

HIV Communication Challenges Faced by HIV Specialist Nurses in Malaysia Government Hospitals

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ABSTRACT

HIV counselling is a communication process between a trained nurse and patient to discuss HIV-related problems with a view to assist the patient to manage these problems adequately and appropriately. Lack of communication about HIV-related problems exists and the fact that nurses do not address these problems appropriately could be associated with the sensitive issues involved or the lack of knowledge as how to overcome these problems. Previous studies have identified the challenges health care workers face in disseminating HIV-related information. However, there is an apparent lack of research examining the challenges faced by HIV specialist nurses in Malaysia. Hence, this paper aims to explore the communication challenges faced by HIV specialist nurses in three general hospitals in Malaysia. Five focus group discussions (25 HIV specialist nurses) have been recorded, transcribed and translated. Thirteen communication challenges have been identified and contended for further research exploring communication during HIV counselling by focusing on the impact of these challenges towards HIV specialist nurses' advice and information giving.

Keywords: HIV counselling, health communication, communication challenges, nursing, nurse communication

INTRODUCTION

Health care workers who offer care to patients living with HIV face numerous challenges at all stages of the disease. Since there is still no cure for AIDS, the diagnosis of HIV infection often has a distressing impact upon the individual, the family and friends, and often places great emotional stress on the nurses themselves (World Health Organization, 1988). There are several issues encountered in HIV counselling which could be categorised as; i) general issues, ii) social issues, iii) sex and drug related culture sensitive issues, and iv) psychological issues. Therefore, it is important for HIV specialist nurses to be able to address the mentioned issues efficiently.

With regard to general issues, lay beliefs and misconceptions have to be corrected, especially the typical misunderstanding that virus can be transmitted through toilet seats, by sharing common utensils and through casual contact such as hand shake (World Health Organization, 1988). It is also a common misconception among the public that asymptomatic carrier and AIDS are considered

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the same category, all drug addicts have AIDS, and infected person cannot have sexual intercourse. It is, therefore, the role of HIV specialist nurses to deal with these issues and to clarify misconceptions. Apart from this, HIV specialist nurses have to deal with the more common social issues among HIV patients such as marriage, divorce, employment and financial problems (World Health Organization, 1988).

Often, HIV specialist nurses need to be concerned with sensitive issues related to sexual and drug practices related to HIV. Hence, careful enquiry and skilful interviewing are required by HIV specialist nurses so as not to offend the patients and to maintain good rapport (World Health Organization, 1988). For instance, there are times when detailed interview has to be done on masturbation and other sexual practices (e.g. use of condom, sexually transmitted disease etc.). In the issue of safer sex, HIV specialist nurses may have to explain the purpose of the enquiry and to mention that the use of condom decreases the risk of HIV transmission. In the current sex and drug related culture, sensitive issues and risky behaviour must be addressed in order to prevent transmission through modification of lifestyles and behaviours (Ministry of Health Malaysia, 2004).

In handling psychological issues of various forms (e.g. denial, shock, fear, anxiety, depression and guilt, suicidal ideas and threat), HIV specialist nurses must be able to recognize the symptoms and the severity, and to deal with them accordingly. In certain instances, the nurses may feel the need to refer the patient to a psychiatrist, specifically when the patient presents signs of cognitive impairments, psychotic symptoms, severe depression, and suicidal thoughts, for further opinion and management (Ministry of Health Malaysia, 2004).

In Malaysia, registered nurses undergo a specialized HIV/AIDS counselling training and upon completion, these HIV specialist nurses 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 specialist 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 and 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). However, there is an apparent lack of research examining the challenges nurses in Malaysia face when communicating sensitive HIV-related information to patients. Therefore, there is a vital need to investigate the challenges faced by HIV specialist nurses when communicating with HIV patients so that they will be better equipped to manage these challenges during HIV counselling sessions.

