

CHALLENGES AND STRATEGIES IN ADVICE AND INFORMATION GIVING
BY HIV NURSE COUNSELLORS

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

Language Academy
Universiti Teknologi Malaysia

MAY 2017

To my beloved parents, husband, and son

ACKNOWLEDGEMENT

In the name of Allah, the most Gracious and the most Compassionate.

I would like to express my deepest gratitude and appreciation to my main supervisor, Dr. Noor Aireen Ibrahim, for she has worked tirelessly in making constructive criticisms, sharing ideas and guiding me from research proposal to the final thesis write-up. I also acknowledge the contribution of Associate Professor Dr. Azizah Rajab, as the co-supervisor, who has guided me and provided constructive advices for successful completion of this thesis.

I would love to express my heartiest appreciation to my husband, Aizuddin Bin Supee, for always being right next to me through thick and thin, and for his willingness to lend a hand throughout the completion of this thesis. To my son, Arif Zafran Bin Aizuddin, I would like to dedicate this thesis to you as you have been a part of this journey. A special thanks to my family. Words cannot express how grateful I am to my parents and my parents-in-law, for all of the sacrifices that you've made on my behalf. Your prayer for me was what sustained me thus far.

I would like to acknowledge the contribution of Dr. Norhayati Shaharudin who has been helping me to get access to HIV counselling sessions, as well as the focus group discussions. I am also indebted to the Ministry of Education (MOE) Malaysia and the Universiti Teknologi Malaysia (UTM) for funding my Ph.D. study. I would also like to thank all of my friends who supported me in writing and encouraged me to strive towards my goal. May Allah bless us all.

ABSTRACT

HIV counselling is a communication process between trained HIV nurse counsellors and patients to discuss and assist patients to deal with HIV-related problems. Despite the training undertaken by these nurses, communicating issues such as sensitive matters, medication adherence, and misconceptions about HIV, remains a challenging task in the Malaysian setting. Due to the lack of research examining the structure of HIV counselling in Malaysia, this study investigated the problem. Moreover, past studies revealed that there are problems with advice and information giving in HIV counselling, hence, this study investigated the advice and information giving challenges, the sequence as well as the strategies. Data were gathered from twenty-four audio recordings of HIV counselling sessions and six focus group discussions from three government hospitals in Malaysia. Thematic analysis of the structure of HIV counselling revealed that the structure differed in terms of its themes and sequence from structures found in past studies. Next, thematic analysis of advice and information giving challenges identified that the most prominent issues were communicating with patients about sensitive matters, and dealing with patients' medication adherence and misconceptions about HIV. In addition, thematic analysis of advice and information giving sequence identified that these challenges have impact on structural prioritization. Finally, discourse analysis of advice and information giving strategies revealed that apology, inclusive 'we', metaphor, and interrogation were the most prominent strategies employed by these nurses. To conclude, based on the findings, recommendations are made by presenting guidelines for advice and information giving strategies in HIV counselling to improve HIV nurse counsellors' advice and information giving skills.

ABSTRAK

Kaunseling HIV merupakan satu proses komunikasi antara jururawat kaunselor HIV terlatih dengan pesakit untuk berbincang dan membantu pesakit menangani masalah berkaitan dengan HIV. Walaupun jururawat telah menjalani latihan, komunikasi berkaitan isu-isu seperti perkara yang sensitif, pematuhan ubat, dan salah faham berkaitan HIV, terus menjadi cabaran di Malaysia. Oleh kerana kurangnya kajian yang menyelidik tentang struktur kaunseling HIV di Malaysia, kajian ini telah mengkaji masalah tersebut. Selain itu, kajian sebelum ini menunjukkan bahawa terdapat masalah berkaitan pemberian nasihat dan maklumat dalam kaunseling HIV, oleh itu, kajian ini telah mengkaji cabaran dalam pemberian nasihat dan maklumat, urutan serta strategi. Data dikumpul daripada dua puluh empat rakaman audio sesi kaunseling HIV dan enam perbincangan kumpulan fokus daripada tiga hospital kerajaan di Malaysia. Analisis tematik struktur kaunseling HIV menjelaskan bahawa terdapat perbezaan struktur dari segi tema dan urutan dari struktur ditemui dalam kajian sebelum ini. Seterusnya, analisis tematik cabaran dalam pemberian nasihat dan maklumat mengenal pasti bahawa isu-isu yang paling menonjol adalah komunikasi dengan pesakit tentang perkara-perkara yang sensitif, dan berurusan dengan pematuhan ubat oleh pesakit dan salah faham berkaitan HIV. Di samping itu, analisis tematik urutan pemberian nasihat dan maklumat mengenal pasti bahawa cabaran ini mempunyai kesan ke atas keutamaan struktur. Akhir sekali, analisis wacana strategi pemberian nasihat dan maklumat menunjukkan bahawa permohonan maaf, *inclusive 'we'*, metafora, dan menyoal siasat adalah strategi yang paling menonjol yang digunakan oleh jururawat. Sebagai kesimpulan, berdasarkan dapatan kajian cadangan dibuat dengan mengemukakan garis panduan strategi pemberian nasihat dan maklumat dalam kaunseling HIV bagi meningkatkan kemahiran pemberian nasihat dan maklumat jururawat kaunselor HIV.

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LIST OF ABBREVIATIONS

AEM	-	AIDS Epidemic Model
ART	-	Antiretroviral Therapy
AT	-	Activity Type
DA	-	Discourse Analysis
DT	-	Discourse Type
HAART	-	Highly Active Antiretroviral Treatment
IVDU	-	Intravenous Drug User
MSM	-	Men who have Sex with Men
MARP	-	Most at Risk Population
NGO	-	Non-Governmental Organizations
PN	-	Partner Notification
RN	-	Registered Nurses
STI	-	Sexually Transmitted Infections
VCT	-	Voluntary, Counselling and Testing
WHO	-	World Health Organization

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CHAPTER 1

INTRODUCTION

1.1 Introduction

This research explores the HIV counselling sessions between HIV nurse counsellors, HIV patients and their spouse/family in the Malaysian government hospitals. This study emerged out of an interest in the communication in HIV counselling; a disease which has been recognized to be both preventable and treatable, yet, remains challenging for healthcare professionals. Although past research asserted that HIV patients present HIV nurse counsellors with numerous challenges, these challenges, however, received little attention in Malaysia. Therefore, the current study explores the HIV nurse counsellors' communication challenges during HIV counselling session and the impact of these challenges on the advice and information sequence. Moreover, this study identifies the strategies used by HIV nurse counsellors in offering advice and information and to recommend guidelines that can be helpful for HIV nurse counsellors to overcome these challenges.

