



ORIGINAL RESEARCH PAPER

Public Health

PUBLIC AWARENESS REGARDING UMBILICAL CORD STEM CELL BANKING : AN EXPERIENCE FROM UTTARAKHAND

KEY WORDS: Umbilical cord stem cells, banking, awareness, general public

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ABSTRACT

Introduction: Umbilical cord stem cell banking is an accepted modality in medical treatment today. Though clinical development in field of cord blood transplantation has reached new heights round the world over the past decade, its potential benefits still remain unexplored due to several factors. Until now the debate has been centred on ethical issues and only a little is known about parental views. The support of the general public is crucial for the success of cord blood transplant programs, Hence this study was conducted to explore the awareness amongst the general public regarding umbilical cord stem cell (UCSC) and its banking. **Material & Methods:** An anonymous pre-validated self-administered questionnaire with 20 questions was presented to 460 participants after taking informed consent. Out of these 400 were aptly attempted and considered valid to be analysed. **Results:** Although 82% (n=328) of the participants, knew the fate of placenta and umbilical cord after baby's birth, only 40% (n=160) had heard about its banking. A majority of respondents, 76% (n= 304) were willing to receive further information. 50% (n=200) respondents indicated that they would like to store their baby's cord blood if given an opportunity. It was found that despite being a non-invasive technique, people still refrain from it. The prime factor being lack of awareness, 70% (n=280). **Conclusion:** Lack of knowledge amongst general public is the prime hindrance in the success of UCSC banking, not their attitude. Institutions and physicians need to realize their crucial role to create awareness and impart unbiased information.

INTRODUCTION

Umbilical cord stem cell banking is an accepted modality in medical treatment today. However many aspects are still debatable and unexplored till date. Two decades back the concept of cord blood banking was alien to India and still continues to remain in a nascent stage. Though clinical development in field of cord blood transplantation has reached new heights round the world over the past decade, its potential benefits still remain unexplored due to several factors. Though clinical development in field of cord blood transplantation has reached new heights round the world over the past decade, its potential benefits still remain unexplored due to several factors. Since the first umbilical cord cell transplant in 1988, cord blood has been established as an alternative source of haematopoietic stem cell for bone marrow reconstitution¹. Cord blood is collected from infant's umbilical cord after delivery and poses no risk to mother or infant. Till date it has been used in the treatment of several malignant and non-malignant diseases such as acute lymphocytic leukemia, chronic myelogenous leukemia, myelodysplastic syndrome, and neuroblastoma along with a variety of non-malignant diseases including Fanconi's Anaemia, Hunter Syndrome, Hurler Syndrome, Idiopathic Aplastic anaemia, Thalessemia, and even osteoporosis².

Research is now under way on using cord blood to combat rheumatoid arthritis, AIDS, multiple sclerosis, sickle cell anemia, cancer of the lung and colon and Hodgkin's lymphoma.

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 period³⁻⁷. Many lives could be saved if umbilical cord blood were routinely banked and made available for transplants.

Currently there are options of both public and private cord blood banking available in India.

Dehradun, the capital city of Uttarakhand state with a birth rate of 18.2%⁸ is an ideal place to conduct survey. Predicted growth projections of the state indicate a possible bright future for cord blood banking to flourish.

Although the ethics related to the use of cord blood has been extensively discussed from a medical perspective, little is known about parental views⁹⁻¹³. Only a handful of surveys have been reported from Indian subcontinent to the best of our knowledge. The support of the general public is crucial for the success of cord blood transplant programs, hence this study was conducted to explore the awareness amongst the general public regarding umbilical cord stem cell (UCSC) and its banking.

Such studies can serve as a need assessment survey tool for establishment of a cord blood banking in the state.

MATERIAL & METHODS

The study was conducted after obtaining approval from Institutional Ethics Committee of the Institute.

Sample Size was calculated using Cochran's formula and thus the survey was done on 460 participants. An anonymous, pre-validated, self-administered questionnaire including 20 objective questions based on socio-demographic factors, knowledge and attitude regarding UCSC, access to information and banking option preferences were offered to 460 participants excluding those aged below 18 years. Only those responses that were found to be aptly attempted were considered valid to be analysed. Microsoft Excel was used for data entry and analysis. The outcomes of the study were expressed in percentages and depicted in form of tables, pie charts and bar graphs.

