Donating umbilical cord blood to a public bank or storing it in a private bank: knowledge and preference of blood donors and of pregnant women

Maria Screnci[1], Emilia Murgi[1], Guglielma Pirrè[2], Elisabetta Valente[1], Paola Gesuiti[1], Francesca Corona[1], Gabriella Girelli[1]

[1]Unit of Immunohaematology and Transfusion Medicine, [2]Unit of Obstetrics and Gynaecology; "Umberto I" Polyclinic Hospital, Rome, Italy

Background. Umbilical cord blood (UCB) is a source of stem cells for allogeneic haematopoietic transplantation in paediatric and adult patients with haematological malignancies and other indications. Voluntary donation is the basis for the success of unrelated UCB transplantation programmes. In the last few years a growing number of private banks offer their services to expectant parents, to store UCB for future use. The debate concerning UCB donation and private preservation has been ongoing for several years. The aims of this single centre study were to explore knowledge about UCB stem cells and attitudes towards voluntary UCB donation or private UCB preservation among both blood donors and pregnant women.

Materials and methods. This study was conducted at the "Sapienza" University of Rome. Two types of anonymous questionnaires were prepared: one type was administered to 1,000 blood donors while the other type was distributed to 300 pregnant women.

Results. Most blood donors as well as the majority of pregnant women had some general knowledge about UCB (89% and 93%, respectively) and were aware of the possibility of donating it (82% and 95%). However, the level of knowledge regarding current therapeutic use resulted generally low, only 91 (10%) among informed blood donors and 69 (31%) among informed pregnant women gave a correct answer. The survey revealed a preference for voluntary donation both among blood donors (76%) and among pregnant woman (55%). Indeed, a minority of blood donors (6.5%) and of pregnant women (9%) would opt to store UCB for private use.

Discussion. The study raises the following considerations: (i) the large support for UCB donation expressed by blood donors and by pregnant women suggests that UCB preservation does not represent an obstacle to the expansion of UCB donation and to development of unrelated transplantation programmes; (ii) information about UCB donation and preservation should be carefully given by professionals and institutions.

Keywords: umbilical cord blood, public cord blood banking, cord blood donation, private cord blood banking.

Introduction

Umbilical cord blood (UCB) is a source of stem cells currently used for allogeneic haematopoietic transplantation in paediatric and adult patients[1,2]. In recent decades, unrelated UCB transplantation has been steadily increasing and consequently the demand for UCB units has increased.

To meet the growing demand for UCB, over the past 20 years public banks have been established and developed worldwide with over 600,000 UCB units donated and stored for unrelated use. Altruistic donation is the basis for the development and the success of unrelated UCB transplantation programmes. UCB from related donors may represent a source of transplantable haematopoietic stem cells for selected families: families already caring for a member affected by a disease treatable with haematopoietic stem cell transplantation and families known to be at risk of having a member with a disease treatable with haematopoietic stem cells transplantation[3-6].

On the other hand, more recently a growing number of private banks are being established in many industrialised countries. These banks provide their services, for a fee, to expectant parents, offering to store UCB for a potential future family use. Thus, expectant parents now have the option of altruistically donating UCB to a public bank, storing it at a private bank for personal use, or discarding it.

Although no accurate estimates exist of the likelihood of a family or child needing their own stored UCB, and despite the lack of support from the scientific community, because of aggressive marketing techniques by for-profit banks offering collection and personal storage as "biological insurance" against future life-threatening conditions, over the last 5 years, private storage of UCB has expanded dramatically, competing with altruistic donation programmes. The debate concerning altruistic UCB donation and private preservation has been ongoing for several years[7,8].

The argument that private banks exploit expectants parents at a time of emotional vulnerability represents the main objection to collection of UCB for private use. Accordingly, in the last few years, some studies have focused on this social behaviour[9] in some North American[10], European[11-16] and Asian countries[17,18], investigating knowledge and attitudes about stem cells and cord blood banking among pregnant women and among future parents.

