Willingness and concerns of transfusion-dependent hematological patients toward the option of home transfusion therapy

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Abstract

Background: One of the main obstacles of providing home-based palliative care to transfusion-dependent hematology patients is the lack of home transfusions services. While healthcare professionals are concerned with safety and cost of home transfusions, the attitude of the patients toward home transfusions are mostly unknown.

Aim: To obtain quantitative data regarding the willingness and concerns of transfusion-dependent patients with hematological diseases toward the option of home transfusions.

Design: A cross sectional survey including a self-administered questionnaire in one of the three main spoken languages in Israel was administered to patients in 17 hospital hematology outpatient clinics between May 2019 and March 2020.

Results: About 52% of 385 patients that participated in the survey preferred home transfusions to hospital transfusions. Gender, age, education, or type of disease were not associated with preference for home transfusions, nor were hospital location or its size. The likelihood to prefer home transfusions was significantly higher among the Hebrew-speakers and those who had not experienced adverse effects previously. The most significant factor associated with preference of home transfusions was a perceived negative effect of hospital-based transfusion on quality of life. The main reason to reject home transfusions was fear of possible adverse effects and concerns over losing contact with the medical staff at the treating hospital.

Conclusion: These data suggest that a significant portion of transfusion-dependent patients in Israel view home transfusions as a preferred treatment option and that its successful implementation requires maintaining ongoing contact with the treating hospital.

Keywords

Transfusion, patient focused care, hematology, physician patient relations, home care, blood

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What is already known about the topic?

- Transfusion-dependent patients are usually excluded from receiving home-based palliative care due to lack of home transfusion services.
- There is almost no quantitative information regarding the opinions of the transfusion-dependent patients toward home transfusions.

What this paper adds?

- Over half of transfusion-dependent hematological patients treated in 17 outpatient clinics nationwide in Israel stated they prefer the option of home transfusions to hospital transfusions.
- Gender, age, education, or type of disease are unrelated to home transfusions preference. Home transfusions preference is associated with spoken language and a perceived negative effect of hospital transfusions on quality of life.
- Fear of adverse effects and of losing contact with the hospital team are negatively associated with willingness to receive home transfusions.

Implications for practice, theory, or policy

- Given the large numbers of hematological transfusion-dependent patients that are interested in home transfusions, its implementation should be considered by medical teams and health policy makers.
- Successful home transfusions implementation relies on sustaining the interaction between the patients and their hospital healthcare team.

Introduction

Despite significant advances in treatment of hematological disorders, patients who suffer from malignant blood illnesses often reach a stage that requires regular blood transfusions to sustain them.[1–3] In Israel, where the healthcare system is universal and all residence are entitled to basic healthcare provided by four non-profit healthcare organizations, funding for the insurance is provided through the national insurance institute. Patients who require blood transfusions receive them exclusively within hospital settings. Whereas home-based palliative care may be advantageous to these patients, they are usually excluded from this service due to the inability of palliative care teams to provide home transfusions.

In an era of growing understanding that active participation of patients in managing their illness is critical to their survival and self-dignity,[4] there is surprisingly little information regarding the opinions of transfusion-dependent patients toward home transfusions.[5–8] Therefore, our aim was to estimate the willingness of transfusion-dependent Israeli patients to receive home transfusions, to identify the socio-economical and cognitive factors that are associated with this decision, and to elucidate the factors that are associated with the negative effect of hospital transfusion on quality of life.

Materials and methods

Design

A cross-sectional survey of hematological patients from 17 hospitals out of 21 hospitals that offer outpatient transfusion services in Israel.

Subjects

Patients over 18 years of age, who received at least one blood product (blood, platelets, or intravenous immunoglobulin transfusions) at least once within the hospital outpatient clinics during May 2019 to March 2020 (pre-COVID-19 epidemic), were approached. Response rates were high (85%–95%). The study complied with the ethical standards of the relevant institutional committees on human experimentation and the Declaration of Helsinki of 1975, as revised in 2008.

