

A commentary on patient and caregiver perceptions of home blood transfusions in the United States

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Abstract

Patients with transfusion dependent cytopenias from their hematologic malignancies experience a high burden of care. They often visit the cancer center 2-3 times a week for Complete blood count (CBC) checks and possible transfusions – spending hours of their day traveling for and receiving care. Home blood transfusions, while available in other countries, have not been well established in the United States (US). Recent studies on home blood transfusions in the US focused on individuals at the end of their life, but other studies have suggested that all patients may benefit from such a service. Herein we review a recent manuscript that evaluated patient and caregiver perceptions of the potential for a home blood transfusion program. The study included both those receiving first line and later lines of therapy and demonstrates a benefit for home-based programs in each population. We further discuss barriers to home blood transfusions and considerations in developing a program.

Introduction

Patients with hematologic malignancies who are cytopenic from their disease, treatment, or both, rely on periodic transfusions of red blood cells and/or platelets for support. While not disease modifying, transfusions can improve symptoms, reduce the risk of complications, and improve one's quality of life [1,2]. In the United States, transfusions are restricted to the healthcare setting, either in an outpatient clinic or hospital; patients must travel to and from one of these facilities to receive this necessary care. For patients with transfusion dependent hematologic malignancies, particularly those with acute leukemia or myelodysplastic syndrome (MDS), that may translate into visits 2-3 times a week for complete blood count checks and possible transfusions [3]. The resultant time and financial burdens for patients and their caregivers are high. Implementing a home blood transfusion program could reduce these burdens while improving access to care [4]. Outside of the US, home blood transfusion programs do exist, but data published about these programs is limited. A systematic review published in 2022 identified only 14 studies assessing home blood transfusion: 13 case-series and 1 cross-sectional, and all were of low methodological quality [5]. Most studies focused on safety as the outcome of interest. Based on these data, home transfusions appear to be safe, with only 144 (1.21%) mild adverse reactions and 6 (0.05%) severe adverse reactions out of 11,928 home blood transfusions administered [5]. Data on other outcomes such as quality of life, cost, and convenience are scarce and few conclusions can be drawn.

Patient Perspective of Home Blood Transfusions

The manuscript published by Binder *et al.* describes the methods, results, and conclusions of a qualitative study evaluating patient and caregiver perceptions of a home blood transfusion program [6]. This study included 9 patients with MDS, 11 patients with acute leukemia, and 9 caregivers. The

patients were transfusion dependent, defined as an average of more than 2 units of blood products transfused every 28 days over at least a 3-month period. Interviews were conducted from December 2022 to April 2023, and data analysis was performed with NVivo. Four themes emerged from the interviews; the first was “current in-person experience”. While reflecting on receiving transfusions in person, both the patients and the caregivers felt that transportation was a major barrier. They cited unpredictable commute times, uncertainty in securing transportation, and long travel distance as some of the main stressors associated with transportation. The second theme was “caregiver burden”, caregivers spoke about needing extra help for childcare while they accompanied the patients to their visits. 50% of caregivers said that taking patients to and from their transfusions interfered with their social lives. Another theme was “perceptions of home blood transfusions”; participants generally had positive feelings about receiving transfusions at home. Participants thought it would be more convenient, as well as the potential to mitigate travel and financial burden. Patients also commented on the additional benefit of decreasing unnecessary exposure to infections in the hospital setting.

Patients and caregivers did have some concerns with home blood transfusions that emerged as the fourth theme, “interest in participating in a home blood transfusion program”. They worried that the home might not be a safe, clean environment as compared to the infusion center. They were also concerned about the ability to properly manage medical complications at home, such as a transfusion reaction. Despite these concerns, only 3 of 20 patients were not interested in participating; 2 declined the option because they enjoyed having social interaction at the infusion center and wanted to continue to see the staff and other patients in person. Overall, the results of this study showed favorable perceptions of at home transfusions. The details captured in the interviews can be used to build a home transfusion program that addresses the needs and concerns of those directly involved. While it was not pre-plan for it, 12 (60%) patients were on 1st line treatment, and 8 (40%) patients were on 2nd or 3rd line treatment at the time of interview. Post hoc analysis revealed that both groups viewed the concept of home blood transfusions favorably. Both groups felt there would be a benefit to reducing the care burden, saving time and money on travel, and there would be increased comfort in receiving transfusions in the home. Those on later lines of therapy perceived additional benefits for individuals who are frail or unable to physically make it to the cancer center. Individuals on first line therapy did not mention this benefit. Both groups agreed that there is a benefit to having the same team care for you and would like to have the same nursing team care for them in a home blood transfusion program. Familiarity with the care team improves the patient’s experience and would help with the success of a program. This last point is reinforced by our findings that among those who were not interested in a home transfusion program, 2 of 3 patients stated the reason was because they enjoyed seeing the staff with whom they had developed a familiarity and relationship.

Study Commentary

There is well established data that patients with hematologic malignancies enroll in hospice later in their disease course, or not at all, for a variety of reasons; one significant factor is the desire to continue to receive blood transfusions [7-10]. As a result, recent research on home blood transfusions in the United States has focused on individuals near the end of life [11]. This, in addition to ongoing

advocacy work, has led to the United States congress introducing legislation to support blood product transfusions for patients receiving hospice services. The bill was introduced in June 2023 and continues to be actively reviewed for consideration [12]. Research and advocacy for blood transfusions near the end-of-life is critical to improving outcomes for patients with hematologic malignancies. However, little work has evaluated patients’ perceptions of home blood transfusions for patients not at end of life. A recent abstract highlighted caregiver burden related to transfusions for patient with low risk MDS [13]. This study highlighted the how even less burdensome transfusion requirements can impact the lives of caregivers, but did not survey the patients’ themselves.