This chapter provides an overview of the entire study. In this chapter, the background of this study will be explained in section 1.2, followed by the statement

of problem in section 1.3. Next, the objectives of this study will be introduced in section 1.4. Research questions will be listed in section 1.5. In section 1.6, scope of this study will be further explained, followed by the significance of this study in section 1.7. Then, the definition of terms will be clarified in section 1.8. Afterward, the theoretical framework for this study will be presented in section 1.9, followed by the conceptual framework in section 10. The thesis structure will be outlined in section 1.11. This chapter will be summarized in section 1.12.

1.2 Background of the study

Nurses in Malaysia are trained in colleges or universities by undertaking a three-year diploma level qualification and are often sponsored by the Ministry of Health or the private hospital. Thus, they will serve the Ministry of Health or a private hospital for a period of time. Entry to a nursing diploma requires the *Sijil Pelajaran Malaysia* (SPM, equivalent to ‘O-level’), on the other hand, entry to a nursing degree requires *Sijil Pelajaran Tinggi Malaysia* (STPM, equivalent to ‘A-level’). The Community Health Nurses (*Jururawat Desa*) are trained separately and work in areas such as child health and family planning clinics and in rural areas where they provide home visits and also service the less advantaged.

Research has shown that the Malaysian authorities have increased the number of public and private institutions providing nursing courses and also have increased the total number of students (Cruetz, 2006). Table 1.1 shows that there was an increase in the number of nurses from 69,110 in 2010 to 99,925 in 2015 (Ministry of Health Malaysia, 2016). To be in line with some neighbouring countries, a total of 174,000 nurses has to be required by the year 2020 to achieve the targeted 1:200 nurse-population ratio (Chua, 2004; Cruetz, 2006; Hameed and Rasiah, 2014).

Table 1.1: Total number of nurses and nurse-population ratio in Malaysia between 2010 and 2015 (Health facts 2011-2016, Ministry of Health Malaysia)

Year	No. of nurses	Nurse: Population
2010	69,110	1:410
2011	74,788	1:387
2012	84,968	1:345
2013	89,167	1:333
2014	92,681	1:325
2015	99,925	1:305

A study by Caris-Verhallen *et al.* (2004) shows that assessing the specific needs of patients, exchanging and negotiating information, delivering physical care, providing psychosocial support are parts of major nursing duties which encompass communication and are obliged to the rules of interaction. In light of this, communication is acknowledged as an essential feature for a top-notch nursing care. Consequently, in order to allow them to share in the patient's experience and concerns, to achieve their communicative goals, and to sustain the values, nurses are required to have skills in creating good interpersonal relationships with patients. These skills do not only provide significance for nursing in general, but also imperative in taking care of patients suffering from life-threatening diseases such as human immunodeficiency virus (HIV). Past research believes that nurses experience high levels of stress and discomfort in HIV patient care and reveal that those nurses who had frequent contact with HIV experienced more stress when providing care and perceived a greater risk of contagion than those who did not have frequent contact (Knussen and Niven, 1999; Rekab Eslamizadeh, 2011; Haoses-Gorases *et al.*, 2013).

As reported by the Global AIDS Response Progress Report Malaysia (2015), Intravenous Drug User (IVDU) were the majority of HIV patients in Malaysia who neither aware of their HIV status nor have begun on the Highly Active Antiretroviral Therapy (HAART) for fear that they would be incapable to adhere to the treatment.

However, it is expected that new HIV cases will decline and stabilize from 2014 onwards, with the intervention efforts arranged in the AIDS Epidemic Model (AEM). Meanwhile, as more of them get tested and treated early, it is assumed that HIV cases among other Most at Risk Population (MARP) would increase (Global AIDS Response Progress Report Malaysia, 2015). Although the estimation exposed that the HIV transmission is still continuing, the rate of HIV cases and AIDS-related death are gradually decreasing.

Presently, HAART is provided either on site or via referral in government hospitals and health clinics. The Global AIDS Response Progress Report Malaysia (2015) reported that every year health staffs including Infectious Disease (ID) Physicians, family medical specialists, and HIV nurse counsellors are trained and distributed to various hospitals and clinics to assist in testing, treatment and counselling. As of December 2014, 51% of all eligible HIV patients have already initiated HAART. Since 2009, the HAART programme is also obtainable at the prisons and detention centres, and among those on HAART, 87% are still alive and identified to be on treatment 24 months after the initiation. However, in order to cope with the issue of adherence, there is certainly a need for treatment education for HIV patients who are recently initiating or presently on treatment (Global AIDS Response Progress Report Malaysia, 2015).

In this context, health care professionals have been encouraged to care for HIV patients and to conduct counselling on safety measures that minimize the rate of infection. This involvement has also obliged health care professionals to inspect their own practice for ways to keep up-to-date with current knowledge of prevention and treatment modifications of HIV (Syed Imran Ahmed *et al.*, 2009). It is also believed that the importance of equipping health professionals, especially HIV specialist nurses, with effective communication skills to ensure that vital information and advice concerning HIV risks and prevention is conveyed among the HIV patients during the HIV counselling session.

MARP are those who are involved with drug addiction, sharing injection needles, unprotected sexual practices, having contact with HIV patients, and infants to mothers with HIV. For MARP and suspected HIV cases, the following counselling will be given (Ministry of Health Malaysia, 2004):

- i. Pre-test – It is compulsory for those who want to have a blood test for HIV for the first time.
- ii. Post-test – Preferably this counselling is given by the same nurses who provide pre-test counselling. The test results must be provided as soon as possible after the test results are known.
- iii. Support/follow-up – For cases which have been confirmed infected with HIV, they would be given support/follow-up counselling (a lifetime) whereby problems can be identified so that further action can be taken or refer the case to a particular party.

During the counselling session, the main goal is to encourage the patient towards self-care, to lead a life as normal as possible, as well as decreasing the risk of disease progression and to avoid the spread of disease to others. Health education offered during the HIV counselling should also be extended to the family and significant others. Information regarding, healthy lifestyle, stress reduction, positive thinking, disease process, application of universal precautions and prevention of transmissions will need to be emphasized during health education session (Ministry of Health, 1992). This study appears to validate the availability of health education as the findings have identified the ‘teacher-like’ discourse by HIV nurse counsellors during the HIV counselling.

