

Data

A Questionnaire Survey of Attitudes and Awareness Among Pregnant Women of the Public Cord Blood Banking System in Japan

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ABSTRACT

Background: To determine effective methods of promoting the public cord blood banking system in Japan, we investigated awareness and reasons influencing donation to the system among pregnant Japanese women. The results were compared with those obtained in a similar survey conducted 3 years earlier, in 1999, before the establishment of the Japan Cord Blood Bank Network.

Methods: A questionnaire survey was distributed to 110 pregnant women at a hospital associated with a public cord blood bank, the Tokyo Cord Blood Bank project.

Results: In total, 92 women replied to the questionnaire. The respondents' degree of familiarity with the public cord blood banking system was almost the same as that in the previous study. One of the most effective methods of increasing awareness of such a system was the mass media, in particular, television. Overall, 83% of respondents indicated that they were aware of the existence and function of the system. It is clear that when they are better informed, they will more willingly participate in the program.

Conclusions: To effectively promote the cord blood banking system and its goals, pregnant women need to be better informed of its importance.

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KEYWORDS: cord blood bank, informed consent, private bank, midwife guidance, regenerative medicine

The aim of cord blood transplantation is to make use of hematopoietic stem cells in blood by transplanting cryo-preserved blood harvested from umbilical cord and placental remains. In the past, both the umbilical cord and placental remains were discarded after delivery. As is the case for bone marrow transplants and peripheral blood stem cell transplants, hematopoietic stem cells are increas-

ingly used in cord blood transplantation as treatments for malignant blood diseases, impaired production of blood-forming cells, and congenital metabolic diseases. As compared with bone marrow transplantation, cord blood transplantation places fewer burdens on patients, has fewer constraints related to human leukocyte antigen (HLA) matching (*i.e.*, a large donor pool is not needed), is associ-

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ated with a lower incidence and severity of graft-versus-host disease after transplantation, and, because there is no need for coordinating bone marrow matching, has the potential to provide a quick supply of cells depending on the patient's condition. However, cord blood transplantation has several challenges, including the necessity of obtaining informed consent from donors, the need for large numbers of donors in order to obtain the amount of blood needed for a transplant (as only a small amount can be collected from each individual), and the considerable expense of building and maintaining refrigerated preservation facilities to store blood until it can be transplanted. As is the case for bone marrow banks, enormous effort is required to secure enough donors. In the present study, the support of pregnant women was sought in order to collect enough cord blood units for a cord blood banking project.

The first cord blood stem cell transplant, between a brother and sister, was performed in France in 1988.¹⁾ In 1992, a cord blood bank was founded at the New York Blood Center in the United States for the benefit of unrelated persons,²⁾ and this resulted in a rapid increase in blood transplant operations between unrelated persons. At this writing, more than 60000 units of cord blood are kept in trust worldwide, and over 2000 transplants have been performed.³⁻⁶⁾ The outcomes of these operations are believed to be comparable with those of bone marrow transplantation.

The first sibling cord blood transplant in Japan was performed in 1994, and cord blood banks were established the next year in various locations across Japan, to facilitate transplants between unrelated persons. The Japan Cord Blood Bank Network was established in 1999,^{7,8)} and there are now 11 cord blood banks affiliated with the network. These banks provide public internet access to data on stored blood and presently keep 20000 units of cord blood as a step toward building a banking network system that could satisfy the demand of 90% of patients who have HLA 1 antigen discordance. At the end of 2002, the registered number was over 13000 units, and nearly 900 transplant cases had been reported.⁹⁾ This number is second only to that of the United States.

Blood transplants are covered by the national health care system in Japan. During the initial stages of the program, transplants were limited to small children who suffered from a deficiency in required cells, but now an increasing number of adults are being transplanted with cord blood. Among 160 cases of cord blood transplantation

using blood provided by the Tokyo Cord Blood Bank, 84 were adults and 76 were children 15 years or younger.

In 1997, the Tokyo Cord Blood Bank was established as a public cord blood bank at the request of voluntary organizations. At the end of fiscal year 2002, it had 5000 units of cord blood, about 2900 of which were registered units open for public examination and available for transplantation. As mentioned above, over 160 units have already been used for transplantation. The bank secured the cooperation of 11 maternity hospitals as blood collecting facilities. The Institute of Medical Science, the University of Tokyo and the Advanced Medical Research Center, the Nihon University School of Medicine both have cell-handling and cell-preservation facilities.