There is both time and financial toxicity associated with transfusion dependence and ongoing work is needed to better understand these toxicities in those receiving active therapy whether for curative or palliative intent. These findings will be critical to designing implementation programs and advocacy work. The burden of care, financial toxicity, and strain on caregiver resources are high throughout the treatment course. When advocating for new programs and reimbursement models, we need to be as inclusive as possible, so all patients have the potential to benefit from these innovative healthcare models. The current standard of practice for administration of a transfusion is either at an infusion center or in a hospital setting; healthcare facilities can invoke a sense of safety, as they are filled with healthcare providers who are quick to action in an emergency. Performing this procedure at home could be psychologically daunting for some people, however, as established, studies [4,14-18] available on home transfusion have demonstrated safety with minimal adverse events. In one study, Patients interviewed were interested in the potential of home transfusions, but highlighted multiple logistical questions related to not only safety in the setting of an adverse event, but also to the space used in the home, impact of children or animals at home, timing of blood draws and home visit, costs, as well as distance to healthcare facilities for emergency care [6].

Many of these concerns can be addressed by carefully considering patient selection criteria and developing a patient centered protocol for home transfusion. While home transfusion has been implemented at some institutions in various countries, there is not a standard approach to implementation. An international forum published in 2021 [19] demonstrated some of these variances. Medical supervision differed amongst the institutions; some required a patient caregiver to be present for the duration of the transfusion, while others instead required a transfusion nurse be present for the duration. Some programs had strict exclusion criteria related to medical comorbidities, others had no such specifics. Two institutions mandated that the patient have a telephone or working mobile phone to enroll, in order to facilitate communication. Some institutions performed same day pre-transfusion testing; others required testing be obtained 24 hours prior. Pick up and transportation of the blood product itself varied from institution to institution as well. While home transfusions have clearly been shown to be a safe and effective way to administer a necessary procedure to those with chronic illnesses, patient hesitancy is noted as this concept is novel to most. As mentioned, there is not a universal protocol or inclusion/exclusion criteria utilized amongst existing institutional home transfusion programs. Looking forward, strict guidelines for home transfusions and clear patient inclusion criteria should be formulated with the assistance of a multidisciplinary team including clinicians, nurses, blood bank staff, as well as patients

and their caregivers to address potential barriers and challenges. Once a protocol is established that can help answer logistical questions as discussed, patient hesitancy should improve. We believe that when starting a program, one should be more conservative in the patient selection process. Patients should live close to the hospital to ensure timely access to care in the case of an infusion related reaction. Patients should have no history of transfusion reactions, no evidence of alloantibody formation, have good cardiac function – minimizing risk for transfusion related circulatory overload, and should not require multiple product transfusions in one day (i.e. no more than 1 bag of platelets and 1 bag of red blood cells). Once a program is more established, the team could consider expanding the criteria to be more inclusive so more patients may benefit from these services. Some patients may not be interested in transitioning to a home transfusion program because of the close relationships they had developed with their healthcare team at the infusion center. While this is a matter of patient preference, one study demonstrated that after enacting a nurse led home transfusion program, patients were more satisfied with care and appreciated having a dedicated transfusion nurse with whom they could build a relationship [14]. Taking the patient experience into consideration, a program should have a small group of transfusion nurses, many of whom may know and already have a previous relationship with many participants, can help improve engagement and satisfaction. Minimizing trips to the hospital or transfusion center may decrease the opportunity cost, leaving more time for other friends and family to socially visit the patient, and potentially reduce caregiver burden. Another useful impact of utilizing a home transfusion program is identifying patient needs that would otherwise go unnoticed in the office. In clinics, patients routinely answer questionnaires designed to identify those at risk of food or financial insecurities, abuse, depression, etc. Patients may not be willing to answer those accurately for fear of judgement or retribution. An indirect benefit from a home transfusion program is identification of potential patient needs when visiting the home. Even identification of a caretaker to be present at the home for a patient may not be possible and can lead to insight for other potential needs [20]. The costs of transfusions rely on several different factors and can vary between institutions. An analysis of publicly available chargemaster documents was published in 2023 [21], that reviewed costs with transfusions in 200 different hospitals. Red blood cell (RBC) acquisition cost was noted to be approximately \$200 per unit for a hospital blood bank, however the subsequent charge for the RBCs was approximately \$600 and the charge for the procedure itself was approximately \$2000. It's suspected that home transfusions would in general have a 25-55% reduction in costs [5], however there is scant literature that has reported cost analysis to verify these estimates. Other types of services (i.e. chemotherapy, infusions, stem cell transplants) have been effectively shifted to the home setting. Home transfusions have the benefit of decreasing patient costs as well, predominantly in transportation fees. As a large amount of the population has shifted to working from home since the COVID-19 pandemic in 2020, home transfusions have the potential to positively impact those patient's ability to earn income, taking less time off for appointments.

Conclusion

There is a growing body of evidence demonstrating the safety of home blood transfusions and the potential it could have at reducing many of the burdens patients and their caregivers experience during treatment. While much of the focus previously has been on patients

near the end of life, a growing body of literature is demonstrating potential value for those on early lines of therapy for both curative and palliative intent. Successful programs will need to be patient centered, with careful consideration of inclusion criteria, logistics around delivery and administration of blood products and how home care will impact the patients experience with the healthcare team. For programs such as this to be sustainable, future research must include economic impact to patients, payers, and healthcare systems.

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