Development of Android-based Mobile Application “Cyber Gen” for Genetic Counselling Implementation among Thalassemia Patients

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Abstract. Thalassemia is a genetic disease that causes various physical and psychosocial problems. Patients will experience psychosocial and emotional disorders in the form of feelings of depression, anxiety and other problems. Nurses as counselors need to provide genetic counseling interventions as a strategy to overcome these problems through information technology media such as android-based mobile applications. Android-based information technology is the most common and easy-to-use medium for nurses to provide health services such as genetic counseling. This research method used Research and Development design which aimed to design, produce and test the validity of the products that have been produced. The research phase used a qualitative approach to find out the problems and needs of the android application for the implementation of genetic counseling. Furthermore, the system development stage used the FAST (Framework for Application of Systems Technology) method which consists of preliminary investigation, problem analysis, requirements analysis, decision analysis, system design and construction. Testing of the Android-based Cyber Gene mobile application for the implementation of genetic counseling in thalassemia patients was carried out by testing all existing menus using secondary data. The result of this research is the Android-based Mobile Application “Cyber Gene” for Genetic Counseling Implementation among Thalassemia Patients. Nurses, thalassemia patients, and their caregivers can use this application for the comprehensive genetic counseling intervention process with instant messaging through the Live Consultation menu based on the predetermined procedure. Testing the system installed on android version 1.1 with the result that all menus and submenus on the system can be accessed and work well. Therefore, the Cyber Gene application can be used for the implementation of genetic counseling in thalassemia patients, both in hospitals and other health facilities.

1. Introduction

Thalassemia is a hereditary disease that occurs due to a lack of red blood cells in the human body so that haemoglobin production is reduced [1]. Although thalassemia is a genetic disease, this case is not difficult to find in Indonesia and even the world. Through its official website, the World Health Organization (WHO) states that 7% of the total world population are carriers of thalassemia traits. In addition, there are 300-400 thousand new births of thalassemia per year. Not much different, the case of thalassemia in Indonesia continues to increase until it ranks 5th in the world. In Indonesia, thalassemia is the most common genetic disorder and is the most common among hemolytic anemia groups [2]. The prevalence of thalassemia major in Indonesia based on UKK Hematology data from the Indonesian Pediatrician Association reached 9,121 people. Based on data from Yayasan Thalassemia
Indonesia/Persatuan Orangtua Penderita Thalassemia Indonesia (YTI / POPTI) it is known that people with thalassemia in Indonesia have increased from 4,896 thalassemia sufferers in 2012 to 9,028 people with thalassemia in 2018 [3].

Thalassemia results from changes in alpha or beta globin synthesis. Beta-thalassemia is caused by impaired production of beta globin chains, reduced globulin supply reduces the production of haemoglobin tetramers, thereby causing hypochromia and microcytosis [4]. The globin gene is part of a group of genes located on chromosome 11. Decreased production of the globin gene product, either -1 globin or -2 globin (the -globin gene is present in duplicate located on chromosome 16 to be exact at 16p13.3 either Both HBA1 and HBA2), produce a relative beta chain excess, which results in a less stable chain, resulting in a clinical disease known as alpha thalassemia [1].

Gene polymorphisms have an impact on intensive care in the long term [3]. Besides being able to cause severe clinical manifestations, polymorphisms can be passed on to the next generation with inheritance patterns that follow Mendelian laws, including autosomal recessive, autosomal dominant, X-linked recessive and X-linked dominant [5]. Thalassemia is inherited in an autosomal recessive manner that carries a risk of more than 25%. Clinical manifestations vary widely from asymptomatic to severe due to an excess of unstable alpha globin chains [6]. Beta thalassemia minor (BTM) is the term used for heterozygotes who have inherited a single gene leading to reduced beta globin production [7].

Thalassemia, not only causes physical problems, but also affects the patient's psychological condition. Physical changes or disorders that may arise include weakness, pale face, difficulty sleeping, and enlarged lymph nodes. So that it will have an impact on the emotional state of the client. Clients will experience psychosocial and emotional disorders in the form of feelings of depression, anxiety and other problems [8]. To overcome this problem, nurses need to provide nursing care with the main intervention of genetic counseling which has been proven to reduce depression and improve quality of life [9]. However, the times have opened up opportunities for the use of information technology as a medium for the delivery of genetic counseling interventions such as websites and mobile applications [10].

Research conducted by the PEW Research Center, (2018) describes that one of the most widely accessed media is a mobile device or cell-phone, therefore efforts to increase knowledge through an Android-based cell-phone application are quite effective in providing knowledge and also reducing the psychosocial impact on thalassemia patients [11]. One of the efforts to reduce the psychosocial impact of thalassemia children is to provide genetic counseling health services based on the Cyber Gen application.

