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Use of a Precious Resource: Parental Decision Making About Using Autologous Umbilical Cord Blood in Studies Involving Young Children with Type 1 Diabetes

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Abstract

Objective—To assess parental decision making and experiences in an autologous umbilical cord blood infusion study in young children with type 1 diabetes (T1D).

Methods—Surveys were completed with 22 parents of children with T1D who received infusion and 22 parents who declined infusion.

Results—Parents who stored umbilical cord blood were middle-aged, highly-educated, Caucasian, married, and privately insured. Parents of children who did not receive infusion declined because they did not want to deplete their cord blood supply. Parents of children who decided to have their children participate in the infusion study were similar on approaches to storing cord blood and attitudes about research as compared to parents who declined to have their children participate in the infusion. Parents of children who received infusion were positive about their experiences and held expectations that infusion would lead to a T1D cure.

Conclusions—The manner in which cord blood is stored needs to be considered so that participation in future studies does not risk depletion of the cord blood supply. In addition, it appears that the process of storing umbilical cord blood leads to restricted demographic characteristics of eligible participants, which may impact recruitment in clinical trials. These results are relevant to designing future cord blood studies in T1D and other non-malignant diseases.

Keywords

Satisfaction; Parents; Children; Type 1 Diabetes; Umbilical Cord Blood; Clinical Trial Decision Making

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1. Introduction

Studies have evaluated physician experiences with procedures regarding cord blood banking [1] and parental knowledge and attitudes about cord blood banking [2,3], but little is known about parental experiences or satisfaction with clinical research involving the use of umbilical cord blood for their young children. Documenting participant and parental experiences in already completed or ongoing trials is important because of the increasing interest in using umbilical cord blood to modulate oncologic [4,5] and metabolic disorders [6], as well as in pediatric populations with sickle cell and hematologic disorders, immune deficiencies, and thalassemias [7].

Recently, there has been increasing interest in the use of autologous umbilical cord blood to modulate type 1 diabetes (T1D) [8–12]. We published preliminary results of the first 15 children to complete 1 year of follow-up as part of participation in a 2-year open-label, phase I observational pilot autologous umbilical cord blood study to determine whether autologous umbilical cord blood infusion preserves endogenous insulin production in very young children with T1D [9,12]. The infusion study included children over one year of age (median age = 5.25 years; range, 2.3–10.5 years) with T1D who had autologous umbilical cord blood stored in an accredited cord blood facility. No baseline insulin production criteria were used. Parents were informed of the experimental nature of the study which emphasized that infusion would not lead to a cure for their child's T1D, but might result in a slowing of ongoing beta cell destruction. Following standardized procedures, a single autologous umbilical cord blood infusion was performed through a peripheral intravenous line [12]. Children were studied before infusion and every 3 months in the first post-infusion year and every 6 months in the second post-infusion year.

The purpose of the current study was to: 1) compare characteristics amongst the parents who decided to enroll their children in the autologous umbilical cord blood infusion study (referred to as the infusion study) to those parents who declined to have their children participate; and 2) describe the experiences and satisfaction of parents whose children received an autologous cord blood infusion.

2. Materials and Methods

All participants included in this survey study had stored umbilical cord blood available and were parents of young children with T1D who either decided to have their children participate in the umbilical cord blood infusion study or parents who declined to have their children receive infusion.

2.1 Survey development

A survey (sixth-grade reading level) was developed to address the following: 1) demographic characteristics; 2) information about umbilical cord blood storage; 3) attitudes about research; 4) decision making around study participation; and 5) study experiences and satisfaction with study enrollment. Institutional review board approval was obtained to administer the survey to parents via telephone. All surveys were conducted by research assistants not associated with the infusion study and were voluntary and confidential. Subjects included in the current survey study were 22 parents of young children who received a cord blood infusion and who were at various stages of study follow-up (of 24 eligible participants 2 could not be reached) and 22 parents who declined to have their children participate in the infusion study (of 45 eligible nonparticipants, 3 declined to complete the survey because of time constraints, 20 could not be reached despite repeated email and telephone attempts; $M_{\text{type 1 diabetes duration}} = 4.16$; $SD = 2.11$).

2.2 Data analysis

Descriptive statistics (frequencies, means, and standard deviations) were calculated for all participants. Chi-square and *t*-tests were conducted to evaluate group differences.

