

Awareness and knowledge of cord blood collection among pregnant women and doctors and effect on cord blood banking in Iran

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Abstract

Background and Objectives: Nowadays, using umbilical cord blood (UCB) as a rich source of hematopoietic stem cells has been an important issue for both researchers and physicians in many parts of the world. According to the benefits of using cord blood in curing disorders, awareness of parents about cord blood utility and cord blood banking is important. The aim of the study was to evaluate the knowledge and willingness of Iranian pregnant women and also the information level of doctors about cord blood banking.

Methods: This is a survey that conducted among at least 28 weeks 824 pregnant women and 152 Obstetric-Gynecologists (OB-GYNs) in private hospitals of 24 provinces of Iran to evaluate the knowledge using a questionnaire.

Results: Our finding indicated that 38.7% of participants were aware of cord blood banking and less than 50% of doctors had complete information about cord blood usage. The mother's attitude is related to their doctor's recommendation. The results show that the level of education, employment status, and occupation, income has an impact on the parent's attitude for cord blood banking.

Conclusion: The level of knowledge among the pregnant women about cord blood usage is low totally. Even the doctors had not complete awareness about cord blood banking. Hence the most of the women tend to get advice from their physician; we should try to introduce Royan cord blood bank and the advantages of cord blood stem cells via holding congresses and medical gathering.

Keywords: Cord Blood Banking; Knowledge; Pregnant women; Hematopoietic stem cell

Background and Objectives

In recent years, scientists have discovered that UCB, like bone marrow and peripheral blood, is a clinically useful source of hematopoietic stem cells (HSCs) and progenitor cells for treatment of various malignant and non-malignant disorders. In comparison with bone marrow, cord blood HSCs have potential advantages: The first one advantage of using UCB is that cord blood transplants do not need a fully matched Human leukocyte antigen (HLA)¹. The second one is an association of cord blood transplantations (CBTs) with a lower incidence of Graft versus host disease (GVHD). Furthermore, cord blood is less likely to transmit some important viruses, like Epstein-Bar virus (EBV), and cytomegalovirus (CMV), and finally, the collection of UCB is done after the delivery of the newborn baby and this procedure is easy and without any risk for mother or infant¹⁻⁵.

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Since, 1988, when the first successful cord blood hematopoietic stem cell transplantation (HSCT) was done to treat a 6-year-old boy with Fanconi anemia⁶, more than 40000 CBUs have been released to transplant centers to treat various blood cell disorders, cancers, metabolic problems and immune disorders⁷. Clinical and pre-clinical trials are being done in the field, treating diabetes, neurological disorders and for some cardiovascular deficiencies^{8,9}. The use of cord blood HSCs, due to providing an appropriate source for curing disease, has attracted the attention of international medical communities. So they have a high interest in supporting cord blood banks (CBBs). There are two different banking options for preservation the stem cells of umbilical cord blood: private (family) and public bank. Cord blood cryopreserved in private banks are used for either autologous or allogeneic transplants for the infant donor or related family members but private cord blood banks are not searchable or available to the public. Public banks collect qualifying cord blood donations from healthy pregnancies and save them in case one of them will be the match to save the life of a patient who needs a stem cell transplant¹⁰⁻¹². Royan Cord Blood Bank (RCBB) was founded in 2005 in Iran. Royan is a hybrid public/private cord blood bank that has collected cord blood all over Iran. So, RCBB has divided into two parts; one part is for the families who pay a fee to store their infants CBUs for potential future use, another part is for families who donate the CBU for the allogeneic purpose. Until now more than 120000 CBUs have been stored in private part of RCBB and about 7000 CBUs have been preserved in public part. Because of success in cord blood HSCT and advantages of storing CBUs as a life insurance for families, the need to inform and encourage parents to store their infants UCB, has felt increasing. In Iran, there has no serious advertisement to persuade families to store their newborn

baby's cord blood stem cells. The only way to inform parents about cord blood banking has been via OB-GYNs. Although the role of midwives and OB-GYNs to advise families about the benefits of storing CBU is very important, it seems that insufficient awareness in parents about UCB banking in general is due to lack of motivation. The aim of this study was to investigate on the knowledge and attitude of pregnant women and medical specialists about UCB banking in Iran and also assessing the factor that may influence on parent's willingness to preserve their baby's UCB, which can help to develop appropriate policies for cord blood banking.

