KNOWLEDGE AND ATTITUDE REGARDING CORD BLOOD BANKING AMONG ANTENATAL MOTHERS IN HOSPITAL UNIVERSITI SAINS MALAYSIA: A QUASI-EXPERIMENTAL STUDY

by

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Dissertation submitted in partial fulfilment of the requirements for the degree of Bachelor of Health Sciences (Nursing)

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DECLARATION

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

CERTIFICATE

This is to certify that the dissertation entitled "Knowledge and Attitude Regarding Cord Blood Banking among Antenatal Mothers in Hospital Universiti Sains Malaysia: A Quasi-Experimental Study" is the bonafide record of research work done by Song Hui Sang, Matric Number: 108669 during the period of September 2013 to June 2014 under my supervision. This dissertation submitted in partial fulfillment for the degree of Bachelor of Health Sciences (Nursing). Research work and collection of data belong to Universiti Sains Malaysia.

Supervisor,

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LIST OF ABBREVIATIONS

GvHD	-	Graft-versus-host disease
HLA	-	Human Leukocyte Antigen
Hospital USM	-	Hospital Universiti Sains Malaysia
HREC	-	Human Research and Ethic Committee
UCB	-	Umbilical Cord Blood
CBB	-	Cord Blood Banking
WHO	-	World Health Organization

ABSTRACT

KNOWLEDGE AND ATTITUDE REGARDING CORD BLOOD BANKING AMONG ANTENATAL MOTHERS IN HOSPITAL UNIVERSITI SAINS MALAYSIA: A QUASI-EXPERIMENTAL STUDY

Background: Umbilical cord blood can be used for therapy in certain malignant and non-malignant diseases by replacing defect or abnormal cells of bone marrow. Thus, cord blood banking for future therapy potential has been recommended; however, there are few references on this subject in the literature. The aim of this study is to investigate the effectiveness of the health education intervention on antenatal mothers' knowledge and attitude regarding cord blood banking (CBB) in Hospital Universiti Sains Malaysia (Hospital USM).

Methods: The population for this study was 60 antenatal mothers that were admitted in the obstetrics wards: 30 from 2 Akik (Experimental Group); and 30 from 2 Baiduri (Control Group) in Hospital Universiti Sains Malaysia (Hospital USM). The research design was a quasi-experimental and utilized both pre- and post-intervention. The time interval between the pre- and post-samples were a week to test the effectiveness of the intervention using a structured patient education brochure and video clip on knowledge and attitude regarding cord blood banking among antenatal mothers in Hospital USM.

Results: The result showed that there is a higher knowledge level in intervention group as compared to control group (p value <0.001). There is also a higher attitude score regarding cord blood banking (CBB) in intervention group compared to control group (p value=0.041). In addition, there is a significant difference in the pre and post-test score of attitude regarding cord blood banking (CBB) in intervention group, indicating that the structured patient education brochure and assisted video clip regarding CCB is effective in enhancing knowledge and attitude. Educational level was found to be significantly associated to pre-test knowledge level with p-value=0.045 whereas number of children was significantly associated to pre-test attitude level with p-value=0.028.

Conclusion: This study reflects that antenatal mothers' knowledge toward cord blood banking is low eventhough the attitude is positive. It also proves that knowledge of the antenatal mothers can be enhanced by patient education via brochure and video. Thus, there is a need to promote CCB knowledge and UCB uses in medical field to create awareness and encourage practice among antenatal mothers in future.

Keywords: Antenatal Mother, Attitude, Brochure, Cord Blood Banking, Knowledge, Stem Cells, Umbilical Cord Blood, Video

ABSTRAK

Pengetahuan dan Sikap terhadap Penyimpanan Darah Tali Pusat dalam kalangan Wanita Hamil di Hospital Universiti Sains Malaysia: Kajian Quasi-Experimen

Latar Belakang: Darah tali pusat boleh digunakan sebagai perawatan untuk penyakit malignan dan bukan malignan tertentu dengan menggantikan kecacatan atau sel-sel tidak normal sum-sum tulang. Jadi, perbankan darah tali pusat untuk potensi terapi masa depan telah diperkenalkan;. Walau bagaimanapun, terdapat beberapa rujukan sahaja mengenai perkara ini dalam kesusasteraan. Tujuan kajian ini adalah untuk melihat keberkesanan intervensi pendidikan kesihatan terhadap pengetahuan dan sikap ibu hamil 'mengenai saraf perbankan darah tali pusat di Hospital Universiti Sains Malaysia (Hospital USM).

Kaedah: Populasi bagi kajian ini adalah 60 orang ibu hamil yang menerima rawatan dalam wad obstetrik : 30 daripada 2 Akik (Kumpulan Eksperimen) dan 30 daripada 2 Baiduri (Kumpulan Kawalan) di Hospital USM. Reka bentuk yang digunakan adalah kuasi – eksperimen. Masa antara pra dan pasca kajian adalah seminggu untuk menilai keberkesanan intervensi menggunakan risalah dan video klip terhadap pengetahuan dan sikap mengenai darah tali perbankan dalam kalangan ibu-ibu antenatal di Hospital USM.

Keputusan: Keputusan menunjukkan bahawa pengetahuan terhadap penyimpanan darah tali adalah lebih tinggi(selepas pendidikan pesakit dijalankan) berbanding kumpulan kawalan ($p<0.001$). Sikap mengenai perbankan darah tali pusat menunjukkan perubahan yang ketara ($p = 0.041$) . Selain itu, terdapat perbezaan yang ketara di antara pengetahuan dan sikap sebelum dan selepas intervensi mengenai penyimpanan darah tali pusat dalam kumpulan intervensi , menunjukkan bahawa risalah pendidikan pesakit berstruktur dan klip video mengenai penyimpanan darah tali pusat adalah berkesan dalam meningkatkan pengetahuan dan sikap. Tahap pendidikan telah didapati berkaitan ketara dengan tahap pengetahuan (p- value = 0.045) manakala bilangan anak didapati berkaitan ketara dengan tahap sikap (p- value = 0.028).

