

Replacement Blood Donation Denials in Children: A Cross-sectional Study

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ABSTRACT

Introduction: Developing countries like India still depend on Replacement Donors (RD) for their blood requirements. Healthcare providers in India often face Replacement Blood Donation (RBD) denials in children especially in rural areas.

Aim: To find reasons for RBD denials in children.

Materials and Methods: A cross-sectional study was done over six months at a tertiary care centre located in rural part of Northern India. Children requiring Blood Transfusion (BT) whose parents refused RBD were included in the study. Children were divided into three groups based on their age and data on various parameters were collected. Observation parameters included sex, birth order, number of siblings, disease for which children were admitted, duration between admission and need for transfusion, indication for transfusion, decision maker in the family, resistance to decision of denial by any other member of family, parental education, socio-economic status and reasons for denial. Data were analysed using Statistical Package for the Social Sciences (SPSS) software, version 17.0, SPSS Inc, Chicago, Ill, USA). The p-values were

computed for categorical variables using Chi-square (χ^2) test. A p-value of less than 0.05 was considered statistically significant.

Results: Out of 356 children requiring BT, parents and relatives of 130 children (36.51%) refused RBD. Of these 130 children, 84 were females and 46 were males with male-female ratio of 1:1.8. Females were more likely to be denied RBD (p-value=0.001). Of these 130 children, only 77 could be included in the study because of various reasons. Age of the study group ranged between 2 days to 15 years. Denials were significantly higher (p-value=0.0032) in children with 3rd or higher birth order. Little benefit in terms of life expectancy was the most common reason for denials in neonates and was found statistically significant (p-value=0.00368). Fear of donation was the most common reason for denial in all the groups combined (38.9%). Considering themselves ineligible and religious beliefs were the other reasons for denials.

Conclusion: RBD denial in children is common in India. Misconceptions, Illiteracy, poverty, sex discrimination and false beliefs are major contributory factors for denial.

Keywords: Misconceptions, Rural, Sex discrimination, Transfusion-transmissible diseases, Voluntary blood donors

INTRODUCTION

Blood is recognised as the most precious element that sustains life and saves innumerable lives across the world [1]. In developed nations having well-structured health system, demands for blood are met by voluntary blood donations. Studies have reported lower prevalence of transfusion-transmissible diseases among voluntary donors than among other types of donors [2]. There is also a marked difference in the level of access to safe blood between high and low income countries [3] as well as between urban and rural areas [4].

It is surprising that India with a population of over one billion and an annual requirement of approximately 13 million units of blood was able to collect only 11 million units in 2016 to 2017, a shortfall equivalent to 60 tankers, of which only 60% was from voluntary blood donors [5]. World Health Organisation (WHO) advocates that 3%-5% of the population should donate blood every year in order to maintain country's stock of blood and blood products. Thus, there is severe mismatch between demand and availability in our country. In spite of Government's efforts in educating the masses and creating awareness regarding blood donations, the problems of illiteracy, poverty, sex discrimination and age-old customs and traditions in rural areas often act as pillars of resistance for such awareness [6]. Recent studies from Africa where RD form a major source of blood supply have found that RD can be considered as a good alternative to altruistic blood donors in low income countries [7,8]. Various studies done across India have shown that many blood banks are still dependent on RD to maintain adequate supply of blood and blood products [9-12].

While transfusion should never be superfluous, and should be administered for very serious medical purposes, healthcare providers

often face RBD denial and occasional BT denial. The denials are commonly seen because of fear and misconceptions. In some situations, parents refuse RBD for their children when they foresee little benefits in term of life expectancy or quality of life. Some parents refuse RBD and BT for their children on religious grounds and several Christian sects including the famous Jehovah's witnesses defy haematology in their refusal of blood [13].

The present study attempts to find clinical correlates and reasons for RBD denials in children at a rural tertiary care centre of northern India.

MATERIALS AND METHODS

This cross-sectional was conducted over six months from October 2019 to March 2020 at a rural tertiary care centre located in Uttar Pradesh. This centre caters primarily to the rural population. Institute's ethical clearance was obtained (IEC no 112/2020-21). Written informed consent was taken from the parents or relatives according to declaration of Helsinki to include them into the study.

Inclusion and Exclusion criteria: Children requiring BT for the first time during the current admission in paediatric and paediatric surgery wards, whose parents or relatives refused RBD despite two sessions of counselling were included in the study. Children with improper/incomplete history, unclear or no reasons given for RBD denial by parents/relatives and children whose parents/relatives did not give consent for the study were excluded.

