



**THE EFFECTIVENESS OF STANDARDISED HIV COUNSELLING
INFORMATION ON POSITIVE DONORS AT NATIONAL BLOOD CENTRE**

By

DR. INTAN SHAFINAZ BINTI SUDIN

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DECLARATION

I hereby declare that this research has been sent to Universiti Sains Malaysia (USM) for the degree of Master of Medicine (Transfusion Medicine). It is not to be sent to any other university. With that, this research can be used for consultation and photocopied as a reference.

A handwritten signature in black ink, consisting of a large, stylized 'I' followed by 'sh' and a period, positioned above a horizontal dotted line.

Dr. Intan Shafinaz binti Sudin

P-IPM004/14

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
BTS	Blood Transfusion Service
CSW	Commercial Sex Worker
HIV	Human Immunodeficiency Virus
HSB	Hospital Sungai Buloh
ID	Infectious Disease
IVDU	Intravenous Drug User
KKKL	Klinik Kesihatan Kuala Lumpur
MOHM	Ministry of Health Malaysia
MSM	Men who have Sex with Men
NBC	National Blood Centre
Q	Question number
RM	Ringgit Malaysia
STI	Sexually Transmitted Infection
TTI	Transfusion Transmitted Infection
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme

USD	United States dollar
WHO	World Health Organization

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ABSTRAK

Latar belakang kajian: Sesi kaunseling selepas menderma darah adalah sebahagian tanggungjawab yang perlu disediakan oleh perkhidmatan transfusi darah kepada penderma yang mempunyai keputusan positif kepada jangkitan kuman. Kaunseling perlu menyampaikan maklumat yang tepat dan mencukupi berkenaan jangkitan kuman yang disebarkan melalui pendermaan darah. Rujukan kepada pakar perubatan untuk rawatan selanjutnya adalah mandatori.

Objektif kajian: Menilai keberkesanan maklumat kaunseling yang seragam keatas penderma darah yang positif kepada kuman HIV di Pusat Darah Negara (PDN) dengan cara mengevaluasi perbezaan pengetahuan tentang HIV sebelum dan selepas kaunseling, menentukan perkaitan antara penambahan pengetahuan dan kehadiran pertama penderma positif di klinik ID, Hospital Sungai Buloh dan Klinik Kesihatan Kuala Lumpur selepas rujukan dari PDN, dan mengenalpasti faktor-faktor yang berkaitan dengan ketidakpatuhan kepada temujanji klinik yang pertama.

Metodologi: Kajian ini ialah bersifat prospektif, intervensi dan dijalankan di PDN. Modul Kaunseling HIV telah disediakan untuk digunakan sebagai bahan rujukan semasa kaunseling penderma positif HIV. Seramai 61 penderma positif HIV telah menyertai kajian ini. Kaunseling dijalankan keatas penderma mengikut perkara dalam Modul Kaunseling HIV. Penderma dikehendaki untuk menjawab soal selidik HIV/AIDS sebelum dan selepas sesi kaunseling. Seterusnya, penderma dirujuk kepada pakar perubatan untuk rawatan

lanjut. Markah bagi soal selidik sebelum dan selepas kaunseling telah direkodkan. Temujanji kehadiran pertama penderma di klinik (klinik ID dan KKKL) selepas dirujuk dari PDN telah direkodkan. Siasatan berkenaan ketidakpatuhan kepada temujanji klinik telah dijalankan. Data telah dianalisis dengan menggunakan statistik *descriptive* dan *inferential*.

Keputusan ujian: Median markah pengetahuan (31.0 IQR 5) selepas kaunseling adalah berbeza secara statistik (p -value < 0.001 ; *Wilcoxon signed-rank test*) berbanding garis asas markah pengetahuan (19.0 IQR 5) setelah menggunakan Module Kaunseling HIV. Purata (SD) peratusan markah kajiselidik HIV-KQ sebelum intervensi ialah 24.45(16.28) dan selepas intervensi ialah 77.51(11.53). Tiada perkaitan yang signifikan antara penambahan pengetahuan selepas kaunseling dan temujanji kehadiran pertama di klinik dikalangan penderma positif HIV (p -value 0.624). MlogR menunjukkan tiada faktor-faktor perkaitan yang signifikan (umur, status perkahwinan, tahap pendidikan, penambahan markah, hubungan seksual berlawanan jenis, hubungan seksual sesama lelaki) dengan ketidakpatuhan kepada temujanji pertama di klinik.

Kesimpulan: Penggunaan Modul Kaunseling HIV semasa kaunseling telah meningkatkan pengetahuan tentang HIV dikalangan penderma positif HIV. Bagaimanapun, tiada perkaitan antara penambahan pengetahuan selepas kaunseling dan temujanji kehadiran pertama penderma di klinik. Tiada faktor-faktor perkaitan yang signifikan dengan ketidakpatuhan temujanji pertama di klinik.

