

Saving Cord Blood and Saving Lives?

A Research Paper

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Abstract

Umbilical cord blood banking has grown into a global phenomenon that both new and experienced expecting parents are drawn to. Because research indicates that stem cells found in cord blood present many benefits, such as treatment of blood cancers and genetic diseases, parents have come to believe that storing their children's cord blood is a form of "biological insurance." In certain aspects, cord blood can be life-saving. However, the storage and maintenance of cord blood, known as cord blood banking, has also become a form of consumerism. There are three types of cord blood banks: private, public, and direct-donation. Private banks allow for the family's personal storage and use of cord blood for various fees. Public and direct-donation banks allow for the free donation of cord blood to the general public or to a specific recipient. Since there is little chance for a family to use their child's cord blood unless that child or a sibling has a condition that can be treated with cord blood, it is often more beneficial for families donate cord blood to the public or use direct donation. Nevertheless, private cord blood banks target expecting parents as customers in order to run their businesses.

Saving Cord Blood and Saving Lives?

Stem cells found in umbilical cord blood have been researched and tested in recent decades as a way to treat certain types of cancers and genetic conditions. In fact, in 1988, the first successful umbilical cord blood stem cell transplant was performed on Matthew Farrow, a young boy with a genetic disorder called Fanconi's anemia. After genetic testing and screening were done on Farrow's newborn sister, Farrow was treated with his sister's umbilical cord blood stem cells and evidently cured of his disease (Cooper & Severson, p. 62, 2013). This new-found medical innovation changed the way that society viewed umbilical cord blood and the umbilical cord banking process. Because stem cells collected from umbilical cord blood have been proven to successfully treat diseases such as leukemia, lymphoma, and some genetic disorders, the decision of whether or not expectant parents should store their child's cord blood has become a prominent issue in the field of perinatal healthcare. There are three distinct types of cord blood banks that can collect and store cord blood immediately after a child is born: public, direct-donation, and private. Public and direct-donation cord blood banks allow for the free donation of cord blood to the general public or to a specific recipient. On the other hand, private cord blood banks allow families to store their child's cord blood for their personal storage and use for a set amount of fees for collection, maintenance, and storage (Waller-Wise, p. 56-58, 2011). As a result of recent research and public emphasis on the effectiveness of umbilical cord blood for treating certain conditions, the process of umbilical cord blood banking has begun to participate in a form of inflated consumerism since private cord blood banks charge many unnecessary and expensive fees. Therefore, families should invest in public or direct-donation cord blood banks since there is no cost to donate their child's cord blood and since they ensure that a child's cord blood will be used to treat someone who is in great need of it.

What is Umbilical Cord Blood?

Umbilical cord blood is blood obtained from the umbilical cord of a newborn immediately after he or she is born. The blood from the umbilical cord is collected and saved because it is rich in hematopoietic stem cells, which build up the body's tissues and organs. While cord blood was historically discarded as medical waste, research over the last few decades has proven that umbilical cord blood stem cells have curable properties for certain cancers and genetic conditions (Waller-Wise, p. 54-55, 2011). In the United States, recent research has shown that most newborns' umbilical cord blood is discarded, but since the media has promoted the advantages of umbilical cord blood and its potentially life-saving properties, there has been more emphasis on the importance of saving newborns' cord blood (Cogdell, p.145-146, 2009). As a result, among other decisions that expectant parents face, the decision of whether or not to store their child's cord blood has become a growing issue.

Furthermore, since more research is continuously being done on umbilical cord blood and its capabilities, there has been more public emphasis on saving cord blood for medical testing. This promotes more medical innovations and discoveries for the future of umbilical cord blood. These medical tests could also discover exactly what is necessary for an individual to be a donor match for transplantation as well as have viable cord blood that can be useful in the future (Cogdell, p.145-146, 2009). As a result, new methods of transplant and treatment could be developed. Through the discovery of umbilical cord blood's capabilities and the development of medical innovations, an improved system of umbilical cord blood collection could be implemented. Not only will individuals benefit from more developments on umbilical cord blood but the public will benefit as well. Through the potential discoveries that come from umbilical cord blood research, there could be more evidence of the advantages of umbilical cord blood.

What Can Umbilical Cord Blood Cure?