In 1999 we conducted the first survey of awareness of the public cord blood banking project among pregnant women; soon after the Japanese Cord Blood Bank Network was formed.¹⁰⁾ At that time, many of the respondents did not have much knowledge of cord blood transplantation or the prospects of a cord blood banking system. The survey concluded that, to raise awareness of the system, accurate information on these matters should be given to women, even before pregnancy, and to their husbands and family members.

Three years after the initial survey, the situation of the public cord blood bank network was very different: the management of the Japanese Cord Blood Bank Network was stabilized and cord blood transplants were being routinely performed. However, problems remain, including an insufficient number of blood collecting facilities and a lack of facilities able to accept around-the-clock donations from willing blood donors. We conducted a repeat survey of the awareness and level of recognition of the cord blood banking system among pregnant. We hope that the results of this survey will be useful in promoting the cord blood bank project and increasing the cooperation of pregnant women in Japan.

In this study, in addition to the survey on private cord blood banks, which have emerged as a social issue, we added a survey of the awareness of regenerative medical treatment, which is a rapidly developing field closely related to cord blood. Such awareness surveys are rarely conducted in Japan,^{10,11)} and we found no such studies in other countries. These surveys may also provide information useful for promoting and gaining cooperation for cord blood banks and blood transplant projects.

Methods

Participants

A questionnaire was distributed to 110 healthy pregnant patients of a hospital in Chiyoda-ku, Tokyo, a cord blood collection facility that is affiliated with the Tokyo Cord Blood Bank. Pregnant women with abnormal conditions, such as pregnancy complications, were excluded. The duration of pregnancy was greater than 30 gestational weeks in all participants (mean [\pm SD] duration, 35.3 \pm 2.5 weeks). We obtained replies from 92 of the 110 pregnant women (83.6% collection rate). The survey was conducted over 4 months, from May through August 2002. A similar survey was conducted in 1999 at the same hospital.

Survey method

The cord blood banking system was explained to pregnant women at a maternity class during the second term of pregnancy. Later, after the project was explained by doctors or birth attendants at a prenatal checkup, the women were given a letter of consent to be signed if they agreed to donate cord blood. The questionnaire form for this study was given at the same time and was collected at the next prenatal checkup. The questions are shown in Table 1. Multiple answers were allowed for some questions.

Ethical considerations

At the time of questionnaire implementation, we obtained the consent of the participants after orally explaining the survey aims and the methods of data handling, after giving assurances that the resulting information would never be used for any other purpose. To protect the privacy of respondents, the questionnaires were distributed and collected independently of other related documents, such as the letter of consent for the Tokyo Cord Blood Bank.

Results

Respondent characteristics

All respondents were residents of the Tokyo metropolitan area. About 75% of them lived in the 23 wards of Tokyo (24% lived in Bunkyo-ku or Chiyoda-ku). About 76% of respondents reported that their husbands were employed by corporations, and most respondents were full-time homemakers or part-time workers/part-time homemakers. Mean annual family income was approximately 8 million yen. The average age of respondents was 31 \pm 4.3 years, and about 30% of respondents were primiparas

(Table 2).

Awareness of the public cord blood banking system

About 72.8% of the respondents were aware of the existence of the public cord blood banking system; 8% of respondents replied that they found out about the system in 2002, *i.e.*, during their pregnancy.

Multiple answers were allowed for the question regarding how they came to know about the public cord blood banking system: 22.5% of respondents answered "by viewing television (TV)" followed by 19.0% who answered "by seeing a poster" (Table 3). About 41.3% of respondents first learned about the banking system through some visual means.¹⁰⁾

A total of 39.1% of the respondents knew that the birthing hospital where this questionnaire study was conducted was a hospital involved with the banking project.

Informed consent and motives for project involvement

About 90% of the respondents received explanations about the public cord blood banking system from maternity nurses, and 83.7% of the respondents replied that they "understood the purpose of the project". Of the respondents who replied that they "fully understood" the public cord blood banking system, 65.2% reported that they would willingly participate in the project, while 64.3% of those who said that they "understood a little" indicated that they would participate only if it were possible (Table 4). Even among those who said that they would participate, 17.7% of respondents said that they still had concerns about donating their blood. Only 37% of respondents were aware that the cord blood bank required a report from donors regarding the result of their infant's 6-month checkup. When recounting their feelings after blood donation (multiple answers were allowed), 92.4% of respondents replied that they felt they had done a good thing that would help people with medical conditions, but 3.3% were concerned that their privacy might be compromised (Table 5).

Awareness of diseases and transplantation

The next item on the questionnaire was related to leukemia, a disease that can be treated with cord blood transplantation. About 90.2% of respondents had some awareness of bone marrow transplantation, and 22.9% knew the difference between bone marrow transplantation and cord blood transplantation.