ABSTRACT

Background: Post-donation counselling is part of care that a blood transfusion service should provide to blood donors with positive infectious markers. The counselling should provide precise and adequate information on the implicated transfusion transmitted infection. Referral to a physician for further management is mandatory.

Objectives: Assessing the effectiveness of standardised counselling information on HIV positive donors at National Blood Centre (NBC) by evaluating the knowledge difference on HIV pre and post counselling, determining the association between knowledge improvement and the first attendance of the positive donors at Infectious Disease (ID) clinic Hospital Sungai Buloh and Klinik Kesihatan Kuala Lumpur (KKKL) after referral from NBC, and identifying factors associated with non-adherence to first clinic appointment.

Methodology: This study was prospective, interventional and conducted at NBC. An HIV Counselling Module was prepared to be used as reference for counselling of HIV positive donors. 61 HIV positive donors participated in this study. Donors were counselled according to items in the HIV Counselling Module. Donors were required to answer the HIV/AIDS questionnaire prior to and after the counselling session. Then, donors were referred to a physician for further management. Questionnaire scores for both before and after the counselling of each donor were recorded. Donors' first attendance to clinic appointment (ID clinic and KKKL) after referral from NBC was traced and recorded. Non-

adherence to clinic appointment was investigated further. The data was analyzed by using descriptive and inferential statistics.

Results: Post counselling median knowledge scoring (31.0 IQR 5) was statistically different (p -value < 0.001 ; *Wilcoxon signed-rank test*) from baseline knowledge scoring (19.0 IQR 5) after using the HIV Counselling Modul. The mean (SD) percentage of HIV-KQ scoring was 24.45(16.28) for pre-intervention and 77.51(11.53) for post-intervention. There was no significant association between knowledge improvement after counselling and first attendance to clinic appointment among HIV positive donors (p -value 0.624). MlogR showed that there were no significant associated factors (age, marital status, educational level, score improvement, sexual activities) with nonadherence to first clinic appointment.

Conclusion: The use of HIV Counselling Module during counselling did improve knowledge on HIV among HIV positive donors. However, there was no association between knowledge improvement post counselling and attendance of donors to their first clinic appointment. There were no significant factors identified which were associated with non adherence to first clinic appointment.

CHAPTER 1: INTRODUCTION

1.1 Overview of Human Immunodeficiency Virus (HIV) and blood transfusion

The practice of blood transfusion is one of the therapeutic interventions that are utilised in a number of clinical departments; however this practice does carry risks (Sharew, 2017). Transfusion medicine has continued to face the challenge of transfusion transmitted infection (TTI) among blood donors who seem healthy and fit for blood donation in particular HIV infection. During the asymptomatic phase, a person can spread HIV infection and this situation contributes to an increased pool of HIV infection in the larger population (Olokoba *et al.*, 2010).

HIV is transmitted from person to person via body fluids, including blood, semen, vaginal discharge and breast milk. It can be spread through unprotected sexual contact with an infected person, by sharing needles with someone who is infected, such as an intravenous drug user (IVDU), from mother to a child (through placenta from an infected pregnant mother to the fetus), and also through breastfeeding or, less commonly (and rare in countries where blood is screened for HIV antibodies), through transfusion with infected blood (MOHM, 2011; WHO, 2014). HIV belongs to the Retroviridae family and replicates in host cells via reverse transcription process. This virus replicates in white blood cells called CD4 T-cells and make many copies of new virus. Then, HIV kills the CD4 T-cell

and the new HIV copies will infect other CD4 T-cells and repeat the cycle again. One of the functions of CD4 T-cells is to fight viral infection invading the human body. The amount of virus in the body goes up and the number of CD4 T-cell goes down. Over time, the immune system becomes weak and a person may develop signs and symptoms of Acquired Immunodeficiency Syndrome (AIDS) (Simon *et al.*, 2006).

In Malaysia, the epidemic of HIV infection was previously transmitted mainly through injecting drugs. However, transmission by sexual activity (heterosexual and homosexual) has been gradually increasing. Almost 80% of new HIV infections are now transmitted by sexual activity. The proportion of cases of HIV transmission by sharing of needle to inject drug has declined considerably from 60-75% in 1990s to less than 20% in 2014, and the transmission by sexual activity has increased significantly from 5-19% in the 1990s to about 80% in 2014. The ratio of injecting drug use to sexual transmission of HIV infection is 3.9 in 2000 declining to 0.2 in 2014 (MOHM, 2015).

The HIV epidemic not only affects the health of individuals, it impacts households, communities, the blood transfusion service, and subsequently the development and economic growth of nations. HIV/AIDS-related illnesses will result in reduction in savings and investments from families because of increased health expenditure (United Nations, 2004). Individuals who receive transfusion with HIV contaminated blood have a 90% chance of becoming infected (Donegan *et al.*, 1990). Previously, the WHO estimated that 5-10% of all HIV infections worldwide have been acquired through transfusions of

infected blood and blood products (Wahdan, 1995). An unsafe blood supply has a severe impact on morbidity and mortality. Unsafe blood transfusions and poor access to safe blood have a particularly severe impact on women with complications of pregnancy; trauma victims with severe bleeding or coagulopathy, children with severe life-threatening anaemia as a result of infection (WHO, 2004) and patients with chronic diseases who are transfusion-dependant for example thalassaemia, and haematological malignancy. An unsafe blood supply will result in lack of confidence by society in the blood transfusion service (BTS) and unwanted medicolegal consequences to the health authorities.