3. Results

Table 1 demonstrates that the demographics of those who participated in the infusion study and those who did not participate were similar on all but three characteristics. Parents who decided to have their children participate in the infusion study had children who were older at the time of their T1D diagnosis than children who did not receive infusion ($t = -2.31, p = 0.03$). However, children who did not receive infusion had T1D longer than children who received infusion ($t = 2.61, p = 0.01$). Children who did not receive infusion were more likely to have both parents working outside of the home than those who received infusion ($\chi^2 = 5.31, p = 0.02$).

Information about umbilical cord blood storage, general attitudes about participating in research and decision making processes are found in Table 2. Half of all children had their cord blood stored in multiple aliquots and had cord blood remaining in storage. Parents who decided to have their children participate in the infusion study paid higher annual storage fees ($M = \$125.00 \pm 56.13$) than parents of children who did not receive infusion ($M = \$80.33 \pm 35.90; t = -2.44, p = 0.02$). Sixty-eight percent of parents who decided to have their children participate in the infusion study and who had remaining cord blood following completion of the infusion indicated they would consider being in another study that required use of their child's cord blood.

Overall, parents exhibited positive attitudes about research. Generally, parents from both groups (i.e., parents who decided to have their children participate in the infusion study and parents who decided against having their children participate in the infusion study) found the decision regarding enrollment in the infusion study to be relatively easy. The most common reason for declining to have children receive infusion was parental concern about using all of the child's umbilical cord blood during the infusion study. Nearly 60% of the parents who decided against having their children receive infusion indicated that they would have enrolled if it could have been guaranteed that some umbilical cord blood would have been preserved for future use. The most common reason for parents' decisions to enroll in the infusion study was hope that beta cell destruction would be delayed.

Parents who decided to have their children participate in the infusion study traveled an average of 7.13 hours ($SD = 5.28$) from 10 states, the District of Columbia, Mexico, and Canada to participate in the infusion study, which was conducted at the University of Florida in Gainesville. The majority (60%) traveled with other family members in addition to the parent and child with T1D. All parents indicated that it was a good decision to participate in the infusion study and that their overall satisfaction with the study was positive. Ninety-six percent of parents indicated that they would recommend the infusion study to other families. On a scale from 0 (disliked it a lot) to 4 (liked it a lot), parents enjoyed being in the study more ($M = 1.91 \pm 0.68$) than they thought their children did ($M = 1.64 \pm 0.95; t(21) = -2.32, p = 0.03$).

When queried with an open-ended question about positive or negative aspects of the study, 12 parents commented about how the professionalism of the study team and their friendliness, responsiveness to questions, and investment in diabetes contributed to their positive feelings about the study. No negative aspects of the study were noted. Additional questions about participants' satisfaction with the cord blood study are found in Table 3.

4. Discussion

With only a few exceptions, parents who decided to have their children participate in the infusion study exhibited similar demographic and cord blood storage characteristics as parents who declined to have their children receive infusion. Children who did not receive infusion were diagnosed with T1D for 1.5 more years than those who received infusion. It is plausible that these parents thought that the longer duration of their child's diabetes combined with the experimental nature of the study would not result in outcomes worthy of using the stored cord blood. Our sample was also comprised of families who had higher socioeconomic backgrounds who likely had more disposable income. However, children who did not receive infusion were more likely to have both parents working outside of the home, which may have impacted their flexibility about taking time off from work and willingness to travel long distances to participate in the infusion study.

Almost all of the parents who decided to have their children participate in the infusion study had an available supply of their child's umbilical cord blood which was stored in a private cord blood bank. There was one exception – a family donated their child's umbilical cord blood to a public bank and was able to retrieve it for use in the infusion study. Given the current costs associated with privately banking cord blood, it may be that the demographic characteristics of samples comprising umbilical cord studies will be restricted to those with the financial means to store their child's cord blood. Alternative paradigms such as a combined public-private cord blood storage partnership could not only provide affordable storage options to all parents, but could also result in increased participation in future umbilical cord blood based studies as the science of autologous cord blood therapies advances.

Overall, attitudes about research were positive. Many of the parents from both groups (children who received infusion and those that did not) who completed our survey indicated that they had participated in prior research studies. Although a small proportion learned of the infusion study from their child's physician, the majority of parents learned about the study by conducting an internet search of ongoing research studies. This suggests that parents who stored their children's cord blood were highly motivated, but that there may also be untapped potential participants who are not aware of such studies or who do not have available resources to find studies.