Data Collection

The counselling for RBD was done by the resident doctors. Children were divided into three groups based on age:

- Group I for neonates (Birth to 1 month),
- Group II for infants (1 month to 1 year)
- Group III comprised of patients of postinfancy age group (>1 year).

Observation parameters included sex, birth order, number of siblings, disease for which admitted, duration between admission and need for transfusion, indication for transfusion, decision maker in the family, resistance to decision of denial by any other member of family, parental education, socio-economic status as per Modified Kuppuswamy scale [14] and reason for denial. Parents or guardians of all children considered eligible for inclusion in this study were interviewed by lead author personally for eliciting reasons behind denial. Data were recorded in paper forms and later transferred to excel charts. The four primary reasons for denial were considering themselves ineligible, fear of donation, little benefit in terms of life expectancy and religious grounds. No child was made to suffer in absence of RBD and was transfused blood when indicated.

STATISTICAL ANALYSIS

Data were summarised in form of proportions and frequent tables for categorical variables. Continuous variables were summarised using means, median, mode and standard deviation. Data were analysed using Statistical Package for the Social Sciences (SPSS) software, version 17.0, SPSS Inc, Chicago, Ill, USA). The p-value were computed for categorical variables using Chi-square (χ^2) test. A p-value of less than 0.05 was considered statistically significant.

RESULTS

Total of 356 children admitted in Paediatric and Paediatric Surgery wards required BT during the study period. Of 356 children, 189 were females (53.08%) and 167 were males (46.92%). Of these 356 children, parents and relatives of 130 children (36.51%) refused RBD. Out of these 130 children, 84 were females (64.62%) and 46 were males (35.38%) with male-female ratio of 1:1.8 [Table/Fig-1]. A chi-square test of independence was performed to examine the relation between gender and denial for RBD. The relation between these variables was significant (p-value=0.001). Female children were more likely to be denied RBD.

Sex	Denied	Donated	Total	p-value
Males	46 (35.38%)	121 (53.53%)	167	0.001*
Females	84 (64.62%)	105 (46.47%)	189	
Total	130	226	356	

[Table/Fig-1]: Replacement Blood Donation (RBD) denial in relation to sex of the children.

*Chi-square test, p-value <0.05 is significant

Out of 130 children whose parents or relatives denied RBD, 77 children were included in the study as the data for remaining patients (n=53) could not be collected because of improper history, unclear or no reasons given for denial, negative consent for inclusion in the study and parents taking the child for leave against medical advice. Of 77 children, 49 were females and 28 were males with male-female ratio of 1:1.7. The age of the children included in the study ranged from two days to 15 years. Thirty-five out of 77 (45.45%) children had more than 2 siblings and the denials were statistically significantly higher (p-value=0.0032) in children who were 3rd or more in birth order.

Group I (Neonatal)

Out of 77 children included in the study, 12 were neonates (15.58%) and formed Group I. Out of 12 neonates, four were male and eight were female with male-female ratio of 1:2 [Table/Fig-2]. The age ranged from two days to 22 days with mean of 5.16 days [Table/Fig-3]. The birth order of neonates ranged from 1st to 4th. Duration between need for BT and admission ranged from 1 day to 4 days. The neonates included in the study had congenital anomalies like

tracheoesophageal fistula, anorectal malformation, gastroschisis, bowel atresia, necrotising enterocolitis that required surgery and medical conditions like early onset neonatal sepsis. Indications for transfusion/RBD in this group included sepsis in seven cases and preoperative in five cases. In this group, the decision maker for refusing the replacement donation was either father, paternal grandmother, paternal grandfather or paternal uncle. Resistance to this decision by other family members were noted in five neonates, of which four were females. Resistance to the decision was unanimously shown by the mothers. The maximum education level in the fathers of the neonates in this group was upto 8th standard and fathers of eight out of 12 neonates were illiterate (66.66%). All children in this group belonged to low socio-economic group as per Modified Kuppuswamy Scale [14] (Score IV and V). The most common reason for denial in this group was little benefit in terms of life expectancy in 6 out of 12 (50%) [Table/Fig-4] and was statistically significant (p-value=0.00368) [Table/Fig-5] when compared with the infancy and postinfancy group.

Sex	Group I	Group II	Group III	Total
Males	4 (33.3%)	11 (40.74%)	13 (34.21%)	28 (36.36%)
Females	8 (66.7%)	16 (59.26%)	25 (65.79%)	49 (63.64%)
Total	12	27	38	77

[Table/Fig-2]: Sex distribution of the cohort.

