

The Lived Experiences of Hematology Patients Undergoing Long-Term Blood Transfusion Therapy: Exploring the Impact on Daily Life, Mental Health, and Social Interactions

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Abstract

This qualitative study explores the experiences of hematology patients undergoing long-term blood transfusion therapy and its impact on their daily lives, mental health, and social interactions. Semi-structured interviews with 15 patients in a tertiary hospital revealed key themes: disruption of daily routines, psychological burden from dependence on transfusions, and social isolation. Participants highlighted the challenges of balancing treatment with work, education, and personal responsibilities, as well as the emotional strain of chronic illness. Strong family support and healthcare provider relationships were identified as crucial coping mechanisms. The findings underscore the need for holistic care, integrating both medical and psychological support for long-term transfusion patients.

Keywords: Long-term blood transfusion, hematology patients, psychological burden, social isolation, qualitative study, patient experiences, healthcare support

Introduction

Long-term blood transfusion therapy is a critical component of treatment for patients with various hematological conditions, including thalassemia, sickle cell disease, and other chronic blood disorders. While this life-sustaining therapy can significantly improve patients' physical health, it also imposes a considerable burden on their daily lives, mental health, and social interactions. Patients who undergo regular blood transfusions must adapt to the demands of frequent medical appointments, physical side effects, and the emotional strain of living with a chronic condition. Despite the growing reliance on transfusion therapy in hematology, there is limited research on how this treatment affects patients' broader life experiences.

Existing literature highlights the physical benefits of blood transfusion therapy in managing hematological disorders, such as reducing fatigue and preventing organ damage (French and Kochhar, 2004). However, less attention has been given to the psychological and social implications of this ongoing treatment. For many patients, the constant need for transfusions can lead to feelings of dependence, loss of control, and anxiety about their health. Research by Messina et al. (2008) suggests that the repetitive nature of transfusions and the chronic nature of hematological diseases can exacerbate feelings of stress and isolation, especially when patients feel different from their peers due to their medical condition.

In addition to the psychological strain, regular blood transfusion therapy can disrupt patients' daily routines and social lives. Frequent hospital visits and the physical side effects of transfusions, such as fatigue or discomfort, often limit patients' ability to participate in work, education, or social activities (Hershko, 2010).

These disruptions can negatively impact patients' quality of life, particularly when compounded by the stigma that sometimes surrounds chronic illness and visible medical treatments.

Given the profound impact that long-term blood transfusion therapy can have on patients' lives, this study seeks to explore their lived experiences through a qualitative lens. By focusing on the perspectives of hematology patients, this research aims to capture the emotional, psychological, and social challenges they face, and how they navigate these obstacles over time. Understanding these experiences is crucial for healthcare providers to develop more holistic support strategies that address not only the physical but also the emotional and social needs of patients undergoing long-term transfusion therapy.

Literature Review

1. Overview of Long-Term Blood Transfusion Therapy

Long-term blood transfusion therapy is a critical treatment for patients with various hematological conditions, including sickle cell disease, thalassemia, and certain forms of anemia. Regular transfusions help maintain stable hemoglobin levels, prevent organ damage, and manage complications associated with these conditions (French and Kochhar, 2004). While the physical benefits of blood transfusion are well-documented, the broader psychosocial impact on patients has been underexplored in the literature. Hematology patients undergoing long-term transfusion often face a variety of challenges that affect their quality of life, including disruptions to daily routines, mental health challenges, and changes in social interactions.

2. Impact on Mental Health

The emotional toll of long-term transfusion therapy can be significant. Research has shown that patients receiving regular transfusions often experience heightened anxiety, stress, and depression related to their chronic condition and ongoing treatment. Messina et al. (2008) conducted a qualitative study that found patients with thalassemia frequently reported feelings of anxiety surrounding their treatment regimen, with many patients expressing concern about their long-term prognosis and dependence on transfusions. In addition to the emotional burden of living with a chronic illness, the physical discomfort associated with regular transfusions can exacerbate feelings of helplessness and psychological distress.

A study by Cappellini et al. (2014) found that hematology patients undergoing long-term transfusion therapy also suffer from anticipatory anxiety, particularly in anticipation of upcoming hospital visits and potential transfusion-related complications. This anxiety is often compounded by the unpredictability of disease progression, making it difficult for patients to plan for the future or feel in control of their health. Mental health professionals have emphasized the need for integrating psychological support into transfusion care to address these challenges, yet such support is often limited or unavailable in many healthcare settings.