It is also worth mentioning that once a person is diagnosed with HIV, it is compulsory for HIV nurse counsellors to inform two people without the patient’s consent (i.e. spouse and sexual partner) known as Partner Notification (PN) in order to protect the health of the spouse or sexual partner. This has become a great

challenge for HIV nurse counsellors and ID physicians as disclosing bad news to patients and their spouse/family is one of the most difficult aspects of the medical profession, and it is necessary for the team to recognize the patients' social, psychological and clinical concerns (Agard, 2002; Abbaszadeh *et al.*, 2014)

The discussion has pointed to the treatment and care of HIV patients which includes the delivery of clinical care, nursing care, and emotional support (Ehon, 2007; Chen *et al.*, 2010). Comprehensive integration of patient-centred medical and social services is required for the treatment and care of HIV patients. The delivery of nursing and clinical care, psychosocial support, health-related information and counselling are among the crucial elements of this approach. The accomplishment of these objectives necessitates multidisciplinary teams to provide a continuum of care comprising patients, their families, healthcare providers, and society at large (Ministry of Health Malaysia, 2004; Ehon, 2007).

1.3 Statement of problem

Over the years, health communication has become a fundamental part of the sociological understanding of a patient's health and well-being, and if communication is not correctly understood, a patient's treatment can be at risk (Roberts, 2000; Adams, 2010; Fisher, 2011). In the context of this research, it is believed that if communication failure occur, the effectiveness of HIV treatment can be affected and drug resistance may happen. This view can be supported by Dingley *et al.* (2008), Moola (2010) and Ibrahim (2014) who assert that failures in communication with patients and their families, ambiguity of authority, breakdowns in communication and coordination among professional caretakers, and poor teamwork are among the causes of many persistent problems in medical care.

Patients infected with HIV present nurses with numerous challenges at all stages of the disease. The knowledge that there is no cure frequently has a disturbing impact upon the individual, the family and friends, and often places great emotional stress on the nurses themselves (World Health Organization, 1988; Ministry of Health Malaysia, 2004; Boyle, 2011). The findings in the current study validate the challenges concerning the management of HIV patients, specifically during the HIV counselling sessions. One of the challenges is the difficulty to get the IVDU patients attention during the HIV counselling sessions as there are a lot of negative effects of drugs on their psychological state such as hallucination, disorientation, lack of concentration, impaired learning and memory (Couper and Logan, 2014). For instance:

“...I think, I find it difficult to tackle IVDU patients. Once, I asked an IVDU patient, but he told me that he did not know that he has the disease. Truth is, doctor had told him the results. But he said, “Doctor did not tell me that I have the disease? Doctor told me that I only have TB. I did not know that I have HIV...” (N4HM)

Another prominent communication challenge emerged is dealing with patients’ denial of their condition. As mentioned by one of the HIV nurse counsellors:

“...firstly, a lot of cases like I have mentioned before, denial is certainly an issue. Denial means he tries to escape himself from the truth. For instance, when he was just diagnosed as HIV positive, then he will try... We will ask, perhaps, indirect questions about what really happen...” (N5HM)

In Malaysia, registered nurses undergo a specialized HIV/AIDS counselling training and upon completion, these specialist HIV nurses carry out pre-test and post-test counselling as well as support counselling for HIV patients and their spouse/family. This is also reflected in the Malaysian National Strategic Plan for Ending AIDS 2016-2030 in which every year health staff including Infectious Disease Physicians, nurses and counsellors are trained and assigned to various hospitals and clinics to assist in HIV testing, treatment and counselling. Despite the training they have received, researchers' personal communications with the nurses revealed that they are still facing challenges in communicating with HIV patients. This comes to no surprise as Malaysia is a moderate Islamic country with the majority of Muslim Malays and other ethnicities living together with the freedom to practice their religion and observe other cultural practices. Like many Islamic societies, issues dealing with sex and sexually transmitted infections (STIs) are seen as taboo and sensitive, and therefore are not discussed openly (Teh, 2008; Ismail and Abdul Hamid, 2016). However, there is an apparent lack of research examining the challenges faced by HIV nurse counsellors in Malaysia when communicating sensitive HIV-related information to patients. Therefore, there is a vital need to investigate the challenges faced by nurses when communicating with HIV patients so that nurses will be better equipped to manage these challenges during HIV counselling sessions.

Previous research by Muturi (2005) highlighted the lack of communication, specifically in providing advice and information, exists between health care providers and their patients. The doctors who do not address the problem appropriately could be associated with confidentiality issues involved or with ignorance as to how to deal with the problem. It could also be associated with the stigma related with HIV which is generally being linked with promiscuity; they do not offer advice and information to the patients as a way of allowing the patients to save face (Muturi, 2005; Mbonu *et al.*, 2009; Fabianova, 2011). Moreover, a study by Kalichman *et al.* (2008) and De Wet *et al.* (2013) found that HIV patients indicated the need to spend more time with healthcare workers, specifically to gain more information regarding the disease. Research conducted by Petros (2011)

indicated similar concerns about HIV knowledge among HIV patients' families, whereby they still appeared to be ambiguous regarding several sexual and social practices pertaining to the transfer of HIV. This is also evident in the data of this study that the most prominent communication challenges are pertaining to HIV-related advice and information, which will be discussed in detailed in Chapter 5.

These findings show that there appears to be some problems with the discourse of advice and information related to HIV. In addition, there is a need for further research on language and the cultural appropriateness of advice and information pertaining to HIV (De Wet *et al.*, 2013). More specifically, with regard to HIV-related advice and information sharing by health professionals, it is essential for the health professional to obtain medical knowledge, communication skills, and self-confidence to establish a trusting rapport with HIV patients. Guidelines with a focus on advice and information giving is important in dealing with HIV clients who come from different backgrounds, and it is seen as a practical and beneficial way to support the efforts to prevent further HIV infection.

As reflected in the Malaysian National Strategic Plan for Ending AIDS 2016-2030, there is a need for better treatment education for HIV patients who are initiating or currently on treatment to address the low adherence. Therefore, it is believed that equipping health professionals with advice and information giving skills is important to ensure that vital advice and information pertaining to HIV treatment and prevention is delivered among the HIV patients. Despite the government's dynamic initiatives to address HIV as a public health issue, Tham *et al.* (2016) assert that little effort is made to rectify the misconceptions as well as the negative perception pertaining to HIV. Nonetheless, the HIV nurse counsellors have to deal with these issues and to correct these misconceptions. A study by Ibrahim and Shaharuddin (2014) indicated that HIV nurse counsellors experience a great deal of difficulties and challenges in communicating pertinent HIV-related advice and information. The study, using a 36-item questionnaire developed by a language and communication expert and an ID physician, gathered the perceptions of 110 HIV

specialist nurses in government hospitals in Malaysia. The findings of the study suggest that HIV nurse counsellors perceived the most challenges in:

- i) ensuring patients are aware of transmission risks,
- ii) ensuring adherence with HIV medication,
- iii) keeping up to date with information about HIV,
- iv) dealing with confidentiality issues, and
- v) communicating with patients from different background.

