MALAYSIAN JOURNAL OF COMPUTING AND APPLIED MATHEMATICS (2024) 7 (1) 1-10

DOI: *https://doi.org/10.37231/myjcam.2024.7.1.116*

Article: Received 02.11.2023; Accepted 16.02.2024; Published 31.03.2024

THALACARE: EMPOWER THALASSEMIA WARRIOR

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Abstract: Thalassemia, a genetic blood disorder characterized by abnormal hemoglobin production, poses significant challenges globally, particularly in regions with high prevalence rates. Despite medical advancements, managing thalassemia remains complex due to ongoing medical interventions, potential treatment side effects, and the psychological impacts of chronic illness. Regular blood transfusions are crucial for maintaining adequate hemoglobin levels, but they come with risks such as iron overload. Thalassemia patients also struggle with treatment side effects, medication adherence, and accessing reliable information and support services. In response to these challenges, the ThalaCare app emerges as a comprehensive solution to empower individuals with thalassemia. The app's Community Forum, powered by collaborative filtering algorithms, facilitates meaningful interactions among users with shared similar experiences and interests. This fosters a supportive environment where users can exchange experiences, provide guidance, and emotionally support each other. By utilizing collaborative filtering, ThalaCare aims to address the psychological needs of thalassemia individuals, reducing feelings of loneliness and fostering a sense of community. Moreover, collaborative filtering enhances the Community Forum's relevance and usefulness by tailoring content recommendations based on individual preferences and past interactions. This personalized approach improves the overall user experience, creating a more supportive and engaging platform for individuals managing thalassemia. ThalaCare's integration of collaborative filtering demonstrates significant potential in meeting the multifaceted needs of thalassemia patients, ultimately striving to alleviate their burdens and enhance their well-being.

Keywords: Thalassemia, Genetic blood disorder, ThalaCare app, Collaborative filtering, Community support

1. INTRODUCTION

Thalassemia is a genetic blood disorder characterized by abnormal hemoglobin production, leading to chronic anemia and potential complications [1]. Patients with thalassemia face numerous challenges in managing their condition, including frequent blood transfusions, iron overload, medication adherence, and accessing reliable information and emotional support [2]. These challenges contribute to a significant burden on patients' physical and emotional well-being, as well as their overall quality of life.

Individuals living with thalassemia encounter various obstacles in their daily lives. These challenges include the need for regular blood transfusions to maintain adequate hemoglobin levels [3], which can be time-consuming and financially burdensome[9]. Additionally, managing iron overload resulting from repeated transfusions poses health risks and requires careful monitoring and treatment. Medication adherence is another critical aspect of thalassemia management, yet patients may struggle to remember their complex medication schedules amidst their already demanding treatment regimen. Moreover, accessing reliable educational resources and finding a supportive community to share experiences and seek emotional support can be challenging for thalassemia patients, leading to feelings of isolation and uncertainty about their condition.

ThalaCare offers a comprehensive solution to address the challenges faced by thalassemia patients. The app provides a Personal Health Journal feature that enables users to effortlessly track their blood transfusions, iron levels, medications, and overall health status. By generating personalized reports and insights based on this data, ThalaCare empowers patients to better understand their health trends and make informed decisions about their treatment plans. Furthermore, ThalaCare includes Treatment Reminders to

ensure patients never miss important medical appointments or medication doses. Through timely alerts and reminders, the app helps users stay organized and compliant with their treatment regimen, ultimately improving their overall health outcomes. ThalaCare also serves as an invaluable educational resource hub, offering a variety of informative materials such as videos, articles, and infographics about thalassemia, treatment options, and lifestyle advice. By providing easily accessible and reliable information, the app equips users with the knowledge they need to effectively manage their condition and make informed decisions about their health. Additionally, ThalaCare features a Community Forum where users can connect with a supportive community of fellow Thalassemia Warriors. Here, users can share their experiences, seek advice, and provide emotional support to one another, fostering a sense of belonging and solidarity within the thalassemia community. Through these features, ThalaCare not only streamlines thalassemia management but also empowers patients to lead healthier, more informed lives while fostering a supportive community of individuals facing similar challengesthe meth-od, results, and discussions of this IoT-integrated irrigation system. This will show how it could help plants grow better in home gardens.