Kesimpulan: Kajian ini menggambarkan bahawa pengetahuan ibu hamil terhadap penyimpanan darah tali pusat adalah rendah walaupun sikap positif. Ia juga membuktikan bahawa pengetahuan wanita hamil boleh dipertingkatkan dengan pendidikan pesakit

melalui risalah dan video itu. Justeru, pengetahuan penyimpanan darah tali pusat dan kegunnaan darah tali pusat dalam bidang perubatan adalah penting untuk mewujudkan kesedaran dan menggalakkan amalan dalam kalangan wanita hamil pada masa depan.

Kata kunci: Wanita Hamil, Sikap, Risalah, Penyimpanan Darah Tali Pusat, Pengetahuan, Sel Stem, Darah Tali Pusat, Video

CHAPTER 1 INTRODUCTION

1.1 Introduction to the chapter

Cord blood banking (CBB) has become more common. According to Palten and Dudenhausen (2010), UCB can be used for therapy in certain malignant and non-malignant diseases by replacing defect or abnormal cells of bone marrow. When discussing the CBB, scientists have indicated that stem cell research is one of the most important and controversial topics of science and technology today (Palten & Dudenhausen, 2010).

The researcher was interested in what antenatal mothers know about CBB and their attitudes on CBB. Hence, prompted the conduct of this research proposal. The introductory section of this chapter is followed by a presentation of background information on the CBB and stem cell transplantation. The problem statement, research objectives (general and specific objectives), research questions, hypotheses, and significance of the study. This chapter concludes with the definition of terms used in this study and the outline of the thesis.

1.2 Background of the Study

Thirty years ago, umbilical cord blood (UCB) was discarded without much consideration. Similarly for thousands of babies born at that time, UCB has been just a delivery room regular clinical waste. At that time, there was no such thing as cord blood banking and none had even heard of haematopoietic stem cell transplant (Lau, 2013) . Then in 1988, a whole new concept utilizing UCB when the first transplant with UCB took place for a patient with Fanconi's anaemia, in France (Gluckman et al., 1989).

UCB has attracted both public and private interests. It has been increasingly used to treat life-threatening immune system disorders and blood diseases, including leukaemia, sickle cell disease and thalassaemia (Frangoul et al., 2010). Recognized and proven to have therapeutic potential, people have started to realize the importance of preserving and

storing cord blood. The hematopoietic stem cells which can be found in the UCB and the placenta offer mankind an alternative for the treatment which was previously much depended on bone marrow transplantation (Brunstein et al., 2010).

In addition, as compared to bone marrow, the advantages of UCB stem cells include ease of collection and availability, no risk to the donor either the mothers or newborn and most importantly does not possess safety and ethical issues (Ariffin, 2009). UCB stem cells are safer because they do not present with as much antigens as in adult stem cells that mark them as foreign, trigger an immune response, and eventually rejecting them. The ability of using minimally matched human leukocyte antigen (HLA) has put the UCB transplantation a favorable method of transplant over bone marrow transplant especially among the paediatric patients.

There are two ways that the cord blood can be stored either in a public cord blood bank or private cord blood bank. If cord blood is cyopreserved publicly, it is considered donated and the bank covers the costs (O'Connor, Samuel, Jordens, & Kerridge, 2012). Whereas, storing the blood in private bank means that the parents need to pay for a fee in order to get it reserved for the child itself (autologous use) or for a family member(related use) (O'Connor et al., 2012). Cord blood in public cord blood bank can be used by anyone in need of a transplantation of stem cells(allogeneic use) (O'Connor et al., 2012).

1.3 Problem Statement

Stem cells are master cells that can form almost any tissue in the human body. Today, one of the most important, at the same time, the most controversial topics of science and technology is stem cells research (Negrin, 2005). Scientists believe that research in this area holds hope for the treatment of many devastating diseases. This significant scientific breakthrough has the potential to revolutionize the practice of medicine and improve the quality and length of life (De Back, 2001). However, most of the pregnant mothers had inadequate knowledge about stem cells and cord blood banking. Studies in the U.S, Canada,

and Switzerland found that women wanted to be informed so that unbiased decision can be made (Danzer, 2003; Fernandez, 2003; Fox et al., 2007; Perlow, 2006).

According to Palten and Dudenhausen (2010), women are believed to overestimating the chances that their child would develop an illness that is treatable with his or her own cord blood or with a sibling's cord blood. According to Medical Defence Malaysia director, Dr Milton Lum, who is also a consultant obstetrician and gynaecologist, private UCB banking would be relevant for families with high risk of blood disorder but these cases are very rare. Most families will never need autologous UCB transplantation (Goh, 2013).

In addition, they are also uninformed about the different methods of transplantation namely autologous, related and allogeneic. Moreover, women also overestimated the chance of finding cord blood in a private bank in case it is needed and misconceived the potential use of UCB when stored in public bank (Palten & Dudenhausen, 2010). Despite UCB is a rich source of hematopoietic progenitor cells (HPC) that are both used in lieu of bone marrow to treat hematologic and oncologic disorders in children and adult, people still believed that using their own child's cord blood is more reliable and definitely be compatible for transplantation. For this reason, they overlooked the possibility of another child's cord blood might be suitable too (Palten & Dudenhausen, 2010).

