



**Value Co-Creation using Activity Theory: Cord Blood  
Donor Recruitment in Hospitals**

تكوين القيمة المشتركة بالاستعانة بنظرية النشاط: استقطاب المتبرعين بدم  
الحبل السري في المستشفيات

by

**FATMA HUSSAIN ALHASHIMI**

A thesis submitted in fulfilment  
of the requirements for the degree of  
**DOCTOR OF PHILOSOPHY IN PROJECT MANAGEMENT**  
at  
**The British University in Dubai**

**August 2018**



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**Thesis Supervisor  
Professor Ashly H. Pinnington**

**Approved for award:**

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## ABSTRACT

Donor management involves major activities including recruitment, invitation, selection, and donation processes. Donor recruitment is one of the critical stages that ensures sufficient amounts of blood are received at blood collection sites. Donor recruitment and blood strategy management need to be researched according to the culture and social environment of the country concerned. Only a few studies have been conducted on a national scale on cord blood donor recruitment processes. Hematopoietic stem cells donations within public cord blood registries are highly important in Arab countries since, out of 20 million Hematopoietic stem cells (HSCs) donors registered globally, less than 50 are registered in the Arabian Gulf countries.

This thesis uses the conceptual resources of cultural-historical activity theory (CHAT) to identify potential mediating instruments between S-D logic and practice-based views. The research problem concerns how to combine these two views. The researcher argues that by using different models and tools of activity theory we will enhance our understanding of issues such as knowledge fragmentation, contradictions and different ambiguities that occur in healthcare contexts. Dubai Cord Blood and Research Center (DCRC) is the only governmental cord blood centre in the UAE. The DCRC provides expectant mothers two main cord blood-banking options which are private (family) banking of newborns' UCB stem cells where the unit is kept for the family use, and public banking where one can donate their newborn's UCB stem cells to be used by others for transplantation.

This is the first study that combines activity-theoretical analysis with value co-creation processes in a particular service where activity theory is used as a tool to expand S-D logic for practice development in cord blood donor recruitment processes in hospitals. In conclusion, several common ingredients emerged between S-D logic and activity theory which include: the role of beneficiary (user), actors as dynamic systems, importance of context as human institutions, and importance of knowledge as an operant resource. This research provides a foundation for improvements to practice in voluntary cord blood recruitment. Knowledge about the importance of public cord blood donation is essential among community, expectant mothers and healthcare providers to develop reliable donor recruitment processes for public cord blood banks.

## ABSTRACT IN ARABIC

### موجز

تتطوي إدارة المتبرعين على أنشطة رئيسية تتضمن استقطاب المتبرع ودعوته واختياره وعملية التبرع. استقطاب المتبرعين هي إحدى المراحل الحاسمة التي تضمن وصول كميات كافية من الدم إلى مواقع الجمع. تستلزم مسألة استقطاب المتبرعين وإدارة استراتيجية الدم بحثاً وفقاً لثقافة الدولة والبيئة الاجتماعية. لم تُجرى سوى دراسات قليلة على المستوى الوطني حول عمليات استقطاب المتبرعين بدم الحبل السري. يعتبر التبرع بالخلايا الجذعية المُكوّنة للدم (HSCs) للبنك العام مُهم للغاية في الدول العربية حيث أن من أصل 20 مليون متبرع بالخلايا الجذعية المُكوّنة للدم المُسجّلين عالمياً، هناك أقل من 50 مُسجّل في دول الخليج العربي

تستخدم هذه النظرية الموارد المفاهيمية لنظرية النشاط الثقافي التاريخي (CHAT) لتحديد أدوات الوساطة المُحتَملة بين منطق هيمنة الخدمة ووجهات النظر القائمة على الممارسة. يهتم إشكال البحث بكيفية الجمع بين منطق هيمنة الخدمة ووجهة النظر القائمة على الممارسة. يناقش الباحث بعرض مسألة أنه باستخدام نماذج وأدوات مختلفة لنظرية النشاط سنعرّض فهمنا لمسائل مثل تجزئة المعرفة والتناقضات وحالات الغموض المختلفة التي تحدث في سياقات الرعاية الصحية. مركز دبي لدم الحبل السري والأبحاث (DCRC) هو مركز دم الحبل السري الحكومي الوحيد في دولة الإمارات العربية المتحدة. يقدم مركز دبي لدم الحبل السري والأبحاث (DCRC) للأمّهات الحوامل خيارين رئيسيين للتبرع في بنك دم الحبل السري وهما حفظ الخلايا الجذعية لدم الحبل السري للطفل في بنك خاص (للعائلة) حيث يتم الإبقاء على الوحدة للاستخدام العائلي، والخيار الثاني هو الحفظ في البنك العام حيث يُمكن للشخص التبرع بالخلايا الجذعية لدم الحبل السري لطفله ليستخدمها الآخرون لعمليات الزراعة.

هذه الدراسة هي الأولى من نوعها والتي تجمع بين تحليل النظرية والنشاط وعمليات تكوين القيمة المشتركة في خدمة معينة حيث يتم استخدام نظرية النشاط كأداة لتوسيع منطق هيمنة الخدمة لتطوير الممارسة في عمليات استقطاب المتبرعين بدم الحبل السري في المستشفيات. في الختام، ظهر العديد من العناصر المشتركة بين منطق هيمنة الخدمة ونظرية النشاط وتضمن ذلك: دور المستفيد (المُستخدِم) والجهات الفاعلة كنظم ديناميكية وأهمية السياق كمؤسسات بشرية وأهمية المعرفة كمصدر فعّال. يقدم هذا البحث أساساً لإجراء تحسينات على الممارسة في مسألة استقطاب المتبرعين بدم الحبل السري. إن المعرفة بأهمية التبرع العام بدم الحبل السري أمر ضروري بين الأمّهات الحوامل ومقدمي الرعاية الصحية للإنشاء عمليات استقطاب معتمدة للمتبرعين لبنوك دم الحبل السري العامة.

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Last but not least I would like to thank my team in the Dubai Cord Blood and Research Center and my friend Kim Petrella – cord blood educator in the USA – for her support and encouragement as both of us share the same interest in and enthusiasm towards learning more about cord blood stem cells and public banking expansion.

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## **LIST OF ABBREVIATIONS**

AABB	American Association of Blood Banks
AT	Activity Theory
BBMR	British Bone Marrow Registry
BI	Business Intelligence
BMT	Bone Marrow Transplant
BOBI	Business Object Business Intelligence
CBB	Cord Blood Bank
CHAT	Cultural-Historical Activity Theory
CME	Continues Medical Education
CRADLE	Center for Research and Activity Development and Learning
DCRC	Dubai Cord Blood and Research Center
FACT	Foundation for Accreditation Cellular Therapy
GVHD	Graft-Versus-Host Disease
HIV	Human Immunodeficiency Virus
HLA	Human Leucocyte Antigen
HSCs	Hematopoietic stem cells
HSCs	Hematopoietic Stem Cell
HSCT	Hematopoietic Stem Cell Transplantation
KAIMRC	King Abdullah International Medical Research Center
KAP	Knowledge, Attitude and Practice
NHSBT	NHS Blood and Transplant
NMDP	National Marrow Donor Program
PAHO	Pan American Health Organization
PHC	Primary Health Clinic
REDS	Retrovirus Epidemiology Donor Study
SDL	Service Dominant Logic
UCB	Umbilical Cord Blood
WHO	World Health Organization

## **CHAPTER 1: INTRODUCTION**

### **1.1 Overview of the Study**

Donor management consists of several key processes to ensure that the proper number of blood donations are provided to help many patients in need of blood products (Veldhuizen, Folléa and De Kort 2013). Donor management involves a series of major key steps and actions including recruitment, invitation, selection, retention and donation processes (De Kort et al. 2010). Donor recruitment is one of the critical stages which ensure that a sufficient and stable number of blood donations are received by the blood collection sites. However, donor recruitment and blood strategy management are difficult tasks that need to be studied and developed according to country-specific culture and social environment (Lee 2016). It is important for all blood collection agencies to understand the life context of blood donors, the barriers that prevent them from donating blood and the different factors that motivate them to donate blood (Masser and Bagot 2015). In this regard, many studies have investigated blood donor recruitment and the different barriers preventing them from donating their blood, however only a few studies have been conducted on a national scale illustrating different strategies required for the cord blood donor recruitment processes (Matsumoto, Dajani and Matthews 2015).

The discovery of umbilical cord blood stem cells as a source for transplantable hematopoietic stem was proposed by Hal Broxmeyer in 1982 along with his colleagues Edward Boyse and Judith Bard. Since the first successful transplantation in 1988 on a child suffering from Fanconi's Anemia (Gluckman et al. 1989), more than 35,000 umbilical cord blood transplants have been achieved worldwide (World Cord Blood Day 2018). Nevertheless, despite the fact that about 22 million bone marrow donors are registered within the bone marrow donor

registry, it is still the case that a suitable donor cannot be found for many patients at the right time (Be The Match 2017). The likelihood of finding a matched human leucocyte antigen (HLA) for an unrelated donor depends to a great extent on ethnic background of the potential recipient (Navarrete and Contreras 2009). Therefore, umbilical cord blood banks were established for patients with blood diseases who cannot find either a matched sibling donor or an unrelated bone marrow donor for stem cell transplantation (Rubinstein 2006). Hence, there is a need to expand public cord blood registries, particularly within Gulf countries, through recruiting more donors to public cord blood banks and conducting different activities such as patient education and counselling (Emirates 24/7 News 2015). In addition, an increased awareness among expectant mothers and involvement of healthcare providers in patient education about cord blood and the different banking options will lead to increased donations of public cord blood units (Herlihy and Delpapa 2013).

Katz et al. (2010) conducted a study on pregnant women's awareness and attitudes towards cord blood banking in five different countries (France, Italy, Spain, Germany and the UK). Results showed that 79.4% of expectant mothers have poor and limited knowledge about cord blood banking and would like to gain more information about the topic. Among the five countries, the survey results showed that more than half of pregnant women received information about cord blood stem cells from different media sources, while only 20.6% of pregnant women received information on cord blood stem cells from their midwife, obstetrician and general practitioner. Almost all the pregnant women from the five countries in the study (91.6%) strongly believe that it is their right to be informed about the benefit of cord blood stem cells. Machin, Brown and McLeod (2012) interviewed in their study one of the senior policy makers who claimed that it is the mother's right to know about the potential benefits of cord blood stem cells in a legal context and it is the responsibility of the midwives

and obstetricians to inform pregnant women about the beneficial value of cord blood in treating many life-threatening diseases.

Matsumoto, Dajani and Matthews (2015) conducted the first study among the Arab Muslim population which was in Jordan. The purpose of the study was to investigate the level of awareness about cord blood donation and the different banking options available to mothers and pregnant women. The results showed that 75% of pregnant women and mothers had no information at all about cord blood banking in Jordan and 50% had never heard about it before. However, most of them had a positive attitude about cord blood storage and would like to hear more about it, particularly from their obstetrician (Matsumoto, Dajani and Matthews 2015). Therefore, to implement successful donor recruitment processes in the UAE, it is important to understand the life context of expectant mothers and healthcare providers as well as cord blood donors' motivations and barriers towards cord blood donation. This will help to tailor the cord blood donor recruitment processes according to the UAE's cultural and environmental context and needs.

Recently, Service Dominant Logic S-D logic has become a popular approach in the analysis of business and marketing. It focuses on service (singular) instead of services (plural) and views it as the process that creates value in use (benefit). Service is defined as "*The application of specialized competences (knowledge and skills) through deeds, processes, and performances for the benefit of another entity or the entity itself*" (Vargo and Lusch 2004, p. 2). Value co-creation is a fundamental process that focuses on reciprocal exchange among actors where all actors work together to create input on each other's activities (Vargo and Lusch 2004, 2008, 2016). Despite the fact that S-D logic is a marketing theory, it is considered to be multidisciplinary as it has adopted elements from different organizations and theories including organization science, sociology, innovation theories and institutional theory (Vargo and Lusch 2011). Recently, a group of researchers became interested in integrating S-

D logic along with the practice-based view (see, for example, Echeverri and Skålén (2011), Kjellberg and Helgesson (2006), Korkman et al. (2010), and Mele and Russo-Spena (2015), particularly the types of practice that focus mainly on ‘way of doing’. In addition, activity theory is a framework that analyses different structures of human practice under the scope of historically developed cultural systems which link individuals with society (Engeström 1999). The historically developed activity system is the context of individual action which is viewed as the smallest unit of analysis within human activity (Kaptelinin et al. 1999). According to activity theory, activity is always collective and determined by a shared object-related motive (Engeström 1999). Socio-cultural resources include the different beneficiaries’ users that are included in the activity systems, material artifacts and language used to mediate actions among service providers (subjects) (Engeström 1987; also Vygotsky 1978). Therefore, in this research, several common ingredients were found between S-D logic and activity theory which are examined in more detail in Chapter 6. These common ingredients include the role of beneficiary (user), actors as dynamic systems, importance of context as human institutions, and importance of knowledge as an operant resource.

## **1.2 Context of the Study**

Dubai Cord Blood and Research Center (DCRC) is used in this study as the case context. The DCRC was established in 2006 in the UAE to help treat many patients with life-threatening diseases. The DCRC is the only governmental centre in its region that provides two types of service; these are *family banking* of umbilical cord blood (UCB) stem cells where the unit is kept for the family’s use, and *public banking* where one can donate their newborns’ UCB stem cells to be used by others in need of transplantation. The Centre consists of two main units which are Administration and Laboratory. The Administration and Donor Recruitment Unit is in charge of recruiting, registering and receiving cord blood units within the centre beside other administrative statistical work. The laboratory unit processes, tests and stores the

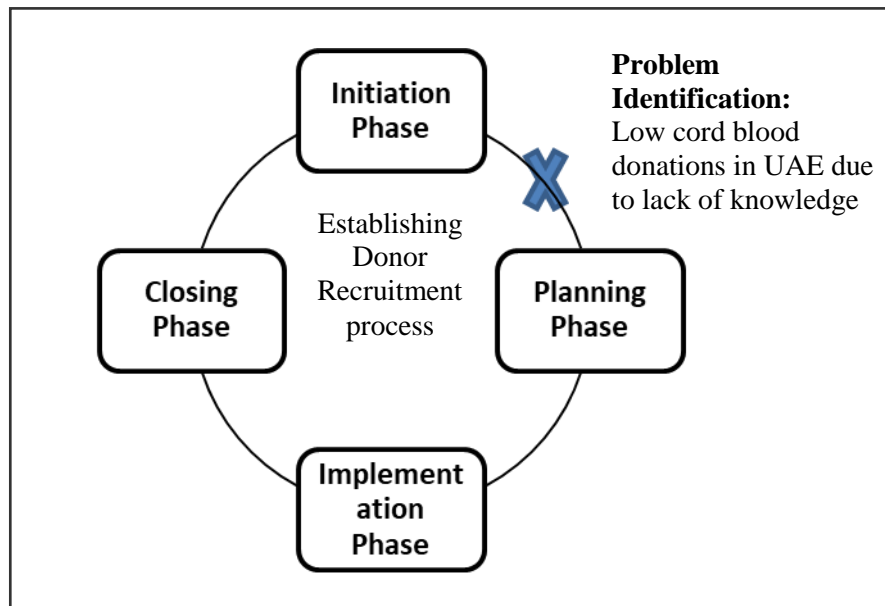
newborns' UCB stem cells in liquid nitrogen tanks for at least 30 years. In 2012, the researcher noticed the low number of received cord blood donation units at the centre despite the presence of one of the biggest governmental maternity hospitals in the same complex (GoDubai 2013). Therefore, in 2012 the researcher decided to distribute a small survey to pregnant women in the maternity hospital to find out the reasons that prevent expectant mothers from donating their newborns' UCB stem cells and identify what might motivate them to donate their newborns' stem cells. The study results showed that the majority of pregnant women do not donate because they do not have enough knowledge about cord blood stem cells to make an informed decision (Alhashimi, 2015). Consequently, at that time, the researcher considered that the best solution was to visit antenatal clinics to conduct short educational sessions for expectant mothers about cord blood stem cells. The session was held in the antenatal clinic waiting area – where all expectant mothers were waiting for their appointments to see their gynecologists – three times a week for a period of one hour. Despite the fact that educating expectant mothers in the waiting area was useful, many expectant mothers were called in during the session for either a general checkup or to see their doctors, which was distracting for the lecturer and some expectant mothers who were very interested in the topic. After being educated and informed about the beneficial use of cord blood stem cells, some expectant mothers expressed their willingness to donate their newborns' UCB stem cells while others preferred to ask their husband/family first before they made any decisions. In 2012, educational sessions were conducted for a period of six months in antenatal clinics along with awareness campaigns, educational video documentary, educational materials such as brochures and roll-up stands demonstrating the importance of cord blood stem cells. The activities in the hospitals were divided between the researcher and two other clinical scientist staff from the centre (Alhashimi 2015). The researcher started monitoring the increase in cord blood registration before and after implementing the change.

Results showed that the number of registered cord blood units has increased significantly by 57% for private cord blood units and 300% for public units, which demonstrated the effectiveness of conducting awareness activities in hospitals (Alhashimi 2015). However, conducting such activities requires a budget and resources. Despite many attempts to maintain the increase in cord blood donation, the lack of resources and the budget were obstacles that led to a reduction in the number of activities conducted each year. This led to a reduced number of cord blood units registered to the centre which prompted the researcher to think about conducting a more in-depth analysis by studying the life context of expectant mothers and healthcare providers, as well as understanding more about hospitals' systems and operations. Because the project is created in relationship to other actions it is very important to take into consideration different factors that may affect it (Jensen, Johansson and Löfström 2006). These factors include different resources such as money, knowledge, and trust which in turn depend heavily on the surrounding environment. Therefore, since no project is completely self-sufficient, the ability to obtain and manage resources is very important (Burke 2013). Therefore, to establish a cord blood donor recruitment process in hospitals the researcher believed in the need for developing a conceptual framework with clearly defined sustainable strategic plans. The researcher aims to integrate the newly designed conceptual framework within the hospital's system so that it becomes part of hospital practice in exactly the same way that breastfeeding education is institutionalized in the hospitals.

The project lifecycle consists of five main stages; these are initiation, planning, executing, controlling and closing (Ward and Daniel 2013). The planning process includes identifying, estimating and preparing the activities in order to attain the objectives and achieve the intended results. Project plan is the output of the project which incorporates project structure, deliverables, resources and activities controlled by time, cost and quality dimensions (Larson et al. 2014). The planning phase is considered one of the most important stages within the



project life cycle as key decisions are made in this phase which can greatly affect the executing phase downstream to the project (Turner, 2006). Figure 1-1 shows that the problem has been identified within the initiation phase of the establishment of the donor recruitment process in hospitals as most of healthcare providers and expectant mothers lack knowledge about the importance of cord blood donation. Matijević and Erjavec (2016) showed that healthcare providers need to play important roles in educating the expectant mothers about the importance of cord blood donation in expanding the public registry to help many patients needing cord blood stem cells. However, knowledge acts as one of the main barriers for their participation within the project. Therefore, this thesis aims to create a sustainable strategic plan for the establishment of a reliable cord blood donor recruitment process that can facilitate stakeholders' engagement and participation in public cord blood bank expansion. Project management (PM) is used as a tool to increase organisations' productivity by creating tangible and intangible benefits depending on culture, organisation needs and the sustainability of the created values (Thomas and Mullaly 2009). Therefore, in this thesis the researcher is studying the barriers and motivations towards cord blood donation among expectant mothers and the challenges that affect healthcare providers' participation within the project. It is important to highlight the causes of project failure and the different factors that lead to project success (Walker, 2015). In 2012, the researcher identified that lack of knowledge acts as one of the main barriers towards the expansion of cord blood banks in the UAE, and the need to understand expectant mothers' and healthcare providers' motives towards cord blood donation is very important.



**Figure 1-1 : project life cycle of establishing Donor Recruitment process in hospitals in UAE, lack of knowledge among expectant mothers and healthcare providers act as barrier for the expansion of public cord blood banks in UAE**

### 1.3 Research Problem

Public awareness is considered one of the main factors affecting the success of cord blood donation (Matsumoto, Dajani and Matthews 2015). The need for public cord blood registries is highly important in Arab counties as from 20 million Hematopoietic stem cells (HSCs) donors registered globally, less than 50 are registered in the Arabian Gulf countries (Matsumoto, Dajani and Matthews 2015). Thus, the probability of, for example, a Jordanian finding related matching stem cell donors in an international registry is only about 2% to 5% which is very low when compared to 50% to 60% of matched donors for the patients of white descent (Elbjeirami, Abdel-Rahman and Hussein 2013). Healthcare providers need to play an important active role in increasing public awareness and encouraging expectant mothers to donate their cord blood stem cells (Matijević and Erjavec 2016). Many mothers do not donate their newborns' UCB stem cells because they lack information about the importance of doing so. Increased awareness can be generated by clarifying important facts within health such as

highlighting the main values, changes in beliefs, attitudes, behaviours and life styles (Busby 2010). Currently, most of the guidelines recommend donation of umbilical cord blood units to the public banks, unless a family has an inherited condition or disease that requires stem cell transplant, in this case it will be useful to store the umbilical cord blood in a private bank for future family use (Martin, Kurtzberg and Hesse 2011). The Arab region needs adequate donor recruitment strategies to ensure a high number of donors are recruited and well selected for cord blood donation. Moreover, it is important to raise awareness about the importance of public donation among expectant mothers and healthcare providers as their participation will help to establish solid local and national frameworks and policies for cord blood banking and donor recruitment (Herlihy and Delpapa 2013). To attain this level of development it is important to determine what kind of expanded conceptual framework is required to create strategic sustainable plans for the establishment of an effective cord blood donor recruitment process in hospitals. In this study, the researcher used S-D logic principles along with activity theory for the analysis of cord blood donor recruitment processes. The researcher identified a research gap concerning the empirical case studies that would combine S-D logic and the practice-based view which in this case is the cord blood donor recruitment processes. Despite the fact that there are a number of studies framed as practice-based, they do not provide an in-depth analysis of real organisational practices (see, for example, Korkman, Storbacka and Harald 2010; Echeverri and Skålén 2011). In addition, previous research that combines S-D logic and practice-based theory lacks ethnographic field research and in-depth analysis methods as well as empirically-tested concepts or analytical tools for exploring different structures and dynamics of organisational practices.

In this study, the researcher uses conceptual resources of cultural-historical activity theory (CHAT) (e.g., Engeström 1987; Engeström et al. 1999; Sannino et al. 2009; also Leont'ev 1978) to identify potential mediating instruments between S-D logic and practice-based

views, and focuses on both theoretical and empirical interests whereas Mele and Russo-Spena's study (2019, forthcoming) focuses on connections at a rather abstract conceptual level by combining innovation in practice with the concept of expansive learning and S-D logic (Engeström 1987).

Cord blood stem cells are an important resource for healthcare development as they can treat almost 80 different blood diseases including leukemia, thalassemia and sickle cell anemia (Liao et al. 2011) which are highly common diseases in the Middle East. To ensure comparative representation of ethnic diversity, there should be strategic recruiting of unrelated donors due to difficulties in finding matched unrelated donors for patients with mixed ethnicity (Akyurekli et al. 2014). It is very important to increase the total number of cord blood donations in the UAE to be able to establish a public cord blood registry with diverse ethnic groups to be able to find unrelated donor match for many people in need of stem cell transplants (Nazzal 2018). Therefore, this research focuses on producing theoretical knowledge that is potentially useful for the development of this activity.

#### **1.4 Research Question and Significance of the Study**

Donor recruitment management acts as a cornerstone for managing blood donor recruitment and increasing awareness among public and healthcare providers (Lee 2016). This research fills a gap in knowledge since there are only a limited number of studies about cord blood donor recruitment management when compared to blood and organ donor recruitment. Moreover, to the best of the researcher's knowledge, no studies have been conducted in the UAE on this topic despite the critical need for improved understanding and a higher level of awareness and informed opinion among the public and healthcare professionals about cord blood donation in Arab countries (Matsumoto, Dajani and Matthews 2015). Thus, this research focuses on understanding the main barriers and motivations for cord blood donation

among expectant mothers and healthcare providers which in turn will help in designing strategic plans for comprehensive and effective cord blood donor recruitment processes. This will lead to improvements to the existing donor recruitment system of involuntary cord blood donation with the aim of increasing public cord blood donation and making it possible to find matched donors to perform transplantations from voluntary unrelated donors to patients with life-threatening diseases in the UAE.

The main aim of the research is developing a new conceptual framework using activity theory and co-creation value to establish a sustainable strategic plan for the cord blood donor recruitment processes in government hospitals in the UAE. This can be achieved by answering the main research question and other sub-questions of this research as shown in Table 1-1. Moreover, healthcare is selected as the main context of the study which is one characterized by challenging experiences due to paradigmatic changes (Hartley 2005). Nowadays, S-D logic researchers are focusing on the importance of increasing the actual practice of value co-creation and resource integration and finding solutions for issues like resource utilization and mobilization. They are also working to identify the best processes for resources integration (Kleinaltenkamp et al. 2012). Herein, the researcher contends that by using different models and tools of activity theory we will enhance our understanding of issues such as knowledge fragmentation, contradictions and different ambiguities that occur in marketing contexts (Witell et al. 2011). Moreover, this is the first study that uses activity-theoretical studies for business and marketing analysis in terms of value co-creation processes in a particular service where activity theory is used as a tool to expand S-D logic for practice development which, in this case, is cord blood donor recruitment processes in hospitals in the UAE. The researcher poses the following research question to guide the work:

**The main research question:** What kind of expanded conceptual framework is needed to create a sustainable strategic plan for the establishment of a reliable cord blood donor recruitment process in hospitals?

**Other sub-research questions include the following and are summarized in Table 1-1:**

1. What are the current motivators and barriers towards donating cord blood stem cells in the UAE?
2. What are the current challenges underlying stakeholders' engagement and involvement with cord blood donor recruitment processes?
3. What changes are needed to increase cord blood donation in the UAE's hospitals?

## 1.5 Research Map

**Table 1-1 Summary research map including research aim, research questions and the underlying theory of the research**

Research Aim	Research Questions	Theory-/ Model	Underlying Theory
	Overall main research question: What kind of expanded conceptual framework is needed to create a sustainable strategic plan for the establishment of a reliable cord blood donor recruitment process in hospitals?		
Developing a new conceptual framework using Activity Theory and Co-creation value to establish a sustainable strategic plan for cord blood donor recruitment processes in hospitals in the UAE	1. What are the current motivators and barriers towards donating cord blood stem cells in the UAE?	Activity Theory, Activity systems and S-D logic	(Engeström 1987, 2000)  (Vargo and Lusch 2014, 2016)
	2. What are the current challenges underlying stakeholders' engagement and involvement with cord blood donor recruitment processes?	Activity Systems and S-D Logic	(Engeström 2000) (Vargo and Lusch 2014, 2016)
	3. What changes are needed to increase cord blood donation in the UAE's hospitals?	Activity Systems and S-D Logic	Engeström 2000) (Vargo and Lusch 2014, 2016)

## **CHAPTER 2: LITERATURE REVIEW: BLOOD & CORD BLOOD DONOR RECRUITMENT**

### **Introduction to the chapter**

This chapter reviews the literature on blood and cord blood donor recruitment, and identifies the main themes underlying barriers and motivations towards blood and cord blood donation. The chapter also assesses the cultural, religious and environmental challenges of cord blood and blood donation. The researcher first discusses blood donation and its motivations and barriers that contribute to ensuring an adequate supply of blood among many developing countries, and summarises these into major themes. Knowledge, Attitudes and Practice (KAP) surveys were used as a tool in 17 developing countries to understand factors that influence blood donation and assist in designing strategies for the development of educational materials and communication plans. Next, hematopoietic stem cells from bone marrow and umbilical cord blood are discussed, with a focus mainly on research studies that highlight topics about cord blood and related motivations and barriers; and factors that prevent expectant mothers from donating their newborns' UCB stem cells. Finally, these are summarised into a set of main themes.

### **2.1 Blood Donor Recruitment**

Blood donation is a voluntary and unpaid act that requires well designed strategies and models that can attract donors to help many patients in need by donating their blood and blood products (Muthivhi et al. 2015). One of the main causes of death worldwide is the blood lost during delivery as well as the lack of blood to treat many diseases such as anemia, malaria and malnutrition which threaten the lives of thousands of children worldwide. The World Health Organization reported that if just 1% of the world's population donated their blood to the public, the blood supply will be enough to cover the basic needs of blood



worldwide (Charles-Sire et al. 2014). However, many blood banks face difficulties in recruiting donors which leads to a low supply of blood and blood products. Most of the research conducted about donor recruitment and strategies are based on personal preference, organisational practice and subjective report and only a few examples were found in literature testing different approaches to blood and bone marrow donor recruitment (Reich et al. 2006). Recruitment of blood donors has always been considered a challenging task as it requires financial support and education of both health professionals and the community (McBarnette, Rosner and Bisserup 1974). Reich et al. (2006) argued that there is very limited scientific evidence to guide decisions related to blood donors as most of the reviews are mainly focused on donors' barriers and motivations towards blood donation.

The main problems facing donor recruitment include cultural and social factors, misconceptions, myths, and weak management of donor programmes, lack of resources, and incorrect uses of blood. One of the main problems in developing an appropriate donor recruitment programme is the lack of strategic plans and national policies, insufficient donor databases, and insufficient educational and promotional materials. To overcome such problems, it is recommended to have long-term plans for donor recruitment with clear objectives that can meet community needs by taking into consideration the cultural and ethical issues involved (Charles-Sire et al. 2014).

## **2.2 Blood Donation Motivations and Barriers**

Understanding the motivations and barriers towards blood donation has helped with establishing an adequate supply of blood among many developing countries around the world (Dhingra 2002). Motivating volunteer blood donors to donate blood acts as one of the important factors to ensure the safe supply of blood. According to Lownik et al. (2012) there are two main strategies to recruit donors. The first one is to obtain the first blood donation

from the donors and the second one is to encourage first-time donors to return and routinely donate their blood. Allain et al. (2008) showed that the rate of positive transmissible disease in repeated donors is much lower. Therefore, to improve the safety of blood supply, it is important to increase the number of repeat donors. Many governments and agencies have used Knowledge, Attitude and Practice (KAP) surveys as a tool which was developed by the American Association of Blood Banks (AABB), Pan American Health Organization (PAHO) and World Health Organization (WHO) since 2000 to understand the general population's behaviours and perceptions toward blood donation (Lownik et al. 2012). Increased understanding and studies of topics surrounding knowledge, attitudes, behaviours and practices of blood donation will lead to better implementation of models that can help with promoting safe, voluntary blood donation in the country. This will also help with designing strategies for the development of educational materials and communication plans.

To understand factors that influence blood donation, KAP surveys have been used as a tool in 17 developing countries despite the differences in structure and population sample size. The survey was carried out by the International Monetary Fund from 1995 to 2011 in a number of emerging and developing countries. Several themes emerged from this study and the most common ones are discussed below (Lownik et al. 2012).

### **2.2.1 Theme 1: Misinformation about Blood Donation**

Eighteen KAP studies conducted in 17 developing countries showed that almost all of the population among non-donors do not donate blood due to lack of information about the importance of blood donation (Lownik et al. 2012). For example, a survey conducted in Trinidad and Tobago showed that 71.3% of non-donors do not donate their blood due to lack of information about blood donation despite the fact that they have shown their willingness to do so if access to blood donation information and its facilities was improved (Sampath et al.

2007). However, a study conducted in North India found that most of the non-donors never donated blood because no one had asked them to do so, and some of them had specific misconceptions that blood donation is linked to infertility (Dubey et al. 2014). Moreover, similar studies conducted in Ireland showed that most of the donors (88%) who did not donate blood lacked awareness about patients' needs for blood (Harrington 2007).

Studies conducted in Arab regions showed that, in the Armed Forces Hospital in Saudi Arabia, a lack of basic knowledge about blood donation among non-donors was one of the main barriers to donating blood. They highlighted the fact that they were not approached or encouraged by anyone to donate blood, but declared that they were willing to donate blood if the organisation approached them to do so (Alam 2004). Therefore, almost all the developing countries require continuous recruitment and educational campaigns to improve and ensure an adequate blood supply. Blood centres in North India should implement specific strategies to promote blood donation and raise the population's general awareness about the importance of blood donation. In this region, television was found to be the most effective form of communication to raise awareness about blood donation (Dubey et al. 2014).

### **2.2.2 Theme 2: Anxiety and Fear from Donating Blood**

A fear of donating blood has been found in most developing countries (Jacobs et al. 1995; Mwaba and Keikelame 1995; Hosain et al. 1997; Javadzadeh and Shahshahani 2007). Donors expressed that their fear is not only about the donation itself but also fear of the needle, overall loss of energy or infertility, and anxiety concerning developing the Human Immunodeficiency Virus (HIV) disease. Similar results were found in Jordan where the most common reasons cited that prevents donors from donating blood were misconceptions such as risk of developing infection and selling donated blood to patients (Abderrahman and Saleh 2014).

### **2.2.3 Theme 3: Being Part of Humanity by Donating Blood**

In 1988, research showed that donors were motivated to donate blood if they are offered some incentive treatments such as cholesterol screening or prostate cancer screening (for males only) which was considered an effective recruitment tool that results in beneficial health outcomes for donors to seek medical evaluation and treatment (Rzasa and Gilcher 1988). However, incentives such as cash and raffle tickets proved to be one of the motivations which generated the highest level of discouragement for donors as many of them do not like to be compensated for charitable actions and assert that such rewards negatively affect their intrinsic motivation (Piliavin 1990). A survey conducted by Retrovirus Epidemiology Donor Study REDS in 1995 showed that 60% of donors who were offered cash to donate blood were more likely to have positive screening tests thus resulting in negative impacts on providing a safe supply of blood (Glynn et al. 2003).

Most of the recent surveys conducted in developing countries showed that the most important motivating factor encouraging donors to donate blood was altruism which is the willingness to help and add value to the community (Lownik et al. 2012). Several studies showed that altruism and charitable acts are the most cited motivation factor encouraging donors to donate blood. Moreover, the French National Blood Bank conducted a field study on blood donor behaviours to test donor commitment to donate blood with concepts of love and promise to the French National Blood Bank. The results showed significant effects not only on donor willingness but also on commitment to donate blood. In many human societal cultures, the concept of love is essential and activation of this concept has shown significant effects on human behaviours in many different contexts (Guéguen, Jacob and Charles-Sire 2011). The French National Blood Bank has associated the concept of “loving” along with “helping” in an equation – loving = helping – which resulted in social interaction and positive change in

behaviours among donors. Therefore, using altruism and humanitarian motivation in donation campaigns is one of the most effective recruitment mechanisms (Charles-Sire et al. 2014).

#### **2.2.4 Theme 4: Fear from Selling the Blood and Failure to Develop Positive Attitudes towards Blood Donation**

A study conducted among university students in Bangladesh showed that even though 82% of students had positive attitudes towards blood donation, only 16% had donated their blood (Hosain et al. 1997). Similarly, although 87.3% of Chilean students had developed positive attitudes about blood donation, only 14% donated their blood (Vasquez, Ibarra and Maldonado 2007). Likewise, in South Africa, while 80% believe in the importance of donation, only 17.5% had donated their blood (Mwaba and Kelkelame 1995). Similar positive attitudes have been shown in other developing countries such as Iran, Haiti, Thailand, Tanzania, Moldova and Togo (Jacobs and Berege 1995; Wiwanitkit 2002; Javadzadeh Shahshahani 2007; Agbovi et al. 2006).

#### **2.2.5 Theme 5: Willingness to Donate Blood to Help Families and Friends**

Most of the donors have a strong willingness to donate blood for friends or families. Some donors are motivated to donate to ensure that their family or friends receive blood, should they need it, without going through the pressure of searching for blood (Boulware et al 2002). Most of the generated themes from the KAP studies can be applied broadly despite the differences in practice and the different function of blood systems in different countries (the different functions of blood systems were not included in the KAP surveys).

Overall, the KAP surveys provide important information about blood donation that can help with designing rationales and strategies to recruit and motivate voluntary non-remunerated donors to donate blood. Despite the fact that the beliefs, attitudes and behaviours of donors are different from one context to another in the developing countries that were studied, five

main themes that emerged from the KAP studies in 17 countries inform the implementation of communication strategies to produce a safe supply of adequate blood to assist many patients who need blood transfusions (Lownik et al. 2012).

### **2.3 Hematopoietic Stem Cells Donor Recruitment**

Hematopoietic stem cells from bone marrow, peripheral blood and umbilical cord blood have been used in allogeneic Hematopoietic Stem Cell Transplantation (HSCT) to treat malignant and non-malignant diseases over the past 30 years (Galanis et al. 2008). However, many patients do not have a suitable matched unrelated donor which is considered one of the major obstacles as donor selection is a key factor for successful transplantation (Elbjeirami, Abdel-Rahman and Hussein 2013). Thus, the need for public stem cell registries is vital to help many patients in need of stem cells transplantation (Cleaver et al. 1997). Today there are large numbers of registries worldwide which have been established to help many patients find volunteer unrelated donors who can be suitable replacements when they lack family donors (Gahrton, van Rood and Oudshoorn 2003). Even though there are 22 million bone marrow donors registered worldwide (Be The Match 2017), it is still the case that a suitable donor cannot be found for many patients at the right time. In addition, white patients have only 50% suitable matched bone marrow donors; this figure is even lower and it is more challenging to find a matched donor for ethnic minority groups which are very poorly represented in the registries (Confer 1997). Out of over 60 registries available worldwide, only one single registry exists in the Arabian Gulf countries; this was established in 2011 at King Abdullah International Medical Research Center (KAIMRC) at the cord blood bank in the Kingdom of Saudi Arabia. Thus, the possibility of a Jordanian, for example, finding an unrelated matched donor is only between 2% to 5% which is significantly low (Matsumoto, Dajani and Matthews 2015). Additionally, even if a matched donor is found, the difficulty remains in the time taken to ship the cord blood unit or transfer the bone marrow volunteer donor to the

transplant centre overseas. Therefore, it is vital to study the motivators and barriers towards donating Hematopoietic stem cells from different sources, notably bone marrow, peripheral blood or cord blood in the context of Arab countries.

Establishment of bone marrow and cord blood registries in Arab countries is essential and will contribute to addressing the current gap by providing different sources for Hematopoietic Stem Cell (HSCs) transplantation for the Arab population. Therefore, it is essential to implement a successful donor recruitment strategy to ensure an adequate supply of HSCs donors. The author of this thesis focuses in detail on the barriers and motivators towards cord blood donation, specifically in the UAE.

## **2.4 Cord Blood Donation and Banking Options**

Since the first successful cord blood transplant in 1988, Umbilical Cord Blood (UCB) became an alternative source of bone marrow hematopoietic stem cells and a standard practice treatment for pediatricians. It is a frequently used source of stem cells for allogeneic hematopoietic stem cells transplantation. UCB stem cells can treat 80 diseases including bone marrow failure syndrome, haemoglobinopathies, immunodeficiencies metabolic and genetic disorders, and leukemia and lymphomas (Ballen, Gluckman and Broxmeyer 2013). Hwang et al. (2007) highlighted that many studies found that the outcome results after UCB transplantation is as good as or even better than transplantation from siblings or matched unrelated bone marrow donors in term of slower engraftment and lower incidence of chronic graft-versus-host disease (GVHD). However, UCB transplantation is more expensive than volunteer unrelated bone marrow transplantation because the healthcare system needs to recruit volunteer donors and then collect, preserve and manage the UCB units in the stem cell banks (Preussler, Denzen and Majhail 2012). UCB samples are collected from the remaining blood in the placenta directly after the delivery of the newborn. The delivery team doctor,

nurse or midwife will collect the cord blood by inserting a sterile needle which is attached to cord blood collection bag into the cord's vein which will allow the withdrawal of the blood into the collection bag using the force of gravity. The collection of cord blood is safe and gives no pain for either the mother or the newborn. After the collection, the cord blood samples are tested for diseases and viability to make sure they are eligible for storage according to the cord blood international standards (Parents' Guide to Cord Blood Foundation 2018). There are three types of banking model – these are *public*, *private* and *hybrid*. Private banking is where the pregnant mother pays a specific fee and stores the cord blood unit exclusively for family use whereas public banking gives an opportunity to pregnant women to donate their cord blood to help many patients in need of transplantation; no fees are involved as the ownership of the unit belongs to the centre which in turn will process the unit and store and sell it to a transplant centre when needed by a patient. Hybrid banks operate a combination of both public and private storage (Ballen, Verter and Kurtzberg 2015). Verter (2013) showed that more than three million cord blood units are stored around the world; of these 2.5 million units are stored in private banks' facilities whereas only 65,000 units are stored in public banks. Public banks are financially funded by governments, charitable sources or revenues generated from exporting the units to transplant centres. The public cord blood units need to meet certain standards to be registered on a database that is accessible to transplant centres. Thus, public banks need to be accredited by certain bodies such as the Foundation for Accreditation Cellular Therapy (FACT) or the American Association of Blood Banks (AABB). Both apply specific quality standards which are universally recognised by all the transplant centres around the world (Matsumoto, Dajani and Matthews 2015). Currently, in the Arab world only one cord blood bank is available and accredited by FACT which is in Riyadh (King Abdullah International Medical Research Center) and received the accreditation in 2015.



Unfortunately, private cord blood banks have attracted greater attention of the population over the public banks by advertising their services to the general public to preserve their cord blood units as “insurance” in case they are needed in the future to treat many diseases. Many private banks are mainly commercial as many parents lack knowledge about UCB banking and they are ready to pay to store their newborns’ UCB even if they do not have the disease conditions within their family (Shearer et al. 2017). Thus leading to reduce number of public cord blood units within public banks.

## **2.5 Cord Blood Donation Motivations and Barriers**

### **2.5.1 Theme 1: Lack of Knowledge about the Importance of Cord Blood Donation among Pregnant Women and Healthcare Professionals**

A few studies have been conducted on the national scale to investigate parents’ expectations and motivations regarding storing their infants’ umbilical cord blood stem cells in cord blood banks (Fernandez et al. 2003). Katz et al. (2010) conducted a study on five European countries – France, Italy, Germany, Spain and the UK – to analyse pregnant women’s awareness of and attitudes towards cord blood stem cells and cord blood banking. The results showed that more than 79.4% of pregnant women said that they have poor knowledge of cord blood banking and almost all of them would like to receive information about this topic whereas a study in the city of Zagreb, Croatia, highlighted that although pregnant women were well aware about different cord blood banking options, but they have insufficient knowledge about the practical information and beneficial use of cord blood banking (Matijević and Erjavec 2016).

More than half of pregnant women in all of the five countries received information about cord blood from the media whereas 20.6% of them received information about cord blood from their general practitioner, midwife and obstetrician. One of the key findings in this study showed that almost 90.6% of pregnant women believed that proper information about cord

blood stem cells should also be shared with the fathers and they must be involved in the decision making. Most of the pregnant women from these studies stated that they prefer to donate their newborns' UCB stem cells to public banks (Katz et al. 2010). However, in many countries, a lack of funds has led to slow expansion of public banks whereas there has been an increase in the expansion of private commercial banks which the consumers are made aware of through campaigns and media advertisements, often bypassing midwives and obstetrics (Benichou 2007). Most of the pregnant women interviewed are influenced by different private cord blood banking advertisements via booklets, online and television, while remaining unaware about the options for public donation (Fox et al. 2007). Pregnant women are willing to donate their infants' umbilical cord blood if they have more information about public donation. Similar results were found among the Indian population where most of the pregnant women had poor knowledge about cord blood donation and the different banking options, and more than half of them expected to receive information about cord blood stem cells from their obstetricians (Pandey, Kaur and Kamath 2016). Moreover, Pandey, Kaur and Kamath (2016) showed that 58% of doctors among the Indian population were either unaware about cord blood donation or misinformed about umbilical cord blood transplantation. Overall, these research findings indicate that there is a huge lack of knowledge about cord blood donation among pregnant women, the general population and obstetricians and thus many healthcare providers should play a greater role in increasing awareness among pregnant women about the importance of cord blood donation (Tuteja, Agarwal and Phadke 2015)

To understand more about healthcare providers' knowledge and opinions towards cord blood donation, research was conducted in the USA to study the level of awareness and understanding among practicing obstetricians about cord blood donation and its therapeutic usage in transplantation (Walker et al. 2012). These results showed that nearly all of the obstetricians had good information about cord blood and different banking options and its

usage in transplantation, and they were confident about answering patients' questions regarding cord blood banking. However, they were not confident about answering questions related to cord blood donation. This outcome was despite the findings that 95% showed their full support in encouraging their patients to donate cord blood and 82% showed interest in encouraging their colleagues to collect more cord blood public samples, thus showing their positive attitudes towards the community and willingness to play a vital role in expanding the public inventory in the USA. Most of the obstetricians were aware that umbilical cord blood stem cell is a suitable and powerful alternative source for bone marrow transplantation for both adults and children (Walker et al. 2012). Almost all of the obstetricians knew that private banking charges fees for storage, but many of them were not aware that there is no cost for a woman to donate her newborn's UCB stem cell to public banks. One of the healthcare providers' goals should be to make sure that pregnant women can make well-informed decisions about the different cord blood banking options (Fox et al. 2007).

Obstetricians and other healthcare providers delivering obstetric and prenatal care should play essential roles in increasing awareness about the importance of cord blood donation and be active participants in expanding public bank activities (Herlihy and Delpapa 2013). Moreover, the first study of its kind was also conducted in Jordan to explore public knowledge and opinion regarding cord blood banking. The survey results showed that more than 75% of respondents had no knowledge at all about cord blood banking in Jordan, while more than 50% had not heard about cord blood banking at all, and stated they would like to receive more information about it from their obstetricians. Despite the global development of umbilical cord blood banking facilities around the world, there is still little known about public awareness and attitudes among the Arab populations (Matsumoto, Dajani and Matthews, 2015). Very few studies have examined the knowledge, awareness, practice and attitudes of obstetricians and midwives towards cord blood donation, despite the existence of cord blood

banking options for expectant mothers and the promising results and increases in its clinical application during the last two decades (Peberdy, Young and Kearney 2016).

Many pregnant women in developing countries are faced with ignorance, fear, confusion and disagreement about the cord blood donation process. Therefore, understanding blood donors' motivations and barrier is crucial to improve the effectiveness of donor recruitment (Grossman et al. 2005). Knowing the main motivators and barrier towards cord blood banking will help in tailoring the targeted campaigns, educational tutorials and effective road shows.

Research has found that knowledge is very important in the decision-making process, and women who have more information about UCB banking are more likely to make the right choices for their children and families (Kharaboyan et al. 2007). Knowing the right information about the importance of UCB banking and its promising potential usage in the future is therefore very important (Fernandez et al. 2003). Recently, a number of internet sites and magazine advertisements are emerging urging women not to lose the once-in-a-lifetime opportunity to store a newborn's UCB. To enable mothers to make the right decisions about UCB banking, it is very important that women have complete and accurate information about cord blood from special health educators and care providers (Armson, Allan and Casper 2015). A survey tool was used to evaluate the main motivators and barriers to cord blood donation among African-American women. Participants believed that promoting awareness about the importance of blood and cord blood donation is the single most important strategy that can be employed to increase the number of cord blood donors (Grossman et al. 2005). Full and complete information about umbilical cord blood storing or donation is essential; however, Armson, Allan and Casper (2015) illustrated that most pregnant women are under-informed about the most important information on cord blood banking. Most of the private cord blood banks only share with parents the information that is in the commercial organisations' best interests in order to gain more customers and profits. Health educators

should clearly explain that there are three main resources for stem cells as many mothers refuse to donate because they are afraid that the cells will be used for embryonic research which brings with it many ethical questions and acts as a barrier to mothers donating (Grossman et al. 2005). Parents should be aware that they should consider banking their newborns' UCB stem cells privately only if they have a relative with a known illness that can be treated by stem cell transplant, otherwise donating the newborn's UCB stem cells to public banks will be more beneficial (Armson, Allan and Casper 2015) . Therefore, due to the poor knowledge of pregnant women about the beneficial usage of UCB, there is an essential need for more effective health education. Increased knowledge can result in introducing changes that raise the level of awareness which in turn will positively affect the level of understanding and quality of decision making among pregnant women (Baba and HakemZadeh 2012).

### **2.5.2 Theme 2: Concerns regarding improper use of Stem Cells**

Many pregnant women in Jordan are disappointed with the availability and the quality of information about cord blood banking. Most of them received information about cord blood banking from the media and promotional material and the least information was received from physicians. The study conducted in Jordan showed that uncertainty of information among women raised misconceptions and ethical concerns about cord blood banking, and that physicians rarely shared information about cord blood and its banking options with pregnant women. This is due to limited cord blood banking options, lack of knowledge among physicians, and the newness of the field in Jordan (Matsumoto, Dajani and Matthews, 2015). A similar study conducted among pregnant women in Korea also showed that the media and internet were the main sources of information available to pregnant women and minimal information was obtained from the obstetricians as they played the smallest role in donor recruitment (Kim and Shin 2015). In addition, a similar study conducted in five different Europe countries highlighted that a proportion of respondents in the five countries (25.5%

Germany, 17.1% UK, 10.2% France, 2% Italy and 5.1% in Spain) prefer to destroy their child's cord blood rather than donate it as their main concern was to protect their children's genetic information from third parties, which reveals their uncertainty about and lack of trust in cord blood banking. The reason for that might be because almost half of pregnant women in the five surveyed countries received information about cord blood from the media, internet and radio which does not consistently deliver the correct and most up-to-date information (Katz et al. 2010). Danzer et al. (2003) showed that there are important valid concerns among pregnant women who donate their umbilical cord blood, and such concerns and issues should be taken into consideration when banking cord blood. These concerns include genetic testing and different laboratory experiments conducted on cord blood samples. Similar concerns were also found among pregnant women in an early study conducted by Surbek et al. (1998) where 40% of pregnant women had concerns about what happens to the placenta after birth. Thus, there is a clear need for counselling pregnant women and providing detailed information to them about cord blood banking and the use of the placenta and its blood, as well as their beneficial clinical use in allogenic transplantation.

### **2.5.3 Theme 3: Receiving Knowledge about Cord Blood Donation from their Obstetricians and Midwives**

Among most of the studies one of the main motivating factors found that inspires pregnant women to donate their newborns' UCB stem cells is when they receive cord blood information from their obstetricians. Antenatal care providers can play an important role in assisting expectant mothers with their decisions by providing accurate, balanced and evidence-based information about cord blood and the banking options (Cooper and Severson 2013; Kharaboyan et al. 2007; Herlihy and Delpapa 2013; Martin, Kutzberg and Hesse 2011).

Despite the positive attitude of pregnant women towards umbilical cord blood banking, most of the studies showed that they lack some important information about cord blood usage,

differences between both banking options, and the importance of cord blood banking (Kharaboyan et al. 2007). In most of the studies reviewed pregnant women also highlighted that media, the internet and commercial advertisements were the main sources of information obtained about cord blood banking (Kharaboyan 2007). The study conducted in five European countries also showed that more than half of pregnant women (59.6%) in the sample countries received information about cord blood banking from the media whereas only 20.6% received information from midwives, obstetricians and general practitioners (Katz et al. 2010). In addition, a study conducted in two university hospitals in Zagreb, Croatia showed that only 6% of pregnant women received information about cord blood banking from their gynecologist, while almost 60% of maternity staff claimed that they do not have enough knowledge about cord blood and need more (Matijević and Erjavec 2016). Thus midwives, nurses and obstetricians should achieve a sufficient level of information about cord blood to motivate pregnant women. Cord blood education, however, should not be the sole responsibility of obstetricians. Other physicians should be considered too such as general pediatricians who also see expectant parents during pregnancy. Thus it is also important to identify their role within cord blood education (Armstrong et al. 2018).

Kharaboyan et al. (2007) showed that it is important to be supplied with adequate and complete information from obstetrical care providers for expectant mother to make informed decisions. Knowledge is probably one of the most important factors in the decision-making process; women who have more information about umbilical cord blood banking are more likely to make the right choices for their family.

#### **2.5.4 Theme 4: Being part of Humanity Act by helping Patients in need for Cord Blood Transplant**

Among the five countries in the European study, 76.5% of women would like to donate their cord blood stem cells to public banks because 59% of women believe that they can contribute

to public health by donating their cord blood to help other patients who are in need of transplantation, whereas 26% will opt for donation because it is free of charge (Katz et al. 2010). This confirms the positive attitudes of pregnant women toward the community and their willingness to increase donations and expand the public registry within EU countries. A similar study conducted in Canada highlighted that most of the pregnant women would like to choose to donate their newborns' UCB stem cells to public banks for altruistic purposes because private bank fees are very expensive and public banks make cord blood available for unrelated receipts (Fernandez et al. 2003). This act of humanity motivates pregnant women to donate their cord blood in an action similar to those who register on an unrelated bone marrow transplant registry. Similar results have been shown among Swiss women who strongly support public donation and show positive attitudes and prosocial actions towards the community (Danzon et al. 2003).

Table 2-1 summarises the different themes obtained from various strands of literature about the main barriers and motivations towards blood and cord blood donation. As shown in Table 2-1 below, the main barriers to expectant mothers donating their cord blood stem cells are lack of knowledge and perceived improper use of stem cells. Conversely, the main motivators that encourage them to donate their newborns' UCB stem cells are when they are informed about the process by their midwives and physicians, and the altruistic desire to take part in humanitarian acts in order to help many patients in need of cord blood stem cells.



**Table 2-1 Summary of the main themes obtained from literature regarding blood and cord blood barriers and motivations.**

<b>Themes obtained from the literature on blood and cord blood donation</b>	<b>Blood donation themes Barriers and motivations towards blood donation</b>	<b>Cord blood donation themes Barriers and motivations themes towards cord blood donation</b>
Theme (1)	<b>Barrier (1):</b> Misinformation about Blood Donation	<b>Barrier (1):</b> Lack of Knowledge about the importance of Cord Blood Donation among Pregnant Women and Healthcare Professionals
Theme (2)	<b>Barrier (2):</b> Anxiety and Fear of Donating Blood	<b>Barrier (2):</b> Concerns Regarding improper use of Stem Cells
Theme (3)	<b>Barrier (3):</b> Fear from Selling the Blood and Failure to Develop Positive Attitudes Towards Blood Donation	<b>Motivator (1):</b> Receiving Knowledge about Cord Blood Donation from their Obstetricians and Midwives
Theme (4)	<b>Motivator (1):</b> Being Part of Humanity by Donating Blood	<b>Motivator (2):</b> Being part of Humanitarian Acts by Helping Patients in Need of Cord Blood Transplants.
Theme (5)	<b>Motivator (2):</b> Willingness to Donate Blood to Help Families and Friends	

## **2.6 Cord Blood Donation: Cultural, Religion and Environmental Challenges**

The study conducted in Jordan is the first independent study in the Arab world on cord blood banking. It is also the first study conducted in a Muslim country with different cultural and religious perspectives when compared to other similar studies conducted internationally about cord blood banking and pregnant women's knowledge and opinions about the issue. In a Muslim country, obtaining religious approval and parental consent for collecting, processing and storing cord blood stem cells is important and needs to be managed cooperatively within banking policies (Matsumoto, Dajani and Matthews 2015). Almost all of the international standards for cord blood collection require the mother's consent before collecting cord blood stem cells but the father's consent is most often not required according to Net-Cord and FACT standards for cord blood collection and banking (NetCord and FACT 2016). However, many respondents within the Jordanian study preferred to obtain the consent of both the mother and the father; this is due to cultural issues within Jordanian society and most of the Arab societies where the father plays a key role in decisions and his authority should always be deferred to when it comes to his wife and children (Petrini 2010). This is one of the most important findings among Arab culture and society where the husband plays a very important role in family decision making.

### **2.6.1 Islamic Perspective towards Cord Blood Banking**

In the Muslim tradition, blood is treated with great respect due to its religious implications. Donation of blood or cord blood is permissible in Islam due to the act of the Prophet Mohammed of traditional medical practice of drawing blood from the skin using vacuum containers for health reasons (Diamond 2015). Donation of fluid and soft parts of living humans is not prohibited in Islam and does not cause any ethical problems. However, Islam bans the sale of any blood products, tissue or any part of the human body because it does not

treat blood, tissue or any part of human being as products for sale (Jordens et al. 2012). Most of the religious scholars have considered blood donation as a “collective duty” that serves the whole Muslim community to ensure an adequate supply of blood to all blood banks for use by patients in emergency cases, wars and accidents. Moreover, placenta and umbilical cord blood is regarded as waste and it was not recognised as having beneficial treatment effects until more recently (Tobin et al. 2012). Therefore, the use of hematopoietic stem cells in terms of collection, donation and use for transplantation does not raise any ethical or legal issues in Muslim culture (Al-Aqeel 2005). Thus, there is no restriction in Islam against donating umbilical cord blood to public banks or preserving it for use even though some Muslims prefer donating umbilical cord blood to public bank as it plays an important role in promoting the health of human beings and treating many patients with life-threatening diseases (Fadel 2007).

### **2.6.2 Jewish Perspective towards Cord Blood Banking**

Judaism encourages screening and preventing illness because it looks at every moment of human life as a holy entity that should be protected from any illness. However, Judaism is against any type of treatment that has a high possibility of causing the death of the patient or requires killing of the donor. Such research includes sperm donation, tissue research and embryo fertility treatment which should be carried out within specific defined parameters according to Jewish law (Jordens et al. 2012).

Despite the fact that there are disagreements regarding embryonic stem cell research in Jewish law, blood and cord blood donation along with its collection, harvesting and storage are very much encouraged in the Jewish religion as they play an important role in promoting human being's health. Donation and banking of umbilical cord blood stem cells for family or public use is thought to be highly advisable in Jewish religion due to their promising results in both

autologous and allogenic transplantation and so long as it does not interfere with the infant's and mother's health during the birth. (Jordens et al. 2012).

However, drawing circulatory blood is one of the prohibitions on the Sabbath as discussed in mediaeval sources but, once umbilical cord blood is separated from the newborn, the blood within the cord is not considered as part of infant circulatory blood flow and both placenta and umbilicus with blood is considered the mother's property according to Jewish law (Fadel 2007). Consequently, the hospital requires the mother's permission to collect and bank umbilical cord blood for both public and private banking purposes. Moreover, if the hospital would like to take commercial advantage of cord blood cells or tissue, the mother's permission should be given. Nevertheless, according to Jewish law, if the mother dies during the delivery then the placenta needs to be burned with her as it is considered part of her circulatory system but the umbilical cord blood can still be collected if that collection will play a role in preserving life (Fadel 2007).

### **2.6.3 Catholic Perspective towards Cord Blood Donation**

In the Catholic tradition, donation of organs, tissue blood and cord blood are very much encouraged, while upholding the most important fact that any therapeutic use of...of blood, organ, tissue or stem cells should not cause any obliteration to human life. The life of an embryo should be given its weight against the beneficial usage obtained from different fields of scientific research (Hug 2006). In cord blood donation, it is the parent's right to choose whether they would like to donate their cord blood stem cells for public or private banking since it is their responsibility to make an informed decision about the health and care of their own child.

Helping others and curing sickness is always encouraged amongst Catholics and primacy should always be given to the patient in need depending on the level of urgency. Therefore,

currently the main debate amongst Catholics is how the donation and banking of stem cells can be made available to patients who are in urgent need, now and in the future. Thus, this raises the question: should Catholic hospitals encourage parents to donate their umbilical cord blood stem cells or store them for their own family use? (Jordens et al. 2012). A Catholic healthcare system should encourage a pregnant women to store her own cord blood stem cells if the family has a medical condition in which hematopoietic stem cells transplant will be useful treatment (Samuel et al. 2007). Otherwise they should encourage pregnant women to contribute to the common good by donating the umbilical cord blood stem cells to public cord blood banks. The most important issue is that Catholic hospitals should not promote cord blood as a commodity (Jordens et al. 2012).

### **Conclusion to chapter**

In this chapter, drawing from literature, the researcher summarised the main barriers and motivations towards blood and cord blood donation, categorised into themes as shown in Table 2-1. The literature shows that two main barriers that prevent donors from donating their blood to others are misinformation about blood donation and anxiety/fear from donating blood. The main barriers that prevent expectant mothers from donating their newborns' UCB stem cells is lack of knowledge about the importance of cord blood donation among pregnant women and healthcare providers as well as concerns regarding improper use of stem cells. All of these reasons and factors fall under the category of "knowledge" as the main factor that can help with overcoming misinformation, lack of information, and fear. Therefore, there is an essential need for continuous awareness and education about blood and cord blood donations. The review of the literature identifies the main motivation factors towards blood and cord blood donation. Both blood and cord blood donors are motivated by being part of humanity and helping patients, families and friends. In addition, cord blood donors would like to receive knowledge about cord blood from their obstetricians and midwives due to the trust

they have in their physicians. Consequently, it will be interesting to know more about the main motivations and barriers towards cord blood donation among expectant mother in the UAE in order to design strategic communications plans between DCRC and hospitals in the UAE.

## **CHAPTER 3: LITERATURE REVIEW: THEORIES INFORMING THE RESEARCH**

### **Introduction to the chapter**

This chapter addresses the literature on Service Dominant Logic and culture historical activity theory. S-D logic has become a common approach in the analysis of business and marketing. It focuses on service (singular) instead of services (plural) and analyses it as the process that creates value in use (benefit). Service is defined as “*the application of specialized competences (knowledge and skills) through deeds, processes, and performances for the benefit of another entity or the entity itself*” (Vargo and Lusch 2004, p.2). Value co-creation is a fundamental process that focuses on reciprocal exchange among actors where all actors work as a team to create input in each other’s activities (Vargo and Lusch 2004, 2008, 2016). Activity theory is a framework that investigates different structures of human practices under the scope of historically developed cultural systems by combining individuals with society (Engeström 1999). Individuals plan and recognise their actions using both theoretical and practical tools and their actions are always studied based on their culturally related contexts. The historically developed activity system is the context of individual action which is viewed as the smallest unit of analysis within human activity (Kaptelinin, Nardi and Macaulay 1999).

### **3.1 Service Dominant Logic – SDL**

Due to the development of the business environment around the world, business scholars became motivated to learn more about how value is created between consumers and suppliers. The economic business exchange based on value co-creation in different service networks is known as Service-Dominant (S-D) logic. The term “logic” in SDL is from a Greek word “logikos” which means coherence, rigour in the reasoning, logical, dialectical, and argumentative. In the economic and business world, the word “logic” means principles and

beliefs that reflect the different values and interests of researchers and specialists adopting it (Kuhn 1970). In 2004, Vargo and Lusch officially introduced Service-Dominant (S-D) logic in the marketing community in their article titled “Evolving to a New Dominant Logic for Marketing”. Based on value co-creation in the service network, Vargo and Lusch proposed logic as an approach for business and economic exchange. Despite the fact that S-D logic has been discussed in a wide range of different settings, only limited research has tested the S-D logic. Most of the research is conceptual as the majority of the publications focus mainly on improving the foundation of S-D logic. In the last few decades, and by taking into consideration the role of the firm, researchers have tried to identify the differences between a good and a service to be able to introduce this new concept among service management (Vargo and Lusch 2004). The view of S-D logic is different than the Good-Dominant (G-D) view. In G-D the value is mainly stored and embedded in the product during the production process as the value is pre-determined and released upon the product consumption. G-D logic focuses on the exchange of the tangible resources where the customer is not involved in the process. This kind of logic is called “Fordism” which is a mid-twentieth century philosophy. However since the 1980s, many scholars such as Gummeson (1987); Håkansson and Snehota (1995); Barney (1991); and Morgan and Hunt (1994) began to challenge the logic of Fordism and replace it with new models and approaches but were still not able to create a new paradigm (Kuhn, 1970). However, by the twenty-first century, many essential changes occurred in attempts to build a new logic for marketing (Gummeson 2008b). Table 3-1 shows the development of New Dominant Logic for marketing from pre-1900 to 2000 and beyond (Vargo and Lusch 2004).

Vargo and Lusch (2004, p.2) introduced S-D logic and defined it as “*the application of specialized competences (knowledge and skills) through deeds, processes, and performances for the benefit of another entity or the entity itself.*”



Thus, this new approach of marketing involves customers and facilitates the process that can help and support customers which is different than “goods logic”. Therefore, the role played by the customer reflects the key difference between “service logic” and “good logic”. Grönroos (2008) highlighted that, in a situation of *good* logic, the customer is unaware about the value created from the interaction between producer and customer whereas in a situation of service logic, resources such as goods, information, people, systems and infrastructure are utilised particularly during consumption and it uses process to create value between producer and customer (Grönroos 2008). The customer is the principal actor of value co-creation and considered the main foundation of S-D logic. The customer is the one who determines the value after utilising the product; therefore the value is always co-created after the interactions take place between the provider and the customer where resources are incorporated and competencies are applied (Vargo et al. 2008). Service is considered the dominant logic of marketing because of its shared process which is shown by “doing something for someone” and thus creating value (Vargo and Lusch 2006).

**Table 3-1 The development of the New Dominant Logic for marketing from pre-1900 to 2000 and beyond (Vargo & Lusch 2004).**

The Development of new Dominant logic for marketing through different years	
Year	Concept of Economic
Pre-1900	Goods such as statics and operand resources were the main Model of Exchange in marketing.
1800- 1920	During these years marketing was viewed as classical Economic “application of motion to matter” (Shaw 1912, p.764) by changing its form and place. The change in form is called “production” and the change in place is called “distribution”.

1900-1950	During these years marketing was viewed as Descriptive Economic through commodities, marketing institutions and marketing functions.
1950-2000	During these years marketing started to shift to new orientation introduced through different management school discussing issues related to customer orientation, value determination, marketing management and techniques.
1980-2000 and beyond	During these years and to the present time marketing was viewed as a social and an economic process through quality management process, service marketing, networking, resource management and competitive process.

### 3.2 Principles of SDL

Firms need to strategically to increase their service orientation to be able to increase profit margins. Service-dominant logic emerged to challenge the traditional marketing practice by positioning service as dominant in marketing logic (Kowalkowski 2010). S-D logic treats any kind of integrated knowledge between buyer and supplier. There are ten foundational premises (FP) of S-D logic where some of them have profound implications for manufacturing firms and are important for further discussion. Below is a summary of the ten foundational premises of S-D logic and the differences between it and G-Dominant logic (Vargo and Lusch 2004).

#### 3.2.1 FP1: The Application of Specialised Skill(s) and Knowledge (i.e. service) is the Fundamental Unit of Exchange:

Where service is exchanged for service, it is referred to as the fundamental unit of exchange. S-D logic mainly focuses on the exchange of operant recourses such as knowledge and skills where “service” is the foundation of all exchange (Vargo and Lusch 2004).

There are two types of operant resources among people which are physical and mental skills that are distributed equally in a population. Each person is specialised in specific skills which make them achieve different scale effects within the community. For the benefit of the society, such specialisations need to be exchanged among people (Macneil 1980). Thus studying the exchange between different ancient societies showed how division of labour within and between clans leads to tendering of “total services” by exchanging (giving and receiving) gifts among the people within the group. However, Mauss (1990, p. 6) highlighted that *“There is total service in the sense that it is indeed the whole clan that contracts on behalf of all, for all that it possesses and for all that it does.”*

This exchange of specialisation highlighted two different views that explained the definition of exchange. The first view highlights performance specialised activities’ output whereas the second one involves specialised activities performance. Thus, one party is specialised in angling knowledge and skills and another party is specialised in disseminating that knowledge and skills. This lead to recognition of the relationship between specialised skills and exchange where the concept of division of labour helped lay a foundation for Smith’s work in economics (Smith 1904). Smith showed that human skills were the foundation of exchange but his view about “productive” activity was limited only to the creation of tangible goods and their exchange output. Frédéric Bastiat was one of the first economic scholars to challenge the dominant view and believed that value was only associated with tangible objects and humans were only able to transfer operand resources to a satisfactory desired output by using their skills (operand resources).Despite the narrow focus in his findings regarding the tangible output and its exchange value, it resulted in several advantages in the early economists’ journeys by shifting the economic philosophy and marketing from distribution of physical goods to the process of exchange (Weld 1916).

### **3.2.2 FP2: Indirect Exchange Masks the Fundamental Unit of Exchange:**

Over time in the vertical marketing system and bureaucratic hierarchical organisations, the idea of exchange has changed and moved from specialised skills of one-to-one trading to indirect exchange of a broad range of skills. Subsequently, direct trading partners disappeared due to the fact that most of the marketing workers stopped interacting with customers due to increased growth of vertical marketing systems, categorised organisations, and the large increase in division of labour in the industrial society (Webster 1992). These forces resulted in the masking of skills-for-skills (services-for-services) natural exchange. The Industrial Revolution had a great impact on the efficiency of the true nature of exchange. To produce what people wanted, workers' specialisations increased and expanded to become micro-specialisations that evolved further into specific narrow-skilled competencies. This made it easier for people to provide the organisations with the micro-specialisations they needed to meet the needs of their consumers. Thus, the micro-specialists completed the products and interacted with the customers but were indirectly compensated monetarily by the organisation in exchange for the skills. Therefore, the organisation masked the nature of skills-for-skills (services-for-services) exchange and it continued to increase in size and realised that workers performing micro-specialization function had lost the sense of interaction with both internal and external customers (Hauser and Clausing 1993).