Based on the findings by Ibrahim and Shaharudin (2014), it is clear that the first two challenges are directly related to information and advice giving. It is, therefore, imperative for the current study to focus on the communication strategies used in advice and information giving in HIV counselling sessions. Very few research in Malaysia, if any, has examined the communication that takes place in HIV counselling sessions, hence, this study is filling a significant gap in this area.

The discussion has pointed to the need for a study to explore HIV nurse counsellors' communication challenges during HIV counselling session. Having established the communication challenges faced by HIV nurse counsellors, this study seeks to determine the impact of these challenges on the advice and information sequence. This study aims to identify the strategies used by HIV nurse counsellors in offering advice and information and to recommend guidelines that can be helpful for HIV nurse counsellors to overcome these challenges. Due to lack of research and guidelines for nurses in offering advice and information to HIV patients, there is a need for new and more structured guidelines for these nurses and this is where this study becomes more relevant. By providing advice and information giving guidelines, HIV communication will be more effective and nurses' communication skills will be enhanced.

1.4 Research objectives

Due to the need for further research on HIV-related advice and information giving by nurses, this study focuses on these objectives:

- 1.3.1 To explore the communication challenges faced by HIV nurse counsellors when offering advice and information to HIV patients and patients' spouse/family.
- 1.3.2 To determine the impact of these challenges on advice and information giving sequence.
- 1.3.3 To identify the communication strategies used by HIV nurse counsellors when offering advice and information to HIV patients and patients' spouse/family.

1.5 Research questions

In an attempt to address the research problems and objectives, this research embarks on answering the following research questions:

- 1.4.1 What are the communication challenges faced by HIV nurse counsellors when offering advice and information to HIV patients and patients' spouse/family?
- 1.4.2 How do these challenges impact on the advice and information giving sequence?
- 1.4.3 What are the communication strategies used by HIV nurse counsellors in offering advice and information to HIV patients and patients' spouse/family?

1.6 Scope of the Study

This study focuses on HIV nurse counsellors at the Department of Infectious Disease from three government hospitals in Malaysia; i) Hospital Melaka, ii) Hospital Sultanah Aminah, Johor, and iii) Hospital Sungai Buloh, Selangor. The HIV nurse counsellors are from three different government hospitals. Table 1.2 provides an overview of the scope of this study.

Table 1.2: Scope of the study.

Research Questions	Key concept	Respondents
1. What are the communication challenges faced by HIV nurse counsellors when offering advice and information to HIV patients and their spouse?	Communication challenges	HIV nurse counsellors dealing with HIV patients: 1. Department of Infectious Disease, Hospital Melaka 2. Department of Infectious Disease, Hospital Sultanah Aminah, Johor
2. How do these challenges impact on the advice and information giving sequence?	Advice and Information giving	3. Department of Infectious Disease, Hospital Sungai Buloh
3. What are the communication strategies used by HIV nurse counsellors in offering advice and information to HIV patients and their spouse?	Communication strategies	

Based on Table 1.2, there are three research questions involved in this study. Firstly, the research question focuses on the communication challenges faced by HIV nurse counsellors when offering advice and information to HIV patients and patients' spouse/family. Secondly, the research question focuses the impact of these

challenges on the advice and information giving sequence. Finally, the research question focuses on the communication strategies used by HIV nurse counsellors in offering advice and information to HIV patients and patients' spouse/family.

1.7 Significance of the study

Based on the discussion in the previous sections, it can be acknowledged that the significance of this study is four-fold; i) importance in terms of the area of the study, ii) lack of research in Malaysia, iii) methodology used, and iv) contribution of the findings to different groups of people. The following sections will explain the significance of this study to various social units.

1.7.1 Significance to HIV nurse counsellors

This study, specifically the guidelines for advice and information giving in HIV counselling proposed by the end of this study, is significant to HIV nurse counsellors in several ways; i) improve nurse-patient communication, ii) provide guidelines in dealing with patients' medication adherence, iii) achieving the goals of HIV counselling, iv) effective HIV counselling, and v) practical strategies to deal with sensitive matters.

Firstly, as shown in Table 1.1 (p. 3) there was an increase in the number of nurses in Malaysia from 69,110 in 2010 to 99,925 in 2015 with a following increase in the nurse to population ratio from 1:410 to 1:305 (Ministry of Health Malaysia,

2016). Due to 'ageing populations and rapid evolution of medical technologies', the demand for nurses has been increasing (Simoens *et al.*, 2005, p. 4). Such astonishing growth placed great stress on more experienced clinical nurses and nurse educators. Barnett, Namasivayam and Narudin (2010) have argued that to improve the working environment of registered nurses (RNs) and to better support new graduates in their transition to the professional role, more fundamental actions should be taken. For instance, this study will provide new guidelines for nurses dealing with HIV patients on how to improve nurse-patient communication, specifically in offering advice and information to HIV patients and their spouse/family

Secondly, as far as the medical world is concerned, there is still no cure for HIV. Although HAART can suppress HIV and delay AIDS-related illness for many years, it cannot clear the virus completely (International AIDS Society, 2012). Past research (Ehon, 2007; Sahay *et al.*, 2011) believe that success with HIV-related medication rest on the essential properties of the drugs as well as the capability of patient to adhere to the medications. As HIV is a chronic disease that is difficult to be treated optimally and there is an indication that adherence decreases over time, HIV patients should be monitored and assessed at each clinic follow-up visit (Ehon, 2007; Kasumu and Balogun, 2014). It is, therefore, believed that advice and information giving in HIV counselling will help patients gain that sense of mastery and also help them cope with the stigma of HIV disease. Hence, this study is significant to help prolong the HIV-positive state before AIDS developed through effective advice and information on HIV-related treatment by the HIV nurse counsellors.

Thirdly, this study is significant in terms of the central roles of HIV nurse counsellors in HIV and the importance of communication. It should be realized that the major nursing tasks such as assessing the specific needs of patients, delivering physical care, providing socio-emotional support, negotiating and exchanging information, have to do with communication and are subject to the rules of interaction (Caris-Verhallen *et al.*, 2004). For that reason, in order to provide high-quality nursing care, effective communication skills are recognized as an essential

aspect to be obtained by nurses. In the context of this study, the above statements have led to the need for HIV nurse counsellors to obtain effective communication skills as a way to build rapport with HIV patients to achieve the goals of HIV counselling as well as upholding the values of healthcare.

