

# Safety and Feasibility of Home Transfusions in Pediatric Palliative Care: A Preliminary Report

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## Abstract

**Background.** While hematological symptoms are considered difficult to manage in a Pediatric Palliative Care setting, home may still represent a safe and convenient place for transfusions in patients with advanced malignancy or chronic conditions. This research focuses on the safety and feasibility of a home transfusion program.

**Methods.** This is a case series of patients between 0 and 18 years diagnosed with advanced malignancy or incurable chronic conditions and eligible to Pediatric Palliative Care who received home platelet or packed red cell transfusions. For all patients, we recorded adverse events such as acute hemolytic reactions, allergic reactions, or any emergency condition requiring hospital admission, equipment failure, blood product transport or storage errors, errors in patient identification, and personnel safety issues. We explored parental satisfaction with a Likert-type questionnaire and short open questions.

**Results.** We reviewed 101 transfusion procedures for six patients in Pediatric Palliative Care performed by the Regional Pediatric Palliative Care network between 2014 and 2020. We did not report any adverse effects. Families reported satisfaction and a sense of safety and positively evaluated the opportunity of having transfusion at home to minimize the disruption in everyday life. The cost analysis resulted in a consistent saving for the Regional Health System.

**Conclusion.** This study supports the safety and feasibility of home transfusion in Pediatric Palliative Care.

## Key Words

*Pediatric palliative care, home transfusion support, symptom management, fatigue, thrombocytopenia*

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**Key Messages:** This retrospective study provides preliminary data on the safety and feasibility of a home transfusion program in Pediatric Palliative Care for children with incurable malignancies or advanced chronic diseases.

## Introduction

Managing hematological symptoms in a palliative care setting may be challenging due to the necessity of balancing the benefits of transfusions, the potential risks, and a fair allocation of resources.<sup>1</sup>

Anemia may cause fatigue, lethargy, and drowsiness so that the decision to perform a packed red cell

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(PRC) transfusion is not strictly dependent on the hemoglobin level but on the extent of distress caused to the patient.<sup>2,3</sup> Previous literature findings showed that transfusions provide a short-term benefit on subjective findings.<sup>4</sup> Packed platelet (PP) transfusions may be appropriate to prevent and control spontaneous bleeding, that is, in clinical scenarios that often require hospitalization.<sup>3</sup>

Furthermore, transfusions account for a high proportion of hospital admissions in palliative care<sup>5</sup> and may represent a relevant source of distress for patients and caregivers.<sup>6</sup>

Choosing the home setting represents an effective strategy in managing patients in palliative care<sup>7</sup>: it is particularly relevant for children because it reduces time and distress of hospital admissions, helps patients and families cope with the disease, and limits the disruptions in daily life.<sup>8</sup>

On the one hand, there is considerable evidence of the safety and effectiveness of home transfusion from adult palliative care research. On the other hand, literature offers scarce evidence on the safety and feasibility of these programs in Pediatric Palliative Care (PPC). In Europe, there is some experience with transfusion support provided at home in PPC. In Germany, a survey on the PPC service provided by 50 Pediatric Cancer Departments showed that six departments offered home transfusions, with 26% of children receiving transfusions at home and 74% returning to the hospital for them.<sup>9</sup> In the UK, a Regional Pediatric Oncology Unit adopted a home platelet transfusion policy for 12 patients in terminal care who received 35 transfusions between 1996 and 2000.<sup>10</sup> In Italy, Manfredini *et al.* developed a home assistance program including transfusion support for children with hematologic malignancies and after stem cell transplantation.<sup>11,12</sup> Another experience in Rome involved both adults and children with advanced hematological malignancies.<sup>13</sup>

In the Friuli Venezia Giulia Region, the Regional Palliative Care network developed a protocol for home transfusion of blood products in a pediatric palliative care setting approved by the Regional Medical Board.

The Regional Palliative Care network includes a dedicated pediatrician and a pediatric nurse, both with experience in PPC, in each province of the region. They refer to a Regional Center directed by a senior pediatrician with post-graduation qualification in PPC. The network includes the local medical (family pediatrician) and nursing (integrated domiciliary care) services in each province. All the staff is employed by the Italian National Health System, which covers all the costs.