Palten and Dudenhausen (2010) reported that the majority of the women who heard about CBB obtained information from mass media and had seen the material distributed by private banks. This is presumably because private banks are "advertising" and they used the "selling" a technique (Palten & Dudenhausen, 2010). Therefore, nurses need to equip themselves with accurate information to educate and guide patient in this new concept of stem cell utilization and cord blood banking (Dinç & Sahin, 2009).

A study by Nayar et al., (2004) found that, while feeling confident in making an anticipatory decision about cord blood banking, women expressed a clear desire to learn

much more about the collection, storage, and use of umbilical cord blood banking (Nayar, Deka, Paul & Takkar, 2004).

A study conducted in 2010 among 300 German speaking pregnant women in Berlin to know whether a correlation between women's knowledge about umbilical cord blood banking and level of education. The data collected by using anonymous questionnaire. Among them, three quarters of the population heard of umbilical cord blood banking, most had no further knowledge about the method. Only one third of the interviewed women was informed about whether certain diseases had been treated with umbilical cord blood banking by the time the survey was being conducted, whereas 50-60% did not know how to answer these questions (Palten & Dudenhausen, 2010).

In this study, the theories of reasoned action and planned behavior are used. It was developed by Ajzen and Fishbein to explain human behavior that is under voluntary control (Nutbeam & Harris, 2002). The main assumption underlying this theory is that people are often rational and will make predictable decision. It also suggested that the intention to act is the most immediate determinant of behavior (Nutbeam & Harris, 2002).

1.4 Research Objective

In conducting a research plan, the most important step is to write the research objectives. According to Polit and Beck (2010), formulating aims and objectives of a research study helps shape and guide the researcher's work after a study topic is decided that should be closely related to the statement of the problem and summarize what the researchers hope to achieve by the research study.

1.4.1 General Objective

To study the effectiveness of the health education intervention on antenatal mothers' knowledge and attitude regarding cord blood banking (CBB) in Hospital Universiti Sains Malaysia (Hospital USM).

1.4.2 Specific Objectives

a) To compare:
   i. The pre and post-test knowledge score between control and intervention group regarding cord blood banking (CBB) in Hospital USM.
   ii. The pre and post-test attitude score between control and intervention group regarding cord blood banking (CBB) in Hospital USM.

b) To determine the effectiveness of intervention using a structured patient education brochure and assisted video clip regarding CBB by assessing post-test knowledge and attitude of antenatal mothers.

c) To determine the association between pre test knowledge and attitude scores regarding cord blood banking and selected socio-demographic variables (age, the number of pregnancies, number of children, educational level, and perceived income level.

1.5 Research Questions

The research questions for this study are:

a. What is the level of knowledge about cord blood banking among antenatal mothers in Hospital USM pre and post-intervention in control and intervention group?
b. What is the attitude about cord blood banking among antenatal mothers in Hospital USM pre and post-intervention in control and intervention group?
c. Is there any association of cord blood banking knowledge and attitude with selected socio-demographic variables of antenatal mothers in the control and the intervention group (age, number of pregnancies, the number of children, educational level and family income)?

d. Is the intervention using a structured patient education brochure and assisted video clip regarding CBB effective in enhancing patient's knowledge and attitude?

1.6 Research Hypotheses

1.6.1 Primary Research Hypothesis

Antenatal mothers who participate in the intervention study using a structured patient education teaching brochure and a video clip will have equal/lower/higher knowledge and attitude of cord blood banking when compared to antenatal mothers in the control group.

1.6.2 Secondary Research Hypotheses

Hypothesis 1 There is no significant difference in the pre and post-test knowledge score regarding cord blood banking (CBB) between control and intervention group in Hospital USM. (Ho)

There is a significant difference in the pre and post-test knowledge score regarding cord blood banking (CBB) between control and intervention group in Hospital USM. (H_A)

Hypothesis 2 There is no significant difference in the pre and post-test attitude score regarding cord blood banking (CBB) between control and intervention group in Hospital USM. (Ho)

There is a significant difference in the pre and post-test attitude score regarding cord blood banking (CBB) between control and intervention group in Hospital USM. (H_A)

Hypothesis 3 : There is no significant difference between the mean pre-test and post-test knowledge scores of antenatal mothers' knowledge level with intervention in Hospital USM. (Ho)

There is a significant difference between the mean pre-test and post-test knowledge scores of antenatal mothers' knowledge level with intervention in Hospital USM. (H_A)

Hypothesis 4 : There is no significant difference between the mean pre-test and post-test attitude scores of antenatal mothers' attitude level with intervention in Hospital USM. (Ho)

: There is a significant difference between the mean pre-test and post-test attitude scores of antenatal mothers' attitude level with intervention in Hospital USM. (H_A)

Hypothesis 5 : There is no significant association between the pre-test scores of antenatal mothers' knowledge and selected socio-demographic variables (age, number of pregnancies, the number of children, education level and perceived income level) regarding cord blood banking in Hospital USM. (Ho)

There is a significant association between the pre-test scores of antenatal mothers' knowledge and selected socio-demographic variables (age, number of pregnancies, the number of children, education level and perceived income level) regarding cord blood banking in Hospital USM. (H_A)

Hypothesis 6 : There is no significant association between the pre-test scores of antenatal mothers' attitude and selected socio-demographic variables (age, number of pregnancies, the number of children, education level and perceived income level) regarding cord blood banking in Hospital USM. (Ho)

There is a significant association between the pre-test scores of antenatal mothers' attitude and selected socio-demographic variables (age, number of pregnancies, the number of children, education level and perceived income level) regarding cord blood banking in Hospital USM. (H_A)

1.7 Definitions of Operational Terms

Assess - It is a statistical measurement of cord blood banking knowledge and attitude of antenatal mothers as observed by close-ended questionnaire.