RESULTS

Out of a total of 460 questionnaires offered, 400 were found valid to be analysed. In present study, 42% (n=168) respondents belonged to urban settings while 58% (n=232) hailed from sub urban and rural areas. Range of age group among the participants was 18-34 years, with mean age being 28 years. More than half, 57% (n= 68) respondents were high school pass. [TABLE 1]

Although 82% (n=328) respondents, knew the fate of placenta and umbilical cord after baby's birth, only 40% (n=160) had heard about its banking [FIG.1]. The most common source of information was mass media constituting about 70% (n=112) [FIG.2]. The survey comprised of 97% (n=388) participants

who were unaware about the therapeutic benefits of cord blood if required. It was found that 76% (n= 304) respondents were willing to receive further information regarding this topic. Only 10% (n=40) of participants had relatives who had experienced cord blood banking for his/her baby. It was observed that 25% (n=100) respondents had a perception that the collection procedure may pose threat to mother or baby [FIG. 1].

Nearly 67% (n= 268) participants had a notion that approximate charges for collection and preservation of cord blood would be affordable for them while rest 33% (n= 132) thought that the cost would be very high and far beyond their expectations. If given an opportunity, 50% (n=200) respondents indicated that they would like to bank their baby's cord blood.

In 62% (n=124) cases reason presumed behind storage remained both therapeutic and research purposes [FIG.3]. Regarding banking options, 48% (n=96) participants would prefer public cord blood banks while 52% (n=104) would choose private ones.

Amongst those who preferred to opt for public banking 67% (n=64) respondents had a motive to provide benefit to all in case of need. A vast majority, 94% (n=98) participants among private bank supporters had a notion that it will guarantee the availability of cord match whenever needed [FIG. 4].

Study revealed that 75% (n=300) respondents wished that cord blood banks should maintain privacy while providing services to non-related beneficiaries. The main factor behind people refraining from cord blood banking was found to be lack of awareness comprising 70% (n=280) respondents. However, as per 48% (n= 192) respondents cost issues cannot be overlooked. It was also found that according to almost 98% (n= 390) respondents, fathers should have a crucial role in decision making regarding storage of UCSC.

DISCUSSION

Blood left in the umbilical cord and placenta after birth has been recognized as a life-saving substance as it contains regenerative "stem" cells like bone marrow.

Since the potential of the stem cells in bone marrow has been recognized, significant number of deaths are being prevented per year by bone marrow transplants. However, bone marrow has its own short comings and these unfavourable factors make umbilical cord blood stem cells use more acceptable.

The survey comprised of fair number of educated participants with a minimal educational qualification of high school. Although only less than half of the population surveyed had heard of cord blood banking before, but still there was a positive response to receive further information regarding this highlighting the loss of potential donations and hence the need to expand the communication networks.

Moreover, 70% of the aware respondents received information via mass media reflecting the need for health care professionals to become more active socially. Information acquired from media - newspapers, magazines, internet and television is incomplete, sometimes unclear and perhaps not always correct. We, therefore, believe that professionals and institutions should make an effort to provide unbiased information and education both about UCB donation and preservation and disclose the myths and false beliefs prevailing in the community. Recruitment for UCB collection should occur after sufficient education. Physicians need to realize their crucial role at the grass root level to create awareness. We believe that real contribution of doctors to society lies not only in treating people, but also spreading awareness and clearing their misconceptions. Physicians are

not just healers, but before anything else they are teachers. Many studies reveal that majority general public wanted to receive more information regarding stem cells and umbilical cord blood banking from health care professionals¹⁴⁻¹⁶.

Half of the surveyed respondents showed their willingness to avail the opportunity of saving cord blood for future purpose if provided. In context of preference for opting public or private cord blood banking, there was not any striking difference in the results. Though those going for private banking were slightly more in number probably due to the fact that most of them were not very clear about the exact charges of the entire procedures. Along with the cost issues, the fact that there still persists a major lack of awareness and appropriate information among the public could not be denied. Since parents are made more aware of private blood banks through advertisements and media coverage, they appeared to be more steered towards private storage of their infant's cord blood¹⁷. However it must be taken care that information provided via these sources are often spurious not always reliable supporting the fact that despite being a non-invasive technique, people still refrain from it.

In India, the first public UCB repository became functional in early 2000¹⁸. However since then there has not been much expected progress in this field. The American College of Obstetricians and Gynaecologists ACOG committee emphasises that balanced and accurate information should be provided to the patients with regards to the advantages and disadvantages of public versus private banking¹⁹.

Currently there is neither public and nor any private cord blood bank in Uttarakhand. With the rising development, the state promises to become an employment hub for the youth, hence providing an appropriate environment for cord blood banks to blossom and contribute to state's medical tourism. Our results provide insights that can be meaningfully incorporated into government regulatory policy and regional cord blood banking policy.

Despite growing evidence of the therapeutic benefits of umbilical cord derived stem cells and promotion of umbilical cord blood collection worldwide, India seems to lag behind in this context.

Surveys done in Europe and Canada had revealed that pregnant women have very limited knowledge about UCB and its banking²⁰⁻²¹. In a study conducted in Turkey, only 26% of the surveyed women had information or knowledge about cord blood banking and donation. In the same study 74% of women would donate to a public bank if given the opportunity (15).

A study done by Venugopal et al. highlighted that nurses knowledge and attitude regarding stem cells and umbilical cord blood banking was inadequate. Most of the subjects had average knowledge and neutral attitude regarding stem cells and umbilical cord blood banking, the possible reason can be attributed to the lack of pre-service and in-service education on stem cells and umbilical cord blood²². It is highly desirable to empower nurses with knowledge and skills related to UCBB. Health care professionals are considered by the public as most credible source of information about stem cells and umbilical cord blood banking.

Having a glimpse at the world scenario, it would be wise for health professionals, paramedical staff, social workers and governing bodies to join hands together as soon as possible, conduct national surveys, educate citizens, contribute funds and much more efforts to make UCSC more than a biomedical waste. Only a sincere team effort by all can lead to successful accomplishment of this tedious journey of UCSC from controversies to consensus.

CONCLUSION

Lack of knowledge amongst general public is the prime hindrance in the success of UCSC banking, not their attitude.

Need of the hour is political commitment and funding to help UCSC banking flourish as a boon for mankind. As UCB is a valuable community resource, obstetricians should encourage UCB donation, providing detailed information especially to pregnant women and to future parents. The institutions should play a more significant role in giving updated and evidence-based information about the usefulness and limitations of UCB to the population.

Finally, the study may help optimize recruitment efforts and confirms that the attitudes of the populations investigated are not an obstacle to the expansion of UCB donation.

Limitations

Since the present study was conducted in a limited population hence the results cannot be generalized to the entire state.

Table 1. Age And Educational Profile Of Participants

TOTAL n=120	NO.OF RESPONDENTS	PERCENTAGE
AGE		
18 - 20 YEARS	84	21%
21-30 YEARS	268	67%
>30YEARS	48	12%
EDUCATIONAL STATUS		
HIGH SCHOOL	228	57%
GRADUATE	100	25%
POST-GRADUATE	72	18%

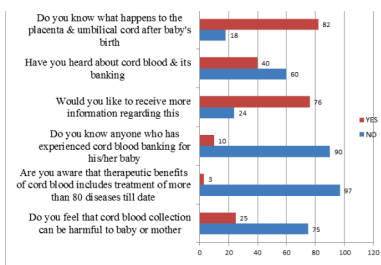


Fig.1 Information Status And Knowledge Of Participants

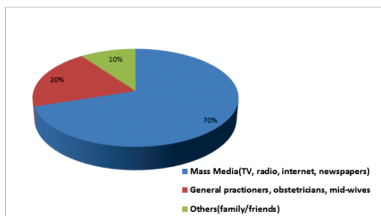


Fig.2 Source Of Information Amongst Participants

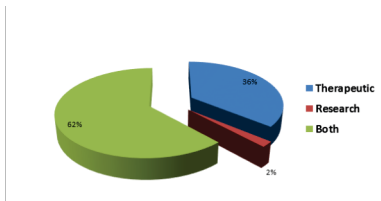


Fig.3 Intentions Behind Cord Blood Banking

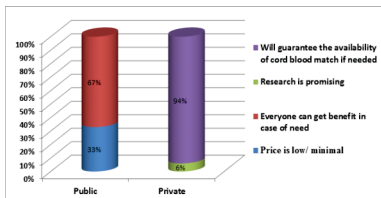


Fig.4 Reasons Behind Cord Blood Banking Choices

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