

Patient-Friendly Information Giving in HIV Counselling through the Use of Metaphors

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ABSTRACT

HIV counselling is a method of communication between patients and certified HIV nurse counsellors to discuss and help patients deal with HIV-related issues. Despite the training received by these nurses, communicating HIV-related issues remains a difficult task in Malaysia. Due to lack of research examining information giving in HIV counselling in Malaysia, this study investigated both the challenges and the strategies in providing information to HIV patients. Twenty-four audio recordings of actual HIV counselling sessions were gathered and six focus group discussions with HIV nurse counsellors from three government hospitals in Malaysia were recorded. The discourse analysis of revealed a prominent use of metaphors as part of information giving strategies to overcome the challenges faced by HIV nurse counsellors when communicating with HIV patients. The metaphors were embedded in HIV nurse counsellors' information giving to HIV patients and their spouse/family as a way to represent some medical jargons pertaining to HIV. Since the HIV patients came from different educational background, it would be much easier for them to understand HIV-related information giving through the use of metaphors. Therefore, the acknowledgement and integration of metaphors can be an amazingly valuable tool for HIV nurse counsellors especially in managing the communication challenges during HIV counselling. It is hoped that the findings provided in this study will serve as a basis for integrating metaphors into counselling practices.

Keywords: HIV Counselling, HIV Nurse Counsellor, Information Giving, Metaphor, Medical Jargon

INTRODUCTION

At the end of 2020, an estimated 92,063 people in Malaysia were living with HIV, 80,428 (87%) of whom were aware of their status and had been notified through the national surveillance system. The estimated HIV incidence rate per 1000 uninfected population has also gradually decreased to 0.19 in 2020, down from 6,978 cases in 2002 to 3,146 cases in 2020 (Ministry of Health, 2021). Presently, Highly Active Antiretroviral Therapy (HAART) is provided either on site or via referral in government hospitals and health clinics. Nurse counsellors play critical roles in HIV counselling, including providing HIV patients with appropriate information and advice to help them make decisions that lead to behaviour change, as well as obtaining treatment and care if necessary.

The Global AIDS Monitoring Report 2021 reported that every year health staffs including Infectious Disease (ID) Physicians, family medical specialists, and HIV nurse counsellors are trained and

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distributed to various hospitals and clinics to assist in testing, treatment and counselling. Since 2009, the HAART programme is also obtainable at the prisons and detention centers, 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 (Yadzir *et al.*, 2021). 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.

During the counselling session, the main goal is to encourage the patients 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 the 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).

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 & Logan, 2014).

Despite the training HIV nurse counsellors have received, researchers' personal communications with the nurses revealed that they are still facing challenges in communicating with HIV patients such as communicating personal issues and sexual behaviours. This comes as no surprise as Malaysia is a moderate Islamic country with the majority of Muslim Malays and other ethnicities 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 (Ismail & Abdul Hamid, 2016; Subbarao & Akhilesh, 2017). 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.

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 (Fabianova, 2011; Subbarao & Akhilesh, 2017). Moreover, a study by 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.

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 perceptions pertaining to HIV. Nonetheless, the HIV nurse counsellors have to deal with these issues and to correct these misconceptions.

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 identify the strategies used by HIV nurse counsellors in offering information. Due to the need for further research on information giving by HIV nurse counsellors in HIV counselling, this study focuses on the following research questions;

1. What are the communication challenges faced by HIV nurse counsellors when providing information to HIV patients and their spouse/family?
2. What are the communication strategies used by HIV nurse counsellors in providing information to HIV patients and their spouse/family?

LITERATURE REVIEW

HIV Counselling Challenges

Given the emphasis placed on HIV prevention and care, as there is neither cure nor vaccination against the disease, providing effective HIV counselling becomes a vital tool in controlling the epidemic (Kaneekar, 2011; Chevo & Bhatasara, 2012). Previous research focusing on the HIV counselling challenges in Malaysia have explored the communication challenges faced by HIV healthcare professionals (Ibrahim & Shaharudin, 2014). The findings in their study suggest that HIV nurse counsellors perceived the most challenges in ensuring patients are aware of transmission risks, ensuring adherence with HIV medication, keeping up to date with HIV-related information, dealing with confidentiality issues and communicating with patients from different background.

