

Original Article

Knowledge and Attitudes about Cord Blood and Cord Blood Banking: Cross Sectional Study

Sibel Ozturk PhD

Assistant Professor, Ataturk University Health Science Faculty, Erzurum, Turkey

Fatma Guducu Tufekci, PhD

Associate Professor, Ataturk University Health Science Faculty, Erzurum, Turkey

Ayfer Kara, MSc

Assistant Ataturk University Health Science Faculty, Erzurum, Turkey

Meral Kilic, PhD

Assistant Professor, Ataturk University Health Science Faculty, Erzurum, Turkey

Correspondence: Sibel Ozturk Assistant Professor, Ataturk University Health Science Faculty, Erzurum, Turkey E-mail: sibelc-06@hotmail.com

Abstract

Background: The Umbilical Cord blood stem cells is emerging as a non-invasive, efficacious alternative source of hematopoietic stem cells to treat a variety of blood and bone marrow diseases, blood cancers, metabolic disorders and immune deficiencies. The collection procedure is easy and without any risk to the donor.

Aim: This study aims to determine Turkish mothers' knowledge level and attitudes about cord blood and cord blood banking.

Methodology: This is a cross sectional study. The study was conducted at five primary healthcare centers in Erzurum city center. The research was made in collaboration with 322 mothers between ages 18 and 49 that came to the healthcare centers. The data was collected using a questionnaire form. Percentages and chi-squares were used to collect data.

Results: It was found that 29.8% of mothers knew about cord blood and stem cells and that they were used for medical treatment. 75.4% of mothers did not know about cord blood banks and 21.1% learned about these issues from the internet or other mass media. It was also found that knowledge level of mothers increased and their attitudes got better in accordance with their educational status ($p < 0.001$).

Conclusions: It was determined that most participants of the study did not have enough knowledge about either stem cells or cord blood banking. Thus it was necessary that they be briefed on these issues. During pregnancy follow-ups, midwives and nurses can inform and direct women about these issues.

Key words: mother, formation, attitudes, cord blood, cord blood bank

Introduction

Umbilical cord blood (UCB) is seen as an ideal resource for hematopoietic stem cells and for other progenitor cells (Aznar & Sánchez, 2011; Kansoy, 2008). It is a very exciting situation that we do not get rid of the cord blood after birth but use it for hematopoietic cord blood transplantation (Kansoy, 2008)

In the present day, with the cordon blood option, the rate of finding an appropriate allogeneic donor is 80% or 90%. Cord blood is now a very significant alternative source of stem cells for all allogeneic transplantations. It also has many positive sides, i.e. it is easily available and

storable, it is stored and ready when needed; tissue rejection or acute or chronic graft-versus-host disease are seen less frequently after cord blood transplantations due to the low immune capacity of fetal blood cells (Apak, 2004; Ates, 2006; İrez & Gazioglu, 2009; Kansoy, 2008).

Allogeneic and autologous hematopoietic stem cell transplantations are successfully used for the treatment of children and some adults with life-threatening recurrent or high-risk hematological malignancy, hemoglobinopathy, genetic immunodeficiency, metabolic disorders and bone marrow failure (Broxmeyer, 2010; Kansoy, 2008; Mohammed & Sayed, 2015; Nietfeld, Pasquini,

Logan, Verter, & Horowitz, 2008). It is seen as a very good choice especially for pediatric patients and adults that cannot find an appropriate donor for their HLA (human leukocyte antigens) (Kansoy, 2008).

Cord blood has many benefits in terms of transplantation due to its cell content; moreover, it has some other advantages, i.e. it has almost no confrontation with viruses or microorganisms during the intrauterine period and it is obtainable without any contact with the newborn. Along with all these advantages, cord blood has a restriction in that it is usually appropriate only for children or adults that are not overweight (Karadeniz & Yucel, 2013).

Stem cells taken from the umbilical cord to be used in stem cell therapy are supposed to be preserved under appropriate conditions. Storing umbilical cord blood in liquid nitrogen tanks for long periods of time is called “Cord Blood Banking”. It has been proven that cord blood can be preserved in the laboratories for up to 15 years in modern facilities (Apak, 2004; Uluhan, 2009).

