ORIGINAL ARTICLE

Need Assessment of Self-Management Information of People Living with HIV/AIDS

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ABSTRACT

Introduction: The long-term treatment and stigma associated with HIV have impacted treatment adherence among people living with HIV. The study aimed to conduct a needs assessment for the development of a mobile application to support PLWHA in Jember Regency. The findings will be the basis of the development of this application, addressing the needs of people living with HIV/AIDS. **Methods:** This is a descriptive qualitative study conducted during March-November 2023 in Jember Regency, Indonesia. The respondents are the HIV programmers of the Jember Regency Health Office, the HIV programmers of the Primary Healthcare (PHCs), NGO officers who work as HIV patient companions, and the ODHIV peer support, and ODHIV. The instrument was FGD and in-depth interviews to identify needs in assisting HIV/AIDS patients. **Results:** The results showed support from health facilities programmers and patients for an Android application for HIV patients containing PLWHA self-management (including clinical symptom control, ARV consumption compliance, and health education information) to improve adherence to treatment and start treatment at health services. Various needs that are expected to be available include a daily record of symptoms, a simple explanation of HIV development accompanied by images, appointment arrangements, an overview of treatment, and reminders for treatment. This study identifies critical challenges faced by PLWHA, including privacy and security concerns and language barriers. **Conclusion:** The proposed Android application design incorporates multilingual support (Madurese, Bahasa Indonesia, Javanese) and robust privacy and security features to ensure confidentiality and accessibility, thereby addressing these barriers to improve treatment adherence and facilitate initiation of care.
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INTRODUCTION

Based on data from the Indonesian Ministry of Health, there were 16,410 new cases of Acquired Immune Deficiency Syndrome (AIDS) in Indonesia throughout 2023 (1). The HIV control program has not yet achieved the 95-95-95 target, which is expected to be achieved by 2030. The aim was to diagnose 95% of all HIV-positive individuals, provide ARV for 95% of those diagnosed, and achieve viral suppression for 95% of those treated by 2030. The number of People living with HIV (PLHIV) who are alive and know their status is 438,231 people (85%). Progress until March 2023: 184,000 people (42%) receive treatment for PLHIV. The number of PLHIV receiving treatment tested for viral load in 2022, at least after six months of ARV treatment with suppressed viral load results, is 50,092 people (27%) (2). East Java has the second highest cases of HIV (2432 cases) after West Java (2575 cases) in 2023 (1). Based on the director of the District Health Office of Jember Regency, the trend of HIV/AIDS cases in Jember tends to increase from year to year. In 2021, there were 637 new cases, an increase to 794 new cases in 2022 and an increase to 911 new cases in 2023.

The management of HIV has evolved significantly over the past few decades. However, ensuring adherence to ARV and managing the disease remains a critical issue. PLHIV often faces difficulties in maintaining adherence to treatment regimens, which can lead to treatment failure. Loss to follow-up cases is still a challenge in Jember Regency. In a preliminary study conducted with HIV programmers at several Primary Healthcare (PHCs) for Care, Support & Treatment (CST) HIV (Puskesmas PDP) in Jember, various factors contributing to patient loss to follow-up were identified. These factors included patients feeling healthy and therefore perceiving no need for treatment, refusal of treatment, denial of their HIV status, concerns about confidentiality regarding their HIV status from family members, work-related commitments, dissatisfaction with the quality of services

at the Primary Healthcare, fear of stigma, relocation to other areas, and, in some cases, mortality. This increases the need for innovative solutions to enhance self-management capabilities among PLHIV.

Self-management is a crucial aspect of HIV care, as it allows individuals to take an active role in monitoring their health and adhering to treatment regimens. Traditional self-management methods, such as paper-based diaries and clinic visits, have limitations. These methods are often burdensome, prone to errors, and may not provide real-time feedback. Moreover, they do not address the specific needs of PLHIV, such as medication adherence, symptom monitoring, and emotional support (3).

Mobile-based applications have emerged as a promising tool for enhancing self-management in various health conditions. These applications can provide real-time monitoring, reminders, and educational resources, improving adherence and overall health outcomes. The use of mobile-based applications in cardiovascular disease management has shown significant benefits, including improved medication adherence and reduced hospitalizations (3–6). However, the application of mobile-based technologies in HIV self-management, especially in the Jember Regency, is currently unavailable. Given the importance of self-management in HIV care, the development of a mobile-based application designed explicitly for PLHIV is essential. Such an application should include features that fulfill the unique needs of PLHIV (3,5,6).