The challenges are particularly great in places where clinicians have become so adapted to using blood transfusion in their daily practice of medicine that it may be difficult for them to minimise their dependence on blood. The requirement for blood products keeps increasing every year due to increasing number of patients require transfusion of blood and blood products such as hematological malignancy, obstetric and trauma cases. World-wide epidemics of various viral diseases, especially HIV, have made the practice of blood transfusion therapy risky to recipients, challenging scientists to create new techniques (including testing all donations by highly sensitive test), technologies and strategies to ensure a continuous supply of safe blood and its components for the benefit of clinical use (Jenkins, 2007).

1.2 HIV positive donors and post-donation counseling

BTS has a responsibility to confirm the infectious status of reactive donors. These involve verifying test results and providing information, counselling and support to enable these individuals to be aware of and respond to unexpected information about their medical condition and risk to others. Counselling is part of care that a BTS offers to blood donors with a positive infectious marker, including referral to a medical practitioner in clinical services for further management (WHO, 2014). It is insufficient as a medical professional to notify a donor or patient of his or her status without discussing behaviours and lifestyle that will reduce their transmission risk to others, providing knowledge of HIV and AIDS, and resources (Canadian Aboriginal AIDS Network, 2012).

Post-donation counselling should provide precise information about the implication of the test results. Donors who have confirmed positive TTI test results should be provided with adequate information about the infection including how it is transmitted, the possible significance on the donor's health, choices of treatment, the prevention of further transmission, and the need to inform donor's contacts who might be at risk of infection so that they can be tested and treated as early as possible. Arrangements should be made for referral to an external agency for further HIV treatment and care. Donors should also be informed that their donated blood has been discarded and that they are deferred from further blood donation, either permanently or temporarily for a defined period of time, depending on the infection (WHO, 2014).

At National Blood Centre (NBC), all the donated blood will be screened for four TTI which are HIV, Hepatitis B, Hepatitis C (by serology and molecular tests) and Syphilis (by serology). The blood donor who has a reactive screening result and a positive confirmatory result from blood they have donated, will receive a telephone call and a notification letter to come to NBC for further investigation. The investigation (a repeat serological HIV test) is to confirm that the reactive donation belongs to the correct donor. The positive case will be notified to the State Health Department. Once the donor responds to the call and reports to NBC, the donor will be reviewed immediately by a doctor to explain the situation. Counselling of HIV positive donor is conducted in a dedicated counselling room by the final year master student of Transfusion Medicine Program with supervision by a specialist. For HIV positive cases, a repeat HIV test will be carried out urgently. At this point of meeting, the doctor will only explain to the donor that there is an infection in the donated blood; however the type of infection cannot be confirmed yet, therefore a repeat test using fresh blood sample should be carried out to confirm the infectious status. The result will be available after two hours. The doctor will review the result of the fresh blood sample and compare with the results of the donated blood (screening and confirmatory test). If all the results are tally and positive to HIV, then the doctor will continue with a thorough counselling about HIV infection to the donor. The explanation on the HIV tests done at NBC is written at 1.4.

However, until recently there has been no module or checklist available as a reference for the doctor during counselling of HIV positive donor. During counselling, the doctor is only provided with a table of 'Management of reactive donors to transfusion transmitted

infection' (refer to appendix page 146). The table outlines the actions need to be carried out by the doctor including identifying the risk factors, type of blood investigation to repeat, duration of appointment dates, and referral of HIV positive donor to physician. This table does not have the details of information about HIV infection and what are the questions should be enquired to donors. The doctor bears the responsibility to counsel the donor regarding the nature of HIV, the implication of HIV infection on the body and health, the mode of transmission, complications of HIV, its prevention, and the impact of HIV on blood recipients. The doctor is required to explain to the donors that he or she will be permanently deferred from blood donation. The donors who are confirmed positive for HIV will be referred to the Infectious Disease (ID) Clinic, Hospital Sungai Buloh (HSB) or to Klinik Kesihatan Kuala Lumpur (KKKL) for further management and treatment. The current practice of clinic appointment at ID clinic and KKKL is 'walk-in' appointment whereby any referral of HIV cases is allowed to register at HIV clinics from Monday to Friday, 8am to 5 pm. Therefore, no specific appointment date and time is given from NCB. The doctor has a responsibility to advise and encourage the donor to be adherent to the referral made to ID clinic or KKKL. HSB and KKKL are the referral centres for infectious diseases in the Klang Valley area.

