be able to maximise the contribution this study makes to the nursing profession, nursing education, and to PLWA. It is also the researcher's intention to continue to conduct further HIV/AIDS related research both within Australia and in neighbouring nations.

In undertaking this research study, the researcher was aware that the study had both strengths limitations and it is important that these be acknowledged. While most of these strengths and limitations have been made apparent throughout the preceding chapters, the researcher considers it advisable to briefly touch on some specific strengths and limitations prior to making recommendations. The study recommendations are made in the context of the study's strengths and limitations being acknowledged.

The most obvious limitation of the study was that the sample of nursing students who became the participants was selected from one university setting only. These nursing students may well be considered to be typical of nursing students throughout Australia, however, this assumption was not examined in the study and therefore the validity of the assumption was not established. Similarly, while there was no reason to believe that the Australian city in which this university is located is not typical, the perceptions and experiences of nursing students towards HIV/AIDS and

PLWA may vary at universities in different geographical locations throughout Australia. While conducting the study at one university only can be seen as a limitation, it can also be seen as a strength. The study university nursing school had, and continues to have, a sizable international student cohort, enabling a culturally diverse study sample being available for this study. This study participant diversity strengthened the study's findings and recommendations, and may not have occurred if the study had been conducted in a university with a small international student population.

As this study was conducted in Australia, the recommendations are made in the context of nursing and nursing education in Australia. However, it was not the intention to try and generalise the findings of this qualitative study, rather to make observations and recommendations based on the findings. These findings need to be seen in the context of the study sample which is quite specific and caution is advised in attempting to transfer the findings to other settings. The focus of qualitative research studies is on relatively small groups of people in specific contexts, transferability of the finding to other settings is not the aim of qualitative research studies (Koch, Niesz & Mccarthy 2014; Polit & Beck 2010). It is for the readers of qualitative research reports to consider the generalization or transferability of the study findings to other contexts, rather than for the writer of the report (Sandelowski & Leeman 2012).

Several scenarios or vignettes were used during the participant interviews. The researcher gave careful consideration to the use of such an approach

before making the decision to proceed with this strategy. These scenarios or vignettes evolved from the researcher's own experiences of nursing PLWA and were based upon real people and situations. While they were used as an aid to stimulate thought and discussion during the interviews, they could be considered to be somewhat confronting for participants, thus influencing their perceptions and discourse during interview. By writing and presenting the scenarios in this manner, there was a risk of reinforcing stereotypical perceptions the nursing students may have previously had of HIV/AIDS and of PLWA.

However, the vignettes were only a starting point, the interviews flowed from there and participants were completely free to expound their own thoughts, beliefs and perceptions. After careful consideration, the researcher formed the opinion that the value of using these vignettes outweighed any negative aspects of their use. It should also be highlighted that the vignettes were independently evaluated and appraised for their suitability by a highly experienced HIV/AIDS nursing clinician. Thus the utilisation of the vignettes was a strength of the study, having input from such a clinician has enhanced the credibility of the study.

Within any study involving people, particularly qualitative studies, a potential exists for the study participants to give what they consider to be socially desirable responses. In the study reported here, participants were interviewed and during interview they may have given socially desirable responses, even if this did not represent their real thoughts, beliefs or

perceptions. Such response bias is a difficult problem to overcome, however it is important for the researcher to recognise and take steps to address. The approach taken in this study was to provide a relaxed atmosphere for each interview and for the interviewer to present an open and non-judgemental demeanour and response to whatever each person said. The researcher went to considerable lengths to reassure the study participants that their confidentiality and anonymity would be strictly maintained. An interviewing environment was provided that was conducive to participant comfort and to give them confidence their rights would be respected and protected. By adopting such an approach the limitation of response bias was minimised, as much as was feasible, and confidence in the study enhanced. Demonstrating respect for study participants, their views and their rights, has been of paramount importance to the researcher throughout this study. By articulating this to study participants and throughout this thesis, gives strength to the study findings.

### ***In conclusion***

This chapter has discussed the maelstrom of stresses that are placed on nursing students, stresses that play out in the minds of each and every one of them as they progress from the role of nursing student to that of qualified Registered Nurse. Based on the study findings, and the above discussion, the study recommendations are presented in Chapter 9, the following and final chapter of this thesis.

# **Chapter 9 – Recommendations and Conclusions**

## ***Introduction***

Based on the findings of this study, recommendations have crystallised through the process of data collection, analysis and comparison with other literature. These recommendations focus on three areas: nursing student education; clinical nursing practice; future research. The underlying purpose of such recommendations is to inform the nursing profession and especially the education sector; to enhance the practice of nursing, and thereby improve patient care. By informing the nursing profession of the findings, this study provides data for evidence-based practice in both education and clinical nursing. While the recommendations have a HIV/AIDS focus, they are also applicable to other health disorders that involve marginalised and vulnerable people such as Indigenous Australians, refugees and people living with mental illness. The implications of the study are much wider than the focus on HIV/AIDS, important implications beyond HIV/AIDS and PLWA are also highlighted following the recommendations.

## ***Recommendations***

### **1. Nursing student education**

Australia has one of the most culturally diverse populations in the world, therefore for Australian society to continue to develop and flourish, cultural plurality must be embraced. We are all shaped by culture and society, a pluralistic society is ‘not only a society with a diversity of cultures and affiliations, it is also a society with a plurality of ways of finding and making meaning’ (Jennings 2009, p. 38). With international nursing students, from a rich diversity of cultures, accounting for some 16% of nursing students in

Australia (Crawford & Candlin 2013; Gaynor et al. 2007; Health Workforce Australia 2013; Jeong et al. 2011), nursing education must be attuned to the wide variety of socio-cultural contexts which shape the perceptions of an increasingly international cohort of nursing students.

### **1.1 Increase education on social aspects of HIV/AIDS**

Whilst HIV/AIDS may be included in nursing curricula in content about infection control, the physiological response to virus infection (and so forth), there may be little attention paid to the aspects of HIV/AIDS that directly impact the nurse-patient relationship. The fiduciary nurse-patient relationship is vital to patient health and wellbeing, yet, as this study has demonstrated, there may be considerable ignorance and insufficient attention paid to aspects of HIV/AIDS which impact this important relationship. Such deficits must be addressed through nursing student education in striving to ensure the provision of unbiased high quality nursing care to all.

However, it is important for educators to recognise that simply providing information to students does not necessarily change stigmatising perceptions (Graham & Harwood 2011; Pasupathi & Wainryb 2010). If students already have negative perceptions about a group in society, such as PLWA, then they may use new information to reinforce rather than change their existing perceptions (Boysen & Vogel 2008; Fox 2011; Wojcieszak 2011). These concepts of attitude polarisation and biased assimilation of information are demonstrated by social researchers in a number of areas including, mental illness, climate change, homosexuality and abortion (Boysen & Vogel 2008; Corner, Whitmarsh & Xenias 2012; Tranter 2013; Wojcieszak 2011).



Nevertheless, knowledge is preferable to ignorance and provides a starting point for tackling negative perceptions, and nurses need to practice from an accurate knowledge base.

While such knowledge in itself may not change the perceptions of nursing students towards PLWA, knowledge brings with it the power to effect change (Burr 2003; Fairclough 2005; Foucault, Michel 1976; Selvadurai et al. 2013). Change that can help to break down the labelling and ‘othering’ associated with HIV/AIDS, will facilitate a model of care based on the needs of individual PLWA. The ability of nursing students to provide a high quality of holistic care is inhibited by a lack of HIV/AIDS education. Therefore, more in-depth and socially focused HIV/AIDS education for nursing students is essential.

Nursing educators also need to be aware that there can be vast differences in knowledge, values, perceptions and beliefs in relation to important social issues between nursing students from different cultural backgrounds (Jeon & Chenoweth 2007; Jeong et al. 2011; Stankiewicz & O'Connor 2014).

Knowledge should not be assumed. Not only can this influence the direct care provided to patients, it can also be a significant consideration in the ability to competently carry out the educational role that nurses perform as part of their duties. Therefore specific inclusion in the nursing curriculum is recommended for education in relation to PLWA, and for comprehending the meaning of being marginalised by society or being part of a stigmatised minority. Understanding the role they play in these issues is something

nursing students need to be encouraged to explore and develop. Thus their ability to provide holistic nursing care to all patients will be enhanced and, through that nursing care, they can increasingly become positive role models to those around them.

### **1.2 Enhance student ability to confront and discuss culturally taboo issues**

Interviewing study participants about intimate or stigmatised issues such as sexuality, homosexuality and illicit drug use, presented considerable challenge as the nursing students demonstrated great discomfort and somewhat of a lack of willingness to discuss such matters. This highlighted the difficulties these nursing students would have discussing stigmatised, intimate or culturally sensitive issues with their patients. Providing knowledge alone will not overcome this reticence to face culturally sensitive issues (Celik et al. 2008; Jeon & Chenoweth 2007; Jeong et al. 2011; Xu, Gutierrez & Kim 2008).

Learning to appropriately address culturally sensitive issues is an essential skill all Registered Nurses need to master (Ussher et al. 2013; Washington & Pereira 2012; Weerakoon, Sitharthan & Skowronski 2008). Education that encourages nursing students to explore and discuss taboo subjects in a culturally safe and sensitive manner is necessary and needs to be incorporated throughout nursing curricula. Undergraduate nursing curricula in Australia are mandated to foster moral and ethical decision making, however, traditionally nursing curricula have tended to be predominantly based on science and clinical skills. While there are nursing curricula which have been

designed to be more values and ethics based (Fahrenwald et al. 2005; Hewitt 2009; Lynch, Hart & Costa 2014; Mclean 2012), the focus has been on developing the ability of students to act on their own values, to be able to stand up for what they believe is right when there is conflict between their values what they are being asked to do. Such preparation of nursing students for ethical professional practice is admirable and to be encouraged, yet there is a implicit assumption that nursing students have values, beliefs and perceptions that accord with the professional values required of the nursing profession. Clearly this is not always the case. Facilitating students to learn the skills necessary to reflect on their own personal values, beliefs and perceptions, will allow them to bring a greater degree of cultural sensitivity to their nursing practice. Self-reflection will help students identify where personal values and beliefs are at odds with the professional requirements of the nursing profession. Educators must then assist students to put into place strategies to manage any such discrepancies.

Nursing students require sufficient knowledge of HIV/AIDS, its aetiology and treatment, the context and impact it has in different parts of the world, and the cultural characterisations of PLWA. Such knowledge would assist in overcoming the myths and misconceptions that many nursing students are exposed to, while these vary around the world, appropriate education is necessary for all students. By providing both knowledge and the confidence to confront challenging issues, nursing students will be able to approach their patients more holistically and with less stigmatising perceptions.

### **1.3 Clearly articulate the wider role of the Registered Nurse**

In addition to emphasising clinical competence, practical knowledge, respect, advocacy and compassion, modern nursing educational programs promote the concept of holistic care. This concept includes promoting a moral strategy of nursing in which nurses not only have care of their patients, but that they are also 'caring about their patients and caring that their patients receive appropriate, constructive nursing care' (Scott 2007, p. 41). An essential aspect of constructive nursing care is patient education, although this is not always performed well, and can be neglected, particularly in relation to sensitive or difficult issues (Friberg, Granum & Bergh 2012; Ivarsson, Fridlund & Sjöberg 2010; Priharjo & Hoy 2011; Yiu, et al. 2011). While there was general agreement among study participants that nurses had an important role in patient education, there was some confusion as to the role of nurses in relation to discussing with patients matters of sexuality, sexual practices, drug use and similar topics.

In general, the Australian students perceived nurses to have a wider role in providing education than their Asian counterparts. Such perceptions were likely to be linked to the cultural taboos discussed previously. Defining and developing the educational role of the Registered Nurse is an important component of the nursing curriculum. Fulfilling this educational role does not come easily to many students, and for some there are considerable cultural barriers to performing such a role (Jeon & Chenoweth 2007; Jeong et al. 2011; Xu, Gutierrez & Kim 2008). Therefore more time and effort needs to be devoted by educators to prepare nursing students to effectively carry out this essential aspect of the Registered Nurse role. This facet of nursing

practice is also required by regulatory authorities in Australia under the National Competency Standards for the Registered Nurse (ANMC 2006b).

Students can and do have differing perceptions of the nursing role. There are considerable differences between nations on what exactly the role of a nurse is. These are not just differences in how the role is defined by regulatory authorities, but also in how the role is culturally construed (Feng & Tsai 2012; Parker et al. 2014; Pennbrant et al. 2013; Teoh, Pua & Chan 2013). Educators need to maintain an awareness of these differences and be able to clearly articulate the role and context of the Registered Nurse. Without this, students will continue to experience confusion about the role and in developing their professional nursing identity, and sense of nursing values.

There is a need for nursing students to have guidance in the development of their professional practicing nursing identity and values, this is more than the physical skills that the students need to master (Graham & Harwood 2011; Kelly, J & Ahern 2009). Educators themselves must have an awareness of the potentially competing sets of values nursing students may contend with personally. They also need to understand how culturally and socially constructed personal values, and professional values, can be in conflict within each student. Deep-seated cultural norms and taboos take time to change (Hernández-Mogollon et al. 2010; Lozano 2010; Patel, Phillips-Caesar & Boutin-Foster 2012; Thornberg 2014), even where there is a desire and willingness for change to occur. This progressive change needs to be nurtured with care and understanding by educators by empowering nursing students to

critically reflect on their own values and beliefs, to assist in developing their ability to become morally competent practitioners (Fahrenwald et al. 2005; Hewitt 2009; Lynch, Hart & Costa 2014; Mclean 2012).

#### **1.4 Give greater prominence to the role structure and agency have in human behaviour**

Individual agency, as the impetus for the spread of HIV, is seen by many as overwhelmingly more significant than societal or structural influences. While the concept of the structure/agency debate may currently be introduced to nursing students in Australia, it needs to be related to the real world for the students. What role might society play in influencing behaviour, why, for example, do people engage in unsafe sex or share needles when injecting drugs? How much freedom of choice do people really have, do they have the means and the freedom to make choices? (Galliot & Graham 2014; Pasupathi & Wainryb 2010; Tomlinson et al. 2013). These are issues that educators should be exploring in greater depth with their nursing students, so the students can better understand difference and embrace diversity (Graham & Harwood 2011; Welzel & Inglehart 2010). Following the real life stories of some PLWA is one approach that could be taken within nursing curricula. This approach would assist in humanising the disease and countering perceptions among nursing students that contracting HIV is all about individual agency. The recommendation is for a wider sociological perspective to be taking in nursing education curricula.

Students also need to be encouraged to examine their own perceptions of identity and self-awareness. Many nursing students have an idealism (Day et

al. 2005; Hayes, et al. 2006; Johnson, Haigh & Yates-Bolton 2007) that should be nurtured and channelled into their professional nursing identity. The 'helping makes you rich' observation made by one study participant was an example of the esoteric idealism that embodies nursing and should be embraced by nursing educators. Nurturing and building on this idealism will help to develop the personal qualities expected of the nursing profession in Australia.

Clinical placements and classroom teaching needs to have a greater focus on expanding the experiences of nursing students beyond developing clinical skills (Graham & Harwood 2011; Kelly & Ahern 2009). The personal boundaries of nursing students need to be challenged by educators. The students should be encouraged to develop the skills and confidence to confront their own fears, phobias, biases and inhibitions. An example of how this could be achieved would be for the students to meet PLWA. Not just in the clinical environment and context of the nurse-patient relationship, but also in other contexts such as guests in the classroom, as fellow citizens discussing common issues.

By encouraging a wider appreciation of how society and culture influence behaviour, nursing students will be able to develop more informed perceptions of PLWA. More empathy and understanding can reduce the culture of blame and 'othering', resulting in a more caring and compassionate approach to nursing PLWA. Before this can take place, educators themselves need to be informed and understand the varied culturally construed

perceptions of unsafe behaviour. Such knowledge and understanding cannot be assumed. Educators are not automatically aware of the differing cultural characterisations of HIV/AIDS and PLWA that exist in different parts of the world. Similarly, educators have their own individual culturally informed position of the roles of structure and agency in human behaviour. Hence, there is a need for nurse educators to be constantly reflecting on their own knowledge and perceptions to ensure they are teaching from a culturally pluralistic and accurate evidence base.