Regenerative medical techniques

About 29.3% of participants reported knowing about re-

Table 1-1 Content of Questionnaire on the Cord Blood Banking System in Japan

Question 1	Place of residence (prefecture and municipality)	
Question 2	Age, occupation, and place of work for your family (head of household, wife). Duration of pregnancy (in weeks), and number of births.	
Question 3	Were you aware of the public cord blood banking system in Japan?	Yes. No. (choose one)
Question 4	When did you learn about the system? Select the year.	2002. 2001. After 1995. Before 1995.
Question 5	How did you learn about the system?	At the prenatal checkup/through a mothers' class/poster/newspaper/magazine or book/friend or acquaintance/TV/other (multiple answers allowed)
Question 6	Did you know that this hospital is a cord blood collection facility?	Yes. No. Have no way of telling. (choose one)
Question 7	Did you understand the explanation of the public cord blood banking system and the purpose of the banking project?	Yes. A little. No. (choose one) (Please give a reason why you couldn't understand.) (open-ended question)
Question 8	From whom did you receive the explanation of the public cord blood banking system?	Doctor/midwife or nurse/other
Question 9	To use your cord blood for transplant, it is necessary to carry out a medical examination of the baby and a checkup for neuroblastoma at age 6 months. Did you know about this requirement?	Yes. No. Have no way of telling. (choose one)
Question 10	In consideration of questions 7 and 9, do you want to cooperate with the public cord blood banking system by donating your cord blood?	Yes, willingly. Yes, if it's possible. No.
Question 11	(If you answered "Yes, willingly" or "Yes, if it's possible" to question 10) Do you have any concerns relating to donation of your blood?	Yes. No. (Please explain any worries) (open-ended question)
Question 12	(If you answered "No" to question 10) Please explain the reason for your refusal.	Because: I don't know the system well. I want to stay out of trouble. I'm concerned about the safety of cord blood treatment. I don't know much about blood transplantation. I'm worried about my fetus. My privacy will be threatened. Other. (multiple answers allowed)
Question 13	What do you think about the public cord blood banking system?	It's a good project because it helps sick people. I'm surprised to learn about advances in medical treatment. I'm happy that I could help babies. I feel familiar with the project now. I'm happy that I could contribute to the public good. I hope I can share the pleasure of childbirth with others. I feel nothing special. Other. (multiple answers allowed)
Question 14	The public cord blood banking system has a new website. Are you interested in visiting it?	Yes. No. Have no way of telling. (choice among the three)
Question 15	Have you visited the website for the public cord blood banking network? (If you answered "Yes") (to visitors) How did you feel?	Yes. No. (choice between the two) (open-ended question)

Table 1-2 Content of Questionnaire on the Cord Blood Banking System in Japan

Question 16	At the moment, the public cord blood banking system is mostly managed as a volunteer project. It is necessary to have stable financial resources to further develop the project. From where do you think the project should get revenue?	Taxes. Social security services. (social insurance, etc.) Patients who need cord blood. Other.
Question 17	What was your family income during the last 12 months? (total amount for all family members)	
Question 18	Do you have any comments about the public cord blood banking project?	(open-ended question)
Question 19	With advances in medical treatment, even leukemia patients (once diagnosed as incurable) have several treatment options. Did you know that one therapy for this disease is bone marrow transplant?	Yes. No. Have no way of telling. (choice among the three)
Question 20	(If you answered "Yes" to question 19) Do you know the difference between bone marrow transplant and cord blood transplant?	Yes. No. Have no way of telling. (choice among the three)
Question 21	Do you have any comments about bone marrow transplants or public cord blood transplants?	(open-ended question)
Question 22	Do you know about regenerative medical techniques?	Yes. No. (choose one)
Question 23	(If you answered "Yes" to question 22) Do you know that cells in the placenta and cord blood can be used for regenerative medical techniques?	Yes. No. (choose one)
Question 24	Regenerative medical techniques are expected to replace traditional use of drugs and organ transplantation methods in the future. May we ask for your comment on this possibility?	(open-ended question)
Question 25	You can have your baby's cord blood collected at your own expense for future use. This is called the private blood banking system. Did you know about the existence of this system?	Yes. No. (choose one)
Question 26	Are you interested in the private cord blood banking system?	Yes. No. Have no way of telling. (choose one)
Question 27	Please share any comments on the public cord blood banking system, regenerative medical techniques, or other medical topics.	(open-ended question)

generative medical techniques, which are expected to increase cord blood use, and about two-thirds knew that cells in the placenta and cord blood could be used for regenerative medical techniques.

