Uncovering the realities of ß-Thalassemia major women through qualitative descriptive study- Policy matters

Rawshan Jabeen (RawshanJabeen@gmail.com)
Aga Khan University

Iqrah Ansari
children's hospital

Butool Durrani
Aga Khan University

Mubarak Jabeen Salman
children's hospital

Laraib Mazhar
University of Pennsylvania

Muhammad Usman Hussain Ansari
Aga Khan University

Ali Hussain Ansari
Aga Khan University

Saba Kabani
Mubarak Al Kabeer Hospital

Saqib Ansari
children's hospital

Research Article

Keywords: Beta-thalassemia, Women's Health and Psychosocial factors associated with wellbeing.

Posted Date: July 7th, 2023

DOI: https://doi.org/10.21203/rs.3.rs-3106742/v1

License: ☀️ This work is licensed under a Creative Commons Attribution 4.0 International License. Read Full License

Additional Declarations: No competing interests reported.
Abstract

Introduction:

ß-Thalassemia is a genetic disorder that affects physical and emotional well-being and has a significant monetary impact on families and the healthcare system. Social support is believed to play a vital role in improving the quality of life for these patients, particularly in terms of mental wellbeing. This study aims to understand the universal psychosocial burdens faced by young women suffering from ß-thalassemia major and their perceptions and role in society.

Methods:

The study design was qualitative descriptive, using purposive sampling. In-depth interviews were conducted with six young women diagnosed with ß-thalassemia major, aged between 16 and 40 years, with varying levels of education. The data was analyzed using NVIVO-12, through coding, categorization, theme development, and mind mapping.

Findings:

This study aimed to understand the psychosocial facilitators and barriers to the wellbeing of female ß-thalassemia patients. Through inductive content analysis. Positive Factors which enhance quality of lives were education, family support, quality of life, and contributions to society however negative influencer factors were depression social segregation/isolation, lack of insurance services, difficulties in school, employment, and social relationships.

Conclusion:

This study highlights the psychosocial facilitators and barriers to the wellbeing of young female ß-thalassemia patients in Pakistan. It highlights the need for further research to understand their needs and the necessary support from society.

Background

Beta thalassemia is a genetic disorder prevalent in our country and responsible for serious physical and emotional wellness comorbidities and is one of the leading causes of financial burden on families and health care systems. 1 Thalassemia is caused by a reduction or failure of production of one of the globin chains i.e. Each year, 50,000 to 100,000 children die of thalassemia with a majority in in low- and middle-income countries, and approximately 7% of the world's population are carriers of a hemoglobin disorder. 2 Over 20,000 people of different ages with thalassemia major are in Iran. An estimated 5000–9000 children with ß-thalassemia are born per year in Pakistan 3 ß-thalassemia is caused by the reduction or defective production of a beta-globin chain. 4 Patients who suffer from this disorder have beta-globin chain production that is usually life-threatening as the patient depends on regular blood transfusion and
thus demands continuous medical management. A study on the psychological wellness of thalassemia patients showed a very high prevalence of depression and anxiety among patients suffering from beta-thalassemia. The increase in anxiety and depression in the patient population is attributed to the absence of social support. Furthermore, previous studies gave insights related to giving social support to such patients for their mental and physical wellbeing. This can effectively decrease the level of depression and anxiety these patients go through in life on both social and emotional grounds. Many studies and surveys have shown that social support has a positive impact on the self-care among patients with beta-thalassemia. Close friends and family play a very important role in providing support and their presence positively influences the psychological health of these patients. With regards to this high prevalence of depression, anxiety, lack of social support, or other psychiatric disorders, the study will be conducted to emphasize the need to design interventions to improve the bio-psycho-social state of girls suffering from beta-thalassemia. Previous studies have reported a higher incidence of depressive, anxiety disorders, and overall growth impairment in the general functioning of patients with β-TM.

Clinical complications have also negatively affected patients with β-TM. These patients suffer a great deal of depression and an emotional fight within themselves. Another study found the low health-related quality of life (LHRQOL) in children with β-TM during the schooling year as one of the most affected aspects of living. Adolescents struggle to achieve a normal routine and manage daily challenges brought about by the chronic condition. Therefore, there was a need to conduct qualitative studies to understand the female’s experience perspectives of adults that have thalassemia. The rationale of targeting females in study suffering from β-thalassemia is to open a new forum of discussion on the sensitivity of this matter and thus to create awareness on a community level so that such patients may lead a healthy lifestyle. Interpretive research employs a theoretical sampling strategy, where study sites, respondents, or cases are selected based on theoretical considerations such as whether they fit the phenomenon being studied. This study aimed to identify the understanding β-TM’s women about their diseases and its associated factors related to their wellbeing. This study also explores the living experience of girls suffering from beta-thalassemia.