## **2. Clinical nursing practice**

In-service clinical nursing education tends to be task orientated and focused on the development of what are often perceived as practical clinical skills, education that is geared towards meeting the immediate physical needs of patients. Organisations such as the Australian Nursing & Midwifery Federation (ANMF) provide continuing professional education (CPE) topics for nurses and midwives to meet mandatory continuing professional development (CPD) requirements in Australia. Of current CPE topics offered by the ANMF, over 75% have a focus on clinical skills rather than reflective or ethical skills (ANMF 2014). While these skills are unquestionably necessary to safe and competent nursing practice, a much wider knowledge base is essential for nurses to provide the holistic care expected of the nursing profession today (D'Antonio 2014; Hatlevik 2012; Sabatino et al. 2014; Stanley & Dougherty 2010). All of the recommendations made above in relation to nursing student education can also be made for educators in the clinical nursing environment. In addition, an emphasis on fostering an appreciation of the wider social determinants of health is important, along



with an understanding of how PLWA can be unintentionally ‘othered’ by nurses.

### **2.1 Foster greater understanding of the wider social determinants of health**

An increasing number of diseases are being characterised as lifestyle diseases with the implication that individual health related behaviour and choices are responsible for the disease. Such characterisations, without due consideration for the many other determinants of health, can lead to victim blaming, labelling, ‘othering’ and behaviour that stigmatises (Talbot & Verrinder 2010). When people engage in behaviours that increase the likelihood of contracting illness, there is a tendency for society to blame them for their behaviour. The illicit drug user, for example, who contracts HIV, is ‘blamed’ for having the disease due to their behaviour. This view ignores the life circumstances of the person that might have led them to drug use, issues of overcoming addiction, and other challenges such as lack of money, self-esteem, social support and motivation (Graham & Harwood 2011; Pasupathi & Wainryb 2010; Talbot & Verrinder 2010).

There is no shortage of Health Behaviour Theories, (Noar & Zimmerman 2005; Pender, Murdaugh & Parsons 2011), although debate continues as to the relative role societal influences and individual agency play in health behaviour. Nursing students do have some exposure to such theories as part of health promotion modules in nursing curricula. However practicing nurses also need to have a familiarity with sociological theories of behaviour, along with an understanding of social determinants of health, and the potential

consequences of assigning blame. It is recommended that in-service education be expanded to include wider sociological perspectives of health, so as to ensure nurses are better equipped to provide holistic care to their patients.

## **2.2 Emphasise the consequences of victim blaming and what constitutes ‘othering’ behaviour and language**

There is a widespread tendency to talk about PLWA in a different way to people living with other diseases. Not only does this occur throughout society in general, but also within the nursing profession and other health care professions. While this is culturally construed, influenced by community perceptions of homosexuality and drug use, the language used can have the effect of ‘othering’ PLWA, even though this may not be intentional. Hence the recommendation is for nursing management and clinical educators to ensure nurses are acquainted with what constitutes ‘othering’ behaviour and ‘othering’ language. This necessitates a strengthening of the ethical knowledge and moral reasoning skills of practicing nurses through enhanced in-service education (Godbold & Lees 2013; Park et al. 2012; Salminen et al. 2013; Theobald 2013; Willsher 2013).

## **2.3 Appreciate the ingrained beliefs and perceptions a culturally diverse workforce brings**

The Australian nursing workforce is culturally diverse with individual nurses having their own culturally construed perceptions and beliefs in relation to important social and health issues such as HIV/AIDS (Brunero, Smith & Bates 2008; Jeong et al. 2011; Omeri & Atkins 2002). This diversity needs to be recognised by healthcare organisation management, and accommodated in

the provision of in-service education. Such education must have a focus on the fostering of tolerance and understanding in the provision of nursing care. Health care organisations in Australia employing international nurses generally have orientation and support programs for these nurses, although the adequacy of these programs has been questioned (Brunero, Smith & Bates 2008; Jeon & Chenoweth 2007; Stankiewicz & O'Connor 2014). It is important for management and clinicians planning and delivering in-service education, as well as programs tailored for international nurses, to understand that the wide cultural diversity of the nursing workforce brings a wide range of ingrained beliefs and perceptions. Without this understanding, in-service, orientation, support and educational programs will not be tailored to adequately meet the needs of a multicultural nursing workforce.

#### **2.4 Ensure all nurses clearly understand the roles expected of the Registered Nurse in Australia**

The recommendations for educators of undergraduate nursing students in relation to ensuring the breadth of the Registered Nurse role is fully appreciated and understood, equally applies to practicing nurses. The provision of knowledge, while essential, is insufficient in itself to change ingrained beliefs and perceptions as discussed above. Strategies need to be put into place to ensure that nurses do fully understand what is expected of the Registered Nurse in Australia (Parker et al. 2014; Pennbrant et al. 2013; Salminen et al. 2013; Teoh, Pua & Chan 2013), and where necessary, guide them and equip them with the skills to meet those expectations. It should also not be assumed that when nurses are registered with the Australian Health Practitioner Regulation Agency, they fully understand their obligations under

the relevant codes and standards, or can meet these obligations without further personal development. Therefore, health care facilities employing nurses who are newly registered, regardless of their cultural or educational background, should ensure these issues are addressed in orientation and transition programs.

### **3. Further research**

While extensive HIV/AIDS research has been, and continues to be, conducted throughout the world, each context has a uniqueness about it. The disease itself and treatment options have and continue to evolve, as have the perceptions of PLWA and the blame and stigma they continue to live with. Hence, ongoing research is necessary to keep learning more about the ever changing face of HIV/AIDS around the world.

#### **3.1 Conduct similar studies in different contexts, within Australia and other nations**

This study explored the experiences and perceptions of nursing students in Australia towards PLWA, and the study took place with students from one university in one Australian city. Although there was no reason to regard this location and the nursing students as not being typical, further research is recommended in different locations and among different nursing student populations. The demographic spread of international nursing students does vary throughout Australia, and there are differences in curricula between Schools of Nursing at various universities, therefore different findings could be made elsewhere.

Within Australia, the proportion of international students enrolled in university undergraduate nursing programs varies considerably, from as little as 2% to over 30%, with an average of approximately 16% (Crawford & Candlin 2013; Gaynor et al. 2007; Health Workforce Australia 2013; Jeong et al. 2011). The university where the study reported here was conducted had a considerably higher than average cohort of international nursing students, with approximately 35% being international. The variability in proportion of enrolled international nursing students could influence findings if similar studies were conducted in different parts of Australia, and in fact elsewhere in the world. As a starting point, it is recommended that a national qualitative survey of nurses' beliefs, values and perceptions about PLWA be conducted. Research of this nature would enable educators, both in universities and the clinical environment, to better tailor programs to the socio-cultural demographic characteristics of their nursing or nursing student cohort.

The current study also specifically focused on nursing students studying at university to achieve the educational qualification allowing them to apply for registration as a Registered Nurse in Australia. Within the licenced nursing workforce in Australia, as well as Registered Nurse, there are two other classifications, Registered Midwife and Enrolled Nurse. The Registered Midwife requires a university degree qualification, whereas the Enrolled Nurse requires a non-university diploma level educational qualification. Research covering the perceptions of these classifications is recommended so as to broaden the scope of the body of knowledge on the issues in focus beyond that of the Registered Nurse alone.

### **3.2 Further explore the development of nursing identity and professional nursing values**

This study has highlighted a conflict between the personal beliefs, perceptions and values of study participants, and their developing professional nursing values (Dinmohammadi, Peyrovi & Mehrdad 2013; Feng & Tsai 2012; Kelly & Ahern 2009). Does this conflict cease upon graduation and becoming a licenced to practice Registered Nurse, is there a shift in personal beliefs and values to accommodate the requirements of the Registered Nurse role? These are questions that only research can answer. Perhaps such conflicts in values are long lasting or even life long, the implications are important for the nursing profession and would further inform the development of nursing education. Hence, future research among graduate practicing nurses is recommended to look further into the development of nursing identity and professional nursing values, exploring how these can influence perceptions of HIV/AIDS and PLWA, along with other stigmatised conditions. Similarly, practicing nurses have a wider nursing experience and are more likely to have had contact with PLWA than nursing students. Further research is recommended, in the Australian context, into the influence experience has on how nurses perceive and interact with PLWA.

This study was based on interviews with nursing students who volunteered to participate in the study. By the act of volunteering the students distinguished themselves from their peers (Robinson 2014), thus they may not be typical of the body of students (Loewenthal 2010). Although a qualitative study of this

nature does not attempt to make claims of generalisation (Koch, Niesz & McCarthy 2014; Polit & Beck 2010; Sandelowski & Leeman 2012), and being typical is not a necessary requirement, a biased sample should nevertheless be avoided. There is no indication that this might have been the case in the study reported in this thesis. However it is recommended that further research be undertaken with different samples to explore their experiences and perceptions with a view to being able to expand the recommendations for nursing education. The recommendations are contextual; studies in different contexts might yield different findings leading to further recommendations.

### **3.3 Conduct philosophical and theoretical exploration of conceptualisations of stigma theory**

The concepts of blame and ‘othering’ that are central to stigma theory, correlate well with the perceptions of blame and ‘othering’ that have become synonymous with PLWA (Brener et al. 2013; Fuster-Ruizdeapodaca et al. 2014; Lawson, Bayly & Cey 2013). While these perceptions clearly existed among study participants, co-existing was a sense of moral outrage at the injustices suffered by victims of HIV/AIDS. There was conflict between personal beliefs and the professional nursing values expected of the Registered Nurse, a conflict traditional stigma theory struggled to encompass.

While this study has been structured around stigma theory, and made recommendations in relation to the theory, the main focus of the study was not on the theory itself. Due to the competing and conflicting values found to exist among study participants, which was not an entirely comfortable fit

with the blame and ‘othering’ focus of stigma theory, stigma theory ultimately played a restricted role in the study. To make stigma theory more relevant to future studies, it is recommended that an in-depth philosophical and theoretical exploration of traditional stigma theory be undertaken to examine how the theory encompasses competing and conflicting values. The intention being to assess the need to develop a re-formulated conceptualisation of existing stigma theory that can more readily embrace strong positive values, along with the negative concepts of blame and ‘othering’.

### ***Summary of Recommendations***

#### 1. Nursing Student Education

Undergraduate nursing curricula to:

- 1.1. Increase education on social aspects of HIV/AIDS
- 1.2. Enhance student ability to confront and discuss culturally taboo issues
- 1.3. More clearly articulate the wider role of the Registered Nurse
- 1.4. Give greater prominence to the role structure and agency have in human behaviour

#### 2. Clinical Nursing Practice

Clinical managers and educators to:

- 2.1. Foster greater understanding of the wider social determinants of health
- 2.2. Emphasise the consequences of victim blaming and what constitutes ‘othering’ behaviour and language
- 2.3. Appreciate the ingrained beliefs and perceptions a culturally diverse workforce brings



2.4. Ensure all nurses clearly understand the roles expected of the  
Registered Nurse in Australia

### 3. Future Research

Researchers to:

- 3.1. Conduct similar studies in different contexts, within Australia and other nations
- 3.2. Further explore the development of nursing identity and professional nursing values
- 3.3. Conduct philosophical and theoretical exploration of conceptualisations of stigma theory

## ***Final reflections***

### **Beyond HIV/AIDS**

This research project has searched for new understanding as a mechanism to suggest possibilities for change that will enhance the perceptions of nursing students and practicing nurses towards PLWA. The inspiration for the study was a desire to lessen misinformation and contribute to overcoming the stigma associated with HIV. More specifically, if nurses and nursing students become more enlightened towards how they characterise PLWA and HIV/AIDS itself, this will contribute to empathetic and holistic nursing care being provide to PLWA. This intention has been met by using the findings of the study to make recommendations to enrich the nursing profession in Australia, and elsewhere, so as to enhance the nursing care PLWA will receive in the future. However, the implications stemming from the study are much wider that just this HIV/AIDS focus.

We constantly make choices in our lives, and we frequently criticise the choices made by others in their lives. This equally applies to health related decisions such as the choice to consume alcohol or smoke tobacco, for example. The relative importance of individual choice varies in Health Behaviour Theories, and similarly in the opinion of every nurse, with some attributing behaviour almost entirely to choice on the part of each individual. Although the emphasis here has been on HIV/AIDS, the implications flowing from the study have the potential to foster greater acceptance and understanding towards people in society who are stigmatised, marginalised or part of a minority. Thus this study has made a contribution to enhancing nursing care for all, particularly the vulnerable, a goal for all nursing educators and researchers to continue to strive for.

Yet this study was in fact only a beginning, and has highlighted a number of avenues beyond nursing care for PLWA and vulnerable populations where further research is needed to enhance the nursing profession. As discussed in Chapter 4, the researcher experienced a number of challenges in conducting this study across cultural groups. While transcultural nursing studies have been published in the Australian context, they have tended to focus on transition issues faced by nurses from overseas as they adapt to participating in the Australian nursing workforce, or research into providing nursing care to a multicultural population. There is limited literature, in the Australian context, on the difficulties faced by researchers when conducting studies among multicultural nursing or nursing student populations. With the ever increasingly multicultural population and nursing workforce in Australia,

researchers need to ensure they are being culturally inclusive when conducting research in relation to nurses or nursing students. The nursing profession in Australia is in a state of transition as it adapts to this increasing multicultural population and nursing workforce. Nursing students and practicing nurses are in transition professionally as they attempt to reconcile personal beliefs and values with professional expectations. The nursing profession, including educators, must play a leading role in this process of transition. Further exploration of these challenges is important and will be pursued by the researcher.

### **In conclusion**

No one study can definitively answer a research question as there is always more to be learned about the topic. Each study contributes to the body of nursing research knowledge. Australia provides a unique cultural context of a multicultural society, with a multicultural nursing workforce, and a multicultural cohort of nursing students. Hence the importance of building an Australian body of knowledge to complement the existing international body of nursing knowledge. This study has added to the body of knowledge on the perceptions of nursing students towards PLWA, and made recommendations that will enhance the future nursing care of PLWA. By making a positive contribution to the nursing profession and the nursing care for PLWA, the researcher considers the aim and objectives in conducting this study to have been achieved. Meanwhile, there is always more that can be done to improve the nursing care of the vulnerable, marginalised and stigmatised in every society throughout the world.

## **Appendices**



## Undergraduate nursing student's attitudes towards caring for people with HIV/AIDS

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### SUMMARY

The aim of this quantitative study was to determine the attitudes of Australian nursing students towards caring for people with HIV/AIDS. This research study was conducted among second year undergraduate nursing students at a university in South Australia, during August 2007. The survey tool consisted of six demographic questions and the AIDS Attitude Scale. This questionnaire was completed by 396 students, giving a response rate of 94.7%. The vast majority (95.7%) of students participating in this study demonstrated very positive attitudes towards caring for people with HIV/AIDS and only 4.3% demonstrated negative attitudes. No statistically significant differences were found in attitude score based on participants' age, gender, previous HIV/AIDS education, previous nursing experience or previous experience of caring for someone with HIV/AIDS. A statistically significant difference in AIDS attitude score was found in relation to participants' country/region of citizenship, with nursing students from China, East Asia, South East Asia, and Central Asia and Middle East having more negative attitudes than students from other countries/regions. As an increasing number of nursing students have been recruited to Australia from these countries/regions, nurse educators need to be aware of such differences when planning and delivering HIV/AIDS educational programs in tertiary institutions.

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### Introduction

#### Background

Acquired immune deficiency syndrome (AIDS) develops following infection with the human immunodeficiency virus (HIV). This virus is an acquired contagion with an estimated 42 million people infected globally (Green, 2007). The first deaths from HIV/AIDS were reported in the early 1980s and around 20 million people have since died from AIDS. There remains no known cure (Green, 2007). Despite the high number of deaths worldwide, people living with HIV in many Western countries are surviving for long periods due to the development of more effective treatments.

Ever since the first cases of HIV/AIDS were diagnosed, nurses have been at the forefront of providing care to those infected with the virus (Williams et al., 2006). The attitudes of nurses and nursing students towards people living with HIV/AIDS have long been under scrutiny. Past studies showed that some nurses and nursing students were reluctant to provide care for people with HIV/AIDS due to the fear of contagion (Goldenberg and Laschinger, 1991; Tierney, 1995; Robinson, 1998). In fact studies reported finding that between 8% and 26% of nurses were of the view that they should be able to choose not to care for

HIV/AIDS patients (Froman and Owen, 1997; Sherman, 2000). According to a United Nations AIDS taskforce report (UNAIDS, 2006) negative attitudes and reluctance to provide care results in a poorer quality of care being provided.

