Usability of Mobile Application for Implementing Genetic Counselling Intervention among Thalassemia Patients and Caregivers: A Case Study of Cyber Gen

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ABSTRACT

Utilization of communication and information technology has been widely used in the health sector, especially nursing. As one of the nursing interventions for thalassemia patients and caregivers, genetic counseling is not only done face to face but can use android-based telenursing facilities through the complete features available in the Cyber Gen application. This study aims to measure the usability level of Cyber Gen application as an indirect genetic counseling medium for thalassemia patients. This application was developed with four main services: basic information about diseases, consultation rooms, social support, and direct surveys. This application is built using the Flutter Framework, the Dart programming language, and Cloud Firestore as the database. Usability was measured by using the System Usability Scale in two groups of 30 respondents, each with an incidental sampling technique. The usability score shows 81.75 for personal users and 82.25 for counselor users with a 100% readiness level for use. These results indicate that the Cyber Gen application can be used to deliver genetic counseling intervention to thalassemia patients and caregivers.

Keywords*: android, genetic counseling, mobile application, thalassemia, usability*

INTRODUCTION

Advances and developments in communication and information technology continue to be developed in various fields including the health sector [1]. As a nurse, of course, you are familiar with maybe even practicing the health service model by using telenursing or telemedicine facilities [2]. The technology that continues to be developed is utilized in clinical services such as technology that deals directly with patients such as clinical decision-making and counseling, as well as non-clinical services such as administrative services to shorten outpatient queues, drug control, and medical records. During the Covid-19 pandemic, of course, information technology plays an important role in controlling the physical activity of the community in preventing the high risk of transmission [3]. Through an android-based application provided by the government of the Republic of Indonesia launched by the Ministry of Health, the Care and Protect Application is able to store a track record of community activities and display areas that have a high level of vulnerability such as shopping centers, schools, and hospitals [4].

Physical and social distancing programmed by the government during the COVID-19 pandemic, of course, limits the space for direct interaction between patients and caregivers, and nurses [5]. This has the potential to reduce the quality of nursing services, thereby reducing the health quality of patients and caregivers. In fact, the majority of nursing actions while in the hospital or in the community are carried out directly through communication interactions [6]. The nursing

process carried out includes assessment, diagnosis, intervention, implementation, and evaluation. All these processes are carried out directly through intensive communication [7].

Genetic counseling is one of the nursing services or nursing interventions that require intensive communication so that patients and caregivers can understand the health changes they experience as a result of genetic problems in their bodies [8]. The standard procedures that are compiled are almost all carried out by direct interaction. After the preparation is done, the nurse as a counselor provides a detailed explanation of health problems starting from the definition, causes, recurrent risk calculations, screening or testing, and psychological maintenance or palliative care [9]–[11]. All of these procedures are not enough to be carried out in just one session, especially since the clinical decision-making process takes a long time. Given the magnitude of the benefits, genetic counseling intervention must still be carried out even during the Covid-19 pandemic. However, the method and model of intervention which was originally carried out face to face, of course needs to be modified with an information technology approach that we know as telenursing [12].

Genetic counseling is certainly given to patients or caregivers who have genetic problems. In hospitals, the most common genetic disease is a blood disorder called thalassemia [13]. Patients with thalassemia have various physical and psychological problems that can affect the quality of family relationships. Physical problems encountered such as severe anemia, short stature, dull face, easily tired, limited activities, can even cause shortness of breath, are caused by genetic mutations on chromosome 11 or 16 [9], [14], [15]. While psychological problems, caused by dependence on transfusions, treatment in a long time duration, economic burden, and bullying that can increase anxiety, fear, stress, and depression, as well as reduce the quality of life of sufferers and their caregivers [16]–[18]. Therefore, genetic counseling needs to be

carried out by utilizing information technology through mobile applications.

The mobile application developed by the researcher is Cyber Gen [19]. This Android-based application is provided for free on the Play Store so that everyone can take advantage of all the available features. However, this application still needs to be tested whether it is ready to use or not with usability considerations. Thus, the purpose of this research is to measure the usability level of the Cyber Gen application as an indirect genetic counseling medium for thalassemia patients.

METHODS

Tests were used to determine whether the performance of the system is in accordance with the results of the design, where testing is carried out using the black box method to test system validation and usability testing methods to determine the level of user satisfaction. From the results of these tests carried out an analysis that will be a reference for constructing the conclusions.

The System Usability Scale (SUS) questionnaire was given to each group of respondents (personal user and counselor user) using incidental sampling. Each group, both the personal user group and the counselor user group, amounted to 30 respondents. The inclusion criteria for personal users were patients and/or caregivers of thalassemia sufferers who routinely carry out transfusions at the hospital, aged 18-50 years, and voluntarily attend genetic counseling in all sessions through the developed application. Thalassemia patients or caregivers who refused to sign an informed consent were excluded. The counselors or consultant users included are nurses who are registered with the Indonesian National Nurse Association and have attended a coaching clinic for genetic counseling practice in the nursing profession.