Fourth, it should also be acknowledged that HIV nurse counsellors often do not have enough time to provide comprehensive counselling (Smith, Golin, and Reif, 2004). It is believed that when there is time shortage, communication skills need to be enhanced. The findings of this study will be significant as nurses will be provided with communication strategies when dealing with HIV patients, especially when initiating sensitive issues via Heritage and Sefi's (1992) Stepwise Entry. When nurses are equipped with guidelines that help enhanced their communication skills, HIV communication will be more effective, despite the time shortage.

Finally, the findings of this study is significant not only to HIV communication area, but can also be applied to other communication settings. Previous researchers theorized that a wide range of actual communication skills is necessary for nurses to communicate effectively with the entire health care team (Apler *et al.*, 2006; McCaffrey *et al.*, 2010). Furthermore, HIV nurse counsellors should be trained to communicate in ways that enhance patient outcomes and they should acquire effective communication skills to work as part of a multidisciplinary team (McCaffrey *et al.*, 2010). By the end of this study, guidelines on effective advice and information giving in HIV counselling will be proposed which also believed to be suitable for other health communication setting such as in critical care and even in end-of-life setting. In short, these guidelines and strategies will be practical for difficult communication and those related with sensitive talks.

1.7.2 Significance to nursing education

HIV nurse counsellors must fulfil several training requirements as listed by the Ministry of Health (2015); i) Counselling courses HIV/AIDS/STI, ii) Communicable Disease Control courses, and iii) Advanced Diploma in Infection Control in Public Health. In addition, another course that should be attended by these nurses is the Post-basic course managed by the Ministry of Health Training Management Division as a way to increase the skill level of Allied Health Sciences in areas related to their professions. These courses are conducted full-time for a period of six (6) months or twelve (12) months. Despite the trainings these nurses received, they are still facing challenges dealing with HIV patients, specifically on advice and information giving.

In their study, Freeman *et al.* (2002) advocate that without a doubt that a “new curriculum for a new century” is needed to prepare nurses who are able to meet new challenges effectively, at the same time maintaining and sustaining the essential nursing contribution to high quality healthcare. Effective communication is recognized as an essential quality of professional nursing practice, and teaching good communication remains an important standard of nursing education (AACN, 1998; Commission on Collegiate Nursing Education, 2003). By proposing guidelines for advice and information giving, it is hoped that this study can contribute to the nursing education as well as to help these nurses manage the communication challenges during the HIV counselling sessions.

1.7.3 Significance to hospital administrators and doctors

Today, many nurses find it difficult to cope with the challenges and achieve the expected level of performance, which invariably lead to stress and burnout (Ahmad and Oranye, 2010). The decline of nurses' working conditions has raised concerns among health professionals, and in response to these concerns, nursing leaders and hospital administrators have been searching for ways to revamp healthcare services and improve the quality of nursing work environment. The findings could raise awareness among hospital administrators and doctors regarding the challenges faced by nurses during HIV counselling. Through this awareness, it is hoped that they will provide support and communication trainings for the nurses as a way to enhance the HIV nurse counsellors' communication skills, particularly on advice and information giving pertaining to HIV.

1.7.4 Significance to communication studies

In this study, authentic data on HIV nurse counsellors' advice and information related challenges, the impact of these challenges on the advice and information advice and information giving sequence, and the strategies used in HIV counselling will be obtained through transcripts of HIV nurse counsellors' face-to-face discussion with HIV patients and their spouse/family during HIV counselling sessions, as well as focus group discussions among HIV nurse counsellors. Analysis of these strategies will contribute to research on advice and information giving in Malaysia, an under-researched area of study, by providing an empirical account of the current situation with regard to HIV counselling. The findings will also contribute to more literature in communicative study.

1.8 Theoretical framework

Since this study focuses on advice and information giving, it is important to highlight that nurses are seen as reliable resources for information on HIV prevention and testing and they should be comfortable discussing these topics with a wide range of people. It is, therefore, believed that HIV nurse counsellors who have been trained with effective communication skills and given the informed knowledge on HIV-related communication strategies, will contribute to a more comprehensive and holistic HIV prevention, and increase the quality of treatment and care services to individuals, families, and communities infected or affected by HIV (Relf *et al.*, 2011; De Wet *et al.*, 2013).

Based on discourse analysis (DA), this study tries to explore the essential parts of HIV counselling; advice and information giving, with the aim to look at the structure of advice and information giving and how the respondents use words as actions. As a whole, this study can be divided into three levels; i) macro level: HIV counselling session, ii) meso level: advice and information giving in HIV counselling, and iii) micro level: strategies of advice and information giving, as illustrated in Figure 1.3.

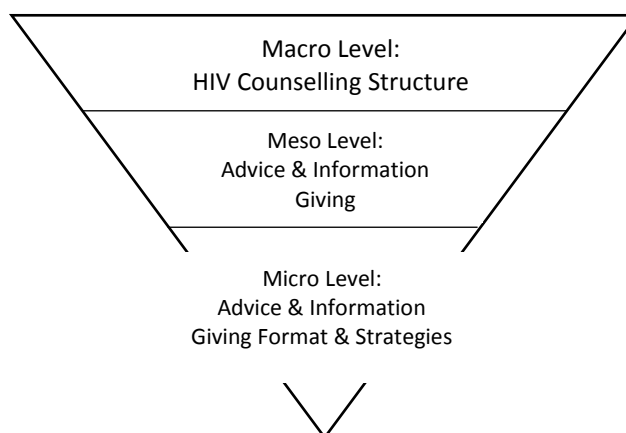


Figure 1.3: Levels of analysis

Only after detailed analysis of naturally occurring data which consist of HIV counselling session between HIV nurse counsellors and HIV patients can one understand the specific characteristics of counselling services and “obtain adequate understanding, leading to soundly based policy interventions” (Silverman, 1997, p. 35). Therefore, the methods on which the analysis of the data will based include Speech Act Theory (Austin, 1962; Searle, 1969), Activity Type and Discourse Type (Sarangi, 2000). A visual representation of the theoretical framework is found in Figure 1.4.