The program includes criteria for patient selection and indications for blood sampling, blood unit collection, transportation, delivery and disposal, and patient monitoring during and after the procedure. Clinical

inclusion criteria are the presence of anemia or thrombocytopenia, which may benefit from planned transfusion, a stable venous catheter, clinical stability, cooperating caregivers, antecedents of safe transfusions (i.e., without adverse reactions to transfusions performed in hospital), and a suitable home environment.

Each home visit includes a physical examination, blood transfusion, post-procedure monitoring, and other procedures (central venous catheter – CVC - care, blood sample drawing...). After evaluating the transfusion necessity, co-joined with the Referral Centre pediatrician, the PPC pediatrician acquires written informed consent from parents and requests the blood product from the Blood Bank. The Blood Bank prepares and delivers blood products according to Italian and European guidelines for preparation, storage, transport, and delivery.<sup>14,15</sup> The PPC nurse collects the patient's immune-hematological assays not earlier than 72 hours from the transfusion procedure. Once ready, the blood products are collected at the Bank by the PPC team and transported from the Bank to home in dedicated storage boxes to keep a controlled temperature (+4/-2°C for PBC units, room temperature for PP) with sterile packages. The transfusion must be completed within two hours from the product delivery from the Blood Bank. The pediatrician and the nurse stay at the patient's home throughout the procedure and 30 minutes after completing the transfusion. After their leaving, they constantly remain available so that families can contact them by phone at any moment to report on any patient's complaint. Staff members are certified Pediatric Advanced Life Support executors and carry all the equipment and drugs to manage any potential adverse reaction.

In this study, we analyze the safety and the impact of home transfusions on the quality of life of children and families and the financial impact on the Regional Health System.

## Methods

This is a retrospective preliminary study carried out by the Regional Reference Centre for PPC and Pain Therapy (PT) of the IRCCS "Burlo Garofolo" of Trieste.

We included patients between 0 and 18 years followed by a PPC service diagnosed with incurable malignancy or advanced chronic disease, needing scheduled transfusion support to control anemia or thrombocytopenia. Patients lived in the Friuli Venezia Giulia region and had limitations to hospital access due to clinical or logistical difficulties, assessed by the PPC service. We excluded patients aged over 18 years or patients who had contraindications to home blood transfusions (e.g., critical conditions requiring emergency hospital admission, unsuitable home environment, inadequate

caregiver, or antecedents of adverse reactions to blood product transfusion).

We analyzed blood products transfusions carried out at home between January 1, 2014 and December 31, 2020.

We collected data on patient’s demographics, age at inclusion in the PPC program, distance from the closest pediatric ward, number and type of transfusion received, duration of the procedure, personnel involved, adverse reactions.

The primary outcome was safety, measured as the frequency of adverse events collected from the clinical records and data on unplanned hospital accesses of the enrolled patients; secondary outcomes were family satisfaction and the financial impact on the Health System.

Adverse events include acute hemolytic reactions, anaphylactic reactions, febrile reactions, transfusion-related lung injury and circulatory overload, or any emergency condition requiring hospital admission, equipment failure (i.e., CVC malfunctioning), blood product transport or storage errors, errors in patient identification, and personnel safety issues (i.e., accidental contamination with blood or needle stick).

We collected socio-demographic data (including nationality, primary caregiver’s education and profession, spouse’s education, and profession), number of family members, number of working days lost due to therapies, and the option of paid leave for the primary caregiver.

As for socio-demographic data and family satisfaction, we administered a questionnaire to collect qualitative data on the impact of home-delivered transfusions on the family routine and the perception of safety and effectiveness in maintaining a good quality of life. A five-item Likert-type scale ranging from “not at all satisfied/completely disagree” to “very satisfied/strongly agree” and short open questions assessed parental satisfaction. The complete questionnaire is provided as a Supplemental file (Supplemental file 1).

As for the financial impact, we performed a comparison between the direct cost of an inpatient treatment for ALL, which may include a blood product transfusion, and the same procedure performed at home.

After the Hospital Revisory Board approval, we emailed all families the project description and a link to the survey. Parents filled a consent form for clinical data collection for scientific purposes during their first hospital admission. The email contained a specific consent question for anonymized data collection.