1.3 Incidence of HIV positive donors at NBC

Table 1.1: Number and percentage of total whole blood donations and HIV positive cases between 2013 and 2015

YEAR	No of total whole blood donations	No of positive blood donations (blood donors) to HIV n (%)	No of HIV positive donors attended HIV reactive clinic, counselled and referred to ID clinic, HSB
2013	159212	98(0.06)	60
2014	166118	74(0.04)	50
2015	173419	62(0.04)	53

Table 1.2: Number and percentage of HIV positive donors attended to ID clinic, HSB between 2013 and 2015

YEAR	No of HIV positive donors attended ID clinic, HSB n (%)	No of HIV positive donors who did not attend ID clinic, HSB n (%)	No of HIV positive donors who delayed attendance for > 7 working days at ID clinic n (%)	Total % of Absence and delayed attendance of HIV positive donors
2013	49 (81.6%)	11 (18.3%)	14 (28.6%)	46.9
2014	41 (82%)	9 (18%)	10 (20%)	38
2015	39 (73.6%)	14 (26.4%)	11 (28.2%)	54.6

Analysis of data between 2013 and 2015 shows that the number of HIV positive donors counselled at NBC and referred to ID clinic, HSB was around 50 – 60 blood donors per

year. About 18 – 26% of HIV positive donors did not attend first appointment at ID clinic and 20 – 28% took more than seven working days to follow the referral done by NBC. HIV positive individuals are required to inform the infectious status to their partner(s) within 24 hours of diagnosis. The doctor has explained regarding partner notification to donors as well as to attend the clinic appointment as soon as possible after referral. However, for the study purpose, seven working days is considered the most appropriate duration given to donors to register at ID clinic or KKKL.

Tracing from the computer system at the ID clinic, there were donors who attended ID clinic after a few months from their counselling at NBC, and the longest documented duration was 3 years. This scenario is dangerous as the donor can spread the infection to the community because they may continue to live with high risk behaviour and/or untreated disease. Currently, HIV positive patient will be started on HIV treatment once confirmed positive to HIV regardless of CD4 count level. Therefore, it is crucial for these HIV positive donors to adhere to the referral to ID clinic or KKKL so that appropriate treatment can be initiated. The question is why these donors did not attend or delay the first attendance at ID clinic? Was the counselling not informative enough for them to understand their medical condition? Did they really understand the implications of being infected with HIV and the need for early treatment?

At present, there is no standardised counselling material for counselling HIV positive donors at NBC. Therefore, the aim of this study was to improve HIV counselling by using a standard HIV Counselling Module for counselling HIV positive donors at NBC. In order

to assess donors' understanding on the information given to them during counselling, a HIV/AIDS questionnaire (HIV-KQ; M. P. Carey, Morrison-Beedy, & Johnson, 1997) was used to identify their knowledge about HIV/AIDS before and after the use of HIV Counselling Module. Then, the questionnaire scores for pre- and post-intervention were assessed, and their first attendance at ID clinic and KKKL after referral from NBC was traced. Donors who did not follow NBC referral were investigated further. Results from previous study reported that HIV-KQ is suitable to be used for low-literacy adults (Carey *et al.*, 1997). There were a number of studies have used the questionnaire successfully to identify level of HIV knowledge (Carey *et al.*, 2004; Hughes, 2011; Koh *et al.*, 2013; Morrison-Beedy *et al.*, 2003).