Data collection

A self-administered anonymous questionnaire that was developed by hematology clinicians based on their prior knowledge of patient attitudes and the scientific literature on the subject,[6,8,9] was tested initially on a small sample of patients (*n* = 20) in two hospitals. The questionnaire, which was available in three prevalent languages in Israel (Hebrew, Arabic, and Russian), consisted of minimal demographic information (age, gender, place of residence, and level of education) and a 14-item multiple-choice questionnaire. The variables were as follows: type of disease (by name); type of blood product (three options); adverse effects (two levels); frequency of transfusions (five levels), time spent reaching the hospital (four levels), duration of treatment (four levels), and comfort level while receiving treatment (three levels). Patients were then asked: "To what extent do you feel that receiving blood transfusions in the hospital has a negative effect on your quality of life" (three levels), and "In your opinion, how likely will home transfusions improve your quality of life" (three levels). Finally, patients were asked: "Are you

afraid to receive home transfusions?" (three levels) and "What are your concerns regarding home transfusions" (marking of more than one answer was possible, as well as an option to add a concern of their own). The main dependent variable was the willingness of patients to receive home transfusions. Four levels of agreement were presented, after which the variable was dichotomized into willing (1) – including "certainly" and "most probably," and not willing (2) – including "not sure" and "not willing." The variable that inquired about the harm to quality of life caused by visits to the hospital for blood transfusion treatment had three possible answers: "very much," "somewhat," and "does not harm at all." These were dichotomized into "no harm" (somewhat and not at all – 2), and "very much" (1). The dichotomized variable was used for the logistic regression model.

Analysis

Analysis was performed by SPSS Statistics 25 and R software. Descriptive statistics were used to obtain information regarding background variables including age, gender, education, and language of questionnaire. The association between variables was evaluated using Chi-square with $p < 0.05$ considered statistically significant. Multivariable logistic regression models were run only on questionnaires that included demographic data in order to identify variables associated with the dependent variables, willingness to receive home transfusions and the perception that hospital visits harms quality of life.

Results

Three hundred and eighty-five participants answered the questionnaire. The mean age of the participants was 66.07 + 17.43, 53% were men, 41% reported having an academic education with only 17.9% reporting elementary school level education or less. Two thirds, (67.5%) chose to take the questionnaire in Hebrew, 10.7% in Russian, and 21.8% in Arabic, consistent with the demographic representation of the Arab population in Israel.[10] A third of the participants suffered from non-malignant hematological disease (34.3%, β thalassemia and sickle cell anemia) and the rest from acute malignant disease (38.2%, lymphomas, multiple myeloma, leukemia), and chronic malignant disease (27.5%, myelodysplastic syndrome, chronic lymphocytic leukemia, and myelofibrosis). Over 90% had received Red Blood Cell (RBC) transfusions, 20% received platelets (some in addition to RBC) and 7% received IVIG. The vast majority of patients (>90%) had never been treated in a home setting.

Fifty two percent of patients stated they are either very interested or probably interested in the option of home transfusions while 48% were either unsure or against home transfusions altogether. Gender and education were not associated with willingness to receive home transfusions.

Table 1. Frequency of characteristics by willingness to receive home transfusions.

	Willing to receive home transfusions		Total
	Yes % (*N*)	No % (*N*)	% (*N*)
Total	51.2 (197)	48.8 (188)	100 (385)
Age			
Mean SD	64.4 (17.47)	67.7 (17.15)	66.1 (17.43)
p	0.09		
Gender			
Men	57.2 (95)	42.8 (71)	53.2 (166)
Women	49.3 (72)	50.7 (74)	45.8 (146)
p	0.16		
Education			
Elementary	42.3 (22)	57.7 (30)	18.8 (52)
High school	54.7 (64)	45.3 (53)	41.0 (117)
Academic	58.6 (68)	41.4 (48)	40.7 (116)
p	0.14		
Interview language			
Hebrew	57.5 (150)	42.5 (111)	(261)
Russian	41.0 (16)	59.0 (23)	(39)
Arabic	36.9 (31)	63.1 (53)	(84)
p	0.0018		

However, Hebrew speakers were significantly more open to the idea of home transfusions compared to the Arab and Russian speakers. Older patients were also less inclined to prefer home transfusions, although the significance was borderline (Table 1).

