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Pregnant women's knowledge and attitudes about stem cells and cord blood banking

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Aim: This study was to determine pregnant women's knowledge and attitudes towards stem cells and cord blood banking in Istanbul, Turkey.

Background: Stem cell research is one of the most important and, at the same time, the most controversial topics of science and technology today. Nurses need to understand stem cell research so they can enter the debate on this issue. They can become important sources of information in order to help parents understand the issues.

Methods: This exploratory descriptive study was conducted in two antenatal outpatient clinics in Istanbul. The sample consisted of 334 pregnant women during routine prenatal visits. Data were collected in interviews by using an interview form developed by the researchers according to the literature. The form included demographic characteristics of participants and 20 questions about stem cells, storing cord blood and banking and 10 independent attitude statements.

Results: The majority of the participants had a lack of knowledge about stem cells and cord blood banking and wanted more information. Before pregnancy, they received some information through the media (newspaper, Internet, television, etc.), but unintentionally. It was determined that they wanted information before becoming pregnant, more from their obstetrician but also from nurses and midwives. The majority also wanted to store their infants' cord blood and stated that they would be more likely to choose a public cord blood bank.

Conclusion: Those giving ante- and perinatal care need to offer accurate and scientific counselling services on this subject to parents who need to be informed.

Keywords: Attitudes, Cord Blood Banking, Knowledge, Pregnant Women, Stem Cells, Turkey

Introduction

Stem cells are master cells that can form virtually any tissue in the human body. Stem cell research is one of the most important and, at the same time, the most controversial topics of science and technology today (Beksac et al. 2004; Davey et al. 2004; Negrin 2005; Timuragaoglu 2004). Scientists believe research in this area holds promise for the treatment of many devastating diseases of humankind. This important scientific breakthrough has the potential to revolutionize the practice of medicine and improve the quality and length of life (De Back 2001).

Nurses need to understand stem cell sources so that they can enter the debate on this issue. Discussions are often intense because of the different positions held by scientific, religious, societal and political sources. Nurses need to equip themselves with accurate information, using the International Council of Nursing Code of Ethics for Nurses (Oulton 2000) and their own ethical decision-making processes. They can then make decisions

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for themselves about the efficacy of stem cell research and become important sources of information to help others understand and debate the direction of this scientific breakthrough (De Back 2001; Yıldırım & Sahin 2007).

Background

A stem cell is a cell that can become established in an appropriate growing environment, has the ability to multiply, can produce cell types that continue to differentiate and renew itself or ensure the continuation of its own population and can regenerate tissue with functional damage. Stem cells, which have been used for a period of time in the treatment of leukaemia and other types of cancer, have recently started to be used in medicine development. and this progress offers us hope for the treatment of diabetes, cardiovascular and neurogenerative diseases, but these applications are still unproven (Ballen 2005; Barker & Wagner 2003a; Genkord 2005; Newman et al. 2003).

Cord blood, which is more advantageous than other sources of stem cells, can be obtained from all infant deliveries conducted under appropriate conditions. The collection of cord blood is primarily carried out by obstetricians, midwives and nurses who have received training in this area. The collection of cord blood occurs after the delivery of the infant and does not cause any kind of injury to the infant or mother (AAP 1999; Barker & Wagner 2003b; Barker et al. 2002; EUC Report 2004; Rocha et al. 2004; Wagner et al. 2002; Wiley & Kuller 1997). As a result of the potential use of cord blood for health problems that develop in the future, a need has arisen for the collection and storage of cord blood throughout the world and, for the purpose of this article, in Turkey in particular. For this reason, there has begun a steady increase in number of cord blood banks. Two different kinds of cord blood banks have been founded internationally. Allogenic Cord Blood Banks are not-for-profit public institutions, open nationally and internationally to all recipient candidates whose tissue group matches. Expenses are paid for by health insurance. As many as 75% of the public cord blood banks are these not-for-profit or for-the-public-benefit type of banks. The others are private Autologous Cord Blood Banks, which are orientated to the individual and/or family. However, these are private institutions that provide a service to tissue owners and whose primary purpose is for profit (EUC Report 2004; Timuragaoglu 2004).