Moreover, a study by De Wet *et al.* (2013) found that HIV patients needed more time spent with health care workers, specifically to gain more information regarding the disease. Although they seemed to comprehend the HIV-related information, they still appear to be uncertain regarding some sexual and social practices pertaining to the transfer of HIV. Similarly, research conducted by Petros (2011) confirms these findings, namely that while most families tend to be knowledgeable about HIV, some still hold strange beliefs about the disease. These findings, therefore, show that there appear to be some problems with the communication of pertinent advice and information in HIV counselling. For example, a research by Teh (2008) on HIV related needs of transgender in Malaysia indicated that although healthcare is easily accessible, findings show that healthcare workers were unable to offer HIV advice and information, specifically related to the needs of transgender.

In their study, De Wet *et al.* (2013) suggested that health professionals should be aware of their important role in sharing HIV-related advice and information, and they should engage in community projects with the purpose of collaborating with HIV-positive patients and their families. It seems crucial that health professionals build a trust relationship with community members in order to ensure continuity and openness in communication regarding HIV-related information. This confirms the importance of including cultural sensitivity as well as communication skills in the nurse education curriculum.

The discussion has pointed to the need for a study to explore HIV specialist nurses' challenges in communicating with HIV patients throughout HIV counselling sessions. Whilst lack of empirical literature on the topic of nursing and HIV-related communication in Malaysia is a major limitation to this study, it is hoped that the findings will be informed through experience. Therefore, it is relevant to conduct this study by interviewing HIV specialist nurses who have experience in HIV counselling in order to obtain authentic and first-hand data. It is hoped that the findings of this study will contribute to Malaysian research, specifically in the area of health communication.

HIV COMMUNICATION CHALLENGES

In counselling HIV patients, talking about the future entails addressing issues such as deterioration in health, disfigurement, pain, loss, and death (Bor and Miller, 1988; George, 1989). Talking about fears of death, dying, illness and its consequences, however, is not an easy task to achieve as the culture has been described as one which avoids such topics (Aries, 1982; Elias, 1985). However, HIV specialist nurses and patients have to engage in particular ways of talking in order to be able to deal with these topics.

Dealing with Stigma Towards HIV Patients

Previous research by Muturi (2005) has found the lack of communication about HIV also exists between health care providers and their patients. The fact that doctors do not address the problem appropriately could either be associated with the confidentiality issues involved or with ignorance as to how to deal with the problem. It could also be associated with the stigma associated with HIV which is often associated with promiscuity; they do not communicate with the patients as a way of allowing patients to 'save face' (Muturi, 2005).

The notion of stigma is the process of identifying a characteristic of another, as deviant from the social expectations that are held by the majority. Stigma has been defined as a feature that is intensely notorious to an individual or a group of people (Goffman, 1963). Stigma ascends in various scopes of life, including relationships with other people, in feelings about oneself, and throughout various interactions individual might have with the community, such as in the workplace or health services. Furthermore, HIV patients experience stigma for several reasons, which primarily relate to shared perceptions around how HIV is transmitted and it has been reported that the groups most commonly associated with HIV in Australia are: i) men who have sex with men (MSM), ii) people who

inject drugs (PWID), iii) immigrants and ethnic minority groups, and iv) commercial sex workers (ASHM and National Centre in HIV Social Research, 2012).

Stigma towards HIV patients has been linked to negative health problems ranging from increased depressive symptoms to engaging in risky sexual behaviour (Vanable *et al.*, 2006; Kinsler *et al.*, 2007; Sayles *et al.*, 2008). Additionally, experiencing stigma in a healthcare setting has been found to adversely affect the health behaviours of HIV patients; such as accessing treatment, seeking testing for HIV, and adhering to medical regimes (Fortenberry *et al.*, 2002; Butt, 2008; Pascoe and Smart Richman, 2009).