The oldest stem cell that has been transplanted successfully to date is 7 years old (Karadeniz & Yucel, 2013). Since the first umbilical cord blood (CB) transplant for hematopoietic reconstitution in 1988, more than 30,000 CB transplants have been performed (Shah & Boelens, 2015). However, the number of autologous transplantations is very small. There are two published autologous cord blood transplantations; one of them in the case of neuroblastoma and the other aplastic anemia (Karadeniz & Yucel, 2013). Even though autologous cord blood banking is not highly recommended by health professionals, it is still suggested that the cord blood be preserved for families with a child that has thalassemia, pregnant women with a thalassemia major fetus or when one parent is a carrier with the aim that it be used for the infant with thalassemia (Karadeniz & Yucel, 2013; Reed, Walters, & Lubin, 2000).

Previous studies about cord blood and cord blood banking have been conducted in other countries. These studies aimed to investigate pregnant women’s knowledge, opinions and attitudes about cord blood and cord blood banking; it has generally been found that women are not adequately informed about these issues (Dinc & Sahin, 2009; Fernandez, Gordon, Van den Hof, Taweel, & Baylis, 2003; Katz et al., 2011). Obstetricians, nurses and midwives are

often the least important information sources (Dinc & Sahin, 2009; Katz et al., 2011; Shin, Yoon, Lee, Kim, & Roh, 2011). In only one study were obstetricians and gynecologists ranked as the most preferable (Karagiorgou, Pantazopoulou, Mainas, Beloukas, & Kriebardis, 2014). Research among Israeli women (Natan, Grinberg, Galula, & Biton, 2014) and Greek citizens (Karagiorgou et al., 2014) showed that the majority of women did not know about these issues during their pregnancy and that healthcare professionals were the last source of information for them (Karagiorgou et al., 2014).

The use of stem cells and cord blood banks is a very comprehensive topic. Healthcare professionals, nurses and midwives are supposed to inform pregnant women on this subject during the prenatal period since it is highly detailed and conventional thoughts on these matters are very dominant (Yildirim, 2007). Nowadays, Turkish women have controversial ideas about stem cell utilization and cord blood banking; in order for their lack of knowledge to be ameliorated, their current thoughts and ideas should be fully understood (Attar, 2004; Beksac, 2004).

Operations dealing with cord blood and cord blood banking started a very short time ago in our country, thus there are no studies on mothers’ knowledge level about this subject. This study aims to examine mothers’ knowledge and opinions about cord blood and cord blood banking.

Methods

Design and sample

This is a cross sectional study. The study was conducted in five primary healthcare centers, in Erzurum Turkey between February 15, 2014 and June 15, 2014. The population of the study consisted of mothers between ages 18 and 49 that were registered in the healthcare centers in Erzurum city center. The study sample consisted of 322 mothers that came to the healthcare centers on the first day of the week and that were between ages 18 and 49; the healthcare centers stated above were chosen through a lottery among the other centers in the city.

Instruments

The data was collected using a questionnaire form which was created by taking previous studies into consideration (Apak, 2004; Ates, 2006; Kansoy, 2008). The form included questions about socio-demographic traits of

mothers and level of knowledge and attitudes about cord blood and cord blood banking.

Data analysis

The research data was analyzed in electronic environment. The research findings were assessed using percentages and chi-square testing. Participants' socio-demographic traits, their levels of information about stem cells and cord blood, their thoughts about cord blood storage and their approaches to the topic of cord blood and stem cells were assessed using these tools. The confidence interval of the results was 95% and the threshold p-value for significance was $p < 0.05$.

Ethical considerations

This study received ethical approval from the institutional review board (IRB-1/2014; Date: 13.01.2014). The principle of "Informed Consent Process" was followed as the participant pregnant women were briefed about the aim of the study prior to the beginning of data collection; the "Privacy Principle" was followed as the information received from them would be kept confidential; the "Respect for Autonomy Principle" was followed as volunteers were also accepted as participants.