Since Michael Farrow's successful cord blood transplantation in 1988, there have been more than 25,000 cord blood transplants performed worldwide (Butler & Menitove, p.669, 2011). These transplants have changed the lives of individuals affected with genetic and chronic diseases that umbilical cord blood stem cells are capable of curing. The four main types of conditions that can be treated with umbilical cord blood stem cells include cancers, blood disorders, congenital metabolic disorders, and immunodeficiencies. Specific diseases that are commonly treated with umbilical cord blood stem cells include leukemia, lymphoma, sickle-cell anemia, Fanconi's anemia, and Tay-Sachs' disease. In addition, investigation of umbilical cord blood stem cells' effects on diseases such as lupus and diabetes are being conducted (Waller-Wise, pg. 55-56, 2011). Because umbilical cord blood has demonstrated promising results for the treatment of various and life-threatening diseases, popularity in umbilical cord blood transplants and therapy has grown. Through decades of research and testing, umbilical cord blood has proven to be an effective cure for diseases that have compromised the lives of many people.

Advantages of Umbilical Cord Blood

In addition, umbilical cord blood stem cells have a variety of advantages over other methods of treatment, particularly bone marrow stem cells. Bone marrow stem cells are stem cells that require an individual to be hospitalized in order for collection from the bone marrow deep within a bone. It is a painful procedure that is usually done by inserting a long needle into the hip bone of an individual. On the other hand, umbilical cord stem cells are not invasive and simpler to collect since blood is taken straight from the umbilical cord of an infant after he or she is born. In addition, cord blood collection has no known risk for the mother or child and also has less processing time, which attributes to faster availability. Umbilical cord blood is also much

less costly, has less chance for infection transmission, and also has less chance for rejection from the transplant recipient (Waller-Wise, pg. 56, 2011). Therefore, because of all of the positive capabilities that cord blood treatments provide, increased investment in the use and development umbilical cord blood has been evident.

Cord Blood Banking Process

Because of the number of diseases that umbilical cord blood stem cells can effectively treat and cure, society has begun to view cord blood as a type of “biological insurance” that can be invested in. Once a family decides that they would like to save their child’s cord blood, the three types of umbilical cord blood banks that families can choose from include private, public, and direct-donation. The process of storing cord blood is known as cord blood banking. Since public emphasis and research has influenced expecting parents to invest in cord blood banking, it has evolved into a form of consumerism. In addition, there is a high cost associated with cord blood banking since it must be collected, maintained, and stored under specific conditions. The process itself requires specific protocols and standards in order for cord blood to be viable. In fact, the NETCORD foundation, which was established in 1998, called for an international registry for cord blood banks as well as procedures with standards for the “safe exchange and clinical use of banked cord blood.” As a result, half of the United States cord blood banks are certified by the American Association of Blood Banks (AABB). This further caused more foundations to be established to regulate the collection, processing, testing, banking, and selection of umbilical cord blood (Butler & Menitove, p. 670, 2011). If the cord blood is donated, a selection process is conducted to see if the donor’s umbilical cord blood is compatible with the recipient. During the collection period, cord blood must be obtained from the umbilical cord after it is disinfected and cleaned, in order to prevent contamination. The cord blood is then

collected in a sterile bag and sent to the selected cord blood bank. During transportation and storage, the cord blood must be maintained at about 22 degrees Celsius or 71.6 degrees Fahrenheit (Butler & Menitove, p. 671, 2011). Therefore, since the cord blood banking process includes several steps and certain requirements, expectant parents who are interested in cord blood banking need to be informed about how cord blood is collected and stored.

Private Cord Blood Banks

According to the article “Umbilical cord blood banking: an update”, there have been more than 780,000 cord blood units stored in over 130 private cord blood banks worldwide as of 2011. These cord blood banks allow families to have personal storage and use of their children’s stored cord blood. This means that cord blood is strictly reserved for the donor child, his or her siblings, or for other family members. Cord blood that is banked privately can be collected by any hospital, and it is the responsibility of the family to make arrangements to send the cord blood to a private bank of the family’s choice. Each family has custody of the umbilical cord blood until the donor child reaches eighteen years old (Butler & Menitove, p. 671, 2011). In addition, private cord blood banking includes fees for transport, testing, processing, and annual storage. The article “Cord Blood and Tissue Banking” reports that the range of these fees in the United States are said to be from approximately \$1,200 to \$2,500, and the annual storage fee ranges from \$125 to \$150. The typical length of storage with a company is about eighteen years, but extended storage may also be provided (Cooper, pg. 64, 2013). Due to the amount of discoveries made in recent years and media attention surrounding the benefits of umbilical cord blood, an increasing number of expectant parents have decided to privately bank their children’s umbilical cord blood. Parents have interpreted this option to be what is best for their child and their family. Moreover, because of all the fees associated with private cord blood banking,

