

# Knowledge and attitudes of pregnant women with regard to collection, testing and banking of cord blood stem cells

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## Abstract

**Background:** Umbilical cord blood is used as a source of hematopoietic stem cells for bone marrow transplantation in the treatment of malignant and nonmalignant disease. We sought to examine pregnant women's knowledge and attitudes regarding cord blood banking, as their support is crucial to the success of cord blood transplant programs.

**Methods:** A questionnaire examining sociodemographic factors and women's attitudes to cord blood banking was developed on the basis of findings from 2 focus groups and a pilot study. The questionnaire was distributed to 650 women attending antenatal clinics at a regional women's hospital between April and July 2001.

**Results:** A total of 443 women (68%) responded. More than half of the women (307/438 or 70% [95% confidence interval, CI, 66% to 74%]) reported poor or very poor knowledge about cord blood banking. Many of the respondents (299/441 or 68% [95% CI 63% to 72%]) thought that physicians should talk to pregnant women about the collection of cord blood, and they wanted to receive information about this topic from health care professionals (290/441 or 66% [95% CI 61% to 70%]) or prenatal classes (308/441 or 70% [95% CI 65% to 74%]). Most of the women (379/442 or 86% [95% CI 82% to 89%]) would elect to store cord blood in a public bank, many citing altruism as the reason for this choice. A much smaller proportion (63/442 or 14% [95% CI 11% to 18%]) would elect private banking, indicating that this would be a good investment or that they would feel guilty if the blood had not been stored. Additional acceptable uses for cord blood included research (mentioned by 294/436 women or 67% [95% CI 63% to 72%]) and gene therapy (mentioned by 169/437 women or 39% [95% CI 34% to 43%]).

**Interpretation:** Most of the women in this study supported the donation of cord blood to public cord blood banks for potential transplantation and research.

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Enthusiasm for umbilical cord blood as a source for hematopoietic reconstitution has been fuelled by reports demonstrating the efficacy of transplantation of cord blood stem cells from unrelated donors in the treatment of a wide variety of disorders.<sup>1-7</sup> Cord blood may be a partial solution to some of the inadequacies of unrelated-

donor bone marrow programs, primarily in terms of increasing the donor pool and decreasing the waiting period.<sup>8-12</sup> The plasticity of stem cells, and thus their potential for use in tissue repair, is also of increasing interest.<sup>13</sup> The marrow transplant community, including both potential recipients and health care professionals, has a vested interest in supporting the proper development and functioning of cord blood banks.

There are at least 25 private and public cord blood banks in North America, including one public bank in Alberta (established in 1996) and one private bank each in Ontario (established in 1997) and British Columbia (established in 1996). Although the ethics related to the use of cord blood has been extensively discussed from a medical perspective,<sup>14-18</sup> little is known about parental views. Why parents choose public cord blood banking (through which stem cells are available to anyone who needs them) or private banking (whereby cord blood is stored for the exclusive use of the donor's family) is underexplored.

In this research study we examined pregnant women's knowledge and attitudes on this subject, which may be used in the development of appropriate policies and procedures for public and private cord blood banking.<sup>19</sup>

## Methods

The study was approved by the Research Ethics Board of the IWK Health Centre, Halifax.

Two focus groups were held in March 2000, one with 13 and the other with 18 pregnant women and their partners. Identified themes were used to develop a self-administered, anonymous questionnaire. A total of 263 pregnant women completed a pilot questionnaire.<sup>20</sup>

The questionnaire used in the current study collected information about self-reported sociodemographic factors. Ethnicity was included to examine if cord blood decision-making might be influenced by specific cultural practices or beliefs. The assistance (of partners or others) in completing the survey was recorded.

The questionnaire explored the following major themes: knowledge about cord blood banking, decision-making authority, attitudes about cord blood banking procedures and attitudes to public versus private cord blood banking.

The survey population consisted of English-speaking pregnant women attending the low- and high-risk antenatal assessment clinics at the IWK Health Centre between April and July

2001. The research nurse (S.T.) attended the antenatal clinics on random days during the study period to administer the questionnaire. Six hundred and fifty (95%) of 687 new attendees at the clinic were given the questionnaire. At the direction of the head nurse of the antenatal clinic, 22 women were not approached either because they were grieving a suspected fetal loss or because they were very young. Six were not approached because of language barriers, and 9 women declined to participate. Other than the questionnaire itself, no additional information was given to participants, except a copy of the consent form (for the study), which indicated that cord blood can be used for transplantation and that it may be banked publicly or privately. A prestamped envelope was provided to allow patients to return questionnaires that were not completed on site.