1.4 Protocol for the management and repeat testing of HIV reactive blood donors at National Blood Centre

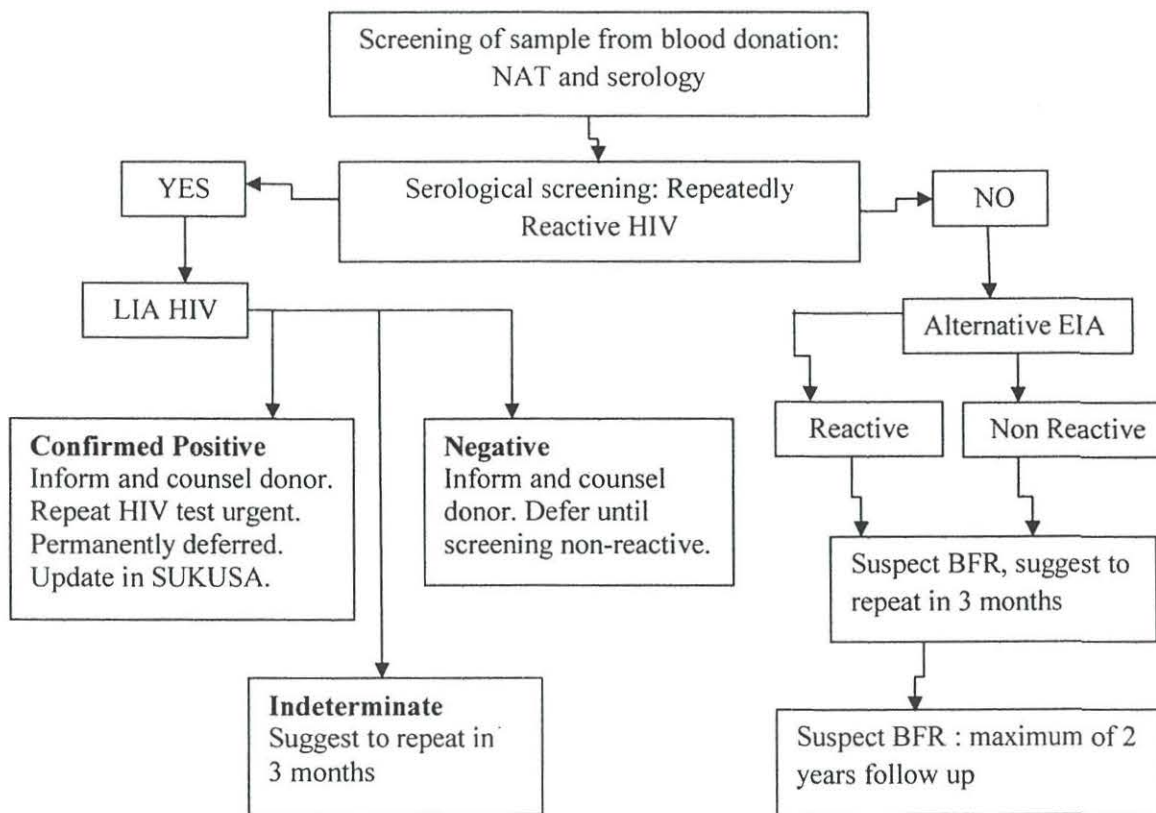


Fig 1.1: Algorithm of management of HIV reactive blood donor at National Blood Centre.

The test for HIV became available in Malaysia in 1986 and since then, it has been compulsory for all donated blood to be screened for HIV. Currently, the donated blood will be tested by serological and molecular test (nucleic acid testing, NAT*) before issuing the blood products to the patients. Firstly, the donated blood will be screened serologically for

HIV by using first analyser (Enzyme Immunoassay, EIA method) and molecularly (nucleic acid testing, NAT). EIA test is to detect antibodies/antigen to HIV. NAT is to detect genetic material (RNA) of HIV. Line Immunoassay (LIA) is the confirmatory test for HIV.

Further steps of serological test:

1. Blood donations found to be reactive to HIV from first analyser will be screened for the second time by using the second analyser (alternative EIA). This test is to detect antibodies/antigen to HIV.
2. If the screening result from the first analyser is reactive and the repeat test using the second analyser is non reactive, then the donor will be called to come to NBC to repeat the investigation (alternative EIA) by using fresh blood sample.
3. From the EIA result (regardless reactive or non reactive), the donor is suspected to be biological false reactive (BFR), because the initial screening result from the donated sample was repeatedly reactive. Then, donor is given appointment dates at fixed schedule to repeat further blood investigation for a maximum of two years.
4. If both screenings (first and second analysers) give reactive results to HIV, then LIA test will be done on the donated sample. This test is to detect antibodies to HIV.
5. If LIA is positive, then the donor will be called to NBC to repeat blood investigation. An urgent HIV test (alternative EIA) using fresh blood sample will be carried out to confirm that the reactive blood donation belongs to the correct donor. If the result of alternative EIA is positive to HIV, then the donor will be permanently deferred from blood donation and referred to ID clinic, HSB or

KKKL. Donor's particulars and medical information will be updated in 'Sistem Statistik Untuk Kutipan dan Saringan' (SUKUSA). The information in SUKUSA can be reviewed by all BTS centres in Malaysia, thus preventing the positive donor from donating blood elsewhere.

6. If LIA is negative or indeterminate, the donor will be called to NBC to repeat blood investigation (alternative EIA) using fresh blood sample. Alternative EIA may give positive, negative or indeterminate results.
7. Blood and blood products that are positive to HIV will be discarded per protocol.

* If the donated blood has a reactive NAT result and a non reactive serological result, the donor would be called to NBC to repeat HIV test (alternative EIA) using fresh blood sample.

1.5 Research justification and benefits

The doctors have been trained on counselling of blood donors. The training includes a one day course on Blood Donor Counselling and one day course on HIV update which are done annually. Every week one doctor will follow rotation to counsel donors at HIV reactive clinic. It is a fixed schedule at NBC so that each doctor has an exposure to counsel and manage donors with HIV positive. However, there is no counselling material available for the doctor to refer to for counselling HIV positive donors. Therefore, the information delivered to donors may vary. A different doctor might give different information to donors and might forget certain information. Donors may not

receive precise and adequate information about HIV infection. The issue is whether the information delivered to HIV positive donors during counselling at NBC is adequate and effective enough to increase their awareness of HIV/AIDS so that they will be adherent to the referral made to ID clinic or KKKL.