The questionnaire has been declared valid and reliable in Indonesian, so there is no need to test the validity and reliability [21]. SUS has 10

questions and 5 answer choices. The answer choices consist of strongly disagree to strongly agree (Likert Scale). SUS has a minimum score of 0 and a maximum score of 100.

After collecting data from respondents, then the data is calculated. In how to use the SUS there are several rules in calculating the SUS score. The score calculation rules apply to one respondent. For further calculations, the SUS score of each respondent is sought by the average score by adding up all scores and dividing by the number of respondents. The following formula calculates the SUS score:

$$\bar{x} = \frac{\sum x}{n}$$

$\bar{x}$: *mean*

$\sum x$: *Total number of Score*

n : *Number of Sample*

The results of data analysis are displayed in the form of a histogram to show the mean, median, minimum and maximum values. The data were interpreted according to the SUS category classification.

RESULT AND DISCUSSION

Testing is carried out using functional requirements validity testing and usability testing to find errors from various possibilities that cause errors before the system is submitted to the client [30]. Validation testing is carried out with the aim of knowing that the system that has been built has been running as expected and in accordance with what was designed during the needs analysis stage. This test uses the black box testing method.

Tests are carried out on the process of registering, logging in, survey results, live consultations, and groups. After testing each process, the results will be obtained where all test cases get the results as expected, which means that they are valid with a validity level of almost 100%. These results have been published in previous conference proceedings [19].

Usability testing is a test conducted by distributing questionnaires to 30 respondents from both personal users and consultant users. The following is the result of the percentage of respondents' answers that have been calculated, which can be seen in Figure 1 and 2.
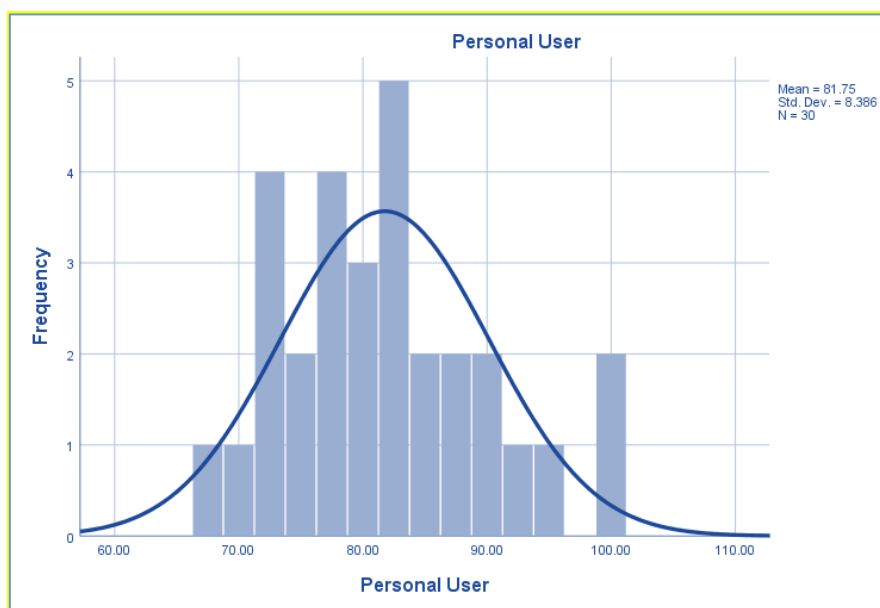

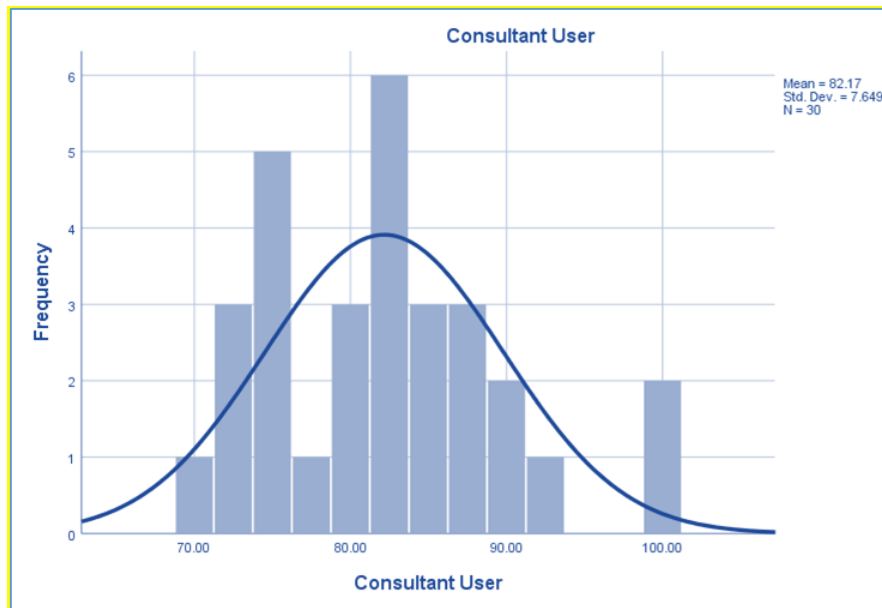Figure 5. SUS Test Result for Personal User