Dealing with Patients' Denial of Their Condition

In a conversation regarding how to approach HIV-positive patients, healthcare providers have pointed out the difficulty especially when communicating with patients they know personally. Nevertheless, healthcare providers associated this challenge with the lack of training in both communication and counselling skills. In addition, other health professionals fail to intervene because of the way some patients react when they receive their HIV test results. For example, the study found that there are instances when infected people, out of bitterness, purposely spread the virus to others by engaging in unprotected sexual activities or rupture their condoms (Muturi, 2005).

People who find out that they are HIV positive often react with the news by denying the truth. They may believe that the HIV test was not accurate or that there was a mistake with the result, even after confirmatory testing shows that it is a true positive. This is an ordinary and typical first reaction. At first, this denial may be helpful as it can give them time to get used to the idea of infection. However, if not dealt with, denial can be dangerous; they may fail to take certain precautions or reach out for the necessary help and medical support. HIV patients who practise denial are expected to avoid health and support services that may confront them with their HIV status, and may seek out health providers who will confirm their avoidance by giving a different diagnosis (Meursing, 1999; Kartikeyan *et al.*, 2007).

Communicating with Patients about Sensitive Matters

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 (George, 1997; 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 and Bang, 1994). In this hegemonic discourse, 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).

A study by Irinoye (1999) demonstrated that talking about the sexual lives of people which in most Nigerian culture is not allowed, even where the counsellor have the confidence on talking about sexual matters, it commonly takes a long time to get all others involved uninhibited enough to discuss

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 “cloak of silence” exist when dealing with sexual matters as these practices appear to be against the culture, traditions, laws and religions of Pakistan. Traditionally women cannot discuss sexual practices with men, or men with women.

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 concern and presenting problem. These sensitive topics should be directed toward helping the patients to explore emotional issues, solve important concerns and make healthy decisions. The Ministry of Health Malaysia (2004) asserts that proper enquiry as well as skills have to be applied by the counsellor so as not to offend the client and maintain good rapport when dealing with sensitive issues related to HIV. For instance, the counsellor may have to explain the purpose of the enquiry prior to 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 are among the most challenging subjects when conducting HIV counselling. However, there is a need for healthcare professionals, mainly the HIV specialist nurses to address these issues in order to fulfil the patients' concerns and needs.

METHODS

A total of five focus group discussions involving four to six HIV specialist nurses per group were collected in three Malaysian general hospitals. The researcher prepared five semi-structured questions based on the research question which act as prompts and help to elicit information which would reveal HIV specialist nurses' insight concerning the issue. Before the start of every discussion, the researcher briefly explained the research and the purpose of the group discussion. Next, the respondents were informed that this study required their experience about the challenges throughout HIV counselling sessions. The rationale behind this is to stimulate the respondents' thought regarding communication challenges in HIV counselling sessions. By listening to the presentation, they will have a gist about what is meant by communication challenges in HIV counselling sessions. Each discussion lasted between 20-30 minutes. The discussions were audio recorded and notes were also taken.

DATA ANALYSIS

The data from the focus group discussions were transcribed and translated using a transcription convention adopted from the Jefferson's Transcription Notation (1978) via Transana software. By using this software, the researcher transcribed, coded and categorized the data accordingly. Once the data has been transcribed and translated, the themes according to the emergent of trends and the relevance of information were identified. The HIV communication challenges themes used in a survey

by Ibrahim and Shaharudin (2014) which was developed from the literature review and health practitioners input were adapted in this study.

RESULTS AND DISCUSSIONS

During the data analysis, the researcher had identified thirteen emerging themes from five focus group discussions among HIV specialist nurses. Table 1 demonstrates the communication challenges faced by HIV specialist nurses in HIV counselling sessions identified in this study.