The European Commission in its report, *Ethical Aspects of Umbilical Cord Blood Banking*, emphasized that it is right to support publicly provided cord blood banking for allogenic purposes and that there was a need to look cautiously at privately supported cord blood banking for autologous purposes under the conditions of today (EUC Report 2004).

Turkey creates a significant market for autologous cord blood banking because of the high birth rate. The ethical and medical aspects of autologous cord blood banking are being discussed with newly passed legal regulations (The Ministry of Health of Turkey, Cord Blood Banking Regulations 2005). Similar discussions have occurred in many other countries, and efforts are being made to keep autologous cord blood banking under tight supervision with legal regulations. In Turkey, there are no public allogenic banks that work on a donation procedure for storing healthy infants' cord blood looking towards the future before illness occurs. Only those with a health insurance system and a medical indication can have the blood taken and stored at university hospitals. Storage in private cord blood banks for autologous purposes in Turkey is a very expensive procedure. If a family wants, the cord blood collection procedure can be carried out at every hospital. However, the storage procedure is only performed at six university hospitals and some private cord blood banks (Baytur & Sen 2004; Eserdag 2003; Tanyeli 2005).

One of the recommendations of the EUC to its own member states (EUC Recommendation 2004:8) was that cord blood stored for autologous purpose is rarely used medically and that it was necessary not to support member nations' health services' autologous cord blood banking. It was recommended that autologous cord blood banking not be performed by states and that serious limitations be placed on current private banks. For this reason, it is necessary for legal regulations to be rapidly prepared and the increasing number of autologous cord blood banks be supervised effectively.

Because of the many issues involved and the widespread public discussion on the issue, nurses and midwives who provide care in the ante- and perinatal period should be able to provide counselling services to pregnant women on the new concept of stem cell utilizations and cord blood banking (Yıldırım & Sahin 2007).

The current discussions in Turkey about stem cells and cord blood banking and the publication of news about autologous cord blood in the media highlight the need to determine pregnant women's attitudes towards this topic (Attar 2004; Beksac et al. 2004).

This study was planned for the purpose of determining pregnant women's knowledge and attitudes towards stem cells and cord blood banking in Istanbul, Turkey.

Methods

This exploratory descriptive study was conducted at the Istanbul University Medical Faculty and the Okmeydani Mother–Child Health and Family Planning Center in Istanbul between October 2005 and June 2006.

The pregnant women were informed about the aim of the study. Information about anonymity, confidentiality and consent

Table 1 The correlations between pregnant women's attitudes about cord blood their educational years

Statements	*Agree*		*Educational years*	
	n	*%*	*Test (χ^2)*	*P (<0.05)*
1. Using my baby's own cord blood is more reliable than using other people's cord blood or bone marrow.	118	35.4	38.017	0.00
2. My baby's cord blood should only be used for my own family.	31	9.3	13.479	0.05
3. If the cost is affordable and I can pay it, I will have my baby's cord blood stored.	165	49.4	27.532	0.00
4. If there is a need, everyone should be able to benefit from banked cord blood.	330	98.8	2.320	Not significant
5. When cord blood is taken, the baby is not harmed at all.	286	85.6	13.893	0.05
6. My child may never need this treatment; I think it is unnecessary to have my baby's cord blood stored.	88	26.3	11.439	0.05
7. I am concerned that my baby's cord blood would be used for different purposes.	204	61.1	10.689	0.05
8. I would prefer to have my baby's cord blood stored in public banks belonging to the government rather than in private banks.	241	72.2	11.970	0.05
9. Only babies born in private hospitals can benefit from cord blood storage services.	24	7.2	21.365	0.001
10. If I was offered the opportunity to store cord blood, I would accept.	247	74.0	13.682	0.05

was included in the explanation, and written permission was obtained. The written ethical approval was obtained from the ethics review board of the Istanbul University Medical Faculty Directors and Istanbul Province Health Ministry.