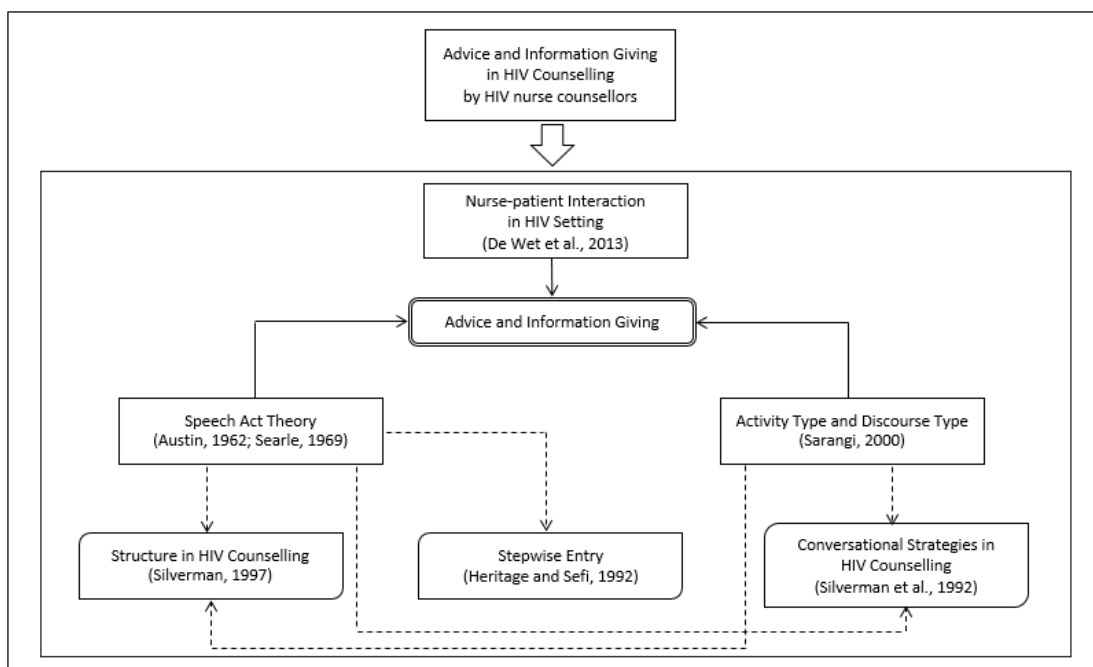


Figure 1.4: Theoretical Framework

According to De Wet *et al.* (2013), there should be a constant interaction between HIV patients, their spouse/family, and the nurses. In addition, as all people are interdependent on one another, the decisions made by the HIV patients affect their spouse/family and vice versa (Minnie, 2003). Thus, the interaction in HIV counselling between HIV nurse counsellors, HIV patients and their spouse/family influences the understanding of HIV-related information as well as the family’s ability to care for the HIV patient (De Wet *et al.*, 2013).

This theoretical framework acknowledges that several factors influence the HIV patient's comprehension of HIV-related information. For instance, awareness, knowledge, family support, the nature of the shared HIV-related information, the method in disseminating the information, as well as HIV patient's interaction with family and nurses. As for the spouse/family, their capability to support and to care for the HIV patient can be influenced by their comprehension of the HIV-related information. Moreover, the functioning of the family, stigma, as well as myths and culture influence patient's understanding of HIV-related information. With regard to nurses, they can play various roles (i.e. clinician, listener, educator, counsellor) in order to share HIV-related information and advice with HIV patient and also his/her family.

As this study is looking at the structures of advice and information giving within the HIV counselling setting, one relevant theory is by Sarangi (2000) who introduced the notion of 'discourse type' (DT) as a means of characterising the forms of talk occurring within 'activity type' (AT). The researcher agrees with Sarangi's (2000) statement that advice and information giving can be viewed as DT, and this study will show how it is deployed in the context of the activity types constituted in HIV support counselling sessions. In a discourse analytic approach to the study of an activity like counselling session, interactants are primarily concerned with the use of language for communicative purposes. This type of situational language use focuses on the purposes for which the language is used in performing different 'human affairs' (Brown and Yule, 1983). Therefore, it is believed that the speech act theory can justify the use of language in performing those activities, as what Austin (1962) emphasizes that the function of speech acts as a way of carrying out actions with words.

As the baseline of this study was adapted from research by Silverman (1997), Silverman *et al.* (1992b), and Heritage and Sefi (1992), the analysis in the current study is concerned with the impact of the communication challenges and the structures of advice and information giving in HIV counselling. This study examined

advice and information giving as they occur throughout the interaction between HIV nurse counsellors, HIV patients and their spouse/family.

Previous research (Sheon, 2010; Heritage and Maynard, 2006; Silverman, 1997) believed that order exists in institutional discourses which distinguishes such discourses from everyday talk and informal conversations. This order, however, varies according to the types of encounters as shown in counselling and medical interactions. For instance, in HIV pre-test counselling sessions, a flexible structure was found as it involved medical history taking (resembles a medical history taking), followed by discussion about sexual matters and then information delivery (Silverman, 1997). Dreaded issues were introduced later on in the session and the session concluded with discussions about the availability of the test result. Although it is important to have an overview, closer examination focused on specific aspects is also required in order to gain a more detailed understanding of the nature of interactions.

A few interaction-based studies have focused on the actual structure of advice giving. By analysing the devices for delivering advice and information, this study pays particular focus on the “how”. Prominent among these studies is Heritage and Sefi’s (1992) analysis of the delivery and receipt of advice in interactions between home health visitors and first time mothers in Britain. In relation to advice and information giving, Heritage and Sefi (1992) assert that the construction of a “problem requiring advice” by the health visitors could be done via stepwise entry. According to Heritage and Sefi (1992), there are several substantial features pertaining to the stepwise approach. First, it permits for a possible problem and the methods for dealing with that problem to “appear as a mutual construction of the participants”. Second, this entry permits the counsellor to offer advice that is sensitive to the patients’ account, supports and strengthens that account. Third, the advice is offered in a way that does not explicitly indicate to the patient as being ignorant or at fault. In sum, the stepwise entry creates a favourable environment for

advice as it allows the professional to fit the advice to the client's perspective, create alignment between the perspectives, and thus minimize resistance.

In terms of setting, a study much closer to this study is by Silverman *et al.* (1992b), who have also audio-recorded counselling sessions in HIV testing clinics. They analysed how counsellors and clients approach "delicate issues" such as sexual practices, to manage the issue of embarrassment, and attempt to reduce discomfort as well as to maximise patients' participation in the talk. Like Heritage and Sefi (1992), they have also found that the majority of the advice giving episodes were initiated by the counsellors. Also, they note that counsellors occasionally offered advice in a way where the health visitor specifies a possible problem on behalf of the mother. Silverman *et al.* (1992b) refer these episodes as "hypothetical advice sequences" and it concerns "with the advice the counsellor would give if someone had a particular test result" (Silverman *et al.*, 1992b, pg. 185).