Table 1 Communication Challenges in HIV Counselling Sessions (Ibrahim and Shaharuddin, 2014)

Communication Challenges	Frequency
1. Communicating with patients about sensitive matters such as risky sexual behaviours, protective sexual intercourse etc.	2
2. Communicating with patients from different ethnic groups and problems with the language barriers	2
3. Communicating with patients with disabilities (i.e. deaf)	1
4. Communicating with patients who are less educated	1
5. Communicating with patients who are educated	2
6. Ensuring adherence with HIV medication	3
7. Dealing with patients' denial of their condition	4
8. Dealing with healthcare workers' stigma towards HIV patients	3
9. Keeping up to date with information about HIV	2
10. Dealing with confidentiality issues	2
11. Dealing with patients with low self-esteem	2
12. Communicating with Intravenous Drug User (IVDU) patients	4
13. Communicating with homosexual, bisexual or transgender patients	2

It can be clarified from Table 1 that the most prominent communication challenges are; i) communicating with Intravenous Drug User (IVDU) patients; ii) dealing with patients' denial of their condition; iii) ensuring adherence with HIV medication; and iv) dealing with healthcare workers' stigma towards HIV patients. Further discussions will be discussed in the following sections.

CHALLENGES IN COMMUNICATING WITH IVDU PATIENTS

The findings indicate that the most prominent communication challenge faced by these HIV specialist nurses is when they communicate with IVDU patients. The excerpt below reveals a HIV specialist nurse's experience when communicating with IVDU patients.

N4HM: saya rasa:: masalah saya (.) su::sah nak tackle patient IVDU lah (.2) patient IVDU ni: sekali kita tanya: (.) dia cakap dia tak tahu dia ada sakit (.2) tapi sebenarnya:: keputusan darah doktor dah bagitahu: ada (.2) tapi dia cakap doktor tak cakap pun saya ada sakit? (.) doktor cakap saya ada TB je: (.) tak tahu pun ada HIV

N4HM: *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.*

The HIV specialist nurse expressed the difficulty that she had experienced, especially in getting IVDU patients attention during the HIV counselling sessions. The nurses have to bear in mind that they are IVDU patients and there are a lot of negative effects of drugs on their psychological state such as hallucination, disorientation, altered time and space perception, lack of concentration, impaired learning and memory, and alterations in thought formation and expression (Couper and Logan, 2014). Therefore, it would be a challenge for HIV specialist nurses to get their concentration and attention throughout the counselling session.

The effects of drugs on IVDU patients’ psychological state do not only affect their concentration during HIV counselling, but it could also affect their adherence to HIV treatment. The following excerpt verifies the above statement.

N9HM: tapi macam saya: (.) sama lah apa yang saya dengar ni selalu: (.) yang IVDU akan ada default (.2) lepas tu:: dia akan ikut arahan kita je (.) tapi dia suka default (.2) tapi lepas tu dia call kita: (.) mintak ubat sebab dia tahu ubat tu support dia

N9HM: *For me, it is similar as what I always heard; IVDU will default. Then, he will follow our instruction, but he likes default. But after that, he will call us asking for medication because he knows that the medication supports him.*

Based on the experience faced by the HIV specialist nurse, it can be seen that IVDU patients have the tendency for treatment default, even though they know the effects of medication to them. Default in HIV counselling can be defined as “being more than one month late for the next scheduled consultation (Miller *et al.*, 2010, p. 49), while, Daniel *et al.* (2008) defined default as “failing to collect medication for more than six consecutive months after the date of the last attendance during the course of treatment” (p. 222). However, in the context of this study, the researcher agrees with the definition of default by Mathebula (2014) that a situation which patient does not follow the treatment plan and does not return for follow-up for at least three months” (p. 11).

Previous research (Van Dyk, 2008; Wasti *et al.*, 2012) have found that risk factor to follow-up were parallel with substance misuse (i.e. drug abuse), thus, it is seen as a cause of non-adherence or default (Mathebula, 2014). However, WHO Europe (2007) reported that IVDU patients are often reluctant to attend HIV treatment due to stigmatization and discrimination. Fear of discrimination

may discourage HIV-infected IVDU from revealing their drug use to HIV/AIDS care specialists which leads to a greater risk of misdiagnosis, or of pharmacological interactions between the HIV treatment regimens and the substances use.