During the research period, all pregnant women who came for routine prenatal visits in the mentioned clinics were eligible for the study. A total of 893 pregnant women came for prenatal visits between October 2005 and June 2006. Of these women, 334 pregnant women volunteered to participate in the study and were included non-randomly in the convenience sample. Data were collected during interviews by using a data collection form (DCF) developed by the researchers according to the literature and revised with a pilot study of 30 women who were not included in the final sample. The DCF included 20 yes/no and open-ended questions about stem cells, storing cord blood and cord blood banking. Examples of some yes/no questions were: Do you have information about stem cells and cord blood? Do you know for which illnesses the cells obtained from cord blood is used? Some questions such as sources of information about stem cells and cord blood were asked as open-ended questions. Additionally, the DCF contained ten independent attitude statements, e.g. 'My baby's cord blood should only be used for my own family', 'If the cost is affordable and I can pay it I will have my baby's cord blood stored', 'If I was offered the opportunity to store cord blood I would accept' (Table 1). The pregnant women were examined as to whether or not they agreed with these statements. Information about the pregnant women's sociodemographic and obstetric characteristics was also obtained.

Data analysis

The Package for Social Sciences (SPSS, Chicago, IL) for Windows 10.0 program was used for the statistical analyses in the evaluation of findings obtained in this study. Mean, frequency and χ^2-test were used in the evaluation of findings related to the subjects' sociodemographic characteristics, knowledge about stem cells and cord blood and their opinions about the storage of cord blood, and attitudes about stem cells and cord blood. The results were evaluated at a 95% confidence interval and at a $P < 0.05$ level of significance.

Results

Descriptive characteristics of the 334 pregnant women are presented in Table 2. A statistically significant relationship was found in that as the women's educational year increased, the incidence of intermarriage decreased (X^2:10.995, p:0.01).

Table 3 shows the women's knowledge about stem cells and cord blood. Pregnant women who had a higher educational level were found to have a statistically significant level of knowledge about stem cells and cord blood (X^2:68.648, p:0.00), knowing for which illnesses cells obtained from cord blood could be used (X^2:47.552, p:0.00), and thinking about storing cord blood (X^2:10.444, p:0.01).

The pregnant women who stated that they were thinking about storage of cord blood were doing so for the following reasons: because it might be necessary in the future (48.9%); because they might regret not having performed it in the future (10.2%); because it was good to store what would have been thrown out (9.8%); because it is beneficial (22.1%); because it would be insurance for the health of their child (8.1%); and, in case a problem developed, because they had married a relative (5.9%).

The pregnant women who were not thinking about storing cord blood gave the following reasons: because it was not necessary (68.7%); because they did not have enough information on

Table 2 Descriptive characteristics of participants

*Variables**	*X ± SD*	*Min–max*
Age	26.49 ± 4.94	17–44
Years of formal education	8.89 ± 3.68	0–17
Number of parity	1.41 ± 0.74	1–5
Number of pregnancy	1.44 ± 0.77	1–5
Number of miscarriages/abortions	1.18 ± 0.42	1–3
	N	*%*
Interfamily marriage (Yes)	42	12.6
Development of problem in children because of intermarriage† (Yes)	3	7.1
Perceived income level		
My income is less than my expenses.	72	21.6
My income and expenses are balanced.	207	62
My income is more than my expenses.	55	16.4

*$N = 334$.
†$n = 42$.

Table 3 Knowledge about stem cells and cord blood of pregnant women

*Knowledge about stem cells and cord blood**	*N*	*%*
Do you have information about stem cells and cord blood? (yes)	90	26.9
Do you know for which illnesses the cells obtained from cord blood is used? (yes)	178	53.3
Do you think about storing your cord blood? (yes)	235	70.4
Do you know about the cost of cord blood storage? (yes)	3	0.9
Sources of information about stem cells and cord blood†		
Media	65	72.2
Obstetrician	25	27.8
From whom they would like to receive information		
Obstetrician	263	78.7
Nurse/Midwife	71	21.3
When parents were informed about cord blood bank		
Prior to pregnancy	202	60.5
Before the 20th week	65	19.5
After the 20th week	46	13.8
During labour	21	6.3

*$N = 334$.
†$n = 90$.

this (21.2%); because their husbands would make the decision about this subject (7.1%); and because they did not trust the banks (3%).

