EDITORIAL

UNDERSTANDING UMBILICAL CORD BLOOD BANKING
What Women Need to Know Before Deciding

Linda Kharaboyan, LLB\textsuperscript{a}, Bartha Maria Knoppers, PhD\textsuperscript{a}, Denise Avard, PhD\textsuperscript{a*}, and
Jeff Nisker, MD, PhD, FRCSC\textsuperscript{b}

\textsuperscript{a}Centre de Recherche en Droit Public, Université de Montréal, Montréal, Québec, Canada
\textsuperscript{b}Shulich School of Medicine & Dentistry, University of Western Ontario, London, Ontario, Canada

Received 6 January 2006; accepted 6 May 2006

Information about umbilical cord blood (UCB) banking is surfacing at a very rapid pace. The messages, largely targeted toward women, encourage mothers-to-be to bank their child’s UCB. Indeed, an ever-growing number of Internet sites and magazine advertisements are cautioning women that storing a newborn’s UCB is a once-in-a-lifetime opportunity and a worthwhile investment that can save their child if it were to ever become necessary. Previously considered as waste and discarded without second thought, the umbilical cord is now actively being sought for hematopoietic stem cell transplantation. Stem cells harvested from UCB have successfully been used to substitute for bone marrow as a source of hematopoietic stem cells for transplants in the treatment of genetic disease, blood malignancies, and immune deficiencies. The promise of private banking, coupled with pleas from public banks asking mothers to donate UCB for altruistic purposes, can become puzzling for pregnant women. To allow them to make an informed choice about UCB banking, it is important that women receive complete and accurate information from their obstetrical care providers. The purpose of this editorial is to raise awareness about UCB banking. Most important, it focuses on the importance of knowledge in the decision-making process. Women who know more about UCB banking are more likely to make appropriate choices for both themselves and their families.

A survey conducted in 2003 revealed that 70\% of 443 pregnant women interviewed felt that their knowledge of UCB banking was poor to very poor. In fact, 68\% of the respondents wanted to receive information about UCB transplantation from their prenatal care provider or at prenatal classes (Fernandez, Gordon, Van den, Taweel, & Baylis, 2003). Obstetricians, family physicians, midwives, and nurses play a key role in assisting parents in making this decision. Women should be informed about the promising or limited clinical potential of UCB stem cells and current indications for their collection, storage and use (Armson & Maternal/Fetal Medicine Committee SOGC, 2005). Even when women do not inquire about UCB banking, obstetrical care providers have a professional obligation to bring up the subject to convey the potential clinical benefits for children, family members, and other persons. Providing adequate information about UCB banking implies discussion about the pros and cons of private and public UCB banks, privacy and confidentiality concerns, and alternative uses of donated or banked samples.

Private Umbilical Cord Blood Banks
Because UCB stem cells must be collected at birth, women should decide what to do with their child’s umbilical cord well in advance. To discard, donate for research, or privately store UCB stem cells—these are potential choices that have to be made. Private banking allows the preservation of a child’s UCB for autologous or familial use. Before choosing to privately bank UCB, women should be advised of both benefits and limitations of private banking. Indeed, although banking UCB for autologous purposes...
can guarantee easy access to one’s own stem cells or for a family member with an actual current or potential need of stem cell transplantation, it is equally important to inform mothers that presently it is highly unlikely for a family with no history of blood disease to ever need the banked UCB (Fisk, Roberts, Markwald, & Mironov, 2005). Families with genetic conditions, if the cord blood contains markers for genetic conditions, its stem cells generally cannot be used. Seeing as most of the diseases in children that currently benefit from stem cell transplants have a genetic basis, if a child develops a genetic condition, his or her own cord blood also contains the disease-causing mutation and is therefore not regarded as suitable treatment. Most professional organizations therefore agree that autologous banking is unwarranted for the time being (American College of Obstetricians and Gynecologists, 1997; American Academy of Pediatrics, 1999; Royal College of Obstetricians and Gynaecologists Scientific Advisory Committee, 2001; National Consultative Ethics Committee for Health and Life Science, 2002; The Society of Obstetricians and Gynaecologists of Canada, 2005).

The insufficient number of stem cells found in cord blood can also explain why familial use is unlikely. Research has shown that the stem cells found in a unit of cord blood would not suffice to treat adults weighing >110 pounds (Kurtzberg et al., 2005). However, techniques to expand the number of stem cells in a unit of cord blood are now being used in clinical trials, and more and more successful UCB transplants are being performed on adults participating in these trials (Rocha et al., 2004). Advances in the expansion of UCB hematopoietic stem cells may then solve the stem cell insufficiency problem, thereby allowing increased transplantations to treat degenerative conditions in adults (Sanz, 2004). This potential fuels the claims made by private UCB banking companies that not banking cord blood amounts to throwing away a one-time opportunity to save a person.

Because public banks make cord blood stem cells available to those who most need it, they cannot reserve units for private use. Consequently, should the need for stem cell transplantation arise for the child in the future, it is likely that the UCB may have already been used. This possibility should be brought to the mother’s attention. Obstetrical care providers should also inform women that infectious and genetic disease testing are an integral part of public cord blood collection. Mothers need to know that testing blood samples may reveal information about paternity, infectious diseases, and predisposition or susceptibility to certain genetic diseases.

