ABSTRACT

UMBILICAL CORD BLOOD BANKING: PUBLIC OPINION AND AWARENESS IN JORDAN

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Introduction

Improvements in clinical applications of cord blood (CB) transplants mirror the recent proliferation of CB banks worldwide. However, CB banks have raised policy questions about funding sustainability and quality standards, as well as ethical debates about a lack of public awareness and medical justification. This project is the first study that investigates public opinion and knowledge about CB banking in Jordan, which is expecting its first private and public CB banks to open in 2016. The results demonstrate an overwhelming information gap among women of all educational and socioeconomic backgrounds about CB banking, with over three-fourths (76%, n=630) indicating they knew nothing about CB banking in Jordan, and half (52%, n=410) indicating they had never heard of CB banking before. However, most women expressed a favorable outlook toward CB transplants, research, and storage, and felt strongly about being more informed on the subject. This study has many implications for the development of policies and educational campaigns in Jordan, especially in preparation for the opening of the new facilities.

Methods

The study was approved by the Institutional Review Board at Rice University (Houston, Texas) as well as the hospitals in Jordan where the survey was administered. The authors developed an anonymous questionnaire in both Arabic and English to investigate the current level of awareness in Jordan about CB banking, public opinion and preferences on issues related to CB banking, and demographic characteristics of the study population. Following a pilot study, the 19-question survey was administered to women in four private hospitals. Data were analyzed using Microsoft Excel 2011.

A total of 899 women in Jordan were surveyed at six hospitals in two governorates: Amman (a) and Zarqa (b). The average response rate for all questions was 91%.

Figure 1: Distribution of survey population and hospitals in Jordan

Figure 2: Awareness and information dissemination among survey participants about CB banking

Respondents were asked if they had heard of about CB banking. (a) The overall level of awareness was very low, but women at private hospitals were more likely to have heard of CB banking than women in public hospitals (p=0.01). (b) Women currently receive most information about CB banking from media sources (television, Internet, etc.). They would prefer more information dissemination from healthcare institutions and professionals, especially obstetricians, than they are currently receiving.

Conclusions

As the first study in Jordan and first independent one in the region to assess public attitudes and awareness about CB banking, this study has important implications, especially for the first public and private CB banks to open in Jordan in 2016. Similar studies that have been carried out in other countries—largely in Europe and North America—have demonstrated their utility for policymaking and advocacy purposes among both patients and physicians. Jordan in particular has several unique demographic and health factors that are positive signs for a public CB banking program, including a high prevalence of leukemias and lymphomas, as well as high rates of fertility, consanguineous marriages, and antenatal care coverage. This project is the first study that investigates public opinion and knowledge about CB banking in Jordan, which is expecting its first private and public CB banks to open in 2016. The results demonstrate an overwhelming information gap among women of all educational and socioeconomic backgrounds about CB banking, with over three-fourths (76%, n=630) indicating they knew nothing about CB banking in Jordan, and half (52%, n=410) indicating they had never heard of CB banking before. However, most women expressed a favorable outlook toward CB transplants, research, and storage, and felt strongly about being more informed on the subject. This study has many implications for the development of policies and educational campaigns in Jordan, especially in preparation for the opening of the new facilities.

Figure 4: Participants’ agreement with statements about CB banking

Survey participants were presented with several statements about CB banking. (a) Women from private hospitals were more likely to donate to a private CB bank (p=0.04), (b) while women at public hospitals were more likely to donate to a public bank (p=0.04). The majority of women from both types of hospitals wanted (c) more information about CB banking and (d) would be more likely to donate with a doctor’s recommendation.

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Further Information

For more information on this or related projects, please contact Kirstin Matthews at kmatthews@rice.edu or visit the Baker Institute International Stem Cell Policy website: www.bakerinstitute.org/GSCP. A PDF version of the poster is also available at www.bakerinstitute.org/sswc2015-jordan.