Variables	Groups	N	Mean±SD	Median (max, min)
Age	Group I	12	5.1667±3.642 (days)	2.5 (22,2) (days)
	Group II	27	6.1481±1.045 (months)	6 (11,1) (months)
	Group III	38	6.6316±1.023 (years)	6.5 (15,1) (years)

[Table/Fig-3]: Age distribution of the cohort.

Groups	Considered themselves ineligible	Fear of donation	Little benefit in terms of life expectancy and quality of life	Religious belief	Total
Group I	2 (16.66%)	3 (25%)	6 (50%)	1 (8.34%)	12
Group II	10 (37.04%)	13 (48.14%)	3 (11.11%)	1 (3.71%)	27
Group III	16 (42.1%)	14 (36.84%)	6 (15.79%)	2 (5.27%)	38
Total	28 (36.36%)	30 (38.96%)	15 (19.48%)	4 (5.2%)	77

[Table/Fig-4]: Reasons for blood donation denial.

Groups	Little benefit in terms of life expectancy and quality of life	Other reasons	Total	p-value
Group I	6 (50%)	6 (50%)	12	0.00368*
Group II and III	9 (13.84%)	56 (86.16%)	65	
Total	15	62	77	

[Table/Fig-5]: Comparison between reasons for denial in neonatal (Group I) and postneonatal groups (Group II and III).
p-value <0.05 considered significant

Group II (Infancy)

A total of 27 infants (27/77; 35%) comprised group II. Out of 27 infants, 11 were male and 16 were female with male-female ratio of 1:1.45. The age ranged from 1 month to 11 months in this group with mean of 6.14 months. The birth order of infants ranged from 1st to 5th. Duration between admission and need for BT ranged from two days to seven days. The infants requiring BT in this group had varied causes ranging from nutritional anaemias, infections to surgical causes. Indications for transfusion/RBD in this group included symptomatic anaemia in 12 cases, sepsis in 10 cases and preoperative in five cases. In this group also, the decision maker for refusing the replacement donation were family members from paternal side. Resistance to the decision by other family members were noted in 11 infants, of which seven were females. In this group also, resistance to the decision was unanimously shown by the mothers. The maximum education level in the fathers of the neonates in this group was up to 9th standard

and fathers of 14 out of 27 infants were illiterate (51.8%). All children in this group also belonged to low socio-economic group as per Modified Kuppuswamy Scale [14] (Score IV and V). Fear of donation was the most common reason for denial in this group noted in 13 out of 27 children (48.14%).

Group III (Postinfancy)

Out of 38 children in this group (38/77=49.35%), 13 were male and 25 were female with male-female ratio of 1:1.9. The age ranged from one year to 15 years with mean of 6.63 years. The birth order of children ranged from 1st to 4th. Duration between admission and need for BT ranged from two days to nine days. The children requiring BT in this group had varied conditions ranging from severe acute malnutrition, anaemia not responding to haematinics, infections like dengue, malaria etc. to surgical causes like acute abdomen, intestinal obstruction and blunt injury abdomen. Indications for transfusion/RBD in this group included symptomatic anaemia in 20 cases, sepsis in 11 cases and preoperative in seven cases. In this group also, the decision maker for refusing the replacement donation were from paternal side. Resistance to the decision by other family members was noted in 16 children, of which 10 were females. In this group resistance to the decision was shown by mothers in 14 cases and by father in two cases. In cases where father showed resistance, other senior member of the family was the decision maker. All children in this group also belonged to low socio-economic group as per Modified Kuppuswamy Scale [14] (Score IV and V). Considering themselves ineligible was the most common reason for denial in this group noted in 16 out of 38 children (42.1%). In all the three groups, low education status and low socio-economic status were found to be associated with poor knowledge and false beliefs regarding blood donation.

DISCUSSION

Total of 356 children admitted in paediatric and paediatric surgery wards required BT for various reasons of which, relatives of 130 children denied RBD; denial rate 36.51%. A review of literature regarding RBD denial failed to retrieve any data for comparison. The denial was statistically significantly higher for female child (p -value=0.001). Further, the authors here have come across scenarios where a female child has been denied a chance of survival by parents especially in cases of congenital anomalies by refusing treatment/surgery and leaving with the child against medical advice, thus letting them perish at home or during transport. Authors have also noted two families within the time frame of study wherein the relatives donated blood for the son who was admitted later to a female sibling who on prior admission was denied RBD, highlighting differential behaviour of same parents when son is admitted vis-à-vis daughter is admitted. It was also observed that when the birth order was more than three, the first three pregnancies resulted in birth of a girl-child; such parents were highly enthusiastic towards treatment of the youngest child who was a boy; when the elder sister was admitted RBD denial was observed. All these observation in the present study can be explained by the fact that sex discrimination is a common problem in this part of India [15,16].