The use of an HIV Counselling Module is intended to standardise and improve the information delivered to HIV positive donors. It is important these donors understand their medical condition and its implications to their health, their spouses, blood donation programme and transfusion recipients. It is the responsibility of the BTS personnel to educate these reactive donors regarding HIV infection and to emphasize that they require follow up at ID clinic or KKKL for further care and treatment. The continuation of care would help to reduce the spread of HIV infection and thus the transmission of TTI. Thus, it is hoped that by having an HIV Counselling Module, more thorough information on HIV will be delivered to positive donors. It is assumed that they would then understand much better the importance of further care and treatment of HIV/AIDS, and so be adherent to referral to ID clinic, HSB and KKKL.

1.6 Research objectives

1.6.1 General objective

To assess the effectiveness of standardised counselling information on HIV positive donors at National Blood Centre between 12th September 2016 and 28th February 2018.

1.6.2 Specific objectives

1. To determine the difference of knowledge scoring before and after counselling among HIV positive donors.
2. To determine the association between knowledge score (after – before counselling) and first attendance to clinic appointment among HIV positive donors.
3. To identify factors associated with non-adherence to first appointment at ID clinic and KKKL appointment among HIV positive donors.

1.7 Research hypothesis

- i) There is a significant difference of knowledge scoring between before and after counselling among HIV positive donors.
- ii) There is a significant association between knowledge score (after - before counselling) and first attendance to clinic appointment among HIV positive donors.
- iii) There are significant associated factors for non-adherence to first appointment at ID clinic and KKKL among HIV positive donors.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

A BTS is a fundamental element of a health-care system in the management of patients. Individuals who donate their blood contribute to saving lives and improving patient health. It is the responsibility of the BTS to build and maintain a pool of safe, voluntary non-remunerated blood donors in order to provide a safe and sufficient blood supply. Blood donors should be provided with high standards of care and assurance of their health and safety (WHO, 2014). In the present time, it is realized that to prevent TTI, the role of blood donor education along with notification and counselling of donors about their seroreactivity is of major importance for blood safety. Research suggests that it should be compulsory for all BTS to follow up reactive donors as these donors are usually asymptomatic and likely pose greater risk to the community at large. The process of notification and disclosure of results should be standardized. A unique identification number and identity proof for each individual donation should be mandatory as this can help to search the donors for traceability purpose (NBC, 2016; WHO, 2012).

The primary responsibility of the BTS is to ensure a safe blood supply and to protect the health of blood donors and blood recipients. The BTS has an obligation to blood donors to ensure the notification of positive test results, to conduct appropriate counselling sessions and refer them to a physician accordingly. All relevant information should be provided to donors. The BTS should give assurance to donors that all personal information they

provide, particularly those related to health and exposure to TTI risks are kept confidential. During counselling of donors positive to TTI, the blood donor is strongly advised to inform his/her sexual partner(s) regarding the positive test results for instance HIV or other TTI. Donors with HIV positive status should be referred to a centre which provides specialized counselling and treatment for them and be able to help in partner counselling (UNAIDS/WHO, 2000; WHO 2012).

2.2 What are HIV and AIDS?

The HIV epidemic arose from zoonotic infections with simian immunodeficiency viruses from African primates. To date there are two types of HIV; HIV-1 and HIV-2. HIV-1 was transmitted from apes and HIV-2 from sooty mangabey monkeys (Maartens *et al.*, 2014). HIV-1 is the cause of the global HIV pandemic and is known to cause AIDS. The marked genetic diversity of HIV-1 is a consequence of the error-prone function of its reverse transcriptase, which results in a high mutation rate. HIV-2 is less transmissible and causes a similar illness to HIV-1, but immunodeficiency advances more slowly and is largely restricted to west Africa (Sharp *et al.*, 2011). AIDS is a conglomerate of signs and symptoms arising from the development of opportunistic infections and unusual tumours which arise as a result of a failing immune system. Management of HIV infection will necessitate a prolonged period of follow-up and monitoring of these HIV-infected individuals because of the chronicity of the infection and the social stigma associated with AIDS (MOHM, 2011).

HIV is not able to survive well outside the human body, thus it cannot be acquired through casual daily contact. HIV is not transmitted by mosquitoes and other insects. HIV is transmitted from one person to another by sexual intercourse with an infected person, by sharing sharp instruments such as needles, syringes or any sharp/ injecting equipment. HIV is able to survive in donated blood, and thus can be transmitted through blood transfusion. However, this route of transmission is less common (and now has become very rare in countries where blood is screened for HIV). HIV infected women who are pregnant can transmit the virus to the babies during pregnancy or delivery or through breastfeeding after birth (Md. Abdul Goni and Md. Mahfuzur Rahman, 2012).

HIV infection is a chronic infection which causes immune dysfunction. The HIV will attach to the CD4 receptors on T-helper Lymphocytes and other cells with CD4 molecule upon entry into human body (Sharp *et al.*, 2011; MOHM, 2011). The virus then enters into the cell and incorporates itself into the cellular genome eventually destroying the cell. The numbers of CD4 cells will progressively decline because of reduced production and increased destruction (Sharp *et al.*, 2011). The body's defence system will be compromised. This situation activates opportunistic organisms to cause life-threatening infections (MOHM, 2011). HIV infected individuals can develop other signs and symptoms such as swollen lymph nodes, weight loss, fever, diarrhoea and cough as the infection progressively weakens the immune system. They could also develop severe illnesses such as tuberculosis, cryptococcal meningitis, and cancers such as lymphomas and Kaposi's sarcoma, if they fail to receive appropriate treatment (MOHM, 2011).