3. Disruptions to Daily Life

Long-term transfusion therapy can have a profound impact on patients' daily lives. Regular hospital visits, the time required for transfusion sessions, and the side effects of treatment—such as fatigue, headaches, or joint pain—disrupt patients' routines and diminish their ability to engage in regular activities (Hershko, 2010). Patients may experience interruptions to their education, employment, and family responsibilities, leading to feelings of frustration and isolation.

In a study focused on transfusion-dependent patients with sickle cell disease, Platzbecker et al. (2012) found that many patients struggled to maintain stable employment or academic progression due to the demands of

frequent transfusions. The physical toll of treatment, combined with the time spent receiving care, often led to absenteeism from work or school, which, in turn, caused financial strain and negatively affected patients' mental well-being. The burden of managing both medical treatment and daily responsibilities was a source of significant stress for many patients, highlighting the need for more flexible and patient-centered approaches to care.

4. Social Interactions and Stigma

Patients undergoing long-term transfusion therapy may also experience changes in their social lives, often feeling isolated from friends, family, or their wider community due to their treatment regimen. The frequent hospital visits and physical symptoms can limit patients' ability to participate in social activities, leading to social withdrawal. In addition, the visible nature of their medical condition can contribute to feelings of stigma, as patients may feel judged or misunderstood by those unfamiliar with their condition (Messina et al., 2008).

Stigma has been widely discussed in the context of chronic illness, and studies have shown that hematology patients often experience this social phenomenon. According to Goffman's (2009) classic work on stigma, individuals with visible medical conditions or treatment needs may experience social exclusion or a sense of "otherness." In the context of long-term transfusion therapy, patients may face questions or misconceptions about their condition from peers, which can lead to uncomfortable social interactions or feelings of embarrassment. Research by Loizou et al. (2016) indicates that this stigma can exacerbate feelings of isolation, as patients may withdraw from social situations to avoid negative experiences or unwanted attention.

5. Coping Strategies and Support Systems

While the challenges of long-term transfusion therapy are significant, many patients develop coping strategies and rely on support systems to manage the psychological and social impacts of their treatment. Family members, friends, and healthcare professionals play a crucial role in helping patients navigate their emotional and practical challenges. Messina et al. (2008) found that patients who had strong social support networks were more likely to report positive mental health outcomes and were better able to cope with the demands of their treatment regimen.

Additionally, the role of peer support has been emphasized in the literature. Support groups, either in-person or online, provide patients with an opportunity to share their experiences with others who understand their unique challenges. Cappellini et al. (2014) reported that patients who participated in transfusion-specific support groups felt less isolated and more empowered to manage their condition. These findings highlight the importance of fostering strong support networks for patients undergoing long-term transfusion therapy.

6. Gaps in the Literature

While there has been growing interest in the psychosocial aspects of long-term transfusion therapy, gaps in the literature remain. Most studies focus on the physical outcomes of transfusion therapy, with limited exploration of the lived experiences of patients undergoing this treatment. Moreover, the available qualitative research primarily focuses on single conditions, such as thalassemia or sickle cell disease, rather than exploring transfusion experiences across a broader population of hematology patients.

This study seeks to address these gaps by providing a comprehensive exploration of the experiences of hematology patients undergoing long-term blood transfusion therapy. By focusing on patients' perceptions

of how transfusion therapy affects their daily lives, mental health, and social interactions, this research aims to contribute to a more holistic understanding of the impact of long-term transfusion on patient well-being.

Methodology

Study Design

This study employed a qualitative research design to explore the lived experiences of hematology patients undergoing long-term blood transfusion therapy. A phenomenological approach was chosen to capture the depth and complexity of the patients' emotional, psychological, and social experiences. The study was conducted in a large tertiary hospital with a dedicated hematology department, providing long-term transfusion services for patients with chronic blood disorders such as thalassemia, sickle cell disease, and aplastic anemia.

Participants

Participants were selected using purposive sampling to ensure that those included in the study had relevant experiences with long-term blood transfusion therapy. A total of 15 participants were recruited from the hospital's hematology department, all of whom had been receiving regular blood transfusions for at least six months. Inclusion criteria were as follows:

- Patients aged 18 years or older.
- Diagnosed with a chronic hematological condition requiring long-term transfusion therapy.
- Able to communicate in English or the local language.
- Willing and able to provide informed consent.