Information About Testing for Diseases
Cord blood transplantation, like other tissue transplantation, is known to transmit viral, bacterial, and fungal agents (Eastlund, 1995). Testing UCB for infectious diseases before engraftment is crucial to reducing the risk of transmitting HIV, hepatitis B and C, syphilis, human T-cell lymphotropic virus, and other pathogens (Warwick & Armitage, 2004). Safe UCB transplantation requires a careful and thorough review of the mother’s medical and social history to exclude those with a transmissible disease. When providing information about public banking, health professionals should inform mothers about infectious disease testing, including which infectious agents are being tested for and how they will be informed if results are positive.

As genetic technology develops and tests become widely available, it has been suggested that testing be carried out on UCB stem cells to identify presymptomatic diseases or disease susceptibility (McCullough et al., 1994). However, the results of testing newborns for adult-onset conditions can have psychological implications and potentially put children at risk of suffering insurance-, education-, and employment-related discrimination (if adequate information and education is provided), if confidentiality is not properly safeguarded. If 1 day such testing is approved, appropriate pretest counseling services and protocols can ensure that women understand the implications of genetic testing of UCB, prior to the test. Undoubtedly, if any genetic testing were to be carried out on UCB, it would be necessary to obtain maternal/parental consent, maintain records of the identity of the mother and infant, and notify the appropriate family member of any abnormal test results (McCullough et al., 1994).

Confidentiality
There is presently no general consensus on the maintenance of long-term donor and recipient linkage records. It is essential to respect both the privacy and the health needs of women and their children and the
privacy of the patients receiving the transplants (Institute of Medicine & Board on Health Sciences Policy, 2005). Linked records allow donors and recipients to be found, informed, and referred for care if infectious or genetic diseases are detected after UCB stem cells have been transplanted (McCullough et al., 1994). They also allow doctors to retrace the donated UCB in the event that a child requires an autologous transplant. In addition, should new genetic or infectious disease tests become available, access to linked stored samples would allow clinicians to recontact donors who have previously consented and obtain informed consent to conduct testing on their materials, thus giving them the possibility of benefiting from early diagnosis and treatment (Pinch, 2001).

Other Uses

Umbilical cord blood units are usually discarded if infectious disease or genetic testing indicate that a child’s cord blood is not suited for storage and transplantation or when the volume or quantity of cells collected is insufficient. In fact, a recent study has demonstrated that more than half of UCB units have been found to be inappropriate for transplantation (Ballen, 2005). Instead of discarding these units, stem cells scientists have requested access to them to advance research in stem cell therapy (Héma-Québec, 2006).

If this practice occurs, obstetrical care providers should inform mothers-to-be of the possibility and obtain consent before banking. Information about the potential commercial applications of the research would also need to be disclosed as part of the informed choice process (National Consultative Ethics Committee for Health and Life Sciences, 2002; European Group on Ethics in Science and New Technologies, 2004).

Furthermore, some private companies have been reported to recruit donors by representing themselves as public banks (Saginur, Kharaboyan & Knoppers, 2004). They store cord blood gratuitously and then sell compatible matches to research companies as well as to patients in urgent need of transplantation and who are willing to pay close to $15,000 per unit (Hundley, 2003). Some of the incentives to recruit women, and have been reported to pay obstetricians a finder’s fee for collecting cord blood from their patients (Hundley, 2003). In view of such confusing practices, in addition to clearly stating the type of bank a woman is being recruited for, obstetrical care providers, counseling mothers about UCB banking, ought to inform them of their personal commercial interests as well as those of the company that stores the cord blood (International Federation of Gynecology and Obstetrics—Committee for the Study of Ethical Aspects of Human Reproduction, 2003).

Conclusion

Donors need accurate and complete information to fully understand and answer the many questions they may have before consenting to donate cord blood. Whether deciding to donate UCB to a public bank or to pay to store UCB in a private bank, informed choice and signed consent for the collection, banking, and future use of the UCB should be integral to the process. Considering that consent to store UCB should be obtained prior to the birth of a child, there are ethical, legal, and professional reasons that justify educating women about UCB banking during prenatal education. Obstetricians, midwives, family doctors, and nurses are in an ideal position to educate them about the potential value and concerns of donating or banking UCB. This includes provision of sufficient information to ensure informed choice as well as discussing the alternative uses of banked cord blood. For this to occur, there is a need to provide educational opportunities for obstetrical care providers and their patients. Ideally, a checklist to allow pregnant women to select among options for various aspects of UCB banking could provide a choice for acceptable uses of donated cord blood, acceptability of look forward/backward programs, donor contact for further testing, and the possibility of subsequent contact between donor and recipient. In conclusion, to ensure transparency, openness, and accountability, information about UCB should be discussed broadly between women and their health care providers.

References


**Author Descriptions**

Linda Kharaboyan, LLB, is a lawyer and research associate affiliated to the Centre de recherche en droit public at the Université de Montréal. She has conducted extensive research on newborn screening and bloodspot storage and is now examining the socio-ethical and legal questions surrounding umbilical cord blood banking.

Bartha Maria Knoppers, PhD, holds the Canada Research Chair in Law and Medicine and the Chaire d’excellence Pierre Fermat (France). She is a Professor at the Faculté de droit, Université de Montréal and Senior Researcher at the Centre de recherche en droit public.

Denise Avard, PhD, is the Research Director for the Genetics and Society Project at the Université de Montréal. Her research interests are in the areas of genetic testing and screening relevant to newborn, children, adolescents and persons with disabilities.

Jeff Nisker, MD, PhD, FRCSC, Coordinator of Health Ethics and Humanities and Professor of Obstetrics-Gynaecology and Oncology at the Schulich School of Medicine and Dentistry, University of Western Ontario (UWO). His research is transdisciplinary, centering on public engagement for health-policy development, particularly regarding emerging genetic technologies.