Private cord blood banks

The last question was related to private cord blood banks. About 17.4% of respondents answered that they knew of such banks, and 40.2% said that they were interested in that kind of banking (Table 6).

Other questions

Concerning the operation of the public cord blood banking system, 34.8% of respondents thought that the system should be financed by tax revenues, while 48.9% thought that it should be financed by social welfare funds, includ-

ing social insurance. About 38.0% of respondents showed some interest in the internet homepage for the public cord blood banking system, but none had visited the site.

Discussion

Our previous investigation¹⁰⁾ found that the level of awareness of the public banking system was 72.0%, which remained almost unchanged over the subsequent 3 years. Primiparous and multiparous women differed as to when they became aware of the system. The results of these survey studies suggest that most women became aware of the existence of the public cord blood banking system only after pregnancy. However, awareness was much greater among multiparous women than among primiparous

Table 2 Background of respondents (n = 92)

Place of residence (%)					
Bunkyo or Chiyoda Ward	In Tokyo 23 wards	Out of Tokyo 23 wards	Others or no response		
23.9	73.9	23.9	2.2		
Householder's occupation (%)					
Office worker	Public servant	Self-employed	Others/no response		
76.1	6.5	7.6	9.8		
Respondent's occupation (%)					
Office worker	Public servant	Self-employed	Others/no response		
76.1	6.5	7.6	9.8		
Parity of respondent (%)					
Primipara	Once	Twice	Thrice	No response	
69.6	23.9	3.3	1.1	2.2	
Respondent's age (%)					
20 ~ 24	25 ~ 29	30 ~ 34	35 ~ 39	40 or older	
6.5	22.8	44.6	23.9	2.2	
Household income (%)					
No response	~ 4 (million)	4 ~ 6 (million)	6 ~ 8 (million)	8 ~ 10 (million)	10 million or more
9.8	6.5	18.5	29.3	17.4	18.5

Table 3 Means of exposure to the public blood banking system (multiple answers allowed)

Means of exposure	1999 Survey (n = 239) (%)	2002 Survey (n = 153) (%)
No response	0.8	0.0
Others	2.9	3.9
Friends or acquaintances	5.0	2.0
Maternity class, etc.	7.9	15.0
Newspaper or magazine	23.0	17.0
Prenatal checkup	15.1	17.6
Poster	33.1	19.0
Television (TV)/radio	12.1	25.5

Table 4 Respondents' understanding and willingness to contribute to the system

Participation/Understanding	Fully understood (%)	Understood a little (%)	I do not understand (%)
Want to participate	60.9	4.3	
Would participate if possible	21.7	10.9	
Do not want to participate	1.1	1.1	0.0

women, indicating that continued exposure to the banking project and its development resulted in greater recognition among multiparous women (Table 7).

More than 40% (head-count basis) of respondents became aware of the existence of the cord blood banking system from information on TV. TV commercials, which started in June 1999, are likely to have played an impor-

tant role in this regard. In the previous survey, which was conducted from January through May 1999, only 12% of respondents had become aware of the existence of the banking system through mass media, including TV and radio, which highlights the importance of visual materials such as posters and TV in increasing awareness of the cord blood banking system. Many respondents became

Table 5 Respondents' comments on the public cord blood banking system

	(%)
Other	2.2
No comment	3.3
Worried about invasion of privacy	3.3
Wanted to share pleasure of delivery	4.3
Had an understanding of the system	18.5
Felt surprised about the advancement of medicine	26.1
Felt happy to have been able to do something good for a baby	27.2
Felt happy to contribute to public welfare	31.5
Felt good about helping sick people	92.4

Table 6 Respondents' degree of awareness and interest with regard to the private blood banking system

The ratio of same reply in multiple-answer Q. (sum = 192) to No. of respondents (n = 92)

Awareness	Showed interest (%)	Showed no interest (%)	Unknown (%)	No response (%)
No response				2.2
Was not aware of the system	20.7	6.5	52.2	
Was aware of the system	10.9	1.1	5.4	

Table 7 Length of public cord banking system awareness between multipara and primipara women

	Have known since 2001 (%)	Have known since 2000 (%)	Did not know (%)
Multipara (n = 26)	3.8	80.8	15.4
Primipara (n = 66)	9.1	59.1	31.8

aware of the project from explanations given at checkup examinations after pregnancy or when attending maternity classes. This indicates that information about the program should also be given after pregnancy (Table 3).