Methods

The survey was conducted at Royan CBB in Iran between November and December 2014. The population of the study were pregnant women and also OB-GYNs in some intended private hospitals of 24 provinces of Iran. This study was done among 824 pregnant women with more than 28-week gestation that attending the private hospitals and 152 OB-GYNs of these hospitals during the study period. The survey was done according to ethics review board of Iran Health Ministry. The questionnaire was initially based on a published questionnaire¹³ which evaluate cord-blood related knowledge and attitude in postpartum women. The questioners introduced the study and encouraged pregnant females and OB-GYNs to participate in the study. The volunteered participants were informed about the aim of the survey and signed the written consent. Data were collected after fulfilling the questionnaire by participants and for confirming the validity of data, all information was reviewed and approved by an independent expert team. Questions were given to the pregnant women. The main topics of the questionnaire were designed in two parts: first part included some personal information, the level of education of

pregnant women and their husbands, household income, employment status and occupation, the second part was consisted of some data about knowledge and attitude of participants towards cord blood banking (Appendix file). Questions were asked from doctors about their awareness of the use of UCB preservation and banking. The filled questionnaires were analyzed to evaluate the knowledge of pregnant women and OB-GYNs regarding UCB.

Results

A total 824 questionnaires were given to pregnant women. Between the age groups, the majority of the respondents were belonged to 29-32 years' group (27.8%). The mean age of pregnant women who completed the questionnaire was 28.7 years. 54.7% of participants had a high school education or less and 38.3% were undergraduate education. About the level of education of respondent's husbands, similar results were observed. In other words, 55.6% of participant's husbands did not have a college

education and 35.8% had attained college degree. The family's monthly income of 43.3% of respondents was between 250 and 500 \$ and the next frequently was belonged to the group with 750-1000 \$ per month. Minimum and maximum income were associated with the families with respectively 250 and 4500 \$ income per month. The majority of women (50.7%) lived in the metropolitan area. 22.8% were in urban places, and 17.2% were staying in the suburbs and finally, 9.3% lived in rural area. About the employment status, the results showed that more than 80% of participants were housewives, 9.7% worked in governmental offices and approximately 7% were self-employed. 66% of the women's husbands had non-governmental jobs, about 31% of them worked in government agencies (Table 2). About Disease status among relatives, 16.3% of participants had some relatives who were suffering from malignant disorders that the most common disease among them was cancer.

Table 2. Socio-demographic characteristics and self-reported knowledge of survey population

Demographic	frequency	percentage
Age (yr)		
>20	50	6.1
21-24	128	15.5
25-28	226	27.4
29-32	229	27.8
33-36	132	16
<37	59	7.2
Education		
Uneducated	1	0.1
High school diploma Or less	451	54.7
Under graduate	316	38.3
Graduated degree	56	6.9
Husband's education level		
Uneducated	3	0.4
High school diploma Or less	458	55.6
Under graduate	295	35.8
Graduated degree	66	8.2
Monthly income		

> 150 \$	96	11.7
150-250 \$	106	12.9
250-500 \$	357	43.3
500-750 \$	31	3.8
750-1000 \$	170	20.6
< 1000 \$	64	7.8
Occupation		
Metropolitan area	413	50.7
Urban	186	22.8
Suburbs	140	17.2
rural area	76	9.3
Employment status		
Governmental job	80	9.7
Self-employed	59	7.3
Housewives	683	83
Husband's employment status		
Governmental job	253	30.9
Non-governmental job	543	66.4
Unemployed	22	2.7

Awareness and willingness about UCB banking

Overall, 38.7% of pregnant women were aware of cord blood usage. The results showed that knowledge of pregnant women about UCB banking increase with age and also the level of education. In addition, people who lived in urban areas and employee of public and private organizations had more information regarding the benefits of UCB banking. Among the women who were aware of cord blood banking, 64% believed that cord blood cryopreservation is just useful for treating the child's disease in future. 51.4% of

participants thought that the stored cord blood can be used for curing the fatal disorders and 42.6% knew that storing cord blood has a chance to be used for some other person. Only 4.4% had information about the use of UCB in scientific researches. A list of treatable disease by cord blood was provided to participants. 75.7% of respondents thought that UCB can be used for curing cancers and 33.1% believed that it is useful for treating anemia. It seems that knowledge of pregnant women about treatable diseases by cord blood HSCs is limited to blood cancer and they had a little awareness about the other treatable diseases by this method (Table 3).

