Patients’ Knowledge of Umbilical Cord Blood Banking

Jordan H. Perlow, M.D.

OBJECTIVE: To determine patients’ knowledge of umbilical cord blood banking (UCBB).

METHODS: A questionnaire was administered. Part 1 queried issues of familiarity with the term UCBB. Those patients with any awareness of UCBB were provided with part 2, asking more detailed questions that assessed knowledge.

RESULTS: Four hundred twenty-five patients completed the survey; 37% had no knowledge of UCBB. Older patients and those with higher degrees of education were more aware of UCBB, and the greatest disparity of knowledge was noted among Native American patients (p < 0.001). Of patients indicating familiarity with UCBB, 2.6% felt “extremely knowledgeable,” while 74% felt “minimally informed.” Fifty percent of the patients were misinformed that UCBB was only for “the child that I will deliver.” Seventy-one percent of patients were not planning UCBB, with “expense” and “insufficient knowledge” as the primary reasons cited. Only 14% of patients were educated about UCBB by their nurse or obstetrician, although 90% of patients expected their obstetrician to answer their questions on UCBB.

CONCLUSIONS: Patients are poorly informed about UCBB, especially ethnic minorities, younger patients and those with lesser degrees of education. Few patients receive UCBB education from health care providers, yet most patients expect their obstetrician to be able to answer questions on UCBB. Lack of knowledge and expense remain barriers to UCBB. Opportunities to educate patients and obstetric providers on UCBB should be pursued. (J Reprod Med 2006;51:642–648)

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Until recently, the cord blood that remains in the placenta and umbilical cord after birth was considered medical waste. Since 1988, however, when the first cord blood stem cell transplant took place to treat a child with Fanconi’s anemia, approximately 6,000 individuals worldwide have received medical treatment consisting of the infusion of human umbilical cord blood hematopoietic stem cells for the treatment of more than 70 life-threatening malignancies.
nant and nonmalignant diseases. Currently, approximately 400 cord blood stem cell transplants occur annually in the United States alone. These hematopoietic stem cells are made available through the process of umbilical cord blood banking (UCBB), which allows the collection and cryopreservation of the remaining placental and umbilical cord blood following delivery. The vast majority of cord blood stem cell recipients are dependent on publicly donated banked cord blood, while others acquire their cord blood stem cells from a related newborn, typically a sibling.

This therapy, known as “stem cell transplantation,” has traditionally been performed utilizing bone marrow or peripheral blood as a source of hematopoietic stem cells, but in many circumstances, stem cells from umbilical cord blood are preferable, given a lower risk of graft vs. host disease, greater human leukocyte antigen (HLA) mismatch tolerance, lower costs, less infectious morbidity, more expeditious time to obtainment and nonexistent risk to the donor. The therapeutic use of umbilical cord blood for this purpose has grown dramatically, especially over the past 5 years, with new breakthroughs reported regularly, both in vivo and in vitro.

Both private cord blood banking and public cord blood donation options exist, each with unique advantages and disadvantages. Private banking allows a family to store umbilical cord blood stem cells for potential future use (“biologic insurance”) or current use if there is a current or likely need for stem cell transplantation by a family member (usually mother or sibling). Several autologous transplants have also taken place from privately banked samples in which no prior risk factors existed and a disease, treatable in this manner, was acquired by the child from whose umbilical cord the stem cells were banked. While private cord blood banks will provide services without charge if there is a likely need for stem cell transplantation, there are significant costs associated with private cord blood banking. Public cord blood donation options are limited at the local level, but cord blood donation is available to most patients (singleton pregnancy, arrangements made by 35 weeks’ gestation, sufficient sample volume collected) without charge to thereby increase the public supply of stem cells.

Given the potential benefits of UCBB and the increasing therapeutic use of umbilical cord blood as a source of stem cell therapy, this study was undertaken to determine the current level of knowledge of UCBB among obstetric patients and thereby to assess their ability to evaluate this obstetric option.

If physicians are unaware of the benefits of UCBB and/or not informing patients of their options in this regard, potential therapeutic options can be missed.