Results

Participants

More than half of the participant mothers were between ages 25 and 34; the majority of them had 1 to 3 children and were primary school graduates.

Mothers' levels of knowledge about cord blood

29.8% of mothers said that they were informed about cord blood and it was determined that they learned about this issue primarily from the internet and other media (20.2%). The rate of mothers that answered the question "Who is the cord blood taken from?" as "From the newborn" was 2.8%, which is very low. 71.2% of the participants said that they did not know the answer. 3.7% of participants said that cord blood was used for stem cell treatment and 88.8% of mothers did not know about the situations in which cord blood should not be taken (Table 1).

Mothers' knowledge about cord blood banking

It was found that 75.4% of mothers did not know about cord blood banking and 21.1% of those that were informed about this issue learned primarily

from the media or the internet. It was also found that 22.4% of mothers did not want the cord blood to be preserved; 97.9% of them had no reason to refuse to preserve it while 2.1% of them did not want because they thought that it was dangerous (Table 2).

Mothers' levels of knowledge and attitudes in relation to their age, educational status, and the number of children

It was found that the attitudes of mothers got better and their level of knowledge increased in accordance with their educational status ($p < 0.001$). Mothers' age and the number of children they had did not affect their knowledge and attitudes (Table 3).

Discussion

In the past decade, the number of studies on stem cells has increased dramatically. Moreover, even more studies are planned to be done on the same subject (Yildirim, 2007). This study examined the attitudes and knowledge of Turkish mothers about cord blood and cord blood banking; the research findings are discussed in the context of the relevant literature. It was determined that the majority of mothers were not informed about cord blood. The unawareness about this issue might have resulted from the fact that it is a quite new phenomenon and there is a lack of health policies about this issue. That research also investigated pregnant women's attitudes about cord blood and stem cells. It was determined that the majority of mothers (73.1%) were not informed about cord blood, which is compatible with the findings of our research (Dinc & Sahin, 2009). The primary source of information of mothers that are properly informed about cord blood was the media and the internet and the secondary source was healthcare professionals. In a previous study on pregnant women's level of knowledge about cord blood banking (Karagiorgou et al., 2014; Screnci et al., 2012), it was found that women received information primarily from their gynecologists and obstetricians; in another study, it was found that the source of information (Dinc & Sahin, 2009) was the internet and media and the secondary source was the obstetricians, which is in compliance with our research. These results of our research indicate that women mainly apply to the internet and the media to learn about cord blood; it is also indicated that healthcare professionals-midwives, nurses and doctors- do not provide sufficient information or explanation.

Table 1. Mothers' levels of knowledge about cord blood

Knowledge about Cord Blood	N	%
General Knowledge about Cord Blood		
Yes	29.8	96
No	226	70.2
Source of Knowledge about Cord Blood		
Media/Internet	65	20.2
Healthcare professionals	20	6.2
Friends	11	3.6
Knowledge about person/s that give cord blood		
Infants	71	22.0
Pregnant women	7	2.2
Newborns	9	2.8
Fetuses	2	0.6
Mother during birth	1	0.3
Siblings	3	0.9
Do not know	229	71.2
Knowledge about the intended purposes of cord blood		
For the therapy of infant diseases	42	13.1
For cancer treatment (for the infant)	14	4.3
Intelligence tests	4	1.2
For stem cell therapy (for the infant)	12	3.7
Do not know	250	77.7
Knowledge about the situations in which cord blood should not be taken		
Mothers with a contagious disease	9	2.8
If the infant is older than eight months	1	0.3
If the mother has a genetic disease	5	1.6
If the infant is sick	21	6.5
Do not know	286	88.8

Table 2. Mothers' knowledge about cord blood banking

Knowledge about cord blood banking		
Sources of information about cord blood banking	N	%
TV/Internet	68	21.1
Healthcare professionals	5	1.6
Friends	6	1.9
Do not know	243	75.4
Knowledge about cord blood banking in our country		
Yes	58	18.0
No	264	82.0
Wish to preserve cord blood if they have another child		
Yes	250	77.6
No	72	22.4
Reason for not wishing to preserve cord blood		
Do not know	65	97.9
It is dangerous	7	2.1