In the literature, negative attitudes towards patients with HIV/AIDS were found in all countries examined, these included: China (Williams et al., 2006); Cameroon (Mbanya et al., 2001); Nigeria (Adepoju, 2006; Oyeyemi et al., 2006); Spain (Pita-Fernandez et al., 2004); Taiwan (Juan et al., 2004); Uganda (Walusimbi and Okonsky, 2004); and USA (O'Sullivan et al., 2000; Preston et al., 2000). Many nurses had a great reluctance to care for people with HIV/AIDS (Juan et al., 2004). Pita-Fernandez et al. (2004) found that almost 10% of the participating nurses in a Spanish study believed that all contact should be avoided with people who are HIV positive.

Almost 20% of the nurses in a Taiwanese study were seriously considering leaving nursing altogether due to their fear of contracting HIV/AIDS (Juan et al., 2004). High levels of fear of self-infection and of infecting family members with the HIV virus were found among nurses in various parts of Africa, such as Nigeria (Adepoju, 2006; Oyeyemi et al., 2006), Uganda (Walusimbi and Okonsky, 2004) and Cameroon (Mbanya et al., 2001). North American studies have linked reluctance to care for people with HIV/AIDS with fear of contagion and high levels of homophobia among the participating nurses (O'Sullivan et al., 2000; Preston et al., 2000).

Among nurses in the USA, one of the major causes of anxiety, fear, negative attitudes and reluctance to care for people with HIV/AIDS was identified as a lack of education (O'Sullivan et al., 2000; Preston

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et al., 2000). Similarly in a Taiwanese study, Juan et al. (2004) found that nurses' anxiety was reduced by education, and concluded that the 'institution of appropriate AIDS/HIV educational programmes has the potential to change nurses attitudes' (Juan et al., 2004, p. 36). These findings were supported by studies conducted in Nigeria (Oyeyemi et al., 2006), and China (Williams et al., 2006).

These fears and concerns are not confined to practicing nurses. An in-depth literature review (Pickles et al., 2009) found similar fears and concerns among nursing students from different regions of the world. These fears result in reluctance on the part of some nursing students to provide care for people with HIV/AIDS. Therefore, there is an obligation upon the nursing profession to develop strategies to understand and overcome such attitudes. Education and change based on research evidence must play a leading role in this challenge to the nursing profession. Nurse educators have a responsibility to ensure that nursing curricula provide students with sufficient knowledge of HIV/AIDS to enable them to provide safe, high quality and compassionate care to people with HIV/AIDS. In reviewing the literature no current studies from the South Pacific region were found highlighting the need for further research from this region.

#### Study aims

1. To determine the attitudes of a cohort of nursing students in South Australia towards caring for people with HIV/AIDS.
2. To ascertain whether the following variables significantly influenced the attitudes of the nursing students towards caring for people with HIV/AIDS: gender; age; country of citizenship; previous HIV/AIDS education; previous nursing experience and previous experience caring for someone with HIV/AIDS.
3. To bridge a gap in the research literature on this issue from the South Pacific region.

#### Methods

##### Participants

Second year undergraduate nursing students were administered a survey questionnaire prior to a scheduled lecture in an unrelated undergraduate topic during August 2007. Of the possible 450 students enrolled in the topic, 418 second year nursing students attended the lecture. Of these, 396 completed the questionnaire giving a response rate of 94.7%. The study sample represented 33% of the total number of undergraduate nursing students ( $n = 1201$ ) enrolled at that time.

Second year students were selected as some had participated in a HIV/AIDS option topic a few weeks before the survey was administered. In addition first year students had little clinical experience and third year students were more likely to be influenced by practicing nurses due to their extensive clinical placements; these factors also influenced the decision to select second year students. The Raosoft Sample Size Calculator (Raosoft, 2004) was used to determine an adequate sample size. To give a confidence level of 95% and a margin of error of 5%, a sample size of 208 was required. The actual sample size was 396, and, therefore, was deemed to be statistically adequate.

##### Data collection instrument

The instrument used in this study was the AIDS Attitude Scale (AAS) developed by Froman et al. (1992) and further validated by Froman and Owen (1997). Permission to use this instrument was granted by the authors. The AAS was specifically developed to measure the attitude of nurses towards caring for people with AIDS, and has been used extensively. However, the AAS uses American vernacular and is based on attitudes and beliefs prevalent in the USA 10–15 years ago. Therefore, it may have limited application in an Australian context.

The AAS is a 21 item self-report survey designed to measure two distinct dimensions of attitude towards people with AIDS. These dimensions, which are inversely related and form two subscales in the AAS, are empathy and avoidance. Nurses with little empathy for people with AIDS exhibit greater avoidance behavior in providing care for people with HIV/AIDS. The more empathy nurses have, the less avoidance behavior they exhibit when caring for people with HIV/AIDS. In addition to administering the AAS, study participants were also asked to provide socio-demographic data. Participants were asked to indicate their gender, age group, citizenship, previous HIV/AIDS education, previous nursing experience, and previous care for someone with HIV/AIDS.

##### Ethical considerations

Approval to conduct this research study was granted by the University's Ethics Committee and the Dean of the School of Nursing. Students were free to complete the survey in their own time and to return it anonymously to a designated collection box. Maintaining the rights of participants remained paramount throughout this study and no identifying information was included with the instrument. All returned individual surveys have been stored as per the Australian National Health and Medical Council guidelines (NHMRC, 2007).

##### Data analysis

Statistical analyses of the survey data were conducted using the computer software, Statistical Package for Social Science (SPSS v 14), to examine students' attitudes in relation to socio-demographic characteristics. The influence of the socio-demographic variables on attitudes to caring for people with HIV/AIDS was determined using the independent, 2 sample T-test. When comparing multiple variables, the Analysis of Variance (ANOVA) *F*-test was used to test for equality of more than two means. Where the *F*-test indicated a significant difference in means when comparing multiple variables, further analysis was carried out using the multiple comparisons Scheffe test.

#### Results

##### Demographic data

Participants in this study were second year undergraduate nursing students, 85% were female and the majority (51.7%) were in the 18–24 year age range. The overall age range of the participants closely resembled the overall undergraduate nursing population. The participating student population comprised citizens of 28 different countries. The majority (67%) was Australian citizens. The second largest group (11%) was Chinese citizens. The remaining countries only had a few representatives, with 15 countries represented by only one student, who therefore, were assigned to regional groups (see Fig. 1).

##### Experience and education

The majority of participants (74%) had no previous nursing experience prior to undertaking the Bachelor of Nursing program. Of the female students, 18% had previous nursing experience, whereas only 2% of the male students had such experience. No significant difference was found in terms of prior nursing experience between the represented countries (Fig. 2). In terms of experience in caring for a person with HIV/AIDS, only 14% of all study participants had knowingly cared for a person with HIV or AIDS. Of these 82% were female and 18% male. China (4.3%) and East Asia (5.6%) had a much lower incidence of previous experience in caring for someone with HIV/AIDS compared with others among the study sample.

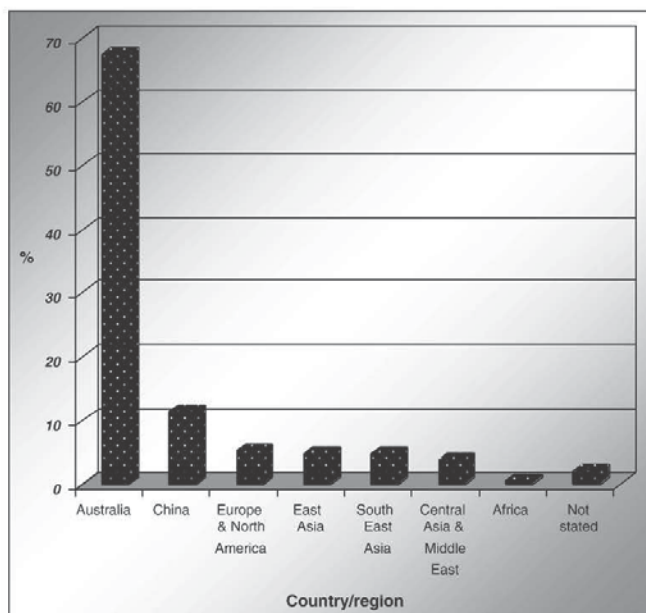


Fig. 1. Citizenship composition of second year nursing students participating in the study.

Findings on the proportion of participants with prior HIV/AIDS education have been illustrated in Fig. 3. Only 30% of participants had undertaken some form of formal HIV/AIDS educational program, the vast majority of these were female (88%) with only 12% male. Therefore, out of the overall sample, 25% of females and 3.5% of males indicated that they had HIV/AIDS education. Considerable variation also was noted between students from different countries/regions. Students from Central Asia and the Middle East comprised the largest group with HIV/AIDS education (46%), while students from Australia and the East Asia region comprised the next largest group (approx. 30%). Although students from China and Southeast Asia made up the second largest cohort in the study, only 22% had HIV/AIDS education.

In contrast, only 10% of participants from Europe and North America indicated that they had previous formal HIV/AIDS education.

*Students' attitudes toward people with HIV/AIDS*

*Overall AIDS attitude score for all study participants*

The AIDS Attitude Scale (AAS) used in this study measured two distinct dimensions of attitude towards people with AIDS. These dimensions were empathy and avoidance. An overall attitude towards AIDS score was calculated for each participant by subtracting the avoidance score from the empathy score, the resultant scores ranged from -5 to +5. Positive scores indicated positive and supportive

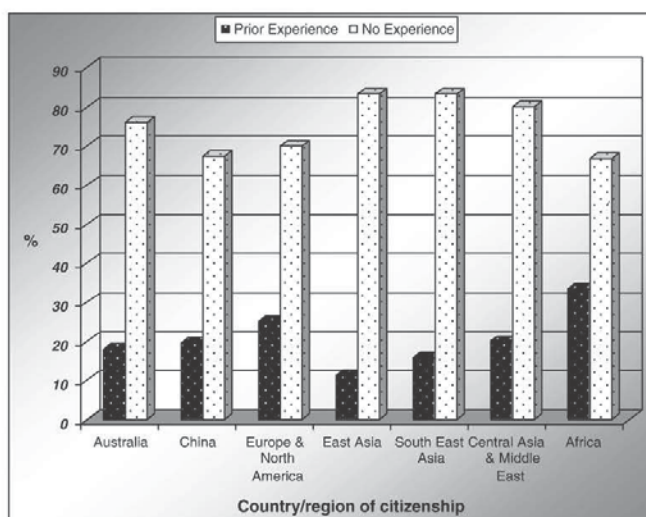


Fig. 2. Participants with/without nursing experience by country/region of citizenship.



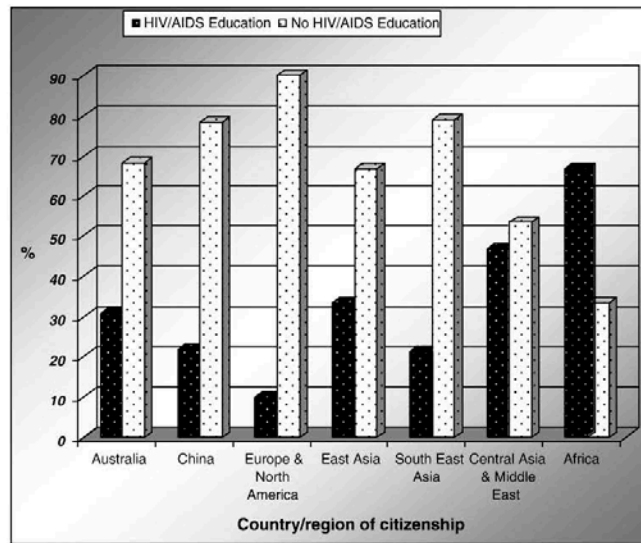


Fig. 3. Participants with/without formal HIV/AIDS education by country/region of citizenship.

attitudes while negative scores indicated negative attitudes and avoidance behavior. The average AIDS attitude score for all 396 participants was 2.73 ( $\pm 1.41$  SD) which indicated generally positive attitudes by the participants. Only 4.3% of participants recorded a negative score ( $\leq 0$ ) indicating that only a small percentage had negative attitudes towards caring for people with HIV/AIDS.

*Impact of socio-demographic factors*

The influence that four of the demographic variables had on the AIDS attitude score is presented in Table 1. The variables: previous HIV/AIDS education; prior experience of caring for someone with HIV/AIDS; previous nursing experience and gender, were all found to have no significant impact on attitudes ( $P > 0.05$ ).

The remaining two socio-demographic variables of age and country/region of citizenship, had multiple sub-sets and were analyzed using an Analysis of Variance (ANOVA) (Table 2). While the result of this test suggested significant differences in attitude towards HIV/AIDS patients among the different age groups, a Scheffe test did not indicate where these significant differences occurred.

Similarly, the country/region of citizenship was found to influence attitudes towards HIV/AIDS patients. Further analysis, through a multiple comparison Scheffe test, showed that students from China,

East Asia, South East Asia and Central Asia and Middle East had mean AIDS attitude scores significantly lower than Australian nursing students. In addition, students who were citizens of China and East Asia also had significantly less positive AIDS attitude scores than nursing students from Europe and North America (Fig. 4). It should be noted that the results for African students could not be statistically analyzed due to insufficient sample size ( $N = 3$ ) and so have not been included in Fig. 4.

*Summary of results*

Overall the sample students had positive attitudes towards caring for people with HIV/AIDS. Using the AIDS Attitude Scale, it was determined that only 4.3% of the sample recorded negative scores indicating negative attitudes. The variables of gender, age group, previous HIV/AIDS education, previous nursing experience, and experience of providing care for someone with HIV/AIDS, were found to have no significant influence on the AIDS attitude score.

The only variable found to have a statistically significant impact on the AIDS attitude score was country/region of citizenship. This

**Table 1**  
Influence of four socio-demographic variables on mean AIDS Attitude Score.

| Variable   | With variable Mean ( $\pm$ SD) | Without variable Mean ( $\pm$ SD) |
|--|--------------------------------|-----------------------------------|
| 1. Previous HIV/AIDS education                       | 2.83 ( $\pm 1.52$ )            | 2.67 ( $\pm 1.35$ )               |
| 2. Prior experience caring for someone with HIV/AIDS | 2.87 ( $\pm 1.37$ )            | 2.71 ( $\pm 1.40$ )               |
| 3. Previous nursing experience                       | 2.85 ( $\pm 1.39$ )            | 2.69 ( $\pm 1.41$ )               |
| 4. Gender  | 2.77 ( $\pm 1.42$ )            | 2.46 ( $\pm 1.27$ )               |

**Table 2**  
Effect of age and country/region of citizenship on attitudes towards people with HIV/AIDS.

| Factor                           | Mean square | F-ratio | P       |
|----------------------------------|-------------|---------|---------|
| 1. Age group                     | 5.855       | 3.012   | <0.03   |
| 2. Country/region of citizenship | 32.263      | 22.006  | <0.0005 |

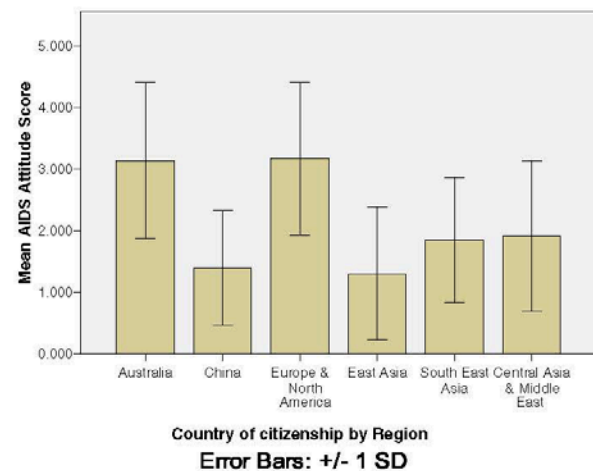


Fig. 4. Mean AIDS attitude score by country/region of citizenship.



influence was significant for students from four countries/regions, namely; China; East Asia; South East Asia; and Central Asia and Middle East. The mean AIDS attitude scores were significantly lower for these countries/regions compared with the other countries/regions.