families are contributing to the consumer market of cord blood banking. Since cord blood banking has become a growing industry, more companies are being established to privately bank cord blood. Common private cord blood banking companies include ViaCord, Cord Blood Registry, and CryoCell International. Naturally, the primary consumers of these private cord blood banks are expecting parents because these banks emphasize how saving cord blood can potentially save their child or family member's life one day. The medical research done about umbilical cord blood also reinforces the idea that umbilical cord blood's stem cells are capable of curing a variety of diseases. However, in order to be deemed viable, a certain amount of blood must be collected and tested in order to be stored. If the cord blood obtained does not fulfill certain qualifications set by the American Association of Blood Banks, privately banking cord blood is not always an option for families.

Public and Direct-Donation Cord Blood Banks

In contrast to private cord blood banks, public and direct donation cord blood banks are umbilical cord blood banks whose aim is to accept umbilical cord blood donations for individuals who are in need of transplants. These banks are more regulated and include more guidelines to ensure that donated cord blood is completely compatible with the recipient's body (Cooper & Severson, pg. 65, 2013). The main difference between public and direct-donation cord blood banks is that donations made to public cord blood banks are provided for the general public. Once the donation to a public bank is made, it is no longer available for the family's use. Furthermore, direct-donation cord blood banks ensure donation to a specific recipient with arrangements made beforehand. Direct-donation banks also have the ability to reserve donations for families, specifically those who have children with a condition that can be treated with umbilical cord blood (Cooper & Severson, pg. 65, 2013). Since these banks are publicly owned,

they do not charge fees for collection and storage. However, since there are only about 200 public cord blood banks around the United States, donating cord blood publicly is not possible at every hospital (Cooper & Severson, pg. 65, 2013). In fact, the article “Umbilical cord blood banking: an update” states that there are over 400,000 cord blood units that are stored in over 100 quality controlled public international cord blood banks. This is about half of the amount of cord blood that is held in private cord blood banks. While there is no charge for collection and storage, it is difficult for public cord blood banks to expand since there is a high cost for maintenance of the donated cord blood (Cooper & Severson, pg. 65, 2013). The limited amount of funds decreases public cord blood banks companies’ abilities to promote public donations. The three main public cord blood banks are also branches of ViaCord, Cord Blood Registry, and CryoCell International. In addition to the private cord blood banking branches, these companies also handle public cord blood banking. However, in recent years, more emphasis has been placed on private cord blood banking rather than public. Public and direct-donation banks ensure that a cord blood donation is being stored for an individual to use. It can potentially save the life of someone who can be treated with umbilical cord blood stem cells. If more emphasis was placed on public cord blood donations, there would be a greater chance that umbilical cord blood will be used rather than just stored away.

Debate Between Public and Private Cord Blood Banking

Statistically, according to the American College of Obstetricians and Gynecologists, there is only a 1 in 2,700 chance for an individual to use their umbilical cord blood if they do not have a history of conditions that can be treated with umbilical cord blood stem cells. This probability is incredibly low considering the cost needed to store and maintain umbilical cord blood privately. Moreover, since fewer restrictions are put on maintaining and storing umbilical cord

blood privately, there is greater risk of mislabeling and mishandling an individual's cord blood. In contrast, public cord blood banks ensure that the cord blood is correctly tested and handled so that the recipient receives the best possible donation. In order to attract consumers, private cord blood banks advertise a common misconception that private cord blood banking allows for "biological insurance" in case a child develops a condition that can be treated with stem cells from cord blood. It is one of the most significant reasons parents decide to store their child's cord blood. However, if the child has little or no chance of developing a condition that can be treated with cord blood stem cells, private cord blood banking can result in unnecessary costs and be of no use to families.