Antenatal mothers - In this study, it refers to all pregnant mothers who attend the Antenatal Clinic/Antenatal Wards of Hospital USM.

Attitude - An attitude is defined as a learned, global evaluation of an object (person, place or issue) that influences thought and action (Perloff, 2010). In this study, it refers to views and opinion of pregnant women regarding cord blood banking.

Cord Blood - Cord blood is the blood found in the vessels of the umbilical cord and placenta (Ali & Al-Mulla, 2012). Cord blood has been also involved in therapeutic applications such as replacing bone marrow for hematology transplantation. In this study, it refers to the blood that remains in the placenta and the connecting umbilical cord from the fetus to the placenta.

Cord blood banking (CBB) - Cord blood banking is the practice of preserving for future use fetal blood that remains in the umbilical cord at the time of birth. There are two types of blood banks for collection and

storage of UCBB: public and private. In this study, it refers to the entire procedure of collecting blood from the umbilical cord after or before the placenta is removed and storing in a special kit.

Knowledge - Facts, information, and skills acquired by a person through experience or education; the theoretical or practical understanding of a subject (Oxford, 2013). In this study, knowledge refers to the level of awareness and understanding of the antenatal mothers regarding cord blood banking.

Patient education brochure - Brochure and video clip is a means of communication that can provide more information and patient resources in a somewhat more private manner. In this study, it refers to information that the patient needs to know about cord blood banking: definitions, and answers to frequently asked questions (Appendix 8)

Private cord blood bank The private bank is a commercial, for-profit entity that often advertises directly to expectant parents. These banks are designed for the sole use of the families who have saved the cord blood (Waller, 2011).

Public Cord Blood Bank - Public cord banks do not charge a fee to collect or store cord blood and thus parents has no ownership right (Fadel, 2009). In this study, it refers to parents of newborns donate the cord blood, and it is then available to anyone who needs it and is an appropriate match.

1.8 Significance of study

Cord blood is a biological insurance against diseases. The umbilical cord blood is a rich source of stem cells that can be derived from two sources: cord blood and cord tissue. Stem cell therapy has been successfully preformed worldwide. Human UCB provides an alternative cell source that is ethically acceptable and widely supported by the public (Fadel, 2009). As the use of autologous or allogeneic hematopoietic stem cell transplantation in the treatment of various diseases has grown rapidly in recent years, the concept of UCB banking for future use has drawn increasing interest (Lee, Jang, Yoo, Sung, & Koo, 2010). Scientists also speculate that cord blood stem cells could be used to revitalize a damage immune system, making them nearly as versatile as embryonic stem cells for treating immune disorders. Baby's cord blood is a valuable source of non-controversial stem cells and the benefits of cord blood collection saves lives (Lee et al., 2010). However, in Malaysia, it is still not widely being practiced. Often, mothers do not know the benefits of cord blood banking and stem cell therapy.

With the global birth rate exceeding 140 millions/year, umbilical cord blood can be considered as one of the most abundant sources of stem cells (World Health Organization, 2012). Besides that, it is a non-invasive collection procedure, umbilical cord blood stem cells also show higher proliferating potential and lower risk of graft-versus-host diseases (GvHD) in comparison with bone marrow transplantation (Ali & Al-Mulla, 2012; Ballen, Barker, Stewart, Greene, & Lane, 2008). It only takes a wise decision from the parents whether to store the cord blood or not.

There are differences in the frequency of certain Human Leukocyte Antigens (HLA) types among ethnic groups. The Human Leukocyte Antigens are proteins in the immune system that determine whether a patient will react against a donor transplant. Patients are believed more likely to find a good match among donors from their own ethnic group. For example, in America, African-American patients who need bone marrow transplantation are having a hard time finding an unrelated bone marrow donor due to minority and greater HLA varieties among them (National Cord Blood Program, 2010). With cord blood, a

partial match is acceptable and most African-American patients can find a suitable cord blood unit. Therefore, large public cord blood bank inventories can help make up for the difficulty in finding suitable bone marrow donors for minority patients.

On the other hand, the low number of stem cells per cord blood unit represents a limitation that is associated with delayed engraftment of these cells into host targeted tissues (Stanevsky, Goldstein, & Nagler, 2009). However, this obstacle can be tackled with the possibility of combining multiple cord blood units in order to increase the final transplanted cell dose resulting in improved engraftment and survival of the transplanted cells (Stanevsky et al., 2009). Thus, large public cord blood bank inventories are significant. According to the honorable Tan Sri Datuk Dr. Hj. Mohd Ismail Merican, the former Director General Ministry of Health, Malaysia, the establishment of cord blood banks in Malaysia is essential for all ethnic groups. However, there will be major challenges face over the next few years in supplying stem cells for treatment of patients in Malaysia. The (Ministry of Health, 2008). He asserted that parents need to be educated and understand about the stem cells in cord blood in treatment therapy.

The genesis of this research study was sparked by the researcher's interest in the practical challenges in examining the level of knowledge and attitude of the pregnant women about cord blood banking. The knowledge and attitude about cord blood banking among pregnant women is poorly defined in Malaysia. In addition, the researcher found that there is very little evidence from local study in Malaysia on UCB. Currently, there is limited study that investigates on this issue available for health care professionals, in particular, nurses. Thus, it is important for researcher to assess the level of knowledge and attitude of the pregnant women about cord blood banking so that they can meet the parents' need for information on this subject (Dinç & S¸ahin, 2009). With valuable finding of this research, perinatal care givers especially nurses and midwives in the hospital can provide effective and evidence based health education and counseling services to the patients.