Information Giving Challenges in HIV Counselling

Studies have shown that in India, the most frequently cited social obstacle to the control of HIV transmission and promotion of sexual health is a reluctance to talk explicitly, including between spouses, about sex and sexual behaviour (Solomon *et al.*, 1998; Bentley *et al.*, 1998; Sethi, 2002). Various researchers have noted the social customs that constrain women from communicating explicitly about matters associated with sex, including menstruation, sexual health and reproductive health problems (Das, 1988; George, 1994; Bang & Bang, 1994). Sex is understood as a private act that can occur appropriately

only within a legitimate marital relationship. Moreover, there is a prohibition on discussing sexuality and sexual practice in the presence of anyone who is sexually inexperienced (Lambert and Wood, 2005).

This is also evident in a study done in Nigerian culture by Irinoye (1999) who demonstrated that talking about the sexual lives of people is not allowed, even when the counsellor has the confidence to talk about sexual matters, it commonly takes a long time to get others involved in an uninhibited discussion of their sexual lives. In addition, the National Institute of Health Islamabad (2001) reported that many care providers find it challenging to openly discuss and often the "cloak of silence" exist when dealing with sexual matters as these practices appear to be against the culture, traditions, laws and religions of Pakistan.

Though it is important to raise issues related to sexuality and/or drug use, such discussions should be commenced with sensitivity to the patient's concerns and presenting problems. These sensitive topics should be directed toward helping the patients explore emotional issues, solve important concerns and make healthy decisions. The Ministry of Health Malaysia (2004) asserts that the counsellor should employ careful enquiry and skills as not to offend the patients and to maintain a good relationship when dealing with HIV-related sensitive matters. For instance, the counsellor may have to explain the purpose of the enquiry prior to a detailed interview on masturbation and other sexual practices (e.g., use of condom, sexually transmitted disease etc.).

The discussion has pointed out the challenges in communicating HIV-related issues found in previous studies. It can be seen that stigma, denial, sensitive matters (i.e., sexual activity, practicing safer sex), and patients from different background (i.e., IVDU patients) are among the most challenging subjects when conducting HIV counselling. The current study validates these challenges as part of the communication challenges faced by HIV nurse counsellors when offering information to HIV patients and patients' spouse/family. Despite the communication challenges faced by these nurses, there is a need for HIV nurse counsellors to address these issues in order to meet the aims of counselling as well as to fulfil the patients' concerns and needs.

Metaphors in HIV Counselling

A study by Sontag (1989) on *AIDS and its Metaphors* defines metaphor based on Aristotle's (1457b) definition as "giving the thing a name that belongs to something else" which is used to comprehend the conversion of meaning from one object to another (Kok *et al.*, 2011). While some metaphors are anti-explanatory (e.g., sermonizing and poetic), some have significant scientific meaning (e.g., the body as a fortress which is an image of the body that features disaster). Sontag (1989) asserts that with the advent of AIDS as a new disease which is not completely understood besides the absence of medication to cure the disease, has impacted on the extensive occasion for the metaphorizing of illness. In addition, AIDS has a dual metaphoric genealogy in which as a micro process, it is described as an invasion, while when the focus is transmission of the disease, it is described as a pollution. Moreover, the military metaphors pertaining to AIDS is commonly used to describe the enemy (what causes the disease) as an infectious agent that derives from the outside (Sontag, 1989).

Furthermore, metaphor is known as the multifaceted figure of speech which has been defined as a "device of the poetic imagination and the rhetorical flourish — a matter of the extraordinary" (Lakoff & Johnson, 1980, p. 3). Past research believe that the use of metaphor helps to construct meaning as ideas embedded in and conveyed through them arise from our world and reflect beliefs and values; create expectations, influence decisions, and a powerful way to increase understanding of things and processes

(Geary, 2009; Beuthin *et al.*, 2014). It is also believed that the use of medical jargon can lead to misunderstandings in interactions, specifically concerning HIV/AIDS which discusses complex concepts that can possibly be explained by the use of metaphors (Liebert, 1999; Hollenberg, 2006). By using metaphor in HIV counselling, the HIV-related medical jargons can be understood and remembered by patients from different education background.