2. OVERVIEW OF THALASSEMIA

2.1 Type of Thalassemia

Thalassemia is a complex group of inherited blood disorders that affect the production of hemoglobin, the protein in red blood cells that carries oxygen throughout the body [4]. This condition results from genetic mutations that affect the synthesis of either alpha or beta globin chains, essential components of hemoglobin [5].

Alpha thalassemia arises from mutations in genes responsible for alpha globin chain production, resulting in a spectrum of conditions. Individuals with Alpha Thalassemia Silent Carrier typically carry one mutated gene and one normal gene [4], often experiencing no symptoms due to sufficient alpha globin chain production. Alpha Thalassemia Trait, affecting two genes, leads to mild anemia with symptoms like fatigue or mild anemia. Hemoglobin H Disease occurs when three alpha globin genes are affected, causing significant anemia accompanied by fatigue, weakness, and pale or yellowish skin. Hydrops Fetalis represents the most severe form, with all four alpha globin genes affected, resulting in severe anemia even before birth, often leading to fetal or newborn death.

Beta thalassemia stems from mutations in the genes responsible for beta globin chain production, leading to varying degrees of severity. Beta Thalassemia Minor (or Beta Thalassemia Trait) arises when individuals carry one mutated beta globin gene and one normal gene, resulting in mild anemia, often with minimal or absent symptoms [5]. Beta Thalassemia Intermedia occurs due to mutations severely reducing beta globin chain production, causing more pronounced symptoms than in Beta Thalassemia Minor but less severe than in Beta Thalassemia Major. Beta Thalassemia Major (also known as Cooley's Anemia) represents the most severe form [5], characterized by either the absence or a severe reduction in beta globin chain production. Individuals with Beta Thalassemia Major require lifelong transfusions and medical management to survive, as untreated cases may lead to severe complications like organ damage, growth retardation, and bone abnormalities.

2.2 Problem in Thalassemia

Thalassemia, characterized by abnormal hemoglobin production due to genetic mutations, presents a primary challenge in the form of chronic anemia, which manifests through a spectrum of symptoms and potential complications [4, 5]. Chronic anemia, stemming from the insufficient production of healthy red blood cells, manifests as persistent fatigue, weakness, and a general sense of lethargy. Individuals affected by thalassemia often experience shortness of breath, especially during physical exertion, due to the decreased oxygen-carrying capacity of their blood. This chronic anemia also results in pallor or pale skin, reflecting the reduced levels of circulating hemoglobin [5].

Beyond these immediate symptoms, thalassemia predisposes individuals to a range of potential complications, further exacerbating the impact of chronic anemia [6]. Bone deformities can develop over time, particularly in the facial bones and skull, due to altered bone marrow activity and changes in bone growth patterns. Growth retardation is a common concern, particularly in children, as inadequate oxygen

delivery to tissues impairs normal growth and development. Additionally, chronic anemia associated with thalassemia can lead to organ damage over time, particularly affecting the heart, liver, and spleen, due to the increased workload placed on these organs to compensate for reduced oxygen levels in the blood [6].

Overall, the primary problem of chronic anemia in thalassemia not only presents immediate challenges in terms of quality of life but also raises significant long-term risks of complications, ranging from bone deformities and growth retardation to organ damage. Managing thalassemia effectively requires a comprehensive approach that addresses both the symptoms of chronic anemia and the potential complications associated with the condition.

2.3 Management of Thalassemia

The Thalassemia management entails a multifaceted approach tailored to address the chronic anemia and potential complications associated with the condition. Regular blood transfusions stand as a cornerstone of treatment to replenish red blood cell counts and sustain hemoglobin levels, thereby alleviating symptoms of fatigue, weakness, and shortness of breath [7]. These transfusions are typically administered on a scheduled basis, with the frequency determined by the severity of the individual's thalassemia subtype.

However, frequent blood transfusions carry the risk of iron overload, which can lead to organ damage over time [7]. To mitigate this risk, individuals with thalassemia may undergo iron chelation therapy, which involves the administration of medications that bind excess iron in the bloodstream and facilitate its excretion from the body. By preventing iron accumulation, chelation therapy helps safeguard against complications such as liver disease, heart failure, and endocrine dysfunction.