When attempting to facilitate comprehension of HIV-related information, the communication between the HIV patient, their spouse/family and the nurses is believed to be crucial. This interaction might also involve support, counselling, communication, treatment and care, as well as referral. In doing so, it is important for nurses to develop appropriate communication skills in order to adapt, to adjust and to overcome communication gaps with HIV patients and patients' spouse/family. Therefore, it could be summarized that this theoretical framework will help to answer the research questions that have been stated in the previous subchapter. This framework illustrates the importance of nurse-patient interaction within the context of HIV communication by applying appropriate rules of interaction. The researcher believes that effective HIV communication could help to facilitate comprehension to HIV patients and patients' spouse/family, thus, helping them to stay optimistic and maintain hope.

1.9 Conceptual framework

There are three key research areas highlighted in this study; i) the communication challenges faced by HIV nurse counsellors when offering advice and information to HIV patients and patients' spouse/family, ii) the impact of the said challenges on advice and information giving, and iii) the communication strategies used by HIV nurse counsellors in offering advice and information to HIV patients and patients' spouse/family. From these three key research areas, four key concepts have been identified; i) HIV counselling structure, ii) advice and information giving challenges, iii) advice and information giving structure, and iv) advice and information giving strategies. To answer the three research questions, three discourse analytic tools were adapted; i) Structure in HIV Counselling Sessions (Silverman, 1997), ii) Stepwise Entry (Heritage and Sefi, 1992), and iii) Formats and Conversational Strategies in HIV Counselling (Silverman *et al.*, 1992b). Figure 1.5 illustrates the conceptual framework of this study.

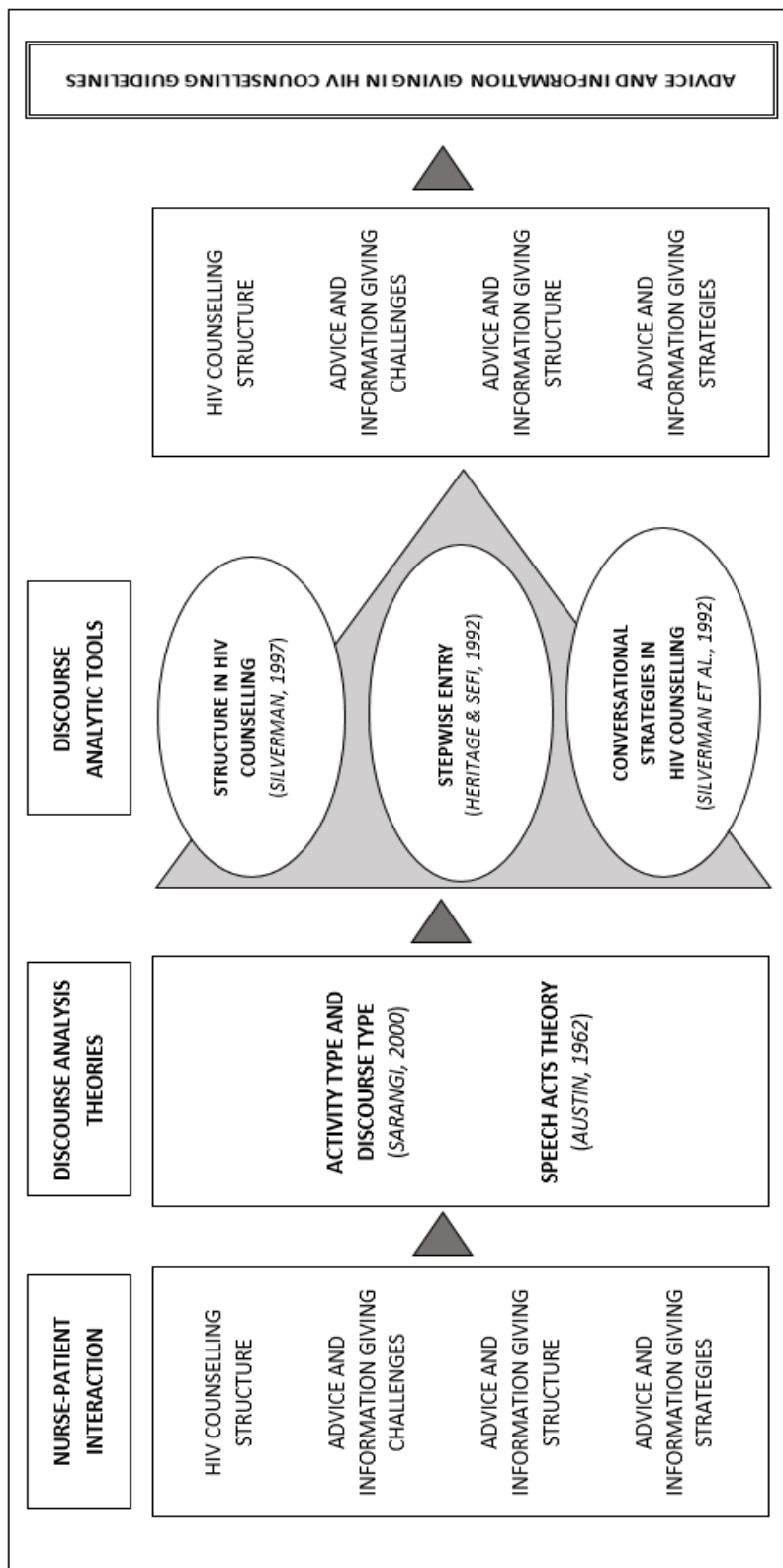


Figure 1.5: Conceptual framework

With the aim of examining the structure of advice and information giving and how the respondents use words as actions, this study explores the essential parts of HIV counselling; advice and information giving. The methods on which the analysis of the data was based include Activity Type and Discourse Type (Sarangi, 2000), and Speech Act Theory (Austin, 1962; Searle, 1969). This discourse analytic study is concerned with the impact of the advice and information giving challenges on the structures of advice and information giving in HIV counselling, hence, the relevance of research by Silverman (1997), Heritage and Sefi (1992), and Silverman *et al.* (1992b).

It is clear from previous research (Sheon, 2010; Heritage and Maynard, 2006; Silverman, 1997) that order exists in institutional discourses which distinguishes such discourses from everyday talk and informal conversations. Although it is important to have an overview, closer examination focused on specific aspects is also required in order to gain a more detailed understanding of the nature of interactions. By analysing devices for delivering advice and information, this study is more specific about the “how”. Prominent among these studies is Heritage and Sefi’s (1992) analysis of the delivery and receipt of advice in interactions between home health visitors and first time mothers in Britain. In relation to advice and information giving, Heritage and Sefi (1992) found an interactional strategy which was later called stepwise entry whereby health visitors collaboratively construct a “problem requiring advice”.