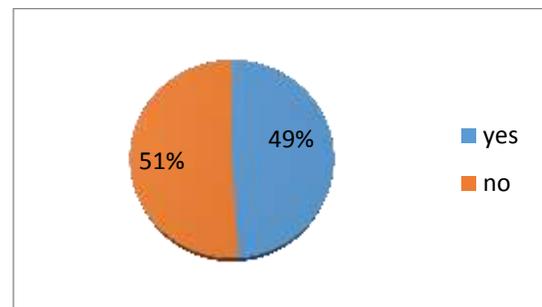
Table 3. The participant's awareness about some diseases that are treatable by cord blood

Disease	YES		NO		NO Information	
	frequency	percentage	frequency	percentage	frequency	percentage
Blood cancer	240	75.7	64	20.2	13	4.1
Anemia	105	33.1	199	62.8	13	4.1
Thalassemia	92	29.0	212	66.9	13	4.1
Hepatitis	46	14.5	258	81.4	13	4.1
Heart disease	44	13.9	260	82.0	13	4.1
Severe burns	38	12.0	266	83.9	13	4.1
Neurological diseases	37	11.7	267	84.2	13	4.1
AIDS	9	2.8	295	93.1	13	4.1

Decisions about cord blood banking

The most important motivation for storing CBUs among participants was their information about the advantages of umbilical cord blood banking. After that, doctor's recommendation is a significant factor to encourage pregnant women to store their baby's cord blood. Because 77.6% of respondents who did not interest to store their newborn's CBU, did not have information about cord blood banking. Furthermore, the second reason for the families who did not make a decision to preserve their baby's cord blood was their concerns about the costs. After reading the information about cord blood banking advantages and also costs that were provided in the questionnaire, 48.5% of participants indicated they would like to store their baby's CBU. Deciding about cord blood banking in women who held a college degree or higher was more than the others. Also, the families with the average monthly income more than 500 \$, were more motivated about cord blood banking. The mothers who were unemployed were less likely to store their baby's cord blood. The most reliable ways to inform cord blood banking were OB-GYNs recommendation (69.2%) and TV programs (17%) according to participants' responds.

Figure 1 - Respondents decision to store their baby's cord blood



Doctor's awareness about cord blood banking

In the study, among 152 OB-GYNs 8% did not have any information about CBU banking. 48.7% of physicians had basic information about the usage of cord blood and 43.3% had specialized information about cord blood. When the OB-GYNs were asked about the curable disease by cord blood HSCs, blood cancers (41.5%) and thalassemia (18.4%) were the most responds. It seems that the OB-GYNs who were in contact with pregnant women, had a little information about the use of CBUs in the treatment of different diseases. Further investigations indicated that job experience of OB-GYNs does not have any relation to their knowledge about cord blood banking. In order to

information source of OB-GYNs about UCB banking, 43.4% of them said that they obtained their information via their scientific researches. 28.3% of them were aware through their colleague's information. 18.4% got their knowledge during their medical courses. 10.5% noticed about the important role of scientific seminars and congress in increasing awareness, and only 6.6% of them introduced Royan institute as their information source. Regarding recommending UCB banking, the responses were different. 15% of them believed that it should be offered to all families, 55.9% said that they recommend it to some parents, and 28.9% thought that it is not necessary to offer it to families.