## Discussion

The vast majority of participants demonstrated positive, empathetic and compassionate attitudes towards caring for people with HIV/AIDS. Only 4.3% of participating nursing students recorded an overall AIDS attitude score equal to or less than zero. The implication being that this small number of students had negative and intolerant attitudes towards people with HIV/AIDS. This corresponds with the findings of studies from other nations, including: the USA (Earl and Penny, 2003); UK (Peate et al., 2002); Turkey (Bektas and Kulakac, 2007) and Singapore (Ngan et al., 2000). The small numbers of students found by this study to have negative attitudes also showed little empathy and were likely to exhibit avoidance behavior when it came to providing care for people with HIV/AIDS. These students were from all age groups and most countries/regions of citizenship.

The variable of country of citizenship was shown to have a significant influence on the AIDS attitude score of students from four countries/regions. Nursing students included in the study whose country of citizenship placed them as being from China, East Asia, South East Asia or Central Asia and the Middle East, had significantly lower AIDS attitude scores than the rest of the study sample. This implied that these students had less empathy towards people with HIV/AIDS and would be less willing to provide care for these people.

Similarly, there were considerable differences between countries/regions in the number of participants who had some experience of caring for someone with HIV/AIDS. This may be a reflection of different infection rates in these countries/regions, or it may indicate differences in people's knowledge about their HIV status or willingness to disclose that status. Other explanations are possibly suggesting a need for further research in this area.

The current study has demonstrated that there are few concerns about the attitudes of nursing students in Australia towards caring for people with HIV/AIDS. A regular process of monitoring and evaluating attitudes is recommended to detect any significant shift in attitudes over time. As a small number have negative attitudes, further research is needed to explore the reasons underlying those attitudes.

The study revealed considerable differences between countries/regions in the degree of formal HIV/AIDS education received by study participants. These differences may have been a result of prevailing social and cultural factors in these countries/regions which influence the delivery of HIV/AIDS education. There is no doubt that there are differences in emphasis placed on HIV/AIDS education by governments and educational authorities represented by the study sample of nursing students. A large difference was also noted between the genders, with seven times the percentage of females than males having had formal HIV/AIDS education. The reason for these differences was not clear from the data, although it may be related to the small number of males in the sample.

### Implications for nursing education

Over the past decade Australian health care providers and Australian universities have been actively recruiting nurses and nursing students from overseas. This has been largely in response to the continuing shortage of nurses throughout the Australian health care system. The majority of those recruited overseas are coming from the same countries/regions where nursing students have been identified by this study as having significantly less positive attitudes towards caring for people with HIV/AIDS. Nurse educators need to be aware of such differences when planning and delivering HIV/AIDS education to nursing students, and educators need to be responsive to

the changing demographic characteristics of undergraduate nursing students.

### Recommendations for further research

The following recommendations all relate to the attitudes of nurses and nursing students towards caring for people with HIV/AIDS. Further research has been recommended into:

1. The thoughts, feelings and beliefs that shape less positive attitudes among students from a number of Asian countries. Socio-cultural influences in the home countries of these nursing students need to be explored.
2. Possible changes in attitudes as people transition from nursing student to practicing nurse.
3. An in-depth exploration into the underlying causes of the negative attitudes shown by a small number of nursing students, particularly from the abovementioned Asian countries.
4. Similar studies to the current study, at different universities around Australia and other nations in the region to determine if the findings are typical.
5. The attitudes of practicing nurses in Australia and elsewhere in the region.

### Limitations

In undertaking this study the researchers were aware that the study had three main limitations. The sample was not randomly selected and came from only one Australian university. The AIDS Attitude Scale was developed in the USA 15 years before this study which could call into question the suitability of the questionnaire for use in Australia. For statistical purposes, the study treated ordinal data (Likert scale) as interval data and used parametric tests when the data distribution approximated a normal distribution, however these are common assumptions in social research. These limitations were acknowledged and recognized as somewhat weakening the overall study. However, the researchers considered that these weaknesses did not seriously impact on the results of the research.

## Conclusion

The evidence has shown that negative attitudes exist towards people with HIV/AIDS among some nursing students studying at an Australian university. These attitudes can result in reluctance to provide care and negatively impact on the quality of care provided to people living with HIV/AIDS. The nursing profession has a responsibility to develop strategies to comprehend and prevail over such attitudes. Tertiary educational institutions must play a primary role in fostering positive attitudes among nursing students by developing educational programs based on research evidence. In addition, programs must be continually evaluated to determine their effectiveness.

It was beyond the scope of the researchers and this study to make comment on attitudes or educational programs that exist in other countries. The study identified concerns in relation to the attitudes of some nursing students recruited from outside Australia towards caring for people with HIV/AIDS. Further research to examine why students from the identified countries/regions have less positive attitudes towards caring for people with HIV/AIDS should be undertaken. Detailed recommendations for changes could then be made to undergraduate nursing curricula at Australian universities.

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## **Appendix 2 – Critical Review Guidelines**

### **Review Guidelines for Qualitative Studies** (Schneider 2004, pp. 61-62)

#### **Title and abstract**

1. Is the title of the research paper congruent with the text?
2. Were the aims and/or objectives stated? What are they?
3. Did the abstract contain sufficient information about the steps of the research process (e.g. aims, research approach, participants, data collection, data analysis, findings)?

#### **Identifying the phenomenon**

1. Is the phenomenon focused on human experience within a natural setting?
2. Is the phenomenon relevant to nursing, midwifery and/or health?

#### **Structuring the study**

1. Is it clear that the selected participants are living the phenomenon of interest?
2. How is published literature used in the study?
3. Does the question identify the context (participant/group/place) of the method to be followed?
4. Is the theoretical framework clearly stated?
5. Does the theoretical framework fit the research question?
6. Is the method of data collection and analysis clearly specified?
7. Does the qualitative method of data collection chosen fit the research question (e.g. grounded theory, ethnography)?
8. Are the limitations of the study stated?

#### **Research question and design**

1. Was the research question determined by the need for the study? How was this determination made?
2. Are the data collection strategies appropriate for the research question?
3. Do the data collection strategies reflect the purpose and theoretical framework of the study (e.g. in-depth interviewing, focus groups)?
4. Can the data analysis strategy be identified and logically followed?

#### **Participants**

1. How were the participants and setting selected (e.g. sampling strategies)?
2. How was the confidentiality of the participants assured?
3. How was the anonymity of the participants assured?
4. What ethical issues were identified in the study?
5. How were the ethical issues addressed?

## **Data analysis**

1. How were the data analysed?
2. Is the analysis technique congruent with the research question?
3. Is there evidence that the researcher's interpretation captured the participants' meaning?
4. Did the researcher say how the criteria for judging the scientific rigour of the study were maintained in terms of credibility, auditability, fittingness and confirmability?

## **Describing the findings**

1. Does the researcher demonstrate to the reader the method (e.g. audit trail) by which the data were analysed?
2. Does the researcher indicate how the findings are related to theory?
3. Is there a link between the findings to existing theory or literature, or is a new theory generated?

## **Researcher's perspective**

1. Are the biases of the researcher reported (e.g. researcher/participant expectations, researcher bias (objectivity-subjectivity) and power imbalance)?
2. Are the limitations of the study acknowledged?
3. Are recommendations suggested for further research?
4. Are implications for healthcare mentioned?

## **Review Guidelines for Quantitative Studies** (Schneider 2004, pp. 63-64)

### **Title and abstract**

1. Is the title of the research paper congruent with the text?
2. Were the aims and/or objectives stated? What are they?
3. Did the abstract contain sufficient information about the stages of the research process (e.g. aims, hypothesis, research approach, sample, instruments, findings)?

### **Structuring the study**

1. How was the investigation carried out?
2. Is the hypothesis stated?
3. Which hypothesis is stated: the scientific hypothesis or the null hypothesis?
4. Does the hypothesis indicate that the researcher is interested in testing for differences between groups or in testing for relationships?
5. Is the motivation for the study demonstrated through the literature review?
6. Is the literature review adequate? Are the references recent?
7. Are the stated limitations and gaps in the reviewed literature appropriate and convincing?

### **The sample**

1. Is the sample size large enough to prevent one extreme score (descriptive statistics) from affecting the summary statistics used?
2. How was the sample size determined?
3. Was the sample size appropriate for the analyses used?

### **Data collection**

1. How were the data collected (questionnaires and other data collection tools)?
2. Who collected the data?
3. What is the origin of the measurement instruments?
4. Are the instruments adequately described?
5. How were the data collection instruments validated?
6. How was the reliability of the measurement instruments assessed?

### **Data analysis**

1. Are descriptive or inferential statistics reported?
2. What tests were used to analyse the data: parametric or non-parametric?
3. Were the descriptive/inferential statistics appropriate to the level of measurement for each variable?
4. Were the appropriate tests used to analyse the data?
5. What is the level of measurement chosen for the independent and dependent variables?
6. Were the statistics appropriate for the research question and design?
7. Are there appropriate summary statistics for each major variable?
8. Were the statistics primarily descriptive, correlational or inferential?
9. Identify the outcome of each statistical analysis.
10. Explain the meaning of each outcome.

### **Findings**

1. Were the findings expected? Which findings were not expected?
2. Is there enough information present to judge the results?
3. Are the results clearly and completely stated?
4. Describe the researcher's report of the findings.
5. Identify any limitations or gaps in the study.
6. Were suggestions for further research made?
7. Did the researcher mention the implications of the study for health care?
8. Was there sufficient information in the report to permit replication of the study?



REVIEW PAPER

Attitudes of nursing students towards caring for people with HIV/AIDS: thematic literature review

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**Abstract**

**Title.** Attitudes of nursing students towards caring for people with HIV/AIDS: thematic literature review.

**Aim.** This paper is a report of a literature review conducted to examine current research studies into attitudes of nursing students towards caring for people with HIV/AIDS and to identify factors that influenced those attitudes to inform current nursing practice and to develop nursing education regarding care provided to people with HIV/AIDS.

**Background.** Attitudes of nurses towards people living with HIV/AIDS have long been scrutinized. Studies show that some nurses have negative attitudes and are reluctant to provide care to people with HIV/AIDS, resulting in poorer quality nursing support being provided. Attitudes of nursing students towards caring for people with HIV/AIDS is thus of vital importance since they become the future practising nurses.

**Data sources.** Eight electronic data bases were searched from 1996–2008.

**Review methods.** Criteria used for study selection were: attitudes of nursing students towards caring for people with HIV/AIDS, primary research studies, published in English language in peer reviewed journals from 1996 to June 2008. Sixteen studies were identified for inclusion in this thematic review.

**Results.** The following themes were identified: education and knowledge of HIV/AIDS; fear of contracting HIV/AIDS; reluctance to care for people with HIV/AIDS; homophobia; and stigma associated with HIV/AIDS.

**Conclusion.** There is reluctance on the part of some nursing students in specific regions of the world to provide care for people with HIV/AIDS. Educational programmes based on research evidence must play a leading role in developing strategies to help nursing students understand and overcome such attitudes.

**Keywords:** attitudes, avoidance, HIV/AIDS, literature review, nurse education, nursing students

## Introduction

Acquired immune deficiency syndrome (AIDS) develops following infection with the human immunodeficiency virus (HIV). This virus is an acquired infection, with an estimated 42 million people infected globally (Green 2007). The first deaths from HIV/AIDS were reported in the early 1980s and around 20 million people have since died from AIDS. There remains no known cure (Green 2007). Despite the high number of deaths worldwide, people living with HIV in many Western countries are surviving for long periods because of the development of more effective treatments. It is suggested that this 'decline in deaths caused by HIV/AIDS because of better antiretroviral medications may be creating a false sense of public complacency concerning the disease' (Kelly & Kalichman 2002, p. 636).

The attitudes of nurses and nursing students towards people living with HIV/AIDS have long been under scrutiny. Past studies showed that some nurses and nursing students were reluctant to provide care for people with HIV/AIDS because of fear of contagion (Goldenberg & Laschinger 1991, Tierney 1995, Robinson 1998). According to a United Nations AIDS taskforce report (UNAIDS 2006), negative attitudes and reluctance to provide care result in a poorer quality care. This review focuses on nursing students, as they become the practising nurses of the future. Nurse educators have an obligation to ensure that nursing curricula provide students with sufficient knowledge of HIV/AIDS to enable them to deliver safe, high quality and compassionate care to people with HIV/AIDS.

Previous researchers have recommended improved HIV/AIDS education for nursing students (Lester & Beard 1988, Oermann & Gignac 1991, Goldenberg & Laschinger 1991, Synoground & Kellmer-Langan 1991). For the purposes of the review, a nursing student was defined as a person studying nursing at the undergraduate level in a tertiary institution. This is in contrast to a nurse who is a licensed or registered practitioner and who may or may not hold a tertiary qualification.

## The review

### Aims

The aims of this thematic literature review were to examine current research studies into attitudes of nursing students towards caring for people with HIV/AIDS and to identify factors that influenced those attitudes to inform current nursing practice and to develop nursing education regarding care provided to people with HIV/AIDS.

### Design

A thematic appraisal was undertaken in this literature review. Specific themes discussed in this paper were identified using a six-step process suggested by Leininger (1985), and were further informed by the open coding strategy suggested by Strauss (1987).

### Search methods

#### Sampling

Electronic databases, including Blackwell Synergy, Journals@Ovid, ScienceDirect, Wiley Interscience, MEDLINE, CINAHL, ProQuest and SAGE Publications, were searched using the following keywords: HIV/AIDS and nursing; HIV and nursing attitudes; HIV and nursing care; HIV/AIDS and nursing students. The search was conducted from 1996–2008.

#### Inclusion/exclusion criteria

Inclusion criteria used for selecting papers were: attitudes of nursing students towards caring for people with HIV/AIDS, primary research studies, studies undertaken across major regions of the world, and published in the English language in peer reviewed journals between 1996 and June 2008. Papers excluded were based on nurses or other healthcare professional groups published earlier than 1996 and focused on aspects of care. Studies in languages other than English which fitted the selection criteria may have been published but were not accessible as we were only literate in English. It is acknowledged that such studies may have given different findings. Major studies on the relevant issues published prior to 1996 were used only for comparison.

### Search outcome

Initial searches identified 496 studies, which were screened for relevance (see Figure 1). The title and abstract of each study was read to determine relevance; 402 studies were discarded as not being directly relevant to the review, leaving 94 for more detailed examination. These were examined to determine whether they met the inclusion criteria, and 28 studies were identified for appraisal and possible inclusion. The initial searches and study selection were undertaken by the principal author.

#### Study location

The included studies incorporated research into nursing students' attitudes in 11 different countries in the five

regions of Europe ( $n = 5$ ), North America ( $n = 5$ ), Africa ( $n = 2$ ), East Asia ( $n = 2$ ) and the Middle East ( $n = 2$ ). No recent studies were found from Latin American or South Pacific countries such as Australia or New Zealand.

*Study design*

Of the included papers, two employed a qualitative research approach, 13 adopted a quantitative method, and only one study (Bektas & Kulakac 2007) used both approaches.

**Quality appraisal**

Each study was summarized according to authors, year of publication and location, and the research processes were critically appraised to determine whether the rigor of the study justified its inclusion. The appraisal process was undertaken jointly by the principal author and co-authors. Each author reviewed papers independently and the results were then compared. In cases where discrepancies were found, resolution was achieved through discussion. Eight critical questions posed by Schneider (2004) were used to evaluate the strengths and weaknesses of qualitative studies. Quantitative studies were evaluated using ten of Schneider's (2004) most relevant critical questions (see Table 1). Not every study met all the criteria specified in Schneider's (2004) guidelines. In fact, some weaknesses were identified in every study. However, these weaknesses were not of sufficient

magnitude to preclude the inclusion of any of the studies which met the majority of the review criteria. Reports that did not include sufficient detail about their research processes were excluded. In addition, studies that did not meet two of three of Schneider's (2004) questions, a level of expectation we set, were not included. Following quality appraisal, 12 studies were discarded (Adepoju *et al.* 2007, Askarian *et al.* 2007, Cornelius 2004a,b; Durkin 2004, Hurley & McGriff 1996, Kumar *et al.* 1999, Lal *et al.* 1998, Loh *et al.* 2004, Tan 2008, West *et al.* 1998, 1996). This left 16 research studies for review (see Table 2).