Table 1 shows the correlations between participants' attitudes about cord blood their educational years.

Discussion

There has been a significant increase in stem cell research in recent years. There are still many reservations in the scientific community and in Turkish society about this subject (Yıldırım & Sahin 2007). There have been three conferences on this subject (stem cell and gene therapy) in Turkey since 2004. During these conferences, scientific studies were presented and legal, ethical and religious issues were debated. It was emphasized that cord blood storage and banking need to be considered for their benefits and not for profit and that current, accurate and consistent information needs to be given to individuals (Yıldırım & Sahin 2007).

Religious authorities who have evaluated cord blood and banking from the Islamic viewpoint have explained the conditions for tissue and organ transplantation. They reported that when a tissue is not vital to the life of the donor, its donation cannot have a negative effect on the donor and that tissue and organ transplantation is appropriate/religiously permissible in conditions where there is no financial gain and there is no other means for treatment (Religious leaders determine the criteria for organ transplantation, see http://www.medimagazin.com.tr/haber_41113.html). Stem cells that are stored in cord blood banks and cord blood are evaluated as being mature stem cells. Consequently, the storage of cord blood, from the viewpoint of families and donors/recipients, is outside the ethical and religious debate about embrionic stem cell studies. The Ministry of Health published Cord Blood Banking Guidelines in 2005, and all private cord blood banks are facilities that work according to this law (Genkord 2005). Because umbilical cord blood is especially rich in stem cells, some parents choose to save it in private cord blood banks in case there is a need in the future as a transplant alternative to bone marrow.

Determining parents' knowledge and attitudes about the collection, storage and transplantation of cord blood can guide those who provide perinatal care. According to Turkish Demographic Health Survey (TDHS 2003) the highest fertility rate was in the 25–29-year-old group. Turkish culture attributes great importance to having children. For example, in families, 'childless women are seen as fruitless trees' in a Turkish proverb. The fertility statistics of our study group are similar to those of the TDHS statistics.

In a study by Fernandez et al. (2003), when pregnant women were asked about their knowledge of stem cells and cord blood, 70% had a little or very little knowledge level. In this study, the pregnant women's knowledge level was similar to that of the Fernandez et al.'s study. In both studies, the women with higher educational levels also had greater interest and awareness about this topic, which was an expected result.

According to research, as a result of haematopoietic stem cell transplantation, some types of cancers can be treated. In addi-

tion, the treatment of many other illnesses is still in the research stage (Barker & Wagner 2003a; Genkord 2005; Newman et al. 2003). Participants who had some knowledge about which illness can be treated with cells obtained from cord blood listed the media as their primary source of information (EUC Report 2004; Genkord 2005). This result shows the importance the media has in providing information. It is necessary for media news not to be based on unscientific information, which is misleading or can cause panic. Health care providers have important roles in providing accurate information.

The majority of the participants who wanted to be informed about cord blood collection and storage wanted this information to be given to them by their obstetrician. They saw nurses and midwives as later sources of information. In the similar study conducted by Fernandez et al. (2003), 68% of the pregnant women stated that they wanted information on this subject from their physician. However, in Turkey, nurses and midwives are the primary staff in perinatal care, so their knowledge and skills on this subject need to be improved (Attar 2004; Fernandez et al. 2003; Ozdemir 2005; Smith & Thomson 2000; The Ministry of Health of Turkey, Cord Blood Banking Regulations 2005; Yıldırım & Sahin 2007).

The appropriate time to inform parents about stem cell and cord blood banking is before pregnancy (Timuragaoglu 2004). Approximately 90% of the pregnant women in this study stated that they had been informed in their 20th–30th week or earlier. Our results are in accordance with Fernandez et al.'s study (83%), which was conducted in Canada where these banks are common (Fernandez et al. 2003).

Even though there are no matching problems in allogenic transplantation (Askari et al. 2002; Timuragaoglu 2004; Wiley & Kuller 1997), one-third of the pregnant women agreed to the statement, 'Using my baby's own cord blood is more reliable than using other people's cord blood or bone marrow', which shows they have been influenced by media news and are inadequately informed. Similar to our results, in Fernandez's study, half of the pregnant women thought that their infants' own cord blood was safer. High educational level supports accurate information (Fernandez et al. 2003).