The aims of this single centre study were to explore knowledge about UCB stem cells and preferences towards voluntary donation or private preservation, as well as the main motivations of their intention, among both blood donors and pregnant women. The blood donor population was chosen for comparison as it is representative of a healthy, relatively young and not emotionally vulnerable population.

Materials and methods

This study was conducted at the "Sapienza" University of Rome. Two types of questionnaires were prepared: one type was administered to blood donors while the other type was distributed to pregnant women. All questionnaires were anonymous.

Over a 6-month period from January to June 2010, a total of 1,000 blood donors were asked to fill in the questionnaire, during the refreshment period after giving blood. Pregnant women received the questionnaire in the waiting areas before the beginning of informative monthly meetings specifically on UCB and during antenatal monitoring. Between January and December 2010, a total of 300 pregnant women were given the questionnaire.

Table I - Characteristics of the 997 blood donors analysed.

	N (%)
Volunteer donors	855 (86)
Occasional donors	142 (14)
Sex	
Male	699 (70)
Female	298 (30)
Age	
Median, years	40
(range)	(18-63)
Nationality	
Italian	965 (97.5)
Others	25 (2.5)
No response	7
Educational level	
Lower school	140 (14.5)
Higher school	499 (51.8)
University	325 (33.7)
No response	33
Previous children	
0	486 (48.75)
≥1	511 (51.25)
History of CB donation	20 (4)
History of CB preservation	14 (2.8)

Legend: The percentages are calculated on the basis of the number of respondents.

In order to explore knowledge about UCB as well as attitudes towards public donation or private preservation, the questionnaires consisted of three parts: the first part included demographic questions (eg. age, sex, education, parity); the second part focused on knowledge about UCB (source, timing and quality of information); the last part examined the preference of participants regarding UCB (altruistic donation, private preservation, discarding or no decision) and the reasons for their choice.

In addition, in order to highlight a possible difference of choice related to emotional vulnerability we reviewed the decision of the pregnant women regarding UCB use by comparing it with the intentions expressed by female blood donors.

The general characteristics of these two study populations were very similar. The preferences expressed were analysed by a chi square test.

Finally, to verify the main motivation for UCB donation, a third type of questionnaire was distributed to a sample of 100 mothers who had donated cord blood. This questionnaire was administered during the maternal-neonatal follow-up, between 6 and 12 months after childbirth.

Results

Almost all contacted blood donors agreed to participate in this study and 997 completed questionnaires were collected. The blood donors who answered the questionnaires were mostly volunteers, Italian and male. A minority of the blood donors had a history of previous altruistic donation or private preservation of UCB. Descriptive characteristics of the respondent blood donors are listed in Table I.

Table II - Characteristics of 239 pregnant women and 298 female blood donors.

	Pregnant women	Female blood donors
Age, years median	34	38
(range)	(18-49)	(18-63)
Nationality		
Italian	197 (83%)	281 (95%)
Others	39 (17%)	14 (5%)
No response	3	3
Educational level		
Primary school	27	33
Secondary school	109	150
University	86	101
No response	17	14
Gestational age, weeks median	37	Not applicable
(range)	(7-40)	
Weeks of pregnancy		
≤35	68	Not applicable
>35	159	Not applicable
No response	12	Not applicable
Parity		
Nulliparous	-	182
Primiparous	139	-
Multiparous	100	116
History of blood donation	57	298
Knowledge about CB	222	289
Previous CB donation	8	5
Previous CB preservation	1	2

Legend: The percentages are calculated on the basis of the number of respondents.

Among 300 pregnant women who were asked to fill in the questionnaires, 61 (20%) refused and 239 (80%) returned the completed forms. Table II shows the characteristics of pregnant women and of female blood donors.