*Levels of evidence*

The majority of studies ( $n = 14$ ) were quantitative; therefore, levels of evidence categories were examined using government guidelines. In Australia, the National Health and Medical Research Council classification system is a four-tier system, with studies classified from level I to level IV. The included studies were all either level III (comparative studies) or IV (post-test or pretest/post-test studies), which are deemed to be at the weaker end of the scale. However, these kinds of quantitative designs, along with qualitative approaches, were seen as the most appropriate to examine the research question.

*Analysis of research processes*

Of the 14 reviewed studies in which a quantitative approach was employed, a total of 19 different data collection instruments were used (see Table 2). The reliability and validity were reported by the researchers using them. In four of the reviewed studies, the instruments used could be seen as a weakness. Stewart (1999) criticized his chosen instrument, the Prejudicial Evaluation and Social Interaction Scale, for using emotive and extreme questions which may have resulted in respondents giving socially-acceptable answers. All and Sullivan (1997) indicated that the instrument they used, the State-Trait Anxiety Inventory, is generic and was developed in the 1970s before the emergence of HIV/AIDS. This raised questions as to the relevance of the instrument for use in the study. Valois *et al.* (2001) and Snowden (1997) developed their own instruments and gave only limited details about reliability and validity. This wide variety of instruments and differences in methods (see Table 2) created difficulties in comparing results from each study and made direct comparison problematic.

**Data abstraction and synthesis**

Manual thematic analysis of the findings was performed by the principal author. Each paper was read several times,

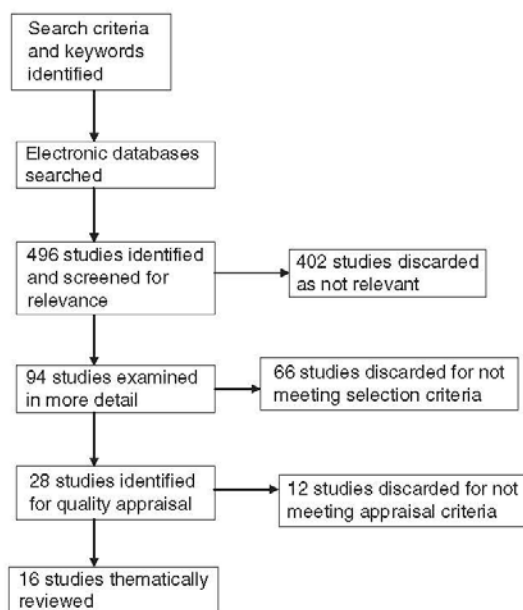


Figure 1 Literature review flowchart.



**Table 1** Quality appraisal questions (Source: Schneider 2004, pp. 61–64)

| Appraisal questions for qualitative studies   | Appraisal questions for quantitative studies   |
|---|--|
| 1. Were the aims and/or objectives stated? What are they?   | 1. Were the aims and/or objectives stated? What are they?                              |
| 2. Are the data collection strategies appropriate for the research question   | 2. How was the sample size determined?   |
| 3. How were the participants and setting selected (e.g. sampling strategies)?   | 3. Was the sample size appropriate for the analyses used?                              |
| 4. How was the anonymity of the participants assured?   | 4. How was the data collection instrument validated?                                   |
| 5. Did the researcher say how the criteria for judging the scientific rigor of the study were maintained in terms of credibility, auditability, fittingness and confirmability? | 5. How was the reliability of the measurement instruments assessed?                    |
| 6. Does the researcher demonstrate to the reader the method (e.g. audit trail) by which the data were analysed?   | 6. Were the appropriate tests used to analyse the data?                                |
| 7. Are the biases of the researcher reported [e.g. researcher/participant expectations, researcher bias (objectivity–subjectivity) and power imbalance]?                        | 7. Identify the outcome of each statistical analysis                                   |
| 8. Are the limitations of the study acknowledged?   | 8. Are the results clearly and completely stated?                                      |
|   | 9. Identify any limitations or gaps in the study                                       |
|   | 10. Was there sufficient information in the report to permit replication of the study? |

analysed and major themes extracted. This process was informed by Roberts and Taylor (2002), Leininger (1985) and Strauss (1987). The method involved a systematic analysis of the findings, grouping connected ideas together and then reducing the groupings as far as possible without losing their meaning.

## Results

Following analysis of the reviewed studies, five major themes were identified. No single theme was identified in all of the 16 reviewed studies. These themes and their empirical sources are detailed in Table 3. The five themes were: education and knowledge of HIV/AIDS, fear of contracting HIV/AIDS, homophobia, reluctance to care for people with HIV/AIDS and stigma associated with HIV/AIDS. Each of the reviewed studies showed that negative attitudes towards caring for people with HIV/AIDS existed among some nursing students. However, in most of these studies overall percentages of participants with negative attitudes were not specified.

### Theme 1 – education and knowledge of HIV/AIDS

Education and knowledge about HIV/AIDS was the most commonly-occurring theme and was identified in 94% ( $n = 15$ ) of the studies. While education and knowledge are discussed here as a specific theme, they also featured to some extent in all the other themes.

Among nursing students in the United States of America (USA) and Canada, one of the major causes of fear, negative

attitudes and reluctance to care for people with HIV/AIDS was identified as lack of education (Earl & Penny 2003, Valois *et al.* 2001). Carney *et al.* (1999) found that a specialized HIV/AIDS training course for a sample of nursing students in the USA increased knowledge of HIV and resulted in more positive attitudes towards caring for people with HIV/AIDS. Also in the USA, the level of anxiety of nursing students about caring for people with HIV/AIDS was reduced by education (All & Sullivan 1997). This view was shared in Singapore, where Ngan *et al.* (2000, p. 32) found that 'weaknesses in the provision of education must be addressed'. These findings are supported by studies conducted in Turkey (Bektas & Kulakac 2007), South Africa (Madumo & Peu 2006), Germany (Lohrmann *et al.* 2000) and Jordan (Petro-Nustas *et al.* 2002).

These results contrast with the findings of a quasi-experimental study conducted in Nigeria by Uwakwe (2000), who found that education did little to reduce fear. However, Uwakwe (2000) did find that education promoted a more positive attitude and reduced the reluctance to care for people with HIV/AIDS. Unlike in the other studies discussed above, only 15% of participants in the Uwakwe (2000) study had experienced nursing someone with HIV/AIDS. This factor, along with the varying nature and duration of these studies, may account for the differing results.

Rondahl *et al.* (2003) concluded that there was a need for nursing students not only to have biomedical knowledge of HIV/AIDS, but also that education should include broader cultural and ethical issues surrounding HIV/AIDS. The authors believed that focused educational programmes would

Table 2 Summary of reviewed studies

| Authors, year and location                     | Sample, size, response rate and type of study  | Instruments  | Major findings  | Limitations   |
|--|--|--|---|---|
| Bekras and Kulakac (2007) Turkey               | 227 Nursing students, 76% response rate. Mixed method. Non-experimental and qualitative – content analysis | Study developed questionnaire. Combined with qualitative essays written to answer open ended questions | Moderate knowledge of HIV/AIDS. Fear of contagion. Previous HIV/AIDS experience linked to greater willingness to provide care. Emphasis on education to encourage humane attitudes          | All female nursing students from one nursing school   |
| Chan <i>et al.</i> (2007) Thailand             | 144 Nursing students, response rate not stated. Descriptive, non-experimental                              | Attitudinal measures adapted from Kelly <i>et al.</i> (1987)   | AIDS, commercial sex (CS) and intravenous drug use (IDU) all stigmatized. Stigma for AIDS with IDU double than AIDS alone. Stigma for AIDS and CS no significant difference than AIDS alone | Participants disproportionately female. All from one nursing school, all senior students      |
| Madumo and Peu (2006) South Africa             | 12 Nursing students, exploratory and descriptive qualitative study. Purposive sample                       | Focus group interviews developed for the study   | Fear of contagion. Compassion for people with HIV/AIDS. Lack of support for students caring for people with HIV/AIDS during clinical placement. Need for more HIV/AIDS education            | All 3rd year nursing students from one university   |
| Earl and Penny (2003) USA                      | 50 <i>n</i> /students qualitative descriptive  | Study developed interview schedule   | Negative attitudes and high levels of homophobia. Poor knowledge of HIV   | All commencing nursing students from rural and remote regions                                 |
| Rondahl <i>et al.</i> (2003) Sweden            | 222 = 57 nurses and 165 <i>n</i> /students, 65% response. Descriptive comparative                          | AIDS Attitude Scale (Froman <i>et al.</i> 1992)  | High levels of homophobia, 36% would refrain from nursing homosexual patients if given the option   | One infectious diseases clinic and one university   |
| Peate <i>et al.</i> (2002) UK                  | 138 <i>n</i> /students, 87% response. Descriptive non-experimental   | SUNY questionnaire (Held 1993); NWQ (Dubbett <i>et al.</i> 1994)                                       | Good knowledge about AIDS. Stressed importance of HIV education for <i>n</i> /students  | All 1st year nursing students from one university   |
| Petro-Nustas <i>et al.</i> 2002 USA and Jordan | 63 USA and 63 Jordanian nursing students, convenience sample. Descriptive comparative study                | Modified questionnaire by Kulwicksi and Cass (1994)  | Considerable misconceptions about modes of transmission and high levels of fear of contagion. Jordanian students less knowledgeable and more fearful than USA students                      | All 4th year nursing students. All from one university in each country.                       |
| Valois <i>et al.</i> (2001) Canada             | 74 Nursing students, response rate not stated. Quasi-experimental design                                   | Modified questionnaire by Lester and Beard (1988)  | Persuasive messages repeated over time effective in changing attitudes, attitudes towards people with HIV/AIDS became more positive   | All 3rd year nursing students from one university. Small experimental sample ( <i>n</i> = 27) |

Table 2 (Continued)

| Authors, year and location            | Sample, size, response rate and type of study  | Instruments   | Major findings   | Limitations   |
|---------------------------------------|--|---|--|---|
| Lohrmann <i>et al.</i> (2000) Germany | 180 <i>n</i> /students, 98% response. Descriptive non-experimental                           | SUNY questionnaire (Held 1993); SSS (Chang & Moore 1993) and Homophobia Scale (Held 1993)           | Low levels of homophobia. Knowledgeable and positive attitudes towards people with HIV. Emphasized success of educational programs                                       | All final year students from one city in Germany  |
| Ngan <i>et al.</i> (2000) Singapore   | 552 Nursing students, 100% response rate. Descriptive, non-experimental                      | Study developed questionnaire   | Significant levels of homophobia. Most show positive attitudes towards caring for people with HIV but 11% would leave nursing before providing care. Poor knowledge base | All 1st year nursing students from one school of nursing.   |
| Uwakwe (2000) Nigeria                 | 141 <i>n</i> /students, no response rate stated. Quasi-experimental                          | Modified questionnaire (from: Uwakwe <i>et al.</i> 1992, Armstrong-Esther & Hewitt 1990)            | Following a specific HIV/AIDS education program, nurses became better informed and more positive about caring for HIV/AIDS pts. Emphasizes need for HIV/AIDS education   | Attitudes influenced by shortages of basic medical supplies. One university                                       |
| Carney <i>et al.</i> (1999) USA       | 60 Nursing students, 29 experimental group, 31 control group. Quasi-experimental             | AIDS Knowledge Inventory (Carney <i>et al.</i> 1994) AIDS Attitude Scale (Shrum <i>et al.</i> 1989) | Specialized HIV/AIDS training course found to increase HIV/AIDS knowledge and improve attitudes towards caring for people with HIV/AIDS                                  | Small sample size. All from one university  |
| Stewart (1999) UK                     | 192 <i>n</i> /students, 100% response  | PESIS (St Lawrence <i>et al.</i> 1990)  | Generally positive attitudes but still some prejudice towards HIV patients. Homophobia no longer a major role in negative attitudes to people with HIV                   | Instrument critiqued by author-emotive, extreme questions may lead to socially acceptable answers. One university |
| Grossman <i>et al.</i> 1998 USA       | 48 Nursing students. Convenience sample, response rate not stated. Quasi-experimental design | Questionnaire developed by Jenmott <i>et al.</i> (1992)   | Knowledge and attitudes improved for students who had RN role model in delivering direct care to people with HIV/AIDS. Significant homophobia                            | All senior nursing students from one nursing school. Small experimental sample ( <i>n</i> = 28)                   |
| All and Sullivan (1997) USA           | 39 <i>n</i> /students, 100% response. Quasi-experimental                                     | STAI (Spielberger <i>et al.</i> 1970)   | Anxiety levels about nursing HIV/AIDS patients reduced by educational programs   | Instrument developed in 1970 before HIV/AIDS, very generic instrument. Small convenience sample. One university   |
| Snowden (1997) UK                     | 112 Nursing students + 39 maths students (control group). Convenience sample                 | Modified questionnaires from Plant <i>et al.</i> (1991), Ryan <i>et al.</i> (1991)                  | Poor levels of HIV knowledge. No significant difference in attitudes between 1st and 3rd year. Education had little impact on attitudes                                  | All students from one university  |

PESIS, Prejudicial Evaluation and Social Interaction Scale; STAI, State-Trait Anxiety Inventory; HIV/AIDS, human immunodeficiency virus/acquired immune deficiency syndrome.

**Table 3** Identified themes and their sources

| Themes identified in the reviewed studies                          | Sources   |
|--|---|
| Theme 1: education and knowledge of HIV/AIDS (15 studies)          | Bektas and Kulakac (2007), Madumo and Peu (2006), Earl and Penny (2003), Rondahl <i>et al.</i> (2003), Peate <i>et al.</i> (2002), Petro-Nustas <i>et al.</i> (2002), Valois <i>et al.</i> (2001), Lohrmann <i>et al.</i> (2000), Ngan <i>et al.</i> (2000), Uwakwe (2000), Carney <i>et al.</i> (1999), Stewart (1999), Grossman <i>et al.</i> (1998), All and Sullivan (1997), Snowden (1997) |
| Theme 2: fear of contracting HIV/AIDS (10 studies)                 | Bektas and Kulakac (2007), Madumo and Peu (2006), Earl and Penny (2003), Rondahl <i>et al.</i> (2003), Petro-Nustas <i>et al.</i> (2002), Lohrmann <i>et al.</i> (2000), Ngan <i>et al.</i> (2000), Uwakwe (2000), Grossman <i>et al.</i> (1998), All and Sullivan (1997)   |
| Theme 3: homophobia (seven studies)                                | Earl and Penny (2003), Rondahl <i>et al.</i> (2003), Peate <i>et al.</i> (2002), Lohrmann <i>et al.</i> (2000), Ngan <i>et al.</i> (2000), Stewart (1999), Grossman <i>et al.</i> (1998)  |
| Theme 4: reluctance to care for people with HIV/AIDS (six studies) | Bektas and Kulakac (2007), Earl and Penny (2003), Rondahl <i>et al.</i> (2003), Peate <i>et al.</i> (2002), Ngan <i>et al.</i> (2000), Grossman <i>et al.</i> (1998)  |
| Theme 5: stigma associated with HIV/AIDS (three studies)           | Chan <i>et al.</i> (2007), Rondahl <i>et al.</i> (2003), Stewart (1999)   |

HIV/AIDS, human immunodeficiency virus/acquired immune deficiency syndrome.

enhance professional behaviour, attitudes and the delivery of compassionate care by nurses (Rondahl *et al.* 2003). These findings are supported by Stewart (1999) and Peate *et al.* (2002), both emphasizing HIV/AIDS education as a means of promoting positive attitudes and a non-judgemental approach among nursing students.

As the number of people infected with HIV/AIDS continues to rise, it is important for nurses to have detailed knowledge of the disease and its treatment to avoid misconceptions. For example, in Jordan, Petro-Nustas *et al.* (2002) found that a statistically significant percentage of nursing students believed that HIV can be contracted by sharing food utensils, sitting on the toilet, donating blood and from mosquito bites. Among a sample of nursing students in Singapore, Ngan *et al.* (2000, p. 31) found that 37.4% were 'unsure if HIV could be transmitted through insect bites'. Earl and Penny (2003) found similar misconceptions among rural nursing students in the USA, who believed that mosquitoes and fishing hooks were potential carriers of the HIV virus.