Complementary to transfusions and iron chelation, supplemental therapies play a vital role in thalassemia management. Folic acid supplementation is commonly prescribed to support red blood cell production and mitigate the risk of folate deficiency, which can exacerbate anemia. Additionally, bone marrow transplantation may be considered as a curative option for select individuals, particularly those with severe forms of thalassemia who have a suitable donor match. This procedure involves replacing the diseased bone marrow with healthy marrow stem cells, offering the potential for long-term remission from thalassemia symptoms [8].

3. EXISTING SYSTEM OF HEALTHCARE

3.1 CareAide: Meds & Pill Reminder

CareAide: Meds & Pill Reminder [10] presents a commendable effort to integrate various health management features into a single, accessible application. Its advantages, such as Guest Mode and multilingual support, contribute to its appeal. However, the presence of paid features and reported usability challenges for first-time users warrant careful consideration. With ongoing updates and user feedback incorporation, CareAide has the potential to evolve into a more user-friendly and inclusive healthcare management solution.

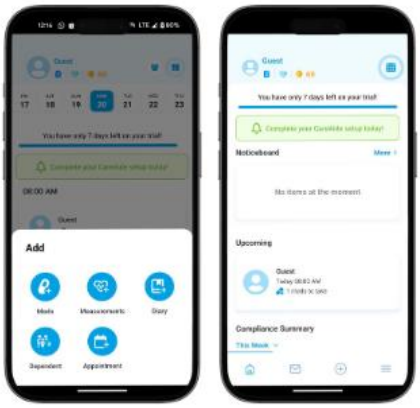

Figure 1: CareAide: Meds & Pill Reminder [10]

3.2 BP Tracker: Blood Pressure Hud

BP Tracker: Blood Pressure Hud [11] distinguishes itself with a user-friendly interface and unique features like healthy recipes, news, and articles, providing a holistic approach to health monitoring. However, the app faces drawbacks in the form of annoying advertisements and notifications, potentially compromising the overall user experience. Additionally, being exclusive to the Android platform limits its accessibility, creating a challenge for users on iOS devices. Despite these concerns, ongoing refinements and updates could position BP Tracker as a more competitive and inclusive health tracking solution.

Figure 2: BP Tracker: Blood Pressure Hud [11]

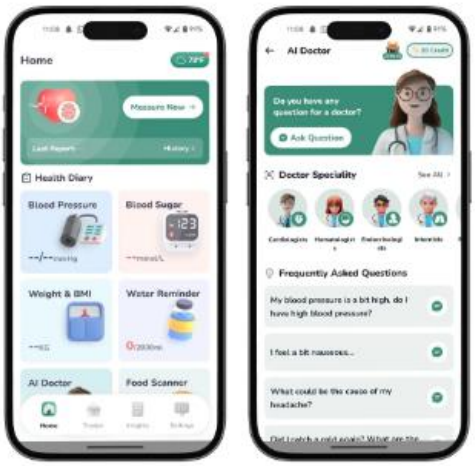

Figure 3: Health Tracker: BP Monitor [12]

3.3 Health Tracker: BP Monitor

Health Tracker: BP Monitor [12] presents a commendable effort in providing a user-friendly and comprehensive health monitoring solution. The integration of an AI doctor based on GPT-4 and

coverage of various health specialties add significant value. However, the presence of advertisements and the credit-based model for AI doctor interactions may pose challenges to user satisfaction and accessibility. As the app evolves, addressing these concerns could elevate its standing in the competitive landscape of health management applications, potentially attracting a more diverse user base. This advanced technology allows for more accurate diagnoses and personalized treatment plans. Patients can benefit from a wide range of medical expertise without having to physically visit multiple specialists.

4. THALACARE FRAMEWORK

4.1 Diagram Framework

The method used in this research is based on systematic development and implementation of Thalacare. By using ADDIE Methodology, the development process intends to deal with problems more effectively, ensure projects beneath control, and make planning more structured [16]

Figure 4: ADDIE Model

The ADDIE methodology is a systematic approach used in instructional design to create effective learning experiences. Standing for Analysis, Design, Development, Implementation, and Evaluation, ADDIE provides a structured framework that guides the development of educational materials, courses, or training programs. It begins with analysing learning needs and goals, progresses through designing and developing instructional content, implements the learning experience, and concludes with evaluating its effectiveness. This iterative process allows for continuous improvement and refinement of the educational content and delivery methods. Overall, ADDIE serves as a versatile and adaptable model for designing and enhancing learning experiences across various contexts and subjects