METHODS

A qualitative research design was chosen for this study due to the nature of the design and its ability to obtain rich and in-depth information from participants. For the purpose of this study, the audio recordings were taken during HIV counselling sessions between HIV nurse counsellors and HIV patients and their spouse/family. Before the counselling session begins, the researcher tried to get consent from the patients with the help from the HIV nurse counsellors as gaining access to HIV patients proved to be difficult and could not be possible without the HIV nurse counsellors' assistance. Once the patients agreed to be recorded, they sign the consent letter before their HIV counselling sessions were recorded. Next, HIV nurse counsellors were asked to fill in the patients' background sheet which consist of patients' age range, gender, mode of transmission, number of years of being infected with HIV, number of counselling sessions attended, and communication challenges faced by HIV nurse counsellors during the HIV counselling sessions.

The researcher decided to employ focus group discussion as it provides insights into HIV nurse counsellors' experience facing the HIV counselling challenges and provide a deeper understanding of the issue being studied. HIV nurse counsellors who were involved in the audio recordings of HIV counselling sessions also participated in the focus group discussions. Five semi-structured questions grounded by the research questions and literature were prepared. These questions act as prompts and help to elicit information which would reveal the nurses' experience concerning the issue. The researcher was given freedom to probe during the discussion for further clarification on the responses given. The six focus group discussions conducted in this study lasted between 20-30 minutes each. The discussions were audio recorded and notes of the discussion were also taken. The discussions were conducted in whatever language that the participants felt comfortable conversing in, as a way to ensure that the respondents felt at ease to share and to express their views and opinions.

In the current study, a thematic analysis was used to interpret and organize the data collected. In order to answer research question 1 which aims to explore the communication challenges faced by HIV nurse counsellors when providing information to HIV patients and/or their spouse/family, data were collected via focus group discussion with HIV nurse counsellors who have had experienced handling HIV counselling session. Data were transcribed using the transcription convention adopted from the Jefferson's Transcription Notation developed by Jefferson (1978). Once the communication challenges faced by HIV nurse counsellors when providing information to HIV patients and/or their spouse/family have been identified, the researcher focused on identifying information giving strategies in HIV counselling.

RESULTS AND DISCUSSION

Communication Challenges

In Malaysia, registered nurses undergo a specialized HIV counselling training and upon completion, these HIV nurse counsellors carry out pre-test counselling, post-test counselling, as well as support counselling for HIV patients and their spouse/family. Despite the training they received, researchers' personal communications with HIV nurse counsellors revealed that they are still facing challenges in communicating with HIV patients. Moreover, there is an apparent lack of research examining the challenges HIV nurse counsellors in Malaysia face when communicating HIV-related information to patients. Therefore, there is a vital need to investigate the challenges faced by HIV nurse counsellors when communicating with HIV patients and their spouse/family so that they will be better equipped to manage these challenges during HIV counselling sessions.

In order to have a much clearer view of the communication challenges in HIV counselling, the researcher has categorized each of the communication challenges that have emerged from this study. Table 1 demonstrates the communication challenges faced by HIV nurse counsellors in HIV counselling sessions.

Table 1 Communication Challenges in HIV Counselling Sessions

Categories	Subcategories	Communication Challenges	Frequency
Patient-related	Patients' background	▪ Communicating with patients from different ethnic groups and problems with the language barriers.	2
		▪ Communicating with patients who are educated.	2
		▪ Communicating with Intravenous Drug User (IVDU) patients.	4
		▪ Communicating with homosexual, bisexual or transgender patients.	2
	Patients' emotional state	▪ Dealing with patients' denial of their condition.	4
		▪ Dealing with patients who are depressed with their HIV diagnosis.	2
Advice and information related	Sensitive issues	▪ Communicating with patients about sensitive matters such as protective sexual intercourse etc.	3
		▪ Ensuring patients openness in talking about their risky sexual behaviour.	2
	Disease related issues	▪ Dealing with patients' medication adherence.	3
		▪ Dealing with patients' misconceptions about HIV.	3
		▪ Keeping up to date with information about HIV.	2

As shown in Table 1, two categories of communication challenges were identified; i) patient related and ii) advice and information giving related. However, as the current study focuses on communication challenges faced by HIV nurse counsellors when offering advice and information to HIV patients and/or their spouse/family, hence, only advice and information giving related communication challenges will be highlighted in the following sections. In addition, the most prominent advice and information related communication challenges are; i) communicating with patients about sensitive matters, ii) dealing with patients’ medication adherence, and iii) dealing with patients’ misconceptions about HIV.