After detailed analysis of the four key concepts of this study (i.e. HIV counselling structure, advice and information giving challenges, advice and information giving structure, and advice and information giving strategies), guidelines on advice and information giving in HIV counselling sessions was proposed by the end of this study. It is believed that nurses who have been trained with effective communication skills and given the informed knowledge on HIV-related communication strategies will contribute to a more comprehensive and holistic HIV prevention, and increase the quality of treatment and care services to

individuals, families, and communities infected or affected by HIV (Relf *et al.*, 2011). As for the HIV patients, they will be able to practice safer sexual practices, safe needle, VCT, and safe delivery, and informed breastfeeding (BF) based on the advice and information giving by nurses. On the other hand, the patients' spouse comprehension of HIV-related information will increase and create awareness of their role as the HIV patient's primary support system.

It is hoped that in the long-term, these changes (i.e. HIV nurse counsellors and HIV patients) could contribute to the reduction of HIV and increase the quality of life of HIV patients. In line with the National Strategic Plan for Ending AIDS 2016-2030 as well as the 2016 United Nations Political Declaration on Ending AIDS which targets to accomplish the following: i) 95% of key populations tested for HIV and know their results, ii) 95% of people with diagnosed HIV receiving ART, iii) 95% of people on ART achieve viral suppression, and iv) 90% of key populations are reached by combination prevention services.

1.10 Definition of terms

1.10.1 ***HIV-related counselling***: HIV counselling sessions in Malaysia consist of three types of counselling; i) Pre-test counselling, ii) Post-test counselling, and iii) Support counselling. To guide HIV patients toward a safer life-style, to curb the spread of infection by seeking compliance in risk-reduction behaviour and to serve as the source of help (Chester, 1987).

1.10.2 ***Health professionals***: The term 'health professionals', for the purpose of this research refer to HIV nurse counsellors working in the Department of Infectious Disease who have had special

counselling training and are responsible for conducting HIV counselling session with HIV patients and their spouse/family.

- 1.10.3 **CD4:** These are group of cells responsible for improving the immune system of an individual (Ehon, 2007).
- 1.10.4 **Viral load:** The term used to describe the amount of HIV virus in a body fluid. The viral load tests measure the amount of HIV virus in a small sample of HIV patient's blood (Carter and Hughson, 2014).
- 1.10.5 **HIV communication challenges:** The failure or difficulties of communication activities to reach the goal of patients' behaviour change (Munodawafa, 2008). In the context of this study, HIV communication challenges are the difficulties and barriers faced by HIV nurse counsellors in offering advice and information to HIV patients and their spouse/family.
- 1.10.6 **Advice giving:** Heritage and Sefi (1992) proposed that advice can be defined as statement which "describes, recommends or forwards a preferred course of action" (p. 368). In the context of this study, HIV nurse counsellors' interaction which involved the use of the modal verbs 'must', 'have to', and 'should' are categorized as advice.
- 1.10.7 **Information giving:** A statement that helps people make sense of their situations, assists them in dealing with challenges that they face (Dervin, 1983). In other words, information is anything that "helps" information seekers (Dervin, 1992; Dervin and Fraser, 1985; Harris and Dewdney, 1994).
- 1.10.8 **HIV counselling structure:** The sequencing of its different parts in a systematic way where each part is filled depending on the tasks which has to be achieved and to arrive at the definitions and treatments of HIV-related problems (Drass, 1982; de Poel *et al.*, 2013).
- 1.10.9 **Sequence mapping:** The themes that are mapped in a particular order in which each theme is defined by different colour (Sheon *et al.*, 2010).
- 1.10.10 **HIV counselling strategies:** In the context of this study, HIV counselling strategies are the methods that seek to convince or to

encourage HIV patients to take-up the advice and information given, hence, strategies are the “tools” used by the HIV nurse counsellors to handle difficulties while offering advice and information in HIV counselling sessions (Kolo, 1997; Hinyard and Kreuter, 2007).

1.10.11 *HIV counselling formats*: In the context of this study, HIV counselling formats are the organization and arrangement of the HIV counselling interaction and strategies in offering advice and information to HIV patients and their spouse/family (Perakyla and Silverman, 1991).

1.11 Thesis structure

This thesis begins with the introduction of the study which includes the background, statement of problem, three research objectives and three research questions, the significance of the study, the scope, the definition of terms used in the study, the theoretical as well as the conceptual framework, and the limitations of the study. In the next chapter, the researcher provides the literature on the areas of HIV counselling, particularly on advice and information giving which are relevant to the research questions. In Chapter 3, the methodology used to achieve the objectives of the study is thoroughly explained.

In order to address the key issues better, the following three chapters (i.e. Chapter 4 until Chapter 6) will be presenting the findings of this study based on the three research questions. Chapter 4 will provide the macro level analysis of HIV counselling in order to have the bird’s eye view of the HIV counselling structure as a whole. This is especially important as no previous research has attempted to examine the structure of HIV counselling sessions in Malaysia. Next, the meso level analysis of the two research questions: i) What are the communication challenges faced by

HIV nurse counsellors when offering advice and information to HIV patients and patients' spouse/family? and ii) How do these challenges impact on the advice and information giving sequence?. The findings of these two research questions will be elaborated in detail in Chapter 5. Finally, Chapter 6 will concentrate on the micro level analysis of the advice and information giving to answer the third research question pertaining to the communication strategies used by HIV nurse counsellors in offering advice and information to HIV patients and patients' spouse/family. Finally, Chapter 7 provides the conclusions and the recommendations based on the findings and for future research.

1.12 Summary

The discussion in this chapter indicated that very few research in Malaysia, if any, has examined the communication that takes place in HIV counselling sessions. Thus, the need of this study to be conducted. Past research has provided evidence on the advice and information giving related challenges. It is, therefore, imperative for this study to focus the need for a study to explore HIV nurse counsellors' communication challenges as well as to determine the impact of these challenges on the advice and information sequence in HIV counselling. This study also aims to identify the strategies used by HIV nurse counsellors in offering advice and information. Due to lack of research and guidelines for nurses in offering advice and information to HIV patients, there is a need for new and more structured guidelines for these nurses and by providing advice and information giving guidelines, HIV communication will be more effective and nurses' communication skills will be enhanced.

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