1.9 Outline of the study

The research thesis consists of six chapters. Chapter One provides a presentation of background of the study related to mothers' knowledge and attitude regarding cord blood banking (CBB). This is followed by the problem statement, research objectives, research questions, hypothesis, significance of the study and definition of operational terms used in this thesis. Finally, the chapter concludes with the thesis structure. Chapter Two details, a review of the literature review which serves as the basis for generating the research questions and the Theory of Planned Behavior as the conceptual framework used in this study. Chapter Three describes the research methodology underpin the phase of the research study. Chapter Four outlines the results of the study. In Chapter Five, the discussion chapter, all the research information drawn from the research study is summarized and discussed with reference to the research questions and finding. Limitation and strength of the study are discussed at the end of this chapter. Chapter Six provides the conclusion and discussed the implications arising from this intervention study about mothers' knowledge and attitude regarding cord blood banking (CBB) in Hospital Universiti Sains Malaysia (Hospital USM).

CHAPTER 2 LITERATURE REVIEW

2.1 Introduction to the chapter

A literature review is a description of the literature relevant to a particular field or topic published by accredited scholars and researchers making a case for further investigation and research. The literature review highlight gaps in knowledge and questions that need to be answered. It allows the researcher to establish theoretical framework and methodology. In addition, the literature review provides an overview of the field of inquiry to the study (Taylor, 2013).

For this study purposes, the databases used in searching for relevant literature includes: Science Direct, Proquest, Wiley, Cumulative Index to Nursing and Allied Health Literature (CINAHL). The related literatures reviewed are grouped under the following headings: umbilical cord blood (UCB), options for cord blood banking(CBB), uses of UCB and knowledge and attitude of CBB among pregnant women. This chapter also details the theoretical framework guiding this study.

2.2 Umbilical cord blood (UCB)

Recently, the hospital has been routinely discarding blood that remained in the umbilical cord and placenta. However, studies show that both primitive hematopoietic stem and pluripotent progenitor cells are present in umbilical cord blood (Lee, Jang, Yoo, Sung, Koo, 2010) Thus, it can be used as a source for experimental and clinical application. Throughout the years, umbilical cord blood has been successfully used as an alternative to bone marrow in transplantation in order to treat various diseases.

For example, cord blood can be considered to treat pediatric and adult patients (Hwang, Samuel, Koh, Lim, & Linn, 2007) with hematologic malignancies and disorders such as leukemia (Eapen et al, 2007; Kurtzberg et al, 2008). In addition, it can also be used in treating bone marrow failures (Bizzetto et al, 2011), inherited metabolic disorders

(Prasad et al, 2008), immunological defects (Frangoul et al, 2010) and other genetic diseases.

There is always demand for compatible donors for patients in need of bone marrow transplants, but there is no available human leukocyte antigen (HLA) matched donors are found. Therefore, umbilical cord blood, which is a potential source of hematopoietic stem cells can be used. As the advancement of science, it serves an important alternative for stem cell transplantation. In addition, umbilical cord blood causes a relatively less chronic graft versus host disease (GvHD) as compared with bone marrow and peripheral blood progenitor cell donors.

More than 20,000 allogeneic cord blood transplantations have been performed since the first cord blood transplantation in 1988. The first cord blood transplantation was done in a patient from Paris, France with Fanconi anemia using an identical HLA matched sibling. Years later, the usefulness of umbilical cord blood as a source of stem cells for marrow reconstitution of HLA-matched siblings have now been extended to the unrelated-donor setting. This eventually emphasize the importance of umbilical cord blood banking for the transplantation in medical field.

According to Parco, Vascotto, and Visconti (2013), more than 780,000 cord blood units are stored in over 130 private cord blood banks worldwide, and over 400,000 are stored in more than 100 quality controlled public cord blood banks.

2.3 Options for cord blood banking (CBB)

The value of stem cells found in cord blood has been established, but the storage and access are still a big consideration. There are two options to store umbilical cord blood, namely public or private cord blood bank. Private cord blood banking is often advertised and promoted in media such as internet, television, brochures in antenatal clinics, and magazines. Healthcare providers need to be aware of the pros and cons of both private and public cord blood banking in order to better educate the patient.

2.3.1 Public Cord Blood Bank

Public cord blood bank's prime aim is to collect and store voluntarily donated cord blood to be used for any unrelated patient who may need a hematopoietic stem cell transplant. This procedure is done on the altruism of donors following an informed parental consent. Thus, the cord blood will belong to the public bank for later use. The inventory is registered and later searched by the public and healthcare providers to access information for transplantation sources. Prior to inclusion in the registry, samples are screened based on volume, cell number and tissue types, health history and infectious disease status.

For example, in Germany, relevant aspects of cord blood selection and collection, testing, storage and processing of releasing frozen cord blood units for use was reviewed by the Mannheim Cord Blood Bank. (Lauber, Latta, Kluter, & Muller-Steinhardt, 2010) This public cord blood bank was first established in 1996. It stores 1,750 cord blood units collected from seven hospitals from southwestern Germany. From 1996 to 2009, data were available on 7,921 collected samples and 2,014 were accepted for long-term storage for transplantation use. Most patients receiving cord blood for transplants suffered from hematological disorders particularly acute leukemias and the others were used for treating immune deficiencies such as severe combined immunodeficiency or metabolic diseases like Hurler syndrome.

The Malaysian first Public Cord Blood Bank, housed in the National Blood Bank, store cord blood units donated by volunteers (Zaleha, 2010). National Blood Bank (PDN) director Dr Roshida Hassan reported that the Malaysian Health Ministry currently has two cord blood banks; and the Cord Blood Unit was first founded in 2002 (Goh, 2013). A total of about 6,000 transplantable units aid were in the unit. There are two public cord blood bank in Malaysia: one in Kuala Lumpur and one in Alor Setar. In addition, there are four collection centres in the Klang Valley – Kuala Lumpur Hospital, Serdang Hospital, Selayang Hospital and Ampang Hospital. In Alor Setar, the collection centre is at the Sultanah Bahiyah Hospital (Goh, 2013).