Figure 6. SUS Test Result for Consultant User

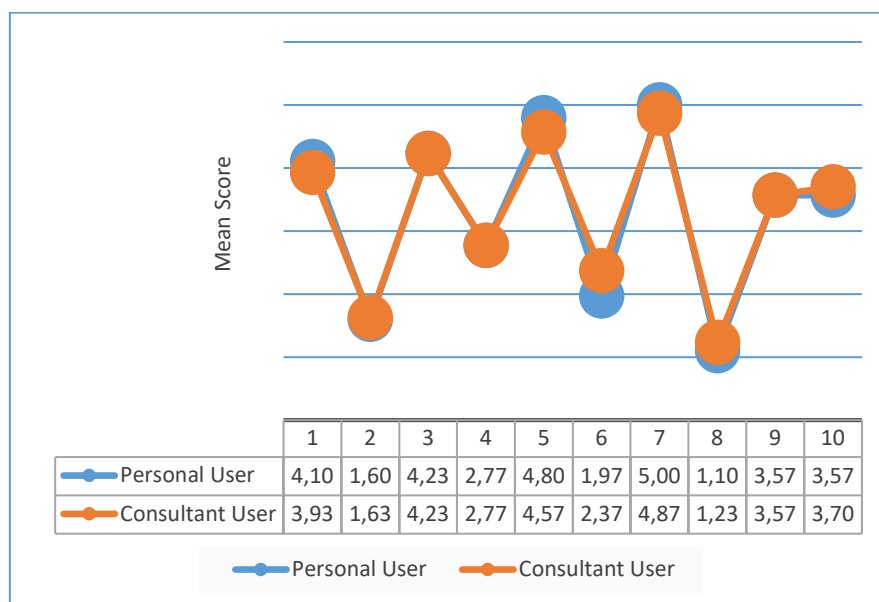|	1	2	3	4	5	6	7	8	9	10
Personal User	4,10	1,60	4,23	2,77	4,80	1,97	5,00	1,10	3,57	3,57
Consultant User	3,93	1,63	4,23	2,77	4,57	2,37	4,87	1,23	3,57	3,70

Figure 7. Mean Score of SUS per-number

Figure 1 and 2 above show that the Cyber Gen application has a high level of usability with an acceptable interpretation of grade B (81.75 for personal user, 82.17 for consultant user) and excellent (mean score $\geq$ 80). The scores of the two groups did not have a significant difference because the interaction model in Cyber Gen was almost the same. The difference is, in the personal chat or live consultation feature, the personal user can only interact personally with the nurse or counselor, while the counselor user can interact personally with all personal users and counselor users [19]. This is distinguished to maintain privacy between users, so that the goal of genetic counseling can be achieved.

The SUS is a usability measurement method used to evaluate the usability of a system or product. Following are some of the advantages of the questionnaire are Sustainability, psychometric power, application

diversity, efficiency, focus on the user, simplicity, and comprehenshive results [31].

The SUS Questionnaire is a proven method and has been widely used in usability research for many years [32]. This provides continuity in usability measurements and allows comparison with previous studies using the SUS questionnaire. Scores generated from the SUS questionnaire provide a comprehensive picture of the usefulness of a system or product [33]. This helps in comparing usability between different products or versions.

The statistical test results shown in Figure 3 shows that the perceptions of the personal user and the consultant user have a high degree of similarity. The mean score for each SUS question is at almost the same point to describe that the average user has the same perception. Questions 2, 6 and 8 have a low mean score (min – max 1.10 – 2.37) because they are unfavorable statements which show a positive value in each statements [34]. The questions number 1, 3, 5, 7, 9, and 10 are favorable statements with a mean score > 3.00 leading to a positive perception of all users.

The statement that needs attention is statement number 4 with an average score of 2.77 which confirms that some respondents need the support of technical personnel to be able to use this system. This is due to technology adaptation issues which include interface complexity device diversity, operating system updates, speed and performance limitations, lack of support and troubleshooting, and privacy and security [35]–[38]. In order to overcome the difficulties of adapting to Android-based technology, it is important for users to take steps such as reading user guides, seeking help from the Android user community, and keeping their devices updated with the latest operating system updates. With time and experience, users will become more familiar with Android technology and be able to get the most out of it [39].

CONCLUSION

Based on the results of the validation test on this application, it shows a value with a percentage of 100% which means the system has met the functional requirements. Meanwhile, the usability level of the application shows a score of 81.75 for personal users and 82.25 for counselor users, which means that the application has been proven to make it easier for users, both for personal users and consultant users. However, a feasibility study on this application still needs to be done so that it can actually be used as a medium for genetic counseling intervention for thalassemia patients and caregivers.

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