Communication Strategies

The most prominent strategy found during information giving in this study is the use of metaphor which was embedded in HIV nurse counsellors’ information giving to HIV patients and their spouse/family as a way to represent some medical jargons pertaining to HIV. In this study, several metaphors related to HIV have been identified during the HIV counselling sessions as outlined in Table 2.

Table 2 Examples of HIV-related metaphors and the concepts related to the metaphors used

Metaphor	Concept	Data samples
<i>Tidur</i> (Sleep)	Viral suppression.	“... <i>virus akak memang</i> (.) well tidur nya (.) <i>memang well suppress...</i> ” (CS10/HM) “...your virus definitely (.) well asleep (.) definitely well suppress...” (CS10/HM)
<i>Askar</i> (Soldier) <i>Komando</i> (Commando) <i>Polis</i> (Police)	The role of CD4 as the protector of our body from ‘invasion’ by certain virus, bacteria etc.	“... <i>dia jenis sel yang jaga badan kita</i> (.2) askar lah...” (CS01/HM) “...it is a type of cell that protect our body (.) soldier ...” (CS01/HM)
<i>Makan</i> (Eat)	The act of HIV virus attacking human immune system causing a decrease of CD4 level in our body.	“... <i>dia makan</i> you punya antibody sikit-sikit...” (CS14/HSB) “...it eats your antibody little by little...” (CS14/HSB)

As shown in Table 1, five metaphors emerged in this study are: i) *tidur* (sleep), ii) *askar* (soldier), iii) *komando* (commando), iv) *polis* (police), and v) *makan* (eat). However, the metaphor ‘askar’, ‘komando’, and ‘polis’ fell under the same concept which is the role of CD4 cells which are a type of white blood cell that work as the protector of our body from ‘invasion’ by certain virus, bacteria etc. These military metaphors provide validation in which Sontag (1989) believe they are commonly used to describe the enemy (what causes the disease) as an infectious agent that derives from the outside. Hence, it is not surprising to find that the military metaphor is embedded in the advice and information giving in this study. This strategy is reflected in Excerpt 1.

Excerpt 1

(CS03/HM)

25. N1: *kita panggil apa daya tahan badan kita tu? (.) askar yang jaga badan kita tu?*
N1: what do we call our antibody? (.) the **soldier** that protects our body?
26. P3: *CD4 =*
P3: CD4 =
27. N1: *= CD4 (.) okay pandai (.) CD4 tu makna ubat ni kita makan seumur hidup (.)*
N1: = CD4 (.) okay brilliant (.) CD4 means we take this medication the whole life (.)
28. *tak boleh berhenti (.) tak boleh lambat (.) kita kena ikut masa ya::ng apa (.2)*
cannot stop (.) cannot delay (.) we have to follow the time tha::t what (.2)
29. *akak pilih sendiri (.) supaya naikkan CD4 (.) kurangkan kadar virus tu (.)*
you have chosen yourself (.) so to increase CD4 (.) decreases the viral load (.)

In Excerpt 1, nurse N1 used the metaphor “soldier” in line 25 to represent the role of CD4 as the protector of our body from ‘invasion’ by certain virus, bacteria etc. Past research (Sontag, 1989) believes that with the advent of AIDS as a new disease which is not completely understood besides the absence of medication to cure the disease, has impacted on the extensive occasion for the metaphorizing of illness. In addition, the use of medical jargon can lead to misunderstandings in interactions, specifically concerning HIV/AIDS which discusses complex concepts that may be more clearly be explained by the use of metaphors (Liebert, 1999; Hollenberg, 2006). However, the findings in this study provided validation that by using metaphor the HIV-related medical jargons can be understood and remembered by patients from different education background (Nyakoe *et al.*, 2014; Beuthin *et al.*, 2014).

Moreover, it is worth noting that the metaphor of ‘tidur’ or ‘sleep’ is widely found in the 24 HIV counselling sessions analysed in this study. An example can be seen in the following excerpt.