Discussion

The purpose of the survey was to evaluate the awareness of the pregnant women and OB-GYNs in regard to UCB banking and investigating the influence of the pregnant women information on their decision to UCB banking. The result demonstrated that 38.7% of pregnant women had knowledge about the usage of UCB. This is in contrasted with the data (5%) that was recorded among participants in Nigeria¹⁴. A similar study conducted in India has shown that 45% of mothers had knowledge about cord blood preservation¹⁵. Whereas, in European countries and United State of America (USA) more than 50% of individuals had awareness about cord blood banking^{16,17}. After evaluating the relation between age, the level of education, employment status, occupation and the amount of participant's information, we found that older women (29-32 years old) and/or more educated women and also employed women had more knowledge about UCB utility and storing. Moreover, the mothers who lived in urban areas were more aware of UCB banking. Our findings are accordance with previous studies^{11,12,14-20}. The results of investigating the responses of

participants indicated that lack of information was the main obstacle to store cord blood. A similar study in USA (2017) showed that absence of knowledge among pregnant mothers was a major barrier to donation¹⁵. Besides, the cost of CBU banking was the second factor that influenced on a family decision about storing their baby's CBU. So, in families with higher income the willingness for CBU banking were more than others. Respondents with higher education had more attitudes to store their newborn's cord blood compared with the less educated participants. Also, some studies showed that the level of education is an important factor regarding willingness about cord blood banking^{15,21}. After giving some relevant information about the benefits of cord blood banking, the number of women who tended to store their baby's CBU increased. Similarly, in 2017 Bhandri et al. indicated that the willingness has a direct relation with the level of awareness¹¹. Another survey in Rome in 2012 found that the level of information has an important role in the attitude of parents toward cord blood banking¹⁰. Most of the participant who had some knowledge about diseases which can be cured with stem cells obtained from cord blood, believed that it is useful for treating cancers. The majority of the respondent who decided to be informed about cord blood banking preferred to get this information from their OB-GYNs. In the similar survey that conducted by Denic and Sahin in 2009, 78.7% of participants wanted that receive the information from their physicians²². In the next step, the results showed that media could be a good source of increasing the knowledge and willingness of people. These results were in compliance with the other studies^{16-18,20,23}. Our findings demonstrated that only 43.3% of OB-GYNs had sufficient information about cord blood banking and CBU usage. According to limited information of OB-GYNs about the diseases that can be treated by CBU, it could

be found that the physicians who are in direct contact with pregnant women, had incomplete and insufficient information about the usage of cord blood. According to the important role of physicians in encouraging families to store the cord blood, it is necessary that serious and extensive operation should be taken to increase their information. The present results were in compliance with Tuteja et al. study²³. They found that the knowledge of Indian doctors and also individuals about the disease which can be cured by cord blood stem cells was poor. Regarding the physicians' answer about offering CBU banking to their patients, only 15.1% of physicians believed that it should be offered to all families and unfortunately less than 50% of them knew that it is necessary to recommend it to families with a history of genetic disorders curable by CBT. In another survey in India, Tuteja et al. in 2016 also indicated that minority of physicians offer cord blood banking to the pregnant women²³. The results showed that most of the OB-GYNs recommended holding seminars and congress to increase their knowledge about RCBB and benefits of cord blood preservation. Therefore, more efforts should be taken in order to hold valuable conferences and medical gathering to introduce cord blood usage to physicians.

Conclusion

The study showed that the level of awareness of pregnant woman and also OB-GYNs about UCB banking and UCB advantages are low in Iran. An appropriate policy should be taken to increase the information about RCBB and the benefits of cord blood banking. More attempts should be made to aware mothers who are young, less educated and live in rural areas. According to the results, extra efforts should be taken to introduce CBB to OB-GYNs as the main factor to increase the mother's attitude about cord blood banking.

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Authorship contributions

All the authors wrote, conceived and revised the manuscript.

Conflict of interest

None of the authors of this paper have relationship with the participants that could inappropriately influence the content or direction of the paper. Furthermore, the data collection process in this survey was performed by independent institute "ISPA".

Abbreviations

CBB	Cord blood bank
CBT	cord blood transplantation
CBU	Cord blood unit
CMV	Cytomegalovirus
EBV	Epstein-Bar virus
GVHD	Graft versus host disease
HLA	Human leukocyte antigen
HSC	Hematopoietic stem cell
HSCT	Hematopoietic stem cell transplantation
UCB	Umbilical cord blood

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