The impact of nursing curricula on knowledge of HIV and attitudes towards people with HIV was questioned by Snowden (1997). In this English study, knowledge and attitudes were compared between first and third year nursing students. While the study showed that third year nursing students were more knowledgeable about HIV than first year nursing students, there was no statistically significant alteration in attitudes towards people with HIV following a 3-year nursing programme. Of concern was that 41% of third year students did not understand the meaning of the term 'universal precautions'. The authors concluded that there was 'a need to relook at the three year programme that is

currently offered for preparation to practice (sic) as a nurse' (Snowden 1997, p. 1172).

## Theme 2 – fear of contracting HIV/AIDS

Nursing students' fears of contracting HIV/AIDS from patients for whom they are caring was the second most frequently-occurring theme found in 62% ( $n = 10$ ) of the reviewed studies, and was noted in studies across different continents and cultures.

In Africa, a study of Nigerian nursing students' attitudes towards caring for people with HIV/AIDS, Uwakwe (2000) showed that 80% of participants' feared self-infection, while 55% feared infecting members of their families. Similarly, Madumo and Peu (2006) found that South African nursing students were fearful of contracting HIV from patients in hospitals.

In Singapore, Ngan *et al.* (2000) found that 48% of the student sample was concerned that they might contract HIV when performing basic nursing tasks. The level of HIV/AIDS knowledge among these nursing students was poor, and 49% were 'unsure if one could be protected from HIV with antibiotic injection' (Ngan *et al.* 2000, p. 30).

Considerable fear of contracting HIV/AIDS from patients was also found amongst nursing students in Europe and North America. A study in Sweden by Rondahl *et al.* (2003) showed that 26% of the participating nursing students did not want to care for patients with HIV/AIDS. Fear of contracting HIV/AIDS was cited as the main reason for this attitude, with 33% of nursing students being fearful of contagion (Rondahl *et al.* 2003). Similarly in a German study, half of the nursing students were afraid of contacting

HIV from nursing people with HIV/AIDS (Lohrmann *et al.* 2000). Importantly, studies from the USA all linked lower levels of fear with increased HIV/AIDS education (Earl & Penny 2003, Petro-Nustas *et al.* 2002, All & Sullivan 1997).

### Theme 3 – homophobia

Homophobia in nursing is the fear of homosexuality, which may result in homosexual patients not receiving quality, holistic and compassionate care (Christensen 2005). This theme was found in 44% ( $n = 7$ ) of the reviewed studies. In a Swedish study, Rondahl *et al.* (2003) indicated that HIV/AIDS had been presented in the media as the 'gay plague'. Such reporting, linking homosexual people with HIV/AIDS, appeared to influence the attitudes of Swedish nursing students. Attitudes of avoidance were widespread, with 26% of study participants stating that they would refrain from nursing HIV-infected patients if the choice existed (Rondahl *et al.* 2003). Two studies in the USA found high levels of homophobia among nursing students (Earl & Penny 2003, Grossman *et al.* 1998). Little compassion was shown towards people with HIV/AIDS unless the disease was contracted via blood transfusion (Earl & Penny 2003).

British and Singaporean nursing students with greater homophobic attitudes were less willing to care for HIV/AIDS patients (Peate *et al.* 2002, Ngan *et al.* 2000). Peate *et al.* (2002) found a correlation between homophobia and reluctance to care for people with HIV/AIDS. Approximately 16% felt uncomfortable caring for homosexual patients *per se* (Peate *et al.* 2002). Similarly, Ngan *et al.*'s (2000) Singaporean study showed that 24% of students felt 'negatively towards gays because of their association with AIDS' (Ngan *et al.* 2000, p. 28).

Presenting different findings in relation to homophobia in a study of British nursing students, Stewart (1999) concluded that 'homosexuality no longer plays such an important role in the negative evaluation of AIDS' (Stewart 1999, p. 746). Similarly, German nursing students were found to have a low level of homophobia and positive attitudes towards people with HIV/AIDS (Lohrmann *et al.* 2000). These findings suggest that attitudes towards homosexuality vary in different parts of the world.

### Theme 4 – reluctance to care for people with HIV/AIDS

Reluctance to care for people with HIV/AIDS was the fourth most frequently-occurring theme (37%,  $n = 6$ ) in the reviewed studies. Studies from Britain and the USA linked reluctance to care for people with HIV/AIDS with fear of contagion and high levels of homophobia among the partic-

ipating nursing students (Earl & Penny 2003, Grossman *et al.* 1998, Peate *et al.* 2002). A study of Turkish nursing students by Bektas and Kulakac (2007) also showed fear of contagion to be a major factor in participants' reluctance to care for people with HIV/AIDS. Homophobia was not identified as an issue in this study. Instead, lack of HIV/AIDS knowledge and the belief that people living with HIV/AIDS were responsible for their own infection were considered major factors in the reluctance to provide care (Bektas & Kulakac 2007).

Ngan *et al.* (2000) found that 24% of nursing students were reluctant to hold the hand of a HIV/AIDS patient, with 14% indicating that they would refuse to shake hands with a person infected with HIV. Furthermore, 11% of the nursing students sampled in Singapore would leave nursing altogether if they had to care for people with HIV/AIDS on a regular basis. These findings indicate considerable reluctance among these nursing students to care for people with HIV/AIDS. Fear of infection and lack of HIV/AIDS knowledge were identified as the primary reasons for this reluctance (Ngan *et al.* 2000).

### Theme 5 – stigma associated with HIV/AIDS

Stigma is a social construct which singles out a person by virtue of a physical or social trait, resulting in negative social reactions such as discrimination and avoidance (Germov 2005). It is often a mark of social disgrace signifying deviance from some norm or ideal. Of the reviewed studies, 19% ( $n = 3$ ) discussed the theme of stigma associated with HIV/AIDS. In general, nursing students reacted negatively towards patients with HIV/AIDS who were also identified as homosexual or intravenous drug users. Overall, the studies indicated a strong link between stigma and homophobia (Rondahl *et al.* 2003, Stewart 1999).

Rondahl *et al.* (2003) found that people with HIV/AIDS who also identified as homosexual experienced double stigma, resulting in the quality of care received being in jeopardy. Stigmatization of people with HIV/AIDS has also been found to be a statistically significant barrier in the provision of patient care in Thailand, although homophobia did not play a major role (Chan *et al.* 2007). In a study among Thai nursing students, the relationships between HIV/AIDS stigma and the co-stigmas of commercial sex and injecting drug use were analysed (Chan *et al.* 2007). The study showed that injecting drug use carried a greater stigma than having HIV/AIDS. Having the co-stigmas of HIV/AIDS and injecting drug use statistically significantly increased the stigmatization directed towards this group of people. The co-stigmas of HIV/AIDS and commercial sex did not increase stigmatization statistically significantly higher than HIV/

AIDS alone. Chan *et al.* (2007) attributed these findings to the socio-cultural context in Thailand, where injecting drug use is highly stigmatized but commercial sex is 'more widely practiced and tolerated' (Chan *et al.* 2007, p. 154).

## Discussion

### Study strengths and limitations

Reviewing international research helps to develop a broader understanding of issues and problems faced on a daily basis in nursing practice. If negative attitudes towards people with HIV/AIDS are found to persist among nursing students, then the nursing profession has an obligation to develop strategies to understand and overcome such attitudes. Clearly the studies reviewed indicate that negative attitudes exist among some nursing students all over the world. While each of the reviewed studies had weaknesses, for example none were conducted at levels of evidence I or II and they had different research approaches, similar conclusions were still drawn from them. As previously discussed, the wide variety of instruments and methods used in the studies limits the degree to which the findings can be generalized. A further limitation was that most of the studies were conducted in only one hospital or university (see Table 2).

This review excluded pre-1996 studies, which can be seen as both a strength and a limitation. Prior to 1996 few studies of the knowledge and attitudes of nurses or nursing students existed outside Europe and the USA. A strength of this review is that 37% of included studies were conducted in Africa, Asia and the Middle East. If we had included pre-1996 studies, particularly from Europe and the USA, the proportion of studies from other regions would have been reduced. It is also important to regularly re-evaluate knowledge and attitudes as HIV/AIDS and its means of transmission have been become better understood over the years. Nevertheless, we recognize that there are pre-1996 studies of the knowledge and attitudes of nursing students in relation to HIV/AIDS.

### Implications of the findings

The most common theme found in the reviewed studies related to education and knowledge of HIV/AIDS. All 15 where this was a major theme supported the view that increased HIV/AIDS education is essential in overcoming negative attitudes by nursing students towards people with HIV/AIDS. Only one study showed that attitudes were not statistically significantly influenced by an existing nursing curriculum, although HIV/AIDS knowledge was improved

(Snowden 1997). The studies also indicated that fear of contracting HIV/AIDS from people being cared for was a great concern for nursing students. This fear of contagion was the major factor behind the reluctance of some nursing students to care for people with HIV/AIDS. The findings of the reviewed studies are, in many cases, similar to those of earlier studies. Those from the USA recommend increased HIV/AIDS education as a means of reducing the nursing students' fear of contracting HIV when giving nursing care (Earl & Penny 2003, Petro-Nustas *et al.* 2002, All & Sullivan 1997). The same recommendations were made 17–20 years earlier in studies conducted in the USA and Canada (Lester & Beard 1988; Oermann & Gignac 1991; Goldenberg & Laschinger 1991, Synoground & Kellmer-Langan 1991).

Some studies also showed that homophobia and stigma played a role in this reluctance to care for people with HIV/AIDS. Further, people who have acquired the illness through drug use or sex between men may experience additional stigma because of their perceived deviant behaviour. Considerable differences in stigmatization and homophobia existed in different regions of the world. These ranged from the high levels of homophobia among nursing students in the USA (Earl & Penny 2003, Grossman *et al.* 1998) to the general acceptance of commercial sex in Thailand (Chan *et al.* 2007). These findings highlight the need to explore, on a local basis, the beliefs and attitudes of nursing students in relation to HIV/AIDS. Without such data, HIV/AIDS education for nursing students may not achieve the aims of improving knowledge and promoting more positive attitudes towards people with HIV/AIDS.

Local attitudes, beliefs and educational policies all play a role in shaping the attitudes of nursing students towards people with HIV/AIDS. It should be noted that no current South Pacific studies were found for inclusion in the review, suggesting a need for research to determine the attitudes of nursing students in countries such as Australia and New Zealand. The review indicates that there are vast differences in the level of HIV/AIDS education throughout the world, and that this influences the willingness of nursing students to care for people with HIV/AIDS. Each country is different and, even within a country, education systems can vary between regions. For example, in Australia each state has its own secondary school curriculum, with varying levels of HIV/AIDS education (Burtney & Duffy 2004). While the authors of the reviewed studies recommend increased HIV/AIDS education for nursing students, this in itself may not lead to more positive attitudes towards caring for people with HIV/AIDS. In relation to nursing students' knowledge and attitudes, Lester and Beard (1988) recommended that 'Nursing faculty must respond by



**What is already known about this topic**

- There is evidence that some nurses and nursing students are reluctant to care for people with HIV/AIDS because of fear of contagion.
- This reluctance results in a poorer quality of care for people with HIV/AIDS.

**What this paper adds**

- Many existing HIV/AIDS educational programmes for nursing students are not sufficiently improving their knowledge and/or attitudes, indicating that findings from past research studies have not been heeded.
- The role of homophobia and stigma in determining nursing students' attitudes toward caring for people with HIV/AIDS varies between nations, and therefore local research is essential.
- Increased education across nations is essential to overcome persisting negative attitudes by some nursing students towards people with HIV/AIDS, and the effectiveness of this education needs to be continually evaluated.

**Implications for practice and/or policy**

- Nursing educators need to develop strategies to assist nursing students to overcome their fear of contagion while caring for people with HIV/AIDS.
- Nurse educators need to evaluate the effectiveness of their HIV/AIDS education programmes.
- Further research is needed to explore the underlying determinants of nursing students' attitudes towards people with HIV/AIDS.

including current, correct information when instructing students about AIDS' (p. 399). The same recommendation is still being made, suggesting past research evidence has not been heeded.

**Conclusion**

While the evidence indicates that education and increased knowledge do not always change attitudes, they form the basis from which informed attitudes can be developed. HIV/AIDS educational programmes implemented for nursing students need to be evaluated for their impact on the

attitudes, knowledge and work practices of those participating. Nursing students become the practising nurses of the future and will be at the forefront of caring for people with HIV/AIDS. Improving their knowledge of HIV/AIDS and promoting positive attitudes towards people with HIV/AIDS will ultimately result in a higher quality of compassionate nursing care. Past studies which have made similar recommendations appear to have gone unheeded by many nursing educational institutions.

The influence of AIDS stigmatization and the co-stigmas of homosexuality and/or injecting drug use must be taken into consideration when HIV/AIDS education is being developed and addressed by such programmes. Local programmes, based on research evidence into local attitudes and beliefs, must be tailored for local nursing students. While HIV/AIDS is a global epidemic, solutions to issues such as the knowledge and attitudes of nursing students must be found and implemented at the local level.

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**Conflict of interest**

No conflict of interest has been declared by the authors.

**Author contributions**

DP was responsible for the study conception and design; DP performed the data collection; DP, LK and IB performed the data analysis; DP was responsible for the drafting of the manuscript; DP, LK and IB made critical revisions to the paper for important intellectual content; LK obtained funding; LK and IB supervised the study.

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## Appendix 4 – Summary of Reviewed Studies

| Summary of Reviewed Studies     |   |  |   |   |
|---------------------------------|---|--|---|---|
| Authors, Year & Location        | Sample, Size, Response_Rate & Type of Study   | Instruments  | Major Findings  | Limitations   |
| Balpande et al (2014)<br>India  | 205 nursing students<br>Quantitative, cross-sectional using a questionnaire   | Researcher designed questionnaire  | Significant correlation between knowledge and gender, and knowledge and age. Male students had greater knowledge than female. Knowledge increased with age. Found no correlation between knowledge & attitudes. Recommends curriculum emphasises in-depth discussion on HIV/AIDS to clarify misconceptions, and discourage discrimination | Researcher designed questionnaire, no details of reliability or validity<br>Small sample size<br>Sample all from one university health service in India |
| Ozakgul et al (2014)<br>Turkey  | 614 nursing students<br>Quantitative, correlational design using a questionnaire  | AIDS Attitude Scale (Bliwise et al 1991) , modified for use in Turkey<br>Scale of Empathic Tendency (Dokmen 2005)  | Greater HIV/AIDS knowledge & greater contact with PLWA associated with more positive attitudes and greater empathy.<br>Recommends curriculum make greater use of simulation, role-playing and case-scenario to increase awareness and empathy for PLWA  | Sample from 2 universities in Turkey  |
| Akin et al (2013)<br>Turkey     | 580 nursing students<br>Quantitative descriptive using questionnaire  | Student Socio-Demographic Questionnaire, HIV/AIDS Knowledge Questionnaire, HIV/AIDS Attitude Questionnaire.  | Poor knowledge of HIV transmission routes and some misconceptions about HIV/AIDS.<br>Generally positive attitudes towards PLWA but some concerns and fears about providing nursing care to PLWA. Recommends improved nursing student education  | Conducted in 3 nursing schools<br>91% of participants were female nursing students  |
| Diesel et al (2013)<br>Cameroon | 54 nursing students participated in HIV/AIDS workshop, 41 participant in all surveys<br>Quantitative, pre & post-test surveys | HIV/AIDS Stigma Instrument – Nursing Student (HASI-NS; Uys et al., 2009), Nurse Willingness Questionnaire (NWQ; Dubbert et al 1994), AIDS Attitude Scale (AAS) (Froman, Owen, & Daisy, 1992), AIDS Knowledge Scale (AKS; Jemmott, Freileicher, & Jemmott, 1992), Obstetrical Knowledge Scale (author developed). | An educational intervention (workshop) improved participants' knowledge and attitudes, but only reduced perceived stigma towards PLWA by students with no prior experience of PLWA, those with experience of PLWA showed little change in their stigmatising perceptions.   | Single study site<br>Sample skewed to a younger, unmarried group of participants<br>Instruments relied on self-reporting<br>Small sample size           |