2.3 The situation of HIV and AIDS: Malaysia and global (The main references : MOHM, 2015 and WHO, 2018)

The first case of HIV was reported in Malaysia in 1986. Since then, HIV has become one of the country's most serious health and development challenges (Talib, 2006). The infection rate of HIV in Malaysia remains high exceeding 5% among key populations which include people who inject drugs, female sex workers, transgender and men who have sex with men population (MOHM, 2015). Previously, drug addicts contributed the highest proportion of HIV infections in Malaysia; however, there is now an increasing trend to HIV infection via sexual transmission among key populations and their close sexual partners, including people who inject drugs, sex workers, men who have sex with men and transgender persons. The proportion of new infections transmitted by sexual activity has been edging up almost to 80% of the annual total by 2015, including sexual transmission with the partners of people who inject drugs (MOHM, 2015).

Since the first case of HIV was reported in Malaysia in 1986 until the end of 2014, the collective number of HIV infection had been 105,189, the AIDS cases 21,384, AIDS-related deaths 17,096 and the number of people living with HIV and alive at the end of 2014 was 88,093. Currently the HIV infection rate has come down by half. In the year 2000, the rate was 21.8 per 100,000 populations and it has declined to 10.9 per 100,000 populations in 2009. The distribution of reported new HIV cases by age group in Malaysia shows that about 35% of infections are among young people between 13-29 years of age, and around 55% among adults aged between 30-49 years in 2014 (MOHM, 2015). The

eligible age for blood donation in Malaysia is between 17 to 70 years old, thus contributing to increased number of new HIV infection among young and adult age population (NBC, 2016).

According to the World Health Organization (WHO), there were approximately 36.7 million people worldwide living with HIV/AIDS and about 1.8 million individuals became newly infected with HIV in 2016. HIV has affected more than 35 million lives and 1.0 million people have died due to variable causes related to HIV. In 2015, the rate of new infections was estimated at about 44% occurred among key populations and their partners. They include people who inject drugs, men who have sex with men, people in prisons, sex workers and their clients, and transgender people. It is estimated only 70% of people with HIV are aware of their status currently. There is no curative treatment for HIV infection so far. However, antiretroviral drugs (ART) which can control the viral replication and help prevent the spread of HIV are now available, thus people with HIV are able to enjoy optimal quality of life. Between 2000 and 2016, the rate of new HIV infections has decreased by 39%, and ART has saved 13.1 million lives with HIV-related deaths fell by one third. This accomplishment was the result of great efforts by national HIV programmes carried out globally (WHO, 2018).

2.4 Burden of HIV on the blood donor and blood transfusion service

The selection of blood donors from lower risk people is essential in order to ensure a sufficient and safe blood supply (WHO, 2004). Lower risk refers to voluntary, regular, and

unpaid blood donors (WHO, 2017). Blood donated by voluntary donors are selected according to strict criteria to reduce risk of contamination with infectious diseases, including HIV (Chaurasia *et al.*, 2014; WHO, 2014). Notification of donors' infectious status and post-donation counselling for reactive donors are crucial aspect of the BTS (Kotwal *et al.*, 2015). Notification of a blood donor about the abnormal test results is a very sensitive and vital aspect of post-donation counselling because it has a huge impact on psychological state and social situation of an individual. Each donor reacts differently ranging from being calm, to being aggressive, and denial behaviour (WHO, 2014; Canadian Aboriginal AIDS Network, 2012).

BTS plays a major role in managing blood donors with positive TTI markers (Roshan *et al.*, 2009) and in counselling them about the TTI and referring them to clinicians for further management and care (Sachdev *et al.*, 2015; WHO, 2014). Such donors are not allowed to donate blood in the future. Permanent deferral of donor from blood donation is to ensure safety of the blood recipient (Dontula *et al.*, 2011; WHO, 2014). An individual's self-esteem may be affected badly when being rejected from blood donation. For a person to be confirmed positive to TTI markers, he or she will experience stigma, silence, denial and discrimination. The BTS is responsible to preserve a supportive environment to reactive donors in which there is no stigmatization or discrimination towards them. The BTS also should encourage donors to disclose their infectious status to his or her sexual partner(s). It is an ethical obligation for the donor to do so. The referral centre will also be able to assist an HIV positive person in informing their partner (Canadian Aboriginal AIDS Network, 2012; WHO 2014).