Figure 5 illustrates a framework of Thalacare Application. The central component of the system is the Patient block, which symbolizes the thalassemia patient whose medical records are kept and handled by many components. All relevant medical information is stored in the Health Record block, including information on past blood transfusions, iron levels, medication use, and general health. The scheduling block is essential for keeping track of the patient's visits and prescription schedules, as well as for guaranteeing prompt interventions and treatment plan compliance. In the meanwhile, patients

are equipped with information for well-informed decision-making and self-care thanks to the Education block's priceless resources on thalassemia, treatment alternatives, and lifestyle advice. Finally, information from all other blocks is centralized and combined by the database, enabling effective, Lastly the Database centralizes and combines data from every other component, making it easier for users of the ThalaCare system to efficiently obtain and utilize full health data. All of these interrelated parts work together to create a comprehensive framework that maximizes the way that thalassemia patients get care and improves their results.

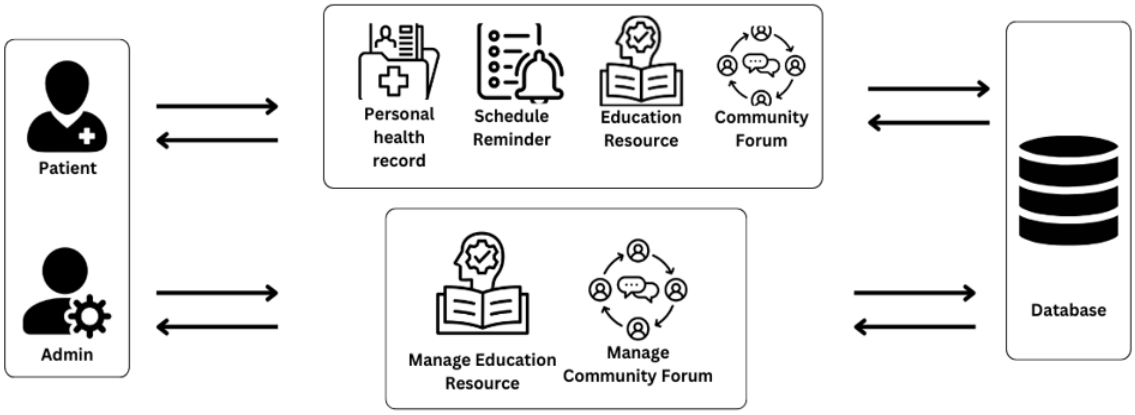

Figure 5: Framework of ThalaCare

4.2 Collaborative Filtering

Collaborative Filtering is a technique used in recommendation systems to predict user preferences for items by leveraging the behavior and preferences of similar users [13]. It works by analyzing user-item interactions, such as ratings or purchases, to identify patterns and similarities among users or items [15]. Memory-based collaborative filtering computes similarities between users or items based on their interactions, while model-based collaborative filtering uses machine learning algorithms to learn patterns from user-item interactions and make predictions [14]. Collaborative filtering allows for personalized recommendations without requiring explicit information about items or users, but it also faces challenges such as the cold start problem and scalability issues with large datasets [13]. Despite its limitations, collaborative filtering remains a powerful approach for building recommendation systems in various domains. As technology advances and more data becomes available, collaborative filtering algorithms will likely become even more sophisticated and accurate in predicting user preferences.

The objective of enhancing the user experience on ThalaCare might be achieved by the implementation of Collaborative Filtering, which serves to recommend forum threads. The system utilizes collaborative insights from the community to suggest forum threads that are relevant to users, considering their interaction patterns and preferences. This personalized approach not only promotes user engagement but also fosters a sense of community and shared experiences. Ultimately, this contributes to the overall well-being of individuals facing the challenges of thalassemia User-Based Collaborative Filtering for a forum involving recommending threads or posts to a user based on the preferences and interactions of users who share similar behaviours or interests [14]. User-Based Collaborative Filtering is well-suited for ThalaCare because it tailors recommendations to each user's preferences, leveraging the collective insights of the community. It handles sparse data effectively, provides transparent recommendations, and scales efficiently with the forum's growth. Compare to Item-Based Collaborative Filtering, it focuses on similarities between forum threads, which can be less effective for personalized recommendations in a community-driven platform like ThalaCare. Therefore, User-Based

Collaborative Filtering is the preferred choice for promoting user engagement and support within the forum.