### **3.2.3 FP3: Goods are Distribution Mechanisms for Service Provision:**

Tangible products are considered the main fundamental components of economic exchange and the manufacturing of goods is the main interest of the developing science of economics (Zaheer and Venkatraman 1995). However, today, marketing has moved beyond distribution and exchange of goods where goods are no longer the common denominator of exchange. Currently, physical skills including specialised knowledge and mental skills are considered

the common denominator of exchange (Vargo and Lusch 2004). Norris (1941) was one of the first scholars to highlight that people want goods because they provide services; thus people buy goods to own them, display them, use them and experience them which, in turn, provides fulfillment and creates stratification and esteem which are more than just basic functions of a product. Therefore, Gutman (1984) confirms that goods are considered either as providers of satisfaction for higher-order needs or distribution mechanisms for services.

### **3.2.4 FP4: Knowledge is the Fundamental Source of Competitive Advantage:**

Knowledge is the key source of wealth and the foundation of competitive advantage. Knowledge is an operant resource that consists of propositional knowledge which refers to techniques that include skills and competencies which are used by the entities to gain competitive advantage (Mokyr 2002). Capon and Glazer (1987) showed that knowledge and technology play important roles in a firm's productivity as technology includes product, process and management technologies. *Product* technology embeds different ideas into the product whereas *process* technology inserts ideas within the manufacturing process of the product, and *management* technology mainly focuses on management procedures associated with product sales. Normann and Ramirez (1993) highlighted that to be able to create a successful system, it is important to have the ability to conceive associated value in its entirety which is the only true source of competitive advantage. Barabba (1995) claimed that marketing, which is based on knowledge and decision making, provide the enterprise with the required core competence to assure competitive advantage.

### **3.2.5 FP5: All Economies are Services Economies:**

In S-D logic, 'service' (singular) defines a process when someone does something for someone else whereas 'services' (plural) indicates the units output which is mainly associated with G-D logic. With increased specialisation and outsourcing in marketing, 'service' has

become more apparent (Lusch and Vargo 2006). People are continually moving towards more detailed and specific specialties, thus making the need for outsourcing from different organisations essential. The traditional economic and marketing businesses underestimated the new changes and the rise in services and specialties; thus services are only more recently becoming more apparent in the economy.

### **3.2.6 FP6: The Customer is always a Co-producer:**

From the manufacturing perspective of the traditional goods-based exchange, the consumer and producer are usually separated to ensure maximum manufacturing productivity. However, from the service-centred view of marketing, the consumer plays an important role by always being involved in the production of value. Production is an intermediate process which does not end in the manufacturing process; instead, goods provide services for the consumer who in turn uses, restores, maintains and adopts the application according to his/her needs, situation and behaviour. Normann and Ramirez (1993, p.69) highlighted that “*The key to creating value is to coproduce offerings that mobilize customers*”. Marketing now provides a venue for proactive customer involvement in the value co-creation process where the customer is the co-producer (operant resource) in the entire value and service chain rather than being an operand resource (Prahalad and Ramaswamy 2000).

### **3.2.7 FP7: The Enterprise can only make Value Propositions:**

The traditional marketing view considered value as something embedded into goods during the manufacturing process. Service marketing scholars reconsidered the idea of value being embedded within tangible goods and studied the different published service marketing literature in depth to redefine and re-examine the value-creation process. Gummesson (1998) and Grönroos (2000) argued that the consumer is the main focal point of marketing and, thus, value co-creation can only occur if a good or a service is consumed because the service

provider cannot produce anything without the customer and an unsold good has no value if it has not been purchased. Vargo and Lusch (2004) agreed with both Gummesson and Grönroos but extended their logic by highlighting the fact that the enterprise can only offer value propositions where the consumer must determine value and create it by participating in the co-production process. A tangible good is embedded with knowledge that has value potential that meets the customer's needs and it is important that the consumer understands that – through production – value potential is exchangeable for specific needs.

### **3.2.8 FP8: A Service-centred View is Customer- oriented and Relational:**

The service-centred view emerged in the sense of doing things not only for the customers but also in concert with the customer. The hallmarks of a service-centred view are integration, interactivity, customisation and co-production. Customer interaction and relationships form one of the most crucial contributions to relationship marketing (Vargo and Lusch 2004). Thus, the human is considered the central and the active participant in the exchange process of the service-centred model. Service is defined as when the customer determines the benefits and is able to co-create value, which creates the opportunities to expand the market and support the consumer in the development of specialisation and value co-creation. The service-centred approach views operant resources such as skills, core competencies and knowledge as a key for attaining competitive advantage where the resources directly and indirectly – are developed and coordinated to deliver the desired benefits to the customers (Vargo and Lusch 2009).

### **3.2.9 FP9: All Social and Economic Actors are Resource Integrators:**

Foundational premise 9 was not included with the original set of FP that was published by Vargo and Lusch (2004). However, it was later introduced by Vargo and Lusch in 2006) where they highlighted the fact that all economic entities are resource integrators. The role of

the firm's resource integration is equally related to individuals and households. Thus, this uniquely integrated resource motivates and creates exchange constructed by economics and social actors.

### **3.2.10 FP10: Value is always uniquely and phenomenologically determined by the Beneficiary:**

It is important to know that there are two main components of value co-creation which are co-creation of value and co-production (Lusch and Vargo 2006). In G-D logic, value is added to the products during the production process and at the point of exchange (value-in-exchange) whereas, in S-D logic, co-creation of value is the most encompassing component as the customer is the only one who determines and creates value in the consumption process and through the use of the product which is called "value-in-use" (Vargo and Lusch 2004). The second component of co-creation is co-production which involves participation in the creation of the essential offering itself. Such participation can be through inventiveness or co-design, and also can involve customers or other partners included in the value network. Therefore, the interplay between interaction and network is considered the central point of value co-creation and exchange as, from the marketing stance, S-D logic involves both social and economic processes (Lusch and Vargo 2006).

### **3.3 Co-creation Value**

S-D logic has introduced a new marketing approach which mainly highlights the significance of the customer role, integration of resources, and interactions between different actors (Payne et al. 2008; Lusch and Vargo 2011). Prahalad and Ramaswamy (2004b) underlined the importance of studying value co-creation in the context of service marketing and consumers. Value co-creation was first defined by Prahalad and Ramaswamy (2004a) who underscored the importance of the joint creation of value between the company and the customer where



both of them create value. However, in 2008, Vargo et al. (2008) defined value co-creation in greater detail by highlighting that value is co-created through the integration of different existing resources available from different service systems where the value is derived from and defined in context. However, Edvardsson, Tronvoll and Gruber (2011) defined value co-creation as something that takes place within social systems where the actors such as customers and suppliers implement certain social rules and positions and interact to produce social structures. Meanwhile, Grönroos and Ravald (2011) defined value co-creation as joint activities between the parties that are interacting with each other and aiming to contribute the value of the outcome.

Value co-creation is a concept that allows products or services to be collaboratively created between producers, customers and stakeholders (Golooba and Ahlan 2013). The process mainly includes assessing resources by one entity through adapting, integrating and applying resources in a specific context. Value co-creation has a number of advantages including understanding customer needs, and promoting inter-organisation co-operation which in turn will result in competitive advantage and superior firm performance (Edvardsson, Tronvoll and Gruber 2011). Service systems are considered one of the main vehicles for value co-creation. A service system is mainly defined as the way an organisation arranges and manages its people, technology and business processes in order to support exchange of services between different organisations and value co-creation. Value propositions can be made based on organisational capabilities and competencies in which other systems are able to accept, adapt and integrate into the context (Vargo, Maglio and Akaka 2008).

Co-creation value is very important for companies and worth consideration in today's economy (Vargo, Maglio and Akaka 2008). Co-creation is essential as it aims to increase the organisational knowledge processes via involving customers and creating value (Ind and Coates 2013). For the purpose of co-creating value, the customer is transformed from being a

passive partner into an active partner (Payne, Storbacka and Frow 2008). Nowadays, customers are educated and want to share their experiences with the organisation (Grönroos and Ravald 2011). In the view of the traditional dominant logic of business, value is linked with both product and services (Prahalad and Ramaswamy 2004a). The process underlying value creation is mainly focused on the organisation which creates and offers value to customers (Grönroos and Voima 2013). Because today's customers are more knowledgeable and better educated, they usually seek to interact with organisations and participate in value co-creation by sharing their own experiences (Grönroos and Voima 2013). Therefore, nowadays we are facing new concepts of business which mainly encourage people's integration and involvement with the surrounding business environment (Prahalad and Ramaswamy 2004 b).

Market offering is considered a conventional way of doing business that seeks to provide value to customers through organising activities and creating goods and service (Prahalad and Ramaswamy 2004a); in this context, the customer will be inactively consuming the services offered by the organisation. However, today, service is viewed in a different way and has moved away from treating customers as passive participants to active ones by empowering them and increasing their interaction with the organisation (Prahalad and Ramaswamy 2004a). Depending on the context, value co-creation needs specific resources and competencies (Vargo and Lusch 2004) in SDL logic and, more specifically, in value co-creation, operant and operand resources are distinguished (Vargo and Lusch 2008). To create value, *operant* resources (knowledge and skills) are able to act upon other resources whereas *operand* resources mainly act to derive benefits such as money, goods and natural resources (Vargo and Akaka 2009). Here, the provider and customer interact to form a co-creation process and create value. Co-creation value is a process that leads to an increase in the customer's satisfaction and happiness (Vargo, Maglio and Akaka 2008).

Vargo and Akaka (2012) showed that value co-creation does not specifically target an individual's activities or resources. However, value is co-created via integration of existing knowledge to create new knowledge along with other resources. The creation of value is not only among customers and firms but also involves government entities and social organisations. For successful value co-creation to take place in S-D logic, the integration of the resource is considered as an essential component (Vargo and Lusch 2011). Maglio and Spohrer (2008) showed the importance of integrating and exchanging resources in initiating sharing of knowledge, risk and goods. Stakeholders, customers and employees are considered operant resources that are capable of contributing and sharing knowledge for value creation (Vargo and Lusch 2008).

In S-D logic, Vargo and Akakka (2012) argue that actors from social and economic arenas are considered resource integrators who are able to contribute to value creation. Social context and structure of organised relationship along with rules and resources play significant roles in facilitating value creation. However, there is an association between value co-creation and social context because when people engage with one another, and enact exchange they will develop different relationships with each other (Akaka and Chandler 2010).

### **3.4 Co-creation Value and Service Dominant Logic in Healthcare**

Previous research on customers' co-creation value showed that, usually customers had a very limited and passive role to play in the development of the new services (Nambisan 2002). However, later approaches showed that customers play active roles as services are developed through the lens of the customer (Gustafsson, Nilsson and Johnson 2003). In healthcare, the patient is considered the only person who understands and experiences the full course of their illness and health problems starting from the symptoms, to the healthcare contact and examination, to treatment and follow up despite that, the focus of most healthcare providers is

on technical quality more than on functional quality (Grönroos 2007). In healthcare services patients are not seen as co-creators for others in the development of healthcare services (Lombarts et al. 2009).

Elg et al. (2012) conducted a study to show how customers' co-creation with others can be used to develop healthcare services. The study highlights the importance of taking patients' ideas through their participation and involvement. Despite the fact that much research has been addressed in the healthcare literature about patient involvement, participation, and patient centred- care (Entwistle and Watt 2006; Longtin et al. 2010), only limited research discusses patients' co-creation value in healthcare services. In healthcare service development, patients can be active contributors of knowledge and skills but they lack the supporting methods and tools that can help them co-create value. Vargo and Lusch (2008) showed that, for the service to be effective, it must be client-oriented with empowered employees who are able to co-create value with the clients by integrating different organizational resources. Competent and skilled employees with positive attitudes play a vital role in interacting with their customers in service exchange and the co-creation value process. Intensive service is created through the contribution of all the participants who play an important role in service formation due to their inter-dependencies. Patients' engagement became common topic of discussion in academic literatures. However, most of the academic contributions are theoretical-based with limited development and application in practice. Issue regarding "value co-creation" has received limited attention regarding patients' engagement and participation in healthcare and this might be due to the fact that National Health Service (NHS) concentrate mainly on issues concerning health at macro-level rather than micro-level (Hardyman , Daunt and Kitchener 2015). SDL theory play important role in healthcare because value co-creation brings a lot of benefits for individuals and the community (Vargo and Lusch 2008). Berry and Bendapudi (2007) showed that healthcare is considered one of

the important application regions for empirical studies. A number of studies show the link between the co-creation concept and healthcare (see e.g. McColl-Kennedy et al. 2012; McColl-Kennedy et al. 2009). McColl-Kennedy et al. (2012, p. 375) highlighted the fact that:

*Customer value co-creation is benefit realized from integration of resources through activities and integrations with collaborators in the client's service network.*

This point indicates that specific work from various different resources can be integrated by customers; such resources include peers, family members and other service providers. The social context and the structure of organised relationships along with rules and resources play significant roles in facilitating value creation (Akaka and Chandler 2010).

In healthcare sectors, the healthcare providers are mainly in control over the patient which generates different concerns in terms of the accuracy of treatment and the patient's rights in the case of complaint (Diesfield 2003). This led to a different way of looking at the patient role; by seeing them as active in their role rather than passive. This resulted in a paradigmatic shift from curing health conditions to health preventative measures and patient self-care., which in turn reduced unnecessary health costs, enhanced the communication and trust between the patient and the doctor, and improved healthcare outcomes (Michie, Miles and Weinman 2003; Ouschan, Sweeney and Johnson 2006). Even though many researchers have highlighted the importance of co-creation value between the individual and the healthcare providers, little is known about how individuals can co-create value (Payne, Storbacka and Frow 2008). Moreover, there are many different styles of co-creation value and it is important to know which style to use as it can result in different outcomes. Patients have the right to engage in different activities that can result in improving the quality of their life. For diseases that currently have no cure, such as cancer, the main goal is to achieve the best possible quality of life for patients by allowing the customers to co-create and co-produce in different ways depending on their values, skills and needs to achieve this outcome (Blanchard et al.

1988). Several different themes in health literature discuss different ways of co-creation between the individual and the health provider. The first theme highlights how patients can participate in the decision-making process along with the healthcare provider where the health problem and solutions are discussed and agreements reached (Frosch and Kaplan 1999). This kind of participation in the form of shared decision making leads to improved psychological well-being; increases the level of satisfaction between the patient and the health provider, and improves medical status (Fallowfield et al. 1994). However, several studies such as Deadman et al. (2001) and Guadagnoli and Ward (1998) showed that decisions should not be left to the patients to make as this increases anxiety at the time of treatment decisions. The second research theme includes patient motivation and involvement in healthcare management which includes preventative health behaviour such as medical checkups, and smoking termination that requires self-help. Beck, Daughtridge and Sloan (2002) showed that physicians' empathy, reassurance, encouragement and support can lead to improvements in patients' health behaviour and outcomes. Grol (2002) revealed that there is no evidence that physicians' interaction with their team is more important than their interaction with the patients in long-term healthcare. Nevertheless, Brody et al. (1989a 1989b) showed that a combination of both approaches is very effective as physicians interact with their team and the patients; this generates healthy preventive healthcare behaviours which in turn lead to positive outcomes and faster recovery (Eisenthal and Lazare 1976). The third research theme represents patient compliance in terms of doctors' recommendations which include keeping health record journals, healthcare provider instructions, and visiting doctors' clinics as instructed. Compliance with doctors' instructions result in improved patient health which is very useful for patients who are suffering from diseases such as cancers, cardiovascular diseases and diabetes , conditions which require the patients to take a more active role in their healthcare (Fattal et al. 2005). Customer co-creation of value has more extensive meaning if compared to

the three different themes discussed. Customer co-creation value includes activities with self or with other members within the service network which includes family, other patients, healthcare providers, friends and the public with who customers conduct different activities to co-create value. Such activities may require more effort such as asking the doctor for alternative therapy, a patient creating their own exercise regime as they understand their body more, or a patient managing their health with a support team around them. Thus, such co-creation activities are mainly defined as “co-production” (Vargo and Lusch 2008).

### **3.5 Cultural-Historical Activity Theory (CHAT)**

CHAT is a framework that looks at different structures of human practices under the scope of historically developed cultural systems which link individuals with society (Engeström 1999). Individuals plan and realise their actions using both theoretical and practical tools and the actions are always studied in a culturally-related context. The historically developed activity system is the context of individual action which is viewed as the smallest unit of analysis within human activity (Kaptelinin, Nardi and Macaulay 1999). In activity theoretical studies, the historical analysis of different work activities and the collective focal unit of analysis are highlighted in order to capture the qualitative transformations of the work. Thus, mental, socio-cultural and material resources that are used for action are viewed as intertwined. Furthermore, activity is intellectualised as cultural; something that is deeply contextual and focused on historical and social organisation, local practices and their defined objects and mediating artifacts. Activity theory mainly focuses on and emphasises the central role of the mediating role of tools and instruments on actions between subjects and objects. Most of the discussions within activity theory research usually deal with the concept of object because the sense and the meaning of the actions are mainly attached to the object of an activity (Engeström 2000).

There are three different generations in the evolution of cultural historical activity theory (Engeström 1996). The first generation was formed by Vygotsky who created the idea of mediation. Vygotsky (1978) showed that human interaction and communication with the social world is not direct; rather, it is mediated by cultural tools (language, text and speech) and signs (formula, numbers and symbols). This idea was depicted in Vygotsky's triangle model of "a complex mediated act" which is mainly described as a triad of subject, object and mediating artifact. However, the unit of analysis within the first generation of activity theory remained individually focused. This limitation was overcome by the development of the second generation of Leont'ev's (1978) work and his famous example of "primeval collective hunt". He expanded the unit of analysis from individual action to collective activity where he demonstrated in his example the vital role of the division of labour in differentiating between a single individual action and different collective activities. In his theory, Leont'ev highlighted that activity is driven by motive, actions are directed by goals, and operations are inspired by conditions and tools (Nussbaumer 2012).

The third generation of activity theory focuses on understanding the network interaction between different activity systems, dialogue, voices, and a range of perspectives to deal with different tensions and contradictions that can lead to change and development. It develops and expands the analysis to tackle multiple connected activity systems along with their shared objects which embody issues of subjectivity, emotion, personal sense, moral commitment and experience (Engeström 2015). Today, activity theory is an international multidisciplinary research approach (Chaiklin, Hedegaard and Jensen 1999; Engeström 1999) which is mainly oriented towards the study of work and technologies (Nardi 1996). This third-generation CHAT (Cultural Historical Activity Theory) sees shared activity or practice as the main unit of analysis where it mainly focuses on social practices and contradictions as internal tensions



that lead to change and development. Activity theory focuses on human activities and social practices by taking into consideration the surrounding specific contexts (Engeström 1987).

This current research applies cultural-historical activity theory (CHAT) (Leont'ev 1978; Engeström, Miettinen and Punamäki 1999; Sannino, Daniels and Gutierrez 2009) which views an activity as collective process that is shared among people and groups (Engeström, 2000). In activity theory, socio-cultural, mental and material resources for action are viewed as intertwined. Actions generated from activity are distributed among different people who share the same goal(s) (Engeström, Sannino 2010). Shared communicative artifacts such as signs, language, checklist and documents act as mediators in this alignment (Kaptelinin et al. 1996). An activity that answers a definite need of the subject is directed toward an object of that need. The object of an activity is true motive, which may be real or imaginary, as activity does not exist without motive (Engeström and Sannino 2010). In activity theory, the core principle is the relationship between collective motive and activity. Moreover, activity is always directed to an object which in turn results in an outcome.

In Figure 3-1, subject stands for a human being or a group of people that takes part in the object-oriented activity (Engeström 1987). Object can be raw material or a problem which, driven by the human's motive to deal with it will lead to an outcome. With the help of instruments, tools or signs, the object will be turned into an outcome. Community mainly consists of people who share the object and desire whereas division of labour mainly refers to different tasks carried out by the members of the community. Rules refer to different regulations, policies, standards and actions included in the activity theory (Engeström 1987). The circle around the object in Figure 3-1 shows the central role and the uncertainty of the activity's object. The object plays an essential role as it is the centre of interpretation, sense production, and general social transformation (Engeström 1987).

There are two types of object within activity theory – one is the *common* object of an activity and the other is the *specific* object which is specific to the subject (Engeström 1987). The generalised object is associated with shared meaning whereas the specific object is linked to personal sense. Taking the healthcare sector as an example, the common object for the medical community is provision of efficient and high-quality care to sick citizens, whereas the specific object will be a specific patient's condition (Engeström 1987). Activity systems are consistent and dependent as the activity generated by human is implemented in a chain of three different levels which are activity/action/operation (Kuutti 1996, original source Leont'ev 1978). Motive in human activity plays a central role in directing the activity into a number of different actions which in turn aim to achieve more specific goals. Depending on specific situations, actions are integrated into operation. Operation is usually adopted as people are not aware of how they are conducting operations as they become routine over time (Kuutti 1991; Kaptelinin et al. 1999).

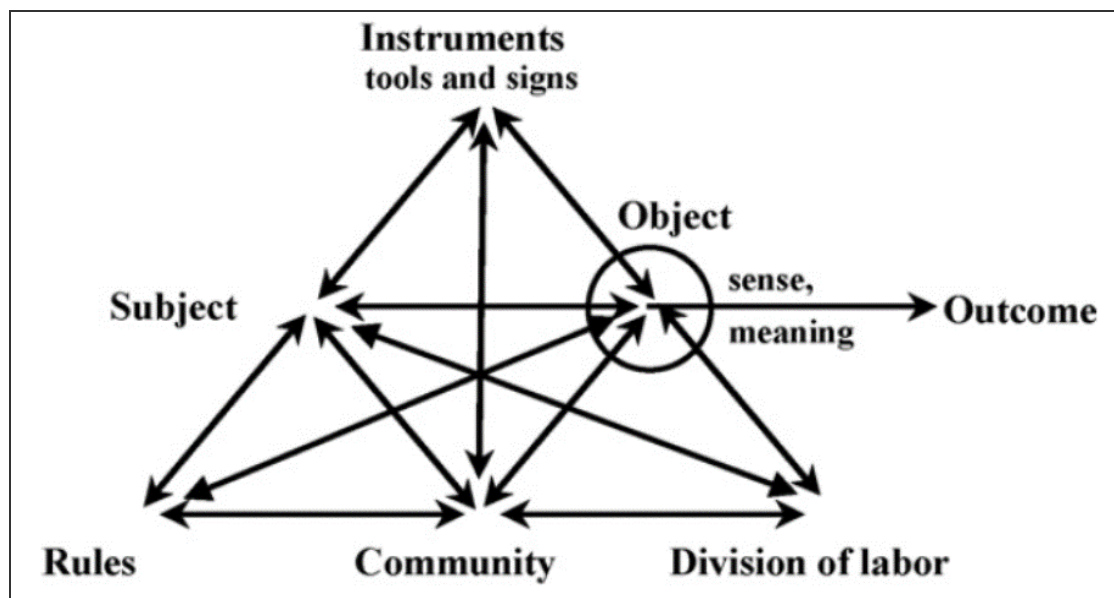


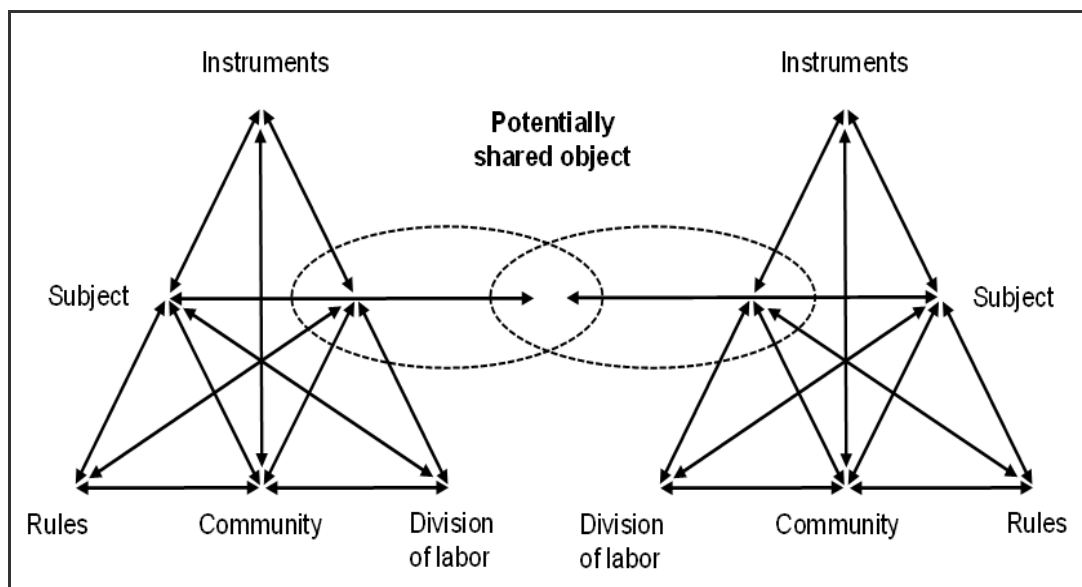
Figure 3-1 General model of an activity system (Engeström 1987, p. 78).

Contradictions are defined as a foundational philosophical concept which is not simply comprised of problems, tensions, paradox, conflicts, double bind or dilemma. Instead, they are “*historically accumulating structural tensions within and between activity systems*” (Engeström 2001, p. 137). They generate “disturbances” and conflicts which lead to activity change. They are considered the main characteristics of activity systems and the key principle in activity theory. They are also considered the driving force that lead to change and development of the activity systems. Kuutti (1996) describes a contradiction as a misfit that occurs within and between the elements of activity theory, between the different activities’ systems, or between different phases of single activity. Contradictions are important as they result in activity system transformation and development leading to innovation if they are well acknowledged and determined (Nelson 2002). However, they might not be visible or obvious to be identified and acknowledged as such (Engeström 2001), and such kinds of invisible contradictions are usually culturally related (Engeström 1993). However, there are some types of contradictions that are not discussed as they are uncomfortable, embarrassing or culturally related. Such contradictions include political issues or personal habits. There are four different types of contradiction in activity systems (Engeström 1987): (i) *primary* contradictions found in a single node of an activity and within the components of activity systems (e.g, within the object or role or any other component of the activity system); (ii) *secondary* contradictions are found between the nodes of the activity system (e.g., between rules and object); (iii) *tertiary* contradictions occur between the object of the central activity and different activity systems as the activity are remodelled to represent new motives of working; and (iv) *quaternary* contradictions are a historical disturbance that occurs between the newly developed activity system (central activity) and the old one.

### **3.5.1 Five Main Principles of Activity Theory**

- **Object-oriented Activity System**

According to Engeström (2001), an activity system is considered the main unit of analysis in activity theory. To proceed with an activity, there must be a goal-directed process that, when undertaken, fulfils an objective. An object of an activity can be anything but at the same time can be changed by the subject(s) of the activity. Objects can be soft objects, physical objects or conceptual objects. Transforming an object can change the nature of an activity, which, in a dynamic relationship, can affect the object. Goal-directed individuals, group actions and automatic operations are mainly independent of each other. Activity systems generate actions and operations and this is the way in which they reproduce themselves (Engeström 1993). Figure 3-2 shows the interlinked activity systems that reflect human activity as a dynamic model and how the object of the activity can be potentially shared.



**Figure 3-2 Human activity as a dynamic model of interlinked activity systems (see Engeström 2000, p. 306, see also Engeström 1987, p. 78)**

- **The Hierarchical Structure of Activity**

In activity theory, operations and actions direct the activity which aim towards an object. For example, actions performed by the nurse such as feeding patients or checking their temperature can contribute to research activity as a ‘caring’ action which has a defined goal.

- **Multi-voicedness**

Multi-voicedness can refer to interests, traditions, multiple perspectives which can be the cause of transformation and trouble in the system. The activity system itself carries multiple different layers of history that was engraved in the object, rules and conventions. Multi-voicedness mainly emerges from the division of labour within the activity that creates different situations as they transfer their own various histories within the activity along with the history of the activity system itself (Engeström 2001). The different multi-voicedness input from different participants interacts significantly with multiple networks involved within activity systems, which make it a source of innovation, development and initiation of new ideas (Engeström 1999).

- **Internalisation/Externalisation of Activities**

Activity theory emphasises internalisation and externalisation of activities. Internalisation is the traditional notion of mental process that cannot be isolated from the external activities. Internal activities cannot be analysed and understood without taking into consideration the external activities. This is because the basis of human cognition and activity mainly depends on continuous transformation between external and internal activities (Kaptelinin et al 1999). Internalisation and externalisation rely on the understanding of different contextual structures and developments in organising the external stimuli and applying them to achieve the objective of the activity (Leont'ev 1978).

- **Mediation**

Originating partly from Vygotsky's (1978) ideas, activity theory stresses the central role of mediation. Artifacts include instruments, signs, language and machines. Tools can be both

external and internal and are used to mediate an activity as they carry a particular culture and history. Therefore, the use of tools increases communication of social knowledge. The importance of the role of the tools shows through the external change of activity that results in the creation of internal ones (Engeström 1993).

- **Change and Development**

Activity Theoretical studies focus on the interaction between human and reality to observe and analyse the activities in the context of development. Development work research is a general research methodology, and is different than traditional laboratory and formative experiments, which mainly involve active participants (Engeström 1993; Engeström 1999; Kaptelinin 2006). In activity theory, contradictions are not viewed as problems; rather, they are viewed as structured tensions that occur within and between the activity systems. An activity system undergoes different transformations which lead to an accumulation of different contradictions of that specific system, thus opening the door to questions and discussions that lead to departure from its established norms (Engeström 1999).

### **3.5.2 Activity Theory as a Tool for understanding Practice in Healthcare**

Activity Theory plays an important role in understanding complexity and ambiguity that occurs in the marketing contexts. Such understanding is driven by identifying contradictions and scattered knowledge and learning (Engeström 2000; Basharina 2007). Activity theory is a framework that looks at different structures of human practices under the scope of historically developed cultural systems that link individuals with society (Engeström 1999). Individuals plan and realise their actions using both theoretical and practical tools and the actions are always studied in culturally related contexts.

In order to participate in a collective work activity, it is necessary to have some common conception about the object of the activity. This conception is constantly formed and reconstructed during participation in the processes and discussion about the work between the participants. Using activity theory to analyse the development of a corporate health service involving different stakeholders offers several benefits. First of all, activity theory suggests that if the members of the networked activities could see themselves as participants in a broader work activity, then it would enhance their ability to coordinate themselves by reflecting their action against the overall object of the activity and the status of the overall transformation process (Engeström 2000). Secondly, in activity theory, activity is viewed as hierarchical in nature where activities are transformed into actions and operations. Thirdly, physical or mental tools act as important mediating tools for facilitating all the activities. Fourthly, activity theory looks at a single activity as an individual action that is culturally and historically inter-related, which shows the importance of organisational influence in healthcare services (Engeström 2001). Activity theory is mainly concerned about the study of practice and focuses on knowledge obtained from participating in practice. Therefore, two approaches can be used to investigate such a complex framework in relation to health services. The first approach is to select suitable concepts from activity theory that are believed to be relevant to the healthcare service. The key deciding factor is that the selected concepts of activity theory should act as a guide in the data-gathering and data analysis processes that can help transfer the results into a designed structure (Engeström 2001). The second approach is to use Engeström's expanded triangle model of an activity system which is the analytical unit of activity theory that considers the relevant concepts from activity theory that are important for analysis and involve all the participants (subject), the material and tools used (artifact) , the policies and regulations involved (rules), and which are organised to collectively achieve the intended aim (object). The power behind the concept of

contradictions is mainly shown in the different contrasting actions that can be achieved in practice (Engeström 2000).

Engeström's expanded triangle model is used to study and identify contradictions between different activity systems within the study. Contradictions that arise around the objects of the activity and across and within activity systems are mainly transformative contradictions which lead to the formation of new aims and alternative ways of working. In healthcare, the doctor's object is to treat patients who require medical help; however, at the same time, his object is to earn a living by doing this job. Therefore, AT can highlight the different conceptualisations involved in a single activity concerning the object or shared aim by assisting the exploration of different values underlying participants' views.



### **3.6 S-D logic and Activity Theory Critiques**

Activity theory has gained popularity among researchers of different scientific disciplines in different fields such as general education and management studies (Blackler 2009; Engeström and Sannino 2010). Activity theory has also been applied in medical education (Larsen et al. 2017; Skipper et al. 2016). It has proven to be a useful theory in many areas of organisation studies, organisation learning, change management and knowledge management. Activity Theory provides researchers and practitioners lenses and tools that assist them to analyse work processes by involving them in dialogical learning and change efforts (Blackler 2009; Engeström and Sannino 2011). In the analysis and redesign of work activities, activity-theoretical studies aim to identify the contrasts of micro and macro's material, mental observation and intervention of the work activities and discover the linkages between social, local and different global events (Engeström, 2000). This is because the basic idea of activity theory is the fact that an activity is always collective and motivated by a shared object-related motive (Leont'ev, 1978). The object of the activity represents the sense and the meaning of essentially mediated actions (Vygotsky 1978). Activity theory stresses that artifacts such as tools and instruments play a central role in mediating the transformation processes of activities between subjects and objects (Engeström 2004). Moreover, the power of activity theory shows in representing functional materialism in which knowledge is viewed as an evolving cultural and historical setting as stabilised knowledge, thereby creating a logic that helps actors deal with complex practices and offers open opportunities for innovation creation and transformation of activity (Engeström 2007). However, activity theory can only conceptualise knowledge/society's information through the engagement with activity systems. This will allow the emergence of new knowledge and transformed relationships (Avis 2007). Thus any transformation of information, learning and identity must happen in a setting that

recognises social antagonism, political context and socio-economic factors as failure to do so will lead to conservative praxis (Avis 2007). Moreover, in activity theory, there are some problematic implications of “activity systems” being the main unit of analysis in understanding different collective learning highlighted by societal practices which are developed and transformed across the different activity systems (Langemeyer and Roth 2006). As a result, the activity system should not be studied as a single activity as it will not represent anything meaningful. The constituents of each activity system include subject, object, tool, community, rules and division of labour which automatically determine each other within the activity (Langemeyer and Roth 2006). So long as this activity is ongoing these components remain unchanged. To understand the context of workplace learning it is important to effect the interaction of at least two activity systems as the “unit of analysis” to be able to understand societal practices and activities (Engeström 2000).

Service-dominant (S-D) logic arises from a different academic tradition and has become a new foundation of marketing theory that seeks to overcome the limitations found in the goods-dominant (G-D) logic (Vargo and Lusch 2016). The knowledge and competencies of both the provider and the recipient play a central role in service (Vargo and Lusch 2004). In S-D logic, “service” is defined as an application of specialised capabilities that is provided through processes, deeds and performance to benefit another party (Vargo and Lusch 2006; Vargo and Akaka 2009). In S-D logic, value co-creation is the core process which is equally exchanged among actors by providing input for each other’s activities (Vargo and Lusch 2004, 2008, 2016). In S-D logic, two main important characteristics of value are, first, value is defined in a specific context among actors with specific reciprocal links (Chandler and Vargo 2011) and second, its experiential nature which is uniquely determined by the beneficiary (Vargo and Lusch 2004). Even though many studies address the conceptual foundations of service-dominant logic (S-D logic), very few explorations describe its

application in practice as previous research connecting S-D logic partly because practice-based views lack analytical tools or tested concepts for modelling and exploring the different dynamic structures of organisational practices (Echeverri and Skålén 2011, Kjellberg and Helgesson 2006; Korkman et al. 2010; Mele and Russo-Spena 2016). Different research studies have attempted to link learning perspective to S-D logic and practice for the purpose of creating new services. However, they have rarely provided micro-level ethnographic or in-depth analysis of real organisational practices (Korkman et al. 2010; Echeverri and Skålén 2011).

### **Conclusion to the chapter**

Common similarities are identified between S-D logic and activity theory which are examined in more detail in this study. These similarities are shown in the role of beneficiary (user), the life context of actors as human institutions, and the importance of resource integration and mediated tools. Activity theory suggests that if the members of the networked activities could see themselves as participants in a broader work activity, then it will enhance their ability to coordinate themselves by reflecting their action against the overall object of work and the status of the overall transformation process, thus leading to co-creation of value. Similarly, in S-D logic, the customer is the principle actor of value co-creation and considered the main foundation of S-D logic. The customer is the one who determines the value after utilising the product; therefore the value is always co-created after the interactions appear between the provider and the customer where resources are incorporated and competencies are applied, and so value can only be created through the interaction of the different actors involved.

## **CHAPTER 4:     METHODOLOGY**

### **Introduction to the chapter**

Methodology refers to the research strategy adopted in a study, and the various ways of obtaining, organising and analysing data whereas methods are defined as the different tools used to collect data. According to the nature of the research question, the researcher should make a suitable choice in terms of which type of methodology to apply in the research (Ramlo 2015). Methodology is also about designing, setting and sampling, as well as methodological limitations, data collection and analysis techniques in a study. It is also described as a means of reasoning according to frameworks, theories and principles that are based on different methods and procedures (Fram 2014). Multiple methods of qualitative and quantitative data collection were used in this research including surveys, interviews, participation observation and focus group interviews. The researcher aimed to study healthcare providers and expectant mothers' opinions about cord blood knowledge in two of the largest public hospitals in the UAE and learn more about cord blood donor recruitment processes from cord blood banks in the UK and the USA by interviewing a selected group of stakeholders within the field of cord blood stem cells. The site visits to these banks were taken as a benchmark to study and learn more about donor recruitment processes in hospitals. In this chapter, the researcher explains the different methods used in the empirical study and discusses the research methodology, research design, research approach and justification, validity and reliability, methods of data collection, data analysis and interpretation, and ethical considerations.

## 4.1 Research Approach and Justification

This study aimed to develop a new conceptual framework using activity theory and co-creation value to establish a sustainable strategic plan for cord blood donor recruitment processes in hospitals in the UAE which should answer the first and second research questions: “What are the current motivators and barriers towards donating cord blood stem cells in the UAE”, and “What are the current challenges underlying stakeholders’ engagement and involvement with cord blood donor recruitment processes”. Answers to these two research questions will help those in the field to understand how to co-create value between different stakeholders to identify the changes that are needed to increase cord donation in the UAE. Thus, the use of qualitative approaches will help address the questions of ‘what’ and ‘how’, which requires rich qualitative data. The case study design method is used in this research to best answer the *how* and *what* research questions (Handfield 1998; Stuart et al. 2002; Venkatesh, Brown and Bala 2013; Voss, Tsikriktsis and Frohlich 2002). The quantitative method was also applied in the research to identify the main motivations and barriers towards cord blood donation in the UAE and the main contradicting answers obtained from expectant mothers’ and healthcare providers’ surveys. The use of the quantitative method helped the researcher to define the study’s related questions, collect different numeric data from expectant mothers’ and healthcare providers’ surveys, and then analyse the data statistically (Mahomed, 2009). Echambadi, Campbell and Agarwal (2006) showed that the quantitative method can play an important role in supporting theory testing which, in this case, is supporting the required tool (knowledge) within different healthcare providers’ activity systems. Results from the survey showed that lack of knowledge about cord blood stem cells among expectant mothers and healthcare providers act as the main barrier towards their participation in the donor recruitment process. Therefore, ensuing that they acquire knowledge about stem cells is essential.

The researcher was interested in applying activity theory within this study along with S-D Logic. CHAT is one of the many practice-based approaches that provide a strong framework for studying different professional work practices. CHAT allows the researcher to analyse complex professional practices by offering a multi-dimensional and systemic approach that includes different kinds of tools and psychological motives that focus on dynamics of power, history and culture (Foot 2014). It is a framework that analyses and interprets different structures of human practices under the scope of historically developed cultural systems that link individuals with society (Engeström 1999). The researcher wanted to study the donor recruitment processes in hospitals in order to increase cord blood donation by encouraging the participation of different stakeholders who have direct contact with expectant mothers. Therefore, this requires studying the human behaviour and relationships under this specific context by taking into consideration the different perspectives and opinions that emerge from the involvement of multiple stakeholders within the donor recruitment process. Therefore, the researcher found that activity theory is suitable for this as it is a practice-based theory that is historically and culturally grounded theory, which allows the analysis of what people do together at a specific point in time and within a particular context. CHAT focuses on learning by doing and views human acts as collective actions. To learn and communicate, humans adopt and employ different kinds of tools, in a context where community is considered the locus of process making and interpretation of meaning (Vygotsky 1987). Activity theory was used in this research as a tool to understand how to co-create value between the different stakeholders involved within donor recruitment processes. To construct such a complex framework in relation to health services, the first approach is to select suitable concepts from activity theory that can act as a guide in the data-gathering and data analysis processes and help transfer the results into a designed structure (Engeström 2001). The second approach is

to use Engeström's expanded triangle model of an activity systems that are important for materials and tools used (artifact) and the policies and regulations involved (rules), and which are organised to collectively achieve the intended aim (object). Drawing an activity system of each stakeholder can help identify the required tool to co-create value between different stakeholders involved within the process.

The researcher experienced some difficulties in understanding and applying the theory and identifying the role of the object within the activity. For the researcher it was clear that the object of the cord blood centre activity system is *cord blood donation*, but to assure healthcare providers and expectant mothers' collaboration and participation within the activity, the researcher needed to develop a shared object with a defined tool of analysis and activity. This was the main challenge when the researcher tried to analyse the research results. She experienced difficulty in arranging all of the obtained data and drawing the activity systems, and needed to understand activity theory, as well as different structures of human practices and their applications in healthcare in much greater depth. Thus, in 2015 the researcher decided to contact Professor Engeström via email and express this interest in theory and the desire to meet him and learn more about activity theory and its application to the selected research domain. The Professor replied with positive feedback showing his interest in the study and invited the researcher to visit Finland to discuss the topic with his CRADLE team. The researcher was delighted and honoured to receive this invitation and arranged accordingly the first of two visits to Finland which was in November 2015. The agenda was prepared by the CRADLE team coordinator (see Appendix 1) which included meeting with the main stakeholder of the CRADLE team and with Professor Engeström to discuss the topic. The visit was very beneficial as the researcher learnt a great deal from attending different sessions along with the CRADLE team and also from meeting post-doctoral researchers to discuss activity theory in more detail. During the meeting with the

Professor, he explained in detail about activity theory and the role of object. He also taught the researcher how to analyse data using the activity system as the means of exploration, analysis and interpretation, which was extremely helpful and added a great deal of value to the research.

In 2016, after completing data collection, the researcher visited Finland for a second time to present the data to Professor Engeström and the CRADLE team. The Professor spent several hours with the researcher demonstrating examples on how to analyse the data based on the activity system. CRADLE team arranged a session for the researcher to give a presentation demonstrating the results obtained to the team and to Professor Engeström. The session was interesting and feedback received was fruitful and added value to the thesis. The agenda for the second visit to Finland is available in Appendix 2.

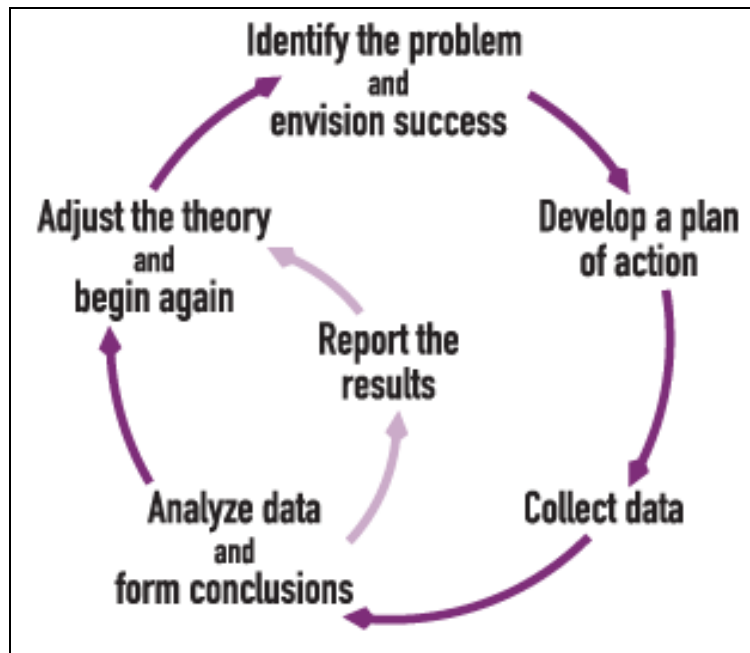
S-D logic was also used in this research for the purpose of co-creating value in practice between different stakeholders involved within cord blood donor recruitment. For the service to be effective, it must be client-oriented with empowered employees who are able to co-create value with the clients by integrating different organisational resources (Vargo and Lusch 2014, 2016). Competent and skilled employees with positive attitudes play a vital role in interacting with their customers in service exchange and the co-creation value process. Intensive service is created through the contribution of all the participants who play an important role in service formation due to their inter-dependencies (Vargo and Lusch 2008). In this study, the research focuses on exploring the main barriers that prevent expectant mothers from donating their cord blood stem cells in UAE and the main motivational factors that can help to encourage expectant mothers to donate the cells. The researcher also examines healthcare providers' knowledge and opinions regarding cord blood and cord blood banking options and their roles in encouraging their patients to donate their cord blood stem cells in the UAE. The main groups of healthcare providers sampled in this study all have



direct contact with expectant mothers during the pregnancy. These groups include antenatal nurses, delivery ward nurses, gynecologists and pediatricians. To learn more about cord blood and donor recruitment processes, the researcher decided to travel to the UK and the USA and visit cord blood banks. The idea was to learn from their experience and knowledge in order to design a suitable model/framework to recruit cord blood donors in the UAE. Thus, activity theory collective studies along with service dominant logic (S-D Logic) principles were used to analyse data obtained from the ethnographic study which includes interviews, focus group discussion, participant observation and surveys. The results obtained were then plotted using activity system models and co-creation processes to create a new expanded value co-creation model for the cord blood donor recruitment process.

## **4.2 Research Methodology Design**

According to Handfield and Melnyk (1998), action research is used as a methodology to collect data. The authors illustrated that for theory extension and refinement, the best data collection techniques involve structured interviews, documents, field experiments, observations and surveys. The researcher has employed these different techniques during different action research cycles as shown in Figure 4.1 below.



**Figure 3-1 Action research cycle taken from:**  
[http://creativeeducator.tech4learning.com/v07/articles/Embracing\\_Action\\_Research](http://creativeeducator.tech4learning.com/v07/articles/Embracing_Action_Research)

Action research can be defined as “an iterative process involving researchers and practitioners acting together on a particular cycle of activities, including problem diagnosis, action intervention, and reflective learning” (Avison et al. 1999, p. 94). As the name suggests, action research mainly integrates research and action in a sequence of flexible cycles that are involved historically rather than being separate single steps (Ehren et al. 2013). The different cycles of action research involve collection of data regarding the topic of investigation followed by analysis and interpretation of the collected data and introduction of the required action strategies that can bring about positive change within the organisation (Brydon-Miller, Greenwood and Maguire 2013). These changes will then be evaluated through further data collection, analysis and interpretation, and the cyclical process will continue to be repeated until the decision is taken and outcomes are published to date (Altrichter et al. 2013). Action research involves ongoing activities and it is conducted by a group of participants who work closely together and collaborate to make appropriate

contributions despite the existing constraints (Baskerville & Wood-Harper 1998). It mainly concentrates on developing knowledge and understanding of an exclusive kind of object, and generally starts from a vision of a social transformation and ambition for greater social successful change and justice as it acts morally and promotes justice through research in which it is politically informed and personally engaged with (Somekh and Zeichner 2009).

Action research also involves high levels of reflexivity in terms of the role of the self in mediating the entire research process. It is a methodology that mainly involves participants in social situations as their values and culture are strongly influential (Somekh and Zeichner 2009). Action research consists of continuous flexible cycles where each single cycle requires the following steps: plan, act, observe and reflect. To perform each cycle, different quantitative and qualitative methods are employed for data collection. Such methods include: closed-ended surveys (questionnaire), semi-structured informal interviews, focus groups and participant observation (Dick, 2006). Each of these is discussed in detail in the following research design section. All the above discussed proposed methodology approaches go through different action research cycles to develop the central activity system using Activity Theory and the selected S-D logic framework. In this research, the data were collected at different points of each cycle. Each cycle included planning, acting, observing and reflecting. In 2015, the researcher employed the first method – participant observation – to understand expectant mothers' opinions and views regarding cord blood donation by taking into consideration the context and the culture of the UAE. Following that, the researcher conducted ethnographical data collection using both qualitative and quantitative methods such as interviews, focus groups and surveys. Using mixed methods in the research can improve the validity of theoretical proposals to achieve a complete picture of the phenomenon under the study (Ihantola and Kihn 2011). Mixed methods research is recommended due to its ability in specifying research questions and understanding the research concept by all

participating respondents (Sommer 2011). Sandelowski (2000) showed that mixed methods help in the investigation of new topics and in supporting theory formation. The qualitative approach is an important method for collecting information about an experience or topic. It is also used to explain or clarify quantitative findings within research. Moreover, the qualitative method was also used to explore different dimensions of respondents' experiences (Sommer 2011).

This study uses The Dubai Cord Blood and Research Center as the case context. The Center was established in 2006 to help treat many patients with life-threatening diseases in the UAE. The Center provides two types of service; these are family (private) banking of newborn's UCB stem cells where the unit is kept for the family use, and public banking where one can donate their newborn's UCB stem cells to be used by others in need for transplantation. The research mainly focuses on public donation by studying the situation of the cord blood donor recruitment processes in two main government hospitals in the UAE which are Hospital A and B.

In Hospitals A and B, qualitative approach using case studies with semi-structured interviews were conducted individually with specific groups of healthcare providers who have direct contact with expectant mothers during the pregnancy. Selected stakeholders include delivery ward nurses, antenatal clinic nurses, gynecologist doctors and general pediatricians. Each participant was interviewed separately for 20-30 minutes. A focus group interview was also arranged with five different groups of healthcare providers from Hospitals A and B. Each focus group consisted of 7-12 individuals who were gathered together to discuss different topics about the cord blood donor recruitment processes. Moreover, closed ended surveys were also distributed to expectant mothers and healthcare providers in Hospitals A and B to gather important data about their opinions regarding cord blood donation. Overall, 1020 surveys were completed and collected from expectant mothers and 193 completed surveys

were collected from healthcare professionals. Interviews were also conducted in the USA and the UK with some of the main stakeholders to gain more knowledge and experience about their donor recruitment systems and processes in hospitals.

### **4.3 Ethical Considerations**

It is very important for any academic researcher to be aware of ethical considerations to produce better research quality. Fundamental principles of ethical research include promoting accuracy, honesty, truthfulness and human rights (Academy of Management Code of Ethics 2011). Other researchers also highlighted the importance of considering other ethical issues such as self-plagiarism, honesty, integrity and confidentiality in research work (Resnik 2011). For the purpose of this study, the first step the researcher had to take was to obtain primary approval from the Director of the Pathology and Genetic Department to conduct this study which is a unique study done for the first time in the UAE (see Appendix 3). As DCRC is the only governmental cord blood centre in Dubai, the Director of Pathology was interested in this research being conducted which he believed would bring numerous benefits to the Center and the community. After gaining his approval, the researcher had to seek approval from the Medical Research Committee at Dubai Health Authority (DHA) to conduct surveys, interviews, focus group discussions, and participant observation studies in the antenatal clinics of Hospitals A and B along with approval to distribute the surveys in Hospitals A and B for both expectant mothers and healthcare providers. It took three weeks for the researcher to receive the approval letter (see Appendix 4). After submitting many required forms and answering the research committee's questions, approval was given for one year, and the researcher had to renew the ethical consent for another year to finalise some pending data collection. A copy of the approval letter was then sent to the hospital directors of both Hospitals A and B and to the Department Head of gynecologists, pediatricians and nursing for permission to start the data collection process. In addition, before distributing the survey to

expectant mothers and healthcare providers, the researcher assured the participants that information gathered for this study will only be used by investigators for research and publication purposes. By signing the consent form, the researcher assured the participants that their names will not be identified in any published report unless approval was taken prior to its mention or publication. Still there were number of participants from the group of expectant mothers who refused to be a part of this study, partly due to the fact it was a long survey and they felt that they did not have sufficient time to answer all of the questions, whereas other expectant mothers were very interested to be part of the study believing it would be a very useful method to inform themselves better. In addition, permission was taken from the hospitals/organisations concerned before conducting case studies in the UAE, the UK and the USA. Emails were sent to the relevant people within the organisations to seek permission and to prepare a meeting agenda for the visit. During the visits to the USA and the UK, the researcher was assisted and supervised by staff from the organisations to access the facility and meet the concerned stakeholders according to the prepared agenda.

#### **4.4 Research Reflexivity**

Bloor and Wood (2006, p.145) define reflexivity as *“Awareness of the self in the situation of action and of the role of the self in constructing that situation”*.

Much attention is now given to the field of relations and reflexivity where reflexive work mainly focuses on understanding different ways in which the self-personal values, characteristics and situation all interact during a research study and thus influence the methodological approach that the researcher takes, the analysis techniques, and the forms of interpretation and evaluation employed (Glesne 2011). Since 2012 the researcher investigated the best ways to increase cord blood donation in the UAE by trying out different methods: some were successful while others failed. The researcher developed experience and

knowledge in this field and wanted to identify a set of sustainable methods to increase cord blood donation in the UAE in order to be able to build a highly successful cord blood stem cell registry for the country so that many patients who suffer with life-threatening diseases can use the available matched donors within the registry in the UAE. Thus, herein, the researcher did simply focus on studying one group of healthcare providers; she focused on studying all the main groups from two different hospitals that have direct contact with expectant mothers during pregnancy such as antenatal nurses, delivery ward nurses, gynecologists and pediatricians, even though the researcher believed that gynecologists are the main group of interest.

The researcher conducted the study in both Hospitals A and B and applied all the research methods in similar ways. She did not focus on studying one single hospital to avoid being biased based on exclusively one case, and arguably for the purpose of validity it can be more informative and persuasive to obtain results from two or more hospitals.

In addition, the researcher conducted two case studies abroad; she visited cord blood centres in the UK and the USA to learn from their experiences and to implement best practices for cord donor recruitment in the UAE. This ensured that she did not depend on her own thoughts, analysis and ideas but also learned about cases (in the USA and the UK) in a real-life context that are similar to the UAE's case study context. All the results generated in this study were backed up with research-based evidence from the literature and with direct quotes from interviewees to avoid bias created by obtaining information and knowledge from limited subjects and sources.

Moreover, the participant observation method was employed by the researcher and two other medical technologists from her team where each one was visiting the antenatal clinics of both Hospitals A and B on different dates to conduct short educational sessions about cord blood

for expectant mothers. By using a specifically designed form (see Appendix 5) notes were written down during the interaction and communication with expectant mothers in these antenatal clinic sessions. These interventions were followed by reflective reports which were written separately by each of the team and then collected and read by the researcher to write up a final report for each month. The researcher noticed that the reflective diaries were written in different ways; however all team members highlighted similar concerns/suggestions and problems within the reflective reports.

Moreover, for each designed interview, focus group and survey, there was a specific consent form that should be signed by the participant to secure participants' confidentiality and identity and assure them that the information they provided would only be used for academic purposes. Before any data collection process started, participants were handed a clear consent form that explained all the pertinent points for the participants contributing within the study. For example, a number of participants refused to have their voices recorded during the interviews and the researcher informed them that it was entirely their choice to either agree to or refuse voice recording. She assured them that all information was confidential and would only be used for the purpose of this study. The researcher made sure that participants read and signed consent forms before participating in any study to ensure they were informed about the study rules, procedures and conditions. For example, in the interviewee's consent form it clearly highlights that participants have the right to accept or reject having their interviews audio-tape recorded, whereas during the focus group study it was clearly stated that the participant could not be part of the study if he/she refused to be audio/video taped. This was because it was hard for the researcher during the focus group discussion to listen to and take notes at the same time from all the participants involved in the study; thus, audio taping was considered essential in this method of data collection. In summary, all ethical codes discussed



by Glesne (2011) in Chapter 6 were taken into consideration before conducting any empirical study.

#### **4.5 Validity and Reliability: Qualitative Research Considerations**

In this study the researcher was mainly testing the selected stakeholders' knowledge about cord blood stem cells. In terms of methodological and theoretical perspectives it is important to validate the knowledge obtained from stakeholders. Therefore, there are three main validation approaches – communicative validity, pragmatic validity, and transgressive validity – used as criteria to justify knowledge obtained from the stakeholders. Each of these is explained below.

*Communicative Validity:* The researcher wanted to understand stakeholders' lived experience and knowledge regarding the topic by initiating communication and dialogue with them through interviews to gain the required knowledge. To obtain high communicative validity, it is important that the researcher initiates dialogue with the interviewees instead of just posing questions and waiting for the answers (Sandberg 2005). Thus, generation of active dialogue during interviews and the focus group discussion led to active conversation and discourse that focuses on the research object. Examples of initiating active dialogue can be through asking the participant to elaborate further on the topic by asking questions such as; “give us some examples”, or “what do you mean by your statement?” Asking these types of questions in between the interviews questions can help the researcher become more focused on interviewees' live experience, and thus attain high communicative validity (Sandberg 2005). When analysing empirical materials such as interviews and focus group transcripts, communicative validity can be assured by searching for logical and coherent interpretations within the empirical materials (Sandberg 2005). In this thesis, the researcher has interviewed healthcare providers from Hospitals A and B. Despite the fact that the study was conducted in

two separate hospitals, similar views and suggestions were obtained about the donor recruitment process and the need for healthcare educators to act as mediators between the healthcare providers and expectant mothers.

*Pragmatic Validity:* This type of validity is used to overcome the weakness within the communicative validity approach which plays an important role in testing the knowledge generated by the interviewees in action (Kvale 1989). Freud (1963) and Kvale (1989) showed that the statements highlighted by the interviewees can be checked by observing their reaction when asking them particular questions as most of the time they react strongly to some answers. For example, during the interviews, the researcher asked the healthcare providers about the reasons that prevent them from discussing the importance of cord blood donation with expectant mothers. Most reacted strongly to this question by highlighting that their knowledge about cord blood stem cells is not sufficient and they do not feel confident discussing cord blood stem cells with expectant mothers because they have limited knowledge about the topic.

*Transgressive validity:* Communicative and pragmatic validity are two suitable criteria to justify and validate to some extent the truth obtained from the collected transcripts by looking at coherent interpretation and testing knowledge in action via asking sub-questions to validate the obtained results. However, both these criteria encourage the researcher to identify consistency and explicit interpretations of lived experience. However, Lather (1993) proposed that to achieve transgressive validity, first, the researcher should review and question the interpretations in a way that can help with generating different codes. The second way is to look for *contradictions* rather than *coherence* in the lived experience; and the third way is to relate it to the scientific framework to produce the required knowledge. Thus, transgressive validity overcomes the weakness found in both communicative and pragmatic validity by focusing on finding contradictions and disturbances obtained within the results. In this thesis,

the researcher used different models and tools of activity theory to enhance the understanding of issues such as knowledge fragmentation, contradictions and different ambiguities that occur in healthcare contexts. According to Engeström (2000), contradictions are not necessarily problems; however, they are structured tensions that need to be understood to achieve change and development. Herein, the researcher identified contradictions within the nodes of the activity system and between healthcare providers' and expectant mothers' activity system which helped in developing a new activity system "healthcare educator". Thus, contradictions between the different activity systems were used in this case to develop the process of donor recruitment practice. Details about the emerging new activity system are discussed in Chapter 6 under section 6.1.3.

#### **4.6 Data and Data Collection**

In this research data were collected in two main phases. The first phase included case studies using ethnographic data collection such as interviews, focus group discussions, and participant observation, and the second phase involved the quantitative method using the questionnaire developed for this study. Interviews were conducted individually with different groups of healthcare providers in both Hospitals A and B. Specific stakeholders were selected to take part in this study; these included delivery ward nurses, antenatal clinic nurses, gynecologist doctors, and pediatricians. Interviews were also conducted abroad in the USA and the UK to learn more about donor recruitment practices. In Hospitals A and B, 102 interviews were conducted with specific groups of healthcare providers in the UAE that have direct contact with expectant mothers whereas 14 interviews were conducted in the USA and the UK with main stakeholders in the field of cord blood stem cells. Each of the participants was interviewed separately in their offices for 20-30 minutes. In addition, a focus group interview was also arranged with five same groups of healthcare providers from Hospitals A and B. Each focus group session consisted of 7-12 individuals who were gathered together to

discuss different topics about cord blood donor recruitment processes. Moreover, in 2015, a participant observation study was conducted for a period of six months in both Hospitals A and B to gather important data about expectant mothers' awareness levels, concerns and suggestions regarding cord blood donation. In 2016, surveys were also distributed to expectant mothers and healthcare providers in Hospitals A and B. The total number of completed surveys collected from expectant mothers was 1020, and a total of 193 completed surveys were collected from healthcare providers in both Hospitals A and B. All salient results obtained were discussed in detail in the written case studies.

#### **4.6.1 Unit of analysis**

The unit of analysis includes individuals, groups, artifacts, social interactions and geographical units. It is the main entity where the researcher is conducting and analyzing the study data (Mitchell, 2002). It is “*who*” or “*what*” the researcher is analysing in the study. In this study there are more than one unit of analysis: the primary and the secondary data. The primary data are mainly collected from selected stakeholders including gynecologists, pediatricians, delivery ward nurses, antenatal nurses and expectant mothers. This group of healthcare providers was selected because they have direct contact with expectant mothers and can play a vital role answering the researcher's questions. The secondary data are derived from the two main hospitals in the UAE (Hospitals A and B) as well as cord blood centres in the UK and the USA. These were the main case studies that were conducted.

#### **4.6.2 Qualitative Method**

- **Case Study Method**

The qualitative case study uses empirical research that mainly focuses on context-rich data from real-life settings to study a specific phenomenon (Meredith 1998). Case study research

is considered one of the most powerful methods in business and management research and in social sciences theory development. The main aim of conducting case study research is to explore and better understand different emerging phenomena or issues that are happening in real-world settings (Flynn et al. 1990; Meredith 1998). Voss, Tsikriktsis and Frohlich (2002) asserted that there are three main strengths of using case study research, as the phenomenon in question can be studied in its natural setting by gaining knowledge and experience through observing natural practice. Case study methods give us the opportunity to ask questions of ‘what, why and how’, which can be answered after full observation and analysis of the case studies. Moreover, case study methods can assist with early investigations of unknown variables and unclear phenomena. However, there are many challenges in conducting multiple case studies as it requires time, a skilled interviewer, and drawing generalised conclusions from limited case studies. Despite these issues, the results from case studies can have high impact and validity and can lead to development of new theory (Voss, Tsikriktsis and Frohlich 2002) which is important in this research seeking to establish a reliable framework for a donor recruitment process using activity theory and S-D logic.

There are four different types of case study – these are *single* cases, *multiple* cases, *retrospective* cases and *longitudinal* cases. The choices, advantages and disadvantages of case studies are summarised in Table 4-1. In this research the focus is on multiple case studies (UAE, USA and UK) to study and learn about donor recruitment processes and practices. All the results obtained from the mixed methods were included in the three case studies which are analysed later based on theoretical ideas and concepts in activity systems and processes of co-creation of value.

The case study examines different distinctive situations that include many interesting variables which rely on multiple sources of evidence (Yin 2009). There are different types of qualitative case study – these are historical and observational, intrinsic and instrumental, and

multi-site case studies. The *historical and observational* case study focuses on the development of a specific organisation over time by studying and presenting a specific phenomenon in terms of its historical perspective (Merriam 2009). The *intrinsic* case study aims to understand a particular case and learn more about it, thus having an intrinsic (specific) interest in the case whereas the *instrumental* case study is more than just understanding the case; it is about inquiry and accomplishing something from the case study (Stake 1995). *Multi-site* case studies are used when the researcher is conducting more than just one case study which includes collective case studies, multi-cases, comparative case studies or cross-case studies. This type of case study method focuses on collecting and analysing data from different cases where each individual case shares some commonalities which somehow are linked to each other (Merriam 2009). Therefore, the three studies conducted in the UAE, the USA and UK, combined, form a multi-site case study that aimed to understand the characteristics and conditions of each single case (UK, USA and UAE) and compare them with each other to implement best practices to recruit cord blood donors in the UAE. Yin (2009) defines case study research as an empirical review that focuses on exploring, in depth, a contemporary phenomenon within its real-life context, mainly when the boundaries are not clear between the phenomenon and the context.

**Table 4-1 Different types of case studies and the advantages and disadvantages of each (Voss, Tsikriktsis and Frohlich 2002, p. 198)**

Choice of the Case Study	Advantages	Disadvantages
Single cases	Greater depth and details in the single case.	Limited to one case study; thus cannot be generalised and conclusion is drawn based on a single event.
Multiple cases	Increases external validity, allow stronger argument and protect against observer bias.	Requires more resources, and there is less depth and fewer details per case.

Retrospective cases	Gives an opportunity to collect data on historical events.	Difficulty in determining cause and effect as researcher might not remember important events.
Longitudinal cases	This type of case study overcomes the problems faced in retrospective cases.	Very long period of elapsed time required, which might be challenging and difficult to do.

Multi-site case studies are sometimes hard to manage and it is highly recommended to carry out field analysis of each case study separately to avoid confusion (Merriam 2009). The UAE, UK and USA case studies were conducted in the same year (2016) and separately, one at a time, before any comparisons were drawn.

- **UAE Case Study**

In 2016, two case studies were conducted in the UAE in two main governmental hospitals (Hospitals A and B). Hospital A is the largest maternity and children's hospital in the UAE whereas Hospital B is a hospital with different specialist centres including cardiology, oncology and obstetrics, and gynecology departments. Interviews, focus group discussions, participation observation and surveys were conducted with specific groups of stakeholders who had direct contact with pregnant women in both Hospitals A and B. The group of stakeholders included pregnant women, obstetricians, gynecologists, pediatricians, antenatal nurses, and delivery ward nurses. The participation observation method was selected by the researcher to study pregnant women's engagement with and level of awareness of cord blood stem cells, and also their feelings and perceptions towards cord blood donation. During the observation, the researcher focused on writing down their suggestions, concerns, perceived obstacles and ideas to improve cord blood donation in the UAE. The observation was conducted on a daily basis for six months and notes were recorded on a form specifically

designed by the researcher (Appendix 5). The form was designed in a way that helped with collecting required data from the expectant mothers. Therefore, in 2015 and for a six-month period, the researcher visited the antenatal clinic in Hospital A on a daily basis to give educational lectures about cord blood stem cells and at the same time observe expectant mothers' awareness and engagement level regarding the topic. Notes were then taken after each session and reflective reports were written up by the end of each week. The aim was to collect rich data from the expectant mothers regarding cord blood stem cell donation to be able to understand their motivation and barriers towards cord blood donation. Interviews, focus group discussion and surveys were the methods selected to collect data from the healthcare providers in Hospitals A and B, and data collection took place over a period of six months from January to June, 2016. Details on interviews, focus group discussion and surveys are discussed later in the chapter.

- **USA Case Study**

The researcher also travelled to the USA from July 10 to July 16, 2016 to learn more about cord blood donor recruitment set-up from the first movers in the field of cord blood and cord blood donor recruitment. The researcher visited the CORD:USE cord blood centre which provides both private and public banking options for expectant mothers and met with the founder of the cord blood centre, Dr Edward Guindi and his team. The trip was organised and the agenda was planned by Dr Guindi as shown in Appendix 6. The agenda mainly focused on interviewing concerned stakeholders in the field of cord blood stem cells and donor recruitment, and the researcher was given tours of the CORD:USE cord blood bank, the Florida Hospital for Women, Walt Disney Children's Pavillion and Florida Children's Hospital including the transplant unit. Moreover, tours were also taken of the Translation Medicine Institute, Alexander Neonatal Intensive care unit, University of Minnesota Medical



Center Adult Transplant Unit, and the University of Minnesota Medical Center Pediatric Transplant Unit. Interviews were conducted with selected stakeholders of the cord blood centre and transplant unit. The researcher was grateful for the chance to interview Matthew Farrow, the world's first cord blood transplant recipient and a survivor of Fanconi anemia in 1988 and also had the honour of interviewing Professor Hal Broxmeyer, founder of the field of cord blood banking and transplantation, along with his team. Interviews questions for the main stakeholders in the USA is shown in Appendix 10.

- **UK Case Study**

The researcher visited the NHS cord blood centre in the UK from October 3 to 6, 2016 to observe different models used in donor recruitment setup and gain knowledge from their experience in the field of cord blood and cord blood donor recruitment. The agenda was prepared (see Appendix 7) to visit Colindale Blood Centre (cord blood collection centre hub) and interview Dr Rachel Pawson, the medical director of Cord Blood Bank (CBB) and Jesmina James, Section Head of CBB collection. The researcher was also scheduled to visit St. George's Hospital collection site to observe how donors are recruited at the collection site and also to interview Edward Dobransky, collection team manager and his team. Part of the agenda also included a visit to Filton Blood Centre to observe processing and issuing cord blood donations and interviewing the team who are in charge of the British Bone Marrow Registry. The researcher also had the opportunity to interview Theo Clark who was in charge of recruiting donors from Black Minority ethnic groups, learn from his experience in the field and find out about the obstacles and challenges he went through while recruiting donors in the UK. Interviews for the main stakeholders in the UK is shown in Appendix 9.