DEALING WITH PATIENTS' DENIAL OF THEIR CONDITION

From the focus group discussions with HIV specialist nurses, it can be seen that another prominent communication challenge in this study is dealing with patients' denial of their condition. The excerpt below reveals a HIV specialist nurse's experience when dealing with patients' denial of their condition.

N5HM: yang pertama: (.) kebanyakan kes seperti yang saya cakap tadi (.) memang ada masalah denial (.2) denial ni: maksudnya:: (.) dia cuba elak diri dia dari perkara yang sebenar (.) contohnya:: bila dia baru:: saja di diagnose sebagai HIV positive eh (.) jadi dia akan cuba:: (.) kita akan tanya eh (.) a:: mungkin soalan yang berlapik mengenai apa sebenarnya yang berlaku lah

Firstly, a lot of cases like I have mentioned before, denial is certainly an issue. Denial means he tries to avoid 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.

Denial is a multifaceted psychological concept frequently encountered in clinical practice for those dealing with serious illnesses (Goldbeck, 1997). Denial can be understood as HIV patients who; i) do not accept their diagnosis; ii) minimise or ignore the implications of their diagnosis, including their potential infectiousness to others; and iii) avoid, delay or comply poorly with treatment (Kartikeyan *et al.*, 2007).

From the excerpt above, the HIV specialist nurse mentioned that HIV patients tend to avoid to accept the truth as well as tried to deny his/her risk behaviour. In their book on *Psychosocial and Biomedical Interaction in HIV Infection*, Nott and Vedhara (2000) stated that HIV infected individuals may deny their involvement in high risk behaviours, even after testing and counselling. They believed that social stigma and fear of isolation from family and significant others could be the prominent factors to the individual's reluctance to disclose his/her high risk behaviours to others.

In the case of stigmatization of HIV patients, studies have shown that women are often even more prone to the stigma associated with HIV/AIDS, hence, triggering them to the denial of the infection (De Bruyn, 1992; Lawless, Kippax, and Crawford, 1996). The following excerpt demonstrates the denial of HIV status by a woman.

N8HM: okay (.) cabaran pasal: woman kan (.) macam yang dia cakap tadi: (.) contoh macam surirumah (.2) dia tak terima dia punya:: status HIV (.) apa kita nak cakap dekat dia? (.) dia kena: makan ubat tapi dia tak nak (.2) dia: lebih sanggup ikut takdir lah contoh (.2) buat apa aku nak makan ubat ni? (.) baik aku mati saja dari dengar cemuhan orang luar:

Okay. Challenges related to women, like what she mentioned just now, I take a housewife as an example. She denies her HIV status. So, what should we tell her? She refuses to take her medication. She is more than willing to follow her fate. “Why should I take this medication? What for? I am better off dead than listening to people’s mockery.

The HIV specialist nurse shares his/her experience dealing with a housewife who could not accept her status as HIV positive and refused to take the medication prescribed. It can be seen clearly that the patient would rather die than facing the stigma and discrimination from the society. Studies have shown that women who disclose her HIV status may experience a range of reactions from support and understanding to accusations, discrimination, physical violence and abandonment (Iwelunmor *et al.*, 2006; Miller and Rubin, 2007; Greeff *et al.*, 2008). According to Goldin (1994), HIV/AIDS has been associated with ‘sexual misbehaviour’ and ‘promiscuity’ contributing to high level of stigma and discrimination associated ever since it was first identified. Hence, the discrimination discourages HIV patients from seeking vital medical and psychological care they need during the illness (Chesney and Smith, 1999).

When people with HIV infection deny the problem, they tend to disregard the required precautions to curtail the progress of AIDS. Moreover, they may also be in casual sexual relationships which further increase the transmission risk. Thus, denial plays a significant role and needs to be dealt with by health professionals in order to help the patients cope better and to prevent further transmission (Venkoba Rao, 1991).