In addition, another claim is that donating cord blood to public banks does not allow families to use cord blood for their own personal use if a family member becomes sick with a condition that could potentially be treated with cord blood. Donating cord blood allows the general public to obtain the cord blood, and anyone could use it if it is compatible with their bodies. Through public cord blood donation, stem cells in cord blood could be used to treat an individual who may need it more than others. In all, donating cord blood to public banks provide more of a chance for the cord blood to be used and even save someone's life. Also, donating cord blood through direct-donation allows families to directly use umbilical cord blood for a family member who can be treated with umbilical cord blood. While private cord blood banking may have its benefits, more good can come from donating cord blood to public or direct-donation cord blood banks. Less money is wasted and more lives could be saved.

In an effort to explain how private cord blood banking has evolved into unnecessary consumerism, the author of the book *Me Medicine vs. We Medicine* discusses the development of an individualized view of medicine. She emphasizes how society has become more inclined to

personalized approaches to medicine, which the book describes as “Me Medicine”. In addition, the book mentions how “Me Medicine” has become more evident because people have begun to use medical advancements such as cord blood banking and genetic testing for their own benefit instead of for the benefit of the public, which the book refers to as “We Medicine”. This contributes to consumerism because people have been investing in medical advancements in order to help themselves and keep themselves healthy. As a result, the consumer market grows from people’s investments. The book highlights the debate of why private cord blood banking is not the most effective option for parents. While companies use convincing studies and rhetoric to attract expecting parents to invest in private cord blood banks, the disadvantages outweigh the benefits. Because the media has contributed to the emphasis on private cord blood banking, consumerism in the cord blood banking industry has become a growing debate. Rather than saving cord blood for an individual who has a relatively low probability of developing a condition that can be treated with umbilical cord blood, donating cord blood to public cord blood banks ensure cord blood is used for an individual who is in greater need of it.

What Do Doctors Recommend?

Overall, doctors recommend that families are fully aware of all of the information about umbilical cord blood and umbilical cord blood banking before making a decision. The journal article “Umbilical Cord Blood: Information for Childbirth Educators” discusses what some organizations believe about umbilical cord blood banking. The American College of Obstetrics and Gynecology (ACOG) specifically states that pregnant women should be given unbiased information about the advantages and disadvantages of cord blood banking. It also recommends the collection and banking of cord blood only if an immediate family member has a known condition that can be treated with stem cells from cord blood. The American Academy of

Pediatrics (AAP) recommends that all families collect their child's cord blood and donate it to banks for the general public instead of investing in private banks. They only recommend investing in private cord blood banks if a full sibling has a condition that can be treated with stem cells from cord blood. It also believes that the public has wrongly advertised cord blood banking by calling it "biological insurance". In addition, Lamaze International does not have a specific policy regarding cord blood banking, but it does prohibit the advertisement of private cord blood banks. The organization believes that parents should be aware of the disadvantages of private cord blood banks. They assert that parents who are expecting are very vulnerable to the marketing strategies that private cord blood banks advertise. The general idea of these organizations is that families should be well-informed before deciding to initiate the cord blood banking process. All of these organizations do not recommend private cord blood banking unless a condition is present in the family that can be treated through umbilical cord blood stem cells. Therefore, the perspectives of medical professionals indicate that private cord blood banking is only recommended under certain circumstances.

Private Cord Blood Banking Experience

An online article written in 2015 by David Warmflash mentions how the private cord blood bank branch ViaCord has used marketing strategies such as promoting on their website, "To date, 30,000 transplants have been performed using these amazing healing cells." The website also incorporates stories of how privately banked umbilical cord blood has saved the lives of many individuals with leukemia and a number of other conditions. However, the website fails to mention that most of these individuals were treated with cord blood that was banked publically rather than privately. The article argues that parents are not as informed as they should be about the differences in cord blood banks. The stories that private cord blood banks tell are

used to attract expectant parents to invest in saving their children's cord blood. Through this method, the private umbilical cord blood banking market has become a more preferred way of saving cord blood. Companies such as ViaCord proved to exaggerate their claims in an effort to make money through expectant parents, rather than emphasizing the need for public donations of umbilical cord blood.