Therefore, the main goal of travelling abroad to the USA and the UK was to gain knowledge from experiences of the experts in the field as they are considered the first movers in the field

of cord blood. Interviewing the main stakeholders within the field was a great advantage and their input constituted a benchmark that was considered when studying and setting up donor recruitment processes within the UAE.

#### **4.6.3 Informal Interview**

- **Interviews in Hospitals A and B**

Interviews were conducted with selected group of stakeholders working in two of the largest government hospitals in Dubai. Hospital A is the women's and children's hospital and one of the largest maternity and children's hospitals in the UAE whereas Hospital B is a specialist hospital with different specialist centres including pediatrics, obstetrics, gynecology and oncology. Interviews were conducted among selected groups of healthcare providers who play important roles in the cord blood donation project. These groups include antenatal nurses, delivery ward nurses, gynecologists and pediatricians. There are other important groups within the hospital such as haematologists, oncologists and pediatricians who play key roles during pregnancy and who can add great value towards cord blood donation; however, these groups were not interviewed in this study due to time limitations. The position and the sample size of the interviewees are summarised in Table 4-2.

Kvale and Brinkmann (2009) highlighted that the main aim of conducting interviews is to understand the meaning and the knowledge production of what the interviewees say. Merriam (2009) supported the importance of carrying out interviews and highlighted the fact that interviews are considered best technique to apply when conducting intensive case studies of a few selected individuals. Therefore, the interview was employed to support the researcher's aim to understand the views, barriers, motivators, knowledge and experience of the selected stakeholders regarding cord blood donation and recruitment processes. This helped in answering research questions 1 and 2. Interviewees' experience and suggestions can result in

significant and informative findings that can help the researcher to understand how hospitals can co-create value between relevant stakeholders within the project. In this thesis, the author interviewed 102 interviewees in the UAE. The interviewees were scheduled for individual interviews, each one lasting for an average of 20-30 minutes. The interviews were conducted in different locations in the hospitals depending on the availability of the interviewees. Interview questions for healthcare providers in both Hospitals A and B are shown in Appendix 8.

**Table 4-2 Number of interviews conducted in Hospitals A and B in the UAE**

<b>Table info</b>	<b>Delivery Ward Nurses Hospitals A and B</b>	<b>Antenatal Nurses Hospitals A and B</b>	<b>Gynecologists Hospitals A and B</b>	<b>Pediatricians Hospitals A and B</b>	<b>Total</b>
<b>No. of interviewees in Hospitals A and B</b>	33	19	28	22	<b>102</b>

- **Interviews in the USA and the UK**

Interviews were also conducted outside of the UAE when the researcher had travelled to the UK and the USA to learn more about the cord blood donor recruitment processes which can help with adopting a best practice model to recruit cord blood donors in the UAE. In the UK, the researcher visited the NHS Blood and Transplant centre from 3 October to 6 October 2016. Dr Rachel Pawson, Consultant Hematologist prepared the agenda for the visit as shown in Appendix 7. The agenda was prepared in a very beneficial way that gave the researcher the chance to visit and interview the management of donor recruitment, visit St. George's Hospital collection site to see how donors are recruited, and also interview the team who are in charge of cord blood collection in hospitals. The researcher also had a great opportunity to

visit Filton Blood Centre to observe cord blood processing and the quality checks that are done to release the public cord blood samples and update the registries. The researcher also interviewed the processing manager in Filton Blood Centre, and Theo Clark who was in charge of recruiting donors from Black Minority ethnic groups. Table 4-3 and

Table 4-4 below summarise the main stakeholders that were interviewed in the USA and the UK and the key points discussed during the interviews. Interview questions for UK and USA cases are shown in Appendices 9 and 10. The results obtained from the interviews can answer the proposed research question (1): *What are the current motivators and barriers towards donating cord blood stem cells in the UAE*; research question (2): *What are the current challenges underlying stakeholders' engagement and involvement with cord blood donor recruitment processes*; and research question (3): *What changes are needed to increase cord blood donation in the UAE's hospitals?*.

**Table 4-3 The main stakeholders interviewed in the UK; their roles and key points discussed**

Facilities in the UK	Name of the Interviewee	Role of the Interviewee	Discussed Topic
Colindale Blood Centre in UK	Dr. Rachel Pawson	Medical Director of Cord Blood Centre	<ul style="list-style-type: none"> <li>- Management of donor recruitment.</li> <li>- Donor registration and eligibility.</li> <li>- Evaluation of the collected public samples.</li> <li>- Expectant mothers' informed consent.</li> </ul>
Colindale Blood Centre in the UK	Jesmina James	Section Head of cord blood bank collection sites	
St. George's Hospital collection site	Edward Dobransky and the team	Collection team manager	<ul style="list-style-type: none"> <li>- Observe ex-utero collection.</li> <li>- Obtaining informed consent.</li> </ul>
Filton Blood Centre	Alexandra Ross	Processing Manager	<ul style="list-style-type: none"> <li>- Processing and issuing of cord blood donation samples.</li> <li>- Quality check for units.</li> </ul>

			- Update registries.
Filton Blood Centre	Theo Clarke	In charge of donor recruitment	- How to recruit donors with specific ethnic diversity.
Filton Blood Centre	David Winstone	BBMR Business Manager	- Search for donors through national bone marrow registry.

**Table 4-4 The main stakeholders interviewed in the USA; their role and key discussed points**

<b>Facilities in the USA</b>	<b>Name of the Interviewee</b>	<b>Role of the Interviewee</b>	<b>Topic Discussed</b>
CORD:USE	Dr Edward Guindi	President and CEO of CORD:USE cord blood bank	<ul style="list-style-type: none"> <li>- How the field of cord blood stem cell recruitment and collection started in Cord:USE.</li> <li>- Creating awareness among public, expectant mothers and healthcare providers.</li> <li>- Putting systems in place to create awareness and understanding of the importance of cord blood stem cells.</li> <li>- Dealing with different minds and over many years of experience we learn how people think.</li> <li>- Effective programme with healthcare providers.</li> <li>- Increasing awareness is a multi-factorial approach.</li> <li>- The message delivered to the mother about cord blood is very important.</li> </ul>
CORD:USE	Michael T.Ernst	Vice President of CORD:USE	
CORD:USE	Thomas Moss	Vice President of Operations	
Maternity Hospital in Delaware, USA	Kim Petrella	Registered nurse and certified in patient obstetrics. Labour delivery nurse with 25 years of experience	<ul style="list-style-type: none"> <li>- Cord blood donor recruitment in hospitals.</li> <li>- Education about cord blood stem cells among expectant mothers.</li> <li>- Obstacles and challenges in recruiting cord blood donors.</li> </ul>

CORD:USE	Matthew Farrow	World's first cord blood transplant recipient	<ul style="list-style-type: none"> <li>- About his success story in cord blood transplantation.</li> <li>- Tools of education to increase awareness.</li> <li>- Importance of social media in cord blood awareness.</li> <li>- Sharing the success story with doctors and nurses to increase quality of the collected units.</li> <li>- Education tools for pregnant women.</li> </ul>
CORD:USE	Joanne Alphonse	Head of public donation programme and registered nurse	<ul style="list-style-type: none"> <li>- Cord blood education in hospital.</li> <li>- Importance of public registry.</li> <li>- Healthcare providers' education.</li> </ul>
University of Minnesota Medical Center-Adult Transplant Unit	Dr John Wagner	World-renowned Cord Blood Scientist and Transplanter	<ul style="list-style-type: none"> <li>- Importance of cord blood stem cells.</li> <li>- Stem cells expansion to overcome low volume units.</li> <li>- Diseases treated using cord blood stem cells.</li> </ul>
University of Minnesota-Dr Broxmeyer Research Facilities	Professor Hal Broxmeyer	Founder of the field of cord blood banking and transplantation	<ul style="list-style-type: none"> <li>- Cord blood stem cells discovery.</li> <li>- Story behind first cord blood transplant in the world.</li> </ul>

#### 4.6.4 Focus Group

Focus group (FG) interview methods include informal discussion among groups of selected individuals about a particulate topic (Krueger and Casey 2009). The aim of conducting focus groups in this research is to gain an understanding of specific issues from the perspectives and experiences of the participants involved within the group. Applying this method in the field of health and medicine showed great advantages (Kitzinger 1995). The FG is also used to understand some health and social issues by interviewing groups of people coming from similar social and cultural backgrounds (Gibbs 2012). The researcher employed the FG

method with selected groups of stakeholders that play important roles in the cord blood donation projects and have direct contact with expectant mothers. They were asked questions related to cord blood and cord blood donor recruitment processes to collect their suggestions and ideas to establish a successful cord blood donor recruitment process for the DCRC. Consent forms and questions for focus group discussion are shown in Appendix 11. The stakeholders involved in focus group discussion include antenatal nurses, delivery ward nurses of Hospitals A and B, and one gynecologist from Hospital B only. The focus group was held in a small seminar room of the hospital. The selected stakeholders' groups, sample size and reason for selection are discussed below.

- **Obstetricians/Gynecologists:**

This group was selected because they are one of the most important groups as they have direct contact with expectant mothers daily and have a powerful influence on expectant mothers' decisions relating to cord blood banking. According to research as discussed in the literature review, most expectant mothers like to learn about cord blood stem cells from their gynecologists who can therefore play an important role in encouraging expectant mothers to donate their cord blood stem cells. Thus, it is very important that obstetricians and gynecologists have the right knowledge about cord blood stem cells and are aware about the importance of cord blood stem cells in treating many life-threatening diseases as their support and contribution can add considerable value to society.

The researcher was able to conduct focus group interview with gynecologists and obstetricians of Hospital A only, and was not able to conduct focus group discussion with gynecologists and obstetricians of Hospital A due to very tight schedules and difficulty of gathering seven gynecologists and obstetricians at the same time in Hospital A.

- **Hospital Delivery Ward Nurses and Antenatal Nurses:**

This group was selected for focus group interview because they are also considered one of the most important groups that have direct contact with expectant mothers and also act as a bridge between the expectant mother and the gynecologist in the antenatal clinic. In the UAE, an expectant mother first has to see the nurse in the antenatal clinic for a quick examination before seeing her gynecologist. Antenatal nurses can play an important role in communicating information to expectant mothers and thus they need to have adequate information about the importance of cord blood donation. Two focus group interviews were conducted separately with antenatal nurses in Hospitals A and B with each group consisting of seven nurses from the antenatal clinic.

Two focus groups were also conducted separately with delivery ward nurses of Hospitals A and B and each focus group consisted of seven nurses. Delivery ward nurses act as a backbone for cord blood centres as they are the group who collects the cord blood stem cells after the delivery of the newborn. Thus, they are in direct contact with the expectant mothers before, during and after the delivery of their newborns. Their collection highly affects the quality of cord blood units that are provided to the cord blood centre. Thus, they should have adequate knowledge about cord blood stem cells which will help them in convincing the expectant mother to donate her cord blood stem cells. A summary of the number of focus groups conducted in Hospitals A and B is given in Table 4-5.



**Table 4-5 Selected stakeholders from Hospitals A and B and the main topics discussed.**

<b>Stakeholders selected from Hospitals A and B</b>	<b>Delivery ward nurses in Hospitals A and B</b>	<b>Antenatal Nurses</b>	<b>Gynecologist</b>	<b>Discussed Topics</b>
<b>No. of focus group participants</b>	2 groups (one from each hospital)	2 groups (one from each hospital)	1 group from Hospital B	<ul style="list-style-type: none"><li>- Best tools used to increase public awareness.</li><li>- Healthcare providers' responsibility in cord blood donation.</li><li>- Creation of successful awareness system in hospitals.</li></ul>

#### **4.6.5 Participant Observation**

Participant observation is used as a method of collecting data for qualitative research studies. It can be defined as a systematic explanation of events, behaviours and situations that are chosen to explain a phenomenon (Glesne 2011). Participant observation is a process which enables the researcher to learn and gain more knowledge about different activities carried out by people (Zahle 2012). Such an approach is conducted by being involved in the day-to-day routine activities of different participants within the study site (Musante and DeWalt 2010). Using observation methods can assist with understanding the ongoing activities and situations of different stakeholders involved in the project as it facilitates understanding important phenomena such as participants' communication with each other, cultural parameters, the organisation's operations, and the main limitations present within different situations (Glesne 2011). The participant observation method was mainly conducted in the antenatal clinic of Hospital A during the time when expectant mothers were waiting to see their gynecologists. The researcher used the opportunity of the expectant mothers' waiting time to educate them

about the importance of cord blood donation and its beneficial usage in treating many life-threatening diseases. At the same time, the researcher was observing and studying the knowledge and engagement level of the expectant mothers toward cord blood donation and she noted down the main concerns, problems and suggestions arising during the session. Notes were recorded in a specifically designed format as shown in Appendix 5. These notes were then studied and reflective reports were written up to summarise the main comments and concerns of expectant mothers. Due to the fact that expectant mothers' educational level varies, the information given to them was very simple and up to the point that they could easily understand the topic and engage with it. The collected information and observation data were then used as a guide to study and analyse different situations that occurred during the observation. Such analysis can then assist the researcher to overcome the concerns of the expectant mothers and encourage them to donate their newborns' UCB stem cells to help others in need of transplantation and to create an effective donor recruitment model that can be implemented within the hospital to achieve the engagement of healthcare providers along with expectant mothers regarding cord blood donation. Data obtained from this method helped the researcher to answer research question (2): *What are the current challenges underlying stakeholders' engagement and involvement with cord blood donor recruitment processes* "and research question (3): *What changes are needed to increase cord blood donation in the UAE's hospitals?*

## **4.7 Quantitative Method**

The main strength of quantitative research is that data can be expressed in numbers to perform statistical tests to interpret the data. Statistical tests include descriptive statistics such as mean, median, standard deviation and t-test. Moreover, the quantitative method offers important tools for research that help in identifying differences between groups, preference trends and demographics. This method can also be used to test hypotheses in experiments due to its capability to measure data using statistical analyses (Coviello 2005).

### **4.7.1 Questionnaire (Survey)**

The questionnaire is a method used in research where everyone in the sample answers exactly the same questions. However, one of the limitations of this method is the fact that the researcher cannot ascertain whether the respondent has understood the questions properly (Fowler 2014). Therefore, to overcome this problem it sometimes can be beneficial if the researcher is present during questionnaire distribution.

Survey research is considered one of the different types of field study that can play an important part in knowledge contribution in different ways (Babbie 1990). There are three different types of survey research: exploratory survey research, confirmatory survey research, and descriptive survey research. In this thesis, the researcher conducted descriptive survey research which does not aim for theory development and testing; rather it mainly focuses on understanding a specific phenomenon and its distribution within a specific context and population (Forza 2002). In the literature review section, the researcher highlighted the specific themes that emerged from studying barriers and motivations towards cord blood donation in different developing countries apply these findings to cord blood donation in the

UAE specifically. Are the barriers and motivations towards cord blood donation in the UAE the same as or different from the findings from literature?

Therefore, surveys were distributed to expectant mothers to assess different motivations and barriers towards cord blood donation in the UAE, and to find out what the best methods are to encourage cord blood donation in a culture like that of the UAE (see Appendices 12 and 13), whereas the survey distributed to healthcare providers assessed their knowledge, comprehension of, opinions and attitudes towards cord blood donation and their roles regarding this topic with their patients (Appendix 14). Such survey questions and their findings can assist our understanding of different factors that motivate or prevent cord blood donation in the culture of the UAE, and thus support the tailoring of culturally appropriate educational methods that play a role in increasing cord blood donation in the UAE. Four main themes emerged from the literature when studying expectant mothers' and healthcare providers' motivations and barriers towards cord blood donation in different countries including France, Italy, Germany, Spain, the UK, Zagreb, Croatia, India and the USA. These themes from literature are: (i) knowledge about the importance of cord blood donation among expectant mothers and healthcare providers; (ii) concerns regarding improper use of stem cells; (ii) receiving knowledge about cord blood from obstetricians and midwives, and (iv) being part of humanitarian acts by helping patients in need of cord blood transplants. The researcher was interested to design the survey's questions in a way that assists the generation of the main themes when studying the barriers and motivation towards cord blood donation among expectant mothers and healthcare providers in the UAE. The themes obtained in this thesis were then compared with themes obtained from the literature.

Answers obtained from the designed survey were used to highlight the main finding to support data analysis and theory development. They helped answer research question (1):

*What are the current motivators and barriers towards donating cord blood stem cells in the UAE?*

The researcher prepared two different types of questionnaire – one to be distributed to expectant mothers and the other to the healthcare providers (gynecologists, pediatricians, antenatal and delivery ward nurses of two main government hospitals in the UAE: Hospitals A and B). After reviewing relevant literature in the topic area, the questions within the survey were re-designed and structured into new closed-ended questions by taking into consideration the culture of the UAE and the aim of the research. For validity reasons, the researcher's aim was to distribute surveys to more than 1,000 expectant mothers, and 200 healthcare professionals. The ideas for the first survey were derived from Martín-Santana and Beerli-Palacio (2007) and re-structured into new questions to be distributed for expectant mothers (see Appendices 12 and 13). The ideas for the second survey were derived from Salvaterra et al. (2010) and re-structured into new questions to be distributed to healthcare providers (see Appendix 14). The first survey was distributed to expectant mothers visiting antenatal clinics in Hospitals A and B for their pregnancy check ups. Local and Arab participants preferred to receive the survey's questions in the Arabic language whereas the expatriates were given the English version of the questions. The English survey was translated to Arabic by an Arabic native speaker to ensure that the wording matched that in the English version. The second survey was distributed to healthcare providers of Hospitals A and B at their clinics and offices. Table 4-6 shows summary of the methods used to analyse the data according to the research questions.

#### **4.7.2 Sample size and description**

The purpose of employing the quantitative method is to support theory/framework development for the establishment of a cord blood donor recruitment process. The results

from the surveys were compared with the different finding from literature which helped in the generation of specific cord blood donation themes in the UAE by taking into consideration the history and the culture of the UAE. The quantitative approach is a method used to define the study-related questions and hypothesis. It facilitates the collection and statistical analysis of numeric data from different participants (Mahomed 2009). In the end, surveys were distributed to 1,020 expectant mothers and 193 healthcare providers who had direct contact with expectant mothers in Hospitals A and B.

## **4.8 Data Analysis**

This research follows a mixed-method approach and the data were analysed both qualitatively and quantitatively. The first part used activity theory as a tool to analyse the qualitative case studies obtained from the UAE, the USA and the UK. The analysis of each case study was conducted separately –single case study analysis – followed by cross-case analysis. Kvale and Brinkmann (2009) described three different approaches to analyse data from case studies; these are (i) analysis focusing on meaning, (ii) analysis focusing on language and (iii) general analysis. Herein, the researcher followed the general analysis approach to allow the use of different tools and techniques (Eltigani 2013). She used the single case analysis alongside cross-case analysis to allow comparison and emergence of different categories and themes. The second part is the analysis of quantitative data using a software package that specialises in business intelligence (BI) that helped the researcher understand and interpret the collected data.

### **4.8.1 Using Activity Systems and Co-creation Value as a Tool for Data Analysis**

The researcher focused on the analysis of activity systems and the processes of co-creation value in cord blood donor recruitment. In terms of activity systems, the first step was to identify the various actors involved within the donor recruitment process. Then, by using

activity systems, tasks and roles were identified for each actor along with knowledge they hold and bring to the donor recruitment process. In terms of S-D logic, attention was given to the role of *beneficiaries* in the process which, in this case, are expectant mothers. Actors were co-creating value and integrating different resources for the benefit of the user. Moreover, the roles of the institutional and hospitals' contexts were identified along with the context of the cord blood centre. In addition, special attention was given specifically to human institutions and the life context of both expectant mothers and healthcare providers in Hospitals A and B. Next, an in-depth analysis was carried out of the groups and communities of actors as *dynamic systems* by applying the activity system model. The activity system acts as a useful tool for representing the system of several interrelated stakeholders with distinct needs and interests in the value co-creation process. It is also considered a dynamic model of the structure of human activity that allows the identification of the different elements involved in this network of activity systems: these are the subjects, objects, outcomes, mediating instruments tools/signs, rules, communities, and divisions of labour (Engeström 2000). The activity system was used as a tool to analyse the activities of different stakeholders involved within the donor recruitment process. This was conducted by first analysing the results obtained from interviews, observations, focus groups and surveys which were then used to draw the activity system for each group involved within the process (antenatal nurses, delivery ward nurses, gynecologists, pediatricians). Details and drawing of each activity system are shown in Chapter 6: Development of the Theoretical Framework.

**Table 4-6 Summary of the findings and the tools used to analyse the data**

Research Questions	Method used	Data Analysis Methods	Main Finding
1-What are the current motivators and barriers towards donating cord blood stem cells in the UAE?	Interviews and surveys	<p>Action Research as the main method for analysis. Data were analysed in different cycles of action research (plan, act, observe, and reflect).</p> <p>Step (1) Coding and development of specific themes from qualitative methods.</p> <p>Common answers obtained from surveys about the barriers and motivations towards cord blood donation.</p> <p>Step (2) Grouping most common answers obtained from mixed methods.</p> <p>Step (3) SAP business object analysis for survey.</p> <p>Step (4) Activity theory as a tool for data analysis by drawing from the activity systems for each group of stakeholders.</p>	<p>Barrier: Lack of knowledge is the main barrier.</p> <p>Motivation: Knowing it helps in treating patients with life-threatening diseases.</p>



2- What are the current challenges underlying stakeholders' engagement and involvement with cord blood donor recruitment processes?	interviews and focus group discussion	<p>Coding and development of specific themes from qualitative study.</p> <p>Activity systems, SDL principles and co-creation value.</p>	<p>-Lack of knowledge.</p> <p>- No defined system in hospitals for cord blood education.</p> <p>- Lack of stakeholders' participation.</p>
3- What changes are needed to increase cord blood donation in the UAE's hospitals?	focus group, participation observation and interviews	<p>Coding and development of specific themes from interview and focus group discussion.</p> <p>-SDL principles.</p> <p>-Co-creation value</p> <p>-Activity systems.</p>	<p>- Cord blood education should be integrated as a part of hospital policy.</p> <p>- Cord blood education should have similar system as breastfeeding education.</p> <p>-Importance of resource integration.</p> <p>-Importance of co-creation value between the firm and customers and identifying the main elements of each activity system.</p> <p>-Identifying the contradictions.</p> <p>-Applying SDL principles.</p> <p>- Co-creation of value with different actors.</p> <p>-Designing new model.</p>

Overall question Developing new conceptual framework using activity theory and co-creation value to establish strategic plan for cord blood donor recruitment process in hospitals in the UAE	<ul style="list-style-type: none"> <li>-Case studies</li> <li>-Interviews</li> <li>-Participation and observation</li> <li>-Focus group</li> <li>-Surveys</li> </ul>	<ul style="list-style-type: none"> <li>-Activity systems</li> <li>-SDL principles</li> <li>-Co-creation value</li> </ul>	<ul style="list-style-type: none"> <li>-What are the main sharing ingredients between S-D logic and activity theory?</li> <li>-Creation of the “expanded value co-creation model”.</li> </ul>
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#### 4.8.2 Development of Categorised Themes for Interviews and Focus Group Data

The researcher used a digital voice recorder to record the interviews and focus group discussions after taking written approval from each interviewee by signing the consent form. The researcher listened to all interviews and focus group discussions and wrote key notes which were then analysed by the researcher and organised under specific themes. The researcher matched the commonly answered questions from each group under specific themes and highlighted them in written quotes giving the main supporting evidence and arguments that answer and shed light on the research questions. In addition, participation observation took place in the antenatal clinics of Hospitals A and B where the researcher and her team were taking notes while visiting the clinic and educating expectant mothers about the importance of cord blood stem cells. Expectant mothers were interacting with the researcher and her team by making various comments, voicing concerns, giving suggestions and asking different questions. The researcher designed a specific form for taking notes which helped her to focus on the key elements that she sought to gain information on from the observations (see Appendix 5). At the end of each week the researcher and her team then reviewed all of the notes and wrote individually a short reflective summary of the key points. These notes were then analysed using activity systems and co-creation value process theory to draw an “*expectant mother activity system*” by taking into consideration the life context of the

expectant mothers and the surrounding culture and community. This was the main approach adopted in analysing the answers obtained from different methods of data collection. These data were further interpreted and refined to create the new model – the “*Expanded Value Co-creation model.*”

#### **4.8.3 SAP Business Object**

This is an enterprise software package that specialises in business intelligence (BI) by giving the opportunity to engage all the data and integrate the results. It is an analytical tool (reporting tool) which produces web-intelligence reports. This software is used by the hospital department where the researcher is working. The researcher prepared all survey data in the template required in an Excel spreadsheet and asked the hospital IT department to assist with analysing the survey data using the software BOBI (Business Object Business Intelligence). Reports were generated for each of the survey questions including tables and graphs demonstrating the results and presenting the main findings. The main findings from the surveys were compared with the themes generated from literature about barriers and motivation towards cord blood donation in the UAE.

#### **Conclusion to the chapter**

Qualitative and quantitative methods were applied in this research project. Using mixed methods in the research study can result in improved validity of theoretical proposals to achieve a complete picture of the phenomenon under study. Similarities were identified and recorded between the two empirical studies: the activity system model along with S-D logic principles were used to analyse the research results which helped in bridging the two models and initiating the expanded co-creation value model for the development of donor recruitment processes in hospitals. The researcher and the quality of the research study benefitted greatly

from the visits to Finland and meetings with Professor Engeström and his CRADLE team to learn more about activity theory and present the collected data for feedback and comments.

## **CHAPTER 5: RESULTS**

### **5.1 Case Study (1): First Movers in Donor Recruitment: Lessons Learnt from Practices Undertaken in the Cord Blood Centre.**

#### **5.1.1 UK Visit to Filton NHS Blood and Transplant**

##### **Introduction of UK Case Study**

To understand more about the donor recruitment process, the researcher decided to visit one of the well-known public organisations in the UK called NHS Blood and Transplant centre which is responsible for inspiring people to donate organs, blood, stem cells and tissue. The NHS Cord Blood Bank (CBB) was established in 1996 to collect, process, test and supply cord blood for others. At NHS CBB they encourage expectant mothers to make voluntary donation to help patients who are in need of cord blood donation in any part of the world. Currently NHS CBB are collecting cord blood from six defined hospitals in the UK where the staff are fully trained to counsel the patients and collect cord blood stem cells after the separation of the placenta. The Medical Director of NHS CBB, Dr. Rachel Pawson prepared a full agenda for the researcher to visit NHS Blood and Transplant from 3-6 October 2016. The researcher had a great opportunity to visit one of the largest collection sites which is St George's Hospital to meet Mr. Edward the collection manager along with his team to learn more about the cord donor recruitment processes. The researcher was also granted the opportunity to interview both Dr. Pawson, the Medical Director of NHS CBB and Jesmina James, Section Head of NHS CBB collection sites for almost two hours. They explained to the researcher about the current procedure for recruiting donors and obtaining expectant mothers' consent at the collection sites. They also highlighted the obstacles and challenges faced during recruiting cord blood donors. During the visit, the researcher also interviewed

Mr. Theo Clarke, the main recruiter at the NHS CBB who focuses on recruiting people from black and minority ethnic backgrounds (Appendix 23). He spoke about the main obstacles faced during recruitment and how to overcome them. He also shared useful advice and recommendations from his experiences in recruiting cord blood donors in the UK.

- **NHS Blood and Transplant Initiating Third-party Agreement with Collection Sites**

The researcher interviewed Dr. Pawson and Ms. James and asked them to share their knowledge and experience in setting up cord blood collection sites in the hospitals. Ms. James (section head of NHS CBB collection sites) highlighted that to start implementing cord blood programmes at the hospitals, first it is important to initiate third-party agreement at the hospital and to get key people involved within the project such as obstetricians or senior midwives who are interested in cord blood programmes and can have a positive effect on the people surrounding them. She said:

*When setting up a site then that is the time when it is most important to get people involved see who your key people are going to be and those different consultants that can help promote cord blood banking so usually we find key obstetricians or senior midwives who are interested in the cord blood programme and they can tell all the people that you need to interact with to take the programme forward.*

She also added a very important point about the need for cord blood banks to have their own staff and resources within the hospital and she highlighted it as the main “*Selling point*” that helps convince the hospitals to start cord blood programmes. She said: “*One of our important selling points is that we have our own staff who would go in and do collection and consents so we are not putting additional work on them*”. Dr. Pawson (Medical Director of NHS CBB) also pointed out that another selling point is the fact that most government hospitals in UK are in favour of public cord blood donation over private banking and most of the private cord blood bank providers in the UK are very irresponsible as they do not explain much to the

mother about the actual usage of cord blood. Furthermore, most of the families who banked their newborn's UCB units with them had not utilised them yet. Therefore, most of the parents prefer donating their newborn's UCB stem cells to help treating other patients in need of transplantation.

➤ **NHS Blood and Transplant: Cord Blood Donor Recruitment Model**

The researcher was interested to learn more about donor recruitment processes conducted at the collection sites and the role of the collectors (healthcare assistance) in recruiting donors and collecting cord blood stem cells at the collection sites. Ms. James highlighted during the interview that NHS CBB has an agreement with six main hospitals (collection sites) and there are six collectors per each hospital working 24 hours seven days a week with one or two nurses per shift. According to CBB statistics, only 45% of the collected public cord blood units will be suitable for processing. Hence, to save time and efforts, expectant mothers' informed consent is taken in two parts; the first part is signing the "*mini consent*" which is a pre-screen form for cord blood collection and includes some information about the cord blood programme and the most important minimum criteria required to allow cord blood collection. By signing the mini consent form, CBB's collectors are allowed to collect cord blood units and process them. The second part of the informed consent process takes place after the delivery of the newborn and acceptance of the cord blood unit for cryopreservation. NHS CBB collectors in the hospital approach the mothers to take their permission for the second part of the consent which permits testing and use of cord blood units. Ms. Jones pointed that all this work is done by the collectors from NHS CBB without adding any extra work to the workload of the healthcare providers in the hospital. She said: "*All these works are done by our own collectors and we do not use the nurses in the hospitals to do that at all*".

Ms. Jones also highlighted that posters and cord blood booklets including mini consent forms are available all around the hospital and in doctors' offices and antenatal clinics to make sure that cord blood information is accessible to all expectant mothers in the hospitals.

Expectant mothers can also enrol on the cord blood programme through the NHS CBB website which provides information about cord blood banking and sets out the most frequently asked questions. Thus, expectant mothers can enrol themselves on the cord blood programme either online or at the antenatal clinic by signing the mini consent form. The CBB's collectors will then contact the expectant mothers and provide them with additional information and a cord blood sticker to be attached to the front of their maternity file so that when they visit the clinic the midwives will recognise that they have been already consented to cord blood collection. Even if expectant mothers forget to attach the sticker to their file, their information will be on the white board at the delivery ward and collectors will approach them again to assure their enrolment to the cord blood programme.

If, however, the expectant mother visited the hospital in active stages of labour and wanted to enrol on the cord blood programme, the midwife in the delivery ward will assist the collectors by filling in a verbal consent form in the delivery room because at this stage the expectant mother may not be able to sign the consent due to labour pains. The expectant mother will not be asked any questions at this stage; the midwife will check her eligibility for cord blood donation through the system or the medical file and, if she is eligible, the cord blood unit will be collected and the midwife will inform the collectors within the hospital.

During the interviews the researcher was also interested to know about the challenges they faced with the hospitals' collection sites and how they overcome these problems. Ms. Jones said that one of the challenges is the fact that each hospital has its own strategies and systems that the cord blood programme needs to adopt into the system. Most of the healthcare



providers are very busy with their daily work and they hardly find time to discuss the cord blood programme with patients. Moreover, other challenges include staff problems and turnover that requires continuous training and education about cord blood. She stated that the hardest part in recruiting donors is education of staff and expectant mothers in hospitals as it requires a great deal of hard work by motivating healthcare providers to convey information about cord blood to their patients.

Dr. Pawson emphasised the staff education point and she said: *“It requires a lot of hard work from the collectors as the collection team need to do it regularly by always trying to talk to midwives”*.

Dr. Pawson and Ms. Jones also highlighted that to be able to increase cord blood donation, it is important to have independent resources in the hospitals without depending on hospital's staff. They emphasised that hospitals' nurses and obstetricians can help in promoting cord blood banking among expectant mothers but they cannot do the job as it is considered extra tasks for them and might not be done probably. Lack of knowledge is considered a barrier in most of the countries and when doctors discuss cord blood with their patients it really makes a big difference in encouraging expectant mothers to donate their newborn's UCB stem cells. Another important motivating factor that encourages expectant mothers to donate their newborn's UCB stem cells is the fact that cord blood collection occurs after the separation of the placenta (*ex utero* collection); thus cord blood collection does not interfere at all with the delivery procedure; nor does it cause any harm for the newborn and the mother. In addition, it imposes less pressure on the midwives knowing that the newborn has already been safely delivered and the placenta is ready to be collected by the collectors. So, by choosing *ex utero* collection, the mother and the newborn become the top priorities during the delivery over cord blood collection. In the UK, the collectors are not necessary nurses – they can hold any qualifications as NHS CBB provides them with a full six months training. The collectors do

not interfere with the newborn's birth because they collect cord blood stem cells *ex utero* after the placenta is out.

The researcher also asked the interviewees about the main factors that motivate/deter expectant mothers when it comes to donating their cord blood stem cells. They said that expectant mothers are motivated to donate their newborn's UCB stem cells due to all the promotion information and materials available at the antenatal clinics as well as the online website which contains all the information needed to register for cord blood donation. In addition, collectors in the hospitals are available at all times to answer expectant mothers' questions during antenatal classes and scanning appointments.

Dr. Pawson and Ms. Jones also underlined that the main obstacles faced when recruiting expectant mothers are language, being in active labour, maternal samples' collection and midwives as, sometimes, collectors are not given the chance to see the expectant mother and to discuss cord blood. Meeting expectant mothers at antenatal clinics is the best time; however, collectors do not have time to visit them at the antenatal clinics and instead, the expectant mothers depend for information on the available marketing materials offered in antenatal clinics such as posters and cord blood booklets. Most of the cord blood education is given in parental classes where the collectors meet the whole group, talk to them about the cord blood programme, and hand them the booklet which contains the mini consent form that they can sign to enrol on the programme.

- **Interview with Cord Blood Collector at St George's Hospital**

The researcher had the opportunity to interview a cord blood collector at St. George's Hospital and ask her about cord blood recruitment processes that take place at the hospitals. She highlighted during the interview that the first time they get to meet expectant mothers is during the antenatal classes where they explain to them about the cord blood programme and

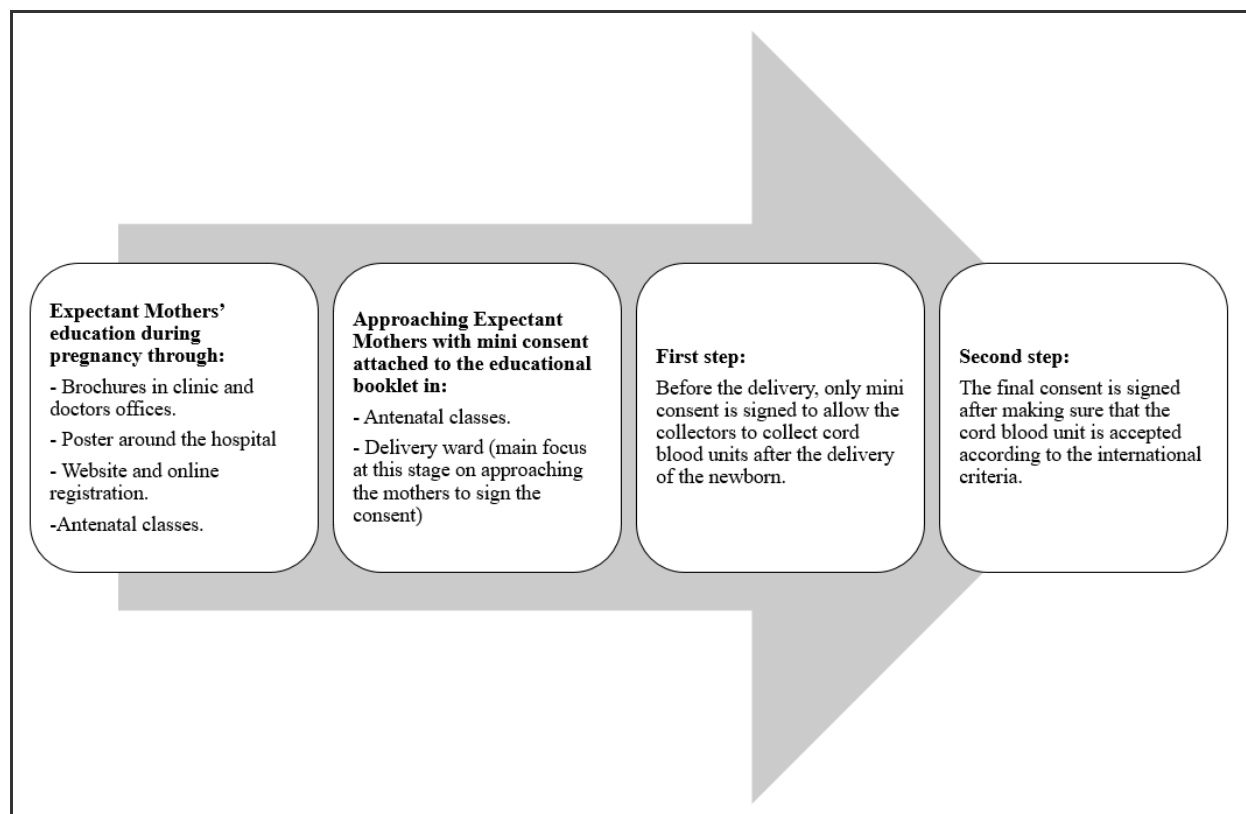
hand them the leaflet that contains the mini consent form to sign if they are interested to enrol on the programme. The researcher also asked the collector during the interview about the person in charge of educating expectant mothers in antenatal clinic and she said that it's mainly the collectors who educate the expectant mothers and midwives and other healthcare providers in the hospital only encourage expectant mothers to donate their newborn's UCB stem cells she said:

*When pregnant women come to visit the antenatal clinic only leaflets are given to her at that time and there is a chance for us to go and speak to her but it's only a short time because in the waiting area pregnant women can be called at any minute by the doctor so we do not find it much helpful at this stage.*

She illustrated during the interview that they encourage expectant mothers to donate their newborn's UCB stem cells by highlighting to them about the benefits of donations in helping many patients around the world including children and adults, so instead of discarding cord blood units, they are used to help others. She said: *"The main reason that encourages them to donate their cord blood is knowing that it can help someone"*. However, the reasons that might prevent expectant mothers from donating their newborn's UCB stem cells might be medical or personal reasons or having a fear from needles during maternal samples collection. The researcher also asked her during the interview about the hospital agreement and the actual cord blood registration stages that occur in the hospital. She answered that cord blood education is part of hospital policy in a way that they allow us as collectors to educate and collect cord blood donations. The authorisation is in the form of agreement between the hospital and the cord blood centre. The researcher also asked the collector for her point of view regarding the best system that can be implemented in the hospital to make sure that no cord blood samples are wasted. She revealed the importance of approaching each single expectant mother who arrives at the delivery ward. She also believed that the delivery ward is the best place to gain the consent of expectant mothers. This is because, at this stage,

collectors can check the medical situation of expectant mothers before the delivery whereas in the antenatal clinic, expectant mothers are still in the very early stages of pregnancy and they might be exposed later to some risk factors that prevent them from donating their newborn's UCB stem cells. She also highlighted during the interview that it is the collectors' job to introduce themselves to the midwives in the hospital and encourage healthcare providers to speak with expectant mothers about cord blood donation. Details of the interview with the collector are shown in Appendix 21.

Figure 5-1 summarise the different stages at which the expectant mothers are informed about cord blood stem cells through their pregnancy to assure layering up cord blood education. Expectant mothers first sign the mini consent form which is enclosed within the cord blood education booklet. This mini consent acts as a pre-screen for cord blood collection which includes some information about cord blood programme and important minimum criteria required to conduct cord blood collection whereas the final consent form allows for the testing, utilising and cryopreservation of the cord blood unit. At this stage the expectant mothers are asked the full medical questionnaire. The final consent is only done if the cord blood unit is accepted for cryopreservation.



**Figure 5-1 NHS Cord Blood Donor Recruitment model**

- **Interview with National Bone Marrow Transplant (BMT) Marketing Manager**

To understand more about donor recruitment motivations, barriers and obstacles that are faced when recruiting cord blood donors in the UK, the researcher had the great opportunity to interview Mr. Theo Clarke, National Bone Marrow Transplant (BMT) marketing manager in NHS Blood and Transplant centre. He is in charge of recruitment and retention of more Black Asian and minority ethnic donors for cord blood registers and also for bone marrow and stem cells recruitment. The researcher asked him about the main obstacles he is facing in recruiting Black Asians and how he overcomes these obstacles. He highlighted that there are some general obstacles and some that are specific to the community and it is important to identify both obstacles and understand them. One of the best solutions is to work with the community as much as possible and to study factors such as religion, culture and ethnicity of

each community (more details about the interview are shown in Appendix 22). The researcher then asked him his point of view in term of culture and how it is affecting cord blood donation in the UK. He said:

*I'm a big believer in "Grass roots" so doing a lot of grass roots engagement I believe grass root is a way we affect change and it is a behaviour change which we want to affect by the end of the day, and it takes a long time. The biggest pressure I guess from our NHSBT point of view is the awareness which is really really progressing very slow to touch this issue.*

Mr. Theo Clarke asked the researcher during the interview: *In terms of educating the donors, do you have gender separation or are they educated together in the same area?*

This was a really very important question and one of the main obstacles that the researcher is facing in the UAE concerning donors' education. Expectant mothers are seen in antenatal clinics without their husbands because in the government hospitals in the UAE, the waiting area in antenatal clinic segregates males from. Thus we only had the chance to educate the expectant mother without her husband. Therefore, most of the time the expectant mother does not make the decision at the same time as she needs to discuss it with her husband first and then get back to us on her next visit. Mr. David Winstone, Business Manager of the British Bone Marrow Registry (BBMR) who was there during the interview commented and provided some solutions for the UAE about the issue of gender separation during antenatal classes and how we can educate both parents at the same time. He suggested that men who are keen about cord blood donation and agree with their wives to donate their newborn's UCB stem cells can play an important role in talking to other men and promoting cord blood donation. All material needed for education can be prepared and sent out to him so he can give a presentation to other men who are working within his organisation. Maybe this man is working in a big organisation so he will be reaching out to a larger number of people.

Mr. Clarke highlighted that here in the UK we work with volunteer Muslim groups who encourage other Muslims to donate their cord blood. We also work with the Islamic society and we have Muslims talking about the importance of cord blood donation in mosques. We also found out that it is useful to set up large hybrid public sessions 2-3 times a year one which was held in London and another one in Birmingham. These helped to reach a large number of people.

He also highlighted that education about blood donation should start in colleges and primary schools and it should be taught at a very early stage so that the outcome of that is people being more aware about the importance of blood and cord blood donation from a much earlier age. We believe that starting education at an early stage will lead to great outcomes. We also try to get members from each community to teach their own community about blood donation.

He also talked about the fact that even though there is ongoing education and awareness about blood donation, but there are still people who do not know about it. He commented that, on some days when you ask you will find many people who know about it, while on another day you find that no one knows about it. Some people who are interested in donation know more as they read about it. Some people become engaged with the topic, while others do not, for a range of different reasons; for example, if the topic does not apply to their personal environment, or they think religion might stop them as they are particularly religious, and some do not even bother to listen to you as they are not interested in knowing about it. He also recommended that we focus on Thalassemia and sickle cell societies as a tool to encourage other people to donate and help those patients. Also it is important to make people talk about it and share their experience and their situation when they needed donors to treat a case within their family. More information about the interview is shown in Appendix 23.

### **5.1.2 USA Visit to CORD:USE Cord Blood Centre in Orlando**

#### **Introduction to USA Case Study**

Interviews were conducted with Dr. Edward Guindi, President & CEO of CORD:USE cord blood bank in the USA and Mr. Michael T. Ernst, vice president and CEO of CORD:USE along with Mr. Thomas Moss, vice president of Operations of CORD:USE in Cord Blood Bank. Dr. Guindi prepared a full agenda for the researcher's visit from 10 July to 16 July 2016. The agenda included a visit to the CORD: USE cord blood centre to meet and interview a number of important stakeholders within the field of cord blood and donor recruitment. Dr. Guindi also arranged for the researcher to take a tour of Florida Hospital for Women to see the cord blood collection room where they collect the cord blood stem cells (*ex utero*). He also arranged a tour to the Walt Disney Children's Pavillon and Florida Children's hospital including transplant unit. The researcher had the great privilege of being able to interview the world's first cord blood transplant recipient and to interview the head of the public donation programme, Ms. Joanne Alphonse, to learn more about cord blood donor recruitment processes in hospitals. The researcher also travelled from Orlando to Minnesota to meet Dr. Hal Broxmeyer, the founder of the field of cord blood banking and transplantation and to interview Dr. John Wagner, world-renowned cord blood scientist and transplanter. The researcher also had the pleasure to learn more about cord blood donor recruitment from interviewing Kim Petrella who is a registered nurse and cord blood educator.

- **Interview with CORD:USE Management**

Dr. Guindi, Mr. Michael and Mr. Thomas were interviewed at CORD: USE cord blood centre for more than one hour. The researcher asked them to share their experiences and knowledge



about how expectant mothers can be encouraged to donate their cord blood stem cells and to explain more about the cord blood donor recruitment set-up in the USA's hospitals.

Dr. Guindi started his interview highlighting the importance of awareness and during the interview he discussed the significant need for proper systems in place to ensure that cord blood information is conveyed to all expectant mothers in hospitals. He focused during the interview on the need for creating a proper system within the hospital but the system should not only be in one place; rather it should connect all the concerned stakeholders within the hospital who can play an important role in making this project successful. Therefore, expectant mothers will be approached at different stages in antenatal classes and doctors' offices, during their scans, and the most important stage which is at the delivery ward. Dr. Guindi also highlighted that healthcare educators from the cord blood banks do not interfere with expectant mothers' decisions about which banking options to select; they simply ask them to select the best option for them. Healthcare educators never want to push expectant mothers to choose a specific option as they need to choose what is right for their family. He said:

*We do not tell people to donate cord blood or preserve it for themselves, we tell people the benefits of public banking are and how it can help in creating the registry and we let them know how many people out there are in need of the cord blood unit.*

During the interview the researcher explained to them that one of the main barriers in the UAE that prevent expectant mothers from donating their newborn's UCB stem cells is lack of knowledge and not knowing the importance of donating cord blood stem cells. He commented:

*We experience people who do not know about cord blood even in the USA. That why we need a multifactorial approach where we have to let the nurse know, physicians know, public know, patients know in that situation; then by putting all that system in place, they will then be having more awareness to make decisions.*

The researcher then asked him about the best method that makes people donate their cord blood stem cells rather than dispose of it. He emphasised: *“When people know that there is no cloning, there no ethical issue and it can help someone in need, when they find that out they donate it rather than dispose of it”*.

Mr. Michael shared his opinion about expectant mothers’ education and stressed the fact that there are different mindsets when talking about cord blood stem cells:

*Understanding and knowing what certain types of individuals you may encounter within healthcare providers system is very helpful to having effective programmes so you are not going to convince everybody; you need to convince the right parties that help you be more effective.*

He also highlighted that the *“Trashcan is the enemy, so it is all about education and awareness. We always tell them do not throw it away, do something about it”*. Thus proper education and awareness among expectant mothers and the public is required to assure that the information is delivered to them in the right way so they can make informed decisions.

- **CORD: USE Donor Recruitment Model in the USA**

- **Interview with Joanne Alphonse in Charge of the Public Donation Programme**

The researcher also interviewed Joanne Alphonse who is working with CORD:USE team as head of the public donation programme and a registered nurse who provides cord blood training and education for collectors as well as healthcare providers in hospitals. The researcher wanted to learn more about the donor recruitment process within the hospitals in the USA. The researcher started the interview by asking her to introduce to us about cord blood awareness and training programmes in term of motivations and challenges faced during education and training. She highlighted during the interview that CORD:USE cord blood

bank has its own collectors who are trained to educate and provide information about cord blood to expectant mothers and healthcare providers in the hospitals. She revealed that training and education is not an easy task and requires significant, continuous effort.

The researcher also asked her about the best and the most challenging part of cord blood education and training. She clearly highlighted that the best part is seeing the results of training on the trained staff particularly when the job is done properly according to the guidelines. However, the challenging part is to keep consistency as in the hospital they do many other tasks beside cord blood education and collection which means that they sometimes miss out on following the guidelines.

The researcher then asked her about her point of view regarding cord blood awareness and education and how it can make changes these days. She said: *“Cord blood education is extremely important; without education it kind of stops everything there - if they are not educated about the role of cord blood then you do not have a programme”*. She also stressed the importance of educating healthcare providers in the hospitals about the benefits of cord blood stem cells to run the programme successfully in the hospital:

*Of course the mother is the most important because she is the one who is giving her child's cord blood but without the doctors and nurses being educated it will not make difference that it should.*

At CORD:USE cord blood centre they have their own staff running the programme at the hospitals and they make contact with the mothers at different stages in the antenatal clinics, antenatal classes, and during hospital tours and usually the hospital staff help them educate the expectant mother about cord blood stem cells. She also highlighted in her interview that the education is not only focused on the expectant mother; they usually educate the entire family who are available in the delivery room at that time. She also highlighted the

importance of understanding each hospital system to be able to implement the cord blood programme accordingly.

➤ **Interview with Mathew Farrow the World's First Cord Blood Transplant Recipient**

Mathew Farrow, a 33-year-old man, has been married for 10 years and has a son aged 12 years old. He is also the first person in the world to have a cord blood transplant. The researcher asked him to share his success story of being the first cord blood transplant recipient in the world. He shared his story with the researcher by illustrating the main important points within his transplant journey (see Appendix 18).

The researcher was honoured to be the first person from the Gulf country to meet him and listen to him telling his own success story. The interview was voice-recorded and videotaped after obtaining his permission to do so. The researcher then continued asking him questions to learn more about his current role in educating and encouraging the public to donate their cord blood stem cells. More details about the interview are shown in Appendix 18.

The researcher also asked him his point of view regarding cord blood education and awareness. During the interview, he stressed in his message about the importance of starting educating people about cord blood from universities and schools and making it part of taught programmes at universities. He said:

*I believe cord blood awareness is essential to everyday life. I believe that making the community more aware of what the differences are between cord blood embryonic stem cells and other types of stem cells is important. I believe that for us to be more aware of the options out there for people to donate or to bank, educating the public is very important. I think education has to start with doctors running courses in school about cord blood banking and stem cells so that the pediatricians and OBs so they can talk to their patients and then patients like me will share their stories to help educate and show there is hope in this kind of technology, but I believe that it needs to start with doctors. There is a lot of misinformed information. The public is getting more aware through social media and it is becoming a big thing in cord blood awareness and there should*

*be more of it done as far as maybe even social events where we can give out information about cord blood and stem cells and what they do and what they treat.*

Being the world's first cord blood transplant recipient, the researcher also questioned him about his role within the community and asked him to share some ideas and suggestions on the best ways to encourage expectant mothers to donate their cord blood stem cells in the UAE. During his interview, he emphasised the importance of awareness and education and making the family aware about the cord blood collection procedure and the fact that there is no harm or risk to either the baby or the mother. Details about his answers are shown in Appendix 18. He also shared with the researcher his advice to the public:

*The best advice is start your education early, doing a lot of research, just talking with pediatricians, figure out from accredited websites, and just doing a lot of early research on cord blood banking... I think would help in making informed decisions.*

➤ **Interview with Dr. Hal Broxmeyer, Founder of the Field of Cord Blood Banking and Transplantation.**

The researcher was honoured to interview Dr. Broxmeyer, the founder of the cord blood transplant field. The researcher wanted to learn more about his success story and his discovery. Dr. Broxmeyer highlighted that his discovery journey was very interesting as he was working with a fantastic and very co-operative team. The researcher asked him to summarise the story behind Mathew's cord blood transplantation and how they thought of cord blood as a source of stem cells. He said during the interview that it was a very long story but he highlighted the main points (Appendix 19). Mathew's story was the first successful cord blood transplantation story in 1988 where Mathew received his little sister's cord blood stem cells. This story led to the discovery of another source of Hematopoietic stem cells because, at that time, bone marrow was the only source of stem cells that are used in transplantation and it has to be a perfect HLA match. He highlighted:

*Bone marrow was used and bone marrow has to be an almost perfect match with a lot of graft versus host disease so cord blood has less graft versus host disease and will be able to be used by crossing some of the HLA barriers for transplantation and we were able to prove that, but it took time to convince the rest of the world; I personally think that the future is cord blood but we have to learn how better we can use it, how better we can collect it and how better we can save it and better transplant it and that is where research comes in.*

Dr. Broxmeyer elaborated more about Mathew's successful case and said that the first step was to find a matched recipient to do the experiment. More details about Dr. Broxmeyer interviews are shown in Appendix 19.

➤ **Interview with Dr. John Wagner World-renowned Cord Blood Scientist and Transplanter.**

The researcher interviewed Dr. John Wagner one of the very famous scientists who performed many cord blood transplantations for children and adults. The researcher had a great opportunity to ask him many questions related to cord blood stem cells and the importance of cord blood donation and ethnic diversity in selecting donors for transplantation. He highlighted that cord blood stem cells are considered one of the important sources of stem cells for patients mainly because it allows us to cross the HLA barrier if compared to bone marrow stem cells which require full HLA match between the donor and recipient. However, one of the problems facing cord blood units is the fact that the numbers of stem cells are variable. Not all cord blood units are collected of good volume as there are many factors that affect the volume such as size of the placenta and weight of the newborn. Therefore, new technologies are out available to expand the number of stem cells two- to three-fold so they can be used for adults. More details about Dr. Wagner's responses are shown in Appendix 20.

There are certain areas in the world where certain diseases are common but the point is that any disease that affects the bone marrow or affects the immune system can be repaired by a Hematopoietic stem cells transplant. The advantage of cord blood is that we do not have the same degree of HLA matching that is particularly important in areas where there is a great

deal of heterogeneity in HLA type, and the Middle East is one of those areas. This is because of the history of the Middle East where invasions have occurred over time with different people from different parts of the world, which has increased HLA heterogeneity, hence making it more difficult to find donors. This is one of the reasons we believe that it is particularly important for umbilical cord blood to be made available in that region so we can better help patients from there. More details about the interview are shown in Appendix 20.

During his interview Dr. Wagner also explained the advantages of having cord blood units over bone marrow as it is available all the time whenever there is a need unlike the bone marrow where we have to call the donor and check its availability (details of his answer are shown in Appendix 20). Despite the fact that the best match can be found within the same society with different ethnicities, there are still individuals who refuse to donate their stem cells due to culture and religious restrictions. He said:

*We also found that across cultures the best chance of finding match donors is within your society and culture. In certain cultures people are resistant to donate. For example in Japanese culture unrelated donor transplant (for others) has been difficult as they fear donation and there are some cultures where it is religiously significant to give their stem cells to somebody else. All these things can interfere with the use of adults' stem cells as donors and sooner it will open up the broader possibilities of how cord blood can be more powerful. In certain cultures cord blood is going to be a key for the success of transplant.*

The researcher also asked him about the importance of public registry and ethnic diversity for each country and how a cord blood registry can help treating many patients from the Middle East. He illustrated in his interview the importance of having cord blood banks with donations from different races and ethnic groups because of HLA diversity and it is essential that each individual country has its own cord blood stem cell bank. For example, the Middle East has the advantage of being a heterogeneous community with populations from different countries, which can lead to the formation of a public registry of different ethnicities. More details about his response including direct quotes are shown in Appendix 20.

➤ **Interview with Kim Petrella, Registered Nurse Working in One of the Maternity Hospitals in Delaware, USA.**

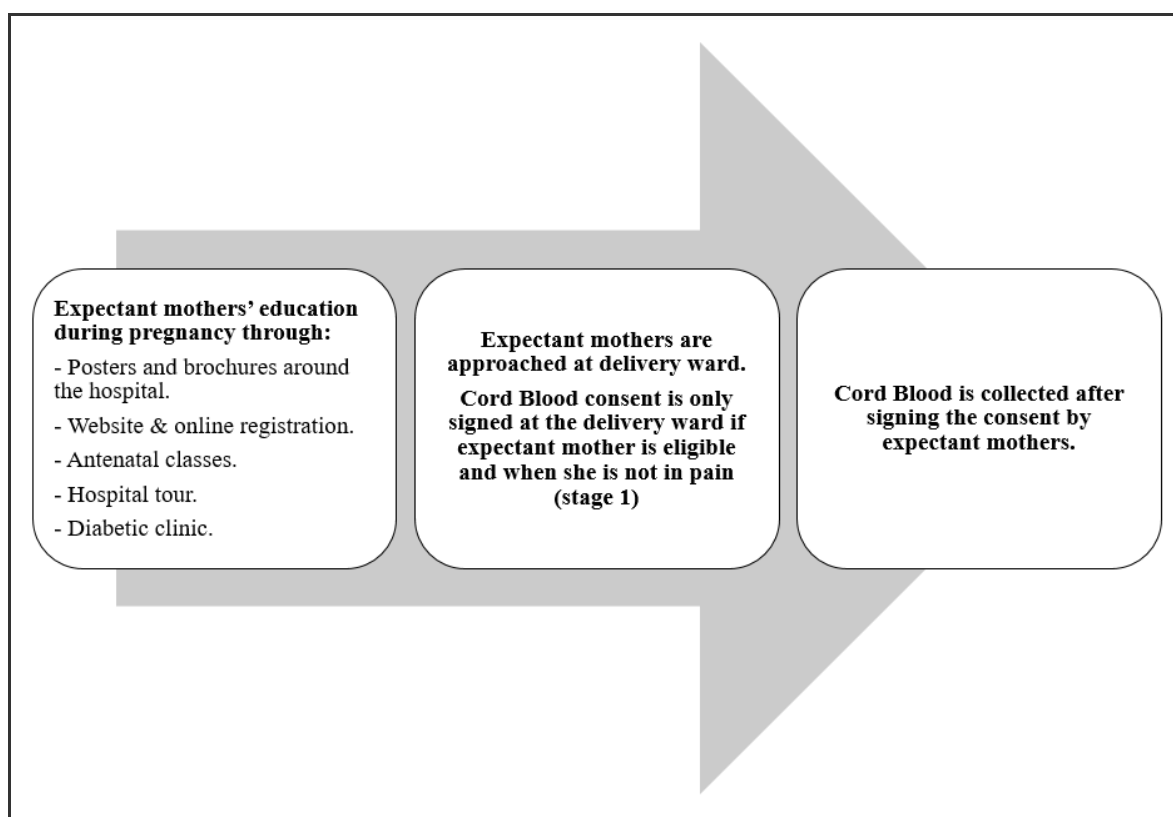
The researcher also interviewed Kim Petrella, a registered nurse and certified in-patient obstetric who has been working in labour and delivery for 25 years. She started in 1991 and became very interested in cord blood education. The researcher asked her about the most challenging aspect she faced during educating expectant mothers and she emphasised that it was that misconceptions and the wrong information about cord blood stem cells that is one of the main barriers that prevents many expectant mothers from donating their newborn's UCB stem cells. She then illustrated that everyone should be educated about cord blood stem cells and the education should not be restricted to hospitals; it should extend to different places like toy stores, ladies' clubs, schools, and universities. She said:

*I think everybody should be educated about cord blood stem cells. I love to go out to the communities, I love to go to church groups. Everyone needs to be educated. It is amazing the misinformation that it is out there and sometimes that misinformation is like a ROCK SOILD WALL BARRIER.*

She also highlighted during the interview about the importance of conveying cord blood information to the expectant mothers at the early stages of pregnancy so they have the chance to think about it and make informed decisions. Layering up education is very important during the different stages of pregnancy so when expectant mothers reach the delivery stage they will be aware about the different cord blood banking options and be able to make a quick decision. Cord blood educators also educate and train nurses and medical staff in hospitals about all the information required about cord blood so they feel confident discussing it with their patients. She also highlighted that there is no specific person who is responsible for cord blood education in the hospital; all of them are in charge of delivering the message to the expectant mothers at different stages during their pregnancy.



Figure 5-2 summarises the cord blood donor recruitment model at one of the maternity hospitals in the USA. Once the expectant mother visits the hospital she is approached at different stages during her pregnancy. She is approached on the hospital tour, through pamphlets and posters, at the diabetic clinic when she does the glucose test, and in the antenatal classes. Thus, the expectant mother is approached at different stages to assure the layering-up of information about cord blood stem cells so that she can make an informed decision at the delivery stage. Cord blood consent is only taken at the delivery ward when the mother comes to deliver her newborn. Details about the full interview with Kim Petrella are shown in Appendix 21.



**Figure 5-2 USA Donor recruitment model**

## **5.2 Case Study 2: Healthcare Providers' Opinions and Attitudes Regarding Cord Blood Donation in Hospitals A and B in the UAE**

### **Introduction to the UAE Case Study**

Qualitative and quantitative data collections were conducted in the two largest governmental hospitals in Dubai. Hospital A is a specialist maternity hospital for women and children that provides neonatal and maternity services while Hospital B is a general hospital with different specialised departments and clinics, one of which is the obstetrics department. A survey was distributed to more than 1000 expectant mothers and 200 healthcare professionals in Hospitals A and B. Next, 106 interviews were conducted in Hospitals A and B and five independent focus group discussions were performed in both Hospitals A and B with different groups of healthcare professionals that have direct interaction with the expectant mothers during pregnancy.

The interviewed groups consist of obstetricians and gynecologists, delivery ward nurses, antenatal clinic nurses, and pediatricians. The interviewees were asked 10 questions at the clinic; this took between 20 and 30 minutes. Each group of healthcare professionals responded differently to some of the interview questions, which reveals the different ways of thinking depending on their work environment and culture surrounding their job. Results generated from the interview data and focus group discussions are classified into the following main themes:

- General knowledge about cord blood stem cells and education responsibility.
- Cord blood donation barriers.
- Importance of public donation and stem cell registry.
- Best tools/methods to help increase cord blood donation in the UAE.
- Guidelines and policies required by healthcare professionals for cord blood education.

### 5.2.1 Qualitative Data Collection and Analysis of Hospital A

Hospital A is one of the largest and accredited maternity hospital in the UAE that consists of 344 beds distributed across different departments. The hospital is fully equipped in order to provide high-quality services for patients. Interviews were conducted with different groups of healthcare professionals at their clinics for 20 to 30 minutes. The number of interviewees from each group is shown in Table 5-1 below.

**Table 5-1 Total number of Interviews conducted for healthcare providers in Hospital A**

<b>Name of Healthcare provider group</b>	<b>Nurses Delivery Ward</b>	<b>Nurses Antenatal clinic</b>	<b>Obstetricians and Gynecologists</b>	<b>General Paediatricians and Neonatologists</b>	<b>Total</b>
<b>Number of interviewees</b>	18	8	16	8	<b>50</b>

#### 5.2.1.1 Healthcare Professionals' Responses during the Interviews in Hospital A

- **Antenatal Nurses**

##### **Knowledge about Cord Blood Stem Cells and Cord Blood Education Responsibility**

Nurses in the antenatal clinic are the first people who see the expectant mothers when they walk into the clinic for their appointments. Their main role is to check the mother's health status and ask her questions related to her pregnancy before she sees her gynecologist doctor. The researcher was very keen to interview this group of healthcare providers as they have direct contact with expectant mothers and are considered the main channel between the expectant mother and the gynecologist doctor at antenatal clinics. Thus, it was important to know their knowledge level regarding cord blood donation and banking options and to learn from their suggestions and ideas on how cord blood donation can be encouraged among

expectant mothers. Their daily connection with expectant mothers at the clinics make them more aware about expectant mothers' thoughts, behaviours and attitudes regarding cord blood donation; and thus learning from them will add great value to the research findings.

Most of the nurses in the antenatal clinic were aware that cord blood stem cells can treat many diseases and there is a great deal of research going on regarding the use of cord blood to treat many other diseases in the future. However, their overall information about cord blood is basic and they were not aware about the many different diseases that are currently treatable by cord blood stem cells. Most of them only highlighted some common treatable diseases such as Thalassemia, leukemia and sickle cell; whereas cerebral palsy and heart and diabetes diseases are future promising diseases so there was a clear misunderstanding about current treatable diseases and possibilities in the future.

Moreover, their information about cord blood stem cells is limited and detailed information is required to be able to share with expectant mothers. Thus, they do not feel confident enough to share detailed information about cord blood with expectant mothers. Almost all of the nurses highlighted during their interviews that they prefer to have a full-time healthcare educator from the DCRC to be available in the clinic to educate expectant mothers in the details about cord blood stem cells, beneficial usage, diseases treated, and the different available banking options. Despite the fact that they said all healthcare providers are responsible for passing on information about cord blood stem cells to the expectant mothers, they still strongly believe that it is the responsibility of the healthcare educators from the DCRC, and the healthcare provider can only help by encouraging the mothers and passing on basic information about cord blood. They also highlighted that expectant mothers need detailed information about cord blood, which requires time and knowledge and is hard with all the responsibilities they have and other education they do at the clinic.

All the nurses believe that it is the mother's right to know the potential benefits of cord blood therapy so she can make an informed decision to help her family if there is any disease and also to donate and help others in the society if needed. Interesting discussion and answers were obtained from antenatal nurses as one of them highlighted that if the mother is not aware about the benefits of the placenta that she was carrying for nine months, how can she then participate in donating her newborn's UCB stem cells to help her family or others in need. She said:

*Of course this is her right if she does not know what she is carrying how she will donate. she needs to know the benefits and for what it can benefit. If she knows that it will benefit somebody she will surely donate it. Cord blood donation will not hurt you and it will not hurt your baby and it will help somebody.*

Another nurse highlighted the fact that if mothers know that cord blood stem cells can save someone's life they will definitely donate their cord blood to help others instead of disposing of it. She said:

*Yes of course it is her right and if they know about the stem cells and it is useful for the people and we can save people's life of course many mothers will go for this, otherwise it will go to garbage and it is better to preserve to save life.*

### **Cord Blood Donation Barriers and Motivations**

One of the interesting questions posed during the interview was to find out nurses' point of view regarding main barriers that stop the mother from donating her newborn's UCB stem cells. All of them agreed that the main barrier is lack of knowledge and not knowing the importance of cord blood donation in treating many diseases and helping many patients in need for transplantation. They are not aware that part of their "placenta" contains stem cells that can be used to treat life-threatening diseases that are very common in the UAE such as Thalassemia, leukemia, and sickle cell anemia. They also highlighted the fact that, as healthcare providers in the hospitals, they do not have much information or latest updates in

the field of cord blood stem cells. They highly emphasised the need for first educating all the healthcare providers in hospitals about cord blood stem cells so they can share the knowledge with their patients. They have also asked for the arranging of intensive Continuous Medical Education (CME) sessions about cord blood for all the staff in the hospital from all different departments so they are aware about the importance of cord blood stem cells.

Nurses think that other reasons that prevent Expectant mothers from donating their cord blood stem cells are culture, religion and fear of giving their own blood to others. One of the nurses said:

*I think in the UAE, their culture, and they need more information about it because they do not know, they think it is only used for family member. We need to educate them during antenatal visit, send somebody and just educate them when they will get the education and knowledge about the stem cells they will donate.*

Another nurse thinks that if the expectant mothers do not know the importance of cord blood stem cells they will definitely waste it. She believes that mothers need to get information about cord blood in antenatal clinics even though the time available is short during the clinic as expectant mothers will be called by their doctors, so there is not enough time to explain about such a detailed subject during the antenatal clinic visit. She highlighted:

*Lack of proper information, if they will get proper information in antenatal clinic the period is very short and the subject is very long. Such topic needs proper information; people they do not know the importance, that is why it is going to waste only.*

Another nurse believed that lack of awareness and religion might also be two of the reasons. She said: “*They are not aware about the advantages and some people’s religious beliefs stop them*”, while another nurse highlighted an interesting point; she said, “*because of lack of education and information and maybe the family or husband refusing and not giving support (family support)*”.

### **Best Tool/Method to Increase Cord Blood Donation in the UAE**

Most of the nurses in the antenatal clinic highlighted that the best methods to increase cord blood donation in the UAE are awareness campaigns, education, and teaching about cord blood in hospitals, as well as good communication between healthcare providers and the patients. They believed that if expectant mothers are not aware about the importance and the benefits of cord blood donation they will not donate their newborn's UCB stem cells. Therefore, it is important that they have adequate knowledge so they can make informed decisions. One of the nurses strongly believed in proper communication between all the healthcare providers and the patients, and also stated that if the patients are hearing about the importance of cord blood stem cells from their doctors they will be motivated to donate their newborn's UCB stem cells for others. When she was asked about the best method to increase cord blood donation she said:

*Communication, Communication, Communication good communication between patients and healthcare providers. How you are giving your message to the patient.*

Another nurse stressed the importance of educating the mother during her antenatal clinic visit when she is coming for her appointment for a checkup with her doctor. She said this time is an important time that she can be given adequate knowledge by someone who is knowledgeable about the topic and can answer their questions and concerns. She said, *“When the mother comes to her antenatal visit somebody needs to be there to educate the mother. During antenatal visits patients need to be totally aware about the usage”*. However, another nurse thought that teaching is the best method as she believes that if we give brochures to the mother to read she might not read it but if we talk to her and explain she will listen: *“Teaching is the best method because if you give a leaflet only if someone is interested will [they] read [it]; if somebody will come and talk to them everybody will listen”*.