2.3.2 Private Cord Blood Bank

Private cord blood banks collect blood samples and store the cord blood for personal use by the child or families (Hollands & McCauley, 2009). It becomes the property of the child under the guardianship of the parents. Since it is personal property, the blood samples are more expensive to collect and maintain in private banks as compared to public cord blood bank. Umbilical cord blood stored in private banks for future transplants for either the infant donor or related family members are not accessible or available to the public.

Despite private UCB banking being promoted as a safeguard against future malignancy or other life-threatening conditions, the controversy surrounding private banking of UCB raises many questions in pediatric clinical practice(Rosenthal et al., 2011). In most cases, stem cell transplant by using an individual's own cord blood is not recommended such as genetic disorders because the genetic mutations which cause these disorders are present in the baby's cord blood. Other diseases that are treated with stem cell transplant, such as leukemia, may also already be present in a baby's cord blood.

The European Commission's Group on Ethics in Science and New Technologies report on the ethics of private umbilical cord banking stated: "The legitimacy of commercial cord blood banks for autologous use should be questioned as they sell a service, which has presently, no real use regarding therapeutic options. Thus, they promise more than they can deliver. The activities of such banks raise serious ethical criticisms (M. Sullivan, Browett, & Patton, 2012).

Stanevskya, Goldsteinb, and Nagler (2009) suggests that autologous CB does not have recognized clinical advantage over standard bone marrow harvested stem cells. According to Sullivan (2008), out of 3372 UCB transplants in 1988-2007, 2965 were unrelated donors, 359 were related but only three were autologous.

The Society of Obstetricians and Gynaecologists of Canada suggested that Collection and long-term storage of umbilical cord blood for autologous donation is not

recommended because of the limited indications and lack of scientific evidence to support the practice (Armson, 2005).

2.4 Uses of Umbilical Cord Blood (UCB)

2.4.1 Hematology Disorders/ Oncology

According to Eapen et al. (2007), the treatment of malignancies by cord blood transplantation in children with acute leukemia is an acceptable alternative to bone marrow. It recorded the outcomes of 530 children with acute leukemia and transplanted with umbilical cord blood and then compared with outcomes of 282 bone marrow transplantations from the USA. In this study, about 7% of their recipients of umbilical cord blood were transplanted with Human Leucocyte Antigen (HLA)-matched graft while the remaining was mismatched for one or two antigens. There were 41% bone marrow recipients who were transplanted with grafts that were matched at an allele level for HLA-A, HLA-B, HLA-C, and HLA-DRB while 59% was mismatched. In comparison with allele-matched bone marrow transplants, 5 year survival in which the patient was leukemia-free, was similar with transplants of umbilical cord blood that was mismatched for either one or two HLA antigens. This showed that umbilical cord blood which are HLA-matched or one or two antigens HLA-mismatched can be used in treating children with acute leukemia.

In Eapen et al. (2010), patients receiving cord blood, peripheral blood progenitor cells, or bone marrow transplantation are compared in term of leukemia-free survival. Cord blood transplantation results showed that transplant mortality was higher with cord blood but acute and chronic Graft-versus-host disease (GvHD) incidence was lower than in those receiving peripheral blood. Chronic GvHD was lower with cord blood than bone marrow transplantation too. This study suggested that cord blood transplantation is an alternative when no HLA-matched unrelated donors are available for emergent transplantation situations.

Kurtzberg et al. (2008) first reported on the outcomes of unrelated donor cord blood transplantation in 191 children with hematologic malignancies. The median time for absolute neutrophil and platelets engraftment was 27 days and 174 days respectively. Acute GvHD III/IV by day 100 was 19.5% and 20.8% for chronic conditions. More than 50% of the patients requiring hematopoietic stem cell transplantation are unable to find a suitable adult stem cell donor within a short time, making donor availability a problem with effective antileukemic therapy. Banked umbilical cord blood is prospectively HLA typed, screened for infections and other risk factors, and is readily available for use in patients who cannot identify a matched related or unrelated donor. Unrelated donor cord blood transplantation from partially HLA-mismatched units can cure many children with leukemias.

2.4.2 Non-oncology

According to Frangoul et al. (2010), studies recorded their experience in using cord blood for non-oncology purposes namely in patient with primary immune deficiency (PID). This study reported the results on 24 children with PID. The median age in this study was 1 year and a median weight of 10.5kg for the 24 children with PID receiving unrelated cord blood units. All patients received identical graft versus host disease prophylaxis and supportive care. Neutrophil engraftment by day 42 was 58% with a probability of survival at 180 days of 67% and 63% at 1 year. Nine of their 24 children experienced graft failure and three patients died. They proposed that unrelated cord blood transplants should be considered for children with PID. Lastly, they concluded that cord blood transplant has the potential advantage of more readily available donor samples that can be searched or accessed rapidly through international registries with a lower risk for viral contamination or other infectious agents in screened cord blood specimens, and with lower risks for graft versus host disease permitting less stringent HLA matching.

In Prasad et al. (2008) survey they summarized the outcomes of 159 young patients with inherited metabolic disorders undergoing unrelated donor umbilical cord blood transplantation. Inherited metabolic disorders such as lysosomal and peroxisomal storage diseases are known to have progressive organ failure and early death. In the past 25 years, there is nearly a thousand patients with metabolic storage disorders have received allogeneic hematopoietic stem cell transplantation using bone marrow. The missing enzyme can be produced and replaced by donor cells circulating in the blood.