**Methodology**

We used qualitative descriptive study data collection from August 2021-September 2021. Purposive sampling was used to select participants and conducted four focus group discussions with β-thalassemia major girls above 18 years that have regular visits to the selected Children Hospital Karachi. A semi-structured validated interview guide was developed based on open-ended questionnaires to interview the girls suffering from beta-thalassemia. Data collection strategy after approval from the institutional review board and informed consent. These patients took in-depth interviews for a broader understanding of their bio-psycho-social problems. The participants were interviewed to understand their psychosocial challenges. All confidential information is kept for five years on password-protected computers and locked filing cabinets and is only accessible to members of the research team. During
transcription, audio recordings were anonymized; the research team removed all identifying information before using the software analysis tool.

**Data Analysis**

The study data was transcribed from Urdu to the English language and was analyzed with the help of qualitative data analysis software NVivo 12. Qualitative content analysis was used to understand the apparent facts to understand the meaning of content through thoroughly reading. The text was divided into 'meaning units,' which were shortened and labeled with a 'code' without losing the study context. Finally, tree codes parallel to the main emergent themes were developed and subdivided into branch codes. Two independent investigators performed coding, category creation, and thematic analysis, resolving discrepancies to reduce the researcher's bias. We used an Inductive approach to analyze content, and two major themes were identified which affected their wellbeing. We used several techniques to enhance the trustworthiness of the following study. To increase the trustworthiness of the research article, we applied many strategies such as double-checking of transcription and its translation, two independent researchers analyzed and interpreted the data separately, and we resolved all discrepancies. The study's progress and method were reported and addressed by the researcher's supervisors during analysis and interpretation.

**Demographics Information:**

The Study participants’ demographic information as described in table 1,

A total of Seven individuals took part in this study with an age range between 18 to 39 years, and varied education level from intermediate to Ph.D. studies. Among the seven participants, three were students, three were professional employed women's and one was stay-at-home parent. These participants perceived their quality of life from normal to excellent. However, all were unmarried women. The family income of all participants was above 50 thousand PKR, and an NGO supported them for their treatment. These participants were from different areas of Pakistan, such as Rawalpindi, Islamabad, Peshawar, and Karachi. (Refer to Table 1)

Six in-depth interviews were conducted and were analyzed with the help of the content analysis. We identified the themes that impacted the wellbeing of major thalassemia patients and their associated factors. Four main themes have been derived from participants' attitudes, thereby drawing the perception of β-TM patients. Based on translated transcriptions, five major themes were identified: positive factors, negative factors, and well-being-related factors and suggestions. (Refer to figure 1)

**Theme I: Positive factors.**

- **Education status**
This positive factor talks about the education status and working in a better environment ensures the participant’s hardship to live a well-settled lifestyle and build their confidence. They shared that many thalassemia children cannot continue their education because of their fear of the severity of the disease however as women, they felt that they lived a contented life due to their education.

“Coordinator in a school and also works in a university, and entrepreneur earns good salary package in Karachi” (Participant 4)

• Financial Stability

Family provided adequacy, limitations, and insufficient support. The study also explored that all patients said that they had received support from friends. A sense of understanding of their responsibilities has also been seen, especially in adult patients. The participants expressed that they do not rely on others for support and instead, strive to take care of their own responsibilities, such as paying for household bills and engaging in social activities. This highlights the participants’ independence and self-sufficiency in managing their life despite the challenges posed by their condition.