The idea that the infant and mother are not at any health risk during or after the blood remaining in the umbilical cord is collected was supported more by those with a higher educational level. However, because of knowledge deficit on this subject, there are those who think this will harm them or their infant. It is suggested that this bias can be overcome by providing accurate information (EUC Report 2004).

Autologous cord blood transplantation is rarely used. If there is a desire to increase the rate of cord blood storage and transplantation in the future, then it is clear that parents need to be accurately informed by health care personnel before pregnancy occurs and during prenatal care (Genkord 2005; Timuragaoglu 2004).

Storing cord blood in private banks will be impossible for the majority of Turkey's population who could not afford the cost of private cord blood banks. In parallel with this study, women did not know about the cost of collecting and storing stem cells and cord blood in Turkey. For this reason, cord blood banks need to be founded and financed by the government (Baytur & Sen 2004; Eserdag 2003; Tanyeli 2005).

Pregnant women who have been informed and agreed to the procedure previously can have access to this service at any hospital that provides prenatal care. If awareness and knowledge are increased, the majority of the participants in this study, primarily those with high educational levels, would want to have cord blood stored. In Fernandez et al.'s (2003) study as well, 75% of the subjects reported that they would choose public banks because the private banks are more expensive.

The results of this study for the reasons why pregnant women agree to storing cord blood are similar to Fernandez et al.'s (2003) study. A difference in this study compared to Fernandez et al.'s study was that, because of the subjects' interfamily marriages, they were concerned about the development of illnesses and wanted the storage for this reason.

Even though public cord blood banks are not common in Turkey, the majority of the pregnant women reported that they would like to have their infants' cord blood stored in public facilities. In the study conducted by Fernandez et al. (2003) in Canada, where public cord blood banking is legal and widespread, 86% of the women preferred to use public banks for storage, which is parallel with our study.

Almost all of the pregnant women had positive attitudes on the subject of everyone being able to use cord blood that belonged to their infants stored in cord blood banking. Benevolent and compassionate values in Turkish culture have an important role in creating these positive attitudes. This positive attitude suggests that public cord blood banking will expand in Turkey (Baytur & Sen 2004; Eserdag 2003; Tanyeli 2005).

A few negative incidents about organ and tissue donation in the past in Turkey may have led to the development of negative attitudes on this subject. These concerns can cause a trust problem in cord blood donors. Religious authorities have determined that when a tissue is not vital to the life of the donor, its donation cannot have a negative effect on the donor and that tissue and organ transplantation is appropriate/religiously permissible in conditions where there is no financial gain or other means for treatment. In Fernandez et al.'s (2003) study, 21% of the subjects stated that they did not want their infants' cord blood used for reasons other than transplantation (for research,

etc.) Even though the cultures are different the presence of this concern in the parents cannot be ignored. In the Fernandez et al. study 7% of the participants had this attitude of lack of trust in private banks.

Conclusion

The majority of the participants had inadequate knowledge about stem cells and cord blood banking and wanted to be informed. The pregnant women preferred to receive this information from their obstetrician rather than nurses/midwives. The majority of the pregnant women wanted to have their infants' cord blood stored and preferred public cord blood banking. They had positive attitudes about anyone in need using cord blood that belonged to their infants. They had the prejudice that private cord blood banking was more expensive and less safe and stated that if they could afford it, they would take advantage of this service. Perinatal caregivers need to meet parents' need for information on this subject by providing accurate and scientific counselling services. The nurses/midwives need to be well informed about the latest developments in stem cell and cord blood and to develop their practice skills in this special area.

Nevertheless, our study has some limitations including that it had consisted of a small, select sample of women in two antenatal outpatient clinics in Istanbul, so the results cannot be generalized to all of society. However, the results are valuable because this study was the first conducted in Turkey on the subject of stem cell and cord blood, which is still developing in Turkey. The data obtained in this study can also provide a basis for future studies.

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