The Wall Street Journal published an article called "Inside the Private Umbilical Cord Blood Banking Business" in which parents experienced private cord blood banks' mishandling of their child's stored cord blood. The article states that government inspections revealed "...a review of lawsuits in the U.S. found problems in the loosely regulated cord-blood-banking business, including dirty storage conditions, leaky blood samples and firms going out of business." This indicates that private cord blood banks are unreliable and must have stricter regulations. This claim is further proven with individual experiences such as Lindsay Bays whose 18-month son needed access to his cord blood for treatment of a condition called cerebral palsy. She had privately stored her son's cord blood with the private cord blood bank named CorCell, but the child's cord blood was mislabeled upon arrival to the facility. When Ms. Bays son needed the cord blood for treatment, no one knew where the cord blood had ended up (Searcey & Stewart, pg. 4, 2014). This situation proves that the risks involved with investing in a private cord blood bank are numerous. The family did not have access to the cord blood that required thousands of dollars to invest in. Had the private cord blood bank have stricter policies about cord blood handling, the family would have been able to access their child's cord blood when they needed it most. Ultimately, the article emphasizes that if families are considering any type of cord blood banking, they should invest in public cord blood banking.

Public Cord Blood Banking Experience

In recent years, an increasing number of parents have decided to experience public cord blood banking. In fact, I recently interviewed a registered nurse named Leticia Johnson who decided to donate her son's umbilical cord blood to the University of Texas Medical Branch at Houston, which has a public cord blood bank for donations and research. Although she is a nurse who works in the neonatal intensive care unit, she gained more experience with cord blood banking through personally donating her son's cord blood than through her patients and their families. She donated her son's cord blood after he was born in June and stated that representatives from the university discussed the option of public cord blood banking with her while she was pregnant. Overall, she emphasized how there were more advantages than disadvantages that came with public cord blood banking. There was no cost of donation, and the process was quick and simple. In addition, the public cord blood bank stated that they would notify the family if the cord blood is ever used for a patient. She stated that she was glad to donate her son's cord blood publicly since it would "do good for others." (L. Johnson, personal communication, November 5, 2016). Therefore, she would definitely recommend public cord blood banking because she was very satisfied with the process. When asked about the disadvantages of public cord blood banks, all she stated was that the cord blood could not be saved for family use. As a result, Mrs. Johnson's experience emphasized how publicly banking cord blood is a positive experience that families should invest in.

When asked about any experience with private cord blood banking, Mrs. Johnson mentioned how she had received price quotes from private cord blood banks and stated that it was too expensive. In relation to Mrs. Johnson's cord blood banking experience, an article in the *International Journal of Nursing Education* stated that, "[Private cord blood banking] is not

recommended... since the costs associated with it are high and the chances of a family member ever using the cord blood are slim.” Both Mrs. Johnson and the article discussed how the financial burden of privately banking cord blood is a contributing factor to families’ decision to choose public cord blood banking over private cord blood banking. Because public cord blood banking is free, there is no need for families to spend unnecessary amounts of money on collection and maintenance fees. Therefore, through a financial perspective, publicly banking cord blood proves to be the more beneficial option for families.

Furthermore, another article titled “Is Cord Blood Worth Saving for Public or Private Banking” discusses how public cord blood banking should be emphasized more to the general public since many people are unaware of the benefits of umbilical cord blood. Similarly, Mrs. Johnson discussed the importance of knowing umbilical cord blood’s benefits, the costs associated with private cord blood banks, the likelihood of individual families needing cord blood to treat conditions, and knowing about the different options for cord blood banking. Mrs. Johnson also stated that she would only recommend private cord blood banking if families can afford it and if they know that a disease that cord blood can treat is present in the family. In contrast, she recommends that every family publicly donate their child’s cord blood. Thus, as families become more educated about umbilical cord blood and the different cord blood banking options, they will recognize that public cord blood banking is the more advantageous and rewarding option.

Conclusion

Umbilical cord blood has been researched and proven to be an effective treatment for conditions such as cancers and genetic diseases. Because society has become more inclined to an individual approach to medicine, more public emphasis has been placed on private cord blood

banking rather than public and direct-donation banking. While parents are faced with many decisions about the health of their child, cord blood banking should be a decision that they are fully satisfied with. Expectant parents should be aware of all of the options and information about cord blood banking before making a decision of whether they would like to invest in cord blood banks at all. Private cord blood banks will continue to attract consumers with impressive statistics, which will cause the private cord blood market to expand. However, expectant parents should be more aware of how public or direct-donation cord blood banks can ultimately be the more effective option to invest in since they have no cost and guarantee that the cord blood will be put to good use. Donating cord blood can save the life of a child whose life is compromised by a condition that can be cured with umbilical cord blood. In the long run, banking umbilical cord blood publicly ensures that the cord blood will be given to a qualifying recipient whose life will be changed for the better.

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