ENSURING ADHERENCE WITH HIV MEDICATION

The findings indicate that ensuring adherence with HIV medication is one of the communication challenges faced by these HIV specialist nurses during HIV counselling. The excerpt below reveals the challenge faced by HIV specialist nurses in one of general hospitals in Malaysia.

N1HSB: a:: kadang-kadang diaorang ni menyalahkan kita:: (.) kadang kita cakap lai::n diaorang faham lai::n (.) lepas tu salahkan kita: (.2) kadang patient yang tak compliant tu: (.) salahkan kita tak bagitahu pasal ubat =

= kata counsellor tak betu:l

N2HSB:

padahal (.) dia yang sendiri tak nak makan ubat (.) lepas tu salahkan kita (.2) >tak nak makan ubat lepas tu salahkan kita lah< (.) cakap tak betul lah apa lah (.2) itu cabaran paling teruk yang akak rasa lah

N1HSB:

Sometimes, they like to blame us. There are times when they misunderstood what we have said, but then, they blamed us. Patients who are not compliant likes to blame us for not informing them about the medication

N1HSB:

They said that the counsellor is wrong

Truth is, they were the ones who refused to consume the medication, but they blamed us for it. They refused to take the medication, but they blamed us by saying that we did not give the right information and what not. For me, that is the worst challenge.

N2HSB:

N1HSB:

Success with any medication depends not only on the essential properties of the drugs, but also on the ability of the patient to take the medications and HIV infection is one of the most difficult chronic diseases to treat optimally (Ehon, 2007). Past research assert that adherence should be monitored and assessed at each clinic follow-up visit as there is an indication that adherence decreases over time (Ehon, 2007).

The HIV specialist nurse shares the difficulty that she had in ensuring adherence to HIV medication. In their book on *Substance Abuse Treatment for Persons with HIV/AIDS*, Batki and Selwyn (2008) assert that adherence to antiretroviral treatment (ART) plays a more important role in long-term outcome than choice of antiretroviral medications as patients who adhere to the medications will likely have a better outcome. It is also important that the HIV specialist nurses discuss with the client why adherence is important and how it could prevent drug resistance. Hence, it is a challenge for HIV specialist nurses to cope with this issue. In light of this challenge, the following excerpt reveals another problem related to medication adherence.

- N22HM: compliance okay tak diaorang?
- N20HM: a:: compliance fail a:: sebab tu pada saya: saya lebih banyak sembang-sembang dan dari situ saya tahu mereka tak compliance pada ubat dan kadang-kadang diaorang su::sah nak ikut time sebab diaorang punya kerjaya a:: kebanyakan diaorang ada ya:ng pilo:t stude::t crew cabi::n
- N22HM: *How is their compliance?*
- N20HM: *Their compliance; fail. For me, that is why I chat a lot and from there I know that they are not compliant to the medication. Sometimes, it is difficult for them to follow the time due to their career. A lot of them are pilots, students, and cabin crew.*

The HIV specialist nurse in the above excerpt reveals the difficulty of patients adhering to medication due to their inconsistent schedule related to their career. Since the antiretroviral medications should be taken several times a day for the rest of their life, the medications must be chosen with care. It is believed that the choice should be based on the patients' daily routine and on any other medical conditions besides HIV/AIDS.

Ehon (2007) suggested that upon initiating ART, clinicians can take additional steps to increase the probability of good adherence; i) integrating the treatment to patient's lifestyle; ii) training the patient with medications and dosing schedule; iii) scheduling follow-up visits soon after initiation to discuss side effects and difficulties in taking the medications; iv) promptly responding to any problems by adjusting, changing, or stopping medications when needed; and v) treating related conditions, such as depression, anxiety, and drug addiction.

DEALING WITH HEALTHCARE WORKERS' STIGMA TOWARDS HIV PATIENTS

Based on the findings from the focus group discussions with HIV specialist nurses, it can be understood that dealing with healthcare workers' stigma towards HIV patients is one of the challenges that they have to face. The excerpt below reveals HIV specialist nurses' views on this issue.