We performed a descriptive analysis, with continuous data presented as median and interquartile ranges (IQR), and categorical data presented as numbers and percentages.

## Results

As for the safety analysis, six patients met the inclusion criteria in the reference time interval (2014–2020). The diagnoses were acute lymphoblastic leukemia (ALL – two), Ewing’s sarcoma (ES - two), Hodgkin lymphoma (HL - one), and epidermolysis bullosa (one). The median age at inclusion in the PPC program was 14 years.

Three Pediatric teams performed 101 transfusion procedures, 76 PP transfusions, and 25 PRC transfusions, following the Regional protocol. The mean duration of the procedure was two hours and a half. A nurse and a physician were always present for the whole duration of the procedure.

**Table 1** summarizes the patients’ transfusion needs.

As for the primary outcome (safety), we did not record any adverse effect, either observed at home or throughout phone call records or Emergency Department access. The staff physicians did not report any adverse effect to the Transfusion Service.

As for the secondary outcomes (satisfaction), five families out of the six enrolled answered the anonymous questionnaire (dropout rate 16%). There were four Italian and one foreign family, but all spoke Italian.

The mother was the most frequent primary caregiver (4/5) and spent the most time with the child during hospital admissions.

**Tables 2** and **3** summarize participants’ socio-demographics, travel, and job-related issues.

The median distance from the closest Pediatric ward was 12 km (4–20 km).

*Table 1*  
**Patients’ Transfusion Needs**

Patient Number	Diagnosis	Time Interval	Number of Transfusions	PRC	PP
1	ES	03/2019–09/2019	38	1	37
2	ALL	03/2017–03/2019	29	12	17
3	EB	02/2015	1	1	0
4	HL	03/2020–05/2020	29	11	18
5	ALL	03/2017	2	0	2
6	ES	11/2020–12/2020	2	0	2

ES = Ewing’s Sarcoma, ALL = Acute Lymphoblastic Leukemia, EB = Epidermolysis Bullosa, HL = Hodgking Lymphoma, PRC = Packed Red Cells, PP = Packed Platelets.

*Table 2*  
**Participants' Socio-demographics**

	<i>N</i>	<i>%</i>
Main caregiver (N=5)		
Mother	4	80%
Father	1	20%
Family nationality (N=5)		
Italian	4	80%
Other	1	20%
Language adopted with the Service team (N=5)		
Italian	5	100%
Other	0	0%
Main caregiver's profession (N=5)		
Housewife	1	
Self-employed	2	
Public employee	1	
Retired	1	
Spouse's profession (N=5)		
Workman	1	
Office worker	2	
Public employee	1	
Self-employed	1	
Main caregiver's instruction level (N=5)		
Primary school diploma	0	
Middle school diploma	0	
High school diploma	2	
University degree	2	
Professional school license	1	
Spouse's instruction level (N=5)		
Primary school diploma	0	
Middle school diploma	1	
High school diploma	1	
University degree	3	
Professional school license	0	
Age of the child when included in the PPC program (N=5)		
0–3 yrs old	0	
4–7 yrs old	0	
8–12 yrs old	1	
>12 yrs old	4	
Total number of family members (N=5)		
4	4	
5	1	
Other children (N=5)		
Yes	5	
No	0	

All families reported reducing the time spent for hospital accesses and traveling to/from the hospital.

Most families felt safe (3/5) or satisfied (2/5) with the proposal of performing such a procedure at home without any fear or doubt.

All families reported that home transfusions helped them maintain their daily routine and perceive the moment of therapy in a less traumatic way. They also reported a positive impact on siblings, who had the possibility of coping with their brother/sister's disease and participate in his/her care.

All parents felt more involved in their children's therapeutic project after performing transfusions at home. None considered the team as intrusive in their private life; on the contrary, all perceived a sense of care and safety.