The study aimed to conduct a needs assessment for the development of a mobile application to support PLWHA in Jember Regency. This study focuses on the needs assessment phase, not the application development itself. The findings of this study will be the foundation for application development. The findings from this study will contribute significantly to the field of HIV management and provide a foundation for future research and development in this area. The application will enhance self-management capabilities, improve medication adherence, and provide real-time monitoring and support.

MATERIALS AND METHODS

Study Design

This study employed a descriptive qualitative study design. The focus was on identifying the needs of People Living with HIV/AIDS (PLWHA) and stakeholders to inform the development of a mobile application for HIV self-management in Jember Regency. This approach was chosen to gain an in-depth understanding of the perspectives and experiences of the target users and stakeholders, which would then be used to inform the design of the application. The study was conducted in two distinct phases.

1. Analysis of the Ongoing PLWHA Assistance System: In this initial phase, the researcher conducted a thorough analysis of the current system related to support for PLWHA, their peer supports, non-governmental organizations (NGOs), Primary Healthcare for Care, Support & Treatment (CST) HIV (Puskesmas PDP), and the District Health Office. This analysis was performed through in-depth interviews and FGDs to gather comprehensive data.

2. Identification of Data and Information Needs: In this phase, the researcher identified the specific data and information requirements necessary for effectively assisting PLWHA. This information was derived from the analysis of the existing system, which included identifying obstacles encountered in implementing the assistance system to date and determining whether additional information was required.

Setting and Participants

This study was conducted in Jember Regency, East Java Province, Indonesia. The trend of HIV/AIDS cases in Jember tended to increase from year to year. In 2021, there were 637 new cases, an increase to 794 new cases in 2022, and an increase to 911 new cases in 2023. The population in this study were stakeholders in the HIV program, including officers from the Jember Regency Health Office, the Primary Healthcare (PHCs) for Care, Support & Treatment (CST) HIV (Puskesmas PDP), NGO representatives (LSM Laskar and KDS Pelangi), PLWHA peer supports, and people living with HIV/AIDS (PLWHA). Using the total population, the sample included 19 officers and peer supports, and 3 confirmed HIV patients, comprising 1 officer from the Jember Health Office, 11 from PHCs for CST, 2 NGO officers, 5 PLWHA peer supports, and 3 confirmed HIV patients. This approach ensured diverse perspectives from those directly involved in the HIV support system.

Data Collection

Data were collected using focus group discussions (FGDs) and in-depth interviews. FGDs were conducted with PLWHA peer supports and NGO representatives. In-depth interviews were conducted with the Jember Regency Health Office officers, the PHCs for CST, and PLWHA. Prepared interview guides were used to ensure thorough data collection, covering topics related to the current PLWHA assistance system, data and information needs, and suggestions for application features.

Ethical Consideration

The study was conducted after obtaining an ethical clearance letter from the Research Ethics Commission of the Faculty of Dentistry, University of Jember Number 2021/UN25.8/KEPK/2023. Each respondent was given information about the intent and purpose of the study and the impacts studied during the study process before data collection began, and a consent form was provided. If the respondent agrees to participate, the respondent will be asked to sign the consent form. If

the respondent refuses to be studied, the researcher will not force and will continue to respect the respondent's rights. The consent form will also include and explain the confidentiality of the respondent and the benefits of the study for the respondent and the community.

Analysis

Data processing involved transcribing the recorded discussions to capture the content accurately. This transcription process converts spoken phrases into condensed meaning units, facilitating analysis. After transcription, the data was coded to identify themes and peer debriefing sessions were held with the research team to enhance the reliability of the qualitative analysis. Open Code software version 4.03 was used to systematically code the transcriptions, with results presented as proportions to summarize the findings (7,8).

RESULTS

Current System and Challenges

Collaboration and Support System: Assistance for PLWHA in Jember Regency is facilitated through collaboration among the District Health Office, PHCs, and NGOs. The District Health Office collaborates with the KDS Pelangi NGO to support HIV patients.

