

Knowledge of umbilical cord blood banking among obstetricians and mothers in Anand and Kheda District, India

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ABSTRACT

Background: To assess the knowledge of obstetricians and expectant mothers towards UCB banking and their awareness regarding pros and cons of the process. **Methods:** Questionnaires from a previously published study were modified contextually and translated into vernacular language (Gujarati). The questionnaires were distributed among 200 obstetricians, of which 100 responded and 100 mothers were in Anand and Kheda districts of India. Informed consent was taken for both. **Results:** Mean (SD) age of obstetricians was 47.5 years (11.14) with mean (SD) work experience of 19.72 years (9.94). Almost all were aware of collection procedure for UCB and felt that UCB banking is useful. Thirty obstetricians thought that stored blood can be used in conditions of Autism, Duchenne Muscular Dystrophy and all genetic conditions. Sixty-three were aware of the procedure technique. Majority felt that the process was feasible and would do it for their own child. All the 100 mothers approached consented for the study with average age (SD) of 26.88 (4.17). Many were not aware of such a procedure and were not certain about the usefulness of the procedure. Seventy-six did not know the conditions in which the stored blood can be used. Only 4 mothers/family members had opted for UCB banking, whereas 27 expressed their willingness to recommend UCB to another mother. Five Muslim women wanted UCB but could not pursue it due to religious norms. **Conclusion:** The level of understanding among obstetricians was not commensurate with the amount of faith with which they promoted UCB banking.

Keywords: Cost, knowledge, obstetricians, umbilical cord blood banking

Introduction

Since the first umbilical cord blood (UCB) transplantation in 1988 for Fanconi's anemia,^[1] UCB has become a safe and dependable alternative donor graft source for use in allogeneic hematopoietic cell transplantation. UCB also contains non-hematopoietic stem and progenitor cells that are capable of differentiating into a variety of different cell types and tissue lineages.^[2] It is an alternative allograft source for various disorders such as those in Table 1.

According to the Council on Ethical and Judicial Affairs of the American Medical Association, "a number of ethical considerations surrounding the collection and storage of UCB deserve careful attention ... and the most basic consideration is the issue of informed consent."^[3] Once, proper consent is obtained, the next issue is that of storage of the collected blood. Current options include private and public cord blood banks.

Private cord blood banks allow families to store cord blood stem cells for themselves and their loved ones exclusively. They are privately funded and typically charge a first-year processing

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fee that ranges from about Rs. 50,000 to 70,000 per month.^[4] Cordlife India, one of the leading private cord blood banks, charges a sum of Rs. 5000 up front and Rs. 1300 per month for the subsequent years.^[5] Public cord blood banks offer free cord blood banking to anyone who meets their donation requirements. They are usually supported by federal or private funding, which is why they can perform these collections at no cost to the family.^[6] The differences between public and private blood banks are summarized in Table 2.

However, the American Academy of Pediatrics does not recommend storing cord blood in private banks as storage is expensive, going up to \$1400 a year,^[7] and the likelihood of it helping the baby is small, maybe even nonexistent.^[8] Yet, it is promoted by obstetricians in India and aggressively marketed by private banks. With no public cord blood banks in the region, UCB banking is essentially private, raising questions of cost versus the benefits. At present, there are 14 approved UCB banks operating in the country, all of these in the private sector^[9] and 4 public cord blood banks in India,^[10] where more than 1000 cord blood transfusions were done in children and adults for various indications, in a safe and efficient manner.^[11]

The main stakeholders in this area are the mothers and obstetricians. Yet in a country that has the largest number of deliveries every year, there is no published literature which gives us an understanding of their opinion on this issue. This

is especially important as for public cord blood banks to be established, the government sector or other nonprofit agencies need to perceive a need that would justify public investment.

The other stakeholders in this process are pediatricians, family physicians, and other health-care professionals who may be approached by decision makers for opinions on UCB banking. At the time of conduct of the study, there was no clarification or guidance on UCB banking from professional organizations in India. Hence, this study assumes importance for all stakeholders as it delineates the current scenario in our milieu. It will provide guidance for primary-care physicians, family physicians, and others about the state of knowledge among the immediate stakeholders.

We have, through this study, attempted to understand and assess the current knowledge and awareness of UCB banking among expectant mothers as they are the chief consent givers for the collection of cord blood and obstetricians who have an important role in providing nonbiased and evidence-based information to expectant parents about cord blood and tissue banking options.^[11]

Methods

We surveyed obstetricians and mothers in Anand and Kheda districts of Gujarat, India through a questionnaire that was modified contextually from a previously published study^[12] to assess for the knowledge of Indications of UCB transplantation as seen in Table 1.^[13] After face validity was conducted among nonpregnant women. The questionnaires were then translated into vernacular language (Gujarati) and back-translated by experts in both languages. Both versions of the questionnaires were administered to mothers who were familiar with both languages so as to assess their understanding of the survey. A patient information sheet and an informed consent form were included with each questionnaire. Considering the informational gap and differences in perspective between the obstetricians and the mothers, different questionnaires were administered to both the groups. With no baseline data available regarding the proportion of females having good knowledge of cord blood banking, the expected knowledge was very limited. Assuming that only 10% of women were adequately aware of cord blood banking in the region, we required a sample of size 140 with 95% confidence level and 5% allowable error. However, considering feasibility, a sample of 100 women was set along with a sample of 100 gynecologists so as to draw a comparison among the groups. Two-hundred obstetricians were

Table 1: Diseases treated by umbilical cord blood transplantation using either sibling or unrelated donors

Malignant diseases	Nonmalignant diseases
ALL	Fanconi anemia
AML	Idiopathic aplastic anemia
JMML	Thalassemia
CLL	Sickle cell anemia
CML	Amegakaryocytic thrombocytopenia
NHL	Severe combined immunodeficiency
HL	X-linked lymphoproliferative syndrome
Neuroblastoma	Osteopetrosis
Myelodysplastic syndrome	Globoid cell leukodystrophy
Myelofibrosis	Metachromatic leukodystrophy
Multiple myeloma	Adrenoleukodystrophy
Solid tumors	Tay-Sachs disease
	Lesch-Nyhan syndrome
	Sandhoff disease
	Other rare metabolic and primary
	Immunodeficiency diseases

Modified from Cairo *et al.*, BBMT, 2008. ALL: Acute lymphoblastic leukemia; AML: Acute myeloblastic leukemia; JMML: Juvenile chronic myelogenous leukemia; CLL: Chronic lymphocytic leukemia; CML: Chronic myelogenous leukemia; NHL: Non-Hodgkin lymphoma; HL: Hodgkin lymphoma

Table 2: Differences between private and public cord blood banks

Private banks	Public banks
Charge a fee for collection and storage	Free collection and storage
Retrieval of your own stem cells for future use is free	Retrieval for future use is not free
Exclusive rights to your stem cells	Anyone can access your family's stem cells after donation has been made
Expensive fees, but quality guarantee to ensure that your stem cells are safely stored	No fees, but sometimes donated stem cells are discarded because the funds needed to process and store them aren't available as public funding is limited

approached from various private and government hospitals in the area, of which 100 responded and were included in the study. One-hundred expectant mothers, preferably in their second and third trimester (time when they ponder on choices such as cord blood banking), were approached randomly (to remove any bias) from the out-patient department and indoor admissions from the hospital where the study was initiated (Shree Krishna Hospital, Karamsad) and private clinics around the area. They were asked to complete the forms individually, while they were filled by the investigators when there were mothers who had difficulty reading even the vernacular language. Those answers were marked on the paper by the investigator in real time. Descriptive analysis was done using STATA 14.2. The study was approved by the Institutional Ethics Committee.

Results

Of the 100 obstetricians that responded, 88% were from private clinics, 4% from a government hospital, and 8% from a teaching institute. The major reasons for not responding included busy schedule, disinterest in the cause, etc. The mean (SD) age was 47.5 years (11.14) with mean (SD) work experience of 19.72 years (9.94). Almost all (96%) who were aware of the procedure for collection of UCB felt that UCB banking is useful (81%) and that it also has no risk to the mother or child (92%). Sixty-three percent of the obstetricians were aware of the procedure and preservation technique, whereas 67% knew the correct amount of UCB to be collected (50–100 ml) of whom 66% found that amount to be sufficient enough for a future autologous transplant if ever required. As far as UCB use for specific conditions was concerned, 34% acknowledged Autism, 33% acknowledged Duchenne Muscular Dystrophy, and 26% responded with all genetic conditions. Ninety percent of the obstetricians felt that UCB banking could serve as a feasible future research prospect for stem cells and that they (81%) would recommend it for their own child [Table 3].

Of the 100 mothers who consented to the study, the mean (SD) age was 26.88 years (4.17). When asked about their primary information source regarding cord blood banking, 11%

identified their doctor, 3% their friends/relatives, 15% the internet/newspaper, and 2% the company agent for the cord blood bank. Sixty-three percent of the mothers were unaware of such a procedure, whereas 65% were not sure about the usefulness of the procedure. When asked about potential risks of the procedure to the mother or the child, only 30% acknowledged no risks, whereas 69% were uninformed on the matter. As many as 76% of the mothers were unaware of specific uses for stored stem cells, with 4% identifying Autism, 27% Duchenne Muscular Dystrophy, and 17% reporting all genetic conditions and hemoglobinopathies. Only 22% of mothers believed that as long as the blood types are accurately and completely matched, the stored cord blood could be used for a child from a different family. Eighty-one percent of the mothers were uninformed about the viable duration for UCB storage. In the presence of such limited knowledge, only four mothers opted for UCB banking. Twenty-seven percent mothers expressed their willingness to recommend UCB banking to another mother, whereas 25% expressed their consideration for storing cord blood for their child's future use. Five Muslim mothers expressed their desire for the process of UCB banking but could not pursue it due to religious norms.

Discussion

We present the results of a survey of obstetricians in Gujarat, an Unmatched attempt for this specialty. We had a good response rate (100%) among mothers and a fairly good response rate (50%) of obstetricians. Hence, our results are likely to represent the views of the overall populace in our region. Since we used the cross-sectional survey design to answer our research question, it has all the limitations of a survey such as recall bias, relatively poor response, inaccurate replies, and the inability to have appropriate associations. However, while we cannot overcome the inherent issues of design methodology, we believe our higher response rate and careful efforts to have surveys completed place our data very close to the actual truth. A recent survey that covered a larger geographical region^[14] and included 254 pregnant women is in agreement with our findings of limited awareness of UCB banking in India. Only 26.5% knew what

Table 3: Knowledge and perception for umbilical cord blood banking among mothers and obstetricians

Mothers	Total number of participants (n=100)	Obstetricians	Total number of participants (n=100)
Knowledge		Knowledge	
Indications for UCB	3	Indications for UCB	22
Risk to mother and child	30	Children treated worldwide by UCB	15
Shelf life of cord blood	11	Shelf life of cord blood	28
Cost	13	Cost	35
Matching required	26	Matching required	83
		Aware of technique of preservation	63
Perceptions/attitude		Perceptions/attitude/practice	
Recommend to another mother	27	Is the process feasible	90
Do it for own child	22	Do it for own child	81
Consider the procedure advantageous	32	Consider the process useful	81

UCB: Umbilical cord blood

exactly was meant by cord blood banking, close to the 37% in our study who had ever heard of the term UCB banking, which did not necessarily mean that they knew what the term entailed. Only 16% of the mentioned study were aware of the concept of “public cord blood banking” compared to the 24% in our study. As seen in our study (67%), more than half (55.1%) of the mothers were unsure of whether they wanted UCB or not at the time of the country-wide study.^[14] During our surveys, we noted that many private obstetricians publicly advertise their associations with various private cord banks in their clinics. From an ethical standpoint, private banks should not be allowed to display their posters and banners advertising their facilities in front of physician offices and hospitals. The representatives from such companies exploit the emotional state of expectant couples by “promising” an “insured” future for their newborns. Meanwhile, cord blood stored in private banks is many times not suitable for use due to technical errors in collection, transport, storage, and inadequate stem-cell population. Yet, the family is charged a huge monetary price without adequate verification of viability and usefulness of the collected material, giving them a false sense of security. It is, therefore, no surprise that 47% of practitioners suggest UCB banking to only those parents who seem to afford it and those parents who initiate the conversation, whereas only 15% suggest it to all the families. Aside from the specialists, it is equally important for the primary-care physicians to be informed on this topic, as often they are the first care providers, have a long-standing rapport with the family, and may serve as advisors and information resources as parents often consult their physicians when inquiring about new health-care modalities.^[8] As a nonbiased and neutral party, they could assist in objectively providing families with information regarding cord blood banking. In comparison, despite being a better informed and highly educated population, a study conducted in USA^[15] reported as low as only 22% of physicians discussing UCB with expectant parents. This discrepancy might result from the fact that, with the rising prices for storage of the cord blood, not all families can afford to opt for such measures. In order to combat the financial constraints of private cord blood banking, public cord blood banks will need to be restructured, keeping health policy makers in collaboration for sufficient government involvement. The issue of individual beliefs of religion versus science may also explain why individuals refrain from acknowledging stem-cell research. Interestingly, a study from Lucknow^[16] found that majority of the doctors believed that even with a complete match, cord blood cannot be used for children from both the same or different families. However, in concordance to the 92% obstetricians in our study, the Indian Academy of Pediatrics believes that UCB can be safely collected from the placenta without any risks to the baby and the mother in an otherwise uncomplicated delivery.^[17]

Though important, cord blood banking is a rare utility commodity, requiring complex collaborations to provide good public banking services. If UCB is to be promoted, we strongly believe that Gujarat could serve as a successful pioneer state in this field. Gujarat is one of five states that is currently leading

the way in organ transplantation^[18] and is also leading the way nationally and globally in blood donations. With such strengths in public health services, Gujarat demonstrates its readiness to initiate UCB banking services.

Our study needs to be pursued further by exploring the opinions of pediatricians, public health specialists, health administrators, and policy makers so that UCB banking is taken to its logical conclusion of public cord banking and that the future of many of our newborns can be secured by UCB banking.

Conclusion

The dissonance between the utility of private cord blood banking and the knowledge of it among obstetricians and mothers needs to be improved.

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Conflicts of interest

There are no conflicts of interest.

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