“I always try to relax my parents. Yes, I do manage my daily routine activities. I do all my work related to diseases, and I also bear all my expenses on my own.” (Participants 3)

• Understanding of disease and its management

The participants in the study shared their experiences related to managing ß-thalassemia, including blood transfusion, mood swings, iron deposition, the use of clinical trial drugs to reduce blood transfusions, and splenectomy. One participant said that they must manage their mood swings by using medications. Other participants shared that they have noticed an improvement in their life after starting Hydrae treatment and experiencing fewer hospital visits and blood transfusions. Another participant discussed undergoing splenectomy and visiting the hospital once a month for blood transfusions, as opposed to twice a week prior. Most of the participants have experienced a deep sense of medication understanding. The treatments given to the patients also experienced a sense of fatigue, weakness, mood swings, and disability in doing their daily activities such as university sports, physical activity, and outdoor work. In a patient, lack of knowledge has also been observed as a hurdle in deciding for the future. For example, in this sense, some participants implied that:

Mood swing and management ”I have an issue of focus, lack of concentration. Think about many things in a time, I use medications because when I was a child, I have gotten fits, so mood changes caused due to this drug, but I must set my mood.” (Participant 3)

Clinical trial drug for reducing blood transfusion: “As I started hydrae life changes. Less blood transfusion now it has ended, very convenient, like when I was on transfusion sometimes, I come with my uncle or cousin bother I really feel like a burden on them. Then fewer hospital visits. Things are better. Then no frequent Hb checks. “No blood transfusion.” (Participant 6)
Splenectomy: “First twice a week but now we are visiting this hospital from 6 months and also undergo operation from the hospital and now once a month I undergo blood transfusion” (Participant 5)

Most of the participants experienced fatigue and tiredness in recreational activities. Few shared that they had difficulties with home chores or hectic routines, such as they felt tired after shopping or long walks due to weak bones. Even some of them tried during their regular home chores. As a woman they also shared that they were not able to contribute to home chores like cooking due to pain and limited physical activities

“I feel exhaustion at the end of the day, can't go shopping with my sister due to tiredness, due to my tough job at school, feel fatigued feel like leave the job, but keep myself busy, my legs get swollen due to thalassemia” (Participant 5)

- **Friends and Family Support**

The result of the study showed that the participants had a mix of experiences with regards to social support from family, friends, and partners. One participant specifically mentioned her partner as a big support in her life, while others had limited but supportive friends. A few participants felt hesitant in socializing with new people due to their disease, but overall, they felt good when spending time with their close friends. This highlights the importance of having strong social support for individuals suffering from β-thalassemia. However, a few participants reported feeling uncomfortable in social situations with people outside of their close circle due to their disease, leading them to have limited but supportive friends.

“My partner is very loving and understanding always motivate me to have a successful life do more studies.” (Participant 5)

“People are supportive and like me. Whenever I go somewhere they serve me and treat me well. I like to work with my friends, but they do not allow me to help them out in their work” (Participant 1)

- **Healthy routine**

Most of the participants have had the incredible experience of being busy in different intellectual and interesting activities daily, but they never ignored their diseases and management. They took healthy food as suggested by physicians and took proper medication. One of the participants shared that they read a research paper that sleep is important to be healthy, so she took care of sleep and advised other patients.

This is from a participant’s expression.

“My day spends in jobs and after returning back from work do home chores, three days in a week I visit Karachi University, moreover I do business so go outside to buy the things and to socialize, work on social notes” (Participant 6)

- **Support by government and NGOs**
Most of the participants have experienced less responsive feedback or support from government organizations. Participants pointed out that the law should endorse the significance of ß-thalassemia testing before marriage.

“No role of them. Some are doing decent work to provide care to major thalassemia patients. Some doctors are like lifesavers. (Participant 5)

“They should conduct workshops for awareness and should give them employment“ (Participant 6)

The participants described their experiences about the shortage of drugs and blood etc. For example, about this matter, one of the participants expressed:

“We do not get medicines in Baluchistan but in Karachi, we get free medicines and easily buy blood for transfusion.” (Participant 3)

It is important to stress that inadequate support and information received from government send NGOs were also reported by half of the participants, accompanied by the desire for more opportunities to talk about care and treatment and for the support provided on a more regular basis.

“NGOs can play their role in patients who are coming from interior Sindh they have blood transfusion so it can be supported by NGOs” (Participant 1)

**Theme II: Negative factors:**

- **Physical appearance**

Participants have often experienced hatred comments about their physical looks. Many of their extended family were taunting them for their looks; they were also asked not to come in front of guests. Few of them shared that people were not inviting them to wedding because of disclosures that they were or had thalassemia diseases. Participants also understood that people did that because of our subjective societal norms. For example, some participants have expressed this in this regard.