### Summary of Reviewed Studies (continued)

| <b>Authors, Year &amp; Location</b> | <b>Sample, Size, Response_Rate &amp; Type of Study</b>  | <b>Instruments</b>   | <b>Major Findings</b>  | <b>Limitations</b>   |
|-------------------------------------|---|--|--|--|
| Praca et al (2013)<br>Brazil        | 2 groups of nursing students, 56 in 1998/9 and 51 in 2010<br>Quantitative, retrospective, descriptive using questionnaire | Researcher designed questionnaire  | There was a decrease in HIV/AIDS knowledge between 1998/9 and 2010<br>Recommends curriculum includes increased contact between students and patients, and increased education to reduce knowledge gaps, particularly in relation to AIDS in women's health                     | Researcher designed questionnaire, no details of reliability or validity<br>Questionnaire modified between 1998/9 and 2010<br>Small sample size<br>Sample all from one university health service in Brazil |
| Akansel et al (2012)<br>Turkey      | 88 first year nursing students<br>Quantitative descriptive using questionnaire  | AIDS Attitude Scale (Bliwise et al 1991) , modified for use in Turkey        | 67% of students afraid of contagion when care for PLWA. Anger towards homosexuals.<br>Education improved knowledge but did little to change perceptions. 35.2% would prefer to not work with AIDS patient if given the choice (same % before & after educational intervention) | Sample all from 1 school of nursing<br>Small sample size   |
| Nazik et al (2012)<br>Turkey        | 311 nursing students,<br>Quantitative, cross-sectional descriptive  | AIDS Attitude Scale (Bliwise et al 1991), modified for use in Turkey         | High levels of fear of contagion among nursing students. Negative perceptions/attitudes towards PLWA. Reluctance to provide care (40.8% said they would prefer not to work with AIDS patients if given the choice)   | Sample taken from one university health school in Turkey<br>Only verbal consent obtained   |
| Rosenburg et al (2012)<br>Cameroon  | 353 nursing students from 5 nursing schools. Quantitative, cross-sectional pilot study                                    | HASI-NS questionnaire which is a modified version of HASI-N (Uys et al 2009) | Nursing students had stigmatising perceptions of AIDS patients, this was reduced if they had previously knowingly cared for PLWA. Further education recommended  | Questionnaire delivered in both English & French, possible language bias introduced when translating into French   |
| Sachdeva et al (2011)<br>India      | First year students:<br>MBBS – 129<br>Nursing – 53<br>Pharmacy – 55<br>Quantitative, cross-sectional descriptive          | Researcher designed questionnaire  | Generally high levels of correct knowledge with regards to modes of transmission, prevention, myths & misconceptions. However some major misconceptions apparent among nursing students with 50% incorrectly stating that smoking was a risk factor for acquiring HIV          | Researcher designed questionnaire<br>Small sample size (of nursing students)<br>Sample all from one university health service in India   |

### Summary of Reviewed Studies (continued)

| <b>Authors, Year &amp; Location</b>      | <b>Sample, Size, Response_Rate &amp; Type of Study</b>  | <b>Instruments</b>  | <b>Major Findings</b>  | <b>Limitations</b>  |
|--|---|---|--|---|
| Earl (2010)<br>Thailand                  | 26 nursing students.<br>Quantitative, cross-sectional<br>descriptive  | AIDS Health Care Belief Scale,<br>adapted from (Champion 1984)<br>AIDS Education Information<br>Questionnaire, adapted from<br>(Dawson et al 1988; Wertz et al<br>1987)   | 27% indicated that they would not provide care<br>for HIV +ve patients<br>41% scared of contracting HIV from patients<br>Recommended more education to improve<br>confidence that they can care for PLWA without<br>contracting HIV  | Sample all from 1 school of<br>nursing<br>Small sample size<br>Only students who spoke both<br>Thai & English included  |
| Jose et al (2011)<br>Papua New<br>Guinea | 1597 tertiary students,<br>including nursing students but<br>% or number of nursing<br>students not specified   | Researcher designed<br>questionnaire  | Majority of tertiary students have a considerate<br>and compassionate attitude toward PLWA. 50%<br>believed AIDS is a punishment from God,<br>affecting basic knowledge. Improved HIV/AIDS<br>education needed at all levels. No difference in<br>knowledge levels between health science/nursing<br>students and other tertiary students  | Researcher designed<br>questionnaire<br>Disciple of students not<br>specified<br>No information given about<br>ethical considerations or<br>permissions   |
| Rutledge et al<br>(2011)<br>USA          | 173 nursing students,<br>purposive sampling<br>Quantitative – validation of<br>the HIV/AIDS Provider<br>Stigma Inventory (HAPSI)  | Study is to validate the<br>instrument (HAPSI) developed<br>by the researchers<br>Derived from Link & Phelan<br>(2001) social psychological<br>stigma framework, and the<br>authors previous Awareness,<br>Acceptance, and Action Model<br>(AAAM) (Rutledge & Abell,<br>2005)<br>Validated using other scales<br>such as AAS & expert panel | The HAPSI was found to be valid and reliable for<br>use among nurses and other health care<br>providers.<br>The scale specifically looks at occupational<br>exposure and judgments related to stereotyping<br>PLWA with stigmas of homosexuality, drug use,<br>and having multiple sex partners. In addition it<br>addresses concerns about nurses being judged by<br>family and others for caring for PLWA. | Sample taken from one<br>university nursing school in<br>USA<br>Student sample had limited<br>clinical experience<br>Length of data collection<br>instrument  |
| Qu et al (2010)<br>China                 | 528 student nurses , cluster<br>sample, 97% response rate<br>Quantitative, cross-sectional<br>survey, structural equation<br>model (SEM) used to<br>determine relationships | Knowledge questionnaire &<br>attitude questionnaire, both<br>developed and validated by the<br>researchers  | Greater knowledge about HIV/AIDS needed to<br>promote more positive attitudes by nursing<br>students towards HIV/AIDS patients.<br>Opportunity to work with HIV/AIDS patients<br>during nursing training is recommended to<br>promote more positive attitudes  | Sample all from 1 university<br>Models other than the SEM<br>used also fit the data with<br>potential for different results<br>Large number of variables,<br>direction of relationships not<br>always clear |

**Summary of Reviewed Studies (continued)**

| <b>Authors, Year &amp; Location</b>   | <b>Sample, Size, Response_Rate &amp; Type of Study</b>  | <b>Instruments</b>   | <b>Major Findings</b>  | <b>Limitations</b>  |
|---|---|--|--|---|
| Yiu et al (2010)<br>China   | 89 nursing students, convenience sample, 87% response rate<br>Quantitative quasi-experimental, pre-test, post-test, & 6 week follow up questionnaires | Researcher developed questionnaires in Chinese based on instruments used in previous studies by: Held (1993); Lau et al (1996); Li et al (2007); Mak et al (2006); McCann & Sharkey (1998)   | A knowledge program + contact with PLWA significantly reduced students' stigmatising attitudes compared with a knowledge only program. However, the effect was only short lived & no difference was found at 6 week follow-up  | Students from only 2 universities in Hong Kong. Small sample size. No control (non-intervention) group. Self-reported changes by students, actual behaviour not verified                        |
| Välämäki et al (2010)<br>Finland, Estonia & Lithuania   | 471 nursing students (Finland 169; Estonia 132; Lithuania 170). Purposive sampling, 83% response rate<br>Quantitative, cross-sectional survey         | Modified version of the Nurse Willingness Questionnaire (NWQ) (Kemppainen et al 1992; Dubbert et al 1994)  | Students' willingness to care for PLWA varied between countries but overall positive. Older age & experience associated with willingness to perform nursing activities for PLWA. Recommends students have opportunity to care for PLWA during clinical placements  | Small sample size (from each country). Vignette used in study related to care of male patient only. Responses related to hypothetical male patient, response to real situation may be different |
| Mahat & Eller (2009)<br>Nepal   | 127 nursing students, convenience sample.<br>Quantitative, descriptive, non-experimental  | HIV/AIDS Knowledge Questionnaire (Carey et al 1997)<br>HIV Attitudes Questionnaire (Ambati et al 1997)<br>HIV Transmission Attitudes Questionnaire (Zimmer & Thurston 1998)<br>Universal Precautions Knowledge Questionnaire (investigator developed tool) | HIV/AIDS related knowledge increased with nursing education, still large knowledge gap regardless of level of education. Majority willing to care for PLWA, however blame, stigma and negative attitudes present at all levels   | Limited sample size, all English speaking respondents. Use of Western instruments in Nepalese cultural context  |
| Suominen et al (2009)<br>Finland, Estonia & Lithuania<br>*Note: this study appears to have the same sample & report different aspects of the (Välämäki et al 2010) study reported above | 471 nursing students (Finland 169; Estonia 132; Lithuania 170). Purposive sampling, 83% response rate<br>Quantitative, cross-sectional survey         | Modified version of the State University of New York at Buffalo School of Nursing AIDS Study Questionnaire (Held 1993)   | Having previous experience with HIV/AIDS patients' most significant factor in promoting +ve attitudes by students towards PLWA. Older nursing students had more negative attitude towards homosexual patients. Education, knowledge and experience with HIV/AIDS patients, all recommended for nursing students. Differences noted between the 3 countries, greater harmonisation of nursing education recommended in European countries | Sample taken from one or two institutions in each country. Instrument developed in USA, its suitability for use in these countries questionable   |

### Summary of Reviewed Studies (continued)

| <b>Authors, Year &amp; Location</b>     | <b>Sample, Size, Response_Rate &amp; Type of Study</b>  | <b>Instruments</b>  | <b>Major Findings</b>   | <b>Limitations</b>  |
|---|---|---|---|---|
| Relf et al (2009)<br>South Africa & USA | 334 nursing students (South Africa 136; USA 198). Convenience sample, participation rate >95%<br>Quantitative, multi-site, descriptive correlational                              | Researcher developed Attitudes, Beliefs, and Practices Survey about HIV and AIDS (ABPSHA), based on pre-existing instruments                      | In the context of ethical standards, nursing students in both countries had attitudes & beliefs incompatible with codes of ethical standards. Students from USA were less likely to have attitudes & beliefs consistent with ethical standards than South African nursing students. Clinical experience caring for PLWA recommended for nursing students, plus guided education of complex ethical issues | Surveys administered differently in the 2 settings. Students reported some survey questions unclear or vague. Only one education facility in each country |
| Veeramah et al (2008)<br>UK             | 47 final year nursing students, convenience sample, 76% response rate<br>Quantitative, cross sectional survey   | SUNY questionnaire (Held 1993); AIDS Attitude Scale (Froman et al 1992)   | Good levels of knowledge, although some deficits. More education wanted, 83% reported they did not have the skills to meet the needs (physical & psychological) of HIV patients. Positive attitudes, low levels of homophobia and fear of contagion present   | Small sample size all from one university in SE England   |
| Li et al (2008)<br>China                | 204 nursing students from 10 nursing schools completing their last clinical placement at the one hospital. Convenience sample, 100% response rate.<br>Quantitative, survey design | Researcher developed instrument based on previous instruments: Wang et al (2003); Jemmott et al (1992); Froman & Owen (2001); Dubbet et al (1994) | Students had basic HIV/AIDS knowledge but major misconceptions found (eg 33% believed HIV can be transmitted by eating food cooked by a PLWA). Reluctance to provide care found to exist due to perceived risk of contagion. Formal HIV/AIDS educational workshops, seminars etc recommended for nursing curricula  | Convenience sample of students all undertaking placement in one hospital in China   |
| Bektas & Kulakac (2007) Turkey          | 227 nursing students, 76 % response rate. Mixed method. Non-experimental & qualitative – content analysis   | Study developed questionnaire. Combined with qualitative essays written to answer open ended questions  | Moderate knowledge of HIV/AIDS. Fear of contagion. Previous HIV/AIDS experience linked to greater willingness to provide care. Emphasis on education to encourage humane attitudes.   | All female nursing students from one nursing school   |
| Chan et al (2007) Thailand              | 144 nursing students, response rate not stated. Descriptive, non-experimental   | Attitudinal measures adapted from Kelly et al (1987)  | AIDS, commercial sex (CS) & intravenous drug use (IDU) all stigmatised. Stigma for AIDS with IDU double than AIDS alone. Stigma for AIDS & CS no significant difference than AIDS alone.  | Participants disproportionately female. All from one nursing school, all senior students  |
| Madumo & Peu (2006) South Africa        | 12 nursing students, exploratory & descriptive qualitative study. Purposive sample.   | Focus group interviews developed for the study  | Fear of contagion. Compassion for people with HIV/AIDS. Lack of support for students caring for people with HIV/AIDS during clinical placement. Need for more HIV/AIDS education.   | All 3 <sup>rd</sup> year nursing students from one university   |

**Summary of Reviewed Studies (continued)**

| <b>Authors, Year &amp; Location</b> | <b>Sample, Size, Response_Rate &amp; Type of Study</b>   | <b>Instruments</b>  | <b>Major Findings</b>  | <b>Limitations</b>   |
|-------------------------------------|--|---|--|--|
| Mahendra et al (2007)<br>India      | Phase 1: Qualitative interviews with 59 hospital staff, patients & caregivers; Focus group discussions with 40 PLWA & caregivers. Convenience samples<br>Phase 2: Quantitative survey of 884 health care workers (doctors, n=134;nurses, n=375; ward staff, n=375). Stratified random sampling | Interviews and focus groups used to generate qualitative data and to develop quantitative HIV-related stigma survey instrument                                    | Phase 1 found judgemental & prejudiced attitudes, as well as discriminatory practices common in hospital, including: testing for HIV without consent; disclosure of results without consent; labelling items as belonging to patient with HIV; unwarranted use of precautions<br>Phase 2 found high levels of fear among staff (59% would not share a meal with someone with HIV), judgemental attitudes (68% indicated HIV is spread by immoral behaviour), blame (43% indicated only women who were sex workers at risk of HIV). Ward staff had expressed greatest stigma toward PLWA, followed by nurses, lowest by doctors<br>Recommendation: stigma reduction interventions need to be introduced into hospital setting | Study carried out in on city in India (New Delhi)  |
| Cornelius (2006)<br>USA             | 70 senior baccalaureate African-American nursing students. Convenience sample. Quantitative, descriptive, correlational study  | Modified version of National Health Interview Survey of AIDS Knowledge (Fitti & Cynamon 1990)<br>Heterosexual Attitudes towards Homosexuality Scale (Larson 1988) | Students had basic HIV knowledge but deficits evident in knowledge relating modes of transmission. Many students had no previous HIV/AIDS education in their nursing curriculum, the majority requested additional HIV/AIDS education. Researchers concluded that nursing student knowledge & attitudes had not changed over the previous 20 years   | Participants all senior baccalaureate African-American nursing students<br>All from one region in South East USA with high AIDS prevalence rate<br>Small sample size |
| Earl & Penny (2003) USA             | 50 n/students<br>Qualitative descriptive.  | Study developed interview schedule  | Negative attitudes & high levels of homophobia. Poor knowledge of HIV  | All commencing nursing students from rural & remote regions  |
| Rondahl et al (2003) Sweden         | 222=57 nurses & 165 n/students. 65% response. Descriptive comparative  | AIDS Attitude Scale (Froman et al 1992)   | High levels of homophobia, 36% would refrain from nursing homosexual patients if given the option  | One infectious diseases clinic and one university  |