As reported in Table III, we first explored general knowledge about cord stem cells and then examined the source of information and level of knowledge about UCB. Among the pregnant women we also investigated the time at which the information was acquired in relation to the pregnancy, i.e. whether before or during the pregnancy.

A considerable proportion of both blood donors and pregnant women had some general knowledge about UCB (89% and 93%, respectively) and the majority, 82% of blood donors and 95% of pregnant women, were aware of the possibility of donating UCB. Most of the pregnant women had gained information about UCB before their pregnancy.

The most common sources of information for blood donors were magazines and newspapers (41%) while, as expected, in most cases information on UCB was provided to the pregnant women by gynaecologists and obstetricians (42%). Approximately one-quarter of both blood donors and pregnant women had obtained information via the Internet. Sometimes there had been more than one source of information. Internet was the main source of information for female blood donors.

Most of the pregnant women had more than minimal knowledge of UCB. Indeed, compared to blood donors a higher proportion of pregnant women had information regarding the difference between public and private UCB banks (58% *vs.* 30%), selection criteria for donation (71 *vs.* 25%), knowledge on the probability of clinical use (41.5% *vs.* 21%) and therapeutic applications of UCB (39.6% *vs.* 15.6%). However, the level of knowledge regarding the proper and real usefulness was generally low (31% *vs.* 10%): only 69 of the informed pregnant women and 91 of 886 informed blood donors gave a correct answer. As summarised in Table III, the quality of information among the pregnant women was better than that among female blood donors.

Additionally, as the Italian Ministry of Health has an official website with information on the

Table III - Timing, source, quality of information and preference about UCB.

	997 blood donors	239 pregnant women	298 female blood donors
	N (%)	N (%)	N (%)
General information about CB	886 (89)	222 (93)	289 (97)
Time of acquiring information			
Before pregnancy		156 (75)	
During pregnancy	Not applicable	53 (25)	Not applicable
No response		13	
Source of information			
Internet	211 (25.3)	56(26.3)	101 (35.5)
Gynaecologist, obstetrician	120 (14.4)	89 (42)	73 (25.7)
Internet + healthcare (associated)	144 (17.3)	20 (9.4)	28 (9.9)
Press	344 (41)	5 (2.3)	78 (27.5)
Other (TV, family, friends, ...)	15 (2)	43 (20)	4 (1.4)
No response	52	9	5
Content of information			
1. Knowledge about donation	730 (82)	211 (95)	257 (89)
2. Knowledge on differences between public and private banks	264 (30)	129 (58)	100 (34.6)
3. Knowledge on criteria for selecting units	222 (25)	158 (71)	80 (27.7)
4. Knowledge on current probability of clinical use	184 (21)	92 (41.5)	73 (25)
5. Knowledge on current therapeutic uses	138 (15.6)	88 (39.6)	69*(23.8)
a) correct	91 (66)	69 (78.4)	39 (56.5)
b) partly correct	6 (4.3)	11 (12.5)	-
c) wrong	41 (29.7)	8 (9.1)	6 (8.7)
Have consulted the Official website of the Ministry of health	40 (4.5)	24 (11)	17 (6)
Intention to public donation	708 (76)	132 (55)	212 (73)
Intention to private storage	86 (9)	15 (6.5)	35 (12)
Intention to discard	0	68 (28.5)	0
No decision yet	0	24 (10)	0
Both donation and preservation	136 (15)	0	42 (14.5)
No response	67	0	9

Legend: The percentages are calculated on the basis of the number of respondents; 24 (34.8%) female blood donors did not specify any clinical use.

appropriate use of UCB stem cells, we examined its effective role in giving information about UCB to these two study groups. Although the majority of blood donors and pregnant women claimed they had information on cord blood stem cells, only a very small proportion (4.5% and 11%, respectively) of them had consulted the specific website section of the Ministry of Health concerning the appropriate use of stem cells from UCB.