“If we talk about society, due to physical appearance we must come across with a lot of taunting that “Uncle and niece “are going and asked me to don’t meet to cousins’ in-laws” (Participant 1)

“Yes. Even some outsides give awfully bad reactions.” (Participant 3)

“Yes exactly. But I tried to overcome and present the sweet, even my aunt told me not to go In-front of my cousins’ in-laws as they will question about myself” (Participant 5)

- **Loneliness in a relationship and physical isolation:**

To describe their own experiences, the participants expressed feelings like lack of friendship, inadequate responses of friends, improper solvency to meet patient’s needs from to be in-laws, and increased hope
from another partner. These factors automatically become the cause of depression and other mental disorders. Emotional problems and difficulties in dealing with feelings were the most common problems of the participants. However, they reported that the mothers, friends, and cousins gave support; it is worth stressing that the people stated that the troubles continued to exist in their lives. Participant three shared their coping mechanism for dealing with their physical pain and emotional distress. They revealed that they would retreat to a private room, close the door, and cry to relieve their feelings. After crying, they would take medication for pain and then return to their normal demeanor, pretending to be sleeping to avoid arousing their mother’s concern. This pattern of behavior indicates a desire to manage their symptoms and emotions in solitude.

Some patients express this in this way.

“We all are facing loneliness, but as time changes people understand us. Because in adult life their in-laws do not accept it the way they should. So that loneliness brings us stress and many other diseases. So, we feel isolated. Which is the reason for many other comorbidities.” (Participant 5)

“Lots of issues, couples should have understood. A major can understand a major thalassemia but if the partner is a normal person so they must understand” (Participant 1)

- **Non-acceptance as a woman or wife**

Many participants have experienced unrealistic attitudes from various family members, such as demotivating comments, irresponsible behavior, etc. For instance, some participants express this in this regard.

“Yes exactly. Parents or family is a big issue. For instance, they are not going to accept the one who is having any disease while the couple has particularly good understanding.”

“Yes, they do. Even some outsiders give awfully bad reactions.” (Participant 2)

**Theme III: Wellbeing of B-thalassemia women**

- **Participants perceived empowerment:**

Participants described their empowering experiences with a few restrictions from their family members. Most of our patients were pursuing higher education with extended periods of work experiences; because of their disease, they indeed believe in bringing change in the thalassemia world with the approach of a successful individual who will surely achieve her milestone of high quality of life of a ß-thalassemia.

“No, nobody helps my father financially, my father’s income goes all in my treatment. To a certain age, my father did this, and now after employment, I am doing this Yes, I do 100 percent. My father empowers me and gives me confidence that I am better than many girls. (Participant 5)
• Self-Recognition and acceptance:

Some of the participants expressed that they had been highly motivated because they know what changes they can bring into the lives of patients by providing them with a way to succeed in life. Higher education level was associated with better psychological health in the understanding of their responsibility as a responsive member for their thalassemia members and make them an insight of their capabilities of being active socially and morally both.

“Work in social modes as to gather charity for the hospital for thalassemia patients, also provide the medication for annual use.” (Participant 6)

“I told them that I can finish all my tasks like others so do not treat me like this. My boss wanted to give sympathy and I really do not like to have it. Then they started to behave in a normal way. So, they show us positive support towards our health. do not show any negative behavior due to our disease” (Participant 1)

Theme: Recommendation for a better future:

Participants expressed their gratitude towards a better future and healthy lifestyle, and an independent working mode.

• The flexible education system for children with disorders

Some of the participants were quite confident and willing to bring certain changes in the lifestyle of thalassemia patients, particularly in women moreover, and they demanded an elevated level of academic and financial aid from the government level.

“I would like to make these women more educated even on the government level because I have limited resources,” (Participant 3)

• Creating awareness among the general population

Participants have shown a great interest in creating innovation in the field of the education system for thalassemia patients. Tiredness is one of the issues which makes a thalassemia patient suffer during school times therefore teachers as well classmates should be given the necessary knowledge on how to deal with these patients during school hours.

“The education system, in primary, is not burden and it is important to tell the other student that understand them as your classmates. Do not discriminate against them, give another student the realization that they are like you and suffering from some problems so you should understand. Society should have awareness of us” (Participant 2)

• Marriage counseling for adult Patients
In this field of relationship development, most of the patients expressed a high hope from the government officials to make sure the marriage decisions. Moreover, they understood the importance of this unique relation, so one of the participant forces in this way.