It was also seen that about 45.45% children had more than two siblings and the denial was statistically significantly higher (p -value=0.0032) in children who were 3rd or more in birth order. All the children included in study belonged to low socio-economic status having illiterate mothers and low level of literacy in fathers thus explaining that illiteracy leads to a vicious cycle of poverty, no family planning, false beliefs and misconceptions. In a study published from India, it was found that education level of at least 10th standard was significantly and positively associated with knowledge of blood donation [17,18]. It was observed that most of the decisions were being taken by the male members of the family, mostly without taking the baby's mother into confidence or with no importance to her opinion. Contrarily, when the first point of contact

was a female (mother/grandmother, etc.), she would, without fail, request time so that the male members were informed and ultimate decision would be from the male member. In one family, the female was more educated than her husband; yet not allowed to take a decision. Resistance to the decision of not donating blood for the child was noted in 32 of 77 children (41.55%) and was mostly shown by mothers. This corroborates that less consideration is given to opinion of the females in Indian families especially of low socio-economic class irrespective of her level of education compared to her husband.

Fear of donation due to various beliefs was the most common reason for denial in the study population, 30 out of 77 (38.96%). It was also the most common reason in infancy group, 13 out of 27 (48.14%). This is comparable to studies reported from other parts of India [6,19]. Another noteworthy finding was that in the neonatal group (Group I) about 50% denials were because the relatives believed that there were little benefits in terms of life expectancy and quality of life which was statistically significant (p -value=0.00368). Possible explanation for this can be attributed to the presence of congenital anomalies like oesophageal atresia, gastroschisis, anorectal malformation, small bowel atresia and complex cardiac anomalies in 8 out of 12 neonates in Group I in which parents and relatives believed that RBD would not be able to save the life of the neonate or improve their quality of life. Few relatives viewed blood donation process as frightening as there was lack of knowledge about what the process entailed thus making blood donation a daunting procedure. Some had concerns about the negative effects of blood donation on their own health while others felt discouraged to donate blood by their family members or believed their blood would fall inadequate for donation. A lack of general awareness regarding high demand of blood and need for human donors was noted. RBD denial on the ground of religion is not uncommon in India as the spiritual essence of blood has been depicted in many academic texts [20] and was observed in 4 out of 77 (5.19%) cases in the present study. Few sects in Christianity [13] and Jainism [21] in whom the principle of life is nonviolence believe in this concept.

In India, National blood policy is focusing on phasing out RD to achieve 100% voluntary donations. Various Indian studies show that many blood banks are still dependent on RD to maintain adequate stock of blood [9-12] indicating that implementation of national blood policy is not uniform and highly decentralised. Most vital step is increasing public awareness of blood donation. Busting myths that keep people away from voluntary blood donation is the need of the hour. Half of India's population is below 25 years of age and quarter is less than 14 years of age. Targeting this age group is essential for successful implementation of national blood policy. Educating and sensitising the youth will have a crucial role in building pool of voluntary blood donation for future thus reducing the dependence on RDs. Another idea worth considering is incorporating sensitising programmes in schools and colleges on various aspects of blood donation to dispel misconceptions and fear and at the same time induce sense of pride among students for saving lives through blood donations.

Limitation(s)

There were certain limitations of the study which included a small sample size, cross-sectional study design and short duration of study. In addition, as stated that in neonatal age group the most common reason for denial was little benefit in terms of life expectancy and it can be attributed to the patient selection as most of these patients had life threatening congenital anomalies thus making little benefit in terms of life expectancy the commonest reason in this group. The results of the study do not represent the knowledge, attitude and practice towards blood donation in rural areas of other parts of the country where literacy is high.

CONCLUSION(S)

In India, Replacement Blood Donation (RBD) still form a major source of blood supply. Misconceptions, false beliefs and fear of donations are the major reasons for denial. Illiteracy, poverty, sex discrimination are the major hindering factors in creating awareness regarding blood donation in rural India. Creating public awareness, educating youth and busting related myths for blood donation are pivotal.

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