Upon entry into the infusion study, parents who decided to have their children participate were explicitly informed, and great care was taken to ensure their understanding that infusion would not lead to a cure of T1D. Yet, almost 50% of the parents who decided to have their children receive infusion indicated that one of the reasons they enrolled was based on hope that their child would be cured. This highlights that despite our best efforts to minimize expectations, parents were optimistic for a cure. Although this may be a common parental reaction, investigators need to be aware that many parents will hope for a cure even when curing the disease is not the focus of the study [13,14].

There were a few important consequences of parents' decisions to have, or not have children undergo infusion. All parents were faced with having to potentially exhaust their supply of cord blood and this dilemma remained the primary reason cited for those who declined to have their children receive infusion. The most common private cord blood storage techniques currently involve storage of 80% or more of the total nucleated cells initially collected in one vial with the remaining 20% being stored in two smaller aliquots typically reserved for testing of sterility, viability, and human leukocyte antigen confirmation. Because current Food and Drug Administration approved protocols do not allow thawing and refreezing a portion of cells, families participating in our trial were often faced with the

dilemma of using 80% or more of their child's cord blood. Notably, however, 50% of the parents who enrolled in the infusion study had cord blood remaining upon completion of the study and chose to continue storing it despite the fact that it was often too few cells to be used for current standard of care therapies. The experimental nature of the study was another reason cited for declining infusion. Although parents who declined to have their children participate in the infusion study were positive and optimistic about the general benefits of research and its potential to cure T1D, they were also generally satisfied with their decision to decline infusion. Those who consented to have their children undergo infusion were also satisfied with their decision – even if they exhausted their supply of umbilical cord blood. In addition, the majority of parents who did not deplete their child's cord blood supply indicated that they would consider being in another study that required its use.

Nevertheless, the manner in which umbilical cord blood is currently stored has implications for the design of future studies. Many of the parents who declined to have their children undergo infusion stated they would have participated in the infusion if multiple aliquots had been available. Once cell expansion techniques are perfected, storage of multiple aliquots could allow parents to participate in a research study while preserving some of the supply for future use. In fact, parents who declined to have their children undergo infusion also indicated that they were worried about using their entire supply of cord blood on an experimental study that might not lead to a cure, which would eliminate them from being able to participate in a future study that could lead to a cure. Companies and public storage facilities may need to consider storing multiple aliquots so that parents have more options regarding allocation of their children's cord blood. In the combined public-private cord blood storage partnership previously mentioned, donors might be required to participate in a national or international registry and release units for allogeneic use in patients in whom the unit could provide a standard of care therapy. At the same time, donors would be given the option of retrieving their own unit should relevant autologous cord blood based therapies be developed.

Limitations of the current study are noteworthy. Rates of participation in the current study were lower for those who declined infusion as compared to those who received infusion, which limits the generalizability of the sample. In addition, children were in generally good metabolic control and they engaged in frequent blood glucose monitoring, which suggests a self-selection bias and also limits the generalizability of participants who seek participation in cord blood studies. Although participation in the infusion study required lengthy travel, multiple study visits, and missed work days, more than 95% of parents who decided to have their children participate indicated that they liked being in the study and that their decision to participate was a good one. As evidenced by the high satisfaction ratings in this survey study, parents of young children with T1D are eager to explore safe and potentially effective therapies to interdict the autoimmune process. That said, lack of clear efficacy data, cost of private cord blood storage, and limited cell number for both current and future studies, result in difficult decision making processes for parents of children with T1D. While our efforts are not yet able to provide clear direction for these families, these data establish a baseline for parental concerns and experiences for participation in cell based therapies in children with T1D.

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Table 1

Demographic Characteristics.