Table 2 depicts the main healthcare, treatment, and psychological factors that were found to be associated with the likelihood to agree to home transfusions. Patients who had experienced adverse effects during previous transfusions were significantly less likely to prefer home transfusions. Two additional reasons that were highly associated with the likelihood to agree to home transfusions were apprehension and the effect of hospital based transfusions on the quality of life. Patients who felt that hospital visits have a negative effect on their quality of life were significantly more inclined toward home transfusions while those who were apprehensive toward the process were more likely to reject it. A quarter of patients listed adverse effects as the main cause of apprehension and 27% were concerned about losing contact with the healthcare staff at the treating hospital. As expected, patients who were concerned about losing contact with the hospital were significantly less inclined to prefer home transfusions.

A logistic regression model to identify the variables that are associated with the willingness for home transfusions, adjusting for age and spoken language showed that the variable that was most strongly associated with willingness to agree to home transfusions was apprehension (Table 3). Patients who reported they did not fear home transfusions were 7.8 times more likely to prefer home

Table 2. Treatment characteristics by willingness to receive home transfusions.

	Willing to receive home transfusions		Total
	Yes % (*N*)	No % (*N*)	% (*N*)
Negative effect of hospital visits on quality of life			
Very much	73.1 (76)	26.9 (28)	28.3 (104)
Somewhat	54.1 (80)	46.0 (68)	40.2 (148)
Not at all	29.3 (34)	70.7 (82)	31.5 (116)
p	<0.0001		
Previous experience of adverse effects from transfusions			
Yes	43.4 (59)	56.6 (77)	51.2 (186)
No	56.0 (127)	44.0 (100)	48.8 (177)
p	0.020		
Apprehension toward home transfusions			
Very	6.9 (7)	93.1 (94)	27.1 (101)
Somewhat	50.0 (57)	50.0 (57)	30.6 (114)
Not at all	81.7 (129)	18.3 (29)	42.4 (158)
p	<0.0001		
Concern over losing contact with treating hospital			
Yes 1	37.5 (39)	62.5 (65)	27.0 (104)
No 0	56.2 (158)	43.8 (123)	73.0 (281)
p	0.001		

Table 3. Variables associated with willingness to receive home transfusions.

Variables	OR	CI	*p*
Age (continuous)	0.97	0.95, 0.99	0.004
Spoken language (Hebrew vs other)	0.42	0.20, 0.89	0.023
Apprehension toward home transfusions	7.82	4.79, 12.76	<0.0001
Fear of adverse effects	2.05	1.01, 4.12	0.046
Negative effect of hospital transfusions on quality of life	0.36	0.23, 0.58	<0.0001

Multivariate logistic regression model OR, CI, and *p* values. *N* = 291.

Table 4. Variables associated with the perception that hospital visits harm quality of life.

Variables	OR	CI	*p*
Hebrew versus other languages	2.58	1.41, 4.72	0.002
Frequency of hospital visits	1.36	1.09, 1.69	0.006
Time to reach hospital	0.59	0.43, 0.81	0.001
Time spent in hospital	0.73	0.53, 1.00	0.05
Conditions at hospital	0.56	0.37, 0.83	0.004

Multivariate logistic regression model OR, CI, and *p* values. *N* = 329.

Table 5. Comparison of home transfusions preferences among transfusion-dependent patients.

Year	No. of patients	Pro-home transfusions(%)	Country	Reference
1996	29	7	USA	Benson[6]
2005	20	30	United Kingdom	Ademokun et al.[5]
2012	136	63	France	Havet et al.[8]
2019	605	63	Japan	Ohashi et al.[11]
2020	385	52	Israel	Current

negative effect on quality of life (Table 4). As expected, the more time and effort it took the patients to arrive at the hospital and the longer they stayed in the hospital, the more likely they were to report a negative effect on their quality of life. Apprehension of home transfusions was also significantly associated with the report of the effect of hospital-based transfusions on quality of life; patients who were apprehensive toward home transfusions were more likely to state that treatment in the hospital does not affect their quality of life.