This is how User-Based Collaborative Filtering applies to a forum community. Firstly, gather data on user interactions within the forum, such as likes, comments, or participation in the forum. Create a user-item interaction matrix where rows represent users, columns represent forum/posts, and the entries contain interaction data (e.g., likes or comments). Table 1 show example of user interaction matrix of ThalaCare.

Table 1: User Interaction Matrix of ThalaCare

Patient / Forum	Forum 1	Forum 2	Forum 3	Forum 4	Forum 5
Patient 1	3	2	0	4	5
Patient 2	1	0	4	3	5
Patient 3	4	5	1	2	0
Patient 4	0	1	5	4	3

To measure the similarity between users based on their interaction patterns using Cosine Similarity. To get the similarity value, the data in the criteria must calculate using the equation 1 above

$$similarity(A,B) = \frac{A \cdot B}{\|A\| \times \|B\|} = \frac{\sum_{i=1}^{n} A_i \times B_i}{\sqrt{\sum_{i=1}^{n} A_i^2} \times \sqrt{\sum_{i=1}^{n} B_i^2}}$$

Equation 1: Cosine Similarity

In this equation, $A \cdot B$ represents the dot product of vectors A and B. This is calculated by multiplying the corresponding components of the two vectors and summing up the results. ||A|| represents the Euclidean norm (magnitude) of vector A, which is the square root of the sum of the squares of its components. It's calculated as $||A|| = \sqrt{(A_1^2 + A_2^2 + \ldots + A_n^2)}$. ||B|| represents the Euclidean norm (magnitude) of vector B, calculated in the same way as ||A||.

First we need to represent each user as a vector where each dimension corresponds to an item, and the value represents the user's interaction with that item. Next, we calculate the dot product of the vectors representing two users. Then, we calculate the magnitude of each vector and multiply them together. Finally, we divide the dot product by the product of the magnitudes to obtain the cosine of the angle between the vectors, which represents the similarity between the users. This similarity value ranges from -1 to 1, where 1 indicates perfect similarity, 0 indicates no similarity, and -1 indicates perfect dissimilarity. This process allows us to quantitatively measure the similarity between users based on their interaction patterns, enabling more effective collaborative filtering for personalized recommendations. Above example calculation between patient 1 & patient 2.

$$\text{Cosine Similarity } (Patient_1, Patient_2 = \frac{(3x1) + (2x0) + (0x4) + (4x3) + (5x5)}{\sqrt{3^2+2^2+0^2+4^2+5^2} \; x \sqrt{0^2+1^2+5^2+4^2+3^2}} = 0.76$$

4.3 Overview of ThalaCare

The interface for ThalaCare that are represented in Figure 6 are an easy-to-use tool that lets people easily record blood transfusions, iron levels, medications, and general health conditions in order to trace their health journey in detail. Based on the data entered, ThalaCare creates informative reports and analyses that offer useful insights into health trends and guarantee that customers never miss important doctor's appointments by sending out timely warnings and reminders. Furthermore, ThalaCare provides a wealth of instructional materials, such as articles, infographics, and videos, to equip users with knowledge about thalassemia and its treatment. ThalaCare encourages a sense of community and support by enabling users to ask questions, share stories, and receive emotional support from other thalassemia warriors through its forum function.