## **Importance of Public Donation and Stem Cell Registry**

The researcher also asked the nurses about their knowledge regarding different cord blood banking options and which option they encourage their patients to go for. Almost all of the nurses said that they would like to encourage their patients to donate their cord blood stem cells if they do not have any family medical history. They believe that donation will play an important role in helping the society and the many patients in need of transplantation. However, almost all of them did not know about public stem cell registry even though they know about the importance of donation, which highlights that they know that cord blood donation is important and can help many patients but they do not know what happens next the cord blood stem cells are donated, and how the patient gets the unit if needed. These points of information are very important so that, if expectant mothers asked them, “What will happen to my cord blood unit after donating it?”, they will be able to provide them with the right answers. Most of the nurses were not aware that these donated cord blood units are processed and registered within a public international registry so that transplant centres can search for donors from all over the world. However, in the UAE, we do not have a cord blood stem registry yet due to many factors; one of these is low cord blood donations levels, which this thesis is focusing on. Thus, it is important to find out the main barriers that stop the mothers from donating their newborn’s UCB stem cells and the main factors that motivate them to do so. This will help in designing proper recruitment processes within UAE hospitals.

Some nurses would like to encourage public donation because it is free of cost, and others believe that it is very beneficial for others. One of the nurses said, “*I will encourage thee public because it is free of cost and you can use it for your family and for the public*”. Usually, public donation is for others and cannot be used by the family unless the unit was



still there within the international public registry and had not been used by patient. Another two nurses highlighted that if the cord blood unit is preserved solely for the family's use, we might not use it as a healthy family and it will be considered a waste where someone else could benefit from it. She commented:

*I encourage public banking because if we secure it for ourselves maybe we will use it and maybe not but when we give it to public banking when it is needed it can be used.*

Another nurse believes that if the family concerned is suffering from diseases, they should keep the unit for their own use in future, but if they are healthy they can donate it. She said:

*That is in her interest if she has diseases that it can cure she can go for private banking but if she does not have anything she can go for public banking, also it is of benefit to both of them, but if she has something according to her choice then I cannot force her.*

### **Guidelines and Policies Required by Healthcare Professionals for Cord Blood Education**

Almost all of the nurses agreed that there should be cord blood educational guidelines for healthcare providers to follow. They said that the guidelines should be short and to the point, and include basic information about cord blood stem cells. They believe the guidelines will help them with the information they need to share with their patients. Almost all of the nurses gave similar answers highlighting the importance of having the guidelines for the healthcare providers. One of the nurses said:

*Yes, good guidelines should include basic needed information but not in detail. We encourage the mothers and talk to them about cord, we do not have time, it's a detailed subject. Doctors and nurses cannot do it in details.*

*Patients nowadays have basic information; they want now detailed information from DCRC and somebody who can discuss with them.*

Another nurse believes that even if there are educational guidelines, it is still the healthcare providers who need to be educated first so they are able to follow the guidelines. She highlighted, "If you educate the healthcare providers then it's okay otherwise no. If they are

*not educated they cannot answer and clarify the doubts of the mothers”,* whereas another nurse believes that, even if we have educational guidelines, someone from the cord blood bank still needs to be available in the clinic to discuss the topic of cord blood stem cells with the patients, in exactly the same way that other topics are discussed in the clinic with specialist staff in the field. She highlighted:

*We have diabetic patients so we have a specialist nurse that is giving patients information about diabetes. So you can have a nurse for DCRC who only does that work and educates the patients about cord blood.*

- **Delivery Ward Nurses**

### **Knowledge about Cord Blood Stem Cells and Education Responsibility**

Nurses in the delivery ward were the most knowledgeable group compared to the others. The main reason for that is the fact that they are the ones who are collecting cord blood stem cells from the patients at the time of delivery, so they are gaining information through their routine daily practice. Moreover, the DCRC is providing educational sessions for nurses each month to enhance their knowledge about cord blood and to update them with the best techniques about cord blood collection. During the interview they were asked about their general knowledge about stem cells and the different banking options. Almost all of them had good knowledge about cord blood stem cells in general and the different common diseases that can be treated using cord blood stem cells. However, they could not differentiate among the diseases that are currently treatable and the one that are undergoing research as they believed that cord blood can treat most of the diseases. Therefore, having accurate and adequate knowledge is very important when educating the patients and informing them about the current treatable diseases and the future promising ones.

One of the nurses was asked about her general information about cord blood and disease treated and she provided the correct answer when she said: “*Stem cells are hematopoietic*

*cells with special properties; it can divide and replicate and they are nonspecific cells. It can treat cancers, blood diseases including thalassemia and also some future promising diseases”*, whereas another nurse said that it can treat neurogenic disease which is in fact currently not treatable by stem cells. She said, *“Stem cells are collected from cord blood after the delivery and it can treat certain diseases such as neurogenic disease”*. Other nurses also said that it can treat diabetes which is one of the promising treatable diseases in the field of stem cells. Thus, some of them have correct information about cord blood while others still have some misconceptions. Most believed that cord blood education should be conducted by specialists in the field of cord blood who can give the patients detailed and accurate information about cord blood.

In addition, during the interview, the researcher asked them: *Who do you think is responsible for providing information about the potential value of publically donating cord blood stem cells, and why did you choose your answer?*

Most of them answered that it is mainly the responsibility of the DCRC staff along with all the healthcare providers and they strongly believed that education should happen in the early stages of expectant mothers’ visits to the antenatal clinic. Other believed that it is mainly the responsibility of the DCRC and should be initiated by them because they are the one who can do this job and answer expectant mothers’ questions and concerns, as one of the nurses said:

*I think the main responsibilities should be shared with DCRC staff but they can utilise and train some healthcare providers for the purpose of this. It has to be initiated by DCRC and the proper education should be given by DCRC.*

Another nurse also stressed that it is the responsibility of the DCRC along with all the healthcare providers and everyone should talk about it and show the importance of it. Meanwhile, another nurse suggested that cord blood education should be similar to

breastfeeding education in the hospital where a dedicated “breastfeeding consultant” is available in the clinic to educate the patients.

Therefore, most agree that it is first the responsibility of the DCRC to educate about the cord blood banking, but healthcare providers can play a role in reinforcing the message and highlighting the main points for the expectant mothers.

### **Cord Blood Donation Barriers**

It was very interesting to listen to different thoughts and answers obtained from the nurses about the main barriers that prevent the mother from donating her newborn’s UCB stem cells. Most of them said that knowledge and not being aware about the benefits of cord blood stem cells is one of the main barriers that stops the expectant mother from donating her newborn’s UCB stem cells, while other reasons can be due to culture and religious issues. Another nurse, however, thinks that expectant mothers do not donate their newborn’s UCB stem cells due to the fact that they do not want their blood to be used for somebody else, like the idea of breast milk donation which is not allowed in Islam, so the need for proper awareness is important. She said: *“I think it’s perception about it that my blood could be used for somebody like milk donation. People could have this perception”*. Another nurse mentioned the fact that awareness should be done from the grass roots, from the catchment areas which are the Primary Health Clinic PHC. When a woman knows she is pregnant, she first visits the PHC and she only comes to Hospital A at the later stage of her pregnancy. Thus informing her at an early stage will give her time to think about the issue and decide accordingly. The nurse said:

*It’s a new innovation and many people have not got the awareness. There is no adequate awareness of this cord blood stem cells collection or donation because some of them have not been really educated during the antenatal period.*

## **Importance of Stem Cell Donation and Public Registry**

Many nurses believe that if the mother can afford the payment for private banking, she should preserve her newborn's UCB stem cells but if she cannot afford it she should at least donate it for others. Another group of nurses believes that it depends on the situation of the mother; if she has a sick child she would be better to preserve the cord blood for their use; however if the family is healthy and they do not suffer from any diseases, they are encouraged to donate it to others. She posited:

*If they do not have a family disease they can go for private banking and if they are able to pay and store the unit. If they do not want to store they can donate it.*

Meanwhile, another group of nurses prefers public donation as it can help others in treating many life-threatening diseases. One said: *"Both are good but I feel public is better because private they cannot give to others and they may use it or they might not and it is costly"*.

Delivery ward nurses believe that cord blood donation is important if the family is not suffering from any diseases. However, if there is a sick child in the family they should privately bank the unit so they can use for treatment. Despite the fact they knew the importance of donation some of them were not aware about the use of public registry and how important it is to initiate one within the country. A few were aware about it and they totally agree that the UAE should have a stem cell registry because there are many patients with Thalassemia, leukemia and sickle cell diseases and they need to find donors from the public registry, but their information about the public registry was still limited. However, some nurses were not aware at all about the stem cell registry and the researcher had to explain it in detail during the interview. Thus, it is really important that all the nurses are aware about the importance of having a stem cell registry in the country, particularly in a country like the

UAE where different nationalities with different ethnic groups live, therefore opening up a valuable opportunity to find matched unrelated donors for many patients.

### **Best Tool/Method to Increase Cord Blood Donation in the UAE**

Most of the nurses agree that the best method to increase cord blood donation is awareness and education. They all highlighted different tools for conducting awareness; some suggested face-to-face counselling in the clinic and others mentioned the importance of media marketing by conducting awareness campaigns, social media, TV and radio. Nurses pointed out that education about cord blood should start earlier, from schools and universities, and should not be limited to hospitals only. An interview was also conducted with the nursing director in Hospital A, who fully supports and encourages cord blood education in the hospital. She said cord blood education should have a system that is similar to breastfeeding education where the expectant mother is approached at each stage of pregnancy starting from first booking in at the antenatal clinic to post-natal clinic attendance. The expectant mother is reminded and provided with information about breastfeeding at every stage during pregnancy. For successful cord blood education, she stressed the fact that healthcare providers and administration staff in the hospitals need to be educated first by providing them with intensive training and lectures about the importance of cord blood stem cells and the services provided within the centre. She said:

*First, healthcare providers need to know about the importance. The best method is you have to approach people wherever they are, do not limit yourself to Dubai, we can go all over the Emirates. The remote areas and far-away emirates, they have a right to be involved in all the education.*

Many of the nurses highlighted the importance of starting education in schools and universities as they can reach many girls and educate them before marriage and getting

pregnant, so that when they hear about cord blood later in the hospitals, it will not be something new for them, She commented:

*The Best method is to start in colleges and schools awareness programmes, also media and TV and also talking about the legal and cultural aspects of this, so if people are aware about this then public donation becomes much easier.*

Another nurse also highlighted the same point:

*The best method is educating pregnant women and couples, I think it should start from college and university level.*

Also, another nurse mentioned the importance of social media and marketing along with early education in schools and universities:

*The best method is social media and advertising, we have also to educate in school and college levels, in the malls where more people are gathering together.*

### **Guidelines and Policies Required by Healthcare Professionals for Cord Blood Education**

All nurses believed that it is really important to have educational guidelines, but they want first to be trained and educated about all the required information, so that they will feel confident enough to share it with their patients. Then the second step is to have guidelines in place as a reference for them to follow during education so they all speak the same language and pass similar information to their patients. The director of the nursing department said:

*Very important to create guidelines for healthcare providers, in breastfeeding we created first policies and guidelines based on WHO recommendation, then we started educating people, then we started asking them to them to teach. We cannot ask them to teach and educate people if they do not know themselves, education is very important for healthcare providers and they have to be involved with you and we as leadership we have to be a role model for our staff. When I ask my staff to do it and they see I have interest in it then it will reflect on them, so start with leadership and start with head of department; then we need policies and guidelines to be set up; then we can go and reach the community in the right way.*

Another nurse also emphasised the same point:

*First thing, even staff do not know whether you have facility to collect cord blood stem cells; do you have kits, is consent needed for everybody? So we need guidelines and education for the staff.*

Another nurse added:

*“Each practice needs guideline so it will be useful to learn more about how to collect it, how to keep it and how to give information to people.*

However, another nurse disagreed and said guidelines can help in education but the main point is to change the patients’ beliefs in regard to cord blood stem cells::

*Guidelines will help education; the main thing is encouraging them by teaching them and also changing some beliefs among the mothers and also educating them in different languages.*

- **Obstetricians and Gynecologists**

### **Knowledge about Cord Blood Stem Cells and Education Responsibility**

All of the obstetricians and gynecologists believed that cord stem cell has many advantages and can treat many diseases. However, their information about cord blood and diseases treated to share with the patients was very limited. Thus, they do not feel confident about discussing cord blood with their patients as they require detailed information about different diseases treated, cord blood banking options, and storage fees. Some of the doctors said during the interview that their information is very limited, and they need to attend many lectures to enhance their knowledge. One said, *“My information about stem cells is very small in this field but I know it can be used later to cure so many diseases”*, while others had good information from the orientation that they did in the cord blood centre when they were employed. One said:

*I actually got very good information about stem cells storage, and when we started orientation here in the hospital, I met people in DCRC and they gave us good*



*information about it. The storage is mainly for hematopoietic problems and also it has great use in treating other diseases.*

The CEO of Hospital A is also a gynecologist who believes very much in cord blood stem cell which plays an important role in treating many life-threatening diseases and many other future diseases. She said:

*They are treating so many things from stem cells and it's advancing very fast and I believe it can be utilised in many many aspects in future.*

Another doctor highlighted that stem cells will be the future medicine and are currently used to treat blood diseases. She said:

*Stem cells have good advantages in the future of the medicine nowadays and it has been used to solve many problems of blood diseases. We have seen so many cases suffering from Thalassemia, leukemia.*

Therefore, most of the doctors were aware that cord blood stem cells are useful but they only knew about a few common diseases that can be treated. Some of them were not aware about the private storage fees, cord blood banking options, and the storage period.

Obstetricians and gynecologists were also asked their opinions regarding who is responsible for providing information about the potential value of cord blood donation and it was very interesting to hear their answers particularly in that they have direct contact with the expectant mothers during their pregnancy. Some think it is the responsibility of DCRC staff; others believed that gynecologists and nurses in the antenatal clinic should play a big role in cord blood education and awareness, while some believed that it should start from media marketing.

The CEO of Hospital A (also a gynecologist) said during her interview:

*I think its obstetricians and pediatricians play a big role also and to be honest with you I think it should be all but maybe mostly and directly related OBG and pediatricians.*

However, another specialist register gynecologist believes that education should be done by the DCRC, and healthcare providers can reinforce the message. She highlighted:

*I think it should start from DCRC educator and at the same time it can be reinforced by the doctors so you can locate educational leaflets in doctors' rooms and in the antenatal clinic.*

Meanwhile another doctor mentioned the fact that any healthcare provider who has direct contact with expectant mothers should inform them about the importance of cord blood stem cells. She said:

*I think the responsible member of this is the medical staff because they are in close contact with the mothers during antenatal time, post-natal and throughout their visiting the hospital.*

### **Cord Blood Donation Barriers**

Most of the doctors agree that expectant mothers do not donate their newborn's UCB stem cells because of lack of knowledge and awareness as expectant mothers require detailed information to be convinced to donate their newborn's UCB stem cells. They highlighted the importance of informing expectant mothers that the procedure is safe and does not cause any harm to the newborn or the mother. Understanding the detailed information in terms of collection, processing and storage procedures will encourage her to donate her newborn's UCB stem cells to help others. Doctors believe that as soon as the mothers have adequate information and understand the benefits, they will definitely donate their newborn's UCB stem cells.

The CEO of Hospital A thinks that knowledge and awareness is the main barrier:

*Probably lack of information and education to be honest with you because I'm a mother myself and if it was offered to me can we take your cord blood I would never say no. I think people... they want to help... it is the nature of everyone, it is how you explain and tell them the benefit of this. I do not think people would mind. People donate their*

*kidney and undergo surgery to remove part of their stuff to give and we are talking about something that will be thrown away.*

Another doctor thinks that it is very important to inform expectant mothers that it is a very safe procedure to collect cord blood after delivery and it can save the lives of many patients:

*I think we need to educate them more, we need to educate them that it is absolutely safe and does not cause any harm for them and at the same time save a lot of lives, so we need to reassure them that it does not really endanger them in any way.*

However, another doctor believes that culture, beliefs and religion can act as barriers too towards cord blood donation as she highlighted:

*Because of their thoughts, they don't want to donate their newborn's stem cells due to religious issue and ethical issue, even nowadays we are facing patients with very low hemoglobin who are not accepting blood from others and they want somebody from their family that they know to give them blood.*

Another doctor mentioned that lack of knowledge is the main barrier and also it is important to make expectant mothers aware that donation is free of charge and there are no fees to pay. She said:

*There is a great lack of information about the general donation, I think the financial issue is an important thing that they do not reveal and we need to educate them that it is free of charge.*

### **Importance of Stem Cell Donation and Public Registry**

Most of the doctors believe that cord blood stem cells should be kept for the family if they have a sick child or a medical case that requires preserving the cord blood unit. However, if the family is not suffering from any diseases they can at least donate the cord blood to help others in need of it. The CEO of Hospital A highlighted that if the parents are keen to preserve cord blood for themselves they can keep it but the main point is not to waste the unit and dispose of it, she said:

*If they are keen to have it for themselves I will encourage them if not at least they should donate it. We should not lose the cord blood sample and waste it.*

A Senior Specialist Register doctor commented about the importance of checking the medical history of the expectant mother and her family to make sure they are not suffering from diseases that require preservation of cord blood unit for their own use:

*I will see her history and I will encourage her to go for private banking if she has family disease and it can help by going for private cord blood banking, but if she does not have family history or any ill child I think we should encourage her to donate her cord blood.*

Another consultant gynecologist also agreed that it depends on the medical history of the family and if they have a sick child they should keep the unit for their own use. She said:

*It depends if they have disease in the family, for example a patient with Thalassemia or she has an affected child and she was thinking in future she might use this. Some patient get pregnant purposely to collect for private banking. Low-risk patients - I advise them to donate.*

One of the Specialist Registrars said that they do not discuss cord blood with their patients. Instead, they ask them to get the leaflet from the antenatal clinic and read about it. She said:

*We do not share with all patients but we give them information and ask them to get the leaflet and read. I feel information still did not reach the population here; maybe only patients who have a history of disease, if they ask, I will advise for public banking as it can help other people also but it also depends on the patient's history and family history of leukemia or bone marrow diseases that she can use for her children.*

Some doctors did not know that DCRC is providing two different cord blood banking options – private and public – and the researcher had to explain about each bank during the interviews.

### **Best Tools/Methods to Help Increase Cord Blood Donation in the UAE**

The researcher wanted to know doctors' opinions regarding best tool/method that can increase cord blood donation in the UAE. The CEO of Hospital A highlighted the importance of

awareness, and the involvement of different channels of main stakeholders and marketing media by informing expectant mothers about the benefits of donation:

*Awareness is important, showing the benefit, awareness is not only us; media need to be involved, different channels need to be involved. People nowadays look at Twitter, snap chat, Instagram.*

Another doctor highlighted a very important point which is catching the girls in high school and colleges before they get married and become mothers so that it is not new information for them when they hear about it at later stage of their life during their pregnancy visit. She said:

*Catching them at a very early stage even before they are mothers. We can also talk to post-natal mothers; they do not stop there; they can come back pregnant again. Give them the leaflet and tell them you missed the opportunity this time but you still have next time.*

Some of the doctors mentioned that the best method to increase donation is individual counselling and counselling in antenatal clinics: *“The best method is individual counselling in the antenatal clinic”*. Others believed that media marketing, campaigns and social media are the best methods to increase awareness; one said: *“The best method is health education; it is very important, with as many different methods as you can”* while another said: *“The best method, leaflet and maybe media and advertisement”*.

### **Guidelines and Policies Required by Healthcare Professionals for Cord Blood Education**

The researcher wanted to listen to doctors’ ideas and points of view regarding the best way to create suitable educational guidelines for the healthcare providers regarding cord blood education in the hospital. Most of them believed that knowledge and awareness regarding cord blood should be first increased among healthcare providers and then guidelines can be used as a reference to refer to if needed. They believed that cord blood education can become practice in hospitals only if it can be approached in the same way as breastfeeding education

where the expectant mothers are approached at different stages and many times along with reinforcement by healthcare providers in clinics and wards. One of the doctors thinks:

*I think it will become practice, when we started breastfeeding everybody in the hospital we got 20 hours teaching so they started educating the staff first before starting educating others. So maybe we should have something like this, CME 20 hours for cord blood education and it should be compulsory. Every Wednesday also we have a dedicated time where gynecologists meet for about 30 minutes so I think if you talk about cord blood at this meeting you will catch a group of doctors and many will be aware. We also have a delivery suite form which you can approach. Every month we have meetings to discuss different issue.*

Another doctor stressed the importance of educating the healthcare providers first as she mentioned:

*Yes, if you are really planning to start with the healthcare providers then maybe you need first to give them lectures on the benefit of cord blood and how to answer frequently asked questions and some technical aspects. If you are planning to keep leaflets update it on a regular basis.*

Another doctor also mentioned the importance of having knowledge to feel confident to discuss cord blood with the patients. She highlighted:

*It will be much easier to have guidelines, doctors should be educated first so they can counsel their patients. We as doctors still have so many questions about cord blood and we cannot raise this issue with the patient until we are confident about it.*

- **Pediatricians**

### **Knowledge about Cord Blood Stem Cells and Education Responsibility**

Pediatricians had the least knowledge about cord blood stem cells and the different banking options. Their knowledge in this field is limited as they have very basic information about collection procedure, banking options, stem cell registry and the storage fees and period. Most of them are aware that cord blood stem cells can treat many common blood diseases such as Thalassemia, leukemia and sickle cell, and many other future promising diseases. However, most of them did not have information about the different banking options, and many of them

did not know that the DCRC is recruiting expectant mothers to donate their newborn's UCB stem cells for public use. They all agree that expectant mothers have the right to receive information about cord blood stem cells so they can make informed decisions. One of the pediatricians believes that if the expectant mother knows about it, she will be able to make the right decision to help her family if they have any disease:

*Yes she has the right, she needs to know if the family has some diseases if there is potential chance of treatment in case they got some diseases.*

Another doctor commented:

*Because people ...they do not know the value of it and I think the problem is also the doctors. If someone asks them their opinion about banking cord blood they will say 'this is only research work and you will get no benefit for the time being'.*

The Consultant Neonatologist and head of the Pediatric Department highlighted that it is important that the expectant mother is aware about the potential value of her newborn's UCB stem cells exactly in the same way that we advise the expectant mother about breastfeeding during her pregnancy and after the delivery. He said:

*Definitely, the mother suffered and carried this pregnancy for nine months and naturally everything which I'm advising her to give breastfeeding I consider that this is the right of the mother to take the information and the right of the baby to take the normal breast feeding because of the benefits. So even if there is 0.1 in 1000 chance that this donation might save her child or other children I think they should be aware of this.*

We also asked the doctors about their opinions regarding who is responsible for informing the parents about the potential value of cord blood donation, and most highlighted that it is the responsibility of the cord blood centre as they are the body who should educate the pregnant women and provide them with detailed information. The Consultant Neonatologist said:

*Cord blood centre has to do it, nobody else is going to do it for you. The staff at cord blood center need to do the job. I do not think the medical staff will help on that because at the end it's the job of cord blood center and they need to take care of it.*

However, another senior register neonatologist thinks that it is the responsibility of healthcare providers and the medical career staff, but they need to be able to explain the information in a simple way. He said:

*It is the hospital's job, it is the medical career people, the healthcare providers but you should choose the one who can make it a simple issue and explain nicely to the parents without increasing their suspicions. Because once you will be speaking about the research work people will stop operating with you.*

Another consultant neonatologist had a different view and he believed that during the antenatal clinic someone from the DCRC needs to be available to explain about cord blood in exactly the same way as it is done now for breastfeeding.

*From my experience, I think for every mother who attends the clinic in the hospital at least one member from the DCRC must meet them and explain all the issues to her. Each member of the team in breastfeeding will talk to her and her husband about the benefit of breastfeeding and what we should do so the baby gets only breast milk. We should do the same thing for cord blood.*

### **Cord Blood Donation Barriers**

All the doctors strongly believed that expectant mothers do not donate their cord blood stem cells because they have poor knowledge about it. Their opinions regarding this are shown below:

The Senior Registrar Neonatologist said:

*Because people they do not know the value of it and I think the problem is also the doctors. If someone asks them their opinion about banking cord blood they will say this is only research work and you will get no benefit for the time being.*

The Consultant Neonatologist added:

*Because of lack information among parents and most important is that we are not counselling the mothers at the time of antenatal and pre-natal clinics and at the time of delivery. Also I think the only major obstacles is that we need to speak with them and counsel them about giving cord blood for donation.*



Another Consultant Neonatologist commented:

*Because they have not been explained to clearly what cord blood is for and what is cord blood donation, I think prenatal time is the best time where each patient should be talked to about it by DCRC people, not the nurses.*

One Consultant Neonatologist thinks that expectant mothers do not donate their cord blood stem cells because of the lack of information and counselling. He said:

*Because of lack of information among parents, and most important is that we are not counselling the mothers at the time of antenatal and pre-natal clinics and at the time of delivery. Also I think the only major obstacles is that we need to speak with them and counsel them about giving cord blood for donation.*

### **Importance of Public Donation and Stem Cell Registry**

Unfortunately, almost all of the pediatricians were not aware about the presence of public cord blood banking within the DCRC. They thought that the centre is only providing private banking for family use. One of the Consultant Neonatologists commented that he wished he had known about it so that he could donate his newborn's UCB stem cells for others. He said: *"I did not know that DCRC has public banking, I wish I knew this before so I would have encouraged my wife who just delivered a few months ago to donate her cord blood"*.

Despite the fact that they were not aware about the existence of the public banking option within the DCRC, some were aware about the importance of donation and public registry in helping many patients in need of cord blood donation. Even though their information about the public stem cell registry was limited, some thought it is a very good idea to establish a public cord blood registry in the UAE while others consider it is a must. They all believed that having such a registry in the UAE will help many patients with Thalassemia, sickle cell anemia and leukemia which are the most common diseases in the Middle East.

One of the consultant neonatologists said: *"Stem cell registry is a must once we have a registry that means we can utilise donations"*.

Another consultant neonatologist totally agreed that the UAE must have a public stem cell registry and he believes that more awareness and marketing about the need for such a registry is important. He commented:

*Yes 100% because UAE is pioneer in everything so having this registry will go with the vision of his highness, but we need more marketing this is very important.*

### **Best Tools/Methods to Help Increase Cord Blood Donation in the UAE**

Doctors believe that the best method to increase cord blood donation in the UAE is by increasing awareness and marketing the services. Some of the doctors highlighted that it is important to start education and awareness at a very early stage in schools and universities. Others think that counselling the parents in the antenatal clinic is considered one of the best methods to increase donation in the UAE.

A Consultant Neonatologist considered that awareness and media are the best methods:

*The best method is awareness, if you believe me it must start right from school then all the colleges we have to educate them and give them simple presentation. We do not expect them to come we need to go to them.*

The Consultant Neonatologist and Head of Pediatrics added his point of view:

*Awareness you have to make publications, interviews on radios, TV to cover the centre, newspaper so it is important to approach the media, also you need to visit schools mainly high schools even boys in the final year, and also make awareness day in shopping malls and distribute leaflet. The awareness needs to involve medical and non-medical staff in the hospitals.*

Another Consultant Neonatologist believed that awareness should cover a bigger range of people:

*The best method is marketing to deliver the information to the bigger scale of people through TV and radio, events in parks and malls. All different way of marketing and also SMS.*

### **Guidelines and Policies Required by Healthcare Professionals for Cord Blood Education**

Most of the doctors agree that guidelines are very important in providing needed information for the healthcare providers so they will all talk same language and pass same information to the patients.

One of the Senior Registrar Neonatologist pointed out that:

*Nothing will succeed without guidelines; you should have guidelines aiming at putting points to explain to the parents and to educate them in a systematic way with skilled people in teaching. If we have guidelines that means we are going through a system.*

The Consultant Neonatologist and Head of the Pediatric Department highlighted that:

*It is always advisable to have such guidelines for simple reasons, we recently received a suggestion in the hospital that someone asking why we do not open in Dubai a centre for treating diabetes. So it is important that in the guidelines they all speak one unified language. Now patients when they come they are more aware about illness than before because we are surrounded with the internet and people can search and read now, not like before.*

On the other hand, another consultant pediatrician believed that guidelines should not be restricted to healthcare providers only; they should also be introduced for the pregnant women. He explained:

*I think it should not only be concentrating on healthcare and doctors, guidelines can be introduced to the pregnant mothers by nurses or educator and doctors so it should not be restricted to the doctors but doctors should play a big role in this.*

When asked about the guidelines, one of the Consultant Neonatologist emphasised the important role that gynecologist doctors can play in encouraging the expectant mothers to donate their cord blood stem cells and the person who approaches the mother should have the appropriate communication skills. He said:

*Gynae people if they have time because they are busy with patients, you need good time to talk to the patients. Maybe you can locate somebody from your side to sit at the Gynae clinic so while they are waiting they can talk to them otherwise do not expect somebody will do the job for you. Somebody who is competent at his job and has got very good communication skills and in a very diplomatic way he should approach the mothers.*

### 5.2.1.2 Focus Group Interview for Healthcare Professionals in Hospital A

In Hospital A, there were many challenges with gathering obstetricians and gynecologists together at one time to conduct focus group interviews. The main challenge was to get all seven of them at one place at the same time around their busy daily schedules. Despite all the emails sent out, and number of attempts to schedule a date, this did not happen. Thus, in Hospital A the focus group interview was conducted with nurses in the delivery ward and nurses in the antenatal clinic, separately, as shown in Table 5-2 below:

**Table 5-2 Healthcare providers who participated in focus group discussion of Hospital A**

<b>Focus Group Name</b>	<b>Delivery Ward Nurses</b>	<b>Antenatal Nurses</b>
<b>Number of Participants</b>	7	7

A focus group was conducted separately for the two main groups who have direct contact with expectant mothers during their pregnancy. The groups included nurses in the delivery ward, and nurses in antenatal clinics. The healthcare professionals were asked six main questions regarding the following themes:

- 1- The best method to increase cord blood donation.
- 2- Details about how cord blood education can become integrated in the antenatal clinics of both Hospitals A and B.
- 3- Cord blood education as part of hospital policy.
- 4- Healthcare providers' role in increasing cord blood awareness.
- 5- Guidelines and policy required for cord blood education

Nurses were asked: “*What are the best methods that can help increase cord blood donation in the UAE?*” All of them agreed that the best method is media such as TV advertisements, newspapers, and campaigns in malls. They also said that education in the antenatal clinic is

very important for the expectant mothers who visit the hospital but education should not be limited to hospitals; it should start from an early stage in schools and universities. They highlighted the fact that ensuring the public is aware about the importance of cord blood from an early stage in people's lives will make it easier for them to accept the idea of cord blood donation. However, the current situation is one where expectant mothers obtain the information primarily through the antenatal clinic which is considered a late stage to be thinking and deciding about cord blood, thus increasing the likelihood of them rejecting the idea of donation.

Healthcare providers in hospitals can play an important role in motivating the expectant mother to donate her cord blood stem cells by supplying her with brochures in the antenatal clinic and brief information about cord blood; however they cannot spend time providing detailed information. Thus, they said that they require healthcare educators from the DCRC to sit with patients in the antenatal clinic and explain to them the importance of cord blood stem cells. They also suggested that the best system to apply in terms of cord blood education in ANC is exactly the same system adopted for breastfeeding so that each mother is contacted and educated about cord blood. Sharing success stories of transplants with patients in ANC will also motivate the mother to donate her cord blood stem cells.

They also highlighted the importance of integrating cord blood education as a policy in hospital similar to breastfeeding. The first step to make that a success is to create a policy to train all healthcare providers about the importance of cord blood donation and increase their awareness on the topic. Only after increasing healthcare providers' knowledge are they able to take part and play a role in reinforcing the message about cord blood.

Media marketing, public awareness and education are some of the best ways to increase cord blood donation in the UAE. Nurses highlighted the fact that we should not only focus on

expectant mothers who visit the hospital; we should increase public awareness through campaigns in malls, TV advertisements and newspapers. One of the nurses highlighted the fact that we need a dedicated member of staff in antenatal clinics who can answer patients' questions and give information on cord blood in more detail since nurses in antenatal do not have detailed information about cord blood to answer expectant mothers' concerns. Nurses were also asked about how we can successfully integrate cord blood education in Antenatal clinics and they came up with different ideas. They highlighted the fact that they as nurses already have a large amount of mother-friendly information to pass on to the patients about their pregnancy, and breastfeeding. When patients are told about cord blood, they become very interested and ask so many questions that nurses have limited knowledge and time to answer all of the mothers' concerns. Thus, a dedicated healthcare educator is needed to pass on information about cord blood for patients and answer their questions in detail. Another nurse highlighted the fact that expectant mothers are overloaded with information when they come for their visit in the antenatal clinic as nurses talk to them about different topics such as the mother-friendly programme, breastfeeding, and other pregnancy concerns. Thus, adding cord blood education on top requires extra staff who can be in charge of delivering information to the patients. Moreover, they also highlighted the fact that cord blood education should not be limited only to expectant mothers; the husband needs to be aware about the importance of cord blood donation so he can encourage his wife to agree to it. In UAE culture, without the husband's permission, the mother cannot donate her cord blood even if she wants too. Healthcare providers in hospitals can play an important role in reinforcing the message about the importance of cord blood to their patients. Patients usually believe very much in doctors' opinions and like to follow their advice, but currently it is not possible to implement donor recruitment process since healthcare providers have limited available information to share.

## 5.2.2 Qualitative Data Collection and Analysis of Hospital B

Hospital B consists of different specialised departments and clinics such as Pediatrics, Obstetrics and Gynecology, Endocrinology, and Oncology. The antenatal clinics are only held three times a week as pregnant women visit these clinics to follow up with the doctors regarding their pregnancy. Interviews were conducted for 20-30 minutes with different groups of healthcare providers including delivery ward nurses, obstetricians and gynecologists, and pediatricians. The numbers of interviews from each group are shown in Table 5-3 below:

**Table 5-3 Total number of Interviews conducted with healthcare providers in Hospital B**

<b>Name of Healthcare provider group</b>	Nurses Delivery Ward	Nurses Antenatal clinic	Obstetricians and Gynecologists	General Pediatrician and Neonatologists	<b>Total</b>
<b>Number of interviewees</b>	19	11	13	13	<b>60</b>

### 5.2.2.1 Healthcare Professionals' Responses during the Interview Sessions in Hospital B

In Hospital B the interviewees were asked 10 different questions which are the same questions that were asked in Hospital A. The answers provided by the interviewees in Hospital B were almost similar to the answers provided by healthcare providers in Hospital A in terms of level of knowledge and awareness about cord blood and different banking options.

- **Antenatal Nurses**

#### **General Knowledge about Cord Blood Stem Cells and Education Responsibility**

During the interviews, antenatal nurses were asked about their general knowledge regarding cord blood stem cells and the banking options. They all believed that stem cells are useful and

can treat many diseases such as leukemia and Thalassemia. However, other believed that they can treat brain tumours and diabetes. Almost all of them did not have clear understanding of the currently treated diseases and the future ones.

All were aware about the two banking options offered by the DCRC and almost all of them would like to encourage their patients to donate their cord blood stem cells to help the community and the patients who are in need of cord blood transplantation. One of the nurses said:

*I will advise always public banking because we can use it for so many cases, but private is only for family. Public we can store for so many patients who are really in need.*

Another nurse believed that donation is the best if the family is not in need of the cord blood unit:

*I will encourage public banking so it will benefit the community. If it's private banking that means it is only for family use and if the family is not in need it will be like a waste.*

Others believed that they should encourage patients to donate their cord blood because it is free of charge and everyone can do it. One said:

*If the patient can afford it they can do private but also it depends on patient condition; maybe some patients cannot afford but donation ... everyone can do it because it is free.*

Another group of nurses believed that it depends on the patient's condition, if they suffer from diseases in the family, then they would be better to preserve the cord blood for the family use. If not, they should donate it to others. One nurse said:

*It depends on patients... if they have any disease it is better to save it for her if she wants to use it for her family if there is no disease we will advise her to donate, but at the end it depends on patient choice.*



The researcher also asked the nurses: *Who do you think is responsible for providing information about the potential value of publically donating cord blood stem cells and why did you choose your answer?*

Most of them said that it is the responsibility of all the healthcare workers and it is team work, and cord blood education should be done in a similar way to breastfeeding where everyone is involved in educating the pregnant women. One said:

*Everybody, it is team work to educate the patient from DCRC, doctors and staff who are educating patients in antenatal and during delivery.*

However, some nurses also believed that everyone is responsible but that also having specialised staff from the DCRC is important so that detailed information about cord blood stem cells is given. One of them said:

*When they come to clinic our staff and doctors, but it is better to have staff from DCRC who are specialised to give more information about cord blood.*

### **Cord Blood Donation Barriers**

The researcher also asked the nurses their opinion about the main reasons that stop the mothers from donating their cord blood stem cells. Most believed that mothers do not donate their cord blood stem cells because of lack of information and education, and others believed that culture and religion might be the reasons that prevent them from donating their cord blood stem cells. One of the nurses highlighted this and said:

*Because they do not have any information they are not aware about it and if I know I will of course I will go and also for other benefits. If it is not for her children it is for others.*

Another nurse also believed that lack of awareness is the main reason:

*Because of lack of information she was not well educated or maybe she never heard about it.*

However, others believed that lack of awareness is the main reason but they also highlighted that culture and religion are also factors that affect cord blood donation; they pointed out this during their interviews:

*Because there is lack of awareness and some patients think if they donate they will have some family relation. And sometimes she wants to donate but the family refuses.*

*Because they do not have any information they are not aware about it and if I know I will of course I will go and also for other benefits. If it is not for her children it is for others.*

Other nurses highlighted that religion, beliefs and culture or family refusing are some of the reasons that prevent expectant mothers from donating their cord blood stem cells:

*Because of religion, custom, beliefs and they are thinking it is our cells that come from our body so we do not want to donate it but some who are well educated, they are aware about the collection procedure and the usage; they are encouraged to donate.*

*They are not aware about the advantages and some people's religious beliefs stop them.*

*Because of lack of education and information and maybe the family or husband refusing and not giving support, family support.*

*Because there is a lack of awareness and some patients think if they donate they will have some family relation. And sometimes she wants to donate but the family refuses.*

They all believed that it is the mother's right to know about the potential benefits of cord blood stem cells because only if she is aware about can she take the decision to donate her cord blood to help treat many patients in need of cord blood transplantation. During the interview one of them said:

*Yes it is her right because if we do not explain for her later on she will regret - why did I not do it - if later somebody is suffering from sickness and they wanted to use it.*

### **Importance of Public Donation and Stem Cell Registry**

Almost all of the nurses encourage their patients to donate their cord blood stem cells for others as they believe that it can help many patients who are suffering from life-threatening diseases. However, most of them were not aware about the importance of stem cell registry and how it can help the community in finding matched donors. Only one of the nurses said: *“It is very important so they can easily find cord blood for patients”*, whereas the rest of them were not aware about stem cell registry and the researcher had to explain this during the interview.

### **Best Tools/Methods to help Increase Cord Blood Donation in the UAE**

Most of the nurses find that education is the best method to increase cord blood donation in the UAE and this can be achieved through media, newspaper, radio, brochures or education in antenatal clinics. They highlighted their views during the interview. The researcher has listed the five most common responses to the interview question:

1. *Education is the best they should understand.*
2. *Best method is to educate the mothers in the antenatal clinic.*
3. *Educating them through different media, magazine, booklet, and brochure.*
4. *Best is education through pamphlets, radio and through all media communication. Like conducting conference, in antenatal clinic during booking you can create one stall to talk about cord blood.*
5. *Best method is media, newspaper because through media mainly more public will be aware of this, not only mothers who visit the hospitals.*

### **Guidelines and Policies Required by Healthcare Professionals for Cord Blood Education**

They all agreed that having guidelines for healthcare providers is very useful and important. It can act as a reference for them when passing on information about cord blood to the expectant mothers. One of the nurses said:

*Yes, it is important to have guidelines, we know exactly what we are doing and we can give proper information to the patients. We are facing some problems because we do not have proper guidelines.*

Another nurse highlighted the fact that healthcare providers need to be aware about the information so they can pass it on to their patients, and guidelines can help them ensure they have the correct information that they need to share with their patients. Guidelines can also help all healthcare providers to speak the same language. The nurse commented:

*Yes, by having guidelines healthcare providers will be more aware which will help. Only if the staff are more aware about cord blood can they can teach the patients. If we have guidelines and policies we speak the same way and we understand the same things and share our thoughts so the patients ... and we can answer them.*

Another nurse also emphasised the same point:

*It will be very helpful having guidelines because the way we will give the health education will be the same, like the same information the nurse will give, same information the doctors will emphasise, all of us will stick to the same point. Especially about who is allowed to give cord blood and who is not allowed, who can preserve the cord blood and who cannot so it will be easier for us to follow this and patients will not be confused - 'the nurse told me something while the doctor told me something else'.*

- **Delivery Ward Nurses**

### **General Knowledge about Cord Blood Stem Cells and Education Responsibility**

Delivery ward nurses had good knowledge about cord blood and diseases treated using stem cells therapy. They were also aware about the different banking options provided by the DCRC. Most were aware that it can treat common diseases such as leukemia, Thalassemia and sickle cell diseases. Despite that, they did not have detailed information about cord blood as a source of stem cells and the process for separating and preserving these stem cells from cord blood. One of the nurses was asked about her general knowledge regarding cord blood and the different banking options: She said:

*Cord blood in our hospital as I know from the last 3-4 years and learned from the healthcare educator from DCRC who was coming to the antenatal clinic to educate the mothers about cord blood stem cells. She highlighted, 'At that time the information was "new" and slowly slowly it increased and now patients are coming and asking us'.*

*I'm aware about the two banking options, and I would like to encourage public because you do not need to think of the payment.*

Another nurse commented:

*I'm aware about banking options and it is collected from the placenta and it is very helpful in life-threatening situations which can be treated with cord blood.*

One of the nurses also highlighted that

*Cord blood ... it is the remaining blood in the baby's cord after the delivery of the baby, banking options are private and public banking, private means the cord blood will be used for the same family, public means if anyone wants to use the cord blood units from the public they can use it.*

### **Cord Blood Donation Barriers**

Nurses were also asked about their opinions regarding the reasons that stop the mothers from donating their cord blood stem cells. Most of them strongly believe that its due to lack of awareness and education and they believe that if mothers are aware about the potential benefits of cord blood stem cells they will definitely donate their cord blood stem cells. They shared their opinions during the interviews and suggested the best ways to motivate the mothers to donate their cord blood stem cells. One of the nurses highlighted that lack of proper information is one of the reason as the mother needs to have adequate knowledge to be able to make informed decisions during her pregnancy:

*Lack of proper information, if they will get proper information in the antenatal clinic the period is very short and the subject is very long. Such a topic needs proper information, people they do not know the importance; that is why the cord blood is going to waste only.*

Another nurse, however, believes that it is due to culture and knowledge:

*I think in the UAE their culture and they need more information about it because they do not know, they think it is only used for family members. We need to educate them during antenatal visit, send somebody and just educate them when they will get the education and knowledge about the stem cells they will donate.*

Another nurse highlighted that mothers are scared to donate their cord blood stem cells because they think it might be used for research or something they are not aware of:

*Maybe they are scared it will be used for something but I think there is no reason to refuse.*

### **Importance of Public Donation and Stem Cell Registry**

Most of the nurses would like to encourage the mothers to donate their cord blood stem cells to help others who are in need of cord blood donation and because it is free of cost. Some of them mentioned that if mothers have a family history of diseases they would be best advised to keep the cord blood unit for their own use; otherwise they can donate it to the public banks for others. However, some of the nurses think that if they donate their cord blood stem cells it can be used for them or for others but the fact is that donation is for others as it enters the international public registry for matched donor selection.

One of the nurses said that she will encourage public banking because it can be used for them or for others who are in need:

*I will encourage public banking at least for somebody else who is in an emergency situation can use it as sometimes family keep it but they might not use it, so by the time they need it they can also get it from others.*

Another nurse highlighted the same point:

*I want to encourage public banking because it can also be used for them in future, and can help others who are in need.*

Meanwhile another nurse thinks public donation is better because it will be used for someone who is in need, and if they do not suffer from blood diseases then there is no need to preserve it for family use.

*I encourage public banking because if we secure for ourselves maybe we will use it and maybe not but when we give to public banking when it is needed it can be used.*

Other nurses thought that if the mothers cannot afford the payment then they should be encouraged to donate their cord blood stem cells to help others. They said:

1. *Depends on the patient; I will explain both options and what is suitable for her she will select. If the patient cannot afford it we will encourage her at least to donate*
2. *I encourage public banking it can be saved without any cost and can be used for any patients if they are in need*

Others, however, believed that it depends on the mother's situation; if she has a history of disease she would be better preserving the cord blood unit for the family use, whereas if they are healthy they can donate their cord blood.

One of the nurses said:

*It depends upon the person if she has genetic disease mainly she will prefer for herself, but if no history of diseases she will give for donation.*

Another one highlighted the same point:

*That is according to the patient, if she has some disease of course she can go for private otherwise she can donate for public.*

### **Best Tools/Methods to Help Increasing Cord Blood Donation in the UAE**

Many of the nurses believed that the best method is media and advertisement through TV, radio, brochures, You Tube and campaigns. Others believe that education and awareness should start from the early stage of school and colleges. One of the nurses also highlighted an important point that the husband should also be educated:

*The best method is to have an awareness day, video and wards education for all people, show in ANC and also in the wards, not only maternity units, it is supposed to be all units. Men also should know about it because if the husband does not know they might not agree to it. We have TV in each ward; we can show videos about DCRC.*

Others highlighted that media and advertisement are the best methods to increase cord blood education in the UAE. They shared their opinions; one of the nurses said:

*“The best method is campaign, TV advertisement, teaching in the hospital”,*

While another nurse said:

*First advertise through newspaper for public awareness because in hospital we can only see the mothers who visit antenatal clinics, and also we need to keep posters in all hospitals.*

Another nurse believes that social media is the best method:

*The best method is awareness via social media, high school and colleges is important to go and speak to them and explain about cord blood so when they come for ANC visit in future and remember that once they have heard about it, so once they have heard, and there is no follow-up, they might not got for it, and reinforcing by doctors and nurses will make them think of it again.*

### **Guidelines and Policies Required by Healthcare Professionals for Cord Blood Education**

All the nurses interviewed believed that guidelines about cord blood stem cells will help them in passing information about cord blood to their patients. They pointed out that guidelines should include general information about cord blood collection, collection procedure, storage period and its beneficial use in helping many patients in need. One of the nurses highlighted this point:

*Yes needed, guidelines should include information about cord blood, how it can be collected, for how long it can be kept, and how it can benefit the public. We will be reading these guidelines and practicing them which will be useful for all of us.*



Another nurse believes that guidelines will help healthcare providers to speak the same language so that patients do not get confused hearing different information from different doctors:

*Yes, if the materials are standardised everybody will talk the same so patients will be convinced but if each one is saying different things the patients will be confused, if it is properly done they can convince the clients.*

However, another nurse strongly believes that it is important first to increase awareness among healthcare providers about cord blood stem cells then provide them with guidelines. She also highlighted that this kind of job needs people who are really interested in the topic and would like to volunteer to be educated about it from their heart. She said:

*Policy means it should be strictly followed by all but I believe cord blood education should come from a belief that it is a good thing. First we need to educate and give good awareness to the healthcare workers themselves and, better, to create a group from the people who are willing for that. It should be deep from their heart otherwise only some results will be there. Policy means all people should follow it strictly, but I feel such a topic is better if there are volunteers who will do this and like to do it from their heart.*

- **Obstetricians and Gynecologists**

### **General Knowledge about Cord Blood Stem Cells and Education Responsibility**

This group of healthcare providers did not have much information about cord blood stem cells compared to the antenatal and delivery ward nurses. Their information is limited and they are only aware about a few diseases that can be treated using cord blood stem cells, and some of them think that it is still under research. All were asked about their general information regarding cord blood stem cells and the diseases treated using stem cells. One of the doctors said that it can treat most of the genetic diseases but in fact cord blood can treat most of the blood diseases. Thus, many of them did not have the right information about stem cells and the current uses and its potential benefits for the public. She said:

*Stem cells are one of the future management for a lot of diseases, and it can treat most of the genetic things that can affect the life of a child; it can be cured and treated by this method.*

Another doctor highlighted that she heard that cord blood can treat cancers but she never experienced it or came across patients treated using stem cell therapy. She commented:

*Stem cells are collected from the blood and they store it to be used for future, it can treat cancer, diabetes, chronic diseases, and according to the literature it says it is very useful but personally I do not have experience about it, in practice we did not see any case treated using cord blood.*

All doctors were also asked their opinions regarding who is responsible for providing information about the potential value of donating cord blood stem cells and most of them said that it is the responsibility of everyone including all healthcare providers and media marketing. However, others highlighted that gynecologists and the DCRC team are the main groups of concern that should inform the mothers about the beneficial use of cord blood stem cells. She said:

*It is everybody's responsibility, but being an obstetrician that is not my first priority to explain it for her having so many other issues with pregnancy. So I think having an educator in the clinic to inform the patients and if the patients have any doubts it can be explained as the topic takes time to explain so giving the full responsibility for the obstetricians to explain it will not work, it should be a special educator there in each obstetric clinic and patients should be given opportunity to ask.*

Another doctor thinks that it is important to have a dedicated person in the clinic to pass on the information about cord blood to the pregnant women; she highlighted her opinion:

*I think there should be a dedicated person in the clinic because when we see the patient we do not have much time to talk about this thing so I think a special person should be sitting in the clinic to educate and encourage the usage of cord blood, like how we have for breastfeeding.*

### **Cord Blood Donation Barriers and Motivations**

Doctors were also asked their opinions regarding the main reasons that prevent mothers from donating their cord blood stem cells. Almost all of them believe that mothers do not donate

because they are not aware about it and they do not know the beneficial use of it along with other reasons such as religion and culture. One of the doctors suggested a way that can encourage the mother to donate her cord blood stem cells:

*Some of them they are not educated, they do not know what the benefits are and they do not know that this will not affect the baby as it is consider wasted. Some of them think it will reduce the blood supply to the baby. We need to demonstrate for them by video how we are collecting the cord blood and if we do not collect it, it will be thrown away and the amount that we are collecting will never affect the baby. So if she will know all these things clearly through demonstration she will be convinced and she will educate others. It is important that she knows the procedure and how it is safe and involves no pain.*

Another doctor thinks that no one will refuse to donate their cord blood if they are well educated and provided with the right information that can help them make informed decisions:

*It is only because of the awareness, she needs to know that it is free and it is not affecting her or baby during the delivery because we are collecting the blood after the delivery of the baby it is just a waste. She needs to be educated more about it, I do not think anyone will refuse if they are educated.*

Another doctor believes that it is due to lack of information and maybe religion and moral issues:

*Because they do not have enough information and maybe because of religion or moral issues plus we are not talking too much about it through the media and TV so people do not hear about it.*

### **Importance of Public Donation and Stem Cell Registry**

Some of the doctors would like to encourage their patients to go for public banking while others believe private banking is the best option for them. They believe that public donation can help others and private banking can be used for the family in case they need it. Another group of doctors believe that it depends on the family situation; if they have disease in the

family they would be better preserving the stem cells. If they are healthy we encourage them to donate it for others. One of the doctors shared her opinion:

*It depends on the case, if she is healthy she would be better to donate the blood but if she has genetic problem I will advise her to store the blood for future offspring.*

Another doctor highlighted that she would like to encourage family banking because she believe that if the family needs it they can use the unit they have preserved without having to take the unit from a stranger:

*I prefer private but the issue is the money for so many people, what I believe that if she saves it, it will be from the same family then why would they have to take from the stranger?*

Most of the doctors were not aware about the stem cell registry and the use of it and a few of them knew that it is useful; but still their information regarding this topic was limited.

One of the doctors said that the stem cell registry can be used for searching for donors for patients in a short period of time:

*It will be a good idea because if you need to get cord blood for a patient you have registry and you can search through it so you can help the patient and it will take a shorter time.*

On the other hand, another doctor believes that having a stem cell registry within the UAE is very useful for the country and can help many patients:

*Usually our country is number 1 and we need to be the pioneer in everything, so it will help many patients and it will help the country too.*

### **Best Tools/Methods to Help Increase Cord Blood Donation in the UAE**

Most of the doctors believe that best tool to increase cord blood donation is education and media marketing through TV, radio, campaigns and social media. They believe that it is important to reach the public in general, not only the pregnant women in the hospital. One of

the doctor commented that media is a very important tool to increase cord blood donation and it is not enough to just talk to the expectant mothers in the clinic. She highlighted her point during the interview:

*Really if you want to increase donation you need to spread it through media if you talk through TV, newspaper and media. People will hear about it and come with questions to ask, but now currently we are only discussing about it in the clinic.*

Another doctor also highlighted that education is the best method for increasing cord blood donation and its best to be done through media:

*I think the best method is education through media and educating all the staff about cord blood and also educating them about how it can help. If we can give the donors' incentives or gifts like reward for their donations and also reward for the staff who are collecting.*

Another doctor also agreed with this point and pointed out that education is one of the best tools; and it can be done through different approaches:

*The best tool is more education to the patients using all types of media - written, videos, brochures - to increase the awareness of the patients regarding the issues because the main problem is that the patient is not aware.*

### **Guidelines and Policies Required by Healthcare Professionals for Cord Blood Education**

Most of the doctors believed that guidelines are important so it can equip them with the knowledge required to be passed to the pregnant women. She highlighted her point with an example:

*Yes guidelines are important, because sometimes patients have questions and we do not know the answer. I will give you one example, If I have patient and her baby had chromosomal abnormality and she might ask me, "can I store my baby cord blood", I will not have the answer because I do not know if she can or not. So we need to know the eligibility of accepting and rejecting the patients, and if she is healthy but a carrier of some intertied genetic disorder, can she donate? So I think we need to know because we do not have all the answers.*

Meanwhile, another doctor thinks that guidelines are important but they still believe that a senior person from the DCRC should educate and inform pregnant women about cord blood stem cells:

*Guidelines can help and I think we need the most senior person who knows about cord blood too, and hospital experience and staff experience to sit together and put clear guidelines in place for the healthcare providers.*

Another doctor also highlighted the importance of the guidelines in providing information and updates:

*Yes guidelines are helpful, we will know what to do exactly and what are the steps and the recent and updated things and how to implement them with the patients.*

- **Pediatricians**

### **General Knowledge about Cord Blood Stem Cells and Education Responsibility**

Most of the Pediatricians had general knowledge about cord blood stem cells and they knew that it can treat common diseases such as leukemia, sickle cell and Thalassemia. However, their knowledge about stem cells, banking options, and cord blood registry was very limited. They are considered the group least aware about cord blood stem cells among the interviewees. One of the doctors said:

*I do not have a lot of information about this but in general I think it is very helpful to treat immunodeficiency, hematological problems and cancers.*

Another doctor highlighted same point - that he is not very much aware about it and he has only basic knowledge about stem cells:

*Actually I do not know about it in details, what I know is basic things only, I know it can be used in many genetic disorders. I do not know other diseases.*

Most were aware that it can treat common diseases such as Thalassemia, leukemia and sickle cell as one of the doctor pointed out:

*Stem cells is the original of all cells and is very important in treating leukemia, lymphoma and some tumors and anemia and thalassemia. It is not treating all the diseases, but it treats some diseases.*

Another doctor highlighted that he saw patients coming from abroad after undertaking transplantation from bone marrow and cord blood:

*Stem cells is new treatment for oncology and hematology diseases and from my experience I know that it is help for patients with Thalassemia and leukemia. I saw many come from abroad who did bone marrow transplant.*

During the interview we also asked the doctors who is responsible for educating pregnant women about the importance of cord blood donation. Many of them think that gynecologists, healthcare providers and whoever has direct contact with expectant mothers are responsible. They also pointed out that it is important to start education in the antenatal clinic so that expectant mothers receive information about cord blood at the early stages of their pregnancy.

One of the doctors said:

*I think mainly gynecologists are responsible. They see pregnant women in antenatal clinics during the check up and me, I'm pregnant now, and when I go for antenatal checkup nobody told me about cord blood and we are not educated about it. No one mentioned it in the clinic or told us about the two banking options because if it is free why would I not donate it. We have breastfeeding; it is compulsory, whenever you go to antenatal clinic you have to attend.*

Another doctor highlighted that two major physicians are responsible – the gynecologist and neonatologist:

*I think two major physicians are responsible - the gynecologist and the neonatologist who will be at the delivery receiving the baby, and also the pediatricians as the patient will follow up with us after, and if we know that there is family history we should encourage her and give her educational materials.*

Another doctor thinks that gynecologists are responsible, but also that someone from the cord blood centre should give information about cord blood stem cells:

*I think starting from physicians in OB Gynae and I think educator from the cord blood bank, and visit the mother and educate her, but main responsibility is OB Gynae.*

Another doctor highlighted the same point:

*Senior physicians working in cord blood bank, hematologist and oncologist people who are taking care of the cord blood bank they are the ones who can give the knowledge in detail. Gynae too if they have knowledge about it they are the first people who are involved and see patients.*

### **Cord Blood Donation Barriers and Motivations**

Doctors were also asked about their opinion regarding the main barriers that stop expectant mothers from donating their cord blood stem cells and the motivation that encourage them to publically donate their cord blood stem cells. Most of them agree that expectant mothers do not donate their cord blood stem cells because they lack awareness and information about cord blood. One of the doctors highlighted that even she, as a member of staff working in the hospital and who has delivered twice, was not aware about cord blood as no one has informed her about it during her first pregnancy:

*Because they do not know, even us working in the hospital and I delivered twice in this hospital I came to know last time only and I donated my cord blood. I heard about from the healthcare educator giving lectures about cord blood in the clinic.*

Another doctor highlighted the same point that she was also pregnant and did not know about it:

*Because I think people they do not know about it, I'm pregnant myself and I did not know about it. Now since I know I want to know more if I want to donate it. If it is free of cost I do not think people will refuse plus it is not painful and will not harm anybody if they collect blood.*

Another doctor highlighted that only expectant mothers who have sick children in their family are aware about cord blood stem cells as they need to preserve the cord blood unit to help the sick child; however most of the expectant mothers are not aware which is why they do not donate their cord blood stem cells. He also thinks it is because of the culture:



*I think because of culture and they do not know about it, and people who know information about this are the one who are facing problems with their children.*

Another doctor pointed out an important fact that expectant mothers need to be aware about the cord blood collection procedure and the fact that it is very safe and does not cause any harm for the newborn or the mother. Knowing it is safe will encourage the mother to donate her newborn's UCB stem cell. He said:

*Because they are not aware about the procedure and its safety, they need to be educated more about it, it is exactly same as blood donation. It needs education.*

### **Importance of Public Donation and Stem Cell Registry**

Many of the pediatricians were not aware about the two different banking options available in the DCRC. They have heard about private preservation but were not aware about the public donation option. The researcher had to explain about it during the interview. Pediatricians who were aware about the different banking options showed their preference towards public donation as they believe that it can help many patients who are in need. One of the doctors highlighted the importance of cord blood donation to the public unless the expectant mother has a sick child in the family and they are in need of the unit. She said:

*Cord blood is rich in stem cells. They collect it and keep it for donation later on. Private banking is for yourself and public for others, for private I think the fees is about 10,000. I will discuss with the mother about the two banking options and she can choose which one she wants, I will advise public banking because I would like to spread the benefits.*

Another doctor said that he was not aware about the two banking options and he came to know about it when he was answering the survey questions, which were distributed by the researcher. He pointed that out in the interview:

*Cord blood from the umbilical cord after the delivery .I did not know about the two banking options. I came to know when I was answering the survey that you gave us, and I know that public is free but I have no idea about the fees for private.*

*I will encourage her for public banking because it will be for everybody and a lot of people will do that, but if they have family disease that they might need it later then I will encourage her to keep it for private banking.*

Another doctor expressed his frustration for not knowing about the availability of the public donation option:

*I know that there is private because my brother saved it for his daughter but I did not know about the public banking but I do not know about the price.*

*It depends, if the patient has a family history they had better preserve it for themselves, they might need it, but if they have healthy children we should always advise them to go for cord blood donation because it will help the society because we have so many Thalassemia and sickle cell patients.*

The researcher also asked them if they are aware about the importance of establishing a stem cell registry in the UAE. Most were aware that it is important but they had very basic knowledge about it and some of them had different ideas about the main purpose of the registry. One of the doctors revealed that finding donors for patients in the UAE is currently a big challenge:

*I think it is very good, we already have a facility in Dubai and we have patients who need it and also we have options for them. We are facing problems here in Dubai whenever the child requires a bone marrow transplant.*

Another doctor highlighted that we must have stem cell registry in the UAE but before that we need to be educated. He pointed out that:

*It is a MUST but before, we need to know about how it can help patients because we do not know about it.*

Meanwhile, another doctor agreed that a stem cell registry is important to help many patients with Thalassemia in the UAE but he said that he does not have much information about it:

*Yes, sure, a stem cell registry is useful as we have so many patients here with Thalassemia which can be treated but I'm not very aware about the stem cell registry, not much information.*

## **Best Tools/Methods to Help Increasing Cord Blood Donation in the UAE**

Doctors were asked about the best methods/tools that can help encourage expectant mothers to donate their cord blood stem cells. They provided different answers and suggestions as some of them said marketing media, brochures and campaigns while others cited the importance of educating healthcare providers and providing someone from the cord blood centre to educate pregnant women in the antenatal clinic.

One of the doctors who believed in media marketing said:

*The best method is media and campaign TV then the patients will start knowing about it then when they come to the hospital we can educate them so when they will have idea they will start asking if they do not have idea and not aware about it they will not ask”*

Another doctor believed that educating pregnant women and conducting lectures are very important approaches:

*The best method is brochures, lectures and workshop for parents, presentation by a well-known lecturer in the field of cord blood.*

Another doctor highlighted the same point about the importance of awareness and teaching;

*The best method is awareness and teaching as 90% of people do not know until now including us first; as pediatricians we do not know.*

Another doctor highlighted the importance of educating the *physicians* because they have direct contact with expectant mothers who hold so much trust in their doctors. He also mentioned that it is important that the expectant mother knows that donation is free of charge:

*The best method is to educate physicians about cord blood especially about public donation that is free so they need to motivate their patients,*

Whereas another doctor believes that that the best method is to have an educator in the hospital:

*The best method is having an educator in the hospital to educate the patients, arranging lectures, campaigns outside; media need to talk about it.*

### **Guidelines and Policies Required by Healthcare Professionals for Cord Blood Education**

Almost all of this group believed that having guidelines is very important so they can all speak the same language and pass on the same information to the expectant mothers. However, one of the doctors believes that pediatricians do not have direct contact with expectant mothers during pregnancy and they mainly see them after they have delivered. He said:

*I think guidelines should be prepared for healthcare providers that have direct contact with the pregnant women, I do not think we as pediatricians can help because when they come to us they have already delivered.*

Another doctor highlighted that guidelines will help them have information about cord blood stem cells which they lack. He said:

*Yes it will be helpful, even us we have a lack of information about cord blood and by having guidelines it will help us have information.*

Another doctor believes that healthcare providers will be happy to share information about cord blood with expectant mothers:

*Yes it is good to have guidelines; it will help them explain to the parents and increase their awareness, at least giving brochures, and I think healthcare providers will be happy to explain and encourage the patients especially certain specialties such as the oncologist, obstetricians and pediatricians,*

While another doctor also highlighted that guidelines should explain in detail the basic information about cord blood, when to educate expectant mothers, and what the registration procedures are so that if we get asked by expectant mothers we will be able to answer them. He said:

*Yes we need clear guidelines on who to educate and when to educate the patients. Is it pre-natal or antenatal? And also a clear idea of what will be done in terms of cord blood procedure and the different banking options.*

#### **5.2.2.2 Focus Group Interview in Hospital B with Healthcare Professionals**

In Hospital B, the researcher managed to conduct focus group discussion with three groups of healthcare providers separately – antenatal nurses, delivery ward nurses, and gynecologists, as shown in Table 5-4 below. The healthcare professionals were asked six main questions about the following themes:

- 1- Best method to increase cord blood donation.
- 2- Details about how cord blood education can be integrated in the antenatal clinics.
- 3- Cord blood education part of hospital policy.
- 4- Healthcare providers' role in increasing cord blood awareness.
- 5- Guidelines and policy required for cord blood education.

**Table 5-4 Number of focus group discussions conducted in Hospital B**

<b>Focus Group name</b>	<b>Delivery Ward Nurses</b>	<b>Antenatal Nurses</b>	<b>Gynecologists and Obstetricians</b>
<b>Number of participants</b>	7	7	12

Delivery ward nurses in the Dubai hospital think the best way to increase cord blood awareness is through media and marketing which includes TV advertisements, newspapers, education in universities and colleges, and social media. A healthcare educator is required in the antenatal clinic to give the expectant mothers proper education about the importance of cord blood stem cells and inquire whether she is interested in registering at the same time.

Nurses think that having a healthcare educator in the antenatal clinic will play an important role in passing information on to expectant mothers in detail about the importance of cord blood stem cells. They highlighted the fact that expectant mothers require continuous education about cord blood to be routinely motivated to donate their cord blood stem cells. Nurses also said that cord blood education in the antenatal clinic should be as important as breastfeeding education to make sure that each expectant mother is educated about the importance of cord blood donation. Nurses in the delivery ward can reinforce the message and encourage the mother to donate her newborn's UCB stem cells at the last minute before delivery (but only if she is at that stage free from delivery pain and can sign the consent form). Nurses also said that they can play a role in explaining to mothers the benefits of cord blood stem cells in treating many life-threatening diseases and also highlighting for the mother that cord blood collection procedure is pain-free. However, they cannot pass the mothers the information in detail as it is too late to educate her at this stage and that education should really start from the antenatal clinic.

The media is considered to be one of the best tools that help with increasing public awareness in the UAE. Use of the media includes awareness campaigns in malls, TV advertisements, newspapers, posters, and banners. Nurses in the antenatal clinic also highlighted the importance of creating a system for cord blood education that is similar to breastfeeding. They suggested creating forms or checklists about cord blood education so that the nurses follow the necessary information required to be provided to mothers. They also emphasised that most expectant mothers like to hear about cord blood information from their gynecologists more so than from the nurses; thus it is important that gynecologists share this information with the mother which is most likely to convince her to donate her newborn's UCB stem cells. The nurses also suggested the need for a full-time healthcare educator in the

antenatal clinic to educate and register the mothers for cord blood donation as they do not have the time and knowledge to do that themselves.

The nurses recommended adopting cord blood education as an integral part of the hospital system with the help of a specifically assigned healthcare educator who has the full knowledge about cord blood stem cells and can educate expectant mothers at the clinic. Nurses can then help direct the expectant mothers to see the assigned staff to gain more information about cord blood and register for cord blood donation if they are interested. However, they also highlighted that resources are important to make cord blood education successful at the clinic. A special room is needed for the assigned staff to meet with the expectant mothers and talk to them about cord blood donation.

Moreover, the nurses highly advised that creating cord blood awareness should be in all hospitals' departments although at present only antenatal clinic and delivery ward nurses are aware about it. Frequent campaigns in hospitals and malls are needed to create awareness among the public. Expectant mothers know about cord blood donation but they do not know about the benefits of donating cord blood stem cells. It is only by creating an effective system in hospitals similar to the breastfeeding awareness programmes that donation will be increased among expectant mothers.

Gynecologists believe that social media is one of the most effective methods to increase cord blood awareness in the UAE along with TV advertising and campaigns in hospitals and malls. They also highlighted the fact that the best way to integrate cord blood education in the hospital's clinic is by having a full-time healthcare educator to educate all the expectant mothers about the importance of cord blood donation. Gynecologists also suggested reinforcing the message about the importance of cord blood stem cells in their offices by handing out brochures about cord blood information to the expectant mothers. They also

highlighted the importance of their participation with the cord blood team in TV programmes, radio channels and social media networks to reinforce the message and make the mothers more supportive of the idea of cord blood donation when seeing their doctors talking about it in public channels. They also suggested that cord blood education should not be limited to gynecologists and nurses. To increase cord blood awareness, the participation of each doctor from each department is important. Thus, during the discussion, they recommended nominating two doctors from each department of the hospital to create a team that will take care of cord blood education issues. However, they strongly highlighted that, to create a successful team, all nominated doctors within the team should be educated and trained by DCRC staff about cord blood stem cells.

### **5.2.3 Quantitative Data Collection in Hospitals A and B**

#### **5.2.3.1 Expectant Mothers' Survey Results in Hospitals A and B**

Surveys were distributed to expectant mothers at the antenatal clinics of Hospitals A and B. While the expectant mothers were waiting to see their doctors, surveys were given to them to complete. The survey consists of 12 questions that focus on studying the barriers, motivators and incentives toward cord blood donation in the UAE to improve cord blood awareness among expectant mothers. In 2016, 1198 surveys were distributed to expectant mothers in Hospitals A and B over a period of four months. Out of 1198 returns, there were only 178 incomplete surveys, which were excluded from the study. Survey results are shown in Appendix 15. The age of most of the expectant mothers who filled the survey was between 21-40 years old and most of them have either a high school certificate or university degree.