This Cyber Gen application offers an intervention which includes thalassemia material, recurrent risk calculation, carrier screening test and decision making, clients can also consult at any time via the application. So, with this it can affect the client's psychosocial status for the better. With increasing information about diseases, especially genetic diseases experienced, the average individual feels calm because they already have certainty about the conditions experienced. In some developed countries such as Australia, the United States and the Netherlands, genetic counseling is carried out as a permanent procedure to treat psychological problems in parents who have children with genetic disorders, including thalassemia [12].

2. Materials and Method
This study used Research and Development (R and D) design, as a scientific way to design, produce and test the validity of the products that have been produced. The research phase used a qualitative approach to find out the problems and needs of the android application for the implementation of genetic counseling. Furthermore, the system development stage used the FAST (Framework for Application of Systems Technology) method [13]. At the research stage, the data collection method used was documentation, namely the data collection method carried out through reference books on Thalassemia which includes definitions, etiology, gene factors, inheritance patterns, diagnostic screening, medication and therapy, and adaptation. At this stage, an analysis of the need for the system to be developed was carried out, including the menus, functions, reports and the required interface. Meanwhile, the system
development stage was the system development stage that will be carried out by researchers in full using the FAST (Framework for the Application of System Thinking) method depicted in figure 1.

2.1. Preliminary Investigation
At this stage, researchers looked for references from reading books and scientific articles from online journals about thalassemia and research in similar fields as reference materials [14], [15]. The data and information become the basis for compiling information that will be displayed on the system.

2.2. Problem Analysis
At this stage the researchers studied and analyzed the problems found through the anamnesis of the thalassemia patient and the nurse on duty [16]. Some of the main problems that arise are the absence of genetic counseling services, patient knowledge about the disease is not comprehensive, genetic counseling has not become a standard procedure for implementing nursing care, and the knowledge and competence of nurses is not adequate.

2.3. Requirements Analysis
Needs analysis was done by means of a literature study about the needs and information that needs to be conveyed in genetic counseling [17]. From the problems that have been collected, it could be concluded that there was a need to create a mobile application that can be installed on the cell-phones of patients and caregivers as clients, and nurses and doctors as counselors.

2.4. Decision Analysis
At this stage the researcher carried out the process of identifying alternative systems in this case determining the system application design [13].

2.5. System Design
At this stage the researcher designed the application, created the necessary database and made menus and display interfaces on Android. Researchers divide the menu into 3 submenus which include basic knowledge, social support and genetic counseling. The design of the developed application can be seen in figure 2.

Figure 1. Framework for the Application of System Thinking

![Framework for the Application of System Thinking](image-url)
2.6. Construction
At this stage, the researcher translated the results of the design into a computer program using the MIT App Inventor application. After this stage, the next step is to test the implementation of the system that was built. At this stage, a functional test of the completed mobile application is carried out. The technique used in the system function test uses a closed list of questions.

3. Result and Discussion
The developed application in this study is called Cyber Gen which was tested by being installed on an android device version 1.1. Figure 3 is a display of the Cyber Gen application shortcut and register form. After installing the program, users can use this application by registering first. The registration form includes the user's identity, education and occupation. It is intended that each user can be classified into 2 groups, namely doctors and nurses as counselors, and patients and their caregivers as clients.

Six of the nine menus provided are references to thalassemia disease as basic knowledge that can be read by users or clients, both thalassemia patients and their caregivers. This basic knowledge includes definitions, causes or etiology, clinical manifestations, gene factors, inheritance patterns, screening diagnostics, medication and therapy, and adaptation. All information provided is the essence of various references to strengthen user knowledge about thalassemia.

Meanwhile Survey, diary and Group chat are facilities provided as a means to strengthen social support. In the survey menu, counselors (both doctors and nurses) can send questionnaires or questionnaires that measure the user's physical and psychosocial status. Diary submenu, provided to facilitate clients in expressing their feelings and experiences. The chatgroup submenu can be used as a means of interaction between users so that there is a fairly strong interpersonal relationship.
In this section, users could register by filling in all available data fields including user name, email address, password, cellphone number, education, occupation, address and date of birth. This registration process is needed to make it easier for counselors to identify user data (patients and caregivers).

The front view of the application menu, shown in figure 4, is a menu of choices that can be used by patients as basic knowledge of Thalassemia which aims to increase user knowledge level. The available content includes "about thalassemia" which contains the definition, prevalence and epidemiology of thalassemia. While the "gene factor" menu contains the involvement of genes that influence the occurrence of thalassemia disease. In the "Inheritance pattern" menu, users can read content about the inheritance pattern of thalassemia based on Mendel’s law and the calculation of recurrent risk that may appear in the next generation.