Materials and Methods

A survey was conducted from January through June 2003 following approval from the institutional review board of Good Samaritan Medical Center, Phoenix, Arizona. Pregnant women presenting to Phoenix Perinatal Associates offices for maternal-fetal medicine consultation or obstetric ultrasound or as a new obstetric patient but not having been to the practice previously were offered participation in the study. Patients agreeing to participate were provided part I of the survey by the patient services coordinator. Part I queried if the patient had ever heard of UCBB or similar terms. Demographic data were also obtained with respect to age, race, ethnic background and formal educational level achieved. After part I was completed, the patient returned it to the patient services coordinator. Patients indicating no knowledge of UCBB were thanked for their participation and not provided with part II of the survey. Patients indicating awareness of the term UCBB or similar terms, indicative of some familiarity with UCBB, were provided with part II of the survey. This was designed to determine how knowledgeable the patient was, what the source of her knowledge was, the patient’s awareness of the usefulness of UCBB, if UCBB was planned for the pregnancy and why, and what barriers might prevent the patient from pursuing UCBB; several questions were aimed at determining expectations for being educated on this topic. Patients then returned part II of the survey to the patient services coordinator, who collected all the surveys and provided them to the study investigator. Surveys were available in both English and Spanish. Information from the surveys was then compiled by the author and analyzed using EpiInfo 2001 computer software. Fisher’s exact test was utilized to compare groups, and p < 0.05 was considered statistically significant.
Results

Four hundred twenty-five patients participated by completing surveys. Of the total study population of 425 patients, more than a third (37%, n = 157) were unaware of UCBB and therefore excluded from further study. Demographic data are presented in Table I. Among the 268 patients aware of UCBB were significantly more women aged 26–50 as compared to women aged 15–25 (68 vs. 53%, p = 0.002). No significant differences in knowledge were noted based on parity. Patients with lesser degrees of education were less likely to be aware of UCBB when compared to those with higher levels of education (Figure 1). Women with less than an eighth grade education were significantly less likely to be aware of UCBB when compared to women who had graduated from high school (22% vs. 59%, p < 0.0001), those with college educations (22% vs. 71%, p < 0.0001) and those who had graduate degrees (22% vs. 78%, p < 0.0001). Women who were members of a racial or ethnic minority were less likely than Caucasian women to be aware of UCBB (p < 0.0001). Awareness of cord blood banking was indicated by 43.2% of Hispanics, 48% of African Americans and 25% of Native Americans (p ≤ 0.001 vs. Caucasians) (Figure 2). 

Of the 268 patients who indicated awareness of UCBB in answering part I of the survey, the majority (74%) described themselves as “minimally informed,” while 2.6% (n = 7, all Caucasian) felt “extremely knowledgeable.” Sixty-two percent of these patients (n = 166) indicated that UCBB was “useful,” while a significant number of respondents (26.4%) stated that it was “experimental only.” One hundred ninety-one of these 268 patients (71.3%)...
were not planning on UCBB, with the most common reasons noted as “too expensive” (29.8%) and “insufficient knowledge” (30.9%). Half the patients (50.3%) were misinformed in stating that UCBB was “only useful for the child I will deliver,” and 10.4% thought UCBB was for research use only. Fifty-seven percent of patients with awareness of UCBB indicated that “both cancer and other diseases” could be treated with cord blood stem cells, but about 1 in 8 of these patients (12.7%) answered that “no diseases have yet been treated with cord blood, but there is hope for the future.”

Significantly fewer patients had received information on UCBB from a health care provider than from other sources (25.7 vs. 74.3%, p < 0.0001). The majority of patients (53%) learned about UCBB from “the news or magazines,” while 17.5% and 8.2% obtained this information from a “physician” or “other health care professional,” respectively. When asked to complete the statement: “I would prefer to receive information on UCBB from whom?” 54.1% answered: “from a doctor or other staff person,” while only 11 patients (5.4% of 205 respondents to this question) preferred to receive information on UCBB from “the cord blood banking company.” Of 248 respondents, 224 (90.3%) answered “yes” to the question: “Do you expect your obstetrician to be able to answer your questions about UCBB?” Finally, when questioned: “Has your doctor or nurse spoken to you during this pregnancy about UCBB?” 85.7% stated that they had not. All questions were answered with the exception of the last 2, for which there were 248 (92.5%) and 205 (76.5%) respondents of 268 patients given part II of the survey.

**Discussion**

The results of this study indicate that patients are poorly informed and lacking education and knowledge regarding UCBB and that the vast majority are not being educated by their obstetric care providers. This is disturbing, given the fact that for patients to be able to take advantage of the single opportunity for the collection of umbilical cord blood stem cells prior to placental delivery, whether for public donation or private family banking, an understanding of the subject is essential. The multitude of conditions for which UCBB is critical may be present in families presenting for obstetric care, and the opportunity for UCBB education is therefore imperative. If physicians are unaware of the benefits of UCBB and/or not informing patients of their options in this regard, and if the patient herself is unaware of the potential benefits, then, clearly, potential therapeutic options can be missed.