As shown in Table III, we subsequently explored the attitudes towards cord blood donation and preservation. Almost all blood donors (93%) expressed a preference: 76% would donate, 9% would preserve UCB privately, 15% would choose both options. No blood donors would have opted to discard UCB. Altruism was the main motivation for donation.

On the other hand, among pregnant women the 55% would choose to donate UCB, 6.5% would opt to store UCB for private use and 28.5% would prefer for their UCB to be destroyed, neither donating nor preserving it. The remaining 10% did not express a preference. The reasons for each choice are detailed in Table IV.

About a third (N=68) of the pregnant women who stated that they were not interested in either donating or preserving UCB gave the following reasons: lack of motivation (28%); logistic reasons (eg. because not all hospitals have UCB collection facilities) (28%); the unsustainable cost for personal storage

Table IV - Intention and reasons for choice of 215 pregnant women.

Intention to public donation, main reasons for choosing public donation	N=132
Altruism	36
Altruism + other*	76
Other	20
Intention to private storage: main reasons for choosing private storage	N=15
"Safeguarding the future"	11
Logistics	3
Other	1
Intention to discard: main reasons for choosing discard	N=68
Cost of preservation unaffordable	12
Logistics	19
Lack of interest	19
Clinical exclusion from donation	6
Other	12

Legend: *respondents could give more than one reason (e.g. the existing possibility of recovering the donated UCB sample; UCB samples should be available to others rather than destroyed; too costly to store privately).

(17.5%); unsuitability for donation because of clinical exclusion criteria (9%); unspecified reason (17.5%).

To assess the possible influence of gestational age on the decision-making process, we examined the preferences expressed by pregnant women according to the gestational age at which the questionnaire was administered. When comparing the options that pregnant women would have chosen, considering the reported gestational age as ≤35 weeks (N=68) or >35 weeks (N=159), there was no difference with respect to donating UCB (62.5% *vs.* 65.7%) but there was a decrease (37% *vs.* 25%) in the choice of discarding UCB and an increase in the choice of preserving the cord (3% *vs.* 9%). These results seem to suggest that gestational age does not affect the decision to donate UCB and that this decision is taken early during pregnancy. On the other hand, the increase during the last period of pregnancy in the choice to preserve UCB is probably due to the procedure for UCB preservation which must be started within a few weeks before the expected date of childbirth.

To highlight a possible difference of choice related to emotional vulnerability we compared the preference expressed by pregnant women with the intentions expressed by female blood donors.

It emerged that 61% of pregnant women who expressed a preference (132/215) and 73% of female blood donors would have chosen to donate UCB (χ^2=7.597, p=0.006), while a minority (7% and 12%, respectively) would have chosen to preserve UCB (χ^2=3.084, p=NS). Thirty-two percent of pregnant women would have opted to discard their UCB while 14.5% of female blood donors would have liked both to donate and to preserve UCB.

Finally, the analysis of questionnaires administered during the follow-up to women who had donated UCB revealed that altruism was the main reason for this choice and confirmed the predominant role of solidarity in all donation processes: all contacted women (100%) confirmed their choice and expressed their contentment and happiness from contributing to help someone and public health care in general. Four women reported having donated UCB since the cost was unsustainable for private preservation.

Discussion

Donation of UCB for public banking is supported by scientific evidence and is considered a gift of moral and social value. Personal or private storage of UCB has expanded over the last years due to parents' decision to provide "biological insurance" to their children in the case of future illness. There has, therefore, been a recent considerable increase in the debate concerning donation and private preservation of UCB and some studies have investigated this social behaviour among pregnant woman.

Our study supports and expands the results of these investigations because it involves not only pregnant women but also blood donors, although the fact of blood donors being a population already selected for altruism could be a limitation.

In this investigation the pregnant women's level of knowledge about UCB was higher than that reported by other authors[10,12,15]. We believe that the fact that the quality of information among pregnant women was better than among blood donors and female blood donors was due to the information provided by professionals.