The "diagnostic screening" menu was provided to explain of the appropriate diagnostic tests to determine the diagnosis of thalassemia disease. This serves to strengthen the suspicion of carriers in groups prone to thalassemia, such as parents of the patient and other family members in the same
pedigree. As for the "medication and therapy" menu, it provides information on therapeutic management that needs to be done in thalassemia patients. While the "adaptation" menu contains information about the future of thalassemia patients related to school, marriage, work to planning a pregnancy.

**Figure 5. Social support menu**

The "Survey" menu in figure 5 contains questions to measure the user's psychosocial status. While the "Community" menu is one of the facilities provided to strengthen social support between users (client-counselor, client-client, and caregiver-caregiver).

**Figure 6. Live Consultation for genetic counseling implementation**

Live consultation is the main interaction that can be used as a medium for the implementation of genetic counseling. All users, both clients and counselors can send messages directly and privately to discuss matters relating to the client's condition. Figure 4-6 are the main menu display, while the audio-visual guide manual for using the application has been uploaded to the YouTube which can be accessed by all users at the following link: https://youtu.be/jylsM5XBXBI

Testing of the Android-based Cyber Gene mobile application for the implementation of genetic counseling in thalassemia patients was carried out by testing all existing menus using secondary data. As a result, the whole system works fine. The three main menus (Basic Knowledge, Social Support, and Genetic Counseling Chat Room) and their derivative submenus work well. Table 1 shows the results of testing the menu on the application.
Table 1. System Test Results on All Menus and Submenus

| No | Menu/Submenu               | Result                          |
|----|----------------------------|--------------------------------|
| 1  | Register Form/Login         | Accessible and working well     |
| 2  | Menu Utama                 | Accessible and working well     |
| 3  | Basic Knowledge             | Accessible and working well     |
| 4  | About Thalasemia            | Accessible and working well     |
| 5  | Gene Factor                 | Accessible and working well     |
| 6  | Inheritance Pattern         | Accessible and working well     |
| 7  | Screening Diagnostic        | Accessible and working well     |
| 8  | Medication and Therapy      | Accessible and working well     |
| 9  | Adaptation                 | Accessible and working well     |
| 10 | Social Support              | Accessible and working well     |
| 11 | Survey                     | Can Save Data                   |
| 12 | Group Chat Room             | Interactive                     |
| 13 | My Diary                   | Can Save Data                   |
| 14 | Live Consultation           | Can Perform Inter-user Interaction |

The test results of the developed system function show that all the features on the system can function and work well. All submenus on the basic knowledge feature can be accessed and read by the user as a source of scientific information to increase user knowledge [18]. Similar applications developed in Indonesia, such as Alodokter, provide basic knowledge about a disease. Although the variety of diseases described in the application is greater, the information provided does not focus on one disease in detail and in depth. That is why, Alodokter provides consulting services about a disease for users who do not fully understand it [19].

The Cyber Gene application is not only aimed at increasing the knowledge of thalasemia patients about the disease they are suffering from, but can adapt to all the implications of the gene problems they are experiencing. For this reason, Cyber Gen focuses more on the implementation of genetic counseling which is one of the nursing interventions for thalasemia sufferers [20]. That is why Cyber Gen adds another feature in the social support or community support menu. The forms of social support provided are chat groups and diaries. Social support refers to the psychological and material resources provided by a social network to help individuals cope with stress [1], [21]. Such social support may come in different forms, and might involve helping a person with various daily tasks when they are ill or offering financial assistance when they are in need, giving advice to a friend when they are facing a difficult situation and providing caring, empathy, and concern for loved ones in need.

The research, published in the September issue of APA's Journal of Experimental Psychology: General (JEP: General) (Vol. 130, No. 3), indicates that expressive writing reduces intrusive and avoidant thoughts about negative events and improves working memory. These improvements, researchers believe, may in turn free up our cognitive resources for other mental activities, including our ability to cope more effectively with stress [22], [23]. This is the difference between the Cyber Gen application and other similar applications. However, the application developed in this study is not integrated with the web, only using a mobile device. So, this is a weakness in this study, and an opportunity for other researchers to continue.

4. Conclusion
The Cyber Gen application for the implementation of genetic counseling in thalasemia patients can run well and testing on menus and sub menus works well. Nurses, thalasemia patients, and their caregivers can use this application for the comprehensive genetic counseling intervention process with instant messaging through the Live Consultation menu based on the predetermined procedure. The resulting database can be accessed by the user. Application construction has not been integrated with the website, so it needs to be developed in further research. The potential for abuse of this application can be
controlled with a neat and orderly mechanism. Counselor and Client use applications based on face to face appointments made during routine therapy at the hospital. Thus, all application users are personal registered at the hospital.

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Conflict of Interest
Author declare there is no conflict of interest.

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