Expectant mothers were first asked if they are aware about the existence of Dubai Cord Blood & Research Center (DCRC) in the UAE; almost all of them (75.2%) were aware about the centre. They were asked if they have information about the importance of cord blood stem



cells; results showed that almost more than half (65%) are aware about the importance of cord blood stem cells but there still were low number of cord blood donations received by the DCRC in the past years. Thus, it was important to elaborate further because if they are aware about the importance of cord blood stem cells why were they not donating their newborn's UCB stem cells even though it is free of charge? It is important to understand the main barriers that stop them from donating their cord blood stem cells. Results showed that the main two reasons for not donating their newborn's UCB stem cells are lack of knowledge and fear of risk to the mother or the newborn during cord blood collection. Most of them highlighted that they lack the information about the importance of publicly donating their newborn's UCB stem cells which means they lack the information about the precise benefits of donating their newborn's UCB stem cells for others. Only few of expectant mothers answered that they do not donate either because of not knowing the final destination of their newborn's UCB stem cell, or not knowing the Islamic view about cord blood donation. A few also said it was because their husband does not allow them to donate their newborn's UCB stem cell. One of the most important findings in the survey is that only a few mothers do not donate because they do not believe in stem cell therapy, which means that most of them have a strong belief that stem cells can help with treating many diseases and it is an effective treatment therapy.

The survey's results also showed that most of the expectant mothers (372: 36.5%) would like to receive information about cord blood stem cells from all of the mentioned different sources in the survey such as educators from the DCRC, social media, awareness campaigns, brochures, and healthcare providers. However, the most preferred selected sources from which they would like to receive information about cord blood stem cells are gynecologists (276 expectant mothers) and healthcare educators from the DCRC (142 expectant mothers). In addition, results also showed that the best time they would like to receive information

about cord blood stem cells is during antenatal clinics and at different places such as ladies' schools, universities, during pre-marital screening, and even before getting pregnant.

Expectant mothers were also asked, "*What are the reasons that would encourage them to publicly donate their newborn's UCB stem cell?*" Almost all of them said knowing that it can help in treating other patients with life-threatening illnesses which confirms their answer to the question that they do not donate because they do not know the significance of publicly donating their newborn's UCB stem cells for others. Thus, if they know the benefits of donation, they will be more likely to donate their newborn's UCB stem cells to help others in need. Almost all of them answered that they do not want any reward or incentives for donating their newborn's UCB stem cells as they feel it is their responsibility to help society.

#### **5.2.3.2 Healthcare Providers' Survey Results in Hospitals A and B**

Surveys were distributed to a group of healthcare providers that have direct interaction with the expectant mothers in Hospital A (LH) and Hospital B (DH), and out of 200 surveys 193 were completed and analysed for this study. The aim of the survey is to study the level of knowledge about cord blood among the healthcare professionals and their opinions regarding encouraging their patients to opt for cord blood donation. Survey results are shown in Appendix 16.

The survey was distributed to a group of healthcare providers consisting of gynecologists, pediatricians, as well as nurses in the delivery ward and the antenatal clinic (who mentioned themselves as others in the survey). Firstly, they were asked if they know that there is a government-run cord blood center located in Dubai and almost all of them answered 'yes'. They were then asked to rate their level of knowledge regarding umbilical cord blood; very few rated themselves as having an excellent knowledge and the majority evaluated themselves as having "good" to "very good" knowledge about cord blood stem cells. They

also highlighted that they would like to enhance their knowledge about cord blood from at least one of the different sources mentioned in the survey and their overall preference for each source is shown in the following sequence: CME lectures (20.7%), educational courses (16%), awareness campaigns (11.4%), conferences (9.8%), and social media (8.8%). However, the most preferred source was CME lectures and this is because they can collect a good number of educational hours that is added to their yearly performance.

During the survey, the healthcare providers were also asked about the importance of sharing information about cord blood with their patients. About 72 of the healthcare providers “agree” and 113 of them “strongly agree” that sharing information about cord blood with their patients is important even though, in their actual daily practice, most of them do not share such information. Healthcare providers who “disagree” or “strongly disagree” about share information about cord blood highlighted that the main reason is because they do not have enough information about stem cells.

Almost all of the healthcare providers (69%) believe that expectant mothers should receive information about cord blood stem cells from all different resources mentioned in the survey: physicians, nurses, cord blood educator, brochures, awareness campaigns, and social media. However, very few of them selected physicians (6%) and nurses (3%) despite the fact that they have direct contact with expectant mothers on a daily basis during pregnancy. In fact, most of them selected cord blood educator (18%) as the best source to deliver information to expectant mothers about cord blood stem cells. One of the significant findings is the fact that healthcare professionals did not select physicians and nurses as important sources to provide the patients with cord blood information. This is because they think a healthcare educator from the DCRC is the most important source of information, despite the fact that physicians and nurses are the ones who mainly interact with the patients on a daily basis compared with healthcare educators from DCRC.

Most of the healthcare providers would like to encourage their patients to opt for public banking if the family is not suffering from diseases that require them to preserve the cord blood for themselves. Only a few healthcare providers think that it is important to donate cord blood stem cells to increase the number of donors within the stem cell registry, which reveals that they are not aware of the importance of having a local public stem cell registry and its role in saving time and efforts to find unrelated matched donors for patients in the UAE.

### **5.3 Case Study (3): Pregnant Women's Views and Participation in Cord Blood Donation**

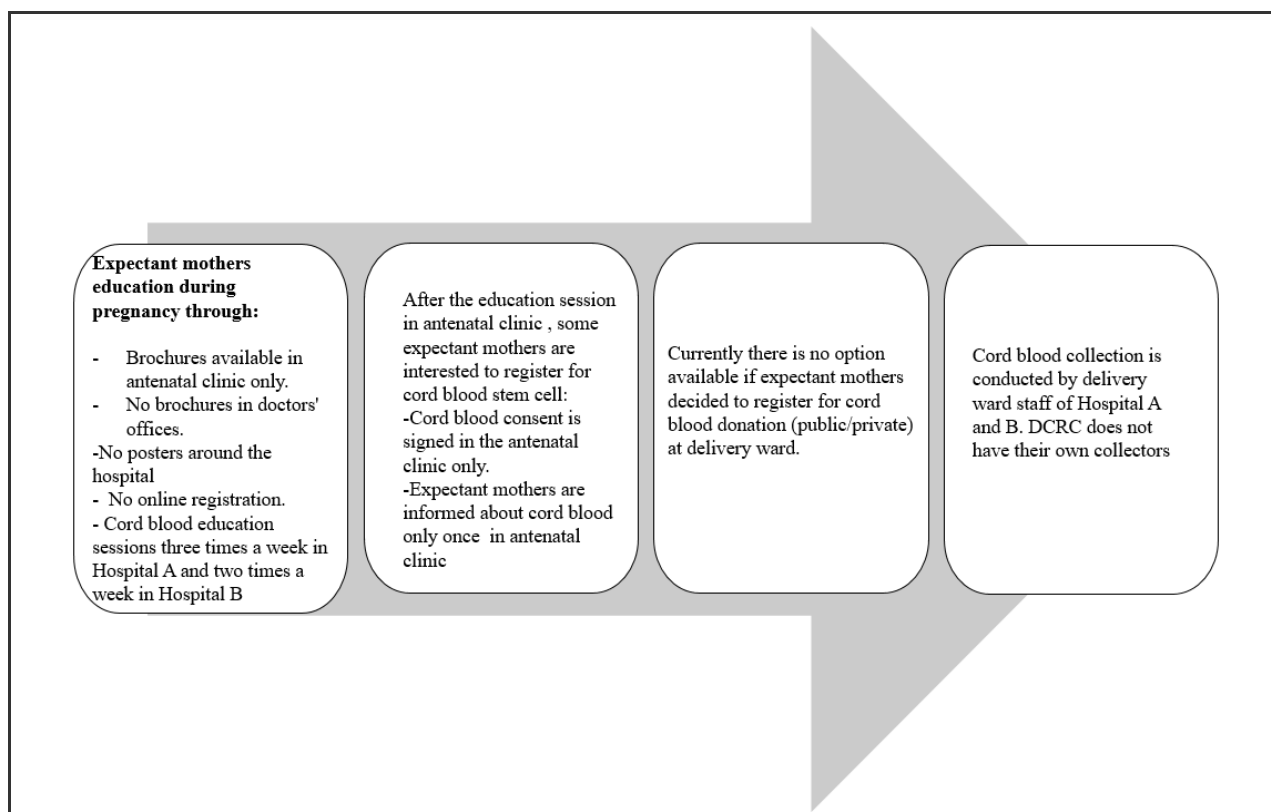
#### **Introduction to the section**

The researcher along with her team visited antenatal clinic of both Hospitals A and B to conduct short educational session about cord blood stem cell for the expectant mothers. The education session was given in the antenatal clinic (waiting area) of both Hospitals A and B. A specific format of reflective report was prepared and followed by the researcher and her team (Appendix 5). The team along with the researcher started visiting the antenatal clinic and writing reflective reports for about eight months from January 2015 to August 2015. Individual reflective reports were written by the researcher and the team members. All the reflective reports were then collected, analysed and summarised by the researcher in this case study. The reflective report form was designed in a way that allowed us to reflect about different issues that the researcher wanted to focus on during the observation. The reflective reports focused mainly on the following topics:

- The location of the antenatal clinic and the organisation of the place.
- The environment and the atmosphere of the antenatal clinic.
- Expectant mothers' engagement and awareness level.
- Expectant mothers' feelings about and expressions towards cord blood donation
- Problems and concerns raised by expectant mothers.
- Interaction with gynecologists/nurses/receptionist.

In this case study the researcher summarised the main findings that were highlighted in all collected reflective reports in 2015. These findings helped the researcher understand expectant mothers' views regarding cord blood stem cells, as well as their concerns, motivations and suggestions regarding cord blood. Expectant mothers' voices and opinions

were very important for the research to be able to understand and initiate best practice for cord blood donor recruitment. Participation observation was the first method conducted by the researcher to understand, first, the life context of the expectant mother in regard to cord blood stem cells as well as their opinions, concerns and suggestions to improve cord blood recruitment process and awareness. The current situation of cord blood donor recruitment in Hospitals A and B is shown in Figure 5-3. The researcher and her team were visiting the antenatal clinics of Hospitals A and B based on a scheduled timetable to conduct short educational sessions about cord blood. Each educational session was given in the antenatal clinic (waiting area) for about one hour. After conducting the session some expectant mothers were excited to join the programme and register for cord blood stem cells' private or public banking. In these cases, the full registration procedure was done in the antenatal clinic without the need for the expectant mother to visit the DCRC. The cord blood consent form was signed by the expectant mother agreeing to allow the DCRC to collect her newborn's cord blood stem cells after the delivery. The education and information about cord blood stem cells is given only at the antenatal clinic and currently DCRC staff are not available at the delivery site to register expectant mothers for the cord blood programme. Thus many opportunities are lost as some expectant mothers decide at the last minute when admitted to the delivery ward.



**Figure 5-3 Summary of the current situation for donor recruitment in Hospitals A and B**

### **The location of the Antenatal Clinics and their Organisation in Hospitals A and B**

In Hospital A the chairs were arranged in a U-shape along with some extra chairs in the middle with rectangle coffee tables. Expectant mothers are seated facing both the reception and the nursing room. The DCRC desk was located under the TV in the antenatal clinic. However, in Hospital B, the arrangement of the chairs was different; the waiting area of the antenatal clinic is located between the physicians' doors in the same hall. The DCRC desk was placed near the breastfeeding room at the other end of the waiting area.

The DCRC desk was used to register expectant mothers for the cord blood programme – either public or private banking. There were no private rooms available in the Hospital to educate expectant mothers and register them on to the programme. DCRC desk was located in waiting area of the antenatal clinic where all the expectant mothers are sitting waiting for their appointment. Many expectant mothers were not happy as they preferred a private room when conducting cord blood registration and education. The reason for that is because part of the

registration procedure is answering a medical questionnaire to assure that the expectant mother is eligible for cord blood donation. The medical questionnaire consisted of some private questions that some expectant mothers do not feel comfortable about answering them in an open area surrounded by all other expectant mothers and staff. Thus they were always requesting a private room to conduct the registration procedure. However, there are no empty rooms in either hospital and we had to manage the situation and discuss the medical questionnaire with expectant mothers in a very low voice if needed.

### **The Environment and the Atmosphere of the Antenatal Clinic**

The antenatal clinics of Hospitals A and B were very busy most of the days but early in the morning between 8-10 am is a bit quieter and suitable to educate expectant mothers about cord blood stem cells. After 11:00 am the place becomes very crowded in both hospitals and it is very challenging to educate them in the waiting area. Some mothers were very interested and were giving full attention to the topic whereas others were busy with their mobiles and some with their children or chatting with their friends. Conducting an educational session in the waiting area was challenging as it was very hard to make sure that expectant mothers will be available for the whole session, because many of them were either called by the nurses for a quick check-up or they were called to see their gynecologist. Therefore, the lecturer and expectant mother were distracted most of the time and some of the expectant mothers were annoyed and wanted to learn about cord blood, while others did not mind. Therefore, this made the researcher think that the antenatal clinic might not be the best place for education despite the fact that it is considered the best place for catching and meeting many expectant mothers at one time. Moreover, the antenatal clinic is a very crowded place with many mothers and children; thus it was not always easy to conduct educational sessions.



## **Expectant Mothers; Engagement and Awareness Level**

Expectant mothers of both hospitals were waiting in the antenatal clinics to see their doctors. While they were waiting, the researcher and her team used this chance to talk to them and educate them about cord blood stem cells and the different banking options. A short educational session was given to them for about 20-30 minutes. The session mainly focused on the main essential information they need to know about cord blood stem cells, collection procedure, fees and storage, diseases treated, and the different banking options. The researcher and her team were assuring the expectant mothers about the safety of the collection procedure during the delivery and exactly what happens to the cord blood unit once received at the DCRC. Some of the expectant mothers showed great interest and were very keen to listen and learn about cord blood stem cells, while others did not pay attention because they have heard about it before from us from their previous visits. In addition, some were not giving attention as they were busy with their mobile phones, busy in conversation with other family members, or with their kids playing games on their iPads. We believed that they were trying to find some source of entertainment as they were waiting for a long time to see their gynecologists. Some of the expectant mothers were annoyed during the educational session as they were hearing it over and over again for many times from their previous visits to the clinic as, in Dubai, the expectant mother comes to see her doctor each month during her pregnancy; and some of them with high-risk pregnancies are more regular patients as they visit the clinic every two weeks. Thus, it will be a good idea to deliver the education materials in a more systematic and scheduled manner, and keep a record of all the expectant mothers who have already received information about cord blood stem cells so they do not get approached again. The researcher was very interested in the breastfeeding system in the hospital and was trying to learn from them to apply a similar system for cord blood donor recruitment. Each expectant

mother who visits the clinic must see the breastfeeding consultant at least once during her visit. The breastfeeding consultant had a special room to run the educational activities. The nurse in the antenatal clinic gives the expectant mother the breastfeeding educational form and asks her to go and see the breastfeeding consultant. Expectant mothers cannot see their gynecologists unless they first pass by the breastfeeding consultant.

Despite the fact that some of the expectant mothers were aware about cord blood stem cells, however, they have very general knowledge as many of them were not aware about the eligibility criteria for cord blood donation. They were not aware if they are suitable candidates to donate their newborn's cord blood for public use or to preserve it for family use. In addition, some of them were aware about the family banking option but did not know that there is an option for donating cord blood stem cells for others.

Thus, in the antenatal clinic, we experienced a mixture of behaviours and knowledge levels. There were days where the researcher and her team meet a group of expectant mothers who had never heard about cord blood stem cells before and it was their first time to hear about it whereas there were other days where many expectant mothers were aware about cord blood as they have attended the sessions earlier in their previous visits to the clinic. The researcher and her team noticed that expectant mothers who never heard about cord blood stem cells before were more eager to listen to the lectures and ask questions. Many expectant mothers were motivated to donate their newborn's UCB stem cell when they know that they can play an important role in helping the society, being aware about the beneficial use of cord blood stem cells, and knowing that the cord blood collection procedure is a safe and painless process that does not harm either the newborn or the mother.

### **Expectant Mothers' Feelings and Expressions towards Cord Blood Donation**

Most of the expectant mothers were very happy to hear about cord blood stem cells for the first time as they engaged with the topic and asked many questions. However, expectant mothers who had already heard about the topic during their visits found it boring to keep listening to the same thing and they did not want to be approached again.

Some of the expectant mothers were disappointed that they did not hear about cord blood stem cells before; they were surprised that it was founded in 2006 and they never knew about it. Moreover, many expectant mothers highlighted that they would like to hear about cord blood from their gynecologist doctors.

When it comes to cord blood registration, many of them would like to discuss cord blood with their husband to seek his permission first before donating their newborn's UCB stem cell and they believe that their husband should also be educated about cord blood so they can both take informed decisions. Many of the mothers were happy to donate their cord blood stem cells and they were asking why the centre needs to take expectant mother's permission before collecting cord blood; they asked why the centre did not just collect it and use it to help others. The researcher explained for them that the placenta is part of them and legally we have to obtain expectant mothers' permission and signature on the consent form before collecting cord blood stem cells.

### **Problems and Concerns Raised by Expectant Mothers**

Many expectant mothers raised the point that their gynecologists are not discussing cord blood stem cells and the different banking options with them at all about. They said if cord blood donation is this important then doctors need to promote it and discuss it with us. Expectant mothers highlighted that during their nine months' pregnancy, they never heard their doctors talking to them about cord blood stem cells. Moreover, some expectant mothers ask their doctors about stem cells and all they say is to refer them back to the DCRC or ask

them to attend the educational session in the antenatal clinic. Thus, many expectant mothers preferred to hear about cord blood from their doctors as they have so much trust in their physicians. For example, one of the pregnant women was very interested to donate her cord blood stem cells; however, when she knew that it gets collected after the delivery of the newborn she refused because she does not want to be involved in any extra procedure that would make her stay longer in the delivery room. Even though it was explained to her that cord blood collection is a very simple and safe procedure that takes five to eight minutes, she still felt discouraged and considered it very inconvenient. Thus, the involvement of nurses and gynecologists in educating the expectant mothers is essential as they will be more convinced to donate their cord blood stem cells if it is been encouraged by their doctors. Providing the expectant mothers with basic information about cord blood and the different banking options is not enough in some cases; expectant mothers place a great deal of trust in their gynecologists conveying the knowledge about cord blood to them, thereby making it much easier.

They also raised another concern regarding the healthcare educator only spending a few hours in the antenatal clinic to give the lecture and register expectant mothers for cord blood. They requested that the healthcare educator is available all day in the antenatal clinic so they can be reachable at any time during the working hours.

One of the important points highlighted in the reflective reports the fact that some expectant mothers said that they cannot focus during the educational session with the lecturer or complete their cord blood registration procedure because they get called by the nurses for either routine check-up or to see their gynecologist. Even though the DCRC educator asks them to come back later after they finish, because they took a long time with their doctor, they either forget to come back or they are just tired and prefer to go home. Thus, cord blood education and registration needs to have its own specific slot, in the same what that

breastfeeding education is conducted in the clinic. Because cord blood education is as important as breastfeeding, a proper educational programme need to be conducted without disturbance so that detailed information can be delivered to the expectant mothers about cord blood so they can make informed decisions.

Many expectant mothers lack basic and detailed knowledge about cord blood stem cells and registration procedures and they would like to learn more about the collection procedure, the safety of mother and newborn, the storage fees, and the different tests applied to the cord blood units.

One of the issues raised during our observation in the antenatal clinic is that some expectant mothers think that after donating cord blood stem cells we sell the cord blood units. We assured them that we do not sell any cord blood units or conduct any non-ethical practices with cord blood units in the centre and that everything is done legally and with prior approval.

Many expectant mothers also suggested translating the medical history questionnaire and the educational material into the Arabic language as many of them cannot read the English language.

### **Interaction with Gynecologists, Antenatal Nurses and Receptionist in the Antenatal Clinics of Hospitals A and B**

As the DCRC team, we were interacting directly with the receptionist and the nurses in the clinic of both Hospitals A and B. However, we did not have direct interaction with gynecologist doctors unless they approached us with questions. Nurses and receptionists did not have detailed information about cord blood stem cells and were not aware about the registration procedures for cord blood collection. They had basic knowledge about cord blood and were only aware about common diseases treated using cord blood stem cells. They completely depended on the healthcare educator from the DCRC for cord blood education and

questions raised by expectant mothers. The researcher noticed the importance of nurses being aware about the registration procedures and available documentation as sometimes expectant mothers ask them questions and it is important that they know how to guide them by providing basic information. Most of the nurses in the antenatal clinic are very helpful as they guide the expectant mothers to the DCRC desk in the clinic and they share with them the information they have about cord blood. However, nurses and receptionists in the clinic only have very basic information about cord blood and they need to be provided with some more information so they can help guide the expectant mothers when needed. They need to be aware about some key information which includes different banking options, diseases treated using cord blood, registration procedures, and general information about cord blood and storage fees.

Nurses in the delivery ward requested many times to have someone from the DCRC to register expectant mothers in the delivery ward. They highlighted the fact that many parents would like to register for cord blood donation at the last minute and, in this case, they need someone there to do the procedure. However, due to staff shortages, it was hard to make someone from the DCRC available all the time in the delivery ward to accommodate expectant mothers' requests regarding cord blood registration.

## **Conclusion to the chapter**

Many experiences and lessons were learnt from visiting cord blood centres in the UK and the USA and observing the donor recruitment processes in hospitals. One of the key learning lessons was the importance of resource. Both the cord blood centres in the UK and the USA have their own staff working as educators and cord blood collectors at the maternity hospitals. They do not depend at all on midwives and physicians for cord blood education and collection as midwives and physicians are busy with their daily routine work and only sometimes get the chance to encourage their patients in cord blood donation; thus, they are not the main source of information when it comes to cord blood education. Another important point was the idea of layering -up education about cord blood stem cells at different stages during pregnancy so expectant mothers learn about cord blood at different stages and get the chance to think about it and discuss with the family until the time of delivery. Information about cord blood stem cells need to be delivered to expectant mothers in detail as well as focusing on highlighting the safety of the procedure and the benefits of donating cord blood stem cells in helping many patients in need of cord blood transplantation. Thus, continuous education and awareness are key factors that encourage expectant mothers to donate their newborn's UCB stem cells.

In Hospital A nurses in the delivery ward and antenatal clinic had a good knowledge about cord blood stem cells and the different diseases treated using cord blood stem cells. They were aware about the different banking options (family banking and public banking) provided by the DCRC. However, gynecologists and pediatricians had limited knowledge or even no information about the availability of public banking option in the DCRC to help others in need of transplantation, and such information had to be explained to them during the interviews.

Most of the healthcare professionals said that they would like to encourage expectant mothers to donate their cord blood stem cells to help others in need of transplantation. They strongly believe that mothers do not donate their cord blood due to lack of awareness and knowledge that prevents them from making informed decisions. All healthcare professionals strongly believe that if expectant mothers are given the adequate information at the early stages of their pregnancy, they can have more time to think about it and make informed decisions. In addition, they all strongly believe that it is the mother's right to know the information about cord blood as it is part of her and only by knowing more about it will she be able to help her family or others by donating her cord blood stem cells. They also believed that the healthcare educators from the DCRC should provide expectant mothers with cord blood information, and they need to be available in the antenatal clinic to educate them.

All healthcare providers were asked, *"If the patients need their advice regarding the banking options, which banking options will you encourage them to go for?"* Most of the nurses replied 'public donation' because it is free and it can help others. However, it was surprising that most of the gynecologists and pediatricians did not know about the availability of public banking as an option in the DCRC that allows mothers to donate their cord blood for others with no required payment. Only after informing them during the interview did they say they would like to encourage their patients to donate their cord blood to help others in need. Moreover, only a few of the healthcare professionals knew about the importance of the public registry as most of them did not know the purpose of an international stem cell registry and the main use of it.

During the interviews, most of the healthcare providers, particularly gynecologists and pediatricians, highlighted the fact that media should play an important role in increasing awareness among the public about cord blood donation. They also said that greater awareness about cord blood donation should be communicated via TV and radio channels and education



should start from schools and universities so that when it comes to the stage of pregnancy, the mother will be aware as she has heard about it before. However, the current situation is that healthcare providers have limited information about cord blood stem cells which often means they are not confident enough to explain it to the patients.

All of the healthcare professionals showed support for creating more guidelines and policies as it will help them all to speak the same language, follow instructions, and pass the same information on to patients. However, they strongly highlighted the fact that they cannot educate others as they would need first to be educated about cord blood stem cells in detail so they can pass the information on to their patients.

Gynecologists and pediatricians were the two groups least aware about the importance of cord blood donation and the different banking options available in the Dubai Cord Blood & Research Center (DCRC). Despite their daily interaction with expectant mothers at the clinics, they had insufficient information about cord blood stem cells to be able to convey it to their patients. However, all healthcare professionals said that they are willing to learn more about the importance of cord blood stem cells and requested access to intensive lectures and more information about the stem cells and their usage in disease treatment so they can help with educating their patients in the clinics.

In Hospital B, nurses in the delivery wards and antenatal clinic had good knowledge about cord blood stem cells, their usage in disease treatment, and the different banking options offered by the DCRC. However, gynecologists and pediatricians had limited knowledge about the presence of two different banking options for cord blood donation as most of them were not aware that the DCRC provides public cord blood banking (free of cost) for donors who would like to donate their cord blood stem cells for others who are in need. Knowing that

made them very excited about encouraging their patients to donate their cord blood stem cells instead of wasting them.

All the healthcare providers believe that it is the mother's right to know about the benefits of cord blood stem cells and its usage in disease treatment. They all believe that cord blood is a precious source of stem cells and knowing about it is very important to be able to help the family or others in need for transplantation. Most of the nurses believe that cord blood education is the responsibility of healthcare providers in hospitals starting from nurses in antenatal clinics, gynecologists, to pediatricians and delivery ward nurses. Gynecologists also believe that it requires team work and is the job of everyone who has direct contact with the patient. However, most of the pediatricians believe that it is the job of gynecologists and antenatal clinics and they cannot see where their role falls in educating pregnant women about cord blood. They also highlighted that they do not have detailed knowledge about cord blood to share with expectant mothers and they prefer to have dedicated staff from the DCRC to do this job along with all the healthcare providers.

Almost all of the healthcare providers agree that cord blood educational guidelines should be created to use as a reference for them to educate the public. However, they all highlighted the fact that they should be educated first about cord blood as their current knowledge is not sufficient to be shared with the patients.

## CHAPTER 6: DEVELOPMENT OF THE THEORETICAL FRAMEWORK FOR THE DONOR RECRUITMENT PROCESS.

### Introduction to the chapter

This chapter focuses on the the development of the theoretical framework from the results obtained from case studies and surveys that were analysed and interpreted using activity system models and the process(es) of value co-creation for the development of a new cord blood donor recruitment process.

The main actors were identified along with their tasks and roles and the kind of knowledge they hold and bring to the donor recruitment processes. In terms of S-D logic, attention was given to the analysis of the role of *beneficiaries* within the process which is, in this case, expectant mothers. The researcher also focused on the role of the *institutional* – in this case the *context* of public Hospitals A and B and the cord blood centre – along with other contexts such as life context of the expectant mothers and the healthcare providers as human institutions. In addition, analysis of the groups and communities of actors as *dynamic systems* were carried out in depth by applying the model of the activity system. Thus, all results were analysed by viewing them through the lenses of both S-D logic and activity theory.

The efforts in developing the theoretical framework were made by the researcher with the help of two of her supervisors, Dr. Kajamaa and Professor Toivonen from Finland, who are specialised in the field of activity theory and S-D logic. We identified that there are several common ingredients between S-D logic and activity theory which are examined in more detail in this thesis. These common ingredients include: the role of *beneficiary (user)*, actors as *dynamic systems*, importance of *context* as human institutions, and *knowledge* as an operant resource. Along with her co-authors in Finland, the author is in process of publishing the

jointly written article titled “*Expanding S-D logic by using Activity Theory as a Tool for Practice Development*” which uses activity theory as a tool to expand S-D logic for practice development (Alhashimi, Kajamaa and Toivonen, forthcoming). The process of developing the theoretical framework of the expanded model is discussed in detail in this chapter.

## **6.1 Main Common Ingredients between S-D Logic and Activity Theory and Practice Development.**

### **6.1.1 First Common Ingredient: Multiplicity of Actors and the role of the Beneficiary (User)**

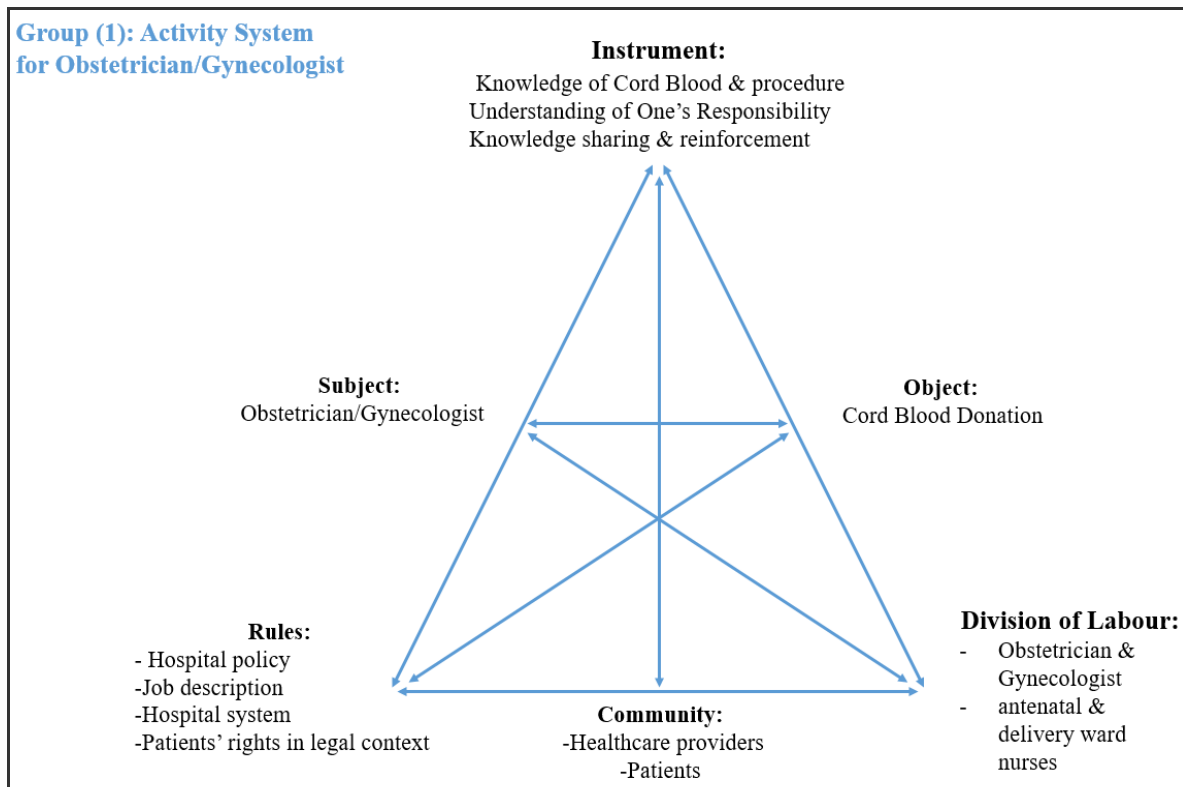
In this study, several common ingredients in S-D logic and activity theory were identified. **The first common ingredient** is the view of production and innovation that includes a *multiplicity of actors and the role of the beneficiary (user)*. According to S-D logic, value is always co-created by the interplay of several actors and this co-creation always includes the beneficiary. This is due to the fact that value is not essential in term of production outcomes and innovation; it becomes important only when it manifests itself in use. Even before the value can be recognised, the input that is obtained from a single provider has to be integrated with other resources, as the user is the one who carries out the integration. Thus, resource integration along with different users is essential because the value of a single resource depends mainly on its relation with other resources (Vargo and Lusch 2004, 2008, 2011).

Similar phenomena are viewed within activity theory; it also highlights the multiplicity of actors and the vital role of the beneficiary (user) in work, production and innovation (e.g., Hasu and Engeström 2000). According to activity theory, activity is always collective and determined by a shared object-related motive (Leont’ev 1978). Socio-cultural resources including the different beneficiaries and users included in the activity systems, material artifacts and language are used to mediate actions between service providers (subjects) (Engeström 1987; also Vygotsky 1978). Activity systems are fundamentally multi-voiced as

the participants come with different conceptualisations of the object such as in patient-centred care where all the users work towards *beneficiary/user-centredness* (Engeström 1999). Removal of resistance is considered important in S-D logic; however in activity theory, instead of removing resistance the construct embraces them as tensions and contradictions which are considered the main drivers for learning and development in organisations. Thus, by applying the model of the Activity System, an activity system was drawn up for each actor involved within the donor recruitment process. These actors include healthcare providers who are working in Hospitals A and B and have direct contact with expectant mothers (user) during their pregnancies.

- **Group (1): Obstetricians/Gynecologist Activity System**

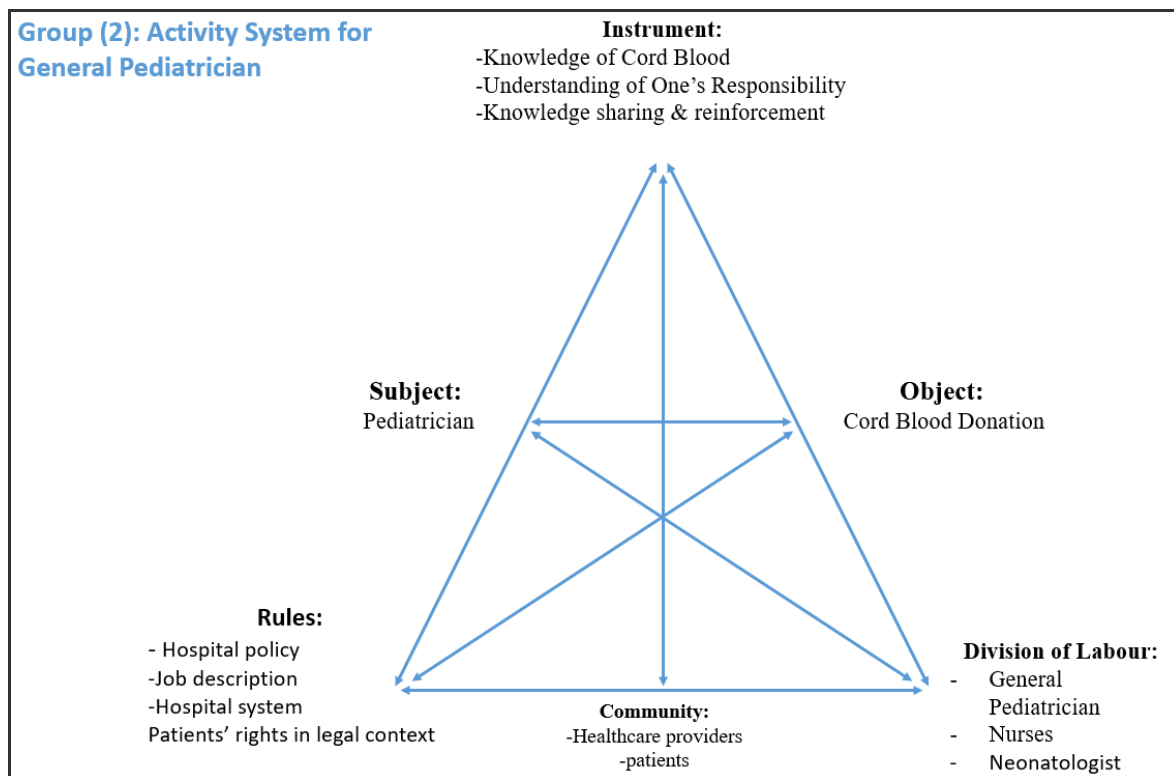
Figure 6-1 represents gynecologist/obstetricians' activity system as they perform the *subject* of the activity. Their *object* in this activity system is cord blood donation. Knowledge about cord blood stem cells and awareness of their role/responsibility within the donor recruitment process is used as a mediational tool or an instrument that is required to accomplish their task within the surrounding *community* of healthcare providers and patients. *Division of labour* constitutes the healthcare providers who will deliver information about the cord blood donation to the patients; the providers include antenatal nurses, delivery ward nurses and gynecologists/obstetricians. Rules consist of different activities that are controlled by each hospital's *rules*, regulations and policies.



**Figure 6-1 The First Activity System Group for Obstetrician and Gynecologist Including Their Subject, Object, Instrument, Division of labour, Community and Rules.**

- **Group 2: General Pediatrician Activity System**

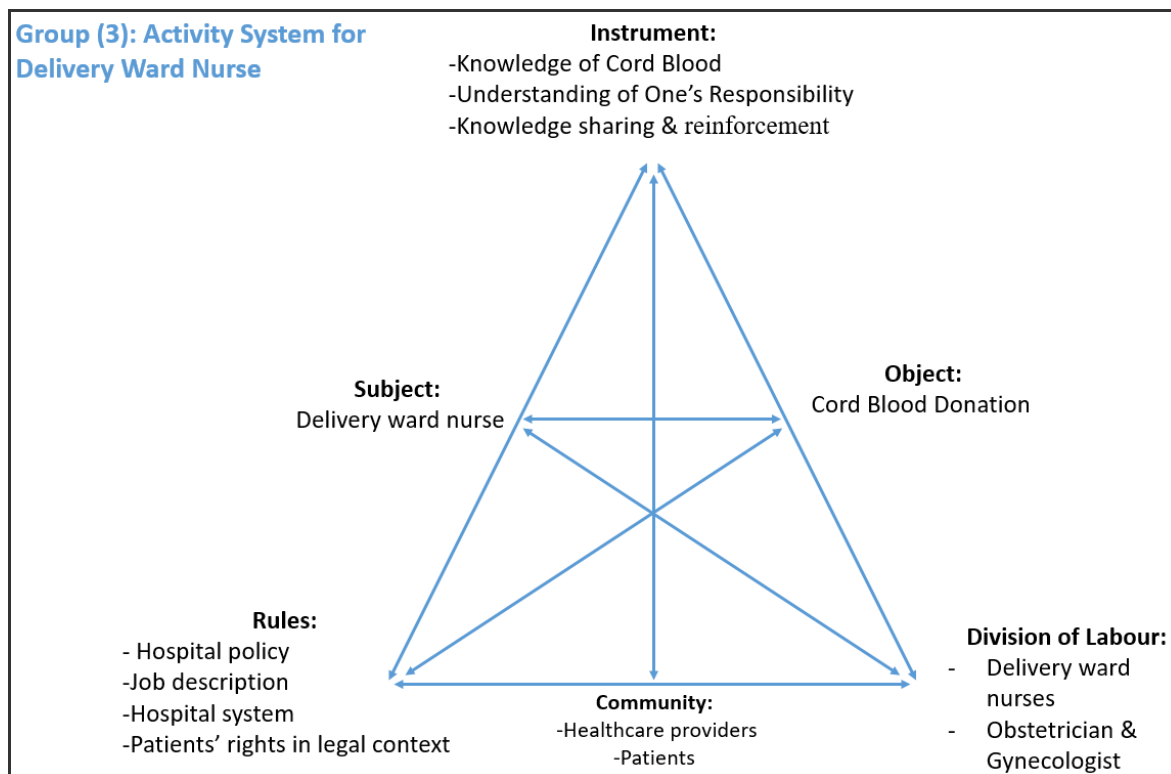
Figure 6-2 represents the general pediatrician activity system as they perform the *subject* of the activity. Their *object* in this activity system is cord blood donation. Knowledge about cord blood stem cells and awareness of their role/responsibility within the donor recruitment process is used as a mediational tool or instrument that is required for them to accomplish their task within the surrounding *community* of healthcare providers and patients. *Division of labour* constitutes the healthcare providers who will deliver information about the cord blood donation to the patients; the providers include general pediatricians, neonatologists and nurses. Rules consist of different activities that are controlled by each hospital's *rules*, regulations and policies.



**Figure 6-2 The Second Activity System Group for General Pediatrician Including Their Subject, Object, Instrument, Division of labour, Community and Rules.**

- **Group 3: Delivery Ward Nurse Activity System**

Figure 6-3 represents the delivery ward nurse activity system as they perform the *subject* of the activity. Their *object* in this activity system is cord blood donation. Knowledge about cord blood stem cells and awareness of their role/responsibility within the donor recruitment process is used as a mediational tool or instrument that is required for them to accomplish their task within the surrounding *community* of healthcare providers and patients. *Division of labour* constitutes the healthcare providers who will deliver information about the cord blood donation to the patients; these providers include delivery ward nurses, obstetricians and gynecologists. Rules consist of different activities that are controlled by each hospital's *rules*, regulations and policies.

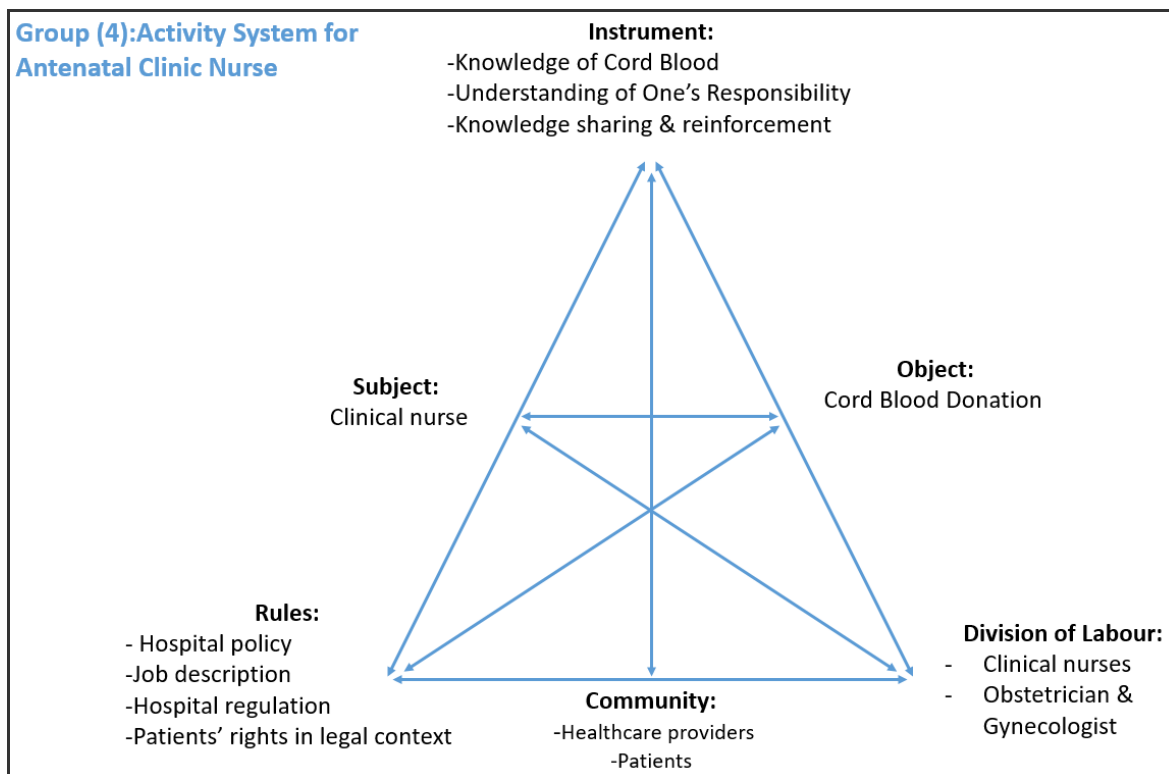


**Figure 6-3 The Third Activity System Group for Delivery Ward Nurse Including Their Subject, Object, Instrument, Division of labour, Community and Rules.**

- **Group 4: Antenatal Clinic Nurse Activity System**

Figure 6-4 represents the delivery antenatal nurse activity system as they perform the *subject* of the activity. Their *object* in this activity system is cord blood donation. Knowledge about cord blood stem cells and awareness of their role/responsibility within the donor recruitment process is used as mediational tool or instrument that is required for them to accomplish their task within surrounding *community* of healthcare providers and patients. *Division of labour* constitutes the healthcare providers who will deliver information about the cord blood donation to the patients; these providers include clinicians, obstetricians and gynecologists. Rules consist of different activities that are controlled by each hospital's *rules*, regulations and policies.

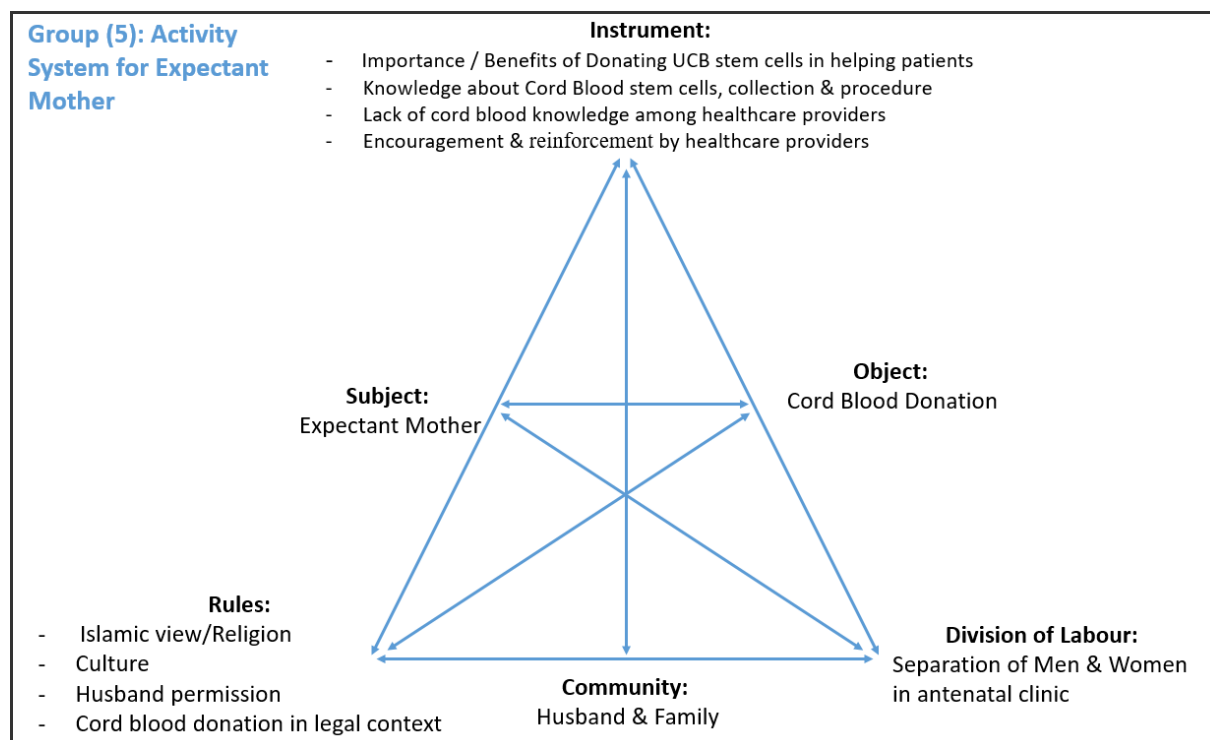




**Figure 6-4 The Forth Activity System Group for Antenatal Nurse Including Their Subject, Object, Instrument, Division of labour, Community and Rules**

- **Group 5: Expectant Mother Activity System**

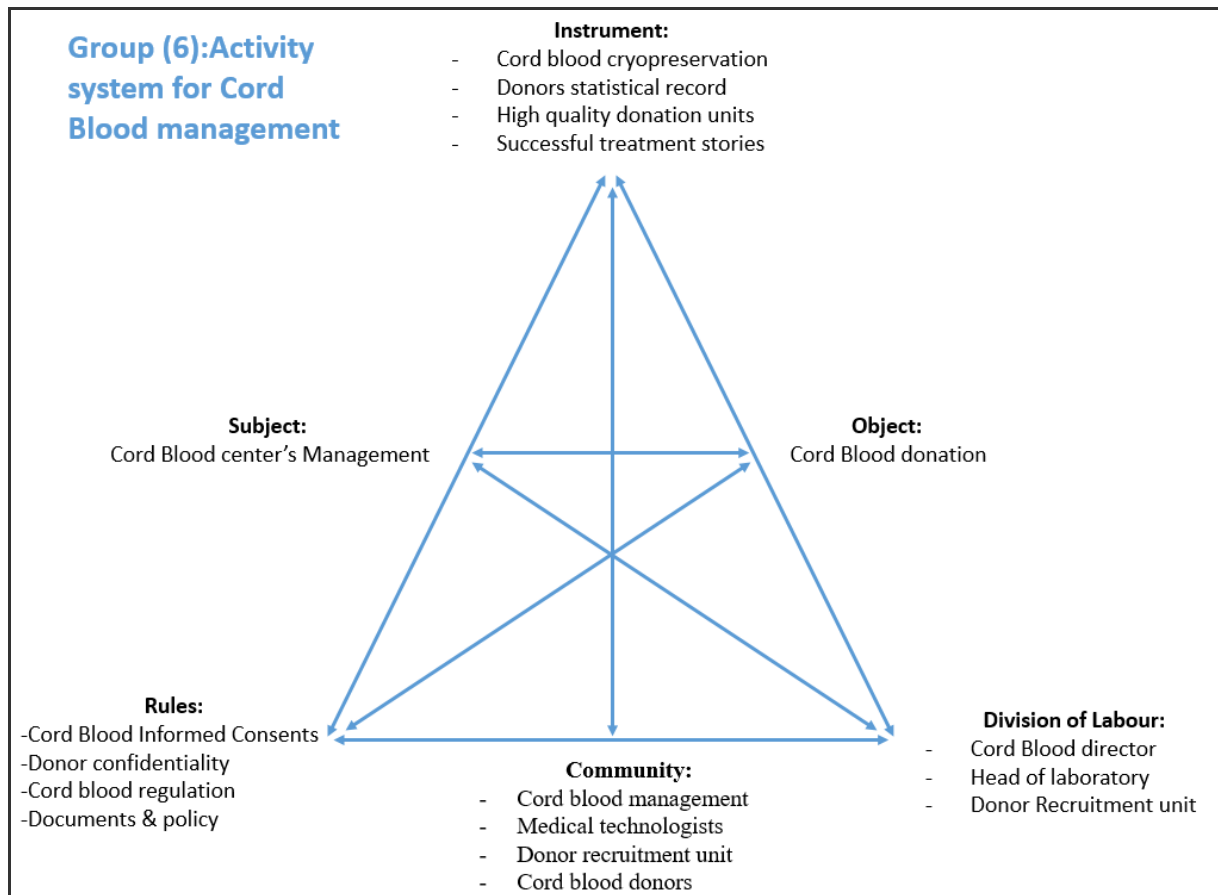
Figure 6-5 represents the expectant mother activity system as they perform the *subject* of the activity. Their *object* in this activity system is cord blood donation which makes them eager to learn more about the benefits of cord blood donation. Knowledge about cord blood stem cells and its beneficial usage in treating many diseases and helping many patients acts as a mediational tool or instrument that is required to accomplish their task within the surrounding *community* of their family and husband. *Division of labour* limits the education provided about cord blood stem cells and its registration procedures to expectant mothers in antenatal clinics. *Rule* limits the activity of cord blood donation due to cultural issues, some Islamic views about cord blood donation, and lack of knowledge about cord blood stem cells among husbands.



**Figure 6-5 The Fifth Activity System Group for Expectant Mothers' Including Their Subject, Object, Instrument, Division of labour, Community and Rules.**

- **Group 6: Cord Blood Management Activity System**

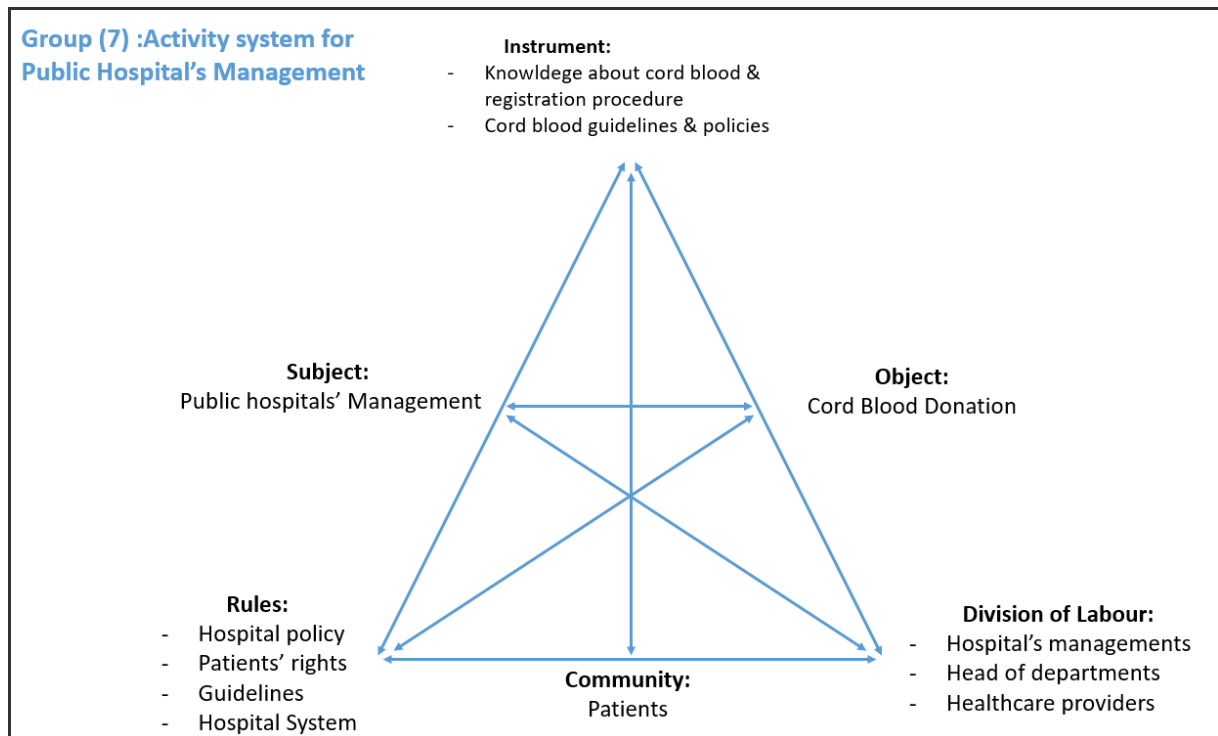
Figure 6-6 represents the cord blood management activity system as they perform the *subject* of the activity. Their *object* in this activity system is cord blood donation. High-quality cord blood donation units that can be used to treat many patients in need of transplantation is used as a mediational tool or instrument that is required to accomplish their task within the surrounding *community* of cord blood management and donors. *Division of labour* includes the cord blood director and donor recruitment management that will deliver information about the cord blood donation to the patients. Rules consist of informed donor consents, donor confidentiality, and guidelines and policies which control the activities of the system.



**Figure 6-6 The Sixth Activity System Group for Cord Blood Management Including Their Subject, Object, Instrument, Division of labour, Community and Rules.**

- **Group 7: Public Hospital Activity System**

Figure 6-7 represents the public hospital activity system as they perform the *subject* of the activity. Their *object* in this activity system is cord blood donation. Knowledge about cord blood, cord blood registration procedures, guidelines and policies are used as a mediational tool or instrument that is required to accomplish their task within the surrounding *community* of cord blood management and donors. *Division of labour* includes hospital management, heads of departments and healthcare providers who will play various roles in initiating the cord blood donor recruitment process in the hospital. Hospital system, patients' rights, policies and guidelines act as the *rule* that controls the activity.



**Figure 6-7 The Seventh Activity System Group for Public Hospital's Management Including Their Subject, Object, Instrument, Division of labour, Community and Rules.**

### 6.1.2 Second Common Ingredient: The Analysis of the Groups and Communities of Actors as Dynamic Systems.

The second common ingredient between S-D logic and activity theory is the analysis of the groups and communities of actors as *dynamic systems*. In S-D logic, value creation does not occur through the activities of any single actor; rather it is a full range of market-facing activities where private and public actors deliver resources and at the same time act as resource integrators themselves (Vargo and Lusch 2016).

S-D logic focuses on actor-to-actor (A2A) perspectives where all economic and social actors function as resource integrators (Vargo and Lusch 2008, 2011). Similarly, activity theoretical studies often focus on several perspectives emerging in organisational processes and systemic relationships, and identify mechanisms for change on multiple levels where participants arrange their activities (see e.g., Engeström 1987, 2000; Toiviainen 2007). Activity theoretical studies are mainly based on dialectical thinking (see Benson 1977; also Van de

Ven and Poole 1995) by using living and dynamic movement as a resource of improvement which is defined as the formation of qualitatively new “functional systems” that are formed within and between individuals or collective activity systems (Engeström 2006). In many activity theoretical studies, an activity system model is used for the analysis of specific elements of different human activity structures (Engeström 1987).

S-D logic reveals that value co-creation does not occur through the activities of any single actor (activities only conducted by cord blood centre). Instead, it requires all social actors to be resource integrators (resource integration with the help of all healthcare providers in hospitals that have direct contact with expectant mothers) and thus all the users co-create value and work towards the *beneficiary* (patients). All the healthcare providers within the hospitals can play an important role in re-enforcing the message about the importance of cord blood stem cells among expectant mothers (see Figure 6-8). If healthcare providers develop a shared object which is in this case “cord blood donation”, then the required tool is knowledge about cord blood. However, the results showed that most of the healthcare providers lack knowledge about cord blood stem cells and thus have been finding it difficult to share relevant information with their patients. However, they are more than happy to play a role in reinforcing the message and encouraging their patients to donate their newborn cord blood stem cells. Thus, expectant mothers can gain information about cord blood stem cells from different resources such as brochures, concerned healthcare providers, DCRC educators and media marketing, but the main source of information is the healthcare educator who has the required knowledge about cord blood (see Figure 6-9). As shown in the USA and UK case studies, education about cord blood stem cells should be layered for the expectant mothers by approaching them at different stages of their pregnancy using different resources so that, by the time of delivery, they will have all the information they need. Moreover, healthcare providers should not be loaded down with extra work in addition to their daily work

requirements; hence they should be used as an additional, collective source of reinforcement and encouragement to assure their participation within the programme.

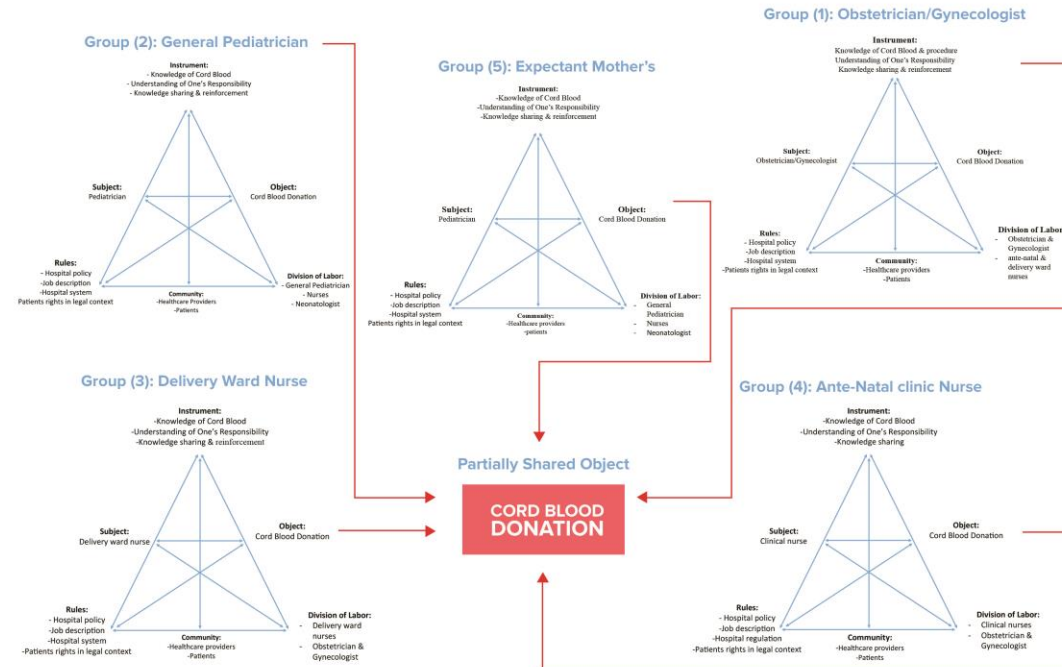


Figure 6-8 Different Dynamic Systems of Different Groups of Healthcare Providers Where All Act as Resource Integrators Towards The Beneficiary (patients).

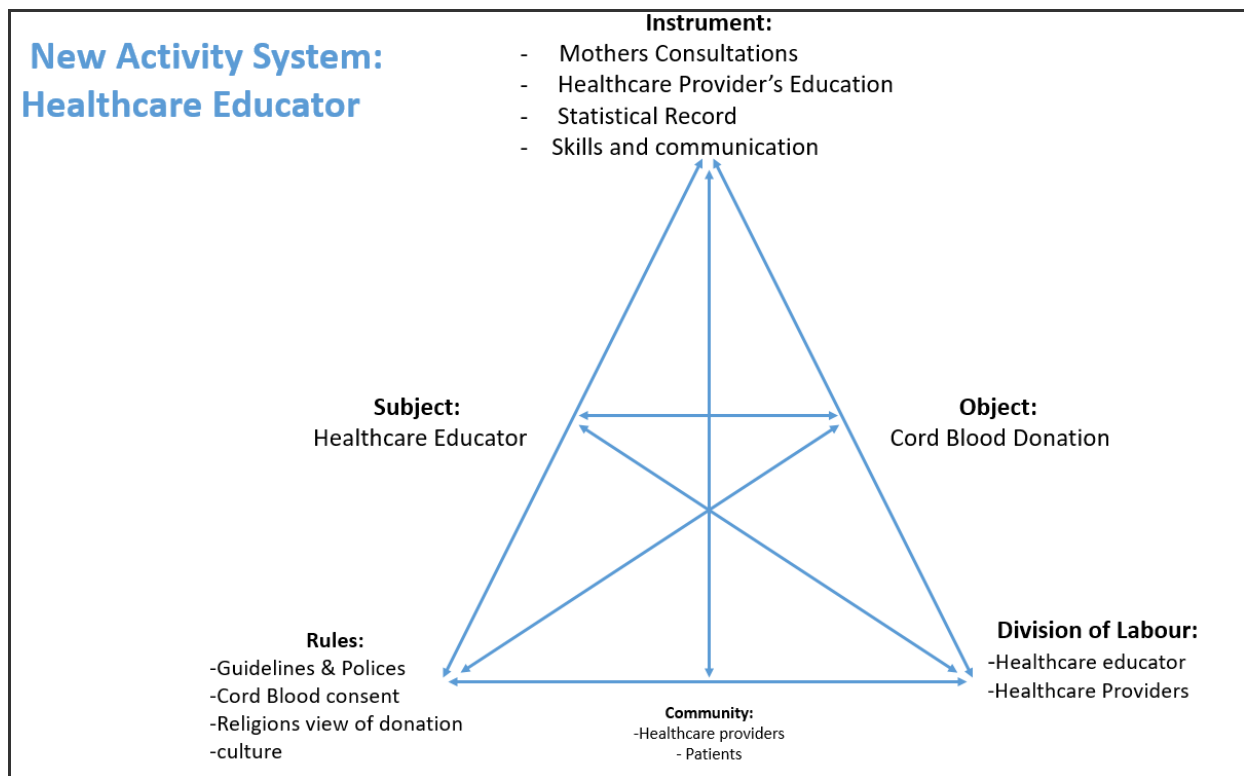
### 6.1.3 Third Common Ingredient: Focus on Knowledge as an Operant Resource

The third common ingredient focuses on knowledge. S-D logic overcomes the limitations found in the goods-dominant (G-D) logic as it focuses on the provider's and the recipient's *knowledge and competencies* during the economic service exchange (Vargo and Lusch 2004). In activity theory, knowledge is viewed as the emerging cultural and historical setting which is distributed and decentred (Engeström 1987, 2000; Toiviainen 2007). Knowledge creation and innovation processes are driven by the development of contradictions and tensions that occur within and between different parties such as the product developer and users during the implementation process. This leads to development of redesigned knowledge-intensive systems with new shared tools that generate practices (services) developed within specific contexts (Hasu and Engeström 2000, also see Engeström, Puonti and Seppänen 2003). In this case study, the researcher developed a new activity system titled the "Healthcare Educator Activity system" which acts as a mediator between expectant mothers' and healthcare providers' activity systems (see Figure 6-9). Due to the fact that all the healthcare providers lack the required tool, *knowledge*, to be able to achieve the object, *cord blood donation*, the healthcare educator from the DCRC must act as a resource integrator which will facilitate the work with the help of other actors who are the healthcare providers. Healthcare providers can play vital roles in reinforcing the message about cord blood donation among expectant mothers while the healthcare educator acts as the main resource; this is because she holds adequate and detailed knowledge that is required by expectant mothers in term of cord blood banking options, collection procedures, diseases treated, and registration processes.

Contradictions and tensions that arose within and between different activity systems were identified and studied, which helped in developing a new activity system, "healthcare educator". In the healthcare providers' surveys, results showed that all healthcare providers



think that the healthcare educator from DCRC is one of the best sources to provide patients with the required information about cord blood. However, in the expectant mother survey, results showed that expectant mothers believe that physicians are the best source of information. In addition, in the survey, expectant mothers stated that one of the barriers that stops them from donation is lack of knowledge about the importance of donation despite the fact that the majority of them said that they have acquired information on the importance of cord blood stem cells. Therefore, the contradictions between the two answers made the researcher realise the fact that even though the expectant mothers have general information about the importance of umbilical cord blood stem cells, that does not mean they understand the importance of publicly donating it and helping many patients in the treatment of many diseases. Thus, they require information in detail about the beneficial usage of public cord blood donation such as being aware that it can save the lives of many patients. As a result, the researcher included “mother consultations” as one of the required tools in the newly developed activity system (see Figure 6-9) that helps the educator to accomplish the *object* by providing information about cord blood and its beneficial use to expectant mothers. Thus, contradictions within activity systems were used in this case for developing the process of donor recruitment practice.



**Figure 6-9 Newly Designed Activity System Titled “Healthcare Educator” Which Acts as Mediator/Resource Integrator between Expectant Mother Activity System and Healthcare Providers.**

#### **6.1.4 Fourth Common Ingredient: is the View about the Importance of Context and Mainly Human Institutions.**

According to S-D logic, context is very important as actors make sense of value co-creation outcomes in a specific related context and not as isolated entities (Vargo and Lusch 2004). During value co-creation, actors work together equally to provide the context with the value they gain in its collective and individual assessment (Vargo and Lusch 2011); likewise in activity theory which describes human behaviour and its participation in social practices of specific contexts (e.g., Engeström 2004; Engeström and Sannino 2010). Activity theory is conceptualised as a deep, contextual and cultural construct that is focused on historically specific social organisations and local practices (Engeström 1987).

Both activity theory and S-D logic focus on the role of *institutions*. S-D logic studies *institutions* as an enabler for organising value-creating activities and resource integration in different multi-actor contexts (Vargo and Lusch 2016; Wieland, Hartmann and Vargo 2017). In addition, activity theory focuses on institutional contradictions and uses them as development and transformational tools for social change by studying different activity systems and different organisation levels, starting from leaders to daily work practices (Engeström and Sannino 2010). Therefore, from the results obtained from quantitative and qualitative data, context was studied for both cord blood centre and public hospitals using the activity system model (for example, see Figure 6-6 and Figure 6-7).

The activity system was studied along with its rules, systems, culture and policies surrounding Hospitals A and B. Results obtained from each group of healthcare providers and expectant mothers were supported in the activity system model of each group which clearly demonstrates the context surrounding each group and the instruments required to deliver information about cord blood stem cells to the expectant mothers.

The researcher found that it is very important to study the hospital system and the surrounding culture and contexts to be able to implement best practices to recruit donors. It is essential to understand healthcare providers' daily routine work. Almost all healthcare providers are willing to encourage expectant mothers to donate their cord blood stem cells; however, the knowledge they hold is basic and they cannot provide detailed information as they believe that this should be done by specialised staff who can provide expectant mothers with full information about cord blood registration, collection procedures, storage fees and banking options. They also highlighted that they are very busy with their daily tasks and it is very hard for them to spend time explaining about cord blood stem cells to the expectant mothers. Most of them suggested locating specialised staff for the full day in the antenatal clinic to educate

the expectant mothers about cord blood in exactly the same way that such staff provide breastfeeding and nutrition education in Hospitals A and B. Thus, the researcher integrated the new activity system model titled “Healthcare Educator Activity System” which acts as a mediator and resource integrator and facilitates the work between expectant mothers and healthcare providers in hospitals (see Figure 6-10). The healthcare educator has the required and detailed knowledge about cord blood stem cells, and is able to answer expectant mothers’ concerns and queries and register them for cord blood collection, if requested. The healthcare educator should not function as a single actor; rather she should work alongside concerned healthcare providers in the hospital such as antenatal nurses, gynecologists, pediatricians and delivery ward nurses, for the benefit of the end user (patients).