Descriptive data are reported here. Tabular data were analyzed by  $\chi^2$  and Fisher's exact tests. To minimize type 1 error, 10 sociodemographic factors (age, ethnicity, education, income, number of children, perceived medical problems related to the pregnancy, knowledge of someone who had received a bone marrow transplant, status as a blood donor, perception of risk of need for a bone marrow transplant and support of alternative uses of cord blood) were declared a priori.

## Results

A total of 443 questionnaires (68%) were returned. A minority of respondents (107/441 or 24% [95% confidence interval, CI, 20% to 29%]) completed the questionnaire with input from someone else (usually her partner). Missing data were rare, averaging 3.6 (1%) (range 0 to 9 [0% to 2%]) per question. Respondents' characteristics are presented in Table 1.

Most respondents (307/438 or 70% [95% CI 66% to 74%]) rated their knowledge about cord blood banking as poor or very poor. Many (299/441 or 68% [95% CI 63% to 72%]) thought that physicians should talk to pregnant women about the collection of cord blood, and they wanted to receive information about this topic directly from a health care professional (290/441 or 66% [95% CI 61% to 70%]) or in a prenatal class (308/441 or 70% [95% CI 65% to 74%]).

About a quarter of the respondents (109/435 or 25% [95% CI 19% to 31%]) overestimated the risk of a child needing a bone marrow transplant before his or her 10th birthday; this risk is currently reported at between 1 in 200 000 and 1 in 10 000.<sup>21</sup>

Most respondents thought a woman should be asked about cord blood banking before 30 weeks of pregnancy (365/439 or 83% [95% CI 79% to 87%]). About two-thirds indicated that a pregnant woman's partner should have a choice about the collection of samples (293/439 or 67% [95% CI 62% to 71%]) and about the choice between private and public banking (297/440 or 68% [95% CI 63% to 72%]). In the event of disagreement between a woman and her partner, 77% of the women (340/440 [95% CI 73% to 81%]) stated that the final choice should rest with the woman, and 20% (89/440 [95% CI 17% to 24%]) stated that the cord blood should not be collected at all.

About a quarter of the respondents (104/437 or 24% [95% CI 20% to 28%]) indicated that the cord blood bank should not be allowed to investigate the health of the donating newborn. More than half of respondents (276/441 or 63% [95% CI 58% to 67%]) wanted to be told if the cord blood was to be used, and a quarter (112/442 or 25% [95% CI 21% to 30%]) wanted the right to veto use of any cord blood given to a public bank. Many respondents (353/438 or 81% [95% CI 77% to 84%]) thought that the mother should be notified if viral or genetic disease was identified in the donated cord blood.

A third of respondents (129/437 or 30% [95% CI 25% to 34%]) indicated that cord blood should be used exclusively for transplantation. Research (294/436 or 67% [95% CI 63% to 72%]), gene therapy (169/437 or 39% [95% CI

**Table 1: Characteristics of pregnant women responding to a questionnaire about cord blood banking**

Characteristic	No. (and %) of respondents*
<b>Mean age (and range), yr (n = 443)</b>	29 (12–44)
<b>Self-reported ethnicity (n = 441)</b>	
White	377 (85)
Native Canadian	19 (4)
Black	16 (4)
Japanese	10 (2)
Middle Eastern	8 (2)
Other	11 (2)
<b>Highest level of education attended (n = 435)</b>	
Grade school	19 (4)
High school	104 (24)
University or college	312 (72)
<b>Total annual family income, \$ (n = 435)</b>	
< 40 000	152 (35)
> 40 000	283 (65)
<b>Previous children (n = 435)</b>	
0	180 (41)
1	175 (40)
> 1	80 (18)
<b>Stage of pregnancy, wk (n = 442)</b>	
< 24	197 (45)
24–35	199 (45)
> 35	46 (10)
<b>Perception of medical complications in current pregnancy† (n = 443)</b>	
Maternal complications	39 (9)
Fetal complications	37 (9)
<b>Blood donor (n = 437)</b>	
Never	273 (62)
Less than once per year	90 (21)
At least once per year	74 (17)

\*Except where indicated otherwise.