Exclusion criteria included patients with acute or terminal conditions that could impair their ability to participate in interviews. The final sample included a range of ages, genders, and diagnoses to ensure diversity in the experiences captured.

Data Collection

Data were collected through semi-structured, in-depth interviews conducted in a private room within the hematology department of the hospital. Interviews were conducted from 40 to 60 minutes in length. The interview guide was designed to explore three main areas:

- The impact of long-term blood transfusion therapy on daily life (e.g., routines, work, education).
- The emotional and psychological effects of receiving regular transfusions (e.g., stress, anxiety, coping mechanisms).
- The influence of transfusion therapy on social interactions and relationships (e.g., family, friends, social activities).

Open-ended questions were used to encourage participants to share their personal experiences in detail. Examples of questions included:

- "Can you describe how regular blood transfusions affect your daily routine?"
- "How do you feel emotionally about the need for long-term transfusion therapy?"
- "How has your social life or relationships been impacted by your transfusion schedule?"

All interviews were audio-recorded with participants' consent and transcribed verbatim for analysis.

Ethical Considerations

This study was approved by the hospital's ethics committee, and all participants provided written informed consent prior to the interviews. Given the potentially sensitive nature of the topics discussed, participants

were informed that they could withdraw from the study at any time without affecting their care. Confidentiality was maintained by anonymizing all participant data, and audio recordings were securely stored and only accessible to the research team. Participants who experienced emotional distress during the interview were offered access to psychological support services provided by the hospital.

Data Analysis

The transcribed interviews were analyzed using thematic analysis, following Braun and Clarke's (2006) six-step process. Thematic analysis was selected to identify and interpret patterns in participants' descriptions of their experiences. The steps involved in the analysis included:

1. Familiarization with the Data: The researchers read and re-read the interview transcripts to become thoroughly familiar with the content.
2. Generating Initial Codes: Codes were assigned to segments of the data that captured key aspects of the participants' experiences, such as "treatment-related anxiety" and "disrupted social life."
3. Searching for Themes: The initial codes were grouped into broader themes that represented overarching patterns in the data. For example, the codes related to anxiety and stress were grouped into a theme titled "Psychological Burden."
4. Reviewing Themes: The identified themes were reviewed to ensure that they accurately reflected the participants' narratives and were coherent across the dataset.
5. Defining and Naming Themes: Themes were clearly defined and named to capture the essence of each category. Major themes included "Daily Life Disruptions," "Psychological Burden," and "Social Isolation."
6. Producing the Report: The final step involved writing up the findings, with illustrative quotes from participants included to support the identified themes.

Findings

Thematic analysis of the interviews with hematology patients undergoing long-term blood transfusion therapy revealed several key themes that encapsulate their experiences. These themes reflect the profound impact of transfusion therapy on patients' daily lives, mental health, and social interactions. The major themes identified include: (1) Disruption of Daily Life, (2) Psychological Burden and Emotional Strain, and (3) Social Isolation and Support.

Theme 1: Disruption of Daily Life

Participants frequently described how the need for regular transfusions disrupted their daily routines and responsibilities. The time commitment for transfusion appointments, combined with the physical side effects, often left them unable to carry out normal activities, affecting their work, education, and personal lives.

Sub-theme 1.1: Time Commitment and Physical Fatigue

Many patients reported that the time required for regular hospital visits significantly interfered with their daily lives, particularly for those balancing work or school. This was compounded by the physical fatigue experienced after transfusions.

- Participant 3 (30-year-old male with thalassemia): "It's hard to hold down a job when you have to go in for transfusions every few weeks. You lose a whole day, and then the next day, you're exhausted. It feels like my life revolves around hospital visits."

- Participant 7 (22-year-old female with sickle cell disease): "I'm always behind in my studies. After a transfusion, I'm wiped out. I can't focus or keep up with my classmates. It's frustrating because no matter how hard I try, I feel like I'm always catching up."

Sub-theme 1.2: Impact on Employment and Finances

Several participants mentioned the financial burden caused by missing work or being unable to pursue full-time employment due to their transfusion schedule. This disruption often led to stress about maintaining financial stability.