Discussion

The data from this study indicate that a large group of transfusion-dependent patients across Israel prefers home transfusions to hospital transfusions, an observation that is in accordance with the global shift toward preference for home transfusions (Table 5). The study has several limitations including the fact that it is a cross sectional survey, therefore causality cannot be inferred. A larger sample size may have identified additional significant associations, and the questionnaire did not inquire for information that could help understand the reasons for choices made by patients. Furthermore, the study was performed prior to the outbreak of COVID-19, which increased anxiety among patients, causing many to refrain from attending hospitals for treatment. Therefore, the implications of the pandemic on home transfusions preference require further examination. Lastly, although the study was heterogeneous in terms of disease type (malignant and non-malignant), the lack of differences in the response of patients strengthens

transfusions to hospital transfusions. Patients who did not experience adverse effects from transfusions were twice as likely to prefer home transfusions as were patients who felt that hospital visits had a negative impact on their quality of life.

Negative perception of patients toward hospital-based treatment was not associated with age, gender, education, and previously experienced adverse effects. However, Hebrew-speaking patients were 2.58 times more inclined to report a negative effect of hospital treatments on their quality of life than speakers of Arabic or Russian. Furthermore, variables that describe the healthcare facilities and conditions including travel time to the hospital, length of hospital stay, frequency of hospital visits, and facility conditions were all associated with a

the conclusion that raised concerns apply to the unique population of transfusion-dependent patients, whether chronic or terminally ill.

The study highlights both universal factors (effect on quality of life and fear of side effects)[6,8,11] and local factors (ethnicity) that affect home transfusions preferences. In Israel, Arabic and Russian speakers who represent immigrant and minority populations, tend to reject home transfusions, possibly due to several health and socioeconomic reasons (e.g. patriarchal attitudes and beliefs, difficulties in receiving high quality social support from immediate social surroundings in time of crisis, lack of appropriate living environments).[12–15] Despite reflecting local populations, these findings likely apply to other immigrant and minorities worldwide. Importantly, our study shows that the vast majority of transfusion-dependent patients arrive at the hospital on a weekly basis and spend a long time at the clinic. Consequently, the bond formed between these patients and their treating medical staff is reflected in their fear of losing contact with the treating physician if they choose home transfusions. Therefore, finding ways of addressing the special needs of unique subpopulations and maintaining constant relations with the hospital treating staff are critical to the success of home transfusions.

One of the main reasons to reject home transfusions among both physicians and patients is the fear of adverse effects. However, several home transfusions studies conducted among patients with different hematological diseases did not find additional risk compared to other healthcare settings.[5,16] Considerable advances in transfusion medicine over the past decades have significantly decreased the incidence of adverse effects and while safety concerns should always be seriously considered, currently there is no quantitative data to support that home transfusions poses greater risk to these patients.

In conclusion, in order to make palliative care available to a population of often frail and immunocompromised transfusion-dependent patients, home transfusions must be a part of the available home palliative services. Our data presents the point of view of the patients and voices their preferences and concerns, which must be heard by medical teams, healthcare managers, and health policy makers.

Author contributions

LBH, AS, VY, and AA made a substantial contribution to the concept and design of the work, and designed the study. AS, LA, YB, ND, DD, TI, MKM, ML, YM, LS, TT, SY, VY, and AA collected the data, LBH and OBE analyzed the data and wrote and revised the article. All authors have sufficiently participated in the work to take public responsibility for appropriate portions of the content and approve the version for publication.

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Data management and sharing

Because it concerns a vulnerable and specific patient population, anonymized data extraction forms are only available on request. The extraction form and statistical data files can be requested from the authors.

Research ethics and patient consent

The hospital Ethics committee documentation are: Hadassah-Hebrew University Medical Center (0235-19-HMO); Galilee Medical Center (0018-20-NHR); Barzilai University Medical Center (0009-20-BRZ); Ziv Medical Center (0089-19-ZIV); Edith Wolfson Medical Center (0115-19-WOMC); Rambam Health Care Campus (0077-20-RMB); Shamir Medical Center (0173-19-ASF); Assuta Ashdod University Hospital (0055-19-AAA); Tel Aviv Sourasky Medical Center (0494-19-TLV); Kaplan Medical Center (0037-20-KMC); Bnai Zion Medical Center (0019-20-BNZ); Padeh Poriah Medical Center and HaEmek Medical Center (written exemption by hospital management); Soroka Medical Center (0120-20-SOR); Lady Davis Carmel Medical Center (0021-20-CMC); Meir Medical Center (0241-19-MMC); Rabin Medical Center (0414-19- RMC).

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