“Yes, they should have; adult patient’s marriage should have been done by them” (Participant 4)

- **Premarital test for General population**

Most of them appreciated the efforts of existing government and how our judicial system developed a marriage certificate which endorsed the thalassemia blood test as mandatory at the time of marriage.

“There should be a compulsory test before marriage in the marriage certificate, issuing health card like in other provinces of Pakistan. Provide them with health benefits and free education”. (Participant 5)

**Discussion**

The results of the study suggest that education and financial stability have a positive impact on the lives of beta-thalassemia women. Participants reported that their level of education allowed them to lead a well-settled lifestyle and build confidence, with many holding higher-level degrees or working in well-paying jobs. However, they also noted that many children with thalassemia are unable to continue their education due to fears about the severity of their condition. In terms of financial stability, participants received support from both their families and friends, and felt a sense of responsibility for managing their own expenses and responsibilities related to their disease. ß-thalassemia is now an entirely separate illness. Recent studies have described the disease’s pathogenesis, and more support has been provided by molecular biology that can detect most thalassemic abnormalities. Patients suffering from this illness are transfused from infancy to avoid bone abnormalities, splenomegaly and many other medical abnormalities.

Our study participants understood and managed their diseases. According to Pignatti et al., individuals with thalassemia experience a longer and improved quality of life in developed countries. However, they are prone to a variety of complications, including heart disease such as heart failure and arrhythmias, liver problems like chronic hepatitis that can lead to cirrhosis and, in some instances, hepatocellular carcinoma, endocrine disorders like hypogonadism, hypothyroidism, diabetes, and hypoparathyroidism, stunted growth, osteoporosis, thrombophilia, and pseudoxanthoma elasticum. However, these complications are becoming less frequent in younger patients who receive transfusions of virus-screened blood, due to advancements in oral iron chelators and imaging technologies.

Our study has also identified the complications experienced by ß-thalassemia women in their life and how they manage the disease. Patients with transfusion-dependent and Hydroxyurea have lived a good life with the help of good clinical provision and family support. All ß-thalassemia patients in our study were continuing their education and believed that because of good education, they were empowered to share their family financial burden and their disease expense. However, they shared their apprehensions related to their exam schedules which does not allow any flexibility and hence they face challenges like absence on the
day of exam because of scheduled appointment for transfusion. Zaheer et al. reported in a short communication that the actual number of the thalassemia centers in the governmental, private, and non-profit sectors is unclear. and the quality of these centers' services varies depending upon their sector i.e., governmental, private, and non-profit. The afflicted families frequently create centers in the private/NGO sector on charitable grounds; however, many of these organizations lack the technical knowledge necessary. Our study also revealed that the study setting was NGO-supported, and it provides treatment at a subsidized rate with quality care.

Societal pressure was the biggest reason for the hardships faced by thalassemia patients as they are not accepted as normal human beings. Informed opinion and active co-operation on the part of the public are of the utmost importance in improving the health of the people. Beta thalassemia major is a fatal condition that threatens the patients' lives and depletes the strength and finances of the families. It is heartbreaking to witness the families of these patients that they need to struggle for their loved ones, knowing that he or she will not be with them for long.

Lack of support system was among the most important concerns of mothers, and reflects many challenges such as lack of holistic care system for families. Similarly, no social acceptability and loneliness are the major distress factors among ß-thalassemia women. Contrary to that our study participants perceived decent quality of life as they had better knowledge related to the management of their signs and symptoms. The absence of comorbidities improves the overall quality of life. Another study revealed that the comorbidities were a strong predictor of the poor physical and total quality of life score.

**Ethical and issues of thalassemia policy in Pakistan**

In Pakistan, there is a significant policy gap when it comes to addressing the issue of Thalassemia. Although the government has taken some steps to address the issue, such as setting up Thalassemia Centers and providing free treatment, there is still a lack of comprehensive policy that addresses all aspects of the problem. One major policy gap is the lack of widespread awareness and education about Thalassemia, both among the general population and the medical community. This leads to late diagnoses and inadequate treatment, which can have serious consequences for the affected individuals and their families. Another policy gap is the lack of access to proper diagnostic and treatment facilities, particularly in rural and underprivileged areas. Many Thalassemia patients struggle to find adequate medical care and face difficulties in getting the treatment they need. There is also a lack of funding and resources dedicated to Thalassemia research and development. This makes it difficult to make progress in finding new treatments and improving the quality of life for Thalassemia patients. Further the policy gap in addressing Thalassemia in Pakistan needs to be filled in order to effectively address this issue and provide support for those affected by the disease. This would require a concerted effort from the government, healthcare providers, and the general public.