- N16HM: dan 1 lagi yang macam di tempat saya kan (.) a:: stigma among healthcare worke::r
(.) that's why our role kena:: (.) pastikan yang healthcare worker alert dengan kes
macam ni lah (.) supaya:: ID patient dapat diterima dengan sepatutnya:
- N17HM: honestly:: (.) dari segi:: stigma dan diskriminasi our staf sendiri tu (.) memang
tinggi lah =
- = ve::ry hi::gh
- N15HM: still ada lagi la::h =
- N16HM: = tak payah staf (.) even doctors pu::n
- N14HM:
- N16HM: *And 1 more, like in my place, the stigma among healthcare workers. That is why our
role is to ensure that healthcare workers are alert with cases like this. So, ID patients can
be accepted appropriately.*
- N17HM: *Honestly, in terms of stigma and discrimination of our own staff is certainly high.*
- N17HM: *Very high.*
- N15HM: *Still there.*
- N16HM: *Not just staff, even the doctors.*
- N14HM:

HIV-related stigma and discrimination can be defined as a process of devaluation that significantly discredits an individual either living with or associated with HIV/AIDS (The Joint United Nations Programme on HIV/AIDS, 2011). As mentioned in the above excerpt, these HIV specialist nurses agree that stigma among healthcare workers' toward HIV patients are still high, including doctors. This comes to no surprise as past research have revealed that stigma and discrimination against patients living with HIV/AIDS is widened globally (Jeevitha *et al.*, 2013). However, it was found that stigma scores varied by type of healthcare providers – physicians reported the least stigmatizing attitudes as compared to nursing and ward staff in the hospitals (Mahendra *et al.*, 2007).

The following excerpt provides examples of stigmatizing attitudes shown by healthcare workers in the Malaysian government hospitals.

- N1HM: tugas kita kena bagi careworker awareness lah (.) untuk mengurangkan atau mensifarkan stigma tu =
- N3HM: = buang stigma tu:
- N2HM: em::
- N1HM: macam attendant kan yang datang tu (.) ada: yang pakai glove pakai mask (.) so kita tanya lah kenapa? (.) perlu ke pakai ni semua? so kita kena create awareness tu lah (.) kita kita:
- N1HM: *Our job is to create awareness among care workers to reduce their stigma*
Get rid of their stigma.
- N3HM: *Em*
- N2HM: *For instance, there were attendants who came wearing gloves and mask. So, we ask them “Why? Do you have to wear all that?” So, we have to create the awareness. Us.*
- N1HM:

The above discussions reveal the stigmatizing attitudes shown by healthcare workers; wearing protective gears when dealing with HIV patients. In previous study by Chan (2009), it was found that healthcare workers would modify their duties (e.g. avoiding taking blood or touching patients with HIV) without realising that they were being discriminatory. Similarly, a study conducted in Nigeria had found the healthcare workers’ fear of treating HIV patients such as fear of being contaminated, contamination of instruments and insufficient equipment to treat HIV patients (Chen *et al.*, 2005). The findings from the previous studies have revealed that healthcare workers’ refusal to treat HIV patients was due to the risk of occupational exposure to HIV infection.

It is important to be aware that stigma and discrimination within the healthcare sector can have a major impact on acceptance of care and may act as a barrier to disclosure, testing, and treatment (Kurtz *et al.*, 2005; Wilson *et al.*, 2010). This can be supported by the following view shared by a HIV specialist nurse.