### Summary of Reviewed Studies (continued)

| <b>Authors, Year &amp; Location</b>    | <b>Sample, Size, Response_Rate &amp; Type of Study</b>  | <b>Instruments</b>   | <b>Major Findings</b>  | <b>Limitations</b>  |
|--|---|--|--|---|
| Peate et al (2002) UK                  | 138 n/students. 87% response. Descriptive non-experimental  | SUNY questionnaire (Held 1993); NWQ (Dubbert et al 1994)                               | Good knowledge about AIDS. Stressed importance of HIV education for n/students   | All 1 <sup>st</sup> year nursing students from one university                                   |
| Petro-Nustas et al (2002) USA & Jordan | 63 USA & 63 Jordanian nursing students, convenience sample. Descriptive comparative study.  | Modified questionnaire by Kulwicki & Cass (1994)                                       | Considerable misconceptions about modes of transmission & high levels of fear of contagion. Jordanian students less knowledgeable & more fearful than USA students.  | All 4 <sup>th</sup> year nursing students. All from one university in each country.             |
| Atulomah & Oladepo (2002) Nigeria      | 359 nursing students & 120 midwifery students. Response rate & method of sample selection not specified. Descriptive study, qualitative focus groups used to develop quantitative questionnaire | Researcher developed questionnaire   | Moderate HIV/AIDS knowledge, considered inadequate for nursing/midwifery students. Low level of "universal precautions" knowledge found (only 15% of nursing & 27.5% of midwifery students knew that needles should not be recapped after injection). Lack of supervision of students found during clinical practice. Increased education & clinical supervision recommended | Students all from metropolitan nursing schools in on Nigerian city                              |
| Valois et al (2001) Canada             | 74 nursing students, response rate not stated. Quasi-experimental design  | Modified questionnaire by Lester & Beard (1988)  | Persuasive messages repeated over time effective in changing attitudes, attitudes towards people with HIV/AIDS became more positive.   | All 3 <sup>rd</sup> year nursing students from one university. Small experimental sample (n=27) |
| Lohrmann et al (2000) Germany          | 180 n/students. 98% response Descriptive non-experimental   | SUNY questionnaire (Held 1993); SSS (Chng & Moore 1993) & Homophobia scale (Held 1993) | Low levels of homophobia. Knowledgeable & positive attitudes towards people with HIV. Emphasised success of educational programs   | All final year students from one city in Germany  |
| Ngan et al (2000) Singapore            | 552 nursing students, 100% response rate. Descriptive, non-experimental   | Study developed questionnaire  | Significant levels of homophobia. Most show positive attitudes towards caring for people with HIV but 11% would leave nursing before providing care. Poor knowledge base   | All 1 <sup>st</sup> year nursing students from one school of nursing.                           |
| Uwakwe (2000) Nigeria                  | 141 n/students No response rate stated. Quasi-experimental  | Modified questionnaire (from Uwakwe et al 1992 & Armstrong-Eshter & Hewitt 1990)       | Following a specific HIV/AIDS education program, nurses became better informed & more positive about caring for HIV/AIDS pts. Emphasises need for HIV/AIDS education   | Attitudes influenced by shortages of basic medical supplies. One university                     |



### Summary of Reviewed Studies (continued)

| Authors, Year & Location  | Authors, Year & Location  | Authors, Year & Location  | Authors, Year & Location  | Authors, Year & Location   |
|---------------------------|---|---|---|--|
| Carney et al (1999) USA   | 60 nursing students, 29 experimental group, 31 control group. Quasi-experimental  | AIDS Knowledge Inventory (Carney et al 1994) AIDS Attitude Scale (Shrum et al 1989)                       | Specialised HIV/AIDS training course found to increase HIV/AIDS knowledge and improve attitudes towards caring for people with HIV/AIDS   | Small sample size. All from one university   |
| Stewart (1999) UK         | 192 n/students<br>100% response   | PESIS (St Lawrence et al 1990)  | Generally positive attitudes but still some prejudice towards HIV patients. Homophobia no longer a major role in negative attitudes to people with HIV  | Instrument critiqued by author- emotive, extreme questions may lead to socially acceptable answers. One university |
| McCann (1998) Australia   | International nurses enrolled in Australian university Bachelor of Nursing program. Pre-test, n=74, post-test, n=65. Quantitative questionnaire to measure effect of educational intervention | Researcher developed questionnaire, adapted from researcher's earlier work and Australian Government data | Educational intervention improved HIV/AIDS knowledge but still need for further improvement. Fear of contagion remains a major factor in participants' perceptions of PLWA. The importance of HIV/AIDS education is emphasised, and this needs to be more inclusive | Participants all from one regional Australian university<br>Small sample size                                      |
| Grossman et al (1998) USA | 48 nursing students. Convenience sample, response rate not stated. Quasi-experimental design  | Questionnaire developed by Jemmott et al (1992)   | Knowledge & attitudes improved for students who had RN role model in delivering direct care to people with HIV/AIDS. Significant homophobia   | All senior nursing students from one nursing school. Small experimental sample (n=28)                              |
| All & Sullivan (1997) USA | 39 n/students. 100% response<br>Quasi-experimental  | STAI (Spielberger et al 1970)   | Anxiety levels about nursing HIV/AIDS patients reduced by educational programs  | Instrument developed in 1970 before HIV/AIDS, very generic instrument. Small convenience sample. One university    |
| Snowden (1997) UK         | 112 nursing students + 39 maths students (control group). Convenience sample  | Modified questionnaires from Plant et al (1991) & Ryan et al (1991)                                       | Poor levels of HIV knowledge. No significant difference in attitudes between 1 <sup>st</sup> & 3 <sup>rd</sup> year. Education had little impact on attitudes   | All students from one university   |

## Appendix 5 – Ethics Approval Notice

Flinders University and Southern Adelaide Health Service

### SOCIAL AND BEHAVIOURAL RESEARCH ETHICS COMMITTEE

Room B1, Union Building, Flinders University,  
GPO Box 2100, ADELAIDE SA 5001  
Phone: (08) 8201 3116  
Email: [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au)

### FINAL APPROVAL NOTICE

Principal Researcher:

Address:

Project Title:

Project No.:  Approval Expiry Date:

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

In accordance with the undertaking you provided in your application for ethics approval for the project, please inform the Social and Behavioural Research Ethics Committee, giving reasons, if the research project is discontinued before the expected date of completion.

You are also required to report anything which might warrant review of ethical approval of the protocol. Such matters include:

- serious or unexpected adverse effects on participants;
- proposed changes in the protocol; and
- unforeseen events that might affect continued ethical acceptability of the project.

In order to comply with monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress and/or final report must be submitted. A copy of the pro forma is available from <http://www.flinders.edu.au/research/info-for-researchers/ethics/committees/social-behavioural.cfm>. Your first report is due on **8 July 2010** or on completion of the project, whichever is the earliest. *Please retain this notice for reference when completing annual progress or final reports.*



Andrea Jacobs  
Acting Secretary  
Social and Behavioural Research Ethics Committee  
14 July 2009

cc: Dr Lindy King, School of Nursing and Midwifery  
Dr Sheryl de Lacey, School of Nursing & Midwifery

**NB:** *If you are a scholarship holder and you receive funding for your research through the National Health & Medical Research Council please forward a copy of this letter to the Head, Higher Degree Administration and Scholarships Office, for forwarding to the NHMRC.*

## Appendix 6 – Ethics Modification Approval Notice

Flinders University and Southern Area Health Service

### SOCIAL AND BEHAVIOURAL RESEARCH ETHICS COMMITTEE

Research Services Office, Union Building, Flinders University  
GPO Box 2100, ADELAIDE SA 5001  
Phone: (08) 8201 3116  
Email: [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au)


### MODIFICATION APPROVAL NOTICE

|                       |   |                             |              |                       |               |
|-----------------------|---|-----------------------------|--------------|-----------------------|---------------|
| Principal Researcher: | Mr David Pickles  |                             |              |                       |               |
| Email:                | <a href="mailto:pick0070@flinders.edu.au">pick0070@flinders.edu.au</a>  |                             |              |                       |               |
| Address:              | PO Box 904<br>North Adelaide SA 5006  |                             |              |                       |               |
| Project Title:        | Attitudes and perceptions of Nursing students towards caring for people with HIV/AIDS: a discourse analysis spanning four cultural contexts |                             |              |                       |               |
| Project No.:          | 4494  | Modification Approval Date: | 13 July 2011 | Approval Expiry Date: | 31 March 2012 |

I refer to your application for a modification of the above project that has been approved previously. I am pleased to inform you that the Deputy Chairperson has approved your request to modify the project as outlined below:

| ✓ | Approved Modification(s)    | Details of approved modification(s)   |         |     |         |
|---|-----------------------------|---|---------|-----|---------|
| ✓ | Extension of Time:          | From:   | 31/3/11 | To: | 31/3/12 |
|   | Change of personnel:        |   |         |     |         |
| ✓ | Modified research protocol: | Addition of a follow-up interview with participants from the original study as outlined in the Modification Request received on the 12 <sup>th</sup> of July. |         |     |         |

**Reminder:** The next annual progress or final report to the Social and Behavioural Research Ethics Committee is due on **8 July 2011** or when the project is completed, whichever is the soonest. If you require an extension of time, please send a request for an extension of time, to a date you specify, to [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au) before the expiry date listed above.

  
Andrea Mather  
Executive Officer  
Social and Behavioural Research Ethics Committee  
14 July 2011

cc: Dr Lindy King, [lindy.king@flinders.edu.au](mailto:lindy.king@flinders.edu.au)  
Dr Sheryl de Lacey, [sheryl.delacey@flinders.edu.au](mailto:sheryl.delacey@flinders.edu.au)

## Appendix 7 – Ethics Modification Approval Notice

### MODIFICATION (#3) APPROVAL NOTICE

Project No.:

Project Title:

Principal Researcher:

Email:

Address:

Modification Approval Date:  Ethics Approval Expiry Date:

I refer to your modification request for the project above that has been approved previously. I am pleased to inform you that the Chairperson has approved your request to modify the project as outlined below:

| ✓ | Approved Modification(s) | Details of approved modification(s) |   |
|---|--------------------------|-------------------------------------|---|
|   | Change of Project Title  | From:                               | Attitudes and perceptions of Nursing students towards caring for people with HIV/AIDS: a discourse analysis spanning four cultural contexts |
|   |                          | To:                                 | Perceptions of nursing students towards caring for people living with HIV/AIDS: A qualitative study spanning multiple cultural contexts     |

Elaine Merritt  
Administration Assistant  
*on behalf of*  
Andrea Fiegert, Executive Officer  
Social and Behavioural Research Ethics Committee

## Appendix 8 – Participant Details

### Initial Interviews

| Assigned Pseudonym | Date of Interview | Length of Interview (minutes) | Country of Citizenship | Gender | Age Range | Study Year |
|--------------------|-------------------|-------------------------------|------------------------|--------|-----------|------------|
| Fiona              | 03/08/2009        | 36                            | Australia              | F      | 25-34     | 2          |
| Anne               | 03/08/2009        | 39                            | Australia              | F      | 25-34     | 2          |
| Kim                | 04/08/2009        | 45                            | South Korea            | F      | 25-34     | 2          |
| Fan                | 04/08/2009        | 51                            | China                  | F      | 18-24     | 2          |
| Mari               | 04/08/2009        | 36                            | Tanzania               | F      | 35-44     | 3          |
| Janet              | 06/08/2009        | 34                            | Australia              | F      | 18-24     | 2          |
| Alice              | 10/08/2009        | 38                            | England                | F      | 35-44     | 2          |
| Susan              | 24/08/2009        | 38                            | Australia              | F      | 25-34     | 2          |
| Ying               | 25/08/2009        | 61                            | China                  | F      | 25-34     | 2          |
| Sandra             | 03/09/2009        | 24                            | Australia              | F      | 25-34     | 2          |
| Rachel             | 30/09/2009        | 34                            | Australia              | F      | 35-44     | 2          |
| Lee                | 02/10/2009        | 48                            | Hong Kong              | F      | 18-24     | 2          |
| Mark               | 02/10/2009        | 24                            | Iran                   | M      | 18-24     | 1          |
| Jiao               | 08/10/2009        | 40                            | China                  | F      | 25-34     | 2          |
| Pearl              | 10/09/2009        | 37                            | Nigeria                | F      | 18-24     | 2          |
| Melanie            | 10/09/2009        | 33                            | Australia              | F      | 25-34     | 1          |
| Deng               | 12/10/2009        | 32                            | China                  | M      | 25-34     | 2          |
| Mieko              | 13/10/2009        | 45                            | Japan                  | F      | 35-44     | 2          |
| Yue                | 21/10/2009        | 40                            | China                  | F      | 18-24     | 2          |
| Sang               | 21/10/2009        | 43                            | South Korea            | F      | 25-34     | 2          |
| Heng               | 21/10/2009        | 48                            | Hong Kong              | M      | 25-34     | 2          |

### Follow-up Interviews

| Assigned Pseudonym | Date of Interview | Length of Interview (minutes) | Completed Bachelor of Nursing Degree? | Working as Registered Nurse? |
|--------------------|-------------------|-------------------------------|---------------------------------------|------------------------------|
| Ying               | 25/08/2011        | 55                            | Yes                                   | No                           |
| Lee                | 06/09/2011        | 42                            | Yes                                   | Yes                          |
| Pearl              | 27/07/2011        | 54                            | Yes                                   | Yes                          |
| Mieko              | 23/08/2011        | 33                            | Yes                                   | No                           |
| Yue                | 03/10/2011        | 40                            | Yes                                   | Yes                          |
| Kim                | 22/09/2011        | 51                            | Yes                                   | Yes                          |

## ***Appendix 9 – Outline of questions to guide/inform interviews.***

Interviews were conducted in an informal manner with minimal structure. I have described them as semi-structured interviews. They were conversations designed to elicit the stories of the interviewees, to have them talk about themselves and their lived world. These discourses helped to define the socio-cultural contexts of the interviewees, forming the basis for an insight into their beliefs and attitudes towards PLWA. While describing the interviews as unstructured, there was, nevertheless, a general framework to assist in encouraging participants to tell their stories.

The following are some cues I used while interviewing the nursing students. Each individual is unique, some talked freely with little prompting, others required encouragement. As each interview progressed I use the following cues as and when required:

- Do you mind telling me a little about your family ...
- How many brothers and sisters do you have?
- Tell me what it was like growing up in ...
- Can you describe your high school experiences for me?
- As you are aware, the topic I want to discuss today is HIV/AIDS, would you consider yourself knowledgeable about this disease?
- Was anything about HIV taught in class when you went to school? How about among your friends, was it something talked about?

## ***Appendix 10 – Scenarios presented to participants during interview***

### **Crystal**

You are working night shift on a medical ward in a large public hospital, so far it has been a quiet night. Crystal is one of your patients, she is 42 years old and was diagnosed with HIV many years ago, now she is close to death from AIDS. Crystal first injected heroin at the age of 15 and soon started prostituting herself to pay for the drug habit. She had two daughters, both became drug addicts, both are now dead, one from overdose, the other from suicide. Crystal has never really been free from drugs during the past 27 years. Tonight is going to be her last night, she knows it, she is scared, she doesn't want to die alone. She asks you to sit with her, hold her hand, be with her until the end.

### **Paul**

Apparently Paul is a regular patient on the ward, often with secondary infections from his HIV positive status. Most of the staff appear to know him but this is the first time you have met him and today Paul is one of your patients. He is on lots of medications including several different IV antibiotics. It takes ages to sort out all his morning medications, you chat to him while you're trying to do that. As you chat, Paul tells you he has to appear in court later in the week, he's facing several charges of endangering life. He laughs as he tells you "if women want to have sex with me then they have to take the risks ... why should I tell them I have HIV ... anyway, how can I have HIV, I feel fine!"

## **Kylie**

You look across the ward at Kylie, sitting there serenely, quite beautiful with long black silky hair, what age do you think, maybe 25? The two guards are a bit out of place on the ward, there are whispers among the other patients and staff about why the guards are there. Kylie is not one of your patients but you listen in as other nurses quietly spread the gossip. It's hard to believe, but according to her passport Kylie is actually male, one of those lady-boys from Thailand. She overstayed her visa and was picked up by Immigration Officers who found her working in a gay brothel. She is awaiting deportation, the guards have brought her from the detention centre as she has a chest infection. Routine testing has found she is HIV positive. The nurses mutter to themselves, "there's no point in doing much for her, she'll be back where she belongs in Thailand in a few days, anyway she's got AIDS, she's going to die anyway, why bother?"

## **Steve**

Following a car crash, Steve had emergency surgery to remove his ruptured spleen, he is still a bit sore but well on the road to recovery. Steve is one of your patients today, you notice the orange Alert sticker on his notes, he's HIV positive. Steve tells you that you don't need to worry about helping him with showering etc, his partner will be coming in to help. That's one less thing for you to worry about, it's been so busy already this morning. Barry arrives at 10am, you didn't realise that Steve is gay and his partner was going to be a man. Anyway, that's their business and you have so much work to do, there's no time to worry about things like that. Helen is the EN helping you to look after your patients. She comes to you and tells you the other patients have complained about Steve and Barry showering together, maybe they're having sex, it's disgusting! You're the RN so you're in charge, the patients want to know what are you going to do about it?



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