The findings in this study demonstrate that within the study population, > 1 in 3 patients had not heard of UCBB or similar terms. Of the 63% of patients who did indicate some familiarity with UCBB, nearly 75% described themselves as “minimally informed,” with only 7 patients (all Caucasian) indicating that they felt “extremely knowledgeable.” Greater awareness was noted with increased age and greater educational attainment, and lesser awareness was noted among minority races and ethnicities. These findings indicate that significant opportunities for education exist to increase knowledge of UCBB within the obstetric population. The disparity in knowledge by educational level is pertinent given that the diseases that can be treated through UCBB “do not discriminate” by education achieved. Individuals with lesser degrees of education may miss opportunities for UCBB, unaware of the specific benefits for themselves or family members. Disparity in knowledge by race or ethnicity is particularly relevant given 2 critical issues: first, many of the diseases successfully treated with UCBB occur with greatest frequency amongst ethnic/racial minorities,16-20 and, second, it is clear that these patients have significantly more difficulty in finding HLA matches for stem cell transplantation given the serious underrepresentation of these populations in bone marrow registries.2,21

While significantly more patients received infor-
mation on UCBB from the media rather than from their health care professionals, more than half the patients with some familiarity with UCBB preferred to receive this information from their obstetrician, and the vast majority (> 90%) had an expectation that their obstetricians would be able to provide information on this subject. This is particularly important given the fact that while nearly two thirds of the study population had familiarity with UCBB, their knowledge was largely lacking, and therefore UCBB-educated obstetric care providers are a potential source of pertinent information for patients. Another pertinent finding of the study is that a significant number of patients were not only unfamiliar with UCBB (37%), but those stating familiarity were clearly misinformed regarding this obstetric option. When one considers that of the patients indicating familiarity with UCBB, > 85% had not received information from their obstetric health care providers, that > 25% indicated incorrectly that UCBB is “experimental only,” > 50% were erroneous in stating that it was “only useful for the child I will deliver,” and > 1 in 8 stated “no diseases have yet been treated,” it is quite possible that clinical scenarios in which UCBB could be useful have been and will be overlooked.

The American College of Obstetricians and Gynecologists Committee Opinion22 from 1997 stated that “Commercial cord blood banks should not represent the service they sell as ‘doing everything possible’ to ensure the health of children. Parents and grandparents should not be made to feel guilty if they are not eager or able to invest these considerable sums in such a highly speculative venture.” Given the significant costs involved in private cord blood banking, using emotional “vulnerabilities” to market this service seems unreasonable. The publication notes the results of “more than 200 transplants” and highlights several points pertinent in 1997, with regard to the questionable acceptability of use of cord blood stem cell transplantation in adult recipients. Since the committee opinion was published, however, a number of papers have addressed this issue and have found benefit in this regard, thus speaking to the acceptability of using cord blood stem cells for treating adult patients with leukemia and other disorders23,24; > 6,000 cord blood transplants have reportedly been performed to date.

In 1999 the American Academy of Pediatrics (AAP) published a statement25 pertaining to UCBB and indicated that “given the difficulty in estimat-
ment. Also, the last 2 questions were not all completed, possibly given insufficient time prior to the patient’s visit. A mailer was not provided as it was not desired that patients have opportunities to research answers.

Prenatal care allows the obstetric health care provider to provide evidenced-based information to patients regarding UCBB and focus on issues of medical and genetic history that may be pertinent to the opportunity of UCBB. Patients in this study indicated that this approach is preferable to leaving the process entirely to the whims and motivations of commercial marketing. Furthermore, it allows the presentation of the altruistic option of public UCBB donation, an option that is acceptable to the vast majority of patients.\(^{29}\) The issue of public cord blood donation and banking is of such paramount importance,\(^{30}\) given the difficulty in obtaining hematopoietic stem cell matches for the diverse ethnicities of our population, that Congress recently passed the Cord Blood Stem Cell Act of 2003, which would set aside $50 million dollars in funding in the next 5 years to create a network of cord blood banks. Patients in this study indicated that this approach is preferable to leaving the process entirely to the whims and motivations of commercial marketing. Furthermore, it allows the presentation of the altruistic option of public UCBB donation, an option that is acceptable to the vast majority of patients.\(^{29}\) The issue of public cord blood donation and banking is of such paramount importance,\(^{30}\) given the difficulty in obtaining hematopoietic stem cell matches for the diverse ethnicities of our population, that Congress recently passed the Cord Blood Stem Cell Act of 2003, which would set aside $50 million dollars in funding in the next 5 years to create a network of cord blood banks that could contain a database of 150,000 genetically diverse cord blood units.\(^{6}\) The Institute of Medicine recently published a report, as charged by Congress, proposing the creation of a national cord blood stem cell bank program and making specific recommendations for the organization and administration, data management and quality control in a national program that would serve the needs of both donors and patients requiring stem cell transplants.\(^{31}\)

With continuing educational efforts aimed at health care providers and patients alike and the increased availability of publicly banked cord blood samples through a national program of cord blood collection and banking, it is hoped that the life-saving opportunities of UCBB will not be missed by anyone who may benefit.

References

14. David Harris, personal communication