- N16HM: saya ada kes yang budak ni belajar kat Cheras (.) tapi asal Sabah (.) so: dia ada tanya-tanya: kan dekat Facebook (.) ada yang HIV Awareness tu ka:n kalau ada siapa-siapa tengok tu: (.2) so: saya one of the commenters lah (.2) last-last dia mintak nombor telefon saya then tanya macam-macam lah pasa:l HIV ni (.) so: saya cakap dekat dia bila balik Sabah nanti pergi lah ke tempat ni (.2) tapi: baru je kat kaunter tak tahu lah nurse ke: apa ke: yang jaga situ bila dia baru je sebut HIV dia terus o::h kau buat nakal-nakal e::? (.) te::rus terbantut dia nak buat rawatan (.) dan akhirnya: dia balik semula Cheras (.) dan buat rawatan dekat sini lah

I have a case about this boy who is studying in Cheras, but he originated from Sabah. So, he always ask on Facebook. There is a page on HIV Awareness, for those who have seen it. So, I am one of the commenters. In the end, he asked for my contact number and asked me a lot of questions related to HIV. So, I suggested a place that he can go when he go back to Sabah. But when he arrived at the counter, the nurse in-charge gave immediate response, “Oh, you are being naughty, aren’t you?” Immediately, his plan to go for treatment were stunted and finally, he came back to Cheras and went for a treatment there.

The experience shared by the HIV specialist nurses have proven that discriminatory behaviour by healthcare workers can lead to less frequent healthcare visits, negative relationships between doctors and patients, and lower levels of adherence to medical regimes (Lawless *et al.*, 1996; Miller *et al.*, 2001; Brener *et al.*, 2010).

Past research by Li *et al.* (2007) concluded that on the front line of the war against HIV/AIDS, health service providers are positioned to respond with needed services, yet, HIV-related stigma and discrimination continue to hinder an effective response for treatment and care for HIV patients worldwide. However, they believed that comprehending the various dimensions of HIV-related discrimination in healthcare settings is the first step in effectively encountering this challenge.

CONCLUSION

HIV is an incurable disease as there is no effective treatment or vaccine to cure the disease until today. This can be further intensified by the psychosocial impact on the person with HIV, the family and the community. However, it must be emphasised that HIV infection can be prevented, mainly related to the lifestyle and behaviour of an individual. It is, therefore, believed that counselling plays a crucial role in the prevention, transmission and management of HIV infection and allows the individual to make informed decisions that can improve lifestyles.

However, communicating with HIV patients in HIV counselling can place great challenge to HIV specialist nurses. This study found thirteen communication challenges faced by HIV specialist nurses in HIV counselling sessions in Malaysian general hospitals and the most prominent communication challenges are; i) communicating with Intravenous Drug User (IVDU) patients; ii) dealing with patients' denial of their condition; iii) ensuring adherence with HIV medication; and iv) dealing with healthcare workers' stigma towards HIV patients. These challenges can directly and indirectly affect the treatment of HIV and stigma.

As HIV specialist nurses were discussing about the difficulty of communicating with IVDU patients, the discussion preceded to IVDU patients' being non-adherent to the medication by not attending follow-up treatment. With regard to patients' denial of their condition, this too precedes to patients' refusal to the medications. Issues related to medication adherence often place stress to HIV specialist nurses as they have to ensure patients' adherence to prolong their life span and minor deviations from the prescribed treatment can result in viral resistance.

Acting through discrimination, denial, and shame, stigmatization is an obstacle to HIV prevention and treatment efforts. Hence, it is important for HIV specialist nurses to help HIV patients to overcome denial as well as to improve their self-esteem. Moreover, friends and family play crucial roles in providing psychosocial support and one of the first steps in providing ample support for HIV patients is to ensure that they are thoroughly aware of the correct understanding of HIV transmission.

RECOMMENDATION FOR FUTURE STUDY

The findings of this study indicate the need of further exploration on HIV counselling in Malaysian general hospitals. The recommendations are as follows:

1. To explore the impact of these challenges on HIV specialist nurses advice and information giving in HIV counselling sessions.
2. To identify the communication strategies used by HIV specialist nurses in offering advice and information to HIV patients and/or their spouse.

Very few research, if any, has examined the communication that takes place in HIV counselling sessions in Malaysia. The findings of the study will have significant implication for the training of HIV specialist nurses and HIV communication research in Malaysia.

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