In addition to the healthcare educator activity system, an activity system model was drawn for the cord blood centre, governmental public hospital and healthcare provider to identify their context, rules, community and tools required as part of the donor recruitment process. Each hospital has its own rules and regulations and it is important to take them into consideration when implementing any new process. To be able to recruit donors (expectant mothers) within the hospital, a cord blood centre needs to provide its own resources that can be integrated with the hospital’s resources. Then, the educator from the cord blood centre can act as a mediator between the expectant mothers and healthcare providers to facilitate cord blood education. The culture and the division of antenatal clinic sections within the hospital act as one of the affecting factors in donor recruitment processes. In the antenatal clinic, husbands in the waiting area are separated from the expectant mothers’ waiting area; thus during her visit to the clinic, the expectant mother can become educated about cord blood stem cells without the presence of her husband. This means that the husband is not being aware about cord blood stem cells and thus does not encourage his wife to donate their newborn’s UCB stem cells.

Most of the expectant mothers are happy to donate their newborn's cord blood stem cells but in the culture of the UAE, they find it mandatory to seek the husband's permission first before deciding to donate her newborn cord blood stem cells. Educating both the expectant mother and her husband at the same time will add a great deal of value and save time and effort.

Another important factor is the Islamic viewpoint about cord blood donation. Some expectant mothers think that the Islamic religion does not allow them to donate their newborn's UCB stem cells. This misunderstanding leads them to think that by donating their newborn's UCB stem cells to others there will be mix in the relationships between the donor and the recipient and they will become siblings which is in fact not true.

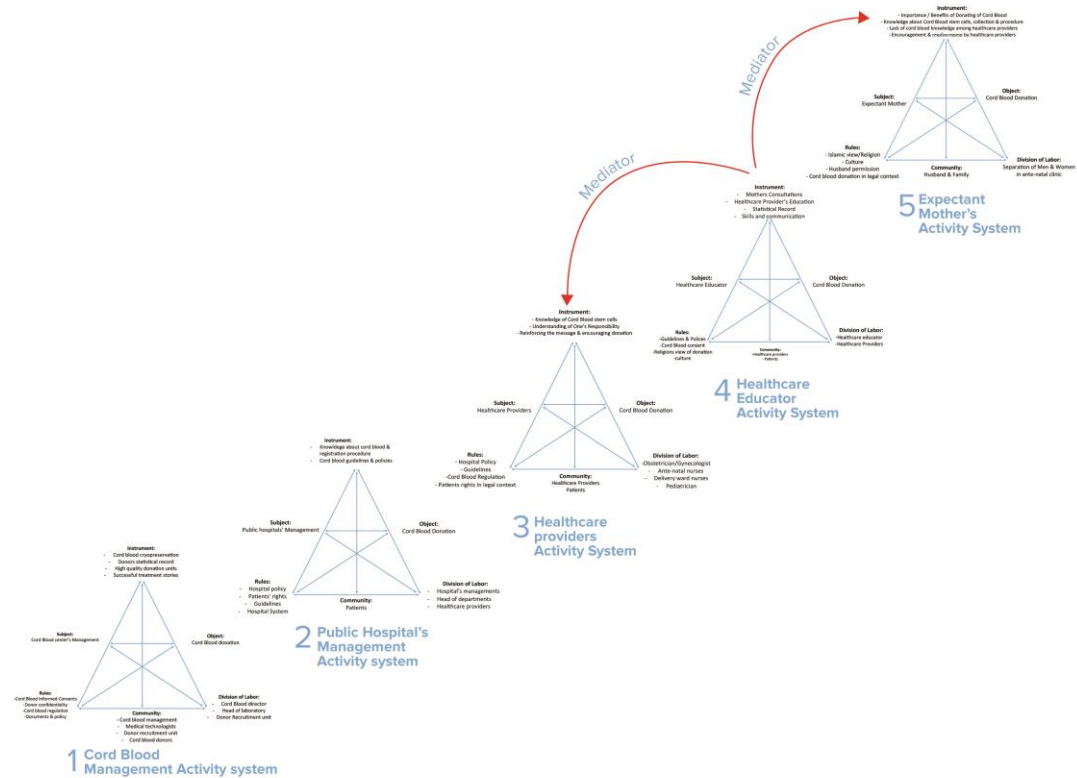
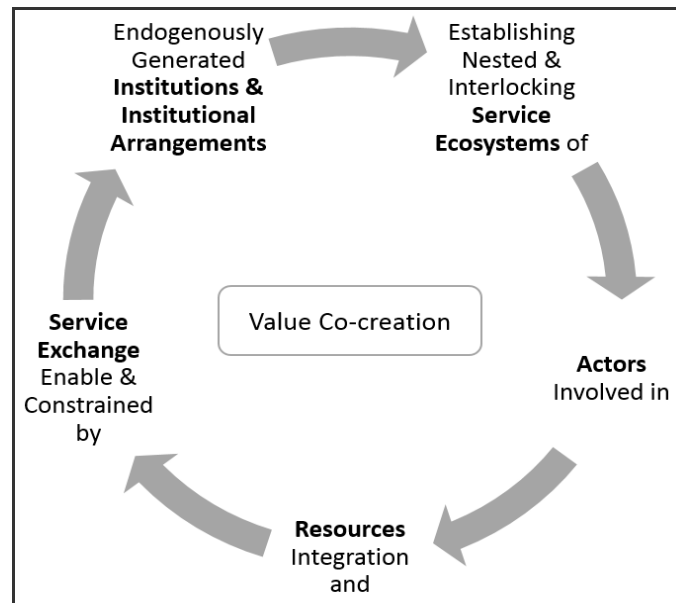


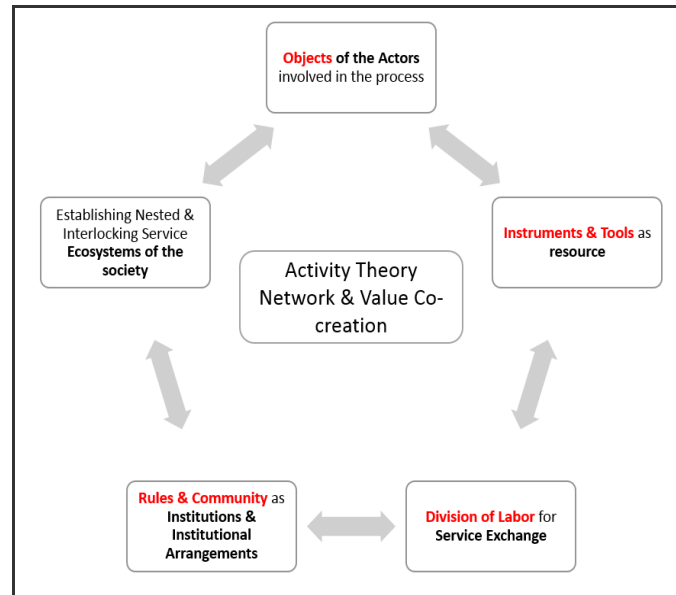
Figure 6-10 Healthcare Educator Activity System Model Acting as Mediator between Healthcare Professional Activity System and Expectant Mother Activity System

## 6.2 Expanding S-D logic by Integrating Different Elements of the Activity System Model for Practice Development



**Figure 6-11 The Narrative and Process of S-D Logic  
Proposed by Vargo and Lusch (2016)**

**Using AT  
as a Tool**



**Figure 6-12 Expanding S-D Logic by Integrating Different  
Elements of the Activity System Model for Practice Development**

Figure 6-11 represents the narrative and the process of S-D logic proposed by Vargo and Lusch (2016) which shows the development of the narrative of value co-creation into one of

resource integrations involving “*actors co-creating values through holistic, meaning-laden experiences in nested and overlapping service ecosystems, governed and evaluated through their institutional arrangement*” (Vargo and Lusch 2016, p.3). However, a research gap has been identified concerning the empirical case studies that would combine S-D logic and the practice-based view (Alhashimi, Kajamaa and Toivonen, forthcoming). Despite the fact that there are a number of studies framed as practice-based, they do not provide in-depth analyses of real organisational practices (Korkman et al. 2010; Echeverri and Skålén 2011). In addition, previous research that combines S-D logic and practice-based theory lacks ethnographic field research and in-depth analysis methods as well as empirically-tested concepts and analytical tools for exploring different structures and dynamics of organisational practices (Alhashimi, Kajamaa and Toivonen, forthcoming). Corresponding to the effort of Mele and Russo-Spena (2019, forthcoming), this study uses the conceptual resources of cultural-historical activity theory (CHAT) (e.g. Engeström 1987; Engeström et al. 1999; Sannino et al. 2009; also Leont’ev 1978) to find potential mediating instruments between S-D logic and practice-based views whereas Mele and Russo-Spena (2019, forthcoming) have focused on creating connections at the abstract conceptual level. In contrast, this study has both theoretical and empirical interest and will be published soon (Alhashimi, Kajamaa and Toivonen, forthcoming).

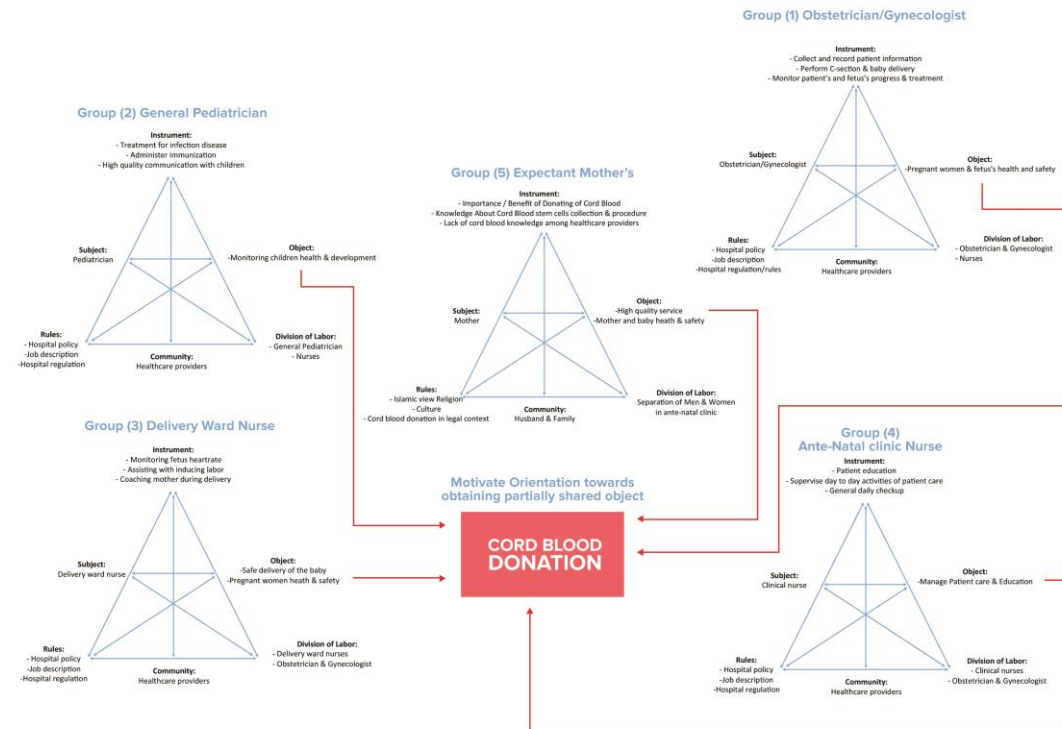
An activity system was drawn for all concerned actors within the donor recruitment process to identify the complexity of the value co-creation process and reveal an essential point from the point of view of *how* to co-create value between the different actors within the activity (see Figure 6-13). Activity theory was used as a tool to expand S-D logic by focusing on the theoretical concept of *the object* which represents the motive and actions that help in directing the activities towards a shared goal (cord blood donation) within the system. This is essential



for the development of customer-centred service processes which, in this case, is the donor recruitment process as volunteer activities.

Figure 6-12 represents the integration of different elements of activity theory (highlighted in red) to expand S-D logic for practice development using the process of activity theory network and value co-creation. In the donor recruitment process, several actors with distinct *objects* are involved in the activity (see Figure 6-13). The first step was identifying the *object* of each single actor which will help in defining the goal of each one of them within the activity and thus help with orienting their motives to share the same object – which is cord blood donation (see Figure 6 -13). For the actors to be able to deliver the information about cord blood stem cells to expectant mothers, a new shard titled *tools/instrument* (*resource integration*) was added to gain more profound knowledge and awareness about cord blood stem cells. In this case the healthcare educator who acts as a mediator between expectant mothers and healthcare providers has the sufficient knowledge about cord blood to educate both expectant mothers and healthcare providers within the hospital. *Division of labour* is also an important element as it represents different responsibilities, tasks and authorities of each actor involved within the activity for the purpose of *service exchange*. In this case study, all actors have their own roles during their daily routine work. Nurses have their own role and responsibility in educating expectant mothers, which is different from the doctors' role, but in the end they all interact with each other (resource integration) as a team in one *community* that shares a similar interest and is surrounded with specific cultural and environmental boundaries (*institutional arrangement and context*). For example, the healthcare educator can provide all the information needed in detail about cord blood stem cells for expectant mothers while healthcare providers such as nurses and gynecologists within the clinic can reinforce the

message by handing them cord blood brochures and encouraging them to donate their newborns' UCB stem cells. Details about the expanded S-D logic are discussed in Chapter 7.



**Figure 6-13 Several Actors with Distinct Objects Are Involved in the Activity Where Identifying Their Goal within Each Activity System Will Help Orient Their Motives to Partially Share the Same Object (Cord Blood Donation)**

### **6.3 Implementation of the Expanded Co-creation Value Model in Hospital A: SDL and Activity Theory Approach**

The researcher was interested in implementing the expanded co-creation value model within the donor recruitment processes and integrating all the concerned actors (healthcare providers) along with a trained healthcare educator who will act as facilitator and resource integrator between expectant mothers and healthcare providers in Hospital A, as shown in Figure 6-10. However, the researcher faced challenging obstacles when deciding to implement the model due to the shortage in staff and the need to hire a healthcare educator to run this process which was impossible at that time due to the limited time and budget available. Thus, the researcher arranged to meet with the director of the nursing department in Hospital A and share with her the ideas of the new expanded model and the benefits that would be obtained from locating a healthcare educator in the antenatal clinic. The researcher asked the director of the nursing department about the possibility of sharing one nurse from the antenatal clinic to do this job for a period of at least six months. The Director of Nursing agreed and was excited to see the results that could be achieved as she believes that it is all for the benefit of the end user (patients).

The next challenge was to train the nurse from the antenatal clinic as she only had very basic knowledge about cord blood stem cells. The researcher decided to provide six training sessions for the nurse for a period of 2-3 weeks followed by a competency checklist to assure that she was competent to do the job. The training sessions included information about cord blood stem cells, different banking options, cord blood collection procedures and cord blood registration procedures. The implementation of the model started on 13 November 2016 and the process lasted until 31 December 2017. This was well over the six months originally

scheduled as the results obtained were very exciting. The healthcare educator (antenatal nurse) was located in the antenatal clinic from 8:00 am to 1:00 pm and the process work flow is shown in Figure 6-13. Expectant mothers were visiting the antenatal clinic for their regular appointment and would then be called by the nurse in the assessment room for a general checkup before seeing their doctor. The nurse in the assessment room gave the healthcare educator the cord blood education form attached with the mother's information. The healthcare educator then called the expectant mother for a one- to-one consultation session.

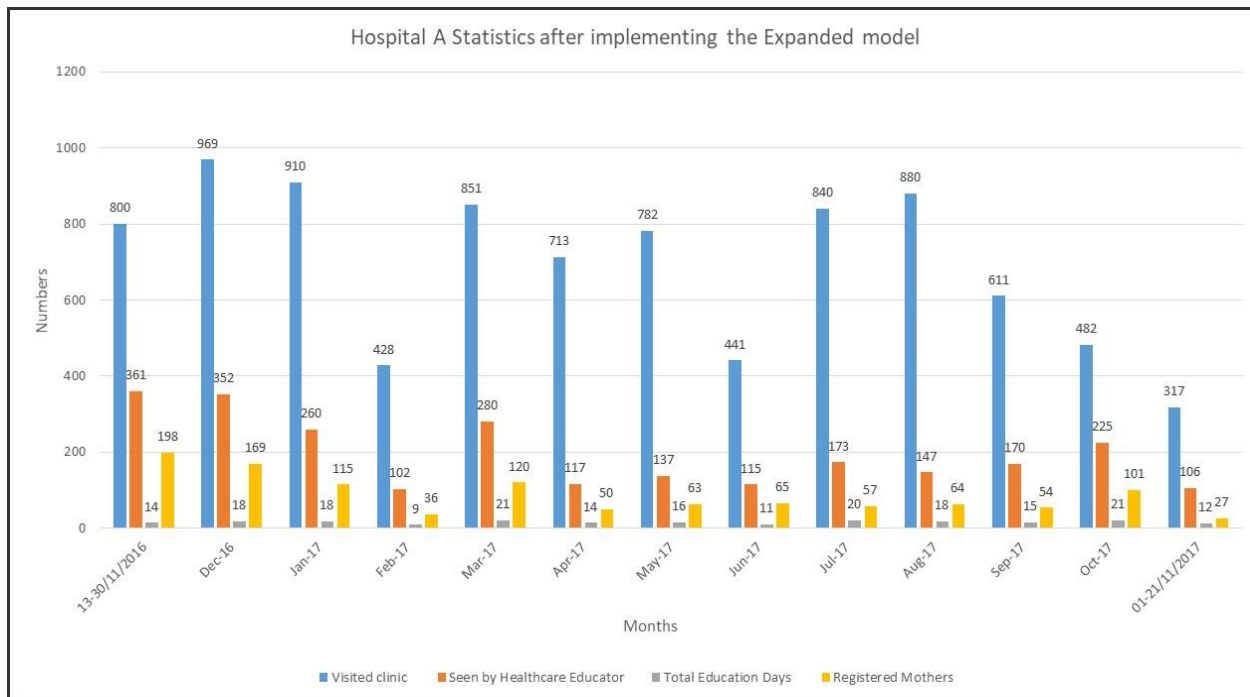
After the consultation session, some expectant mothers were convinced of the value of cord blood cell donation, and wanted to register and sign the consent form, accepting collection for their cord blood unit after the delivery. However, many of them said that they would like to think about it and ask their husband and their family before they took this decision.

The message about the importance of cord donation is reinforced during the expectant mother's visit to see her gynecologist doctor. Thus, most of the information is given to the expectant mothers during the antenatal clinic session so she has enough time to think about it and make informed decisions. For expectant mothers who did not get the chance to receive information about cord blood during the antenatal visit, nurses in the delivery ward talk to expectant mothers when they are not in pain and ask them if they are interested in donating their cord blood stem cells. Thus, information about cord blood stem cells was given at different stages during the pregnancy with the help of the healthcare educator and healthcare providers. This helps to co-create value between the different actors within the activity where all actors collaborate as resource integrators.

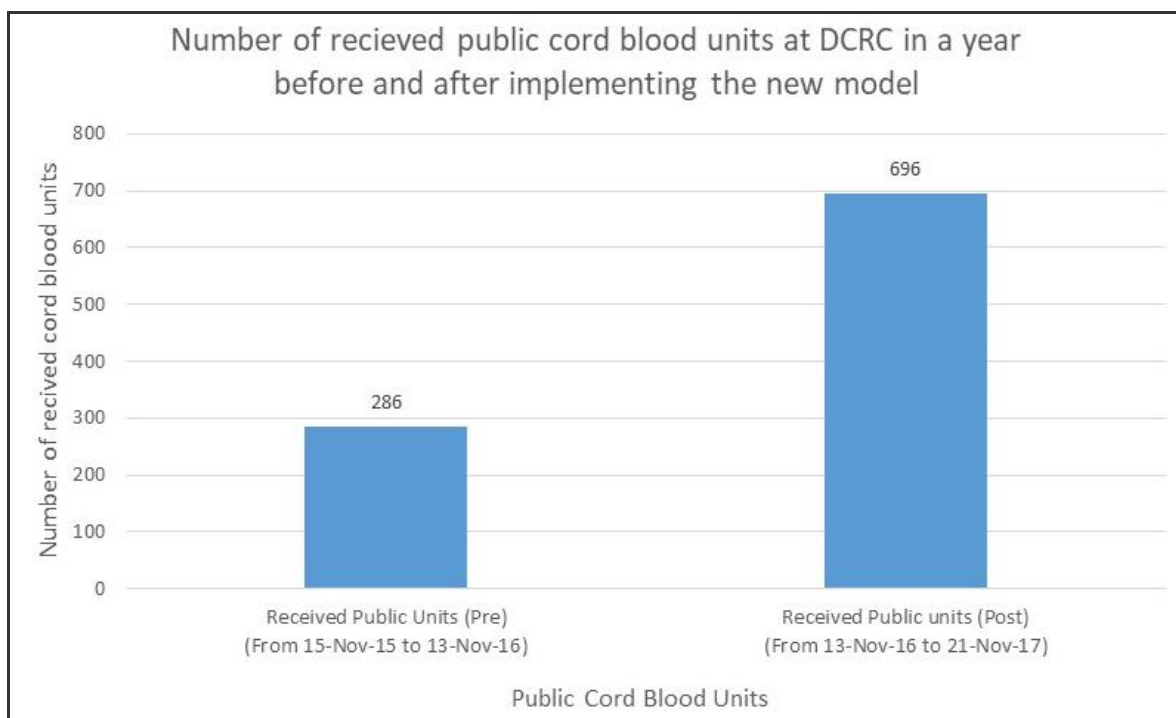
Figure 6-14 shows the results obtained one year from implementing the model these results include: number of expectant mothers who visited the clinic/month, number of education days (face-to-face consultation by healthcare provider), and number of expectant mothers registered for cord blood donation. Results showed that the number of expectant mothers visiting the clinic is high and a single healthcare educator will not be able to see them all as each face-to-face consultation takes about 20 minutes. For example, in the month of December, the healthcare educator managed to consult 352 expectant mothers in 18 days and was able to register 169 expectant mothers for cord blood donation, whereas in November 2017, the healthcare educator only managed to consult with patients for 12 days in a month. She was able to see 106 expectant mothers but only registered 27. Some expectant mothers expressed interest in donating their newborn's UCB stem cells but were not eligible for donation according to international standards and others did not decide immediately as they needed to ask their husband before they make these decisions. Thus, the more time that the healthcare educator spends in the clinic meeting the expectant mothers, the more successful she is in registering them on the cord blood programme.

Figure 6-15 represents the number of received cord blood units to DCRC before and after implementing the new model and recruiting a healthcare educator as resource integrator in the clinic. Before implementing the new model, staff from the cord blood centre visited the antenatal clinic (waiting area) to give lectures to the expectant mothers about cord blood stem cells, and after the lectures they asked the expectant mothers if they would like to register for cord blood donation public or private banking. Through this approach, they were spending around 2-3 hours at the clinic, three times a week. The change that the new model brought to the clinic is the fact that the researcher located a specific member of staff purely for cord

blood education and arranged a specific workflow process as seen in Figure 6-16. The expectant mother visits the clinic for her appointment, she receives a brochure about cord blood stem cells from the receptionist at the clinic and then she is called by the staff nurse to the assessment room for her general checkup before she sees her gynecologist doctor. The nurse in the assessment room will then pass the educational checklist form along with the mother's information to the healthcare educator, who will in turn call the mother for a face-to-face consultation. The healthcare educator will then provide the expectant mothers with all of the information needed and inform her about the two different options available in DCRC. The expectant mother is then called to see her doctor who will also reinforce the message and encourage her to donate her cord blood stem cells. At the delivery time, stage one, when the expectant mother is not in pain, delivery ward nurses reinforce the message once again and ask her if she still would like to donate her cord blood stem cells. This progressive layering of the provision of education at each stage of pregnancy assures that expectant mothers are aware and able to make fully informed decisions, which is one of the main lessons/practices learnt from the UK and USA case studies.

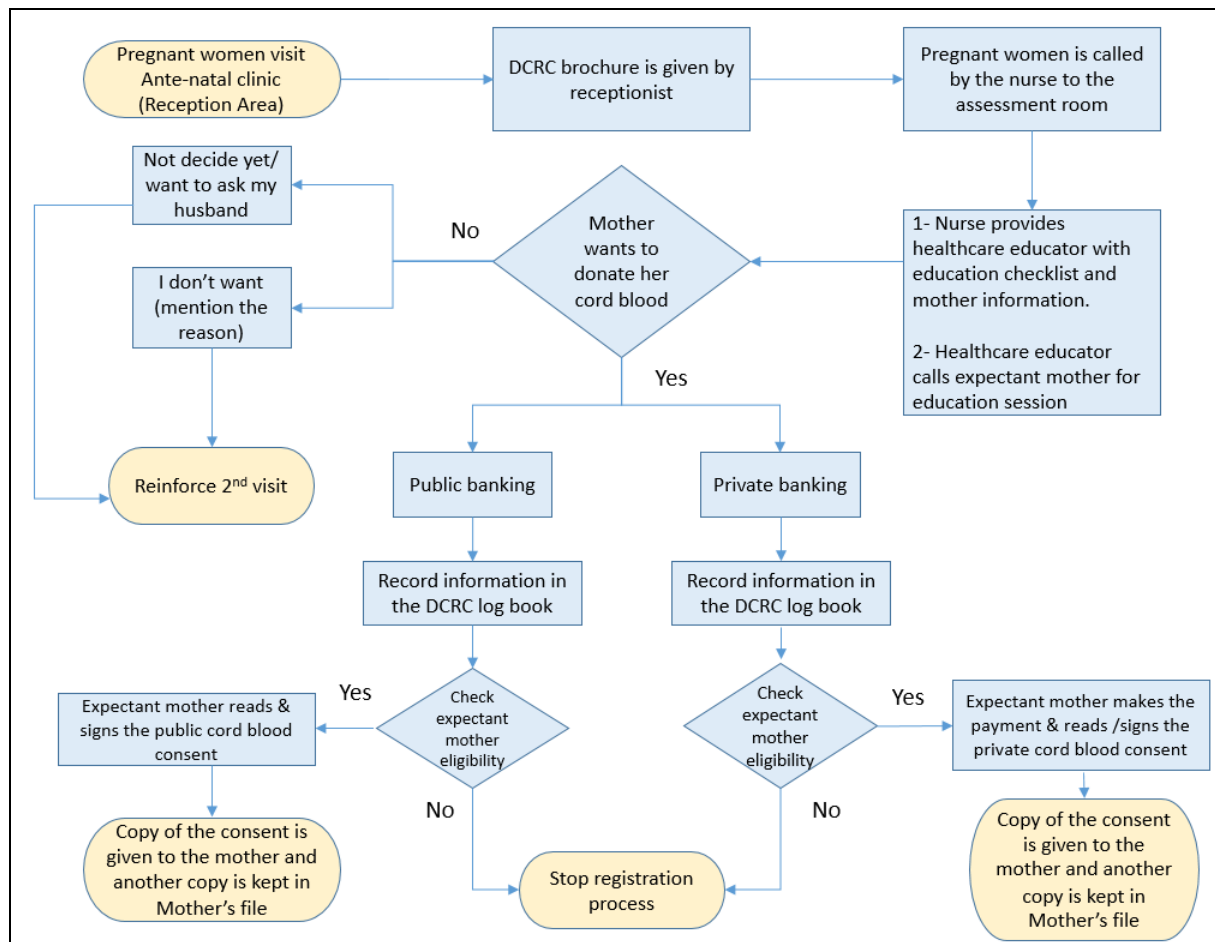


**Figure 6-14 Number of Expectant Mothers Visited the Antenatal Clinic and Educated by Healthcare Educator and Agreed to Register for Cord Blood Donation**



**Figure 6-15 Number of Received Cord Blood Units (Public) before and after Implementing the New Model**





**Figure 6-16 The Workflow of Donor Recruitment Processes in the Antenatal Clinic of Hospital A after the Implementation of the new Expanded Model**

## Conclusion to the chapter

Four common ingredients were identified in this study: these are the role of the beneficiary (user); actors as dynamic systems; importance of context as human institutions; and knowledge as an operant resource. All actors were identified within the process and the activity system was drawn for each single actor. Actors' roles, tasks and knowledge about cord blood were also identified within the process. The need for a healthcare educator was found to be particularly important within the process as she acts as a mediator/facilitator between expectant mothers and healthcare providers and is the main resource for knowledge

about cord blood while healthcare providers are used to reinforce the message and encourage expectant mothers to donate their cord blood stem cells. In this way, all actors can work together by integrating different resources to achieve the same object within the process – which in this case is cord blood donation. After implementing the expanded model, the result was a significant increase in cord blood donation when compared to before making the change, as the increase in received public cord blood units increased by more than two folds.

## **CHAPTER 7: DISCUSSION**

### **Introduction to the chapter**

In this chapter, the researcher discusses in detail the results obtained from this study in relation to the different points raised within the literature review. First, the researcher focuses on highlighting motivations, barriers and attitudes towards cord blood donation among expectant mothers in the UAE. In addition, she assesses the healthcare providers' knowledge and attitudes towards cord blood donation and their role in encouraging patients to donate their newborns' UCB stem cells. Four main themes obtained from this study are reviewed in this chapter including the new emerging theme. Moreover, the researcher also discusses the four common ingredients identified between activity theory and S-D logic which helped in creating a new expanded co-creation value model. The new expanded model was then implemented in Hospital A which led to a significant increase in public cord blood units in the DCRC.

### **7.1 Cord Blood Motivations, Barriers and Attitudes towards Cord Blood Donation among Expectant Mothers and Healthcare Providers in the UAE.**

Table 7-1 shows the four main driving themes obtained from a range of literature in comparison with themes achieved from this study. The four themes include motivations and barriers towards cord blood donation.

**Table 7-1 Comparison of themes in the literature with this study on cord blood donation motivations and barriers**

<b>Themes in the Literature</b>	<b>Findings from this study</b>
Barriers and Motivations toward cord blood donation	Barriers and Motivations toward cord blood donation among expectant mothers
<b>Barrier (1):</b> Lack of knowledge about the importance of cord blood donation among pregnant women and healthcare professionals	<b>Barrier (1):</b> Lack of information about the importance of publicly donating umbilical cord blood among expectant mothers and healthcare providers
<b>Barrier (2):</b> Concerns regarding improper use of stem cells	<b>Barrier (2):</b> Fear of any risks to the mother or the baby during cord blood collection
<b>Motivator (1):</b> Receiving knowledge about cord blood donation from their obstetricians and midwives	<b>Motivator (1):</b> It is a humanitarian and noble act
<b>Motivator (2):</b> Being part of humane action by helping patients in need of cord blood transplant	<b>Motivator (2):</b> Knowing it helps in treating other patients with life-threatening Disease

### **7.1.1 Theme (1): Lack of Knowledge about the Importance of Donating Umbilical Cord Blood Stem Cells among Expectant Mothers and Healthcare Providers**

- Expectant Mothers in Hospitals A and B**

Parents' decisions to either donate or privately store their newborn's UCB stem cells is mainly personal (Herlihy and Delpapa 2013). Most of the expectant mothers do not know which option is best for them; thus, it is important to inform them the benefits of each option so they can make an informed decision. However, Peberdy, Young and Kearney (2016) showed that their decisions are mainly influenced by the people who take care of them during the antenatal period. During prenatal care, healthcare providers regularly counsel and discuss with patients about a wide range of different topics such as genetic testing, weight gain, proper nutrition and methods of delivery. Cord blood donation and the different banking

options are appropriate topics to include along with routinely discussed topics before the delivery. This will allow more involvement of healthcare providers including obstetricians, hence a greater number of patients being educated (Herlihy and Delpapa 2013).

The researcher was interested to conduct this study in two main hospitals in Dubai to explore the motivations and barriers and attitudes towards cord blood donation among expectant mothers in the UAE. The survey was distributed to expectant mothers in antenatal clinic during their waiting time before they see their physicians. Participants were from different nationalities; however the majority of them were from the UAE. Expectant mothers were asked about the reasons that might prevent them from publicly donating their cord blood stem cells and the first reason (32%) was due to a lack of information about the importance of publicly donating their newborns' UCB stem cell. Despite the fact that 65% said they do have information about the importance of umbilical cord blood stem cells they still did not donate their newborns' UCB stem cells. This lack of participation might be because the information they have is not enough for them to make an informed decision about which banking option is best for them. Moreover, a similar study was conducted in European countries to analyse pregnant women's awareness and attitudes towards cord blood stem cells and cord blood banking. More than 79.4% of pregnant women have poor knowledge of the different cord blood banking options and would like to receive more information about this topic (Katz et al. 2010). However, a study conducted in the city of Zagreb, Croatia showed that pregnant women were well aware about different cord blood banking options, but they have insufficient knowledge about the practical information and therapeutic use of cord blood banking in future (Buković et al. 2000). In comparison, the results obtained from this participant observation study conducted among expectant mothers in the UAE showed that

expectant mothers' knowledge about cord blood is very basic as they lack information about the benefits of each cord blood banking option, cord blood collection procedures, and different diseases that can be treated using cord blood stem cells. A study conducted among pregnant Australian women showed some similar findings; that parents require sufficient and accurate information and they would like to be informed of the advantages and disadvantages of each of the banking options so they can make an informed decision (Jordens et al. 2014). Moreover, Armson (2005) highlighted that education about cord blood should be passed to pregnant Canadian women before storing or donating their newborns' UCB stem cells and it should be conducted within ethical, legal and professional parameters. In addition, Kharaboyan et al. (2007) found that it is important to have adequate and complete information from obstetrical care providers to make informed decisions.

During the survey, expectant mothers were also asked about the reasons that prevent them from privately storing their newborn's UCB stem cells and the first three reasons were in order as follows: 222 (31%) of expectant mothers said because they would prefer to donate them to help other patients, 167 expectant mothers (23%) said because they lack information about the importance of cord blood stem cells, and 127 (18%) of expectant mothers said it was due to the fact that there is no family history of any life-threatening diseases. These results reveal the willingness of majority of expectant mothers to donate their cord blood stem cells to help others in need as they consider it a noble act to help patients within the community. Moreover, expectant mothers were also asked about the reasons that encourage them to privately store their newborn's UCB stem cells and 63% of expectant mothers said it is a means of assurance for the newborn's health in case they need to use it in the future to treat some diseases. Thus, many of them store their newborns' UCB stem cells just in case

someone in the family might develop diseases in future and might need to use the preserved cord blood units. There is a growing volume of marketing content through internet sites and magazine advertisements encouraging expectant mothers to privately store their newborn's UCB stem cells by highlighting the phrase "it is a once-in-a-lifetime" chance that can save your child if ever needed. This elicits a promise from cord blood private banking that has a negative influence on the expectant mothers to donate their newborns' UCB stem cells for altruistic purposes, therefore creating confusion over which banking option to select (Kharaboyan 2007).

Moreover, during the survey, expectant mothers were also asked about their opinion regarding the best sources from which to receive information about cord blood stem cells. Results showed that 276 of expectant mothers (27.09%) would like to receive information about cord blood stem cells from their gynecologist doctors and 142 (13.9%) of expectant mothers would like to receive information about cord blood from DCRC healthcare educators. However, the majority of expectant mothers –372 (36.5%) – prefer to receive information about cord blood from all of the different sources and their overall preference for each source is shown in the following sequence: gynecologists (27.09%), healthcare educators from the DCRC (13.94%), DCRC brochures (7.56%), awareness campaigns (5.79%), social media network (5.2%), hematologist (1.96%), nurses (1.37%), and pediatricians (0.29%). Therefore, besides the fact that they would like to receive information about cord blood from all the different sources, during participant observation study they also highlighted that gynecologists are the best source to receive information about cord blood. Moreover, when healthcare providers were asked about their opinion regarding the best sources to provide information about cord blood to their patients, 69% also believed that all the sources are important but healthcare educators

from the DCRC, awareness campaigns and brochures are the top three sources selected by healthcare providers.

Conversely, physicians and nurses were the two least selected sources by most of the healthcare providers who responded to the survey. These contradictions between the expectant mother activity system and healthcare provider raised tensions between the two activity systems which in turn led to transformation and change (Engeström 2015). Due to the fact that healthcare providers only have basic knowledge about cord blood and do not feel confident to share detailed information with expectant mothers, and also because sharing knowledge about cord blood with expectant mothers is often not their first priority, a new activity system emerged, the “healthcare educator” (see Figure 6-9) . Healthcare Educator acts as a facilitator and resource integrator between the two activity systems ‘expectant mother’ and ‘healthcare provider’. In the survey, the healthcare educator from the DCRC is one of the top three preferred sources of information among both expectant mothers and healthcare providers. Despite the fact that obstetricians/gynecologists are considered the best source of information to expectant mothers, expectant mothers still prefer to receive information about cord blood from all of the different sources; this indicates the importance of integrating all the various resources for the sake of the beneficiary which in this case is the patients (users).

Results from different studies showed that most expectant mothers seek to receive information about cord blood and the different banking options from their antenatal care providers (Smith and Thomson 2000; Schuman 2007). Thus, antenatal care providers can play important roles in assisting expectant mothers with their decisions by providing accurate, balanced and evidence-based information about cord blood and the available banking options (Kharaboyan et al. 2007; Martin, Kutzberg and Hesse 2011; Cooper and Severson 2013;



Herlihy and Delpapa 2013). In some countries, it is recommended or required that healthcare providers convey information about cord blood to expectant parents which acknowledges their important role in helping expectant patients with making their decisions (Dinc and Şahin 2009). Moreover, the survey results showed that 340 expectant mothers (33%) think that the best time to receive information about cord blood stem cells is during antenatal clinics, whereas 325 expectant mothers (31.8%) think that information about cord blood stem cells should be communicated to expectant mothers at all different stages, and 19% of expectant mothers believe that information should be provided to expectant mothers even before pregnancy.

The researcher learnt many lessons from visiting both USA and UK cord blood banks and observing the donor recruitment processes in hospitals. One of the key learning lessons from both banks is the need for independent resources in the hospital. Ms. Jesmina James, section head of CBB collection sites, highlighted that the key selling point for initiating third-party agreement in the hospital is to have your own staff doing the work at the hospital without the need to add more pressure on the physicians and nurses. She said:

*One of our important selling points is that we have our own staff who would go in and do collection and consents so we are not putting additional work on them and because all our staff are trained – phlebotomists- so in case they might want blood gases or even have samples taken from the mothers all our staff can help out in that process.*

She also added another important point:

*We have about six collectors per each hospital working 24 hours seven days a week with one or two nurses per shift in each hospital. Most of the collectors' time is in the delivery ward and they are seeing expectant mothers during antenatal classes and during scanning appointment. During the 20 weeks scan they receive scanning letter along with cord blood information.*

However, currently in Hospitals A and B in UAE, healthcare educators from the DCRC are only visiting the clinic for a few hours during the day to conduct educational sessions about cord blood stem cells and register expectant mothers for private/public cord blood banking, if requested. The full registration procedure including obtaining informed consent is completed in the antenatal clinic. According to the Foundation for the Accreditation of Cellular Therapy (FACT 2013), consent should be obtained prior to or within seven days after delivery of the infant subject to the following two conditions: firstly, consent should not be obtained when an expectant mother is in pain (active labour) and secondly when cord blood is collected *in utero*. These two conditions are upheld in Hospitals A and B, whereby consent for cord blood collection is obtained in antenatal clinics before the collection procedure and the newborns' UCB stem cells is collected *in utero*. Obtaining consent from expectant mother should be in early labour before the expectant mother goes through active labour pain. However, there are no specific guidelines stating at what point before labour the consent should be obtained (FACT 2013). In the DCRC and the UK the consent for cord blood collection is taken during prenatal care while in the USA consent is only taken before the delivery at an early stage. Thus, policies for cord blood consent differ depending on the accreditation body guidelines and whether it is *in utero* or *ex utero* (Vawter et al. 2002).

### **7.1.2 Healthcare Providers in Hospitals A and B**

Four main groups of healthcare providers were interviewed in this study – gynecologists, pediatricians, delivery ward nurses, and antenatal nurses. The interview results show that healthcare providers from both Hospitals A and B had a basic knowledge about cord blood stem cells and the different banking options. Antenatal and delivery ward nurses were the most knowledgeable groups when compared to gynecologists and pediatricians.

Most of the healthcare providers were aware about the availability of the private banking option but many of them were not aware about the presence of the public cord blood bank in the DCRC. Despite the fact that many healthcare providers encourage their patients to opt for public cord blood donation, they were however not sufficiently aware about the importance of cord blood stem cell registry and why it is needed in the country. This explains the fact that they do not know what happens next after expectant mothers donate their newborn's UCB stem cells, as they are only aware that these donations can help in treating many patients with life-threatening diseases. Thus, healthcare providers require clear information about cord blood donation and the benefits of different banking options as well as information about the cord blood registration procedure, collection, and storage .It is also essential that they are aware about the importance of cord blood stem cell registry, donor selection and transplantation procedures so they are able to answer expectant mothers' concerns and questions. Results obtained from this study for each of the groups of healthcare provider are discussed in more detail below:

- **Group (1): Obstetricians/Gynecologists**

All of the obstetricians and gynecologist doctors interviewed in UAE believed that cord stem cell has several advantages and is considered an alternative source of bone marrow in that it can treat common life-threatening diseases such as thalassemia, leukemia and sickle cell anemia. However, some of them were not aware about public cord blood banking and the majority of them were not aware about the important role of cord blood donation in expanding the public donor registry. Obstetricians and other healthcare providers delivering obstetric and prenatal play important role in increasing awareness about cord blood donation and they should be active participants in expanding public bank activities (Herlihy and

Delpapa 2013). However, their information about cord blood and understanding of cord blood collection, storage and transportation is insufficient to share with expectant mothers (Roh et al. 2014). Obstetricians and gynecologist in UAE were aware that cord blood stem cells can treat common diseases such as leukemia, thalassemia and sickle cell anemia and some of them believed that it can nowadays treat the future promising diseases such as diabetes, cerebral palsy and spinal injuries. Overall, they were confused to some extent between the current treatable diseases and the future promising interventions. A study by Hatzistilli et al (2014) showed that healthcare professionals lack basic information about umbilical cord blood and transplantation and most of their knowledge gained about cord blood is from sources such as private banks, TV advertisements and magazines. However, Jawdat et al. (2018) revealed that in Saudi Arabia the majority of expectant mothers were mostly informed about cord blood stem cells and different banking options from social media and only 10 % were informed and educated by the medical staff. There is thus the danger that a great deal of misinformation is collected from these sources, not just accurate information. Therefore, healthcare providers need to have clear detailed and adequate information about different aspects of cord blood stem cells including treated diseases, cord blood registration and collection procedures, importance of stem cell registry. In addition, the benefits of each cord blood banking option so they can discuss information about cord blood with their patients and help them to make informed decisions. Currently, not all healthcare providers feel confident enough to discuss information cord blood with their patients. A study conducted by Walker et al. (2012) highlighted that half of obstetricians feel that their knowledge is not sufficient to answer patients' questions and concerns about umbilical cord blood donation, thus it is

important to promote obstetricians' knowledge and awareness about cord blood collection and usage.

During the interviews, one of the doctors highlighted her knowledge level about cord blood and said: *"My information about stem cells are very less in this field but I know it can be used later to cure so many diseases"*.

Another doctor also said: *"Stem cells is the blood we are collecting from the cord after the delivery and we know that it is very useful in treating many diseases especially blood disease and some cancers and bone marrow disease"*.

While another doctor also highlighted that they did not discuss with their patients about cord blood and the different banking options at all. She said: *"Cord blood is the blood from the umbilical of the baby and I do not know about the two banking options, we do not discuss this at all with the patients"*. Many of the gynecologists were not sufficiently aware about the two different banking options provided by the DCRC and the researcher had to explain it to them during the interview. Therefore, most of the doctors think that information about cord blood stem cells should be communicated by people who are specialised in the field of cord blood and they believe that they are not responsible for providing detailed knowledge about cord blood to expectant mothers. Rather, they think that they can only play a role in reinforcing the message about the importance of cord blood donation and encourage expectant mothers to donate their newborn's UCB stem cells. However, others believed that it is the responsibility of gynecologists and nurses because they have direct contact with expectant mothers during their pregnancy. First, though, they need to be trained and educated about cord blood so they can pass relevant information on to the expectant mothers. Another group of gynecologists

suggested that awareness raising should start with the media marketing department while many others think it is everyone's responsibility and all healthcare providers should participate in educating expectant mothers during pregnancy.

The CEO of the hospital who is also a gynecologist doctor said: *"I think its obstetricians and pediatricians play a big role also and to be honest with you I think it should be all but maybe mostly and directly related OBG and pediatricians"*. However, another doctor thinks it should start from DCRC; she said, *"I think it should start from DCRC educator and at the same time it can be reinforced by the doctors so you can locate educational leaflet in doctors' rooms and in the antenatal clinic"*, while another doctor highlighted the same point: *"I think cord blood banks are responsible or somebody specialised in blood diseases who knows how it will benefit patients in the future, I think Gynae are busy - maybe the midwives and nurses are better because they are with the patients all the time"*. On the other hand, another doctor believes that cord blood education should be promoted by all the staff and everywhere: *"Most important is doctors but we can work in a team and encourage the staff also and we can have leaflets and education in antenatal clinics, labour room and we can promote this everywhere"*.

Most of the doctors in UAE believed that the best method to increase cord blood donation is by increasing awareness and education among expectant mothers and healthcare providers. They specifically highlighted some important methods such as individual counselling in antenatal clinics, education at an early stage even before they become pregnant, media marketing, and the important role of the doctors in informing their patients. They all strongly believe that guidelines about cord blood education will support and guide them about how they disseminate cord blood information. However, they believe that training and education

sessions about cord blood should be provided first for all the healthcare providers in hospitals to enhance their knowledge about cord blood. One of the doctors said: *“Yes if you are really planning to start with the healthcare providers then maybe you need first to give them lectures on the benefit of cord blood and how to answer frequently asked questions and some technical aspects. If you are planning to keep leaflets do update them systematically on a daily basis”*. Another doctor also mentioned the need for educating healthcare providers, so they can counsel their patients. She said: *“It will be much easier to have guidelines, doctors should be educated first so they can counsel their patients. We as doctors still have so many questions about cord blood and we cannot raise this issue with the patient until we are confident about it”*. One of the consultant gynecologists thinks that cord blood education should be delivered in the same way as breastfeeding education is provided in hospitals. She said:

*I think it will become practice when we start it when we started breastfeeding practice. Everybody in the hospital got 20 hours teaching so they started educating the staff first before starting educating others. So maybe we should have something like this CME 20 hours which is compulsory. Every Wednesday also we have dedicated time where gynecologists meet for about 30 minutes so I think if you talk about cord blood at this meeting you will catch groups of doctors and many will be aware. We also have delivery suite form which you can approach. Every month we have meetings to discuss different issues.*

Hatzistilli et al. (2014) argued that even medical and paramedical professionals should be considered potential donors that require appropriate education about cord blood stem cells from the early stages of studying for their profession starting from schools and universities and by including information about cord blood stem cells within their courses' syllabi and programmes. These improvements will lead to change in the knowledge and attitudes of employees towards cord blood donation and transplantation, as they will understand the

importance of donation in expanding public bank registries and, in turn, will motivate and educate the new generation about the importance of public cord blood donation.

Most of the healthcare providers responding to the survey rated their knowledge about cord blood stem cells from 'very good' to 'good'. However, during the interviews the researcher noted that their knowledge about cord blood is basic and they are missing many essential pieces of information. The survey results obtained from different groups of healthcare providers showed that 60% said that they would like to receive information about umbilical cord blood stem cells from all of the different sources, and their overall preference for each source is shown in the following sequence: 20.7% Continuous Medical Education (CME) lectures, 16% educational courses, 11.4% awareness campaigns, 9.8% conferences, 8.8% social media, and 5% emails. Moreover, they were also asked during the survey about their opinion regarding sharing information about cord blood stem cells with their patients and over half of them, 58%, strongly agreed that information about umbilical cord blood should be shared with the expectant mothers. For the percentage of healthcare providers who disagreed, the reason is that they feel that they do not have enough information about cord blood to share with their patients. Bhandari et al. (2017) highlighted in his study that most of pregnant women would like to receive information about cord blood stem cell from their healthcare providers. However healthcare providers claim that due to time constraints it is difficult to discuss all the required information about cord blood with pregnant women.

In UAE case study, most of the healthcare providers would like to encourage their patients to opt for public banking as 70% of them believe that all the reasons mentioned in the survey are important. They would like to encourage their patients to opt for public banking due to the following reasons in the subsequent sequence: 15% of them indicate that it can treat many



patients with life-threatening diseases, 8% state that it is a humanitarian and noble act, 3% selected because it is free of cost, and only 2% chose because it can lead to increase number of donors within stem cell registry. A lack of knowledge about cord blood donation acts as a barrier to many efforts that aim to expand the public donors' pool within the international cord blood inventory (Dunbar and Szczepiorkowski 2011). These results strongly indicate that many of the healthcare providers are not aware about the importance of stem cells registries as many patients with life-threatening diseases are looking for matched donors within a stem cell registry. Increasing the number of donors within the public registry will play a vital role in finding matched donors for many patients in need of transplantation. The possibility of finding at least one matched HLA-donor for a specific population is considered a key parameter in planning for a donor registry (Hwang et al. 2007). Expansion of the cord blood pool is achieved through patient education, counselling and recruitment about the different available banking options for storing newborn's UCB stem cells (Herlihy and Delpapa 2013).

Gynecologists were also asked their opinions about who they think is responsible for passing on information about cord blood to expectant mothers. Most of them think that all healthcare providers along with DCRC staff and media marketing are responsible for informing expectant mothers about cord blood. However, they believed that the most important group is the physicians who have direct contact with expectant mothers during the antenatal clinics. However, despite this viewpoint, they also believe that it is everyone's responsibility; one of the gynecologist doctors highlighted an important point when he said:

*It is everybody's responsibility, but being obstetrician that is not my first priority to explain it for her having so many other issues with pregnancy. So I think having an educator in the clinic to inform the patients and if the patients have any doubts it can be explained as the topic takes time to explain, so giving the full responsibility for the*

*obstetrician to explain it will not work. It should be a special educator there in each obstetric clinic and patients should be given opportunity to ask.*

Another doctor also believed that having a cord blood educator who works in the same way as breastfeeding educator within the clinic will add a lot of value; she said:

*I think there should be a dedicated person in the clinic because when we see the patient we do not have much time to talk about this thing, so I think a special person should be sitting in the clinic to educate and encourage the usage of cord blood, like how we have for breastfeeding.*

Hatzistilli et al. (2014) conducted a study in Greece to examine level of knowledge among healthcare providers towards cord blood donation. Results showed that majority of healthcare providers (93.5%) lack information about cord blood and they are mainly unaware about UCB's collection, storage and transplantation. In addition, due to lack of knowledge healthcare providers don't feel confident enough to convey information about cord blood stem cells to expectant mothers. Thus he emphasised in his study the need to acquire experts in the field of cord blood who are able to provide correct and complete information about UCB stem cells and the advantages/disadvantages of each banking option.

Most the results obtained from healthcare providers in the UAE showed that a cord blood centre needs to provide independent resources such as a healthcare educator who is well trained and has detailed knowledge about cord blood stem cells to share with expectant mothers. Then, healthcare providers such as gynecologists, nurses in antenatal clinics and delivery wards and pediatricians all have important roles by reinforcing the message and encouraging cord blood donation which can be done through giving them brochures or reminding them to either store or donate their newborn's UCB stem cells instead of disposing them in the trash. In S-D logic, customers are seen as active actors and the firm can only create value if it is collaboratively co-created with the beneficiary (Vargo and Lusch 2016).

Moreover, in S-D logic, the role of beneficiary is not an optional or normative one; rather the beneficiary should be included since beneficiaries play a key role in value co-creation. Value co-creation does not occur from the activities of one single actor; actors are carefully analysed as soon as the resources are made available to them (Vargo and Lusch 2011). One particular resource-specific source is moderated by the presence of other resources from different sources thus leading to resource utilisation and integration by the beneficiary (Lusch and Vargo 2010).

- **Group 2: General Pediatrician**

This group of healthcare providers was the group with least knowledge about cord blood stem cells and this may be because they do not have direct contact on a daily basis with expectant mothers during their pregnancy. However, they play an important role in cord blood education as they can encourage expectant mothers to store their newborn's UCB stem cells if they have a sick child within the family. Many of them were not aware about the existence of the public banking option within the DCRC; they only had basic information and sometimes misinformation about stem cells and disease treated. Current American Academy of Pediatrics (AAP) guidance encourages physicians to learn about the importance of umbilical cord blood banking and to be familiar with the availability of two types of cord blood banking option (private and public). Cord blood education should not be the responsibility of only obstetricians but also other physicians such as general pediatricians who also see expectant parents. Therefore, it is important to identify their role within cord blood education (Armstrong et al. 2018).

One of the pediatricians said: *“Cord blood, maybe they are taking it from the placenta and I think they collected it from the placenta not the cord. No, I do not know that DCRC has two*

*different banking options, I know about the centre but not the services that are provided”.*

Another senior specialist registrar highlighted that he did not know about the two different banking options and was not aware exactly about the cord blood collection procedure: *“Cord blood from cord at the time of the delivery after the delivery of the baby but I do not know if it is before the placenta is out or after. I came to know about it when I was answering the survey you gave us”.*

Almost all of the pediatricians in the study believe that expectant mothers do not donate their newborn’s UCB stem cell because they lack knowledge and information about the different banking options, the collection procedure, and the beneficial use of stem cells. They strongly believe that expectant mothers need education and awareness on the topic. One of the specialist pediatricians said: *“Because they are not aware about the procedure and its safety, they need to be educated more about it, it is exactly same as blood donation, it needs education”.* Another pediatrician doctor who is working in the hospital and was herself pregnant highlighted her point of view, saying, *“Because I think people they do not know about it, I’m pregnant myself and I did not know about it now since I know I want to know more to decide if I want to donate it. If it is free of cost I do not think people will refuse plus it is not painful and will not harm anybody if they collect blood”.* One of the doctors however highlighted a different perspective; he believed that some expectant mothers do not donate their newborn’s UCB stem cell due to culture and religious issues: *“Because some of them feel they do not want part of them to go to others, they do not feel happy about it - I feel this is most likely. And also misunderstanding as they do not have education about it and maybe they think it is not allowed to give the blood in religion”.* All of them agreed that all expectant mothers have the right to know about the potential benefits of cord blood stem cells so they

can either store it to use it later for their family or donate it to help patients within the community.

Most pediatricians believe that gynecologists are mainly responsible to pass on information about cord blood stem cells to expectant mothers as they see them on a daily basis and have direct contact with them. Herlihy and Delpapa (2013) revealed that the current focus on delivering information about cord blood banking options is on obstetricians as they are the group responsible for cord blood collection during the delivery; however, pediatricians demonstrated a critical lack of knowledge about cord blood banking. This important problem can be alleviated by providing educational sessions about cord blood for pediatricians.

Other pediatricians believed that primary and family physicians as well as physicians from the cord blood centre are mainly responsible to educate expectant mothers. One of the doctors highlighted an important point that when she was pregnant and during her visit to the antenatal clinic in Hospital B, no one had talked to her about cord blood stem cells:

*I think mainly gynecologists are responsible, they see pregnant women in antenatal clinics during the check up and me I'm pregnant now and when I go for antenatal checkup nobody told me about cord blood and we are not educated about it. No one mentioned it in the clinic or told us about the two banking options because if it is free why do I not donate it? We have breastfeeding - it is compulsory. Whenever you go to antenatal clinic you have to attend.*

Another doctor strongly believes that it is a multiple responsibility that should start from schools and universities. He said: *"I think there are multiple responsibilities; you need to communicate with the community at different levels starting from schools; after school in universities, media, and healthcare providers also has multiple responsibilities".*

Most of the pediatricians were not aware about the cord blood stem cell registry and the importance of having one in the UAE. They commented that it will be good for the country and can help many patients. One of the senior specialist registrars said: *“It is MUST but first, we need to know about how it can help patients because we do not know about it”*. Another highlighted some other points: *“Yes, sure stem cell registry is useful as we have so many patients here with Thalassemia which can be treated but I’m not very aware about the stem cell registry not much information”*.

- **Groups 3 and 4: Delivery Ward and Antenatal Nurses**

These two groups were the most knowledgeable groups in relation to possessing information about cord blood stem cells and different banking options. They were also aware about the benefits of each of the banking options. However, their knowledge about different diseases treated and the importance of the stem cell registry were limited. Delivery ward nurses were fully aware about cord blood collection procedures as they are the ones who collect cord blood stem cells after the delivery of the newborn. They are considered the backbone of the DCRC as they are required to collect good-quality cord blood units with good volume and free from contamination. Therefore, the DCRC is providing monthly training workshops for both antenatal and delivery ward nurses about the importance of cord blood stem cells and the actual collection procedures for cord blood. Following the workshop session many questions and concerns are addresses.

Salvaterra et al. (2010) showed that midwives offer their support towards cord blood donation as they find it to be associated with social and moral aspects. However, they did not show support towards private cord blood banking as they consider it to be a comparatively useless and selfish act. In this study, most of the antenatal and delivery ward nurses were in favour of

public cord blood banking and they would like to encourage expectant mothers to opt for it as they believe that it can help many patients in need of cord blood transplant. However, they added that they would like to encourage private banking if the family has a known medical condition and need to store their newborn's UCB stem cells.

One of the antenatal nurses said, *"I encourage public banking because if we secure for ourselves maybe we will use it and maybe not but when we give to public banking when it is needed it can be used"*, while another nurse would like to encourage it because it is free of cost; she said: *"I'm aware about the two banking options, and I would like to encourage public banking because you do not need to think about payment"*. Delivery ward nurses also encourage public donation as it can help others and it is free for charge. However, one of the nurses said that she would like to encourage private banking if they have a medical condition and they might use it: *"I will encourage public banking because everyone can use it. If a family member is sick they can go for private banking"*. Also, the same point was raised by another nurse who highlighted that everyone should donate if they are eligible for donation:

*If you ask me I will advise private banking if they have chronic disease in their family but on the other hand I believe everyone can donate their cord blood if they are fit because as donors they can help many people. I believe everyone should donate it why not.*

Both antenatal and delivery ward nurses have direct contact with expectant mothers during their pregnancy. Antenatal nurses are the ones who see expectant mothers more frequently during their clinic visits. Both antenatal and delivery ward nurses would like to encourage their patients to opt for public banking; however they would advise them to store their newborn's UCB stem cell cord blood stem cells if the family suffer from diseases and is in need of a cord blood unit. Both were asked their opinions about the reasons that prevent

expectant mothers from donating their cord blood stem cells. Almost all of them agreed that lack of knowledge and awareness are the main reasons and they believe that if expectant mothers are well educated about cord blood stem cells they will definitely donate their newborn's UCB stem cells because it is safe and free of charge. One of the antenatal nurses said:

*Because they do not know about the importance of stem cells, and if we educate the mothers they will agree, we are giving the mothers an outline of cord blood but if they are interested we are referring them to the DCRC and they will give you the proper information.*

Another nurse from the ante-antenatal clinic highlighted a similar point and added that culture might also be one of the reasons:

*I think in the UAE, their culture, and they need more information about it because they do not know, they think it is only used for family members. We need to educate them during antenatal visits - send somebody and just educate them. When they get the education and knowledge about stem cells they will donate.*

Moreover, one of the delivery ward nurses showed that lack of knowledge and culture are the main two reasons that prevent expectant mothers from donating their cord blood stem cells:

*It is new innovation and many people have not got the awareness; there is no adequate awareness of this cord blood stem cells collection or donation because some of them have not been really educated during the antenatal period and also the culture of different areas affects this collection and public donation. Because they are lacking knowledge this is the main reason, no adequate awareness from the grass roots from the catchment areas, so they need to be educated. Because some of them do not come direct to this hospital when they are pregnant, they go to Public Health Clinic (PHC) and then from there they come to us, so culture and lack of knowledge is affecting a lot the willingness to donate cord blood.*

Another delivery ward nurse highlighted important points about expectant mothers' beliefs:



*Maybe because of their beliefs they do not want to give or because they do not know what is happening and what we are doing with this blood and what is important about this blood, and some of them do not have interest to give their own cells to other people.*

Another nurse also added an interesting point about people's ideas and beliefs, saying:

*Because of lack of education definitely and lack of awareness because some people believe that the placenta is part of the baby so it should not be used for others; some beliefs are also there, really people need good education, they have deficient knowledge.*

All of the nurses from the delivery ward and antenatal clinic strongly believe that it is a mother's right to receive information about cord blood stem cells. One of the nurses from the delivery ward believes that hiding such information from expectant mothers is considered a crime. She said:

*Absolutely it is very important because hiding this information from them or keeping it away from them is a crime because we give them a chance to help others and themselves if they have issues in their families. It is very very important to inform everybody about it and we need to work very hard in this direction.*

Another nurse from the delivery ward said that education about cord blood and stem cells should start from schools and universities, and it is too late to start informing them during their hospital visits because every human should receive information about stem cells, not just expectant mothers. She added:

*Every human been right from school age and onwards have the right to know what is stem cells if we emphasis about the importance of stem cells and the importance of collection from these ages by the time they reach age where they are able to give birth they will adequately be prepared and well aware to give blood and public donation can be increased in this way.*

Delivery ward and antenatal nurses were asked their opinion about who they think is responsible to pass information about cord blood stem cells on to expectant mothers and most

of them think that all healthcare providers are responsible along with healthcare educators from the DCRC. They believe that a member of staff from the DCRC needs to be available in the clinic to educate expectant mothers and answer their questions as they are busy and they do not have detailed information to answer all of the expectant mothers' concerns. One of the delivery ward nurses said:

*It is not only those staff who is working in DCRC, it is every healthcare provider from the grass roots when they are coming. Medical and paramedical staff are supposed to give information about cord blood collection and usage. Automatically there is a need for everyone to be educated so when they give the knowledge to the patient there should be time they can talk to them. When there is a wide range of awareness people will say this thing everybody is talking about and it is very important and it can improve our community and the health of our children.*

Meanwhile, another nurse from the delivery ward stresses the need for healthcare educators from the DCRC to educate expectant mothers in the same way that breastfeeding education works in the clinic. She said:

*Either DCRC people or those in antenatal clinics like what we do in breastfeeding education. Doctors, nurses and DCRC members and mainly gynecologists in antenatal as this time is the best time. Here at delivery patients who come are in pain and it is hard to educate them. Nurses can help but it is important for DCRC people to be present.*

Another nurse from the antenatal clinic highlighted that everybody should have basic information, but detailed information should be held by the DCRC and ultimately expectant mothers:

*Everyone should inform the patient, the doctors, the nurses, the paramedic, breastfeeding educators. Everybody should have basic information and everybody should guide the patient but specific education should be from the DCRC staff because they know more details.*

### **7.1.3 Theme (2): Fear of any Risks to the Mother or the Newborn during Cord Blood Collection**

This newly emerged theme obtained from the survey results collected from 1020 expectant mothers revealed that the second main barrier towards cord blood donation is fear of any risks to the mother or the newborn during cord blood collection. Sugarman et al. (1998) found that all pregnant women believed that it is very important to receive not only general education about umbilical cord blood but also information about cord blood collection and its beneficial usage and storage. Education should not be restricted to expectant mothers; it should also include the general public. Sugarman et al. (1998) also demonstrated during a focus group study that women did not want to donate their newborn's UCB stem cells due to fears that the cord blood collection procedure might cause harm to the newborn or the mother. Expectant mothers are scared that something might go wrong during the delivery if cord blood stem cells are collected. They believe that obstetricians' primary focus might be on the collection of cord blood rather than on the newborn and the mother.

Healthcare professionals are responsible for providing information about cord blood stem cells to the expectant mothers and the information should include correct understanding of cord blood usage, collection and practices including sample processing, storage and donation (Kim, Han and Shin 2015). It is often believed that socio-cultural values affect people's decision making; thus, it is important to examine the cultural impact on cord blood donation (Kim, Han and Shin 2015). The researcher believes that healthcare providers' knowledge and attitudes towards cord blood donation affects expectant mothers' decisions towards cord blood donation. This was observed during a participant observation study as many expectant mothers were questioning the healthcare educators from the DCRC about the reasons that

prevent obstetricians and gynecologists from discussing cord blood donation and the banking options with them. They expressed an opinion that if cord blood donation is an important topic, then it should be highlighted by the doctors during the antenatal visits.

Obstetricians and other healthcare practitioners are known to be a patient's primary source of medical information and knowledge. From them, patients expect to receive all the required information and guidance regarding cord blood banking options and activities (Herlihy and Delpapa 2013).

The most important barriers toward cord blood donation and expansion of public cord blood banks include inaccurate and inadequate information about cord blood such as misunderstanding the therapeutic use of the cord blood, over-estimating the importance of private cord blood preservation, and under-estimating the important value of cord blood donation (Perlow 2006; Shin et al. 2011; Kharaboyan et al. 2007). Sugarman et al. (1998) explained that women would like to learn more about umbilical cord blood collection procedures for the sake of the safety of the mother and the newborn. They want to make sure that the collection procedure is free of pain and there is no harm to either the mother or the newborn. Therefore, it is highly important that expectant mothers are provided with detailed knowledge about cord blood donation, technical information and safety of the collection procedure so that they can make informed decisions.

#### **7.1.4 Theme (3): It is a Humanitarian and Noble Act**

Expectant mothers were asked during the survey about the main reasons that motivate them to publicly donate their newborn's UCB stem cells. Almost half of them, 42%, said it is a humanitarian and noble act to be active donors within the community. A similar study

conducted among five Europe countries showed that 76.5% of women would like to donate their cord blood stem cells to public banks because 59% of women believe that they can contribute to public health by donating their cord blood to help other patients who are in need of transplantation, whereas 26% of them would like to opt for donation because it is free of charge. This confirms the positive attitudes of pregnant women toward the community and their willingness to increase donations and expand the public registry within EU countries. Another study conducted in Canada also highlighted that most of the pregnant women would like to choose to donate their child's UCB stem cells to public banks because private banks' fees are very expensive; they also would like to donate due to altruism as public banks make cord blood available for unrelated recipients. This act of humanity motivates pregnant women to donate their UCB stem cells in a similar way to those who register for an unrelated bone marrow transplant registry. Comparable results have been found among Swiss women who strongly encourage public donation and want to engage in prosocial action towards the community (Danzon et al. 2003).

Moreover, during the survey, expectant mothers were also asked about the type of reward they would like to receive for donating their newborn's UCB cord blood stem cells and 90% of them said no reward was needed because it is their duty to society. This result significantly highlights expectant mothers' willingness to publicly donate their newborn's UCB stem cells to help others in need within the community without seeking any rewards.

### **7.1.5 Theme (3): Knowing it helps in treating other Patients with Life-Threatening Disease**

Another motivation factor revealed during the survey showed that 32% of expectant mothers feel motivated to donate their newborn's UCB stem cells because it helps in treating other

patients with life-threatening diseases. There is no cost associated with cord blood donation and the key motivation is to help patients who are in need of stem cells donors. Public programmes worldwide recruit expectant mothers to donate their newborn's UCB stem cells to contribute to expanding the public registry by increasing the collected number of public cord blood units and make them available for anyone who needs them (Herlihy and Delpapa 2013). Since the first success story of cord blood stem cells transplant in 1988 that took place to treat a child with Fanconi's anemia, almost 35,000 umbilical cord blood transplants have been performed to date (Roura et al. 2015). Currently there are about 730,000 umbilical cord blood units stored in more than 160 umbilical cord blood public banks while more than four million umbilical cord blood units are stored in 215 private cord blood banks (Ballen, Verter and Kurtzberg 2015). Katz et al. (2010) conducted a study on pregnant women's awareness and attitudes towards cord blood banking in five different countries European: France, Italy, Spain, Germany and UK. Findings revealed that expectant mothers in these five countries prefer to donate their child's UCB stem cells to public banks to help others in need for stem cells donors. Pregnant women are willing to donate their newborn's UCB stem cells if they know more information about public donation. A similar study conducted among Canadian expectant mothers highlighted that most of the pregnant women would like to choose to donate their newborn's UCB stem cells to public banks because private bank fees are very expensive; they also wanted to donate for altruistic purposes as public banks make cord blood available for unrelated receipts (Fernandez et al. 2003).

## **7.2 Bridging S-D Logic and Activity Theory**

Four common ingredients between S-D logic and activity theory were identified in this study; these are the role of the beneficiary (user), actors as dynamic systems, importance of context

as human institutions, and knowledge as an operant resource. Value is always co-created and determined when actors interact with each other for the purpose of integrating different resources (Helkkula et al. 2012). Customers' roles change from being passive participants to active ones when they play central roles in co-creating value (McColl-Kennedy et al., 2012). If expectant mothers' object is cord blood donation, this will lead to value creation and implementation of a series of activities by customers to achieve the desired results (Payne et al. 2008). To attain value co-creation with customers and the people surrounding the customers, it is important to give attention to customers' voices and participation within the service (Verhoef et al. 2009). In this case study, expectant mothers are the customers whose voices and opinions about cord blood donation are very important, as well as the people surrounding them who are the healthcare providers in the hospitals. Studying expectant mothers' motivations and barriers along with healthcare providers' opinions and attitudes toward cord blood donation in the UAE will result in better understanding and hence designing of donor recruitment processes.