The public cord blood banking system was explained to each participant by a doctor or maternity nurse before answering the questionnaire. If the participant agreed, she was then asked to submit a letter of consent for donation, which was distributed with the questionnaire form. The level of comprehension of the final explanation appeared to be correlated with the rate of participation in the public cord blood banking project, which indicates that explanations have a role in obtaining proper informed consent. However, 18% of respondents hesitated to participate and commented on dubious concerns that might not have been raised had the system been properly explained (no data available). This suggests that, when trying to obtain informed consent, explanations should be detailed but easy to understand (Table 4).

When obtaining consent for participation with the pub-

lic cord blood banking system, donors were told that they would be required to answer a questionnaire regarding the results of an infancy checkup examination and blood collection. This was also explained in maternity classes but was acknowledged by only 37.0% of respondents.

The actual initial collection rate of the post-6-month check-up questionnaire was 60% for the Tokyo Cord Blood Bank, so donors had to be reminded repeatedly to reply to the questionnaire before a final collection rate of 90% or higher was attained (no data available). This suggests that many donors did not understand the donating procedure and system when they gave consent, even though they had said they understood the purpose of the cord blood banking system and would participate. In the future, additional efforts will be required at the time of child birth education to improve donor understanding of the cord blood banking system.

The motives for donating cord blood to the bank can be inferred to some extent from replies obtained for question 13, which asked for "impressions of the public cord blood

banking system.” Most respondents indicated that they wanted to “help those who have diseases.” This type of reply was almost three times as common as the answer of “to feel glad to have served society.” This indicates that motives for participating were better expressed in terms of contribution to concrete purposes rather than for general service to public interests. However, many respondents had privacy concerns, which suggests that pregnant women need additional information, as noted for the post-6-month questionnaire mentioned above (Table 5).

Questions concerning the financial resources needed to operate the public cord blood banking system were designed to assess respondent comprehension of the public nature of the banking project. Although cord blood transplants are presently covered by the national health care system, the operating costs of the banking system are mostly borne by the administrative body of each bank, with some subsidies provided by the Ministry of Health, Labor and Welfare. Future banking project governing structures are now being discussed by a special committee in the Ministry. Most respondents expected these costs to be paid by tax revenues or social insurance premiums, which suggests that the public nature and social role of the cord blood banking system was understood by most respondents.

Bone marrow cells have a multipotent differentiative capability, and regenerative medical techniques have advanced considerably. Cells from cord blood can produce blood cells and differentiate into vascular cells¹²⁾ and possibly nerve, muscle, and hepatic cells.¹³⁾ Questions concerning regenerative medical techniques were prepared in order to gauge awareness among pregnant women of modern medical care and the future potential of the public cord blood banking system. The level of awareness of regeneration medicine was low in this survey, about 30%, and replies to the open-ended question did not clearly show participant expectations regarding the future potential of regenerative medicine, although there were some comments in this regard (no data available). This confirms the necessity of providing accurate information to potential donors, without unnecessarily increasing expectations.

Recently, for-profit commercial private cord blood banks have been established to conduct cord blood banking business only for pregnant women and their relatives. These private banks have been making inroads into the public cord blood banking project and have become an issue of public concern. Only 17% of respondents knew of the exist-

tence of such private banks, but more than 30% replied that they were interested in them (Table 7). It will be necessary in the future to consider how to make the private blood banking business consistent with the public system.

Conclusions

(1) Awareness of cord blood banks and the hospitals involved increased among pregnant women during the period 1999–2002. (2) Pregnant women obtain information mainly from mass media, particularly TV. (3) Many pregnant women still lack sufficient information, so they should receive additional relevant education.

We are deeply grateful to those who willingly answered the questionnaire and those who helped analyze the survey results.

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日本の公的臍帯血バンクシステムに関する妊婦の意識調査

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要約

目的：公的臍帯血バンクに臍帯血を提供する日本人妊婦の知識および動機の調査を行い、また、公的臍帯血の認知度を調べることにより、公的臍帯血バンクの推進に役立てる。「日本さい帯血バンクネットワーク」設立前の1999年に実施した調査と比較検討を行う。

方法：公的臍帯血バンクである「東京臍帯血バンク」の1採取協力病院にて、対象となる妊婦110名にアンケート調査を行った。

結果：92名の妊婦から回答を得た。公的臍帯血バンクの認知度は前回調査とほぼ変わらず、また、認知手段についてはテレビなどのマスメディアの効果が大きいことが確認された。調査実施時点での妊婦の公的臍帯血バンクに対する理解度は83%であり、その理解度が高いほど積極的に臍帯血提供に協力したいとする傾向がみられた。

結語：妊婦の臍帯血バンクへの協力を推進していくために、妊婦に対してより正確な、また多くの情報を与えることが必要である。

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