Excerpt 2

(CS01/HM)

93. N2: *kena ingat eh (.) ubat apa makan (.) warna apa (.) sebab apa kena makan ubat (.2) sebab apa kena makan ubat?*
N2: you have to remember (.) what medicine you are taking (.) which colour (.) why you have to take the medicine (.2) why do you have to take the medicine?
94. P4: *seba::b (.2) nak **menidurkan** (.3)*
P4: becau::se (.2) to make it **sleep** (.3)
95. N2: ***tidurkan** apa?*
N2: to make what **sleep**?
96. P4: *ehe **tidurkan***
P4: ehe to make it **sleep**
97. N2: ***TIDURKAN** SAYA?*
N2: **TO MAKE ME SLEEP?**
98. P4: *ehehehe*
P4: ehehehe

Further analysis on the use of metaphor indicates that the metaphor '*tidur*' (*sleep*) is commonly used by HIV nurse counsellors in HIV counselling sessions in order to clarify the effects of HAART which is viral suppression. Since the HIV patients came from different background, it would be difficult for some of the patients to understand the medical jargons such as viral suppression. It is, therefore, much easier for the patients to understand the effects of HAART by using such metaphor.

The final metaphor often used during the HIV counselling sessions is '*makan*' or eat in English. The use of this metaphor can be seen in Excerpt 3.

Excerpt 3

(CS02/HSB)

67. N5: *tu saja la:h (.2) okay you (.) apa yang you tahu berkaitan HIV? (.) ada idea? (.) bila doktor sahkan you ada virus ini kan (.) you ada google dekat internet? (.) boleh cerita sebelum saya cerita?*
 N5: that's all (.2) okay you (.) what do you know about HIV? (.) any idea?
 (.) when the doctor confirmed that you have this virus (.) do you google from the internet?
 (.) can you tell me before I explain to you?
68. P14: got 1 idea (.) maybe I would die
69. N5: *semua orang akan mati: (.) okay a:: HIV ni virus lah (.) bila dia masuk badan you (.) pada peringkat awal memang tak ada symptom lah (.2) a: macam orang biasa (.) tapi dia akan attack you punya antibody lah*
 N5: every one will die (.) okay a:: HIV is a virus (.) when it enters your body
 (.) at the early stage there is no symptom (.2) a: just like normal people (.)
 but it will attack your antibody
70. P14: em
71. N5: *bila dia masuk dalam bada:n (.) dia makan you punya antibody sikit sikit (.2) dia bukan serang terus kita jatuh sakit (.2) sebab tu kita tak tahu bila virus tu (.) ada dalam badan ni (.2) since you ada expose dengan risiko tu (.) kemungkinan dah ada virus tu dalam badan (.2) e:r every time sex tu (.) you ada pakai condom tak?*
 N5: when it enters your body (.) it will **eat** your antibody bit by bit (.2)
 it does not attack you until you are sick (.2) that's why we don't know when the virus (.)
 is in the body (.2) since you are exposed with the risks (.) maybe the virus is already in
 your body (.2) e:r every time you are having sex (.) do you wear condom?
72. P14: *ada*
 P14: I do

The metaphor '*makan*' (eat) is often being used to explain the act of HIV virus attacking human immune system causing a decrease of CD4 level in our body. By doing so, patients will find it easier to have clearer understanding of how the HIV virus affect their antibody. The findings support past researchers believes that the use of medical jargon can lead to misunderstandings in interactions, specifically concerning HIV/AIDS which discusses complex concepts that can possibly be explained by the use of metaphors (Liebert, 1999; Hollenberg, 2006). By using metaphor in HIV counselling, the HIV-related medical jargons can be understood and remembered by patients from different education background.

CONCLUSION

The analysis carried out in this study revealed twelve communication challenges faced by HIV nurse counsellors in the HIV counselling sessions. However, as the focus of this study is on information giving, further analysis of the communication challenges concentrated on challenges pertaining to information giving. Hence, to answer the first research question of this study, the information giving related communication challenges faced by HIV nurse counsellors are as follows:

- i) dealing with patients' medication adherence
- ii) dealing with patients' misconceptions about HIV
- iii) communicating with patients about sensitive matters

As asserted by Silverman *et al.* (1992), there are certain formats of providing information which could "shield" the counsellors from interactional difficulties. The analyses have shown that information giving in this study is organized in order to manage the communication challenges the HIV nurse counsellors face. This is evident through the use of metaphor, which was embedded in HIV nurse counsellors' information giving to HIV patients and their spouse/family as a way to represent some medical jargons pertaining to HIV. This study yielded five metaphors: i) *tidur* (sleep), ii) *askar* (soldier), iii) *komando* (commando), iv) *polis* (police), and v) *makan* (food) (eat). Despite of the interesting findings regarding the use of metaphor in HIV counselling, it is highly suggested for future research to focus on the use of metaphor when giving advice and providing information regarding sexual-related matters in HIV counselling in Malaysia.

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