When assisting PLWHA, we work with NGOs, especially for patients who are hard to reach. Without NGO support, we struggle due to the high number of patients spread across the area (HIV programmer of PHC 2)

The primary goal of these assistance activities is to ensure that patients access treatment, which is essential for improving their quality of life. Antiretroviral therapy is important for managing HIV, as it reduces transmission risk, prevents opportunistic infections, and lowers the viral load to undetectable levels. Continuous access to ARV therapy is vital; failure to adhere can worsen the patient's condition and increase the risk of death. One significant barrier to treatment is that many patients do not feel ill, leading to low treatment adherence. The objective of the assistance is to ensure that patients consistently access and take their medications.

Treatment Adherence and Barriers: The primary goal of the assistance activities is to ensure that patients access treatment, which is essential for improving their quality of life. However, several barriers hinder treatment adherence. Patients often initially resist treatment and support. Communication challenges, particularly when patients relocate for work and change their contact information, make follow-up difficult.

The most frequent challenge we face is when patients do not disclose their status to their families and work outside the city, leading us to lose track of them, especially if they change their phone numbers (HIV programmer of PHC 4)

Limitations of the Current System: The current support system emphasizes the roles of PHCs for CST and NGOs, rather than actively involving patients in monitoring their health. The SIHA application is used to record patient information, but it is only accessible to those responsible for the HIV program. Health workers utilize the SIHA application (HIV/AIDS Information System) to record patient information, which is only accessible to those responsible for the HIV program. This system serves as a medical record, enabling health workers to track patients' conditions during visits. However, if patients do not seek services, health workers cannot ascertain their whereabouts.

Identification of Data and Information Needs

Need for Self-Management Tools: The findings indicate a strong demand for features that facilitate effective health management.

Yes, we need a tool like this. It would be great if we could also share our experiences and express what we need. Additionally, it would be helpful to interact directly with our doctors (PLHWA 1)

Essential Application Features: Participants expressed a need for features including Daily symptom-tracking function. The findings indicate a strong demand for features that facilitate effective health management, including a daily symptom-tracking function, simple explanations of HIV progression accompanied by visual, appointment scheduling and reminders, treatment overviews, multilingual support (Madurese, Bahasa Indonesia, Javanese), and privacy and security concerns.

Need for Enhanced Collaboration: A comprehensive application is needed that can be utilized by all parties involved in patient care. Effective treatment for HIV/AIDS relies on collaboration among various stakeholders, including healthcare providers, NGOs, and the patients themselves. It is crucial that patients feel comfortable engaging in their treatment and that support personnel find the process manageable. To streamline this collaboration, a comprehensive application is needed that can be utilized by all parties involved in patient care. This application should empower patients to communicate their issues and needs without difficulty, moving beyond the previous systems that primarily served as medical records accessible only to healthcare providers. This sentiment was echoed by HIV/AIDS peer support from the Laskar NGO and KDS Pelangi NGO, who agreed that such an application would enhance their ability to monitor patients. They emphasized the need for features that allow for tracking patient locations and providing information on where to access ARV medications, especially for those who work outside the city.

It would be beneficial to have an application that shows where patients are located, making it easier to

monitor them. Some of our patients do not access their medications because they work out of town and are unaware of where to obtain their ARVs (Laskar NGO Representative)

Technical Considerations: A barcode system for easy access during patient visits; The application should clarify the stages of AIDS and its symptoms with real images to enhance understanding; The application should be based on the national identification number (NIK) system. This approach is crucial due to the high number of patients who become lost to follow-up after learning their HIV status but fail to continue treatment. Health workers often struggle to contact these patients due to inaccurate addresses or phone numbers provided. By using the NIK, the application could minimize issues related to identity fraud and improve the tracking of patient progress.

If it could be downloaded via a barcode, patients could find it easier to download it during their visits. I believe it should also track the treatment progress and health status of PLWHA (HIV Programmer of PHC 5)

The main issue we face is with the identities provided by patients during visits to the health center. Currently, the SIHA system is based on NIK, which helps reduce the use of aliases that complicate our tracking efforts. If the application could also use NIK, it would facilitate easier tracking of patients who may go missing (HIV Programmer of PHC 6).

Suggestions for Application Features

The proposed features for the application centered on enhancing clinical management, accessibility, and user trust. Participants emphasized the necessity of core functional tools, specifically daily symptom tracking, ARV medication reminders, and an integrated appointment management system for scheduling and notifications. To improve health literacy and inclusivity, the findