

Parents view on the awareness, knowledge and acceptance of stem cell banking as a future saver of life in metropolitan region.

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Abstract

Introduction - Society doesn't understand and accept anything easily. We gradually accept things, it's our human nature. Similarly, stem cell banking is going to occur. Stem cell is the master cells of the human body. Stem cells can become indefinitely unique cells of various kinds, such as blood cells, heart cells, and other organ cells. Stem cell banking is a way of collecting and preserving stem cells that help to cure a number of deadly diseases. Umbilical cord has become the world's leading source of stem cells; the United State and Japan are using stem cells for the therapy of life - threatening diseases; umbilical cord banking is considered a major global initiative. In India after two decade stem cell banking still a new emerging idea because of lack of knowledge to the parents about stem cell. Stem cell Banking is becoming increasing popular for expecting parents as a unique form of insurance since it provides them the confirmation about their child's safety and healthy future. Thus, this study is all about the awareness, knowledge and acceptance of stem cell banking as a future saver of life in metropolitan region.

Methods: A cross sectional questionnaire was asked to the parents on the basics of their knowledge, awareness and acceptance regarding stem cell banking. The sample for the study comprised of 140 parents associated with various gynecologist clinics and hospitals of Delhi-NCR.

Results: This study included 140 participants. Of 20 people has not been heard about stem cell banking, and 10 are unaware of stem cell. Parental knowledge indicates that 84.5% are fully familiar with the storage of umbilical cord, and 96.4% are aware of stem cell banking. The main source of parents' knowledge on stem cell banking is gynecologist, along with internet and advertisement. The source of information is highly significant to the parent's awareness about stem cell banking. Perception of parents are changed almost 45% feel this is crucial for treatment of major disease in the future. Now, parents are interested in the stem cell banking but they need more information about the advantages and

disadvantages about the stem cell banking. The perceptions are highly significant to the information about umbilical storage.

Concluded- Therefore, It was concluded that parents have become more aware of stem cell banking over the last five years, almost two decades, so that the understanding of stem cell banking is expanding rapidly in metropolitan cities, which is very important for the growth of stem cell banking in India. Increase parent's involvement in stem cell banking to recognize parent's doubts about stem cell banking.

Keywords – Awareness, Knowledge, Acceptance, Stem cell banking, Umbilical cord

1. Introduction

Every year, thousands of patients suffer from serious diseases such as thalassemia, leukemia and cancer. There is still no effective treatment or vaccine for these diseases, but they are expected to treat with stem cell therapy. Stem cells are the body's master cell able to produce more than 200 different types of organ cells. Stem cells used for the treatment of many diseases. Stem cell preservation and storage for future use will be termed as stem cell banking. Stem cell can be collected from the cord segment, still attached to the placenta, when the baby is delivered and the umbilical cord is divided. The blood stem cells present in the other umbilical cord and placenta are called "Umbilical cord (UCB) stem cells. A rich source of stem cells is the cord that has not been used by mother or baby and has been treated with medical waste for decades. (Deeksha Pandey, 2016) Stem cells collected in particular from cord blood have high regenerative properties and the capacity to treat more than 80 diseases. These stem cells may become blood cells to replace diseased cells.

In recent years, Cord Blood Banking has gained an enormous confidence on the treating cancer, such as leukemia and lymphomas, genetic abnormalities, metabolism and immune system diseases. Doctors around the world are highly advised to do Umbilical Cord Blood Banking at birth.(Harris, 2008) Stem cells are a new field that might alter the world of diagnosis, treatment and development of drugs "Stem cells are cells that can divide into culture over an indefinite specified period and generate specialized cells." Stem cells are unique from other cells in the body because they are unspecified cells capable of regenerating themselves by cell division and can be induced to become tissue or organ specific cells with the useful purpose under certain physiological and experimental conditions (Landis, 2017). Stem cell is a very promising method for stem cell therapy, regenerative medicine and treatment, drug discovery, toxicology and developmental biology studies. Stem cell banks are established in the worldwide for the fundamental research and clinical trials for the current and future application of stem cell. (Changbin Sun, 2016)

1.1 Two types of stem cell banking

- Private cord blood banks are managed by private companies. Based on health reasons, the organization will save the umbilical cord at the time of delivery. Private banking takes charges for the collection and storage. The public banking benefits are that, if a family person or the child need in future they used own stem cell for treatment. Cord blood and stem cell from a healthy child without heritable illnesses can be maintained as an assurance. The major private stem cell banks in India are Life Cell International private limited, Cryoviva private limited, Reliance life sciences private limited. (Amit Kumar, 2011)
- Public cord banking is government organization no collection and storage charges are applicable. The downside of this program is that a donor does not always receive Cord Blood if he or she needs it. Parents are required to donate Cord Blood to Public Banks for the matches from many other donated examples, however, can be found. Correspondence between the human leukocyte antigen (HLA) of the donor and the recipient is required. The closer the match is, the better the opportunity for the body to accept a new stem. The public banking is Jeevan stem cell foundation. Other public banks are only store stem cell for research purpose. (Amit Kumar, 2011)

After two decade stem cell banking is still in nascent stage in India. Parents want their child safe future but the cost and less awareness about stem cell banking created confusion about the stem cell banking. In effort to expand the use of stem cell banking by parents for their children, a better knowledge and understanding of stem cell banking are needed; if the perception towards stem cell banking is positive, stem cell management may become an essential life saver for future. In addition to defining the role of stem cell banking as a biomedical security, this paper aims to assess the awareness, knowledge and parents view on the acceptance of stem cell banking.

2. Literature Review

Stem cell banking has become a worldwide massive industry. In other developing countries, they control at least 60% of the market such as the USA and Japan But in India it's on the developing stage; Indian parents need a worthy and lasting assurance for stem cell banking. Pregnant women had a positive mindset towards stem cell management, which prevented private cord blood banking from being cheaper and more convenient, and said they would use it if they were able to afford it. (H. Dinc, 2009) The use of cord blood as a biological insurance should be encouraged by medical professionals and supported by parents in making the right decision on stem cell banking. (Moni Tuteja, 2015)

In Punjab, the 2015 study on the knowledge of mothers on cord-blood banking indicates that most antenatal mothers have average knowledge of cord-blood bank and the knowledge of mothers needs to be strengthened with a pamphlet. (Savita, 2015) The awareness and acceptance of pregnant women of stem cell banking in the Mumbai region is based on expecting mother's profile like education, occupation. (Abha Ashish Wankhede, 2015)

A Cord Blood Banking Awareness Study in the Vidarbha region shows quite smaller percentage awareness among customers for the Nagpur and Amravati cord blood banking concept. The factors that impact consumer awareness are communication gap, education status, and socio-economic status. (Chetan V Dubey, 2016). The research in Pondicherry, India of the awareness that cord blood banking is a lack of knowledge on cord blood banking among pregnant women in semi-urban areas. Private banking for families affected by HSC transplantation diseases can be useful. More government funding and private organizations are required to help the public about the cord blood banking. (Poomalar G. K., 2016). Another study on umbilical cord banking awareness among pregnant women in 2016 showed that women were more aware of private banking than they were of public banking because of advertising. Obstetricians should play a more active role in informing patients about the benefits and drawbacks of UCB banking. (Deeksha Pandey, 2016). The findings show that 48% of individuals in India know about stem cell banking and also evaluate their sense and ability to do so, in order to assess knowledge of umbilical cord blood banking among individuals, 89% have been prepared to do stem cell banking in the future. Knowledge contributes to better recruitment, and obstetrics also can play a more active part in informing patients of the UCB banking advantages and disadvantages. (N.Tiwari, 2016) In 2017, the research conducted in Srinagar City in determining the awareness and attitude of expectant mothers about stem cells and dental stem cells concluded that there was a lack of information that stem cell treatment is beneficial to pregnant women. Many do not know the use of dental stem cells. (Sultan, 2017). The information booklet has had a positive effect on the awareness of umbilical cord stem cell banking. (Nisha Philip, 2017) According to the health care professional study, 55.33% of medical professionals had insufficient awareness. (Rachna Gill, 2017) From the existing research it shown the parents consider stem cell banking very crucial for the treatment of various disease but the gradually awareness level and acceptance is processing slowly.

3. Research objective

1. To determine the awareness and knowledge level of stem cell management among the parents in metropolitan cities.

2. To determine the impact of the socio-demographic variable on parent's awareness and knowledge about stem cell management.
3. To determine the source of information regarding stem cell banking.
4. To determine the perception of parents on the stem cell management.

4. Research Methodology

This study was conducted using descriptive research design, where 140 pregnant women from different hospitals and gynecology clinics in the Delhi-NCR area were included in the total sample range. The data were collected through a questionnaire designed to measure parent's awareness of stem cell banking in Delhi-NCR. Of the 110 questionnaires, 30 were rejected for lack of value. So the final sample consisted of just 80 respondents. The collected data were studied and analyzed in terms of objectives of the study using descriptive and inferential statistics. The level of statistical significance was set at $p < 0.05$ (Chi square test).

5. Data Analysis

Data analysis depends on the questionnaire and the study objectives. In this paper, the first research question was asked on the knowledge and awareness about stem cell management through questionnaire, about the source of information, then about the socio demographic.

5.1 Demographic Interpretation

Four demographic variables, age, education status, occupational status and monthly family income were measured in this survey.

The majority of respondents between 31- 35 years of age are 46.4% of respondents, while between 26 -30 years of age are 31.8% and over 35 years are 15.5% of respondents. More than 60 % are post graduated, 30% graduated and others belong to higher education. Full-time employees are 40% of those interviewed, homemaker are 37.3%, part time employed and self-employed are 10% and 11.8 %. About 48.2 percent of those surveyed recorded a monthly income of over Rs 90,000 family members and 32.7% reported a monthly income of less than Rs 90,000 family members but over Rs 60,000. Only 16.4% of the income is between 30,000 and 60,000 and the remaining 2.6% is below 30,000.

5.2 Awareness regarding stem cell

Awareness requires knowledge and understanding of stem cells. The question is addressed to parents to test their awareness of stem cell management. When parents do not understand and have never heard of stem cell management, their data has not been collected. Parents with basic understanding and knowledge of stem cell management should be asked to complete a questionnaire. In total, 106 participants are aware of stem cell management and 4 are only familiar with the idea of stem cell banking, but are not aware of the applications of stem cell management.

Table 1

Are you aware about the stem cell management?			
	Frequency	Percent	Cumulative Percent
No	4	3.6	3.6
Yes	106	96.4	100.0
Total	110	100.0	

To determine the impact of the socio-demographic variable on parent's awareness about stem cell management.

Null Hypothesis- There is no association between awareness and socio demographic variables.

Alternative Hypothesis- There is association between awareness and socio demographic variable.

Result indicates that the age range 31-35 is the largest number of parents 47.2% who are aware of stem cell management. 63.5% of postgraduate parents are more aware of the stem cell than 31.1% of graduate's parents. Similarly, full-time employment and family income is more than 90,000 rupees per month more aware of stem cell management. The impacts of the socio demographic variable on parent's awareness are measured by the chi square test.

In statically testing hypothesis if p-value less than 0.05 (typically ≤ 0.05) is statistically significant, if p-value higher than 0.05 (> 0.05) is not statistically significant and indicates strong evidence for the null hypothesis. This means we retain the null hypothesis and reject the alternative hypothesis. The table show that p value of socio- demographic variable(age, education, occupation and monthly family income) is

greater than the 0.05(> 0.05) is not statistically significantly and indicates strong evidence for the null hypothesis hence there is rejected the alternative hypothesis and accepted the null hypothesis.

Similarly in the study in 2016 shown that awareness does not correlate with the socio demographic variables like age, occupation and monthly family income, in this study show that the awareness has a relation with the education but this may be vary because the studies belong to semi urban area. (Poomalar G. K., 2016)

5.3 Knowledge of parent's on stem cell management.

To determine the knowledge on stem cell management, asked parents about the storage of umbilical cord of their baby for future treatment. It concluded that 84.% had knowledge of the umbilical cord used as a stem cell source, but 15.% of parents are less know about the umbilical cord storage and have doubts on the stem cell present in the umbilical cord.

Table 2

Do you know about the umbilical cord stored as a source of stem cell for future used?			
	Frequency	Percent	Cumulative Percent
No	17	15.5	15.5
Yes	93	84.5	100.0
Total	110	100.0	

To determine the impact of the socio-demographic variable on parent's knowledge about stem cell management.

Null Hypothesis- There is no association between Knowledge and socio demographic variables.

Alternative Hypothesis- There is association between knowledge and socio demographic variable.

The data shows that age (yrs), education status and occupation were not significantly associated with the knowledge of umbilical cord but the monthly family income was found to be significantly associated with the knowledge score. That means monthly family income impact the storage of umbilical cord. So, for the

socio demographic variables like age, education and occupation the alternative hypothesis is rejected and for the monthly family income the alternative hypothesis accepted. Similarly in the study in 2017 about stem cell storage show that p-value corresponding to monthly family income is small, monthly family income is the demographic variable which was found to have significant association with Attitude of antenatal mothers regarding umbilical cord stem cell banking. (Nisha Philip, 2017)

Table 3

Correlate		Awareness about stem cell management			Knowledge about umbilical cord banking		
		Parents Aware %	Chi-Square	P value	Knowledge %	Chi-Square	P value
Age	18-25years	6.6%	3.747	.290 Not Significant <0.05	5.4%	4.113	.249 Not Significant <0.05
	26-30years	30.2%			29.0%		
	31-35years	47.2%			48.4%		
	Above 35 years	16.0%			17.2%		
Educational status	Doctor	3.8%	.358	.949 Not Significant <0.05	4.3%	7.760	.051 Not Significant <0.050
	Graduate	31.1%			25.8%		
	Higher Education	1.9%			2.2%		
	Post- Graduate	63.2%			67.7%		
Occupational Status	Full time employed	40.6%	1.170	.760 Not Significant <0.05	40.9%	2.528	.470 Not Significant <0.05
	Homemaker	36.8%			35.5%		
	Part time employed	10.4%			11.8%		

	Self employed	12.3%			11.8%		
Monthly Family Income	> Rs 90,000	49.1%	3.522	.318 Not Significant <0.05	53.8%	17.546	.001 Significant <0.05
	Rs 10,000- Rs 30,000	2.8%			1.1%		
	Rs 30,000 - Rs 60,000	15.1%			11.8%		
	Rs 60,000 - Rs 90,000	33.0%			33.3%		

The table above shows that parents are aware of stem cell banking and are gradually processing understanding about stem cell banking. The various studies appear to have a socio-demographic impact on parents' awareness and knowledge, but now parents are more educated and almost all metropolitan hospitals are providing advice on stem cell banking, so now there is no impact of the socio-demographic variable on awareness, and only monthly income can be closely correlated to knowledge. Similarly in the study conducted 2018 in the South India region, concluded that more urban women have been found to have improved awareness of stem-cell banking than rural women. The monthly family incomes below Rs. 50,000 families are aware but does not willing to do the stem cell banking. (Sharun Rajendran, 2018)

5.4 Sources of information

The following analyses indicate that the information parents have from gynecologists is 32.9 % and the information on stem cell management is accessible on the internet by 22.7 % of parents. Ironically, the sources of information among parents are based on advertising and the family together, (13.6%). Company counselor also plays a significant role as a source of knowledge for stem cell management.

Ho: The source of information (Gynecologist, company counseling, advertising by Stem Cell Banks, the family and the internet) does not have a significant impact on increasing parent's awareness about Stem Cell management.

Ha: The source of information (Gynecologist, company counseling, advertising by Stem Cell Banks, the family and the Internet) on parents awareness about Stem Cell management.

Table 4

Different source of information	Total	Percent	Aware from the source of information	Chi-square	P Value
Advertisement	15	13.6	14.2%	28.246	.000
All	5	4.5	4.7%		
Company counselor	14	13.8	13.2%		
Doctor	36	32.9	32.1%		
Family	15	13.6	13.2%		
Internet	25	22.7	22.6%		

The relationship between awareness and information source shows that doctors / gynecologists contribute actually 32.1% of awareness. The Chi -square demonstrates that sources of information (Gynecologist, company counselor, advertisement, family and internet) have significant influence on the rising of parent’s awareness about stem cell management because the p value is .000. That means the various source of information directly affect awareness of parents. The information source, particularly doctors, is initiative to raise awareness about stem cell banking in parents. Similarly, in 2016, the study concluded that the doctors provided the necessary details on stem banking. The study found that individuals have been aware of stem cell banking through some daily advertising. Mass media approaches the promotion of awareness of the benefits and advantages of umbilical storage. (N.Tiwari, 2016).

5.5 Parents view on the acceptance of new technology stem cell management.

Acceptance of stem cell management basically depends on the parent's interest in enrolling in stem cell management for their child. According to results, just 18.2% of parents are very interested in stem cell management and 45.5% are somewhat interested. 16.4% have not yet decided on the stem cells management due to lack of knowledge on the application of stem cell.

Table 5

Perception of parents about stem cell banking.	Frequency	Percentage
Really essential.	20	18.2
Very crucial for specific disease treatment	50	45.5
In future it may be worthwhile.	18	16.4
Just a company's hype	19	17.3
Has an irrelevant value	3	2.7

The table below shows the relation between the parents interest to enrolled in stem cell banking and have knowledge about the stem cell used for the treatment of major disease like thalassemia, cancer, anemia and other diseases.

Further research on stem cell banking is needed by families.

From the below chart its shown that 68% parents need more information about stem cell banking because they are interested to get know about the advantages and disadvantages of stem cell banking. During survey its seems parents are very much interested to know about the diseases treatment through stem cell banking and they want to know the future applications also. Only 32% are not interested to know about stem cell banking because they may be enrolled and have a counseling session so they feel its satisfied to them for stem cell banking and some are not believe in the stem cell banking concept.

Table 6

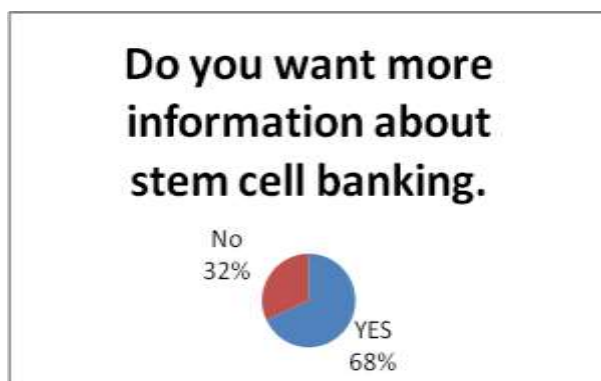


Table 7

More information about stem cell management.		Acceptance of stem cell banking				
		It is really essential.	Somewhat interested	Undecided	Not very interested	Not at all interested
Yes		10	41	14	9	1
No		10	9	4	10	2

Table 8

Chi-Square Tests			
	Value	Df	Asymp. Sig. (2-sided)
Pearson Chi-Square	13.686 ^a	4	.008
Likelihood Ratio	13.567	4	.009
N of Valid Cases	110		

a. 2 cells (20.0%) have expected count less than 5. The minimum expected count is .95.

The chi square value is 13.686 and p value is .008 means is smaller than .05. The alternative hypothesis is accepted, there is relation between the interesting parents want more information about stem cell banking. Similarly in the study in 2015 on the expecting mother of Mumbai region show that acceptance of the stem cell banking based on the attitude and awareness about stem cell banking. (Abha Ashish Wankhede, 2015)

6. Discussion

The aim of this study is to identify awareness, knowledge and perception of stem cell banking in metro cities such as Delhi-NCR. The respondent surveyed were aged 18-42 as the majority of the new parents (i.e. the first parents) are in this age group. Participants were asked whether they aware about stem cell banking or not. The majority of parents 106 in a total of 110 respondents are aware of stem cell banking, while the remaining 4 are not much aware about stem cell banking. . The research has shown that the awareness and perception of the parents regarding stem cell banking was substantially improved. The present study shows that there was no relationship between awareness and the socio-demographic variable. Further, the study shows that parents' knowledge of umbilical cord storage is low compared to parents' awareness, and parents' knowledge does not have a significant relationship with socio-demographic variables such as age, education, and occupational status, but the relationship between monthly income and knowledge is significant because the cost of umbilical cord storage is high, so some families would not be able to afford it.

The role of source of information is improved and hypothesis significant that doctors, advertisement, internet and family play an important role in improvement of awareness and knowledge on stem cell management. Especially Chi-square statically is used to find the relation between awareness and information sources, it reveals that there is hypothesis significant relation between source of information and parent's awareness regarding stem cell banking.

Acceptance of stem cell banking is measured by parents' perception of stem cell banking and their interest in obtaining more knowledgeable information about stem cell banking. 45 per cent of parents believe that

stem cell banking is necessary because it will help in the treatment of major diseases in the future. Some parents think it might be valuable in the future, and others think it's just a hype created by the company. 68 per cent of people were interested in stem cell banking, but they want more information about the use of stem cells. This study shows that parents' perception of stem cells is based on parents' interest in obtaining more information about stem cell banking, thus the perception and interest of parents in stem cell banking are highly associated. Finally, the study has shown that parents are more aware of stem cell banking in the metro major cities, but more information is also needed on stem cell banking to enable them to become more interested in stem cell banking, and the government has to approve several clinical studies so that more people benefit from stem cell storage.

7. Conclusion

As per the literature review it concluded that parents are less aware about stem cell management but this study finds that parents are very well know about the stem cell banking, but still doubts about their future use, so most parents are not interested in stem cell banking. Gynecologist is the major source of information regarding stem cell banking. Pamphlets and brochures are present in hospitals and clinics that have raised awareness of stem cell banking. In the metro towns major hospitals have ties with the Stem Cell Company, and parents provide advice on stem cell banking and more knowledge on stem cell banking from the counselor. Parent perceptions are doubtful due to lack of interest of the doctors, and there is no scientifically proven treatment of the illnesses, therefore the parents' perception and acceptance of stem cell banking are only rising when they are satisfied by the counselor as well as the gynecologists to clear up the doubts of the parents. The study reveals that parents are also aware through some advertisement in day to day life so need of more advertisement about the umbilical storage. This study only about the cities in small town, village, peoples are not aware about stem cell management. Nevertheless, Our study has some limitations including that it had consisted of a small sample and mostly, the data is collected in the hospitals/clinic of Delhi-NCR mainly Noida, so the results cannot be generalized to all of society.

The small town's data may be given different result because they stem cell banking companies do not spread in small towns. In this study only parents opinion consider for further study doctors/gynecologist study will be consider. In order to draw more detailed conclusions, more research on this subject must also be carried out among the parents. We suggest that research be done to gain a thorough understanding of people's storage and banking attitudes towards UCBs and, in particular, to record and understand parenting views on this issue.

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