In accordance with previous reports[16,17], it emerged from our study that more than half of pregnant women (55%) would have chosen to donate cord blood to a public bank for altruism and also for the existing possibility of recovering, if necessary, the donated sample if it were to be still available.

In this survey, the cost associated with private

banking did not seem to influence the preference to donate UCB, but did seem to be a reason for not choosing the option of private preservation.

Unexpectedly, about one-third (28.5%) of pregnant women, even if informed, expressed a lack of interest in both donation and preservation. Apart from logistic reasons, this attitude is probably due to existing concerns related to the pregnancy and present difficulties, leading the women to exclude both donation and preservation, as if they were fully occupied by real problems and did not want to consider hypothetical future problems.

Moreover, it would seem that gestational age does not affect the decision to donate UCB but that it does influence the decision to preserve UCB. During a pregnancy, the decision to donate UCB is taken earlier than the decision to preserve it. The decision to preserve UCB seems to be pondered more. In this survey a total of 7% of pregnant women would have opted for UCB preservation: this low percentage compared to the 12% of female blood donors who would have chosen to store their UCB suggests that the emotional vulnerability of expectant parents does not exert such an important influence on the decision-making process to the advantage of UCB preservation.

As the controversy surrounding private storage of UCB as a safeguard against future life-threatening conditions raises many questions in expectant parents and as most advertising is for private preservation of UCB, almost all pregnant women greatly appreciated opportunities to discuss and investigate this issue and most of them welcomed the chance to learn more about the usefulness and limitations of UCB.

This survey revealed a strong preference for donation also among blood donors (76%) and specifically among female blood donors (73%). Some blood donors (15%) expressed the wish both to donate and to preserve UCB. Solidarity and future personal needs were the reasons for their choice. They wanted strongly to choose both options. We believe that adequate information about public banking, therapeutic uses of cord stem cells and the possibility of recovering donated UCB or looking for a compatible sample in the worldwide inventory could influence this choice.

Indeed, the quality of information among blood donors was generally lower than that among pregnant women suggesting that, information acquired from media -newspapers, magazines, internet[19] and television- is incomplete, sometimes unclear and perhaps not always correct.

Unexpectedly, also most of blood donors welcomed the opportunity to know more about UCB, especially with regards to differences between public and private banks, probability of clinical need, and current therapeutic uses. Mostly, they were not aware that, as previously reported[20], public banks have specific criteria and thresholds for banking, while private banks generally store the majority of UCB samples collected.

We, therefore, believe that professionals and institutions should make an effort to provide unbiased information and education both about UCB donation and preservation, focusing on the utilisation of UCB stem cells. In particular, as UCB is a valuable community resource, obstetricians should encourage UCB donation, providing detailed information especially to pregnant women and to future parents. We found that the official website of the Ministry of Health was consulted very little. The institutions should play a more significant role in giving updated and evidence-based information about the usefulness and limitations of UCB to the population.

Our study suggests that correct and complete information would be especially useful in times when the person involved is not emotionally vulnerable, since this would facilitate a serene and informed choice. Finally, the study confirms that the attitudes of the populations investigated are not an obstacle to the expansion of UCB donation and to development of unrelated transplant programmes.

Acknowledgments

The Authors thank Johanna Preiswerk, regional secretary of ADISCO (Italian Association of UCB donors), Antonietta Leoni, president of ADSPEM (Italian, regional association of blood donors), and Mara Marchiori, member of the directive council of ADSPEM, for having carefully distributed and collected the questionnaires.

The Authors declare no conflicts of interest.