2.5 Burden of HIV on society and the economy

HIV and AIDS are a major public-health problem worldwide and unfortunately, it is mostly young people at the most productive part of life that is affected. This health-hazard causes weakening of the most productive segment of the population in society. It results in negative implications on the economy and social construction of any nation or country (Ghailan *et al.*, 2010). The HIV/AIDS pandemic intensely impairs the employment of an individual, workers productivity, education of children living with HIV/AIDS affected people, and extra care work in AIDS-affected households (International Labour Organization 2018). HIV infected individuals may face loss of job and loss of earnings due to inability to work because of HIV illness (United Nations Country Team, Malaysia 2014). This infectious threat causes a global economic challenge in South East Asian countries, including Malaysia. The immediate effect is the reduction of government assets as considerable finances are diverted to the health division (UNDP, 2011).

The health care costs have progressively increased because of the rising number of HIV cases on therapy, therefore they have longer survival time, resulting in increased costs of HIV related medical care such as HIV medications and treatment for co-morbid conditions (Ritchwood *et al.*, 2017). In Malaysia, about RM186 million was spent on HIV/AIDS related activities in 2013 which include activities on prevention, care and treatment for out/inpatient, orphans and children, programme coordination, human resources, social protection and services and research purposes. The cost has increased to RM196 million in 2014 (MOHM, 2015). About USD19 billion has been invested in HIV related therapy

globally; and it is predicted that about USD25-26 billion per year is required through to 2030 to execute prevention programmes and care in the future (Max Roser and Hannah Ritchie, 2018).

2.6 Knowledge on HIV/AIDS among blood donors

It is postulated in developing country, most of the people do not have adequate information about the significance of blood test prior to blood donation and majority of blood donors have poor knowledge about HIV/AIDS. Poor knowledge about HIV/AIDS among blood donors might increase risk of disease transmission to others if this knowledge gap is not properly tackled (Md. Abdul Goni and Md. Mahfuzur Rahman, 2012). Existing literature shows that there is HIV positive individuals who keep engaging in dangerous lifestyles despite knowing their status. HIV-related educational programmes must emphasize on giving precise information including correcting misconceptions about HIV transmission. This is an important strategy in order to encourage behaviour change (Hong *et al.*, 2012).

Previous studies in Bangladesh revealed that the majority of participants had heard of HIV/AIDS, however, they did not have satisfactory understanding about the disease such as the risk factors of HIV/AIDS, routes of transmission, its relation with STI and the complications of the disease (Md. Abdul Goni and Md. Mahfuzur Rahman, 2012, Sultana, 2009). Studies on HIV/AIDS-related knowledge were done among adults in Malaysia

(Wong *et al.*, 2008; Zulkifli and Wong, 2001); however these studies did not focus on blood donors. Wong *et al.* described that the HIV/AIDS knowledge was moderate among the participants whereby misconceptions about HIV/AIDS were still present even though knowledge on transmission and prevention was accurate generally. Zulkifli and Wong also concluded that there were misconceptions about HIV/AIDS among respondents despite high scoring on transmission and prevention. HIV/AIDS is one of the incurable diseases that does not have definitive cure so far, thus enhancing the awareness about HIV/AIDS among the blood donors is one strategy to reduce the transmission of the disease. Knowledge on HIV transmission among HIV-positive individuals is crucial to reduce risk of worsening infection and also to put a stop to continuous spread of the disease (Hong *et al.*, 2012).

2.7 Factors that influence non-adherence to clinic appointment or treatment

Non-adherence to clinic appointments has been associated with poor HIV outcomes. Previous studies have shown that patients who fail to follow HIV clinic appointments are more likely to present with an advanced state of the disease, and have higher morbidity and mortality (Jones *et al.*, 2013). According to Lignani *et al.*, they found that factors such as medication side-effects, education level and age were also identified as significant predictors of non-adherence with HIV therapy (Lignani *et al.*, 2001).

Dyrehave *et al.*, reported that poor adherence to treatment is one of the most important barriers to the effectiveness of HIV therapy in Africa. A number of factors may

compromise patients' adherence especially in resource-limited settings. Among the contributing factors are discontinuous drug supply, fear of stigmatization, location of the clinic far from patient's residence, transportation problems to clinic, starvation, side effects of treatment, and poor access to correct health information (Dyrehave *et al.*, 2015). The attitude of non-adherence results in continuous viral transmission, worsening illness, more difficult management, unsuccessful treatment, unsure prognosis, increased burden to healthcare cost, and increased morbidity and mortality (Hansana *et al.*, 2013). Counselling may help patients build up an understanding of their illness and its management, prepare patients to start treatment, and to face its challenges, and assist them to develop a good attitude towards the treatment's plan (MOHM, 2011; WHO, 2014).

It is important to recognize the associated factors of poor adherence to HIV clinic appointments because this could assist the development of interventions that might reduce the viral transmission and optimize the benefits of treatment (Jones *et al.*, 2013). Knowledge on health related issues contributes significantly to one's health status. Literacy on HIV-specific health information may impact the attitude and motivation of patients to acquire and utilize the information to maintain their health. It is postulated that individuals with low health literacy may have less knowledge about the disease, signs and symptoms, and they probably understand less about the importance of preventive medical care and routine laboratory investigations (Dyrehave *et al.*, 2015; Wolf *et al.*, 2005)