In this study, theoretically, the researcher suggested that the activity system model adds analytical power to the narrative and process of S-D logic (Alhashimi, Kajamaa and Toivonen, forthcoming). This is achieved by providing an intermediate concept which is the concept of object that is oriented within the activity system (Engeström et al. 2003). The object plays an important role in connecting the value co-creation process to the collective sense and motive of the activity as well as to the social dynamics leading to reconceptualisation of the organization/system within its shared object, thus creating the change. The analysis of the activity systems extends our understanding of the service development including customer initiatives, shared tools and collaboration of multi-actors in

the process of value co-creation. Figure 6-12 shown in Chapter 6 is our first attempt to bridge SDL and activity theory (Alhashimi, Kajamaa and Toivonen, forthcoming). This is obtained by focusing on one of the most important strengths of the S-D logic which is understanding the concept of “exchange” and explaining how customers can co-create value and integrate with each other (Vargo and Lusch, 2016).

Vargo and Lucsh (2016) proposed the narrative and the process of S-D logic (see Figure 6-11) which highlights the main factors involved within the cycle of value co-creation. These factors include: *actors, resources, service exchange, institution and institutional arrangement to establish interlocking service ecosystem of actors* (Vargo and Lusch 2016). For successful resources integration and service exchange, all actors’ involvement is important and customers are always considered co-creators of value (Vargo and Lusch 2006). However, Figure 6-11 does not explain how these actors can integrate the different available resources; it highlights the factors that are involved in the value co-creation process but lacks the tool that is required for resource integration and value co-creation among all the actors (Alhashimi, Kajamaa and Toivonen, forthcoming).

In Figure 6-12, however, the researcher uses different elements from the activity system as a tool to combine the narrative and the process of S-D logic for practice development. The term “service ecosystems” used in the value co-creation process within the narrative process of S-D logic in Figure 6-11 is defined by Vargo and Lusch (2016, p.11) as “*a relatively self-contained, self-adjusting system of resource-integrating actors connected by shared institutional arrangements and mutual value creation through service exchange*”. This highlights that value co-creation requires the integration of different resources from various



sources to allow the exchange and explains why it does not take place from the activities of just a single actor or from the activity of only the firm (Vargo and Lusch 2016).

In this study the researcher used the concepts from Engeström's (1987) activity system model to "*study object-oriented and culturally mediated human activity along with its elements: the object, rules, community, division of labor and tools*" (Engeström 1987, p. 78) and integrated them into Vargo and Lusch's inspired model shown in Figure 6-11. This been achieved by identifying the activity systems and their elements for all the involved actors within a cord donor recruitment process. The first step was drawing the different activity systems of each actor involved within the cord blood donor recruitment process (expectant mother, gynecologist, pediatricians, antenatal nurse and delivery ward nurses). When drawing the activity system of each actor, the researcher was able to identify the practice and the complexity of the value co-creation process from the point of view of *how* to co-create value between the different actors within the activity. Activity theory was used as a tool to expand S-D logic by focusing on the theoretical concept of the object which represents the motive and actions that help in directing the activities towards the partially shared goal (cord blood donation) within the activity system, which is essential for the development of customer-centred service processes in all contexts (Kajamaa, 2010); specifically, society's service ecosystem (Vargo and Lusch 2016).

In the donor recruitment process, several *actors with distinct objects* are involved in the activity (Figure 6 -13). Identifying the object of each single actor will help in defining the goal of each one of them within the activity and thus contribute to orienting their motives to partially share the same object – which in this case is cord blood donation. For the actors to be able to deliver the information about cord blood stem cells to expectant mothers, a new shard,

*tools/instruments for resource integration*, was added to gain more profound knowledge and awareness about cord blood stem cells. *Division of labour* is also an important element as it represents different responsibilities, tasks and authorities of each actor involved within the activity for the purpose of *service exchange*. In this case study, each actor has its own roles during their daily routine work. Nurses have their role and responsibility in informing expectant mothers which is different from doctors' role but, in the end, they all interact with each other (resource integration) as a team in one community that shares similar interests and is encased within specific cultural and environmental boundaries (institutional arrangement and context). For example, nurses can contribute by introducing expectant mothers to information about cord blood programmes and banking options or by helping healthcare educators in the clinic and encouraging expectant mothers to enroll in the programme, while doctors can reinforce the message by handing them a cord blood brochure and encouraging them to donate their newborn's UCB stem cells. However, detailed knowledge about cord blood stem cells should be given by the healthcare educator from the DCRC who acts as a mediating instrument and resource integrator between expectant mothers and healthcare providers' activity systems. Thus, knowing the object of each actor involved within the process will play an essential role in helping everyone orient e their motives towards sharing the same object. Tools and instruments within the activity system are the defined tools used by actors to interact and integrate resources. In the case of cord blood donor recruitment processes, the required tool is knowledge about cord blood stem cells. Knowledge should include adequate information about cord blood banking options, collection procedures, and the importance of public donation in expanding the public stem cell registry and helping patients who are in need of a matched donor. Kharaboyan et al. (2007) concluded that it is

important to have adequate and complete information from obstetrical care providers to be able to make informed decisions. Skabla, McGadney and Hampton (2010) asserted that the greatest challenges for the development of cord blood collection and banking is lack of knowledge among healthcare providers and the public. Increasing knowledge and awareness about the benefits of umbilical cord blood donation results in increased demand for cord blood collection and donation among expectant mothers (Skabla, McGadney and Hampton 2010).

Results obtained from interviewing healthcare providers in this study showed that they have basic and limited knowledge about cord blood stem cells which makes them hesitant about sharing information with their patients. Walker et al. (2012) found that half of obstetricians feel that their knowledge is not sufficient to answer patients' questions and concerns about umbilical cord blood donation, which highlights the essential need for educational programmes and activities that develop their knowledge and awareness about cord blood donation, collection and usage. Moreover, in this study, healthcare providers think that cord blood centres should provide healthcare educators in the antenatal clinics to educate expectant mothers and provide them with the required information about cord blood. They believe that cord blood education should be delivered in the hospitals in a similar way to breastfeeding education, through providing a special consultant in the field of cord blood. Additionally, healthcare educators from the DCRC can also play a role in educating the surrounding healthcare providers in the hospital, and encourage them to share information about cord blood with their patients. Increasing healthcare providers' knowledge about cord blood and encouraging them to motivate their patients to donate their newborn's UCB stem cells will add value as they will feel more confident about becoming involved within the donor

recruitment processes. According to the research, obstetricians and other healthcare providers and prenatal care should play vital roles in increasing awareness about cord blood donation which will result in expanding public bank activities (Herlihy and Delpapa 2013). Once the healthcare providers are educated about the required information regarding cord blood, the actors will then develop a shared object, and co-creation of value will then occur between the cord blood center (DCRC), healthcare providers in hospitals, and expectant mothers. In this way, each actor will have defined *rules and responsibility* that are controlled within the *community* for *service exchange* and value in use, and hence lead to the establishment of *society's service ecosystem* (Vargo and Lusch 2016).

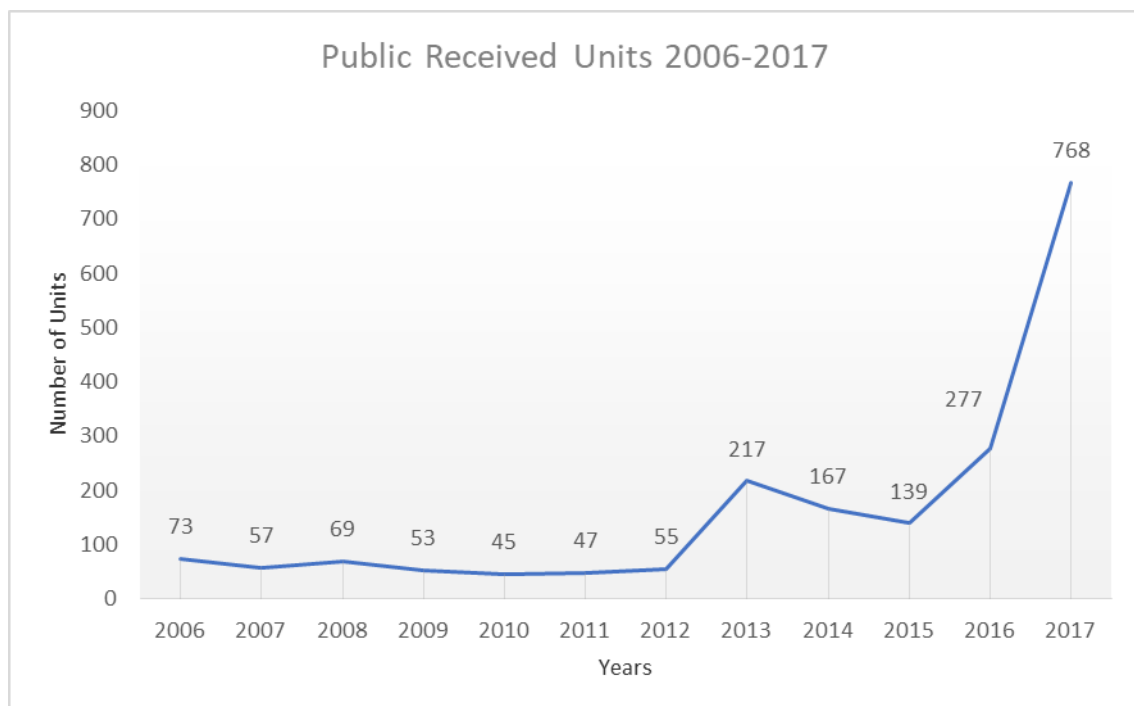
### **7.3 Implementation of the Expanded S-D logic in Hospital A**

Since 2012 the researcher has made many attempts to improve cord blood donor recruitment processes in hospitals. Since the opening of the DCRC the numbers of received public cord blood units were very low, ranging between 55 to 73 public cord blood units a year (see Figure 7-1). In 2012, the researcher decided to investigate the reasons for these low numbers of public cord blood units within the centre and to develop an effective donor recruitment process that would attract an increased number of public cord blood donations in the UAE to help many patients in need of cord blood units from Arabic ethnic groups (GoDubai 2013). Currently, most of the guidelines are recommending donation of umbilical cord blood units to the public banks unless the family concerned is suffering from diseases that require stem cell transplant in which cases it will then be useful to store the umbilical cord blood for family use (Martin, Kurtzberg and Hesse 2011). The discovery of umbilical cord blood stem cells as a source for transplantable hematopoietic stem was proposed by Hal Broxmeyer in 1982 along with his colleges Edward A. Boyse and Judith Bard. Since the first successful transplantation

in 1988 on a child suffering from Fanconi's anemia (Gluckman et al. 1989), today more than 35,000 umbilical cord blood transplants have been achieved worldwide (World Cord Blood Day 2018). However, even though there are about 22 million bone marrow donors registered within bone marrow donor registries, suitable donors cannot be found for many patients at the right time. Thus difficulty in finding a matched human leucocyte antigen (HLA) for an unrelated donor due to ethnic background and HLA matching (Navarrete and Contreras 2009). Therefore, umbilical cord blood banks were established for patients who cannot find either a matched sibling donor or an unrelated bone marrow donor for stem cell transplantation (Rubinstein 2006). There is a need to expand cord blood public registries, particularly within the Gulf countries, through recruiting more donors within public cord blood banks and conducting different activities such as patient education and counselling about the different available cord blood banking options (Emirates 24/7 News 2015). Cord blood education should not be restricted to expectant mothers and the public but also should focus on healthcare practitioners and obstetricians. Results from different studies showed that most expectant mothers seek to receive information about cord blood and the different banking options from their antenatal care providers (Smith and Thomson 2000 ; Schuman 2007). In some countries, it is recommended or required that healthcare providers communicate information about cord blood to expectant parents; this acknowledges the important role of these providers in helping expectant mothers make their decisions (Dinc and Şahin 2009).

In 2012, healthcare educators from the DCRC were visiting antenatal clinics of Hospital A and B to conduct educational sessions for expectant mothers about cord blood stem cells. However, the researcher noticed that conducting such activities requires budget, time and

other resources as most of the expectant mothers had so many questions and would like the healthcare educator to spend more time in the clinic and address their concerns. A study conducted by Ford and Wallace (1975) showed that face-to-face recruitment is three times more effective than telephone recruitment particularly for the first-time donors as the relationship developed between recruiter and donor is important. Moreover, the recruitment message should be simple and complete, and include reasonable justification for donation.



**Figure 7-1 Number of cord blood units received in the DCRC from 2006-2017 and the significant increase in public cord blood units after implementing the expanded framework and assigning a healthcare educator as resource integrator and facilitator in the hospital.**

The researcher believed in the need for the development of a robust conceptual framework with defined and sustainable strategic plans for the establishment of a cord blood donor recruitment process in hospitals. This was achieved by initiating a new conceptual framework based on activity theory and co-creation value which was implemented in Hospital A for nearly a year. The implementation of the new expanded model started on 13 November 2016

and was in place until 31 December 2017, almost a year. It resulted in a significant increase in public cord blood units in comparison to previous years (see Figure 7-1 above) (Nazzal 2018).

Two main challenges were faced when implementing a new model in the hospital. First, there was a lack of manpower due to shortage of staff in the DCRC so the researcher had to ask for help from the nursing department of Hospital A to share one staff member from the nursing department to help run the process and be assigned as the cord blood healthcare educator. The second challenge was to train the assigned antenatal nurse and enhance her knowledge about cord blood so that she felt fully confident to provide information about cord blood donation to expectant mothers. Six training sessions were provided for the nurse by the researcher for a period of 2-3 weeks. The training sessions included information about cord blood stem cells, different banking options, cord blood collection procedures and cord blood registration procedures.

The healthcare educator (antenatal nurse) was available in the antenatal clinic from 8:00 am to 1:00 pm for face-to-face consultation with expectant mothers by following the process work flow (shown in Figure 6-16). The process workflow was as follows: When expectant mothers visited the antenatal clinic for their regular appointment, they received a brochure about cord blood stem cells from the receptionist at the clinic and then a few minutes later they were called by the nurse into the assessment room for their general checkup. The nurse in the assessment room assisted the healthcare educator by handing her the “cord blood education form” attached with the mother’s information so she can call the expectant mother for a face-to-face consultation session. After the consultation session, some expectant mothers were convinced and expressed their willingness to register and sign the consent giving permission for their newborn’s UCB stem cells to be collected after the delivery of the newborn.

However, many of them said that they would like to think about it and ask their husbands and family before they take these decisions. Following that, the message about the importance of cord donation was reinforced by the gynecologist doctors in their offices in the clinic. Most of the information is provided to expectant mothers by the healthcare educator before she meets her gynecologist doctor. This saves time and effort as most of the physicians have limited time to spend with each patient. Moreover, for expectant mothers who did not get the chance to see their healthcare educator in the antenatal clinic, delivery ward nurses would brief them about the cord blood programme and the different banking options. Once an expectant mother had decided to donate/preserve her newborn UCB stem cells, the DCRC would approach the delivery room to complete the registration procedure. Hence, information about cord blood stem cells was delivered to expectant mothers at different stages during the pregnancy and detailed information was given by the healthcare educator to avoid overloading healthcare providers as they are busy with their daily routine work. For successful resources integration and service exchange, all actors' involvement is important and customers are always considered as co-creators of value (Vargo and Lusch 2006). This is established by focusing on one of the most important strengths of the S-D logic which is to understand the concept of "exchange" and explain how customers can co-create value and integrate with each other's activities (Vargo and Lusch 2016).

When implementing the model, each actor was conferred a defined responsibility. For example, the healthcare educator in the antenatal clinic was the main source of information which acts as facilitator between expectant mothers and healthcare providers. Receptionists in the clinic were handing out brochures about cord blood to expectant mothers. Gynecologists were reinforcing the message among the expectant mothers about the importance of cord



blood donation. Antenatal nurses were helping the healthcare educator in encouraging expectant mothers to attend face-to-face consultation sessions. The researcher assumes that healthcare providers should possess adequate knowledge about cord blood and their role should be limited to reinforcing the issue and encouraging expectant mothers to donate their newborn's UCB stem cells, while healthcare educators from the cord blood centre should be in charge of communicating detailed information about cord blood to expectant mothers. Healthcare providers should have the required knowledge about cord blood, but they should not be the main source of information due to their limited level of knowledge, daily work routines, duties, and responsibilities. According to the results obtained from the survey, expectant mothers and healthcare providers believe that all of the sources are important to provide information about cord blood and the information on the recruitment and donation processes should not be the responsibility of one single source. S-D logic focuses on the role of the beneficiary that is always included as the beneficiary plays a key role in all cases of value co-creation. In this case the primary beneficiaries (end user) are the patients who are in need of umbilical cord blood donations to use them to treat many life-threatening diseases. The beneficiary (patients) play key roles in value co-creation as they communicate their successful treatment stories to the community resulting in encouraging many patients with life-threatening diseases to opt for stem cells transplantation.

Value co-creation does not occur from the activities of one single actor; all involved actors are carefully analysed as soon as the resources are available to them (Vargo and Lusch 2011). Thus, any particular resource from any specific source is moderated by the presence of other resources from different sources leading to resource utilisation and integration by the beneficiary (Lusch et al. 2010). Accordingly, receiving information about cord blood from

different sources such as the healthcare educator in the antenatal clinic, physicians' offices, antenatal classes, delivery wards, media marketing, brochures and posters, and social media and awareness campaigns will lead to the development of a partially shared object among all actors and co-create value between the cord blood centre (DCRC), healthcare providers in hospitals, and expectant mothers. Cord blood education should be conducted as a team where each member of staff has defined responsibility to assure their participation and involvement within donor recruitment processes. Most of the research studies highlight the important role that healthcare providers play to increase awareness about cord blood stem cells. Herlihy and Delpapa (2013) revealed that obstetricians and other healthcare providers and prenatal care staff can play active roles in increasing awareness about the importance of cord blood donation and be active participants in expanding public bank activities. In addition, research has shown that antenatal care providers can have great influence on expectant mothers' decisions regarding cord blood banking. This can be achieved by providing accurate and evidence-based information about cord blood and the available banking options (Kharaboyan et al. 2007; Martin, Kutzberg and Hesse 2011; Cooper and Severson 2013; Herlihy and Delpapa 2013). However, none of these research works specifies the exact role and responsibility of each healthcare provider as they only emphasise the importance of their involvement in educating the expectant mothers and increasing their awareness about the importance of cord blood donation (Herlihy and Delpapa 2013). The findings of the research for this thesis indicate that it is important to identify healthcare providers' exact role and responsibility within cord blood recruitment processes while taking into consideration that the assigned role should be within their capability and knowledge. For example, in this study, healthcare providers including nurses, gynecologists and pediatricians showed their

willingness to discuss cord blood donation issues with the expectant mothers, and encourage them to donate their newborn's UCB stem cells by reinforcing the message, providing them with cord blood brochures, and collaborating with the cord blood bank in the awareness campaigns. However, they asserted that healthcare educators from the cord blood center should be the main source of information about cord blood as they hold the required detailed knowledge to communicate with expectant mothers. During this study healthcare providers were asked: *Who do you think is responsible for providing information about the potential value of publicly donating cord blood stem cells and why did you choose your answer?* Many of them believe that healthcare providers from the cord blood centre (DCRC) should provide detailed information about cord blood to expectant mothers. Appendix 17 lists all of the direct quotes obtained from healthcare providers' interviews from Hospitals A and B where they expressed their preference to have the healthcare educator from the cord blood bank to educate expectant mothers.

Figure 6-14 shows the results obtained from implementing the expanded model for a period of about one year which includes: number of expectant mothers who visited the clinic/month, number of education days (face-to-face consultation with healthcare provider), and number of expectant mothers registered for cord blood donation. The results show that the number of visited expectant mothers in antenatal clinics was high and it should be emphasised that any one single healthcare educator cannot counsel all the visiting expectant mothers in a day as each face-to-face consultation takes about 20 minutes. For example, during the month of December 2017, the healthcare educator managed to counsel 352 expectant mothers in 18 days and was able to register 169 expectant mothers for the cord blood programme whereas, in November 2017, she only managed to be in the antenatal clinic for 12 days and was able to

counsel 106 expectant mothers and register 27 of them. Not all counselled expectant mother will register on the cord blood programme as some of them are not eligible to donate/preserve their newborns' UCB stem cells while others need time to think and ask their husbands before they take these decisions. Thus, the more time that the healthcare educator spends in the antenatal clinic, the more expectant mothers she is able to meet and spend time with, and introduce them to the cord blood programme.

Figure 6-15 represents the number of received public cord blood units to DCRC before and after implementing the new model and assigning the healthcare educator as the resource integrator in the clinic. Before implementing the new model, healthcare educators from the cord blood centre were visiting the antenatal clinic (waiting area) to conduct cord blood educational sessions for expectant mothers and enrol the interested expectant mothers on the cord blood programme. Healthcare educators were spending around 2-3 hours at the clinic three times a week. After implementing the new model and assigning a healthcare educator in the antenatal clinic, the new work flow process was followed by the healthcare educator and the surrounding healthcare providers (see Figure 6-16) to improve the donor recruitment process and increase the number of public cord blood units.

#### **7.4 Limitation of the Research Study**

This study is limited to one case study in healthcare organisations in the context of voluntary cord blood recruitment processes. The new expanded S-D logic framework using activity theory as a tool was implemented only in the field of healthcare practice. It will be interesting to apply the new expanded model in other fields of research such as Education and Engineering. Currently there is some research studying Consumer Culture Theory (CCT) to

understand more about the theoretical perspective underlying co-creation of value in the consumption field. Arnould and Thompson (2005, p.869) defined CCT as a theory that *“denotes a social arrangement in which the relations between lived culture and social resources, and between meaningful ways of life and the symbolic and material resources on which they depend, are mediated through markets”*. This description highlights the importance of understanding the phenomenon of the existing sociocultural context to be able to understand the consumption phenomenon. This study focuses on blood product as an essential consumption activity that is used by the society to treat many patients with life-threatening diseases. Thus, to provide the best service for the patients and meet their demands, it is important to understand the sociocultural context of the blood donation activity in its entirety.

In Hospitals A and B, interviews were conducted with four main groups of healthcare providers that have direct contact with expectant mothers during pregnancy; however, there are other important groups of healthcare professionals such as hematologists, oncologists and genetic counsellors that were not included in this study. In addition, one of the challenges in this study was interviewing and conducting focus group discussions with healthcare providers due to their busy schedules attending to patients. Many scheduled focus group meetings and interviews were cancelled at the last minute and the researcher had to re-schedule them many times. Some interviews were conducted in the hallway or during healthcare providers' break-time while, with others, the researcher had to book an appointment as a patient to meet the doctor and interview him/her. Due to these challenges, most of the published research has resorted to conducting quantitative methods when studying healthcare providers' knowledge and attitudes regarding cord blood donation as qualitative methods require in-depth analysis

which involves a great deal of time and effort, but which can generate significant findings that add a great deal of value to the research.

Moreover, participant observation method was conducted among expectant mothers for a period of six months. Due to time constraints the researcher did not get the chance to interview each expectant mother individually to gain more understanding of her opinions and concerns regarding cord blood donation. The survey was distributed to both expectant mothers and healthcare providers. The researcher aimed to collect 500 surveys from healthcare providers but was only able to collect 193 completed surveys due to their busy schedules. It was challenging to find an opportunity to interview healthcare providers as they were always busy attending to patients.

Moreover, in this study the husband's/father's opinion about cord blood donation was not included. The researcher believes that, in this cultural context (e.g. Arab/Muslim context), it is very important to interview the husband/father as they have a great influence on the expectant mother's decision regarding cord blood donation. Many respondents within the Jordanian study preferred to obtain the consent of both the mother and the father and this is due to cultural issues within Jordanian society and most Arab societies where the father authority should always be deferred to when it comes to his wife and family (Petrini 2010).

The DCRC is the only governmental cord blood centre in the UAE that offers private and public donation of umbilical cord blood stem cells. Cord blood stem cell is considered a new technology in the UAE and so, to gain more knowledge and experience about this field, the researcher travelled to the USA and the UK to visit cord blood banks and learn from their experience. However, again due to time constraints, the researcher did not have the

opportunity to visit cord blood banks in Saudi Arabia and Jordan. Since the culture and context of both of Middle East and North African (MENA) countries is similar to that of the UAE, it will be interesting for future research to learn from their experiences and challenges in the field of cord blood donation.

## **CHAPTER 8: CONCLUSION AND RECOMMENDATIONS**

Donor management involves major activities including recruitment, invitation, selection and donation processes (De Kort et al. 2010). Donor recruitment is one of the critical stages that ensures sufficient amounts of blood are received at blood collection sites. Donor recruitment and blood strategy management need to be researched according to the country's culture and social environment (Lee 2016). This thesis uses the conceptual resources of cultural-historical activity theory (CHAT) to identify potential mediating instruments between S-D logic and practice-based views. The research problem concerns how to combine S-D logic and the practice-based view. The researcher argues that by using different models and tools of activity theory we will enhance our understanding of issues such as knowledge fragmentation, contradictions and different ambiguities that occur in healthcare contexts. This is the first study that combines activity-theoretical analysis with value co-creation processes in a particular service where activity theory is used as a tool to expand S-D logic for practice development in cord blood donor recruitment processes in hospitals. Four main themes emerged from studying the motivations and barriers towards cord blood donation in hospitals in UAE. These themes are: lack of information about cord blood; fear of potential risks to the mother or the newborn during cord blood collection; donation of cord blood is a humanitarian and noble act; and being motivated by knowing it helps in treating other patients with life-threatening diseases.



S-D logic focuses on the role of beneficiary which should always be included as it plays a key role in all cases of value co-creation (Vargo and Lusch 2011). Thus expectant mothers' opinions and suggestions are very important to design a strategic and sustainable framework for donor recruitment processes. To attain value co-creation with customers and the people surrounding the customers, it is essential to give attention to customers' voices and contribution within the service (Verhoef et al. 2009). In this case study, expectant mothers are the customers and their voices and opinions about cord blood donation are very important; as are the people surrounding them who are the healthcare providers in the hospitals. Studying expectant mothers' motivations and barriers along with healthcare providers' opinions and attitudes toward cord blood donation in UAE will lead to better understanding and designing of a conceptual framework for cord donor recruitment processes. Integrating and exchanging resources is very important in knowledge sharing, risk and supply of goods (Maglio and Spohrer 2008). Stakeholders, customers and employees play important roles as operant resources in sharing knowledge and encouraging value creation (Vargo and Lusch 2008). The aim is to achieve a shared object (cord blood donation) among all actors so that the co-creation of value will occur between the cord blood centre, healthcare providers in hospitals, and expectant mothers. Many-to-many is a stakeholder approach that applies to a network to ensure that the creation of service is carried out by different stakeholders and not limited to one supplier and customer (Gummesson 2008a). McColl-Kennedy et al. (2012, p. 375) highlighted the fact that *"customer value co-creation is benefit realized from integration of resources through activities and integrations with collaborators in the client's service network"*. This point clearly illustrates that customers can integrate resources from various different stakeholders including peers, family, private sources and other service providers.

This highlights that it is not only the customer who represents the actors of the two distinct agents (client and service provider/organisation). Thus, creation of value is not limited to customers and firms; rather it includes government entities and social organisations (Alhashimi, Kajamaa and Toivonen, forthcoming). Vargo and Lush (2016) highlighted the role of institutions in value co-creation and service exchange as it helps actors to achieve different tasks and promotes the level of service exchange within cognitive and tight constraints controlled by rules, guidelines and regulation of the institutions and institutional arrangements. From an activity theory perspective, an activity system is considered the main unit of analysis in understanding different collective learning highlighted by societal practices which are established and transformed across the different activity systems (Engeström 2001). One of the main vehicles for value co-creation is service systems which organise, arrange and manage people to support service exchanges between different organisations (Golooba and Ahlan 2013).

In donor recruitment processes, several actors with distinct objects were identified within the activity. For the actors to be able to deliver the information about cord blood stem cells to expectant mothers, new shared tools/instruments were added to gain a more profound knowledge and awareness about cord blood stem cells. Division of labour is also an important element as it represents different responsibilities, tasks and authorities of each actor involved within the activity for the purpose of service exchange. In cord blood donor recruitment processes, the required tool is knowledge about cord blood stem cells. Knowledge should include adequate information about cord blood banking options, collection procedures and importance of public donation in expanding the public stem cell registry and helping patients in need to find a matched donor. Kharaboyan et al. (2007) showed that it is important to

receive satisfactory information about cord blood from obstetrical care providers to make informed decisions. Knowledge is one of the key factors in decision-making processes; women who have more information about umbilical cord blood banking are more likely to make the right choices for their family (Kharaboyan et al. 2017). Skabla, McGadney and Hampton (2010) highlighted that the greatest challenge for the development of cord blood collection and banking is lack of knowledge among healthcare providers and the public. Healthcare providers only have basic knowledge about cord blood and they do not feel confident to share such information with expectant mothers. Moreover, healthcare providers highlighted that educating expectant mothers about cord blood is often not their first priority as they have their own daily responsibilities and routine work. Therefore, during the interviews most of the participants highlighted the importance of providing a “healthcare educator” from the cord blood centre who is specialised in the field and able to communicate to patients the required information about cord blood. They believe that cord blood education should function in the same way as breastfeeding education in the clinic where they assign a breastfeeding consultant to educate expectant mothers about all the information needed regarding this topic. Therefore, contradictions and tensions within and between different activity systems were identified and studied, which helped in developing a new activity system – the “healthcare educator”. A healthcare educator acts as mediator tool between the expectant mother and healthcare provider. This newly generated activity system can act as a facilitating tool to overcome the lack of knowledge among the healthcare providers and expectant mothers. It therefore plays a vital role in integrating different resources from various sources for the purpose of service exchange and value in use. According to the survey, the healthcare educator from DCRC is one of the top three preferred sources of

information among both expectant mothers and healthcare providers despite the fact that obstetricians/gynecologists are considered to be the best source of information for expectant mothers. The healthcare provider from DCRC was selected as the second source to receive information about cord blood. However, the first selected source is to receive information about cord blood from all the different places which indicates the importance of integrating all the various resources for the sake of the beneficiary which, in this case, is the patients (users).

In S-D logic, customers are seen as active actors and the firm can only create value if this value is collaboratively co-created with the beneficiary (Vargo and Lusch 2016). In addition, activity theory also highlights the central roles of different actors and the beneficiary in work, production and innovation processes, thus helping to identify users' problems (e.g., Hasu and Engeström 2000). Therefore, the phenomenon of resource integration is essential due to the fact that the value of any single resource depends on its relationships with other resources (Vargo and Lusch 2004, 2008, 2011).

The researcher believes that it is very important to specify the role/responsibility of each healthcare provider involved within donor recruitment processes, including antenatal and delivery ward nurses, gynecologists, and pediatricians. Moreover, their role should be designed according to their capability by considering their knowledge about the topic and their daily work responsibilities. During this study all healthcare providers showed their willingness to play a role within the donor recruitment processes. They highlighted that they can play an effective role in reinforcing the message about the importance of cord blood donation and help expectant mothers to make the right decisions. Therefore, it is important to acknowledge the interest of healthcare providers and their willingness to be part of the cord donor recruitment process by listening to their needs and requirements to assure their

participation. In this study one of the main findings was identifying the role of healthcare educators who act as a mediator between expectant mothers and healthcare providers. This research contributes to filling the gap in knowledge by identifying one viable channel and activity system for co-creation of value that connects expectant mothers and healthcare providers, hence providing the required information in detail for expectant mothers and saving some of the time and effort of other healthcare providers. Some of the challenges facing the researcher were questions surrounding who should be appointed as healthcare educator, what occupation she/he should hold, and will it make a difference for expectant mothers in terms of their willingness to receive information about cord blood from healthcare educators from a specific occupation? Will expectant mothers prefer to receive information about cord blood when the healthcare educator is a gynecologist doctor or nurse or some other healthcare specialty?

In this thesis, the healthcare educator was a nurse from the antenatal clinic and many expectant mothers were attracted to listen to her and this may be due to her occupation and appearance as a nurse wearing nursing uniform made it seem different when compared to healthcare educators from DCRC who were visiting the clinic in the traditional local black dress, the “Abaya”. More attention was given by mothers to the nurse occupying the role of healthcare educator compared to the DCRC staff medical technologist wearing the traditional “Abaya” uniform which is similar to what an expectant mother wears during her visit to the clinic. Further research should be conducted to identify the best occupation and specialty that needs to be assigned for healthcare educators for optimal influence in delivering the message about cord blood, thereby assuring expectant mothers’ involvement and participation within cord blood programmes. Most important overall, this thesis illustrates the potential benefits

that can be derived from designing, implementing and evaluating cord blood programmes informed by theoretical concepts based on activity theory and service-dominant logic.

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## APPENDICES

### Appendix 1. First Agenda Prepared for the Researcher on the First Visit to Finland



**CERTIFICATE  
ON THE ACTIVITIES  
OF THE VISITING  
DOCTORAL STUDENT**

November 27, 2015

**FATMA AL HASHIMI**  
PhD Candidate of the British University of Dubai BUiD


**Developing Activity Theory & Co-Creation Value Framework for Cord Blood Centre: The Case of Establishing the First National Stem Cell Registry in United Arab Emirates**

Fatma Al Hashimi visited The Faculty of Behavioural Sciences, University of Helsinki Finland, and the Center for Research on Activity, Development and Learning CRADLE under the supervision of Professor Yrjö Engeström from November the 23rd, 2015 until November 27th, 2015.

CRADLE conducts research in foundational issues of cultural-historical activity theory. CRADLE shares deep interest with Fatma Alhashimi in especially work related to technology and organizations going through transformations.

Al Hashimi's research plan, entitled as "Developing Activity Theory & Co-Creation Value Framework for Cord Blood Centre: The Case of Establishing the First National Stem Cell Registry in UAE", has been the basis of her enquires and the discussions with CRADLE researchers and other experts on her work during her stay in CRADLE. Fatma has been involved in a number of activities in our research group. The strongest emphasis she has put on developing her own research work further and working on the theoretical aspects of her PhD thesis.

Fatma Al Hashimi gave a presentation at CRADLE of her own research work.

Sincerely,   
Yrjö Engeström, Professor  
Director, Center for Research on Activity, Development and Learning CRADLE  
Institute of Behavioural Sciences, University of Helsinki

**Institute of Behavioural Sciences  
Psychology  
P.O. Box 9 (Siltavuorenpenger 1 A)  
FIN-00014 HELSINGIN YLIOPISTO**

HELSINGIN YLIOPISTO  
HELSINGFORS UNIVERSITET  
UNIVERSITY OF HELSINKI

**KÄYTTÄYTYMISTEORETTILINEN TIEDEKUNTA  
BETRIENDEVESTERENKUNTA FAKULTÄT  
FACULTY OF BEHAVIOURAL SCIENCES**

Toiminnan, kehityksen ja oppimisen tutkimusyksikkö CRADLE  
Käyttäytymistieteiden laitos, PL 9 (Siltavuorenpenger 1A) 00014 Helsingin yliopisto  
Puhelin 02941 44165, [www.helsinki.fi/cradle/](http://www.helsinki.fi/cradle/)

Center for Research on Activity Development and Learning CRADLE  
Institute of Behavioural Sciences, P.O. Box 9 (Siltavuorenpenger 1A), 00014 University of Helsinki  
Telephone +358 050 4156636, [www.helsinki.fi/cradle/](http://www.helsinki.fi/cradle/)

**REPORT**  
23.-27.11.2015

**Fatma Al Hashimi**

Monday the 23<sup>rd</sup>

- 10:00-11:00 Meeting with Auli Pasanen, Coordinator, Center for Research on Activity, Development and Learning CRADLE: "Facilitation and the scheduling of the visit"
- 11:00-12:30 Meeting with Daniele Morselli, Post-doctoral researcher and Rosemary Francisco, visiting Doctoral student from Brazil: "Presenting the Change Laboratory Reading group of CRADLE"
- 13:00-16:00 Meeting with Professor Yrjö Engeström UH, IBS, CRADLE, Siltavuorenpenger 1A Room 227: "Discussions on Fatma Al Hashimi's research plan"

Tuesday the 24<sup>th</sup>

- 09:30-12:00 Meeting with Docent Anu Kajamaa, UH, IBS CRADLE Siltavuorenpenger 1A Room 222: "Discussions on the Change Laboratory Method".
- 13:00 -15:00 Presentation: Fatma Al Hashimi presents CRADLE researchers her own research plan: "Developing Activity Theory & Co-Creation Value Framework for Cord Blood Centre: The Case of Establishing the First National Stem Cell Registry in United Arab Emirates"

Wednesday the 25<sup>th</sup>

- 10:45-11:30 Meeting with Professor Yrjö Engeström UH, IBS, CRADLE, Siltavuorenpenger 1A Room 227 "Double stimulation method, concept of a shared object and Co-configuration type of working"
- 12:00 Meeting with Director Anne Arvola, Finnish Red Cross Blood Service Kivihaantie 7, 00310 Helsinki: "History of the Stem Cell Registry in Finland"
- 14:00-16:00 Taking part in the CRADLE's Change Laboratory Reading Group's\*) weekly meeting: "Contradictions in activity"

Thursday the 26<sup>th</sup>

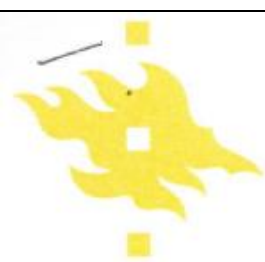

- 11.45-12:30 Meeting with Docent Hannele Kerosuo, UH, IBS CRADLE Siltavuorenpenger 1A Room 224: "Experiences on Developmental projects and Change Laboratory implementations in Health Care"
- 14:00-15:00 Skype Meeting with Docent Marianne Teräs, UH IBS CRADLE: "Exchanging ideas and experiences on Change Laboratory implementation in Health care"

Friday the 27<sup>th</sup>

- 10:00-11:00 Meeting with Docent Hanna Toiviainen, UH, IBS CRADLE Siltavuorenpenger 1A Room 127: "Discussion on Development projects in Health Care and Change Laboratory implementations connected to them."
- 12:30-13:30 Lunch meeting with CRADLE's doctoral students "Discussions on each other's Research Work"

\*) The "gaps" in the programme during the period of Al Hashimi's stay in CRADLE, she will be spending by studying Activity theory and the Change laboratory method through CRADLE Change Laboratory Reading Group's study material in Moodle.

## Appendix 2. Second Agenda Prepared for the Researcher on the Second Visit to Finland

	<p><b>CERTIFICATE ON THE ACTIVITIES OF THE VISITING DOCTORAL STUDENT</b></p> <p>October 14, 2016</p>
<p><b>FATMA ALHASHIMI</b> Phd Candidate at British University of Dubai BUID, United Arab Emirates</p>	
<p><b>Using activity theory to create donor recruitment process in hospitals: The Case of Dubai Cord Blood &amp; Research center</b></p>	
<p>Fatma AlHashimi visited The Faculty of Behavioural Sciences, University of Helsinki Finland/ the Center for Research on Activity, Development and Learning CRADLE under the supervision of Professor Yrjö Engeström from <b>October the 10<sup>th</sup> until October the 14<sup>th</sup>, 2016.</b></p>	
<p>CRADLE conducts research in foundational issues of cultural-historical activity theory, especially related to work, technology and organizations going through transformations.</p>	
<p>AlHashimi's presentation, entitled as "Using Activity Theory to create donor recruitment process in hospitals: The Case of Dubai Cord Blood &amp; Research Center", has been the basis of her research work during her stay in CRADLE. The strongest emphasis she has put on developing her own research work further and on working on the theoretical aspects of her PhD thesis.</p>	
<p>Fatma Alhashimi has also presented her own research work in CRADLE Research seminar on October the 14, 2016.</p>	
<p>Sincerely,</p>  <p>Yrjö Engeström, Professor Director, Center for Research on Activity, Development and Learning CRADLE Director, Doctoral Program for Developmental Work Research and Adult Education Institute of Behavioural Sciences, University of Helsinki</p>	<p>Institute of Behavioural Sciences Psychology P.O. Box 9 (Siltavuorenpenger 1 A) FIN-00014 HELSINGIN YLIOPISTO</p>
<p>HELSINGIN YLIOPISTO HELSINGFORS UNIVERSITET UNIVERSITY OF HELSINKI</p> <p>KÄYTTÄYTYMISTEELLINEN TIEDEKUNTA BETÄNDEVETENSKAPLIGA FAKULTETEN FACULTY OF BEHAVIOURAL SCIENCES</p>	<p>Toiminnan, kehityksen ja oppimisen tutkimusyksikkö CRADLE Käyttäytymistieteiden laitos, PL 9 (Siltavuorenpenger 3A) 00014 Helsingin yliopisto Puhelin (09) 191 44165, faksi (09) 191 44579, <a href="http://www.helsinki.fi/cradle/">www.helsinki.fi/cradle/</a></p> <p>Center for Research on Activity Development and Learning CRADLE Institute of Behavioural Sciences, P.O. Box 9 (Siltavuorenpenger 3A), 00014 University of Helsinki Telephone +358 9 191 44165, fax +358 9 191 44579, <a href="http://www.helsinki.fi/cradle/">www.helsinki.fi/cradle/</a></p>

REPORT 14.10.2016

Fatma AlHashimi

Monday 10.10.

09:00 – 10:00

Auli Pasanen, Coordinator, Center for Research on Activity, Development and Learning CRADLE

10:00 – 16:00

Studies on Activity Theory and Change Laboratory, meeting with CRADLE researchers

Tuesday 11.10.

10:00 – 12:00

Professor Yrjö Engeström UH, IBS, CRADLE, Siltavuorenpenger 1A Room 227

13:00 – 16:00

Studies on Activity Theory and Change Laboratory method, meeting with CRADLE researchers

Wednesday 12.10.

09:00 – 12:00

Meeting with the supervisor, Docent Anu Kajamaa in Espoo city

13:00 – 16:00

Studies on Activity Theory and Change Laboratory method, meeting with CRADLE researchers

Thursday 13.10.

09:00 – 12:00

Studies on Activity Theory and Change Laboratory method, meeting with CRADLE researchers

13:00 – 16:00

Meeting with the supervisor, Docent Anu Kajamaa in Espoo city

Friday 14.10.

09:30 – 12:00

Cradle Research seminar: Fatma Al Hashimi, British University of Dubai, United Arab Emirates, presents her work in seminar room 229 in the Psychologicum building (Siltavuorenpenger 1A, 2nd floor: Using activity theory to create donor recruitment process in hospitals: The Case of Dubai Cord Blood &amp; Research center

Institute of Behavioural Sciences  
Psychology  
P.O. Box 9 (Siltavuorenpenger 1 A)  
FIN-00014 HELSINGIN YLIOPISTO

Skype connection to supervisors in British University of Dubai, United Arab Emirates.

13:00 – 16:00

Studies on Activity Theory and Change Laboratory, meeting with CRADLE researchers



### Appendix 3. Ethical Approval Obtained from Director of Pathology & Genetic Department

To: Mr. Ali Ridha AlHashimi  
Director of HQ - Pathology & Genetics Department

**Subject: Fatma Alhashimi (118570) PHD research approval**

Dear Sir,

Mrs. Fatma Alhashimi shows interest to pursue her study to PhD level. Her study and research are sponsored by H.H. the Ruler's court. The title of her research is ( The cord blood banking project in the UAE: The case of establishing a local stem cell registry).

The aims of the research are:

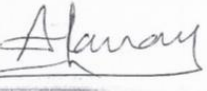
1. To find out the barriers and motivators in the UAE culture that stop people from cord blood donation.
2. To highlight the importance of having a cord blood registry.
3. To study the challenges towards building a local cord blood registry for the UAE.

Given the unique ethnic diversity of the UAE population highlights the importance of creation a cord blood registry and it is important to mention that no project has been ever there to study this fact.

I support Mrs. Fatma request to conduct this study using DCRC data as this is going to reflect positively on the center itself and put it up as a research center.

Hereby she needs your final approval so she can take the primary research approval formalities further with the research committee of the DHA.


Your understanding and support are always appreciated.

Sincerely yours,  
Dr. Kareema Salim AlArrayed 



---

Head of DCRC.

Date:17/02/1014

Approved   
25/2/14

**Appendix 4. Ethical Approval Obtained from Medical Research Committee of Dubai Health Authority and from director of Pathology and Genetic Department**

 GOVERNMENT OF DUBAI	<b>MEDICAL RESEARCH COMMITTEE APPROVAL LETTER</b>	 هيئة الصحة بدبي DUBAI HEALTH AUTHORITY
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<b>From :</b>	Dr. Azan Salem BinBrek Chairman-Medical Research Committee Dubai Health Authority	<b>Date :</b>	28 Sep 2014
<b>To :</b>	Ms. Fatma Hussain Mohd Al Hashimi, Acting Head of the Administration and Education Unit, Dubai Cord Blood & Research Centre, Latifa Hospital, Pathology and Genetics Department, DHA	<b>Ref :</b>	MRC-SR-09/2014_02

Subject: Approval for the research proposal, **"The Cord Blood Banking Project in UAE: The Case of Establishing Local Stem Cell Registry"**

Dear Ms. Fatma Hussain Mohd Al Hashimi


Thank you for submitting the above mentioned research proposal to the Medical Research Committee, DHA. The Medical Research Committee has been organized and operates in accordance with the ICH/GCP guidelines.

Your request was discussed with the Medical Research Committee. I am pleased to advice you that the committee has granted ethical approval for the above mentioned study to be conducted in Dubai Health Authority. However you will have to approach the Medical Director of the Hospitals to secure permission to review any hospital records and to carry out your study in the hospital.

Please note that it is the MRC's policy that the principal investigator should report to the committee of the following:

1. Anything which might warrant review of ethical approval of the project in the specified format, including:
  - any serious or unexpected adverse events and
  - unforeseen events that might affect continued ethical acceptability of the project
2. Any proposed changes to the research protocol or to the conduct of research
3. Any new information that may affect adversely the safety of the subjects
4. If the project is discontinued before the expected date of completion (reason to be specified)
5. Annual report to the MRC about the progress of the study
6. A final report of the finding on completion of the study

Please note that this approval is valid for **one year** from the date of this letter. It is your responsibility to ensure that an application for continuing review approval has been submitted at the required time.

  
Page 1 of 2



**MEDICAL RESEARCH COMMITTEE  
APPROVAL LETTER**



The MRC wishes you every success in your research.

Yours faithfully,

Dr. A.S. Binbrek  
Chairman  
Medical Research Committee  
Dubai Health Authority

**Dr. Azan BinBrek**  
**Chairman-Medical Research Committee**  
**Dubai Health Authority**  
**Dubai, UAE.**



## **Appendix 5. Cord Blood Monthly Reflective Report Template While Conducting Awareness and Education in Antenatal Clinic for Hospital A**

**Duration Dates:**

**Report Generation Date:**

1. Material and methods you use to conduct education in antenatal clinic (Hospital A), what do you think was the best method?
2. Summary reflection on what you see, feel and think while conducting education for pregnant women in in terms of the following:

<b>Location</b>	<b>Environment and atmosphere</b>	<b>Expectant mother's engagement level</b>	<b>Expectant mothers' awareness level</b>	<b>Expectant mothers' feeling and expression</b>	<b>Problems , suggestion and concerns raised by expectant mothers</b>

1. General notes taken in antenatal clinic on receptionist, antenatal nurses and doctors?
2. General feedback
3. Comments and suggestions
4. Future plans for improvement

## Appendix 6. Agenda Prepared to Visit Cord Blood Center in the USA and Main Stakeholders within the Field of Cord Blood



Fatma Al Hashimi Research Trip to United States  
Sunday, July 10 - Saturday, July 16, 2016

Tour of CORD:USE Cord Blood Bank

Interview of Dr. Edward S. Guindi,  
President & CEO, CORD:USE Cord Blood Bank

Interview of Michael T. Ernst, Executive Vice President & CFO, CORD:USE

Interview of Thomas Moss, Vice President of Operations, CORD:USE

Tour of Florida Hospital for Women and Cord Blood Room there

Tour of Walt Disney Children's Pavillon and Florida Children's Hospital including Transplant Unit

Interview of Matthew Farrow, World's 1st Cord Blood Transplant Recipient

Interview of Joanne Alphonse, Head of Public Donation Program at CORD:USE

Tour of Translational Medicine Institute.

Tour of Alexander Neonatal Intensive Care Unit - 164 beds

Tour of University of Minnesota Medical Center Adult Transplant Unit

Interview of Dr. John Wagner, World Renowned Cord Blood Scientist and Transplanter

Tour of Stem Cell Research Facilities at University of Minnesota

Tour of University of Minnesota Medical Center Pediatric Transplant Unit

Interview of Dr. Hal Broxmeyer, Founder of the Field of Cord Blood Banking and Transplantation


Tour of Dr. Broxmeyer Research Facilities

Interview Kim Petrella, Cord Blood Educator

Edward S. Guindi, M.D.  
President & CEO

  
4/9/16

## Appendix 7. Agenda Prepared for Visiting NHS Blood and Transplant in UK



**Blood and Transplant**

in NHS Blood Transplant  
North Bristol Park  
thway  
stol  
34 7QH

### AGENDA

#### 3rd October

10:00 Colindale Blood Centre (see attached map).  
The day will be spent at the collection centre hub.

- You will have the opportunity to observe the management of donor recruitment through to the evaluation of collected donations for processing.
- You will see how we register donors and determine their eligibility.
- Hosts: Jesmina James, Section Head CBB Collection; Rachel Pawson, Medical Director CBB.

#### 4th October

The day will be spent at our St. George's Hospital collection site.

- Shadow one of our collectors and see how we recruit donors and obtain consent for collection on site.
- Observe ex utero collection of cord blood donations.
- Observe how we obtain informed consent.
- Host: Edward Dobransky, collection team manager.

#### 5th October



10:00 Filton Blood Centre (see attached map)

- Processing and issuing of cord blood donations is done at our laboratory in Filton. You will see processing of cord blood donations and be talked through the issuing process.
- You will have the opportunity to see how we quality check donations for release. Following release you will see how we update the registries with our searchable units.
- Host: Alexandra Ross, processing manager.

#### 6th October

10:00 Filton Blood Centre (see attached map)  
The day will be spent in the British Bone Marrow Registry Office. You will have the opportunity to speak with Theo Clarke who is the main recruitment person for people from Black and Minority Ethnic backgrounds.  
Host: David Winstone, BBMR business manager.

This is an outline not an exhaustive summary of what you will see. The agenda is fluid and so there is scope for change on any areas of interest you might have. The 7<sup>th</sup> October is left open for you to decide what you would like to do.



BBMR  
Filton NHS Blood Transplant  
500 North Bristol Park  
Northway  
Bristol  
BS34 7QH

*Rachel Pawson*  
CONSULTANT HEMATOLOGIST  
06/10/16



## **Appendix 8. Interview Questions for Healthcare Providers in Hospitals A and B Along with the Consent Form.**

### **Consent for Participation in the Interview Research**

I volunteer to participate in a research project conducted by Fatma AlHashimi and the purpose of the study is to gather different suggestions obtained from the physicians and healthcare professionals to be able to initiate best practice to increase cord blood donation in the UAE and build the first national stem cell registry in Dubai.

1. I understand that the purpose of the interview is to study interviewees' points of view in regard to cord blood donation and different banking option.
2. I understand that my participation in this project is voluntary and I may withdraw and discontinue participation at any time.
3. The interview will take 20-30 minute approximately.
4. I understand that notes will be written during the interview.
5. I understand there will be also an audio/video tape of the interview and if I do not want it to be taped I have the right to reject it.
6. I understand that the researcher will not identify me by name in any reports using information obtained from this study.
7. I understand that this research study has been reviewed and approved by the ethical committee of the DHA.
8. I have read and understand the explanation provided to me.
9. I have been given a copy of this consent form.

\_\_\_\_\_  
My signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
My printed name

### **Interview Questions**

- 1- What is your information about stem cell and their usage for disease treatment?
- 2- What is your information about cord blood and cord blood banking?
- 3- Which banking options (private/public) would you encourage your patient to go for and why?
- 4- Even though public donation is free of cost, what do you think prevents expectant mothers from donating their baby's cord blood?
- 5- Do you think each mother has the right to know the potential benefits of cord blood therapy within a legal context and why?
- 6- Who do you think is responsible for providing information about the potential value of publically donating cord blood stem cells and why did you choose your answer?
- 7- What do you think about establishing a stem cell registry in the UAE and why?
- 8- Do you think it is a good practice to create a group of healthcare professionals to discuss the best way to increase awareness among public donors and why?
- 9- What do you think is the best method that can help encourage increasing cord blood awareness in the UAE?
- 10- Do you think it is a good practice to create educational guidelines or policies for healthcare professionals to educate public donors about the importance of cord blood stem cells and why?



## **Appendix 9. Interview Questions for the Main Stakeholders in the UK**

- **Interview with Dr. Rachel Pawson Medical Director and Jesmina James, Head of Section and in Charge of the Collectors in the Colindale Blood Centre**

1. How is cord blood education set up in hospitals?
2. What is the procedure for signing the cord blood consent in the hospital?
3. What are the main challenges in your job being a part of donor recruitment and cord blood education?
4. What are the main reasons that stop mothers from donating their cord blood stem cells?
5. Who is in charge of educating the pregnant women in the hospitals?
6. How are the pregnant women encouraged to donate their cord blood stem cells?
7. What are the obstacles faced while recruiting pregnant women in hospital?
8. When is the best time to approach the expectant mothers in hospital?
9. Who is in charge of educating the healthcare providers in the hospitals about cord blood and what are the challenges you are facing with them?

- **Interview with Cord Blood Collector at St. George's Hospital**

1. How does the donor recruitment management work in the NHS?
2. Who is in charge of educating the pregnant women about the importance of cord blood?
3. How are pregnant women encouraged to donate their cord blood stem cells?
4. What are the obstacles that are faced when asking the pregnant women about cord blood donation?
5. Is cord blood education mandatory in hospitals? Is it part of hospital policy?
6. Do we need to ask all the 53 long questions by AABB to pregnant women? Is there an easy way to check their eligibility?

7. Who is checking pregnant women's eligibility for donation? And who is in charge of taking pregnant women's consent form for donation?
  8. What are the reasons that can stop the mothers from donating their cord blood stem cells?
  9. What is the best system that can be implanted in antenatal clinics to make sure all cord blood samples are donated and nothing gets discarded in the trash?
  10. Who is in charge of educating the healthcare providers such as doctors and nurses about cord blood stem cells?
  11. How can we encourage gynecologist doctors and nurses to be part of this project and educate the pregnant women about cord blood?
- **Interview Questions with Theo Clark, National BME Marketing Manager and in Charge of Recruiting Black African Community and for Cord Blood and Bone Marrow.**
1. What are the main challenges and obstacles in recruiting black agents and how do you overcome these obstacles?
  2. How can the culture affect recruiting donors?
  3. How do you overcome lack of awareness about cord blood when recruiting donors?
  4. How do you recruit female Muslims in the UK? What challenges are you facing?
  5. What are the best strategies for recruiting donors in UK?
  6. Despite a lot of awareness and education done in the UK, how do you explain why there is still a lack of awareness among some groups in the UK about the importance of cord blood donation?

## **Appendix 10. Interview Question for the Main Stakeholders in the USA**

### **Interview Consent Form**

I accept to participate in an interview conducted by Ms. Fatma Alhashimi, which is part of research studying the different views of doctors, public donors, donor recruitment specialist and transplant patients about cord blood stem cells and their beneficial usage in future.

I understand that my part in in this study is entirely voluntary and I am free to refuse to participate in this study at any time. I understand that the interview will take 20-30 minutes.

I also understand that all the information gathered for this study will be used by investigators for research and publications, provided that I will not be identified in any published report.

Interviewee name

Interviewer name

Date

Signature

Signature

- **Matthew Farrow Interview Questions:**

- 1- Could you please share with us your success story as being the first cord blood transplant patient in the world?
- 2- Could you explain how much cord blood awareness is important these days?
- 3- What do you like to do to express your gratitude to getting your life back?
- 4- Who do you like to advocate for?
- 5- What does it mean to you to know that cord blood stem cells have given you a new life? And what can you say for patients who need to go for cord blood transplantation?
- 6- From your experience, could you please share with us some of your ideas about how we can encourage pregnant women to donate their cord blood stem cells in the UAE?
- 7- What is the best system that can be implanted in the antenatal clinic to make sure all cord blood samples are donated and nothing gets discarded in the trash?
- 8- Which cord blood banking do you encourage the pregnant mother to go for? Public or private?
- 9- From your experience, what is the best advice you can share with the parents?

- **Joanne Alphonse's Interview Questions**

- 1- Could you please brief us about your role in cord blood awareness and education? And what is the best part about cord blood education? And what is the most challenging part in your job?
- 2- From your experience, how much do you think cord blood awareness and education is important? And how it can play a role and make a change these days?
- 3- Who do you think should be educated about cord blood stem cells; parents, public or healthcare providers?
- 4- Could you please let us know how cord blood recruitment and education is conducted in the USA, is there any specific system implemented in hospitals?
- 5- How do the pregnant women get registered for cord blood collection? Kindly explain for us how the system works in the USA.
- 6- Are the healthcare providers in hospitals involved in educating the pregnant women about cord blood? What is their role in hospital in regard to cord blood education?
- 7- When is the information about cord blood stem cells passed to pregnant women?
- 8- Is it important to educate the pregnant women only or the father and the entire family too and why?
- 9- Which banking options do you encourage the patients to go for, public or private and why?
- 10- How important is public cord blood inventory for the USA?

- **Dr. John Wagner's Interview Questions**

- 1- From your experience, can you please let us know how important is cord blood stem cells nowadays?
- 2- What are the different diseases that are treated using cord blood stem cells and what are the future promising treatments in this field?
- 3- How many patients have been treated so far using cord blood stem cells from the public registry?
- 4- How much do you think cord blood awareness and education is important? And how can it play a role and make a change these days?
- 5- How much important is public donation for the country? And what is the role of the public registry in facilitating the needs of the community?
- 6- Doctor, do you think it is important that each country has its own public cord blood registry?
- 7- How many patients do you see from Middle East countries that require cord blood transplantation but fail to find a match from the same ethnic diversity?
- 8- What kind of advice/recommendations can you provide us in regard to increasing public cord blood donation in the UAE?

- **Professor Hal Broxmeyer Interview Questions:**

- 1- Could you please brief us about your cord blood stem cells discovery and how it has changed the world?
- 2- Can you please tell us about the first successful cord blood transplant story and how it made a big difference in the healthcare field?
- 3- From your experience, can you please let us know how important are cord blood stem cells nowadays?
- 4- What are the different diseases that are treated using cord blood stem cells and what are the future promising treatments in this field?
- 5- How many patients have been treated so far using cord blood stem cells from the public registry?
- 6- How much do you think cord blood awareness and education is important? And how can it play a role in making changes these days?
- 7- How important is public donation for the country? And what is the role of the public cord blood registry in facilitating the needs of the community?
- 8- Doctor, do you think it is important that each country has its own cord blood public registry?
- 9- How many patients have you seen from Middle East countries that require cord blood transplantation but fail to find a match from the same ethnic diversity?
- 10- What kind of advice/recommendations can you provide us in regard to increasing public cord blood donation in the UAE?

- **CORD:USE Management's Interview Questions for Dr. Edward Guindi, Michael T.Ernst and Thomas Moss.**

- 1- How did the field of cord blood start in CORD: USE?
- 2- How important is cord blood donor recruitment?
- 3- In term of the operational part of cord blood donor recruitment, how can awareness and education affect it? And should cord blood education start in antenatal clinics in the hospitals?
- 4- How we can encourage the expectant mother to donate her cord blood stem cells?
- 5- From your experience in this field, what do you think is the best method or technique that encourages the expectant mothers to donate their cord blood stem cells?
- 6- What advice can you share with us that can help us establish a cord blood donor recruitment process in our hospitals in the UAE?



- **Kim Petrella Interview Questions (Register Nurse and Certified in Patient Obstetrics)**

- 1- What is your role in cord blood education? What are the most challenging parts about your job and what are the best parts about your job?
- 2- How is cord blood education conducted in the hospital? From where does it start? Can you please explain for us how the system works in the hospital?
- 3- Who is responsible for cord blood education in the hospital?
- 4- From your experience how much do you think cord blood education is important and how it can make a change nowadays?
- 5- Who do you think should be educated about cord blood stem cells?
- 6- If pregnant mothers came to you and ask you for your advice for which banking options they should choose, what advice can you provide her?
- 7- What kind of system does the hospital follow in recruiting cord blood donors?
- 8- At what stage are the pregnant women signing the cord blood consent form?
- 9- Does the hospital involve the healthcare providers in educating the pregnant women about cord blood, and what is their role in regards to cord blood education?
- 10- What advice and suggestions can you share with us in regard to setting up donor recruitment in UAE hospitals? What is the best programme to follow?

## Appendix 11.

### Appendix 11. Focus Group Questions for Healthcare Providers in Hospitals A and B along with the Consent Form.

#### Consent for Participation in Focus Group Discussion

I volunteer to participate in a research project conducted by Fatma AlHashimi and the purpose of the study is to gather different suggestions obtained from the physicians and healthcare professionals to be able to initiate best practice to increase cord blood donation in the UAE and build the first national stem cell registry in Dubai.

1. I understand that the purpose of focus group discussion is to gather and study the different ideas and suggestions commented by the group in regard to cord blood donation and different banking options.
2. I understand that my participation in this project is voluntary and I may withdraw and discontinue participation at any time.
3. The focus group discussion will take one hour approximately.
4. I understand that notes will be written during the discussion.
5. I understand there will be also an audio/video tape of the interview and if I do not want that I cannot be part of the study.
6. I understand that the researcher will not identify me by name in any reports using information obtained from this study.
7. I understand that this research study has been reviewed and approved by the ethical committee of the DHA.
8. I have read and understand the explanation provided to me.
9. I have been given a copy of this consent form.

\_\_\_\_\_  
My signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
My printed name

The discussion will be based on the following questions:

1. What is the best method/technique that can be applied to increase knowledge and awareness about cord blood among public donors?
2. How can healthcare providers play an important role to motivate the expectant mother to donate her baby's cord blood stem cells?
3. How can we divide the responsibilities among the healthcare providers so that they can participate in informing the expectant mother about the importance of cord blood stem cells?
4. What is the best method that can be designed for the public to encourage them to donate their baby's cord blood stem cells? How can we make cord blood registration services available most of the time for donation?
5. How can we create a successful system in hospitals? What kind of guidelines and policies are required to make cord blood donation services available for expectant mothers whenever needed?
6. Do you think a donor family needs the advice from their healthcare provider to opt for public donation? Can the healthcare provider help them make the right decision? Explain your statement.

## Appendix 12. Expectant Mothers' Survey in English along with the Consent Form

### Consent Form

The questionnaire at hand is part of a research effort to study the barriers, motivators and incentives toward cord blood donation in the UAE, to improve cord blood awareness and education.

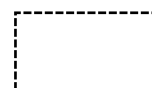
I understand that I will complete a simple questionnaire testing my level of knowledge about the importance of cord blood stem cells, banking options that I would choose and the different sources that I want to gain information from.

I understand that my participation in this study is entirely voluntary and I am free to refuse to participate in this study.

All information gathered for this study will be used by investigators for research, and publications provided that I will not be identified in any published report.

I confirm my approval to participate in this study.

Signature .....



Date:.....Hospital/Center:.....  
... Nationality:.....

**1- What is your age group?**

- a- 15 – 20 years
- b- 21 – 30 years
- c- 31 – 40 years
- d- 40 years and above

**2- What is your level of education?**

- a- Lower than High School
- b- High School
- c- Diploma
- d- University Graduate Degree
- e- Postgraduate University Degree

**3- Did you know that there is a cord blood bank at Dubai Health Authority?**

- a- Yes
- b- No

**4- Do you have information about the importance of Umbilical cord blood stem cells?**

- a- Yes
- b- No

**5- What are the different sources that you would prefer to receive information about umbilical cord blood stem-cell and banking options from?**

- a- Physicians : 1- Gynecologists                      2 -Hematologists 3- Pediatricians
- b- Nurses
- c- Educators form Dubai Cord Blood Centre
- d- Awareness campaigns

- e- DCRC Brochures
  - f- Social media networks
  - g- All of the above
  - h- Others, specify.....
- 6- What is the best time that you would like to receive information about the importance of umbilical cord blood and banking options?**
- a- Before getting pregnant
  - b- Antenatal Clinics
  - c- While doing pre-marital screening tests
  - d- While registering at the DCRC
  - e- Ladies' Schools & Universities
  - f- Others, specify .....
- 7- If you registered at the Dubai Cord Blood & Research Centre, which choice of cord blood banking would you go for?**
- a- Private (preserve your baby's unit for baby's family) ... answer questions (8/11)
  - b- Public (donate your baby's unit to other patients) ... answer questions (9/10/12)
  - c- I do not want to go for private or public bank ... answer questions (9 /11)
- 8- What are the reasons that would encourage you to privately preserve your baby's umbilical cord blood?**
- a- It is an act influenced by media
  - b- It is a community tradition
  - c- It is an assurance for the baby's health
  - d- Urgent need by a family member or a friend
  - e- Others, specify .....
- 9- What reasons would discourage you from privately preserving your baby's umbilical cord blood?**
- a- Lack of information about the importance of cord blood stem cell
  - b- No family history for any life-threatening disease
  - c- Fear of any risks to the mother or the baby during cord blood collection
  - d- Would like to publicly donate my baby's cord blood to help other patients
  - e- Expensive fees
  - f- Husband's disapproval to preserve my baby's cord blood
  - g- I do not believe in stem cell therapy
  - h- Others, specify.....

**10- What are the reasons that would encourage you to publicly donate your baby's umbilical cord blood?**

- a- It is a humanitarian and noble act
- b- It helps in treating other patients with life-threatening disease
- c- It is free of cost
- d- Provide us with Islamic documents supporting umbilical cord blood donation
- e- Media advertising campaigns
- f- Advice and information provided to me by the doctors
- g- Share some successful transplantation stories
- h- Personal satisfaction by helping others to benefit from my baby's cord blood
- i- Others, specify.....

**11- What reasons would discourage you from publicly donating your baby's umbilical cord blood?**

- a- Lack of information about the importance of publicly donating my baby's cord blood
- b- Fear of any risks to the mother or the baby during cord blood collection
- c- Might find out that I have a disease
- d- Not knowing the final destination of my baby's cord blood after donation
- e- I do not believe in stem cell therapy
- f- I do not know the Islamic view regarding cord blood donation
- g- I am going to deliver at a private hospital
- h- Husband's disapproval to donate my baby's cord blood
- i- Others , specify .....

**12- How would you like to be rewarded for publicly donating your baby's umbilical cord blood?**

- a- Social acknowledgment by receiving certificates, medals, membership cards
- b- Praise in public events for being a donor
- c- Financial Reward
- d- No rewards are needed because it is my duty to the society

### Appendix 13. Expectant Mothers Survey in Arabic Along with the Consent Form

#### نموذج موافقة على المشاركة في بحث

أنا الموقعة أدناه أقر بمشاركتي في البحث الذي يعنى بفهم أفضل للمعوقات و المحفزات التي تؤثر سلباً أو إيجاباً على عملية التبرع بدم الحبل السري في دولة الإمارات العربية المتحدة ، وسبل تطوير و تحسين أساليب التثقيف و التوعية بموضوع دم الحبل السري .

و قد أعلمت بأن ذلك يتطلب مني الإجابة على نموذج مسح استبباني بسيط ، يقاس من خلاله مستوى معلوماتي حول موضوع أهمية الخلايا الجذعية لدم الحبل السري ، و خيارات التخزين التي أرغب باختيارها و المصادر التي أود من خلالها الحصول على المعلومات المتعلقة بموضوع الخلايا الجذعية لدم الحبل السري.

كما علمت أن مشاركتي في هذا البحث هي مشاركة تطوعية و لي كامل الحرية في رفض المشاركة دون أن يؤثر ذلك علي بأي شكل من الأشكال.

و أن جميع البيانات المقدمة ستعامل بسرية تامة ، و أن المعلومات و النتائج المستخلصة من هذه الدراسة قد يتم نشرها في الدوريات و المجلات العالمية دون الإشارة إلى أي معلومات عني.

و هذا إقرار مني بذلك ،

التوقيع .....





التاريخ : ..... المستشفى/المركز : .....  
الجنسية : .....