Variable	Children Did Not Receive Infusion N(%) or M(SD); range	Children Received Infusion N(%) or M(SD); range
<u>Survey Respondent Demographics</u>		
Survey Respondent Age (years)	42.17 (4.42); range = 5–13	44.11 (6.48); range = 5–12
Survey Respondent Sex		
<i>Female</i>	19 (86.4%)	17 (77.3%)
<i>Male</i>	3 (13.6%)	5 (22.7%)
Survey Respondent Race		
<i>Caucasian</i>	21 (95.5%)	18 (81.8%)
<i>Non-Caucasian</i>	1 (4.5%)	4 (18.2%)
Respondent Education*		
$\leq$ High school	1 (4.8%)	0 (0.0%)
$\geq$ Some college	20 (95.2%)	22 (100%)
Marital Status		
<i>Not Married</i>	0 (0.0%)	3 (13.6%)
<i>Married</i>	22 (100%)	19 (86.4%)
Works Outside of Home*		
<i>Both Parents Work</i>	15 (71.4%)	8 (36.4%)
<i>One Parent Works</i>	6 (28.6%)	14 (63.6%)
Number of People in Home	4.27 (1.20)	3.95 (1.00)
Number of Siblings	1.76 (1.20)	1.50 (0.82)
<i>Only Child</i>	5 (22.7%)	6 (27.3%)
<i>1 Sibling</i>	10 (45.5%)	10 (45.4%)
≥ 2 Siblings	7 (31.8%)	6 (27.3%)
<u>Child Demographics</u>		
Age (years)	8.32 (1.76)	8.50 (2.46)
Child's Sex		
<i>Female</i>	10 (45.5%)	14 (63.6%)
<i>Male</i>	12 (54.5%)	8 (36.4%)
Race		
<i>Caucasian</i>	21 (95.5%)	18 (81.8%)
<i>Non-Caucasian</i>	1 (4.5%)	4 (18.2%)
First Degree Relative with Diabetes	9 (40.9%)	5 (22.7%)
<u>Health Insurance Status</u>		
<i>Public</i>	1 (4.5%)	1 (4.5%)
<i>Private</i>	20 (91.0%)	21 (95.5%)
<i>Public and Private</i>	1 (4.5%)	0 (0.0%)
<u>Disease-Related</u>		
Age at Diagnosis (years)	3.54 (2.28)	5.17 (2.40)
Disease duration	4.22 (1.95); range = 1.28–8.09	2.85 (1.51); range = 0.81–6.28

Variable	Children Did Not Receive Infusion N(%) or M(SD); range	Children Received Infusion N(%) or M(SD); range
Number of blood glucose tests per day	8.36 (2.61)	7.57 (1.46)
A1C	7.41 (0.77)	7.28 (0.59)
Uses insulin pump	14 (63.6%)	12 (54.5%)
Other illnesses	6 (27.3%)	5 (22.7%)
Type of physician		
<i>Endocrinologist</i>	22 (100%)	21 (95.5%)
<i>Pediatrician</i>	0 (0.0%)	1 (4.5%)

Note.

* 1 parent declined to provide this information.

Table 2

Umbilical Cord Blood Storage Characteristics, Parents' Attitudes Toward Research and Decision Making Processes About the Umbilical Cord Study.

Variable	Children Did Not Receive Infusion N(%) or M(SD)	Children Received Infusion N(%) or M(SD)
<u>Umbilical Cord Blood Storage</u>		
How Parents Learned About Storing Cord Blood ⁺		
<i>Health Professionals</i>	11 (50.0%)	15 (68.2%)
<i>Internet</i>	3 (13.6%)	1 (4.5%)
<i>Other media</i>	2 (9.1%)	4 (18.2%)
<i>Family Member</i>	2 (9.1%)	3 (13.6%)
<i>Friend/Colleagues</i>	5 (22.7%)	1 (4.5%)
With Whom Parents Discussed Decision to Store Cord Blood ⁺		
<i>Health Professionals</i>	13 (59.1%)	7 (31.8%)
<i>Spouse</i>	20 (90.9%)	17 (77.3%)
<i>Other Family Members</i>	3 (13.7%)	2 (9.1%)
<i>Friends/Colleagues</i>	1 (4.5%)	1 (4.5%)
<i>Cord Blood Company</i>	2 (9.1%)	3 (13.7%)
Who Paid for Cord Blood Storage ⁺⁺		
<i>Parents</i>	22 (100.0%)	19 (90.5%)
<i>Grandparents</i>	0 (0.0%)	2 (9.5%)
Families Storing Other Children's Cord Blood	6 (27.3%)	9 (40.9%)
Initial Cost for Storing Cord Blood	1240.00 (870.94)	1122.08 (395.48)
Annual Cost of Storing Cord Blood	80.33 (35.90)	125.00 (56.13)
Most Common Cord Blood Storage Companies Used		
<i>Cord Blood Registry</i>	7 (31.8%)	5 (22.7%)
<i>Viacord</i>	4 (18.2%)	2 (9.1%)
<i>CryoCell International</i>	4 (18.2%)	3 (13.6%)
<i>Other Cord Blood Storage Company</i>	7 (31.8%)	12 (54.6%)
<u>General Attitudes About Research</u>		
Previously Participated in Research Studies	7 (31.8%)	6 (27.3%)
Research in T1D Will Help Their Child		
<i>Yes</i>	21 (95.5%)	22 (100%)
<i>No</i>	0 (0.0%)	0 (0.0%)
<i>Not Sure</i>	1 (4.5%)	0 (0.0%)
Research in T1D Will Lead to a Cure		
<i>Yes</i>	19 (86.4%)	19 (86.4%)
<i>No</i>	0 (0.0%)	1 (4.5%)
<i>Maybe</i>	3 (13.6%)	2 (9.1%)
<u>Decision Making Processes About Umbilical Cord Study</u>		
Source of Information About Umbilical Cord Study		