†Mother's perception of whether there were any serious problems (for her or for her baby).

34% to 43%]) and drug manufacturing (145/437 or 33% [95% CI 29% to 38%]) were considered permissible alternative uses for publicly stored cord blood.

The following factors were determined by  $\chi^2$  analysis to be predictive of support for alternative uses: older age ( $p = 0.002$ ), higher education ( $p = 0.018$ ), white ethnicity ( $p = 0.001$ ), previous blood donation ( $p = 0.001$ ) and willingness to allow follow-up testing of a donor child ( $p = 0.02$ ).

The women were asked if they would choose to save cord blood in a private or public bank and to indicate their main reasons (Table 2). The only predictors for choosing public cord blood banking were white ethnicity ( $p = 0.02$ ) and support for alternative uses of cord blood ( $p = 0.01$ ).

In a post hoc analysis, level of knowledge was not associated with the choice between public and private banking ( $p = 0.51$ ).

## Interpretation

Most of the women in this study (379/442 or 86% [95% CI 82% to 89%]) would have chosen to donate cord blood to a public bank for 2 main reasons: altruism and the expense associated with private banking. We believe that the cost of private cord blood banking<sup>22-24</sup> would need to drop substantially to influence the preference for public banking, as high income was not a significant factor in the choice between private and public banking. Although the advantages of private banking are less clear, at least from the perspective of the research team, 63 of 442 respondents (14% [95% CI 11% to 18%]) would have chosen this option. In addition to the high cost of private banking, the risk of an individual needing a stem cell transplant is low<sup>21</sup> and, to an increasing extent, the safety of autologous transplantation is questioned.<sup>25</sup> Recent re-

ports have suggested that some children in whom acute lymphoblastic leukemia occurs have an initiating chromosomal translocation that is detectable in the blood at birth.<sup>26,27</sup> This situation calls into question the potential safety of using autologous cord blood for this, one of the most common indications for stem cell transplantation in children.

Because publicly banked cord blood is a valuable resource for unrelated recipients, the motivation of altruism seems justified.<sup>28,29</sup> This motivation is the same as for those who register with an unrelated-donor bone marrow transplant registry.<sup>30</sup> The only other published study that examined parental attitudes to cord blood banking found strong support for public donation in a sample of Swiss women.<sup>15</sup>

This study had some limitations. We had a high proportion of university- or college-educated participants. The Maritime region is not as ethnically diverse as other areas in Canada, nor does it have established private or public cord blood banks. Conducting a study such as this one in a different sociogeographic area, where the profile of cord blood banking is higher, might yield different results.

Our results provide insights that can be meaningfully incorporated into government regulatory policy and regional cord blood banking policy. We suggest that checklists be designed to allow women to select from among options for various aspects of cord blood banking, such as acceptable uses of donated cord blood, acceptability of look-forward programs, donor contact for further testing and subsequent contact between donor and recipient. The study also illustrates a gap in parental education that should be addressed early in pregnancy so that parents have adequate time to contemplate their choices.<sup>31</sup>

**Table 2: Choice and reasons for storing cord blood in private versus public banks (n = 442)**

Choice and reason*	No. of respondents	% of respondents† (and 95% CI)
<b>Public bank</b>	379	86 (82-89)
Cord blood is available to others	281	75 (71-80)
Too costly to store privately	210	56 (51-61)
Child is unlikely to need own cord blood	124	33 (29-38)
Concern about regulation of private banks	26	7 (5-10)
<b>Private bank</b>	63	14 (11-18)
Good investment in case child needs it	57	90 (80-96)
Anticipation of feelings of guilt if child needed cord blood and it had not been stored	39	62 (49-74)
Own cord blood is thought to be safer than that of others	31	49 (36-62)
Cost is acceptable	15	24 (14-36)
Worry that publicly stored cord blood might be used for purposes other than transplantation	13	21 (11-33)

Note: CI = confidence interval.

\*A respondent could give more than one reason for her choice.

†The percentages for each type of banking are calculated on the basis of the number of respondents choosing that type.

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