References

1) Gluckman E, Rocha V. Cord blood transplantation: state of the art. Haematologica 2009; **94**: 451-4.
2) Sanz J, Sanz MA, Saavedra S, et al. Cord blood transplantation from unrelated donors in adults with

high-risk acute myeloid leukemia. Biol Blood Marrow Transplant 2010; **16**: 86-94.
3) Locatelli F, Rocha V, Reed W, et al. Related umbilical cord blood transplantation in patients with thalassemia and sickle cell disease. Blood 2003; **101**: 2137-43.
4) Herr AL, Kabbara N, Bonfim C, et al. Long-term follow-up and factors influencing outcomes influencing related HLA identical cord blood transplantation for patients with malignancies: an analysis on behalf of Eurocord-EBMT. Blood 2010; **116**: 1849-56.
5) Screnci M, Murgi E, Carmini D, et al. Related cord blood banking for haematopoietic stem cell transplantation. Transf Med 2010; **20**: 185-90.
6) Gluckman E, Ruggeri A, Rocha V, et al. Family-directed umbilical cord blood banking. Haematologica 2011; **96**: 1700-7.
7) Ballen K. Challenges in umbilical cord blood stem cell banking for stem cell reviews and reports. Stem Cell Rev 2010; **6**: 8-14.
8) Rosenthal J, Woolfrey AE, Pawlowska A, et al. Hematopoietic cell transplantation with autologous cord blood in patients with severe aplastic anemia: an opportunity to revisit the controversy regarding cord blood banking for private use. Pediatr Blood Cancer 2011; **56**: 1009-12.
9) Waldby C. Umbilical cord blood: from social gift to venture capital. BioSocieties 2006; **1**: 55-70.
10) Fernandez CV, Gordon K, Van den Hof M, et al. Knowledge and attitudes of pregnant women with regard to collection, testing and banking of cord blood stem cells. CMAJ 2003; **168**: 695-8.
11) Danzer E, Holzgreve W, Troeger C, et al. Attitudes of Swiss mothers toward unrelated umbilical cord blood banking 6 months after donation. Transfusion 2003; **43**: 604-8.
12) Dinç H, Şahin NH. Pregnant women's knowledge and attitudes about stem cells and cord blood banking. International Nursing Rev 2009; **56**: 250-6.
13) Manegold G, Meyer-Monard S, Tichelli A, et al. Controversies in hybrid banking: attitudes of Swiss public umbilical cord blood toward private and public banking. Arch Gynecol Obstet 2010; **284**: 99-104.
14) Salvaterra E, Casati S, Bottardi S, et al. An analysis of decision making in cord blood donation through a participatory approach. Transfus Apher Sci 2010; **42**: 299-305.
15) Palten PE, Dudenhausen JW. A great lack of knowledge regarding umbilical cord blood banking among pregnant women in Berlin, Germany. J Perinat Med 2010; **38**: 651-7.
16) Katz G, Mills A, Garcia J, et al. Banking cord blood stem cells: attitude and knowledge of pregnant women in five European countries. Transfusion 2011; **51**: 578-86.
17) Shin S, Hyun Yoon J, Ryun Lee H, et al. Perspectives of potential donors on cord blood and cord blood cryopreservation: a survey of highly educated, pregnant Korean women receiving active prenatal care. Transfusion 2011; **51**: 277-83.
18) Suen SS, Lao TT, Chan OK, et al. Maternal understanding of commercial cord blood storage for their offspring - a survey among pregnant women in Hong Kong. Acta Obstet Gynecol Scand 2011; **90**: 1005-9.
19) Capone F, Lombardini L, Pupella S, et al. Cord blood stem cell banking: a snapshot of the Italian situation. Transfusion 2011; **51**: 1985-94.
20) Sun J, Allison J, McLaughlin C, et al. Differences in quality between privately and publicly banked umbilical cord blood units: a pilot study of autologous cord blood infusion in children with acquired neurologic disorders. Transfusion 2010; **50**: 1980-7.

Arrived: 27 July 2011 - Revision accepted: 18 January 2012
Correspondence: Maria Screnci
Unità di Immunoematologia e Medicina Trasfusionale
Policlinico Umberto I
Via Chieti 7
00161 Roma, Italy
e-mail: screnci@bce.uniroma1.it