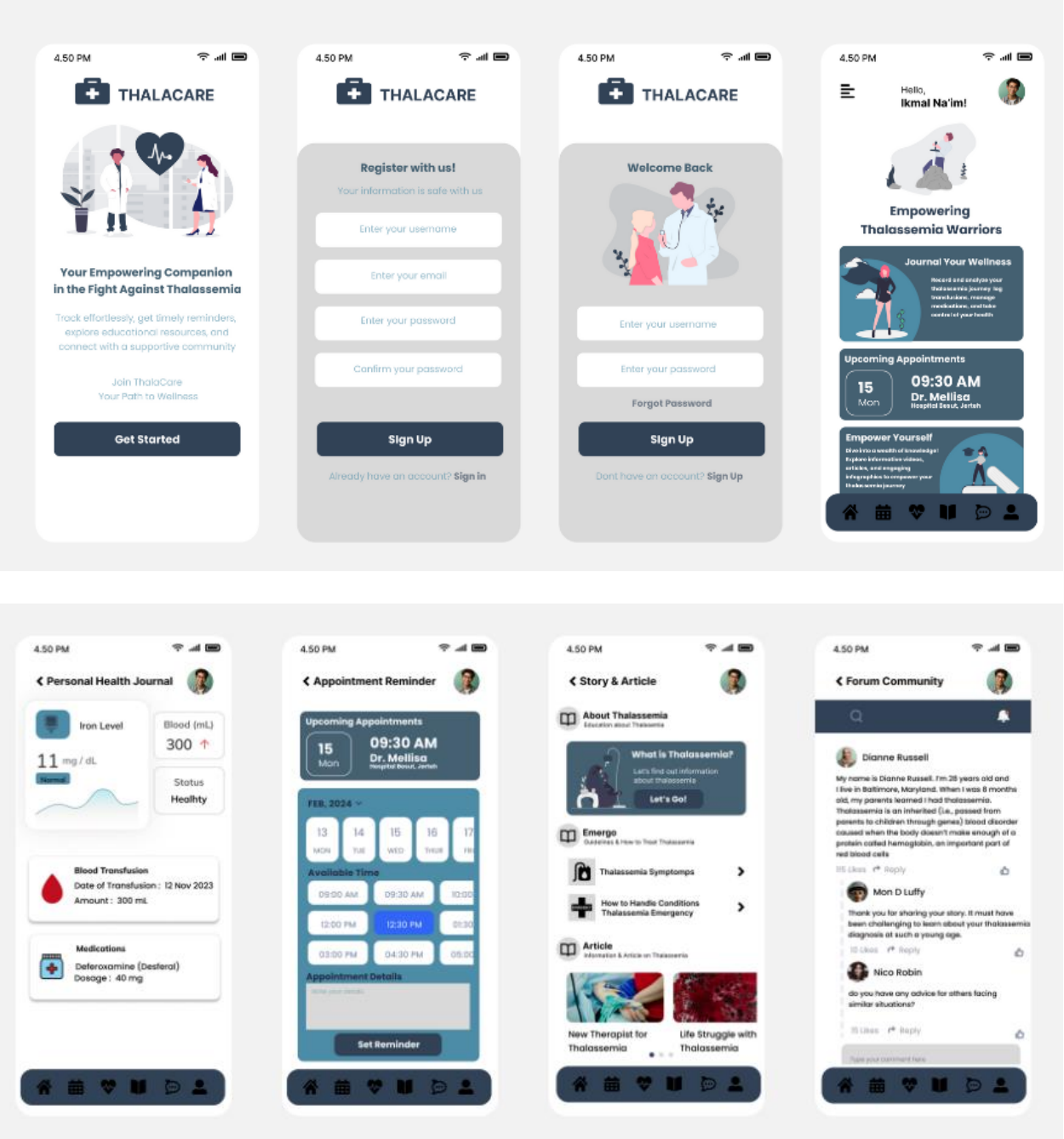

Figure 6: Interface of ThalaCare

5. CONCLUSION

In conclusion, thalassemia presents significant challenges for patients, including chronic anemia, potential complications, and the burdens associated with managing the condition. These challenges encompass the need for frequent blood transfusions, the risk of iron overload, medication adherence, and accessing reliable information and emotional support. These factors collectively contribute to a substantial burden on patients' physical and emotional well-being, as well as their overall quality of life.

However, solutions like ThalaCare offer a comprehensive approach to address these challenges. By providing features such as Personal Health Journal for tracking health metrics, Treatment Reminders for medication adherence, and a Community Forum for emotional support, ThalaCare empowers patients to manage their condition effectively. Additionally, ThalaCare serves as an educational resource hub, offering valuable information about thalassemia and treatment options. Through these features, ThalaCare not only streamlines thalassemia management but also enhances patients' knowledge, adherence to treatment, and sense of community support, ultimately improving their overall health outcomes and quality of life.

ACKNOWLEDGEMENT

We would like to express our gratitude to all UniSZA colleagues for networking and technical assistance in proofreading and synchronization issues, as well as for their constructive remarks and recommendations.

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