Table 3. Mothers' levels of knowledge and attitudes in relation to their age, educational status, and the number of children

Knowledge and attitudes	Agree		Mothers' Age	Period of Study (year)	Number of Children
	n	%	Test and p	Test and p	Test and p
State of knowing or not knowing that cord blood is used for stem cell treatment*	16	20.3	$X^2=1.588$ $p>0.005$	$X^2=21.039$ $p<0.001$	$X^2=2.646$ $p>0.005$
State of knowing or not knowing that there is a cord blood bank in our country*	58	18.0	$X^2=11.774$ $p>0.005$	$X^2=67.580$ $p<0.001$	$X^2=10.274$ $p>0.005$
State of wishing or not wishing to preserve infant's cord blood*	250	77.6	$X^2=10.816$ $p<0.005$	$X^2=13.70$ $p<0.001$	$X^2=0.651$ $p>0.005$

The main responsibility in perinatal care is carried by nurses and midwives in Turkey; thus it is required that they receive further training regarding these issues (Beksac, 2004; Fernandez et al., 2003; Yildirim, 2007).

In this study, the majority of mothers said that they did not know who the cord blood was taken from. Those saying that they did know stated that it was taken from “the pregnant woman, the deliverer mother, the fetus and the sibling”. It is a contradictory point that the rate of mothers stating that knew about the subject was low and the correctness of the answers they gave was questionable.

In this study, mothers said that the cord blood was used for stem cell and cancer treatment, for the treatment of infant diseases and for intelligence tests. Mothers thought that the only usage of the cord blood was in the infant and they did not know about the intended purposes of it, which indicates a lack of knowledge. In a previous study on this subject, participants said that the cord blood was used for the treatment of the diseases that pregnant women had and for “infant diseases, cancer treatment and intelligence test”, which is in compliance with the outcomes of our research (Table 1).

The research determined that only a very small number of mothers heard that there was a cord blood bank in our country. This indicates that healthcare professionals are not a reliable source of information about these issues and that our society is not aware of the significance of this subject.

In this study, the majority of mothers said that they wished the cord blood to be preserved; however, the others said they did not want to keep it as they did not know about the purpose and thought that it was dangerous. In other studies (Dinc & Sahin, 2009; Katz et al., 2011; Natan et al., 2014), it has been found that the majority of pregnant women similarly wished the cord blood to be preserved and did not think that it was dangerous, which is in contrast to our research (Table 2).

It was determined that mothers' attitudes and knowledge level about cord blood and cord blood banking increased in direct proportion with their educational status.

Prior research found that pregnant women that had received higher education were more concerned and conscious about these issues, which is surely not surprising. Correct knowledge results from a higher educational status (Dinc & Sahin, 2009; Fernandez et al., 2003). Educated mothers are more likely to know that neither the mother nor the infant is endangered by the drawing of blood from the umbilical cord (Dinc & Sahin, 2009).

On the other hand, some other participants thought that it was a threat for the infant or for themselves since they did not have enough information on the issue. Autologous cord blood transplantation is not a common procedure. Healthcare professionals should brief expectant mothers and fathers about these matters during pregnancy and the prenatal period in order to have a higher rate of cord blood storage and to be

able make more transplantation (Dinc & Sahin, 2009; Katz et al., 2011; Mohammed & Sayed, 2015).

Conclusion

The research results indicate that only a small number of participants had adequate information about stem cells and cord blood banking. Level of knowledge amongst expecting mothers should be increased. It was also found that the media and the internet were the main sources of information for mothers. It was found that the majority of mothers had a positive attitude about the preservation of their infants' cord blood. It was also found that their level of knowledge about cord blood and cord blood banking increased in direct proportion to their educational status.

Nurses and midwives should be briefed about the most recent developments in this field; they should also receive further training on these issues. If expectant parents' thoughts and level of knowledge about the collection, storage and transplantation of cord blood is identified, it would allow health professionals to provide much better perinatal care to families. The main responsibility in perinatal care belongs to nurses and midwives in Turkey, which means that their professional competences regarding these issues is crucial.

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