Prasad et al. (2008) studied on partially HLA-mismatched unrelated donor umbilical cord blood used for patients receiving myeloablative chemotherapy and cyclosporine-based prophylaxis. Of the 159 children in their report, the top five metabolic diseases were: Hurler syndrome (n = 45 patients); Krabbe disease (n = 36); Sanfilippo syndrome (n = 19); metachromatic leukodystrophy (n = 15); and adrenoleukodystrophy (n = 13). All grafted patients, except three, achieved donor chimerism of greater than 90% and all but four engrafted patients achieved and sustained normal enzyme levels relating to each specific metabolic disease when measurable in the blood. Their probability of 1 year survival in Hurler syndrome was 77%, Krabbe disease (74%), Sanflippo syndrome (79%), metachromatic leukodystrophy (65%) and adrenoleukodystrophy (77%). As anticipated, the children who underwent transplantation as newborns had better outcomes than those with progressive symptoms of the disease.

Bizzetto (2011) reported on 64 patients with hereditary bone marrow failure syndromes receiving cord blood transplants from related and unrelated donors. By 60 days, 95% of related cord blood transplants achieved neutrophil engraftment. All but one received HLA-matched sibling grafts. Two of the 20 receiving related grafts developed Grade II–IV acute GvHD and the 2 year incidence of chronic GvHD was 11%. Three year survival was 95%. Among those receiving unrelated cord blood transplants, 86% received HLA-mismatched grafts. Neutrophil recovery at day 60 occurred in 55%. Grade II–IV acute GvHD occurred in 24% by day 100 and the 2 year incidence of chronic GvHD was 53%. Overall survival at 3 years was 61%. This showed that HLA-matched sibling grafts

was much more efficient and caused less adverse effect as compared to unrelated cord blood transplants.

2.4.3 Cord blood derived stem cells and regenerative medicine

According to Navarrete and Contreras (2009), approximately 10,000 patients worldwide that are diseased with malignancies, bone marrow failure, hemoglobinopathies, inborn errors of metabolism and genetic or immune disorders have now received umbilical cord blood transplant. Throughout years of research and studies, cord blood stem cells have shown the potential to be able to differentiate into specialized cell type and thus produce useful specific body tissue. Other than hematopoietic stem cells, cord blood also contains endothelial cells, mesenchymal stromal cells, T-regulatory cells, dendritic cells and natural killer cells. All these cells are an important area to study in medicine because it allows potential new options for diseases or symptoms, including brain injuring, strokes, Parkinson's, Alzheimer's, Hungtinton and amyotrophic lateral sclerosis. There are still some other diseases in early stages of investigation, including liver disorders, diabetes, and myocardial infarction. The stem cells from cord blood are also targeted for orthopedic applications such as cartilage repair, spinal fusion and regenerative medicine.
However, it is still unclear if therapeutic efficacy relates to injured or pathologic cell replacement, growth factor and cytokine release from infused cells, or stimulation/regeneration of host stem cells.

2.5 Knowledge and Attitude Of UCB among Pregnant Women

Only very few studies worldwide deal with the views and education of pregnant women about UCB banking. Currently, there is only a dearth of studies conducted in the USA, Canada and in Germany (Fox et al., 2007; Palten & Dudenhausen, 2010; Perlow, 2006). All showed a general lack of knowledge among women regarding cord blood banking. The researchers highlighted in their study that the majority of the pregnant women had a lack of knowledge about stem cells and UCB; and wanted more information. They also indicated that women wanted the information before pregnancy and more from their

doctors and nurses. The majority of the women population also stated that they want to store their infants' cord blood and more likely choose a public cord blood bank largely due to the positive attitudes of the importance of UCB and the benefit from UCB (Perlow, 2006; Fox et al., 2007; Dinc & Sahin, 2009; Palten & Dudenhausen, 2010).

2.6 Health Education

Health education is any combination of learning experiences designed to help individuals and communities improve their health, by increasing their knowledge or influencing their attitudes (WHO, 2014). Health education is the profession of educating people about health (McKenzie, Neiger & Thackeray, 2009). Physical health, environmental health, emotional health, intellectual health, social health and spiritual health are areas within this profession. (Donatelle, 2009). It can be defined as the principle by which individuals and groups of people learn to behave in a manner conducive to the promotion, maintenance, or restoration of health. However, as there are multiple definitions of health, there are also multiple definitions of health education. The World Health Organization defined Health Education as comprising of consciously constructed opportunities for learning involves some form of communication designed to improve health literacy, including improving knowledge, and developing life skills which are conducive to individual and community health (WHO, 1998).

2.7 Conceptual Framework: Theory of Planned Behavior

This study was informed by the Ajzen and Fishbein's Theory of Planned Behavior (TPB). This theory explains that people are usually rational and will make predictable decisions in well-defined circumstances. The model suggests that intention to act is the most immediate determinant of behavior, and behavioral intention will influence behavior. Figure 2.1 shows how behavioral intentions are influenced by attitudes towards behaviors and subjective norms.