*Table 3*  
**Means of Transport, Distance and Parental Job-related Issues**

	<i>N</i>	<i>%</i>
Means of transport used during therapy (N=5)		
On foot	0	0%
Car	5	100%
Taxi	0	0%
Train/bus	0	0%
Average monthly frequency of travels to hospital for visits, procedures and therapies (N=5)		
Less than 5 times a month	2	
Between 5 and 10 times a month	1	
More than 10 times a month	2	
Distance from the nearest hospital (km) (N=5)		
Less than 5 km	2	
Between 5 and 20 km	1	
More than 20 km	2	
Home transfusion service helped the family in the use of family car? (N=5)		
Yes	3	
No	0	
More than 1 car available	2	
Average monthly frequency of absences from work for the main caregiver due to visits, procedures and therapies (N=5)		
<30 days	1	
30–365 days	2	
>365 days	0	
Layoff	2	
Main caregiver allowed some paid leave from work (N=5)		
Yes	2	
No	3	

In the end, all families valued home transfusion service helpful for maintaining a good quality of life and suggested expanding the program.

According to the Friuli Venezia Giulia Health System price table, the daily cost of a single inpatient treatment for ALL, which may include transfusion, is 969 €, whereas the daily charge of a single home visit for a PP transfusion is € 549 (with a net save of € 420) and € 496 for a PRC transfusion (with a net save of € 473).

## **Discussion**

Providing transfusion support at home may offer a substantial improvement in the care of pediatric patients with advanced malignancies or advanced chronic conditions.

Literature provides some evidence of the safety of home transfusion for adult and pediatric patients.<sup>11,16</sup>

Our data further support these findings, with no reaction requiring emergency hospital admission during 101 home transfusions.

As for the secondary outcomes, the literature provides clear evidence that a home setting is preferable in the pediatric palliative care context, as it helps to maintain a family routine, limiting the physical and the mental burden of hospitalization and helping children and siblings in maintaining a sense of normality.<sup>8,17</sup>

Data from our survey confirm these findings. Families positively evaluated the possibility of maintaining their daily routine, minimizing the impact on both the sick child and his/her siblings.

When asked about the presence of the PPC team at home, no family reported it as intrusive: on the contrary, they all expressed satisfaction and a sense of comfort, sharing, and safety. Moreover, they describe a feeling of increased control over the treatment and felt involved in the decisional process regarding their child's illness trajectory, as reported from other experiences.<sup>18</sup>

Literature offers clear evidence that an increasing number of pediatric patients need palliative care services in Italy.<sup>19</sup> Understanding this need, which is often unmet, is paramount to provide effective strategies for alleviating patients' and families' suffering and fairly allocate financial resources, thus relieving the pressure on the National Health System.<sup>19</sup>

Literature already states the financial benefit of a home assistance program for adult and pediatric patients with hematologic malignancies.<sup>12,20</sup> The economic evaluation also highlights the favorable impact of home transfusions, allowing significant savings for the Health System and families. In fact, in Italy, the National Health System ensures complete coverage of health expenses for registered patients, even in the palliative care setting, with region-based assistance programs. However, families often must face other expenses, such as traveling to and from the hospital or missed working days. Such a program may help reduce these burdens, as observed elsewhere with home-delivered chemotherapy programs.<sup>21</sup> The simultaneous presence of a physician and a nurse for the whole duration of the transfusion procedure was considered a safety add-on, seen in our limited previous experience and the limited evidence available from the literature. Since there is increasing evidence of the safety of this approach, we could hypothesize the presence of a nurse only, considering possible different medical regulations and resources.

Limitations of our study include its retrospective nature, with a risk of recall bias for parents' opinions, and the small number of patients included. As for the safety analysis, the sample size is too small to entirely rule out the risks of serious adverse events attributable to transfusion, so more extensive series are needed to confirm these findings. Moreover, we performed only a comparison between the direct costs of the procedures without considering indirect costs (e.g., exact travel costs for families and the PPC team or costs derived from missed working days). The strengths include the number of procedures performed for each patient and the extended time window, and the evaluation of parents' opinions. In this perspective, this experience is an add-on to an overall still limited available evidence from the literature in children.

While acknowledging the small sample size, this study provides further evidence that home transfusions are feasible and may offer a safe option for pediatric patients in PPC to improve their quality of life. More research should provide a broader picture to extend this service on a national basis.

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Ethical approval: The hospital IRB approved the study. All participants provided their written consent to the use of the retrospectively collected data for the purposes of this study.

Availability of data and materials: Data that support the findings of this study are available on reasonable request from the corresponding author.

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