- Participant 9 (45-year-old female with aplastic anemia): "I had to go part-time at work because I just couldn't keep up with the hours. But now, with less income, I worry about paying my bills. It's a constant balancing act between managing my health and making ends meet."

Theme 2: Psychological Burden and Emotional Strain

The emotional and psychological toll of living with a chronic condition that requires frequent transfusions emerged as a prominent theme. Participants shared feelings of anxiety, helplessness, and frustration over their reliance on transfusion therapy and the uncertainty of their condition.

Sub-theme 2.1: Anxiety and Fear of Complications

Many participants expressed ongoing anxiety about their health, particularly related to potential complications from their condition or the transfusions themselves. This included fears about iron overload, transfusion reactions, and the unpredictability of their health.

- Participant 5 (37-year-old male with sickle cell disease): "I worry every time I go in for a transfusion. There's always this fear in the back of my mind—what if I have a reaction? Or what if my body doesn't respond this time? You try to stay positive, but it's hard."

- Participant 12 (28-year-old female with thalassemia): "The iron buildup is a constant fear. I'm always thinking about it, wondering what damage it's doing to my organs. It's like there's always something to worry about, and it never ends."

Sub-theme 2.2: Emotional Toll of Dependence on Transfusions

The psychological burden of relying on regular transfusions led to feelings of frustration and helplessness for many participants, who felt that their lives were dictated by their treatment schedule.

- Participant 4 (50-year-old male with aplastic anemia): "It's like you lose control of your life. I feel dependent on these transfusions just to keep going. It's frustrating because I don't want my life to revolve around this, but it does."

- Participant 8 (19-year-old female with sickle cell disease): "Sometimes I feel like I'm stuck. Like no matter how much I try to live normally, I'll always be tied to these hospital visits. It's hard not to feel trapped by it."

Theme 3: Social Isolation and Support

Participants highlighted the social consequences of living with a chronic condition that requires regular medical intervention. Many described feelings of isolation, as their treatment schedule and the physical effects of transfusions limited their ability to participate in social activities. However, support from family, friends, and healthcare professionals was identified as a crucial coping mechanism.

Sub-theme 3.1: Social Isolation and Stigma

Frequent hospital visits and physical symptoms of their condition often caused participants to withdraw from social interactions. Some also reported feeling stigmatized due to their visible medical needs or misconceptions about their condition.

- Participant 6 (25-year-old male with thalassemia): "I've stopped going out with friends as much because I'm always tired or just don't feel well after transfusions. And when I do go out, people sometimes treat me differently because they don't really understand what I'm going through."
- Participant 11 (33-year-old female with sickle cell disease): "People don't realize how hard it is to keep up socially. You feel left out because you can't always join in, and after a while, you just start avoiding things."

Sub-theme 3.2: Support from Family and Healthcare Providers

While isolation was a common experience, participants also expressed appreciation for the support they received from family members and healthcare professionals. This support helped them manage the emotional and physical challenges of long-term transfusion therapy.

- Participant 2 (40-year-old female with aplastic anemia): "My family has been amazing. They understand when I need help and when I need space. Without them, I don't know how I'd manage this."
- Participant 10 (55-year-old male with thalassemia): "The nurses and doctors here have been a huge support. They always take the time to explain things and reassure me, especially when I'm feeling anxious. That makes a big difference."

Discussion

This study aimed to explore the lived experiences of hematology patients undergoing long-term blood transfusion therapy, focusing on the impact of this treatment on their daily lives, mental health, and social interactions. The findings revealed several key themes, including the disruption of daily life, the psychological burden of dependence on transfusions, and the social isolation experienced by many patients. These results provide a deeper understanding of the challenges faced by individuals receiving regular transfusions, contributing to the broader body of literature on chronic illness and long-term medical treatments.

Disruption of Daily Life

One of the most significant findings was the extent to which long-term blood transfusion therapy disrupted patients' daily routines and responsibilities. Participants reported that frequent hospital visits and the physical side effects of transfusions interfered with their ability to maintain stable employment, education, and family responsibilities. These results align with previous research by Hershko (2010), who found that the time and physical demands of transfusion therapy often limit patients' ability to engage in regular activities, contributing to feelings of frustration and helplessness.