**Strength and limitations**
It is important to note that this study is qualitative descriptive research, which means that its purpose was to explore and describe the experiences of the participants, rather than to generalize the results to a larger population. The study highlights the various emotional and physical challenges faced by young girls with beta-thalassemia, including anxiety, depression, social fear, peer pressure, and other difficulties. These difficulties stem from an inadequate and non-supportive environment, as well as a lack of understanding and knowledge about disease in society. The findings of this study should be interpreted with caution as it only focuses on the experiences of female participants and does not provide insight into the perspectives of males. Additionally, the nature of focus group discussions (FGD) is such that dominant participants may have influenced the thoughts and perspectives of others during the sessions.

This study helped to understand the social issues that women with thalassemia face in metropolitan locations. However, it is critical to investigate the extra challenges faced by women in rural regions, where there is a significant lack of education and access to healthcare services.

**Recommendations:**

To enhance the quality of life of thalassemia women in Pakistan and other low- and middle-income countries (LMICs), the following policy recommendations can be made:

a. **Improved Access to Treatment:**

Governments should ensure that thalassemia women have access to comprehensive and affordable treatment, including regular blood transfusions and iron chelation therapy.

b. **Awareness and Education Campaigns:**

Governments and non-governmental organizations should launch awareness and education campaigns to educate the public about thalassemia and the challenges faced by thalassemia women. Further, efforts must be made by all stake holders, including government and non-government organizations to work for prevention of thalassemia.

c. **Supportive Workplace Environments:**

Governments and employers should work to create supportive workplace environments for thalassemia women, including flexible work arrangements and accommodations for medical appointments.

d. **Social and Psychological Support:**

Governments should provide social and psychological support for thalassemia women, including counseling and support groups, to help them manage the emotional and social challenges of living with thalassemia. Moreover, psychosocial support groups should be formed, which are a good support for these patients and their families.
e. **Improved Data Collection and Research:** Governments should invest in improving data collection and research on thalassemia, including studies on the experiences of thalassemia women, to better understand their needs and improve policies and programs to support them. By implementing these recommendations, thalassemia women in Pakistan and other LMICs can lead healthier, happier lives with improved quality of life.

**Conclusion**

The study provides important insights into the challenges faced by individuals with thalassemia. It highlights the need for policy revision to raise awareness and understanding about the disease in communities. This would help beta-thalassemia patients better manage the pressures and fears they face from society, peers, friends, family, and emotions. The study presents a valuable opportunity to improve hospital policies by incorporating psychological services and emphasizing the significance of social and psychological support in patient care.

**Declarations**

- **Conflict of interest:** Authors has no conflict of interest
- **Consent and participation:** All participants provided written consent prior to the interviews.
- **Acknowledgements:** Not applicable
- **Funding:** Not applicable
- **Authorship contribution**

Rawshan Jabeen was the Principal Investigators (PIs) and Saqib Ansari Senior author conceptualized the study and both were involved in study design, Butool durrani, Mubarak Jabeen, Saba Kabani and Iqrah Ansari designed the study protocol and obtained IRB approval. All team members were involved in formulating study methodology, developing study tools, and finalizing the data analysis to ensure rigor. Rawshan Jabeen, Ali Husain, Usman Husain and Mubarak Jabeen were involved in data collection and transcription and translations process. Rawshan and Larib Mazhar conducted a review of the literature and were involved in reviewing and draft manuscript and finalize the manuscript. All team members reviewed the main article and were involved in feedback and support.

**References**


Figures

**Social economical Status**
- Education, Occupation and Family income

**Positive factors**
- Understanding of disease and its management
- Friends and Family Support
- Healthy routine
- Support by government and NGOs

**Negative factors**
- Physical appearance
- Loneness in a relationship and Social Isolation
- Non-acceptance as a woman or wife of anyone

**Wellbeing factors**
- Empowerment
- Recognitions
- Self-care and Acceptance

**Recommendations**
- Premarital test of β-thalassemia 1-minors and marriage counseling of β-thalassemia major
- Creating awareness among society
- Better Education system and Job employment for β-thalassemia patients

**Figure 1**

Living experience of beta-thalassemia major women in Pakistan.