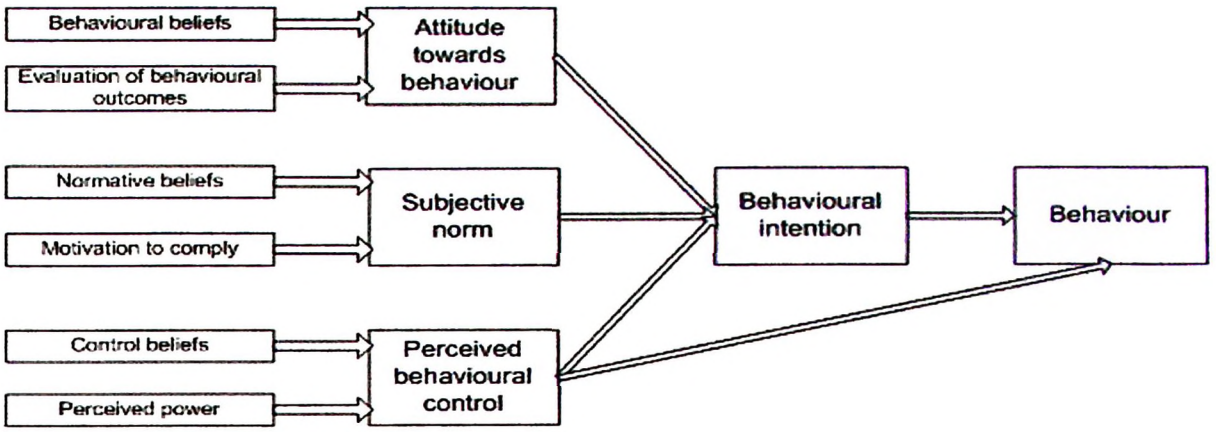

Figure 2.1 Ajzen and Fishbein's Theory Of Reasoned Action And Planned Behavior

Attitude, in this case is determined by the belief that a desired outcome will occur if a particular behavior and the outcome will be beneficial to health. For example, in this study, when a woman knows that cord blood is an alternative for bone marrow transplantation and there is less complication arises, she will most likely to donate cord blood so that more lives can be saved by using cord blood transplantation.

Subjective norms in this case relate to a person's belief about what other people think he or she should do (normative beliefs) and by an individual's motivation to comply with those other people's wishes. For example, if an individual is surrounded by a group of people who strongly support cord blood donation program, when she pregnant, she will most likely consider that there is a norm which favors such action. Ajzen and Fishbein take this analysis further by indicating subjective norms are most affected by significant others. These significant others include a person's valued peer, favorite celebrities who act as role models. Therefore, advertising cord blood banking with media celebrities can be one of the powerful instruments to promote such program.

Perceived behavioral control is third influence on the behavioral intentions. This supports that a person's intentions will become significantly greater if they feel they have greater personal control over a behavior. In making this adjustment, Ajzen recognized that there are many factors beyond the immediate control of individuals which will shape their

ability to behave in the desired way, hence proposed changing the name of the theory to the theory of planned behavior.

Figure 2.2 shows the adopted Theory of Planned Behavior of Ajzen and Fishbein, the conceptual framework guiding this study in relation to participation in the structured patient education with a brochure with information regarding cord blood banking (Appendix 8).

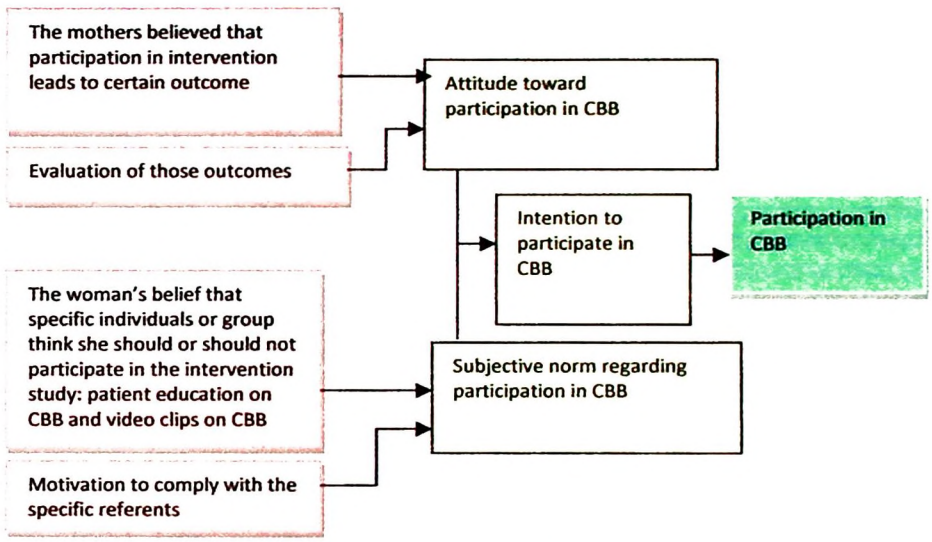

Figure 2.2 Ajzen and Fishbein's Theory of Planned Behavior: Influence of Knowledge, Attitude and Subjective Norm in Intent and Behavior
[Sources: Theory of Planned Behavior from Ajzen & Fishbein, (1980)]

CHAPTER 3 METHODOLOGY

3.1 Introduction to the chapter

Research methodology and method is a systematic way to solve the research problem. It defines the problem, hypotheses, and methods adopted for data collection. It also includes the statistical technique used for analyzing the data with logical reasoning (Polit & Beck, 2012).

In deciding on a methodology, the researcher kept in mind the following words from Polit and Beck (2012, p. 18), '... no single study can ever definitely answer a research question. Each completed study adds to the body of accumulated knowledge'. This chapter covers the research design and methodology, including sampling, population, establishing rigor during data collection, ethical considerations and data analysis. There is limited research into the assessment of pregnant women's knowledge and attitude regarding cord blood banking held by Malaysian nurses; hence leds to the researcher to conduct a quasi-experimental study. The aim of this study was to determine the effectiveness of CCB education via video clips and brochure and to assess the knowledge and attitude towards CCB among pregnant women in Hospital USM, Kelantan.

3.2 Research Design

The research design was a quasi-experimental and utilized both pre- and post-intervention. The time interval between the pre- and post-samples were a week to test the effectiveness of the intervention using a structured patient education brochure and video clip on knowledge and attitude regarding cord blood banking among antenatal mothers in Hospital Universiti Sains Malaysia (Hospital USM). This design provides an understanding of the effectiveness the intervention on cord blood banking knowledge and attitude.