Variable	Children Did Not Receive Infusion N(%) or M(SD)	Children Received Infusion N(%) or M(SD)
<i>Internet</i>	13 (59.1%)	13 (59.1%)
<i>Health care professional</i>	6 (27.3%)	6 (27.3%)
<i>Media</i>	1 (4.5%)	2 (9.1%)
<i>Cord Blood Company</i>	2 (9.1%)	0 (0%)
<i>Friend</i>	0 (0.0%)	1 (4.5%)
Ease of Difficulty in Making the Decision to Not Participate <i>or</i> to Participate	1.86 (0.99)	1.55 (1.22)
<i>Scale: 0=very easy to 4=very hard</i>		
Reasons for Deciding NOT to Participate in the Umbilical Cord Study ⁺		
<i>Had to use entire supply of cord blood</i>	21 (95.5%)	---
<i>Experimental nature of study</i>	19 (86.4%)	---
<i>Too much travel</i>	4 (18.2%)	---
<i>Time commitment too great</i>	2 (9.1%)	---
Reasons for Deciding TO Participate in the Umbilical Cord Study ⁺		
<i>Hoped to slow beta cell destruction or prolong honeymoon period</i>	---	15 (68.2%)
<i>Wanted to help field of diabetes/science</i>	---	14 (63.6%)
<i>Hoped it would improve their child's health</i>	---	11 (50.0%)
<i>Hoped it would cure child's diabetes</i>	---	10 (45.5%)
<i>Wanted to help other children</i>	---	1 (4.5%)

⁺ More than one answer possible

⁺⁺ One family stored cord blood in a public bank.

Table 3**Parents' Experiences with the Autologous Umbilical Cord Blood Infusion Study**

Variable	N(%)
How difficult was it for you (the respondent) to travel to Gainesville?	
<i>Not difficult at all</i>	14 (63.6%)
<i>A little difficult</i>	8 (36.4%)
<i>Very difficult</i>	0 (0.0%)
How difficult was it for other family members to travel to Gainesville?	
<i>Not difficult at all</i>	11 (78.6%)
<i>A little difficult</i>	3 (21.4%)
<i>Very difficult</i>	0 (0.0%)
If other children were left at home, how difficult was it to arrange child care?	
<i>Not difficult at all</i>	1 (33.3%)
<i>A little difficult</i>	2 (66.7%)
<i>Very difficult</i>	0 (0.0%)
How difficult was it for you (the respondent) to arrange to miss work?	
<i>Not difficult at all</i>	13 (86.7%)
<i>A little difficult</i>	1 (6.7%)
<i>Very difficult</i>	1 (6.7%)
Did insertion of the IV (for the umbilical cord blood infusion) hurt the child?	
<i>Did not hurt at all</i>	7 (31.8%)
<i>Hurt a little</i>	6 (27.3%)
<i>Hurt a lot</i>	9 (40.9%)
How difficult was it for your child to receive the IV?	
<i>Not difficult at all</i>	8 (36.4%)
<i>A little difficult</i>	9 (40.9%)
<i>Very difficult</i>	5 (22.7%)
How difficult was it for you (the respondent) to have the child receive the IV?	
<i>Not difficult at all</i>	10 (45.5%)
<i>A little difficult</i>	10 (45.5%)
<i>Very difficult</i>	2 (9.0%)
How did your child feel about receiving the IV?	
<i>Liked it/Like it a little/Neutral</i>	14 (63.6%)
<i>Disliked it a little/Disliked it a lot</i>	8 (36.4%)
How did you (the respondent) feel about your child receiving the IV?	
<i>Liked it/Like it a little/Neutral</i>	19 (86.4%)
<i>Disliked it a little/Disliked it a lot</i>	3 (13.6%)