**1- الفئة العمرية ؟**

- أ- 15- 20 سنة
- ب- 21- 30 سنة
- ت- 31- 40 سنة
- ث- 40 سنة فما فوق

**2- المستوى التعليمي ؟**

- أ- أقل من الثانوية العامة
- ب- ثانوية عامة
- ت- دبلوم
- ث- شهادة جامعية
- ج- شهادة جامعية عليا

**3- هل تعلمين أن هناك مركز لتخزين دم الحبل السري في هيئة الصحة بدبي؟**

- أ- نعم
- ب- لا

**4- هل لديك معلومات عن أهمية الخلايا الجذعية لدم الحبل السري؟**

- أ- نعم
- ب- لا

**5- برأيك، ما هي المصادر التي تودين من خلالها الحصول على المعلومات عن أهمية دم الحبل السري و خيارات التخزين؟**

- أ- أطباء: 1- النساء و التوليد 2- أخصائي أمراض الدم 3- أخصائي الأطفال
- ب- الممرضات
- ت- المثقف الصحي من مركز دبي لدم الحبل السري و الأبحاث
- ث- الحملات التوعوية و التثقيفية

- ج- كتيبات مركز دبي لدم الحبل السري
- ح- شبكات التواصل الاجتماعي
- خ- جميع ما سبق
- د- مصادر أخرى، يرجى التحديد.....

6- أي من المراحل التالية برأيك هي الأفضل لتقديم المعلومات عن أهمية دم الحبل السري و خيارات التخزين؟

- أ- قبل الحمل
- ب- عيادات النساء و التوليد
- ت- عند إجراء فحوصات ما قبل الزواج
- ث- عند التسجيل في مركز دبي لدم الحبل السري
- ج- خلال المرحلة الثانوية و الجامعية للطالبات
- ح- جميع ما سبق
- خ- مراحل أخرى ، يرجى التحديد

7- إذا قمت بالتسجيل معنا في مركز دبي لدم الحبل السري و الأبحاث ، فأَي من أنواع التخزين ترغبين ؟

- أ- الاحتفاظ الخاص ( تخزين وحدة دم الحبل السري لأحد أقرباء الطفل) (يرجى الإجابة على سؤال (8 و 11))
- ب- التبرع العام ( إعطاء وحدة دم الحبل السري لأي من المرضى المحتاجين) ( يرجى الإجابة على سؤال (9 و 10 و 12))
- ت- لا أرغب بالاحتفاظ أو التبرع ( يرجى الإجابة على سؤال (9 و 11))

8- ما هي الأسباب التي دفعتك لاختيار بنك الاحتفاظ الخاص؟

- أ- لأنه عمل متأثر بالترويج الإعلامي
- ب- الرغبة في تقليد الآخرين
- ت- ضمان لصحة الطفل مستقبلا
- ث- الحاجة الطارئة لدم الحبل السري من قبل أحد أفراد العائلة أو الأصدقاء
- ج- أسباب أخرى ، يرجى التحديد

9- ما هي الأسباب التي تمنعك من الاحتفاظ الخاص بدم الحبل السري لطفلك ؟

- أ- ليست لدي المعلومات الكافية عن أهمية الموضوع
- ب- لا يوجد لدينا أي تاريخ وراثي مرضي في العائلة
- ت- الخوف من الأضرار التي من الممكن أن تلحق بالأم أو الطفل عند عملية تجميع دم الحبل السري
- ث- أرغب بالتبرع العام بوحدة دم الحبل السري لطفلي لأي مريض محتاج
- ج- القدرة المالية و ارتفاع تكلفة الاحتفاظ الخاص
- ح- عدم موافقة الزوج لرغبتي بالاحتفاظ بدم الحبل السري
- خ- لا أؤمن / غير مقتنعة بالعلاج بالخلايا الجذعية لدم الحبل السري

د- أسباب أخرى ، يرجى التحديد .....

**10- ما هي الأسباب التي دفعتك لاختيار بنك التبرع العام؟**

- أ- عمل إنساني و نبيل
- ب- من الممكن أن يساعد في علاج المرضى الآخرين
- ت- التبرع مجاني
- ث- وجود فتاوى شرعية متعلقة بموضوع التبرع بدم الحبل السري
- ج- حملات التوعية الاجتماعية
- ح- نصيحة و معلومات موفرة لي من قبل الطبيب
- خ- وجود شواهد حية لحالات تم علاجها بدم الحبل السري
- د- الشعور بالرضى من خلال مساعدة الآخرين بالاستفادة من دم الحبل السري لطفلي
- ذ- أسباب أخرى ، يرجى التحديد .....

**11- ما هي الأسباب التي تمنعك من التبرع العام بدم الحبل السري لطفلك ؟**

- أ- ليست لدي المعلومات الكافية عن أهمية التبرع العام بدم الحبل السري لطفلي
- ب- الخوف من الأضرار التي من الممكن أن تلحق بالأم أو الطفل عند عملية تجميع دم الحبل السري
- ت- بعض الفحوصات الطبية قد تكشف حالتي الصحية
- ث- عدم معرفة الوجهة النهائية لوحدة دم الحبل السري لطفلي بعد التبرع بها
- ج- لا أؤمن/ غير مقتنعة بالعلاج بالخلايا الجذعية لدم الحبل السري
- ح- لا أعلم وجهة النظر الدينية حول موضوع التبرع العام بدم الحبل السري
- خ- ولادتي ستكون في مستشفى خاص
- د- عدم موافقة الزوج لرغبتي بالتبرع بدم الحبل السري
- ذ- أسباب أخرى، يرجى التحديد

**12- كيف ترغبين أن تكافئي على تبرعك بدم الحبل السري لطفلك؟**

- أ- التقدير الأدبي (الرمزي) من خلال حصولي على ميداليات و شهادات
- ب- الاشادة في المناسبات العامة لكوني متبرعة
- ت- مكافأة مالية
- ث- لا أحتاج مكافأة لأنها خدمة اجتماعية

## **Appendix 14. Healthcare Providers' Survey Along with the Consent Form**

### **Consent Form**

I understand that I will complete a simple questionnaire, which is part of research studying the level of knowledge among the Physicians and health care professionals about umbilical cord blood stem cells and the banking options for their patients, and that my participation in this study is entirely voluntary and I am free to refuse to participate in this study at any time.

I also understand that all the information gathered for this study will be used by investigators for research and publications, provided that I will not be identified in any published report.

**Please state your occupation:**

- ☐ Nurse                      ☐ Gynecologist                      ☐ Pediatric                      ☐ Hematologist  
☐ Oncologist                      ☒ Others, Specify.....

I confirm my approval to participate in this study.

Signature .....

Date:.....  
Hospital:.....  
Nationality:.....

**1- What is your age group?**

- a- 20 – 30 years
- b- 31 – 40 years
- c- 41 – 50 years
- d- 50 years and above

**2- What is your role within the Department?**

- a- Consultant
- b- Senior Specialist
- c- Specialist
- d- General Practitioner
- e- Registrar
- f- Others, Specify .....

**3- Do you know that there is cord blood banking facility in DHA?**

- a- Yes
- b- N

**4- How would you rate your level of Knowledge about umbilical cord blood stem cell?**

- a- Excellent
- b- Very Good
- c- Good
- d- Little
- e- Fair

**5- What are the different sources that you would prefer to enhance your knowledge about umbilical cord blood stem cells?**

- a- Conferences
- b- CME lectures

- c- Social media
- d- Electronic Mail (E-mail)
- e- Educational courses
- f- Awareness Campaign
- g- All of the above
- h- Others, specify.....

**6- Do you think that it is important to share information about Umbilical cord blood stem cells with your patients?**

- a- Strongly agree
- b- Agree
- c- Neutral
- d- Disagree
- e- Strongly disagree

**7- If you “disagree or strongly disagree” what are the reasons that would prevent you from sharing information about umbilical cord blood stem cells with your patients ?**

- a- Not enough information about the importance of cord blood stem cells
- b- Not believing in stem cell therapy
- c- I am not the one responsible to educate my patients about this topic
- d- Busy schedule, I do not have time to share information
- e- All of the above
- f- Other, specify .....

**8- What are the best sources to provide patients with information about umbilical cord blood stem cells?**

- a- Physician
- b- Nurses
- c- Cord blood educators from the DCRC
- d- Brochures and leaflet
- e- Awareness campaign
- f- Social Media Networks
- g- All of the above
- h- Others, specify.....

**9- When do you think is the best time to provide patients with information about umbilical cord blood stem cells?**

- a-** Before getting pregnant
- b-** Antenatal clinic
- c-** While doing pre-marital screening tests
- d-** While registering at the DCRC
- e-** At school and university age
- f-** All of the above
- g-** Others, specify .....

**10- Which banking options do you encourage your patients to go for?**

- a-** Public Banking (Donate their baby's cord blood to any other patients)... **Answer Question (11)**
- b-** Private banking (Preserve their baby's cord blood for their family)... **Answer Question (12)**

**11- If you encourage your patients to opt for “public donation” what are the reasons?**

- a-** It is a humanitarian and noble act
- b-** It help in treating other patients with life-threatening disease
- c-** To increase number of donors within stem cell registry
- d-** It is free of cost
- e-** All of the above
- f-** Others, specify .....

**12- If you encourage your patients to opt for “private donation” what are the reasons?**

- a-** It is an act influenced by media
- b-** It is a community tradition
- c-** It is an assurance for the baby's health
- d-** Urgent need by a family member or friend
- e-** Family history of hereditary disease
- f-** All of the above
- g-** Others, specify .....

**13- On the patient's next visit to you, do you follow up the subject of umbilical cord blood banking with them?**

**a-** Yes

**b-** No

**14- If “No” what are the reasons?**

**a-** Patients referred to other doctors

**b-** I do not think it is important to remind them again

**c-** Busy schedule, I do not have time

**d-** All of the above

**e-** Others, Specify



## Appendix 15. Results Obtained from Expectant Mothers' Surveys



**PATHOLOGY AND GENETICS DEPARTMENT**  
DEVELOPMENT AND FOLLOW UP SECTION  
LABORATORY INFORMATION SYSTEM UNIT  
**DCRC - Mothers Survey**

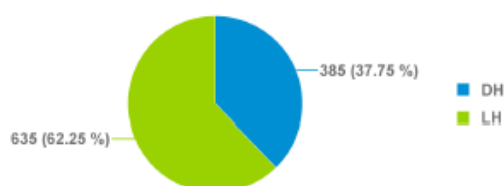


### Survey Participation

Total Count 1,020

#### Survey Participation by Hospital

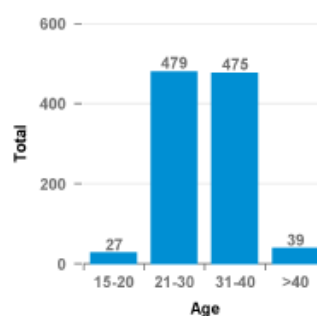
Hospital/Center	Total Count	Total Percen
DH	385	37.75%
LH	635	62.25%



#### Survey Participation by Age v/s Nationality

Nationality	Count	15-20	21-30	31-40	40 and above
UAE	631	17	290	293	31
NM	81	3	37	41	
Indian	79		36	43	
Yemen	32	2	19	9	2
Omani	19	1	10	8	
Pakistani	18	1	8	9	
Iran	17	1	9	7	
Egypt	12		6	5	1
Comoros	11	1	5	5	
Sudan	11		3	7	1
Syria	11		7	4	
Filipino	9		3	6	
Jordan	9		5	4	
Morocco	9		5	4	
Palestine	8		4	4	
Saudi	7	1	6		
Iraq	5		2	3	
Bahrain	4		3		1
Lebanese	4		1	2	1
Russian	3			3	
Tanzanian	3		1	2	

Q1 Age a- 15-20	27	2.65%
Q1 Age b- 21-30	479	46.96%
Q1 Age c- 31-40	475	46.57%
Q1 Age d- 40 and above	39	3.82%



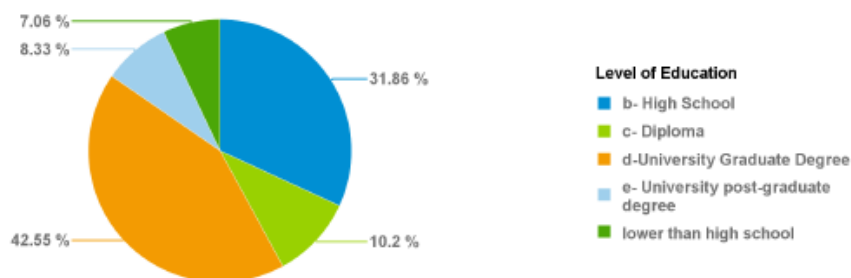
Prepared by LIS Team.

DCRC - Mothers Survey

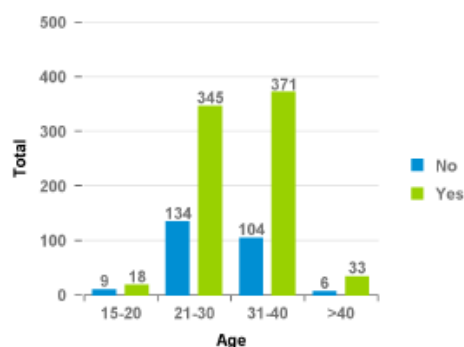
??	2			1	1
china	2		2		
China	2		1	1	
Libya	2		1	1	
Philippine	2			2	
Qatar	2		2		
Bangladesh	1		1		
Bangladesh	1		1		
British	1		1		
Canadian	1		1		
Eretria	1			1	
French	1			1	
Germany	1		1		
Indonesian	1			1	
Iranian	1			1	
Irish	1		1		
Kazakhstan	1		1		
Lebanon	1		1		
Mauritania	1			1	
Moldavian	1		1		
Moldova	1			1	
Nigeria	1			1	
OzPakistan	1			1	
Romania	1			1	
Tajikistan	1			1	
Thailand	1		1		
Tunais	1		1		
Tunisian	1				1
Ukraine	1		1		
Ukrainian	1			1	
UZB	1		1		

## Survey Analysis

### 2- What is your level of education ?

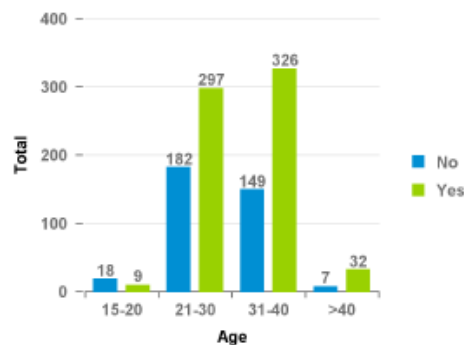


### 3- Did you Know that there is Cord Blood Bank at DHA?



	No	Yes
15-20	9 (0.88%)	18 (1.76%)
21-30	134 (13.14%)	345 (33.82%)
31-40	104 (10.2%)	371 (36.37%)
>40	6 (0.59%)	33 (3.24%)
Total	253 (24.8%)	767 (75.2%)

### 4- Do you have information about the importance of UCB stem cells?



	No	Yes
15-20	18 (1.76%)	9 (0.88%)
21-30	182 (17.84%)	297 (29.12%)
31-40	149 (14.61%)	326 (31.96%)
>40	7 (0.69%)	32 (3.14%)
Total	356 (34.9%)	664 (65.1%)

		Did you Know that there is Cord Blood Bank at DHA?	
		No	Yes
Do you have information about the importance of UCB stem cells?	No	197	159
	Yes	56	608

## Survey Analysis

5- what are the different sources that you would prefer to receive information about UCB stem cell and banking options ?

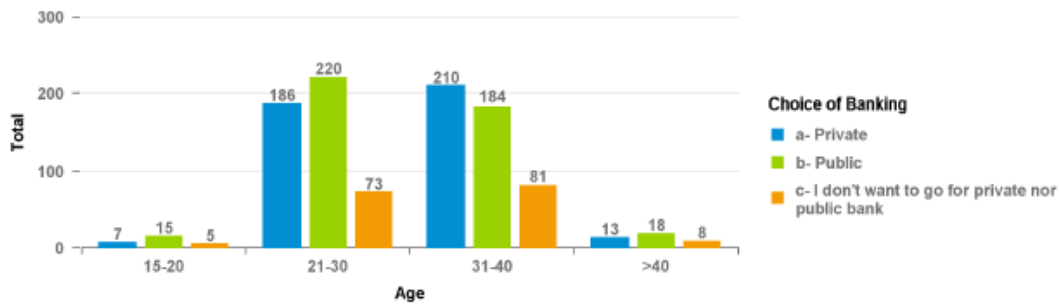
	15-20		21-30		31-40		>40		Total :	
a-Physician 1-Gynecology	7	0.69%	151	14.82%	108	10.60%	10	0.98%	276	27.09%
a-Physician 2-Hematologists			11	1.08%	8	0.79%	1	0.10%	20	1.96%
a-Physician 3-Pediatricians	1	0.10%			2	0.20%			3	0.29%
b- Nurses			5	0.49%	9	0.88%			14	1.37%
c- Educators from DCRC	4	0.39%	54	5.30%	76	7.46%	8	0.79%	142	13.94%
d- Awareness Campaign			28	2.75%	29	2.85%	2	0.20%	59	5.79%
e- DCRC brochures	1	0.10%	30	2.94%	42	4.12%	4	0.39%	77	7.56%
f- Social Media Network	4	0.39%	25	2.45%	21	2.06%	3	0.29%	53	5.20%
g- All of the above	10	0.98%	172	16.88%	179	17.57%	11	1.08%	372	36.51%
h- others, Specify			3	0.29%					3	0.29%

6- what is the best time that you would like to receive information about the importance of UCB & banking options ?

	15-20		21-30		31-40		>40		Total :	
a- before getting pregnant	4	0.39%	105	10.29%	81	7.94%	7	0.69%	197	19.31%
b- Antenatal clinics	6	0.59%	161	15.78%	161	15.78%	12	1.18%	340	33.33%
c- while doing premarital screening	2	0.20%	30	2.94%	22	2.16%	2	0.20%	56	5.49%
d- while registering at DCRC	3	0.29%	18	1.76%	11	1.08%			32	3.14%
e- Ladies School & University	1	0.10%	31	3.04%	29	2.84%	5	0.49%	66	6.47%
f- All of the above	11	1.08%	131	12.84%	170	16.67%	13	1.27%	325	31.86%
g- Others, Specify			3	0.29%	1	0.10%			4	0.39%

7- if you registered at DCRC which choice of CB banking would you go for?

	15-20		21-30		31-40		>40		Total :	
a- Private	7	0.69%	186	18.24%	210	20.59%	13	1.27%	416	40.78%
b- Public	15	1.47%	220	21.57%	184	18.04%	18	1.76%	437	42.84%
c- I don't want to go for private nor public bank	5	0.49%	73	7.16%	81	7.94%	8	0.78%	167	16.37%



8- what are the reasons that would encourage you to privately preserve your baby's UCB?

	15-20		21-30		31-40		>40		Total :	
a- It's an act influenced by media	1	0.19%	7	1.31%	1	0.19%			9	1.69%
b- It is a community tradition			1	0.19%	1	0.19%			2	0.37%
c- It is an assurance for the baby's health	3	0.56%	166	31.09%	159	29.78%	11	2.06%	339	63.48%
d- Urgent need by a family member or a friend	4	0.75%	65	12.17%	86	16.10%	11	2.06%	166	31.09%
e- others, specify...	1	0.19%	12	2.25%	4	0.75%	1	0.19%	18	3.37%

9- What reasons would prevent you from privately preserving your baby's umbilical cord blood ?

	15-20		21-30		31-40		>40		Total :	
a- Lack of information about the importance of cord blood stem cell	9	1.28%	85	12.06%	69	9.79%	4	0.57%	167	23.69%
b- No family history for any life-threatening disease	3	0.43%	62	8.79%	58	8.23%	4	0.57%	127	18.01%
c- Fear of any risks to the mother or the baby during cord blood collection			16	2.27%	21	2.98%	2	0.28%	39	5.53%
d- Would like to publicly donate my baby's cord blood to help other patients	5	0.71%	108	15.32%	98	13.90%	11	1.56%	222	31.49%
e- Expensive fees	2	0.28%	42	5.96%	46	6.52%	6	0.85%	96	13.62%
f- Husband disapproval to preserve my baby's cord blood			7	0.99%	14	1.99%			21	2.98%
g- I don't believe in stem cell therapy	1	0.14%	3	0.43%	3	0.43%	1	0.14%	8	1.13%
Others, specify...	1	0.14%	11	1.56%	11	1.56%	2	0.28%	25	3.55%

10- What are the reasons that would encourage you to publicly donate your baby's UCB?

	15-20		21-30		31-40		>40		Total :	
a- It is humanitarian and noble act	4	0.73%	115	20.91%	102	18.55%	10	1.82%	231	42.00%
b- It helps in treating other patients with life-threatening disease	6	1.09%	89	16.18%	74	13.45%	7	1.27%	176	32.00%
c- It's free of cost	2	0.36%	8	1.45%	9	1.64%	1	0.18%	20	3.64%
d- Provide us with Islamic documents supporting umbilical cord blood donation	1	0.18%	4	0.73%	3	0.55%			8	1.45%
e- Media advertising campaigns	1	0.18%	6	1.09%	7	1.27%			14	2.55%
f- Advice and information provided to me by the doctors			3	0.55%	4	0.73%	1	0.18%	8	1.45%
g- Share some successful transplantation stories			5	0.91%	10	1.82%			15	2.73%
h- Personal satisfaction by helping others to benefit from my baby's cord blood	3	0.55%	30	5.45%	31	5.64%	4	0.73%	68	12.36%
i- Others, specify			7	1.27%	3	0.55%			10	1.82%

## Survey Analysis

### 11- What reasons would prevent you from publicly donating your baby's umbilical cord blood?

	15-20		21-30		31-40		>40		Total :	
a- Lack of information about the importance of publicly donating my baby's cord blood	9	1.33%	97	14.35%	105	15.53%	5	0.74%	216	31.95%
b- Fear of any risks to the mother or the baby during cord blood collection	2	0.30%	46	6.80%	50	7.40%	3	0.44%	101	14.94%
c- Might find out that I have a disease	1	0.15%	20	2.96%	12	1.78%	1	0.15%	34	5.03%
e- not knowing the final destination for my baby's cord blood after donation	1	0.15%	27	3.99%	37	5.47%	2	0.30%	67	9.91%
f- I don't believe in stem cell therapy			5	0.74%	2	0.30%	1	0.15%	8	1.18%
g- I don't know the Islamic view regarding cord blood donation			34	5.03%	24	3.55%	3	0.44%	61	9.02%
h- I am going to deliver at private hospital			13	1.92%	9	1.33%			22	3.25%
i- Husband disapproval to donate my baby's cord blood	1	0.15%	24	3.55%	28	4.14%	1	0.15%	54	7.99%
j- Others , specify	2	0.30%	45	6.66%	58	8.58%	8	1.18%	113	16.72%

### 12- How would you like to be rewarded for publicly donating your baby's cord blood?

	15-20		21-30		31-40		>40		Total :	
a- Social acknowledgment by receiving certificates, medals, membership cards			13	2.24%	15	2.58%	1	0.17%	29	4.99%
b- Praise in public events for being a donor	1	0.17%	9	1.55%	3	0.52%			13	2.24%
c- Financial Reward			6	1.03%	9	1.55%			15	2.58%
d- No rewards are needed because it's my duty to the society	16	2.75%	249	42.86%	235	40.45%	24	4.13%	524	90.19%

## Appendix 16. Results Obtained from Healthcare Providers' Surveys



### PATHOLOGY AND GENETICS DEPARTMENT

DEVELOPMENT AND FOLLOW UP SECTION

LABORATORY INFORMATION SYSTEM UNIT

DCRC Registration Survey 2016

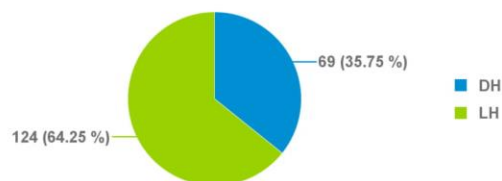


### Survey Participation

Total Count 193

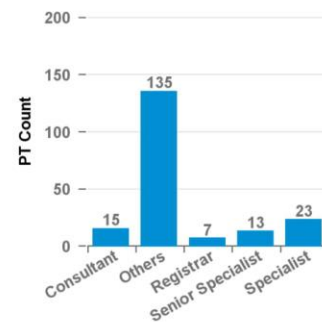
#### Survey Participation by Hospital

Hospital	Total Count	Total Percen
DH	69	35.75%
LH	124	64.25%

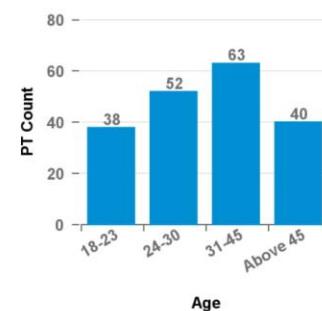


#### Survey by Role within the Department

	18-23	24-30	31-45	Above 45
	38 19.69%	52 26.94%	63 32.64%	40 20.73%
Consultant			6 3.11%	9 4.66%
Others	34 17.62%	30 15.54%	43 22.28%	28 14.51%
Registrar	3 1.55%	2 1.04%	1 0.52%	1 0.52%
Senior Specialist		3 1.55%	8 4.15%	2 1.04%
Specialist	1 0.52%	17 8.81%	5 2.59%	



	Total	DH	LH
		69 35.75%	124 64.25%
18-23	38 19.69%	11 5.70%	27 13.99%
24-30	52 26.94%	15 7.77%	37 19.17%
31-45	63 32.64%	28 14.51%	35 18.13%
Above 45	40 20.73%	15 7.77%	25 12.95%

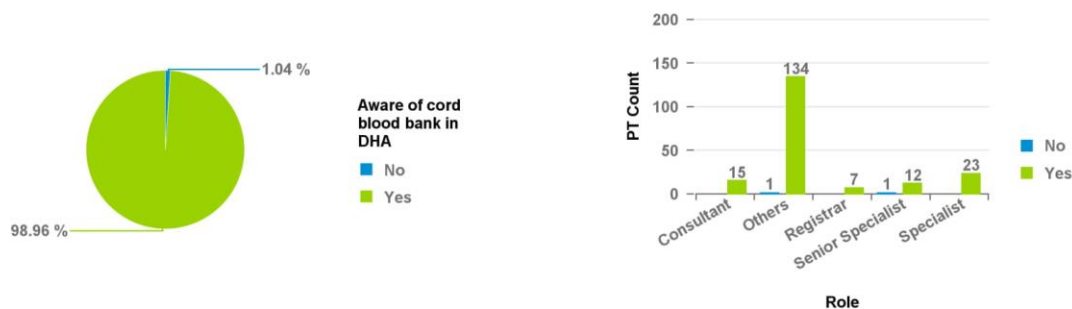


Prepared by LIS Team.

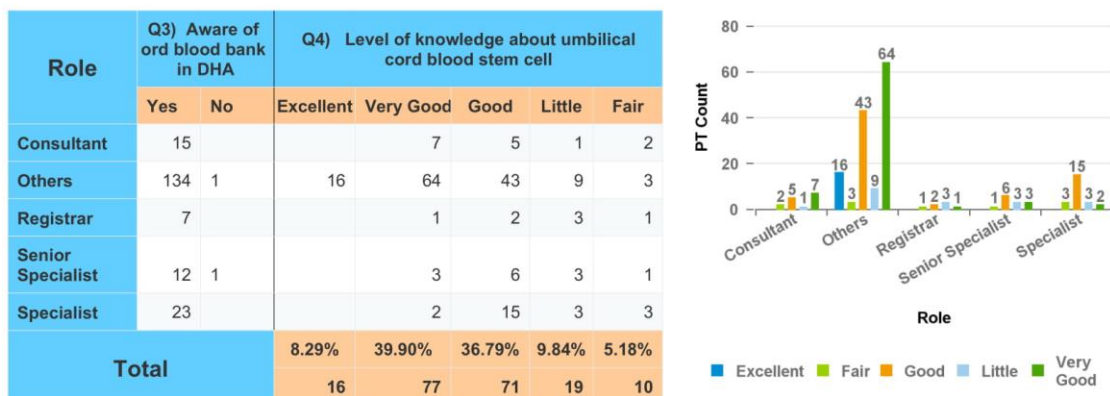


## Survey Analysis

### 3- Do you know that there is cord blood banking facility in DHA?



### 4- How would you rate your level of knowledge about umbilical cord blood stem cell?



Role	5- What are the different sources that you would prefer to enhance your knowledge about umbilical cord blood stem cell?							
	Conferences	CME lectures	Social media	Email	Educational Courses	Awareness Campaign	All of the above	Others
Consultant	2 (1.04)%	2 (1.04)%	1 (0.52)%	1 (0.52)%	1 (0.52)%	3 (1.55)%	8 (4.15)%	
Others	13 (6.74)%	26 (13.47)%	11 (5.7)%	7 (3.63)%	22 (11.4)%	15 (7.77)%	90 (46.63)%	
Registrar		3 (1.55)%					4 (2.07)%	
Senior Specialist	1 (0.52)%	2 (1.04)%	1 (0.52)%	1 (0.52)%	3 (1.55)%	3 (1.55)%	5 (2.59)%	
Specialist	3 (1.55)%	7 (3.63)%	4 (2.07)%	1 (0.52)%	5 (2.59)%	1 (0.52)%	10 (5.18)%	
<b>Total</b>	9.84% 19	20.73% 40	8.81% 17	5.18% 10	16.06% 31	11.40% 22	60.62% 117	

Prepared by LIS Team.

## Survey Analysis

6- Do you think that it is important to share information about umbilical cord blood stem cell with your patients?

Role	Strongly agree		Agree		Neutral		Disagree		Strongly disagree	
Consultant	9	7.96%	4	5.56%			2	100.00%		
Others									1	50.00%
Others	87	76.99%	45	62.50%	1	33.33%				
Registrar	4	3.54%	3	4.17%						
Senior Specialist									1	50.00%
Senior Specialist	7	6.19%	5	6.94%						
Specialist	6	5.31%	15	20.83%	2	66.67%				
Total	113		72		3		2		2	
	58.55%		37.31%		1.55%		1.04%		1.04%	

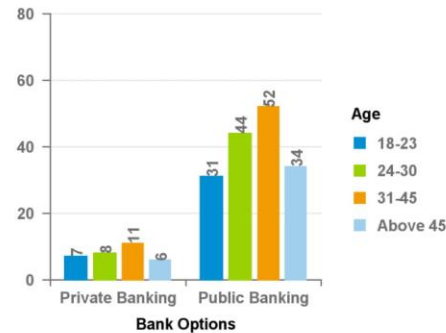
7- If you "disagree or strongly disagree" what are the reasons that would prevent you from sharing information about umbilical cord blood stem cell with your patients?

Q7 Reasons a-Not enough information about the importance of cord blood stem	14	7.25%
Q7 Reasons b- Not believing in stem cell therapy		
Q7 Reasons c- I am not the one responsible to educate my patients about this topic	6	3.11%
Q7 Reasons d- Busy Schedule, I don't have time to share information	13	6.74%
Q7 Reasons e- All of the above	9	4.66%
Q7 Reasons f- Other, specify....	4	2.07%

## Survey Analysis

### 10- Which bank options do you encourage your patients to go for?

	Private Banking	Public Banking
Consultant	3	12
Others	17	118
Registrar	4	3
Senior Specialist	1	12
Specialist	7	16



### 11- If you encourage your patients to opt "public donation" what are the reasons?

Q11 Public Donation a-It's humanitarian and noble act	17	8.81%
Q11 Public Donation b- It help in treating other patients with life-threatening disease	29	15.03%
Q11 Public Donation c- To increase number of donors within stem cell registry	4	2.07%
Q11 Public Donation d- It is free of cost	7	3.63%
Q11 Public Donation e- All of the above	138	71.50%
Q11 Public Donation f- Other, specify....	1	0.52%

### 12- If you encourage your patients to opt "private donation" what are the reasons?

Q12 Private Donation a-It is and act influenced by media	1	0.52%
Q12 Private Donation b- It is a community tradition	4	2.07%
Q12 Private Donation c-It is an assurance for the baby's health	27	13.99%
Q12 Private Donation d-Urgent need by a family member or friend	47	24.35%
Q12 Private Donation e-Family history of hereditary disease	63	32.64%
Q12 Private Donation f- All of the above	51	26.42%
Q12 Private Donation g- Others, Specify.....	1	0.52%

## Appendix 15.

### Appendix 17. Direct Quotes Obtained from All Healthcare Providers Highlighting the Need for a Healthcare Educator from DCRC in the Hospital Clinic

Question 6: Who do you think is responsible of providing information about the potential value of publically donating cord blood stem cells and why did you choose your answer?	
Antenatal Nurse	<p>1- <i>“Everyone should inform the patient, the doctors, the nurses the paramedic, breastfeeding education. Everybody should have basic information and everybody should guide the patient but specific education should be DCRC staff because they know more details”.</i></p> <p>2- <i>“Healthcare can help but more information can be given by DCRC staff because our knowledge is limited. If we are more educated then later on we can be also be one of the educators. I feel that among all the knowledge is poor. I do not think we can educate the mothers”.</i></p> <p>3- <i>“I think from the DCRC department you are the people who know more about cord blood donation, for education someday from your department should come and explain for them then they will get adequate knowledge, if I will go and teach the mother they will ask questions I do not know too much about these things I cannot answer their questions”.</i></p> <p>4- <i>“DCRC staff are the ones who know more, we do not know much and they can give information. Others can help but they have other work to do, they cannot give more information”.</i></p> <p>5- <i>“When they come to clinic our staff and doctors, but it is better to have staff from DCRC who are specialised to give more information about cord blood”.</i></p> <p>6- <i>“All responsible, everybody, and also responsible person from DCRC”.</i></p>
Delivery Ward	<p>1- <i>“This has to be educated in the antenatal clinic, some educator need to be there either from DCRC or staff side, and also</i></p>

Nurse	<p><i>antenatal wards is good place to educate the mothers and take their consent”.</i></p> <p>2- <i>“Either DCRC people or in antenatal clinic like how we do in breastfeeding education. Doctors, nurses and DCRC members and mainly gynecologists in antenatal as this time is the best time. Here at delivery patients who come are in pain and it is hard to educate them. Nurse can help but DCRC people are important to be present”.</i></p> <p>3- <i>“All healthcare members have to be involved; it is a team activity, DCRC cannot do it alone, when pregnant women come to the antenatal clinic doctors should tell the patient about cord blood facility in the hospital”.</i></p> <p>4- <i>“I think the main responsibilities should be shared with DCRC staff but they can utilise and train some healthcare providers for the purpose of this. It has to be initiated by DCRC and the proper education should be given by DCRC”.</i></p> <p>5- <i>“Definitely the first people should be DCRC staff then we need to start like a breastfeeding clinic so who is coming for booking can be educated about cord blood. A lot of patients after delivery will ask the nurse to keep this placenta which means they heard about it but they do not know exactly the procedure”.</i></p> <p>6- <i>“People who are in charge of the cord blood centre should explain at the beginning they are the one but later some people can help them explain or they can have brochures for patients to read”.</i></p> <p>7- <i>“I think first in the antenatal clinic doctors and nurses and health workers also have same responsibility as when the mother comes to the antenatal clinic they need to give a brochure and tell them the importance of it and also the team from DCRC”.</i></p> <p>8- <i>I think the health educator from DCRC should be in the ANC clinic in the labour room not the correct place because they are in labour and pain. Maybe a group of nurses can help in ANC”.</i></p> <p>9- <i>“Responsibility I feel when the patient comes for antenatal checkup they should give information about this and they also need DCRC staff to come and explain for them. I feel ANC is the</i></p>
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	<p><i>best place to take consent also”.</i></p> <p>10- <i>“It is the responsibility of DCRC and Gynae doctors, because we are the one who are seeing the patients in antenatal”.</i></p> <p>11- <i>“It is everybody’s responsibility, but being an obstetrician that is not my first priority to explain it for her having so many other issues with pregnancy. So I think having an educator in the clinic to inform the patients, and if the patients have any doubts it can be explained as the topic takes time to explain, so giving the full responsibility for the obstetricians to explain it will not work, it should be especial educator there in each obstetric clinic and patients should be given opportunity to ask”.</i></p> <p>12- <i>“I think there should be dedicated person in the clinic because when we see the patient we do not have much time to talk about this thing so I think especial person should be sitting in the clinic to educate and encourage the usage of cord blood, like how we have for breastfeeding”.</i></p>
<b>Obstetricians and Gynecologist</b>	<p>1- <i>“All healthcare providers doctors, nurses, DCRC, everybody”.</i></p> <p>2- <i>“I think it should start from the DCRC educator and at the same time it can be reinforced by the doctors so you can locate educational leaflets in the doctors’ room and in the antenatal clinic”.</i></p> <p>3- <i>“I think all healthcare providers should contribute and take part in that education, I have a suggestion. I think we can ask for help from cord blood to give good information about cord blood”.</i></p> <p>4- <i>“I think cord blood banking are responsible or somebody specialised in blood diseases who knows how it will benefit patients in the future, I think Gynae are busy maybe the midwives and nurses are better because they are with the patients all the time”.</i></p> <p>5- <i>“It is the responsibility of the cord blood centre and also the doctors”.</i></p> <p>6- <i>“I think all healthcare providers should be giving information about it even the nurse and doctors and healthcare educator, everywhere they should receive information about it”.</i></p>

	<p>7- <i>“It is the responsibility of DCRC and Gynae doctors, because we are the ones who are seeing the patients in antenatal”.</i></p> <p>8- <i>It is everybody’s responsibility, but being an obstetrician that is not my first priority to explain it for her having so many other issues with pregnancy. So I think having an educator in the clinic to inform the patients and if the patients have any doubts it can be explained as the topic takes time to explain so giving the full responsibility for the obstetricians to explain it will not work, it should be a special educator there in each obstetric clinic and patients should be given the opportunity to ask”.</i></p> <p>9- <i>“I think there should be a dedicated person in the clinic because when we see the patient we do not have much time to talk about this thing, so I think a special person should be sitting in the clinic to educate and encourage the usage of cord blood, like how we have for breastfeeding”.</i></p>
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<p><b>Pediatricians</b></p>	<ol style="list-style-type: none"> <li>1- <i>Cord blood centre has to do it, nobody else is going to do it for you, you and your staff. I do not think the medical staff will help on that because at the end its “your baby you need to take care of it”, for example, even you tell us to tell our patients just in case if she is pregnant again, you think she will remember it will not work”.</i></li> <li>2- <i>“For my experience, I think for every mother who attends the clinic in the hospital, at least one member from DCRC must meet them and explain to her all the issues”.</i></li> <li>3- <i>Each member of the team in breastfeeding will talk to her and her husband about the benefit of breastfeeding and what we should do so the baby gets only breast milk; the same thing we should do for cord blood”.</i></li> <li>4- <i>“It can be nurse, staff from cord blood, can be Gynae because they see the mother frequently; the pediatricians they rarely see the patients and if they see it will be after the delivery”.</i></li> <li>5- <i>“I think the first responsibility are the cord blood centre who is collecting and banking these cells, and then obstetricians who have the direct contact with the mother and see her during pregnancy, and the third one is pediatricians and other physicians to help directing the patients about it”.</i></li> <li>6- <i>Senior physicians working in the cord blood bank, hematologist and oncologist people who are taking care of the cord blood bank, they are the ones who can give the knowledge in details. Gynae too if they have knowledge about it; they are the first people who are involved and see patients”.</i></li> <li>7- <i>“I think starting from physicians in OB Gynae and I think an educator from the cord blood bank and visit the mother and educate her, but the main responsibility is OB Gynae”.</i></li> </ol>
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## **Appendix 18. Success story of the world's first cord blood transplant recipient**

Mathew Farrow, 33-year-old man, married for 10 years and has a 12-year-old son is the first person in the world to have a cord blood transplant. The researcher asked him to share his success story of being the first cord blood transplant recipient in the world. He shared with the researcher his success story by illustrating the main important points within his story:

*Age two and half years old I was diagnosed with Fanconi Anemia and it was a bone marrow failure and needed bone marrow transplant. At the time there were no bone marrow matches in my family. Every single one was tested from my older sister to my parents, my grandparents, anyone in my family, but no match whatsoever. We were going to Duke University medical centre just to get treatment and hopefully to find a match for me to do bone marrow transplant to save my life. I was given until the age of six years old because of my progressive Fanconi Anemia, a lot of adults live until the age of 33 because of no cure so I guess the important part is how my sister came about. My parents were looking not for a replacement but something to ease the burden when they will lose me because there was no match they just wanted another child, not to replace me, just to help ease the burden and also because my older sister would not be alone as well. God decided that he had other plans, that little child that was born was found that she does not have the disease and she was actually a perfect match for bone marrow transplant. However, the way my disease was progressing and by the time my little sister would be old enough to do bone marrow transplant it would probably be too late. So at Duke University where we were going for treatment my family was contacted by Dr. Broxmayer because they were looking for a family who were willing to take part in experimental on treatment and they presented the options to my family and gave them less than 5% chance that this new treatment that will actually work, and if they were to choose this they have to leave the country because the United States will not allow the trial so they will have to leave their family and bring three kids to a foreign country not knowing if one will come back alive with them. My parents decided that it was a very good option and 5% chance is better than none, so they went to Paris-France after my baby sister's cord blood was collected by Dr. Broxmayer and his associates. They counted each little cell by hand and made sure that all was perfect. We went to Paris-France in September 1988 and on October 6 1988 I received my little sister's cord blood at five years old; my little sister was 6 months old. October 6 is my lucky number and it is my mum's dad's birthday so it has been a special number for her as well.*

The researcher asked him his point of view about the importance of cord blood education and awareness nowadays. He stressed in his message about the importance of starting cord blood education in universities and schools and including it in their courses at universities. He said:

*I believe cord blood awareness is essential to everyday life. I believe in making the community more aware of what the differences are between cord blood embryonic stem cells and other types of stem cells. I believe that for us to be more aware of the options out there for people to donate or to bank, educating the public is very important. I think education has to start with doctors having courses in school about cord blood banking and stem cells so that the pediatricians and OBs can talk to their patients and then patients like me will share their stories to help educating and show there is hope in this kind of technology, but I believe that it needs to start with doctors. There is a lot of misinformed information. The public is getting more aware with social media and it is becoming a big thing in cord blood awareness, and there should be more of it done as far as maybe even social events where we can give out information about cord blood and stem cells and what they do and what they treat.*

The researcher also asked him, “To whom you would like to express your gratitude for getting your life back?” and he was so happy to get the chance to answer this question as he said:

*This is an amazing question because the more I find out about my disease itself having no cure and for many years thinking I was cured because of my cord blood transplant I have a different outlook on life itself and know that I’m 33 years old and the chances are getting higher and higher to develop different cancers because of my disease so the biggest gratitude that I take away is I get to see milestones in my life and my parents get to see these milestones as well, of me getting married, buying a house, adopting my child because I cannot have true biological child due to my disease so I have adopted a son who takes up my entire world and helps give me hope and pushes me to continue to do better and stay healthy and stay on top of my medical condition, and I love telling my story and it sharing with people that are going into situations just like my family went through, where they feel like there is no hope and you know being able just to be alive and do not do anything and just people look and say there is hope is very very overwhelming and very gratifying and rewarding.*

The researcher also asked him who he would like to advocate for and he said:

*I advocate a lot for families with my disease now but also really enjoy going to public cord blood sites and showing the nurses and doctors that their hard work for collecting these units is not going unnoticed and there are patients like myself that I have met that have had successful transplant units that were in public cord blood banks and share*

*more of the word “hope” with doctors and nurses working in hospitals as well as families.*

He also highlighted in his interview his gratefulness to these stem cells that are just thrown away as medical waste and it is amazing to see how these cells helped him rebuild his immune system and gave him a second chance in life. He clearly stated that:

*I still carry the disease but not the bone marrow failure along with it and I have 500 to 1000 times more likely of developing certain cancers but I just ensure that I stay healthy with a healthy lifestyle and I feel that I’m very lucky one and blessed and humbled by being here.*

The researcher also asked him to talk about his role within the community and to share with us some ideas and suggestions on the best ways to encourage pregnant women to donate their cord blood stem cells in the UAE. He stressed during his interview about the importance of education and making the family aware about cord blood collection procedure and the fact that there is no harm or risk on either the baby or the mother. He clearly said:

*First of all educate them about what is actually going to be happening to that cord blood, where it may be going and who it might help, and a very big thing is that it is not going to hurt the child to collect cord blood. It is either going to be donated or its going to be thrown away in the trash and there could be life in those stem cells and it is just thrown away sitting in the trash. I think parents who are having a child may enjoy the thought of saving someone’s life in that process and giving someone else a second chance as well. So help to encourage them in that way and just educate them.*

## **Appendix 19. Interview with Dr. Hal Broxmeyer, Founder of the Field of Cord Blood Banking and Transplantation.**

The researcher was honoured to interview Dr. Broxmeyer, the founder of the cord blood transplant field. The researcher wanted to learn more about his successful story and his discovery. Dr. Broxmeyer highlighted that his discovery journey was very interesting as he was working with a fantastic and very co-operative team. The researcher asked him to summarise the story behind Mathew's cord blood transplantation and how they thought of cord blood as a source of stem cells. He said during the interview that it was a very long story but he highlighted the main points:

*I was having a meeting with Dr. Edward Boyse and we had a discussion because Dr. Boyse was interested in cord blood and he thought it will be really good to use these cells for transfusion - collect the white blood cells, red blood cells and the platelets instead of throwing them away and I said that is very interesting but I did not see that would really be fruitful and I said it would probably Hematopoietic stem cells progenitor cells in cord blood and maybe that was something we should work on. So we started the collaboration between Dr. Boyse and myself and his assistant, his wife Judith Bart. At that time Dr. Boyse was the only living member of both the international Academy of Science in the United States and the Royal Society of Medicine in England so he was an immunologist and he really knew nothing about stem cells then. But we liked each other and we got along so I gave him a one-hour personal lecture on stem cell biology as we knew it in the early 1980s. Then afterwards he said, "That sounds great, let's do it and then he said, "We should start a company". I'm a scientist and he is a scientist but he know a lot of good people and one of the people was Dr. Lewis Thomas who was at that time the president of the cancer centre. So Dr. Boyse said, 'Let's go and meet Lewis', so we went to this office. Lewis was very famous and he wrote a lot of books including "The life of a cell" and he knew a lot of very big people so he introduced us to the son of the vice-president of the United States. So Lewis Thomas, Edward Boyse and myself along with other people started our first cord blood company called Biocyte and by that time I have moved out of the university. So I was going back to York to attend meetings with all these famous people and we would sit around the table and we have been talking about cord blood, getting it to really work and getting it to really happen. So I would sit there and listen and I will not say too much until I realised they were all looking at me asking me for advice; so they said,*

*‘what do you think?’ So I told them what I thought that ‘yes’ it could be used for transplantation but a lot of research was needed. So they said, ‘well what would you do? I said, ‘I know the research that I would do and the work that I need to do I need funding for, so they said, ‘Okay we will give you a grant whatever you want’, so I wrote and all the work I wrote was eventually published in the proceeding International Academy of Science 1989, but the story and all this information we knew about it in the early-mid 1980s but we did not publish the paper until 1989. So the story started with Biocyte and me; we started freezing cells and showed that there are a lot of progenitor cells in cord blood and those cells can be frozen and then thawed and retrieved in very high efficacy with viable progenitors so we needed to do a test case and we – a bunch of people – it was not just me got together and decided the best way to do it, it was defined to see if it can treat.*

Then Dr. Broxmeyer elaborated more about Mathew’s success story and he said that the first step was to find a matched recipient to do the experiment. Thus, Dr. Godden Deckles Head of Obstetricians and Gynecology collected the cord blood stem cells from Mathew’s newborn sister and sent them to Dr. Broxmeyer who took the cells, tested and froze them. Dr. Broxmeyer contacted Éliane Gluckman the best transplant doctor in Paris who was conducting bone marrow transplantation for Fanconi Anemia patients. He called her and asked her if she would be willing to do a cord blood transplant for a Fanconi Anemia patient using stem cells from cord blood. She fully agreed. Dr. Broxmeyer said:

*I told her, you must do it the way I want it to be done otherwise I’m not going to give you these cells. What I want was I’m going to give you frozen cells but the cells are not separated I want you to thaw these cells quickly and then transfuse them all with DMSO with everything I said... are you willing to do that?, and she said ‘yes’, so together we discussed it. All the experiment done way before, I stayed for a week, they had pictures of me going to see Mathew when he was in the room. We kept in contact by fax and phone - there were no emails then - and I actually coordinated and wrote the paper for the journal and we agreed that if Éliane did it she will be the first author because she did the transplant and I will be the second author and Dr. Boyse will be the last author. It was all planned and agreed.*

Therefore, Mathew’s story was the first successful cord blood transplantation story in 1988 where Mathew received his little sister’s cord blood stem cells. This story led to the discovery of another source of hematopoietic stem cells because at that time bone marrow was the only

source of stem cells used in transplantation and it has to be a perfect HLA match. He highlighted:

*Bone marrow was used and bone marrow has to be an almost perfect match with a lot of graft versus host disease so cord blood has less graft versus host disease and will be able to be used by crossing some of the HLA barriers for transplantation and we were able to prove that, but it took time to convince the rest of the world and I personally think that the future is cord blood but we have to learn how better we can use it, how better we can collect it, and how better we can save it and better transplant it, and that is where research comes in.*

#### **Appendix 20. Interview Dr. John Wagner, World-renowned Cord Blood Scientist and Transplanter.**

The researcher interviewed Dr. John Wagner, a world-famous scientist who has performed many cord blood transplantations for children and adults. The researcher had a great opportunity to ask him many questions related to cord blood stem cells and the importance of cord blood donation and ethnic diversity in selecting donors for transplantation. He highlighted that cord blood stem cells are considered one of the most important sources of stem cells for patients mainly because it allows us to cross the HLA barrier if compared to bone marrow stem cells which require full HLA match between the donor and recipient. However, one of the problems facing cord blood units is the fact that the numbers of stem cells are variable. Not all cord blood units are collected with a good volume as there are many factors affecting the volume such as size of the placenta and weight of the newborn. Therefore, new technologies are out now to expand the number of stem cells by two- to three-fold so it can be used for adults. He said:

*Over the past couple of years a number of discoveries have really expanding the use of cord blood. One of the problems of umbilical cord blood transplant was that the numbers of stem cells were variable. New technology today allows us to expand the*

*number of stem cells even if when the cord blood unit itself is small, so this is a really important strategy for even improving further on the results with cord blood transplants because what we know is stem cell dose is important and we also know that HLA match is also important to some extent, so by being able to increase the number of stem cells, that means all units can be searched, increasing the opportunity of better matching. So, in combination, we have higher cell dose and we have better matching for patients so we think that will actually improve the results even more than it does today with cord blood transplant for leukemia, Thalassemia, myeloma – a whole host of disease.*

There are certain areas in the world where certain diseases are common but the point is that whatever disease affects the bone marrow or affects the immune system can be repaired by a hematopoietic stem cells transplant. The advantage of cord blood is that we do not have the same degree of HLA matching that is particularly important in areas where there is a lot of heterogeneity in HLA type, and the Middle East is one of those areas just because of the history of the Middle East where there has been invasions over time with different people from different parts of the world, which increase HLA heterogeneity and that makes it more difficult to find donors. This is one of the reasons we think it is particularly important for umbilical cord blood to be developed in that region so we can better help patients from there.

During his interview he also showed the advantages of having cord blood units over bone marrow as it is available all the time whenever it is needed unlike the bone marrow where we have to call the donor and check its availability. Thus he stated that:

*Historically bone marrow was the stem cell source of preference but we also all learned very quickly that HLA restriction prevented its widespread use. The larger the registry size of adult volunteer donors, the more likely you find a match particularly individuals of Northern European descent and it is becoming more difficult when you go beyond populations and in that group of patients finding a matched donor is hard and when you do not have a matched donor it means your chance of failure during transplant goes up significantly with every degree of mismatch. In addition, the problems that are faced in unrelated registries are the long time period to find a donor. I might be able to identify you as a donor in a matter of seconds by using computer but it I have to confirm your HLA type, your health status to verify you are not pregnant if you are women, verify you do not have genetic disease in your family, verify you do not have infectious diseases,*

*and all that takes time so it takes an average of 3-4 months to identify the donor and confirm the donor, and during that period of time many patients will die while waiting or move to higher risk status. Unrelated donor registry, individuals listed as active donors available for donation but you find out when you contact them they are not available because they really did not want to be part of the registry or they are not available temporarily because of vacations or work schedules, and that becomes a problem because even if you find a donor that is matched they are not available when you need them.*

Despite the fact that the best match can be found within the same society with different ethnicities, there are still individuals who refuse to donate their stem cells due to culture and religion restrictions. He said:

*We also found that across cultures the best chance of finding match donors is within your society and culture. In certain cultures people are resistant to donate. For example in Japanese culture unrelated donor transplant (for others) has been difficult as they fear donation and there are some cultures where it is religiously significant to give their stem cells to somebody else. All these things can interfere with the use of adults' stem cells as donors and soon it will open up the broader possibilities of how cord blood can be more powerful. In certain cultures cord blood is going to be a key for the success of transplant.*

The researcher also asked him about the importance of public registry and ethnic diversity for each country and how a cord blood registry can help treating many patients from the Middle East. He illustrated in his interview the advantage of using cord blood stem cells over adult bone marrow stem cells. For example, the Middle East has the advantage of being a heterogeneous community with populations from different countries which lead to the formation of a public registry with different ethnicities. He highlighted during his interview:

*I think each country can expand the registry and the most important thing is to have a cord blood bank with different races and ethnic groups because of HLA diversity. However within specific race and ethnic populations is it necessary that each individual country has its own cord blood bank? Well the answer is not necessarily but surely sharing responsibilities between different countries because obviously collecting cord blood and storing it has a cost associated with it. So my feeling is that the most important thing is to have races and ethnic groups which are all represented equally*



*but also to share the burden of collection and storage across the countries, so yes it is important for all countries to play a role.*

The researcher also asked him about his point of view regarding cord blood education and awareness among the public. He shared his point of view by highlighting that healthcare providers are in need of more education about cord blood so they can help and encourage the community to donate their cord blood stem cells. He said:

*From my point of view I think that people are increasingly aware and I think there is a lot of lack of clarity in setting up private banking. People are aware of it increasingly because of brochures and advertisements over internet but I think there is a lot of misinformation in the medical community that actually prevented further development because often times when the mother is pregnant, she will talk to her pediatrician or obstetrician when they have a child and often time those doctors do not really know how cord blood is being used. They are aware of it but this is not their field so what we can do is try to focus on that particular population of doctors and try to speak to them about the power of umbilical cord blood and how they can help us further developing this to move forward.*

The researcher also wanted to know more about the patients who are visiting Dr. Wagner from the Middle East for cord blood transplantation and what challenges he is facing in terms of finding a match for these patients, as we know that in the UAE we still do not have a public cord blood registry that is internationally shared with National Marrow Donor Program (NMDP). He stated that:

*We see an increasing number of patients from the Middle East with specific genetic diseases, we have been focused on that because it is unique area that we are well known for, so, for example, Fanconi Anemia, Thalassemia, sickle cell disease. In terms of finding donors we can find donors for the majority of those patients but we are finding very very mismatched donors so we know that matching is also important, not that important and critical as with adult bone marrow and peripheral blood, but what we also know that the better the match the better the outcome so if we have donors from the Middle East for our Middle East patients that will be marked improvement and big chances of success. What we know in general is that the patient needs to be race-matched and probably ethnic-matched as well. That would be important; that's what we would like to achieve. There are certain countries where there are much more heterogeneous in ethnic population which offers particular advantages. If you are in a*

*very homogenous population you will not be able to have all the presentation that you could if compared with heterogeneous population. So take a country like for example the United Arab Emirates, there is a lot of diversity there - people from all over the Middle East - so it offers you some more advantages that a homogeneous population will not have. Regardless, we would like to have donors from all over Middle East but certain countries have more advantages of being able to improve in ethnic and race diversity than others.*

The researcher also shared with Dr. Wagner the fact that most of the donors in Dubai are privately storing their cord blood stem cells as they are afraid of developing disease in future and not getting a matched unit for transplantation, so the researcher asked him for his opinion on the best way to encourage the donors to donate their cord blood stem cells. He commented that:

*I think that the problem is education, not that you have banked all cord blood privately, so even your argument that there is a divide between those who store privately and those who store publically is really not a real problem because only a small proportion of patients have banked anything and the majority of your patients are not banking at all and that is true everywhere in the world, so we need to improve on the knowledge base of people because only people who have genetic diseases in their families or people who have sufficient financial ability will be storing privately. Many many people will not fit in those criteria and therefore will probably be happy to give it up to public banks. So we have to better educate the hospitals and the obstetricians and pediatricians to say that we have two needs - we have a need for the public benefit and families who are interested and capable and knowledgeable about the future potential of cord blood they may store privately. So both are equally important to promote but even if everyone who is able to store privately stores their cord blood, there will still be plenty of cord blood units for public donating.*

## **Appendix 21. Interview with Kim Petrella, Registered Nurse Working in One of the Maternity Hospitals in Delaware, USA**

The researcher also interviewed Kim Petrella a registered nurse and certified inpatient obstetrician who has been working in labour and delivery as a nurse for 25 years. She started in 1991 and came very interested in cord blood sometime around 2005 and 2006. She introduced herself by saying:

*Actually the first time I have heard about cord blood transplant, I went to volunteer organisation that were educating expectant mothers so I became very involved with that and through the years I just loved cord blood so I started visiting a lot of labs in the United States. I have been in eight different cord blood labs in the United States and there was just something about that I realised that, 'that going to be my life and my passion' and I really enjoyed it. So I work in a hospital where we have about 7000 deliveries a year and I worked with them to bring a cord blood programme to our hospital so there are patients who could participate. I work in a hospital in Delaware and it is the only hospital in Delaware that has a cord blood programme and we allow for public donation so mums can come in in labour and make the decision they want to donate and we can ask them questions and take their consent and maternal blood while they actually are being admitted in labour, so if they can, they can make the decision right in there. If they like to privately store their cord blood we can also allow them to do that so we do a lot of education either in labour or we do education even before in doctors' offices, antenatal classes, child birth classes; and I help run that programme in our hospital along with another person that works in our lab.*

The researcher also asked her about the most challenging part that she is facing during cord blood education among expectant mothers and she stressed that misconception and having wrong information about cord blood stem cells was one of the main barriers that stops many expectant women from donating their cord blood stem cells. She highlighted that:

*I will start with the most challenging part. I almost have to fight against what people think and what they think they know. A lot of people have heard about stem cells but they are not sure exactly what they are and what they used for and sometimes they have wrong information, so sometimes my education starts with explaining things that stem*

*cells are not. And once I can clear up the misconception that we are not using the fetal cells and we are not using embryonic cells, then we can start with education and awareness of what cord blood really is.*

She then illustrated that everyone should be educated about cord blood stem cells and the education should not be restricted to hospitals only and it should reach out to different places like toys stores, ladies clubs, schools and universities. She said:

*I think everybody should be educated about cord blood stem cells I love to go out to the communities, I love to go to church groups. Everyone needs to be educated. It is amazing the misinformation that it is out there and sometimes that misinformation is like a ROCK SOILD WALL BARRIER and if no one ever talked to them again that is all they are going to think, but if you are able to go in there and talk to them and explain to them in a non-judgmental friendly up-beat sort of way they may tear down that wall and listen and then learn and when they learn something they can go home and say 'oh my gosh' to their next-door neighbour, 'I learned greatest thing about stem cells today and cord blood'.*

She also highlighted during the interview the importance of conveying cord blood information to the expectant mothers at the early stages of pregnancy so they get the chance to think and make informed decisions. Layering-up education is very important during different stages of pregnancy so when expectant mothers reach the delivery stage they will be aware about the different banking options and can make a quick decision. She commented that:

*So a lot of times we will contact when they come to the hospital for child birth classes and sometimes they will come in for hospital tours and when I go in and talk to them I like to be very exciting and explaining to them that this something that they can save somebody's life literally by deciding not throwing away the cord blood so instead of being waste, we could actually use it for something that could be great and if they can save a life that can be one option but we can also use it for research and I think a lot of people especially if they have someone in their family maybe who suffers with sickle cell anemia or Thalassemia then it becomes very important to them, so it is a programme that they can participate in for free and they can do so much for others.*

She then added:

*One of the things I love to do is to link cord blood education with diabetic testing so when someone comes in and we know that they will be doing their glucose intolerance test. I have tried to tell our doctors in our area to link the two together. Here something sweet for you meaning this is the description for your glucose intolerance test and this is something sweet for the society or something sweet for your baby meaning, 'think about what you would like to do with your cord blood. Would you like to donate it or would you like to privately bank it'.*

The cord blood team also educates nurses and medical staff in hospital about all the different things they need to know so they feel confident talking to their patients. She also highlighted that there is no specific person who is responsible for cord blood education in the hospital. We are all in charge of that and we try our level best to deliver the message to the expectant mothers at different stages during their pregnancy. She also mentioned that cord blood education is not compulsory in Delaware; however, there are some states where cord blood education is mandatory so she pointed out that:

*Delaware is not the state that have mandatory education. In the mandatory states, it is different in every state. In some states all the doctors have to do is comply with legislation to hand the patient the pamphlet, in other states they actually have to discuss it during a visit when the family need to sign a piece of paper that says 'my doctor talked to me about cord blood options that the state of Arizona has'. Other states have mandatory education but they just have to have pamphlets so it depends on the state. The State of California actually has something where they have to have mandatory education but they can also charge the parents extra fees if they want a second copy of their child's birth certificate and that two dollars goes to a larger education fund and public banking funds that parents might be more willing to donate.*

The researcher then asked, if cord blood education is not mandatory in Delaware, then how do you recruit donors and encourage them to donate their cord blood stem cells? The researcher wanted to learn more about the donor recruitment process and set-up in hospitals. She highlighted that,

*In the USA we do not have clinics we have doctors' offices so when they go for the first prenatal visit at this stage where they are given so much information a bag with pamphlets about everything that has to do with pregnancy. So the nurses are going*

*through the contents of that bag. At the beginning they go one every 6 weeks or once every month to see their doctors but once they get closer and closer to their due date the appointments become closer. When patients come in to be admitted in the hospital they are asked so many questions so the admitting nurse will spend about half an hour to 45 minutes asking her questions about her history, her pregnancy, her labouring plans and if she has any special request for her baby or for her, but one question that is asked during the admission is “Do you have plans for your cord blood?”. I mean the admission into the delivery room so maybe she is coming in for induction or C-section or maybe she is coming in labour. But if she says “yes” we ask her what your plans is but if they say we do not have plans we tell them about the cord blood programme here in the hospital would you like to learn more we give her then pamphlet one on public and one on private and we say ‘this is something you can look through and if you have any questions let us know’.*

She then added:

*Our healthcare provider tends to do some education, we have been doing this programme since 2013 and it is amazing how much our community already knows. It is all about constantly layering the education everywhere it is possible.*

Finally, before ending our interview I asked her for the best advice she can share with us for setting up a donor recruitment process in our hospitals in the UAE:

*Sometimes you have to look at ages of where one typically goes, sometimes I will put pamphlets at baby’s stores, I will go to clubs where women meet... sometimes there is a reading club and they have discussion about books. I also talk to students because when students learn something exciting they will go home and share it at the dinner table and they tell their parents so I try to hit all of the age groups so the expectant mother is going to get the education from her children, from her community, from her doctors, so it is not only hitting information for pregnant women, it is also hitting it to all women and when all women feel empowered and educated that when they share with others and it eventually trickles down to the pregnant women.*

## **Appendix 22. Interview with Cord Blood Collector at St George's Hospital**

The researcher had the opportunity to interview the cord blood collector at St. George hospital and ask her about the full recruitment procedure that takes place at the hospital. She highlighted:

*Basically mothers come to antenatal classes and this is the first place we get the opportunity to speak to them and introduce ourselves. The mother will be about 12 to 14 weeks pregnant and some join late about 34-35 weeks pregnant. During the antenatal classes they get lessons with the midwives and at the same time we can go out there and speak to them and explain to them what we do. We also give them the leaflet which contains a mini consent for them to sign if they are interested. We talk to them about cord blood donation and some of them already know what cord blood donation is because they have done it before.*

The researcher asked the collector during the interview about the person in charge of educating pregnant women in the antenatal clinic and she highlighted that it is mainly the collectors who speak to the pregnant women, but midwives only encourage the pregnant women to donate their cord blood. She illustrated that:

*When pregnant women come to visit the antenatal clinic only leaflets are given to her at that time and there is a chance for us to go and speak to her but it's only a short time because in the waiting area pregnant women can be called at any minute by the doctor so we do not find it much helpful at this stage.*

She illustrated that they encourage the expectant mother to donate her cord blood by speaking to her about the benefit of it and how it can help cancer patients and it can go to anywhere in the world to help anyone - children or adults, so instead of discarding it we use it to help others. She also demonstrated that:

*The main reason that encourages them to donate their cord blood is knowing that it can help someone.*

The reasons that might make the mothers refuse to donate her cord blood can be medical reason, personal reasons or having fear of needles during maternal samples collection.

The researcher was also asking her during the interview about the hospital agreement and the actual registration stages that occur in the hospital. She answered that cord blood education is part of hospital policy in a way that they allow us as collectors to educate and collect cord blood donations. The authorisation is in the form of agreement between the hospital and the cord blood centre. Expectant mother consent is taken at two main stages. The first stage is the mini consent where we ask the mother if she is happy to allow us to collect cord blood from the placenta. Then we tell her, if it was a good collection, we will come back to see her for 5 to 10 minutes to ask other questions (35 long questions). However, if the collection was not good and the collected blood was not enough then we go back to the mother and tell her that it did not meet the criteria and was not enough and we will not collect the maternal samples. The cord blood units will not be processed until we have the full consent and donor screening.

The researcher also asked the collector for her point of view regarding the best system that can be implemented in the hospital to make sure that no cord blood samples are wasted. She highlighted that:

*Every mother who arrives in the delivery ward has a personal contact and we reach most of the mothers in the delivery ward as the mothers are not seen every month in the clinic, if she is categorised as low risk pregnancy then she has two scans to do only: first scan 12 weeks and another one 22 weeks, and it is the only two scans we get to meet the mother unless she is in high-risk pregnancy then they need to see their doctors more often. From our experience, reaching the mothers in the delivery suite is more likely to have more and better consent as we get more mothers to consent because we can know at this stage the mother's situation from reading the board in the delivery; for example, she is full term, happy, low risk and we can read everything about her medical situation from her file or through the system.*



Edward, a collection manager who was in the room during my interview with the collector commented that:

*The advantages of counselling mothers in antenatal classes is that you get to explain more about the programme and you can see several mothers at the same time so you can consent 12 people in 10 minutes. The disadvantage is that at 15 weeks we do not know what risk factors will change until donation time. The disadvantages of having it in the delivery suite is that you have to share that little time you have with mum when she is relaxed; you have to share it with the midwife who also takes care of the mum so the opportunities are shorter, so you have to find a balance when you meet the mum to provide all the information.*

After having good cord blood collection we go and speak to the mothers and ask the rest of medical questions. It is the collector's job to keep an eye on the mother and try to reach her to answer the questions before she is discharged from the hospital.

They also highlighted the fact that as collectors they are in charge during their shift to approach each single midwife to introduce themselves and tell them that they are around if there is anything needed. To encourage healthcare providers to speak with mothers about cord blood donation, she commented that:

*Every time we have new nurses and new doctors we go and introduce ourselves, give them leaflets and show posters, explain what we do and that this is a good thing to save someone's life. We do meetings for the midwives and show them how we did well during that time and we also show them how many units went out and how many lives are saved.*

### **Appendix 23. Interview with Theo Clarke, National Bone Marrow Transplant (BMT) Marketing Manager**

The history in the past and the way the Black African community was treated in the past is affecting their decisions on cord blood and blood donation, as they do not want to be a part of helping the NHS which is a governmental entity. He then commented: *“We had to get our head around it in terms of what we are getting after and what we actually wanted”*. The researcher then asked him his point of view in terms of culture and how it is affecting cord blood donation in the UK. He highlighted that:

*We are different cultures, we definitely try where we can to keep within the existing community framework so instead of trying to re-invent the wheel which is what we used to do in big projects where we do everything by ourselves, now we have two key opportunities that we go with: one is building an awareness and another one is engaging with existing structures. So in term of existing communities' structures you have got...Basically communities help which are ideal sending out your messages and getting people interested such as in schools and colleges,. I'm a big believer in “Grass roots” so doing a lot of grass roots engagement rather than going behind issues which I believe are not attempted by and I believe grass roots is a way we affect change and it is a behaviour change which we want to effect by the end of the day and it takes a long time. The biggest pressure I guess from our NHSBT point of view is the awareness which is really really moving very hard to touch that issue.*

Therefore, NHSBTs work hard to engage with the community in a long-term relationship and has started to be closer to them and engage with them to be able to learn more about them and about their culture and religion. They focus on a more long-term relationship and try to keep interactions ongoing. He also highlighted the importance of giving back to the community:

*In general we do not give them money. We might help them out by marketing a poster or produce a T-shirt for them. Something to say that we are giving something back to the communities.*

He also highlighted that engaging and understanding communities is slow going and takes a lot but once you commit to it and you get a framework to work with it you will gain a lot. He then gave an example about dealing with different communities:

*We found that for example we are more successful with South Asian community if compared with black community because we got more time from many years ago to learn about them, so 10 years later we started becoming stronger in dealing with them. He then added, 'To start off we pick up the below hanging groups that are less interacted with us. So for example the Sikh community are very proactive in terms of coming towards to us, the Muslim community are cashing up now and they are more approachable now than they used to be, they were very strict about their religion but we worked a lot on that. Indian communities are hardest due to religious issues and ethical issues.*