The disruption to daily life was particularly pronounced in patients who had to balance their treatment with work or academic obligations. As Platzbecker et al. (2012) noted in their study of sickle cell patients, managing a chronic illness requiring regular transfusions often leads to absenteeism and financial strain. The findings from this study highlight the need for more flexible healthcare solutions that allow patients to better manage their treatment schedule without sacrificing their personal and professional lives. Employers and educational institutions should also consider accommodating the unique needs of these patients, providing the necessary flexibility to balance treatment with daily responsibilities.

Psychological Burden and Emotional Strain

The psychological toll of long-term transfusion therapy was another prominent theme in this study. Many participants expressed feelings of anxiety and fear related to their condition, particularly concerning the long-term effects of transfusions, such as iron overload or potential complications during transfusions. This is consistent with the findings of Messina et al. (2008), who highlighted the emotional distress experienced

by patients managing chronic blood disorders. The unpredictability of their health and dependence on transfusions contributed to a sense of helplessness, as many participants felt they had little control over their own lives.

This psychological burden underscores the importance of integrating mental health support into the care of hematology patients. Currently, the focus is often on the physical aspects of transfusion therapy, with limited attention paid to the emotional and psychological well-being of patients. By providing access to counseling or peer support groups, healthcare providers can help alleviate some of the emotional strain these patients experience. Cappellini et al. (2014) emphasized the role of peer support in helping patients manage their mental health, and this study's findings reinforce the value of offering structured emotional support alongside medical treatment.

Social Isolation and Stigma

The impact of long-term transfusion therapy on social interactions was another critical finding. Many participants reported feelings of isolation, both due to the physical limitations imposed by their treatment and the stigma associated with their condition. This mirrors the findings of Loizou et al. (2016), who reported that hematology patients often withdraw from social interactions due to fatigue or fear of being misunderstood by others. The stigma surrounding visible medical treatments, such as blood transfusions, can exacerbate feelings of isolation and lead to further social withdrawal.

The role of support systems, particularly family and healthcare providers, was highlighted as a key factor in mitigating social isolation. Participants who had strong support networks were more likely to cope effectively with the challenges of long-term treatment, reflecting the findings of Messina et al. (2008). Healthcare providers should be aware of the social challenges faced by long-term transfusion patients and offer resources to strengthen social support. This could include facilitating connections with peer support groups or providing educational resources to help patients explain their condition to friends and family, reducing the stigma they might face.

Practical Implications for Healthcare Providers

The findings of this study have important implications for healthcare providers. First, the disruption to daily life and the psychological burden faced by long-term transfusion patients suggest that more comprehensive care plans are needed. These plans should not only address the medical aspects of transfusion therapy but also the psychological and social challenges that patients encounter. Providing flexible transfusion schedules, offering psychological support, and helping patients navigate the financial implications of their treatment are critical areas where healthcare providers can improve patient care.

Additionally, healthcare teams should be more proactive in identifying patients at risk of social isolation or stigma and work to connect them with supportive resources. This could include arranging patient support groups, offering counseling, or creating educational programs that reduce misconceptions about blood transfusions. By adopting a more holistic approach to patient care, healthcare providers can better meet the needs of long-term transfusion patients and improve their overall quality of life.

Limitations and Future Research

While this study provides valuable insights into the experiences of hematology patients undergoing long-term transfusion therapy, it is important to acknowledge its limitations. The study was conducted in a single tertiary hospital, which may limit the generalizability of the findings to other healthcare settings. Additionally, the sample size, though adequate for qualitative research, may not capture the full diversity of

experiences among all patients undergoing transfusion therapy. Future research could expand on these findings by exploring patient experiences across multiple healthcare settings or by focusing on specific subgroups, such as pediatric or elderly patients.

Moreover, this study focused on the short-term experiences of patients currently undergoing transfusion therapy. Longitudinal research is needed to explore how these experiences evolve over time, particularly regarding the long-term psychological and social impact of transfusion therapy. Such studies could provide further insights into how healthcare providers can better support patients as their treatment progresses.

Conclusion

This study highlights the significant impact of long-term blood transfusion therapy on patients' daily lives, mental health, and social interactions. The findings emphasize the need for a more holistic approach to patient care, addressing not only the medical aspects of transfusion therapy but also the psychological and social challenges that patients face. By providing more comprehensive support, healthcare providers can improve the overall well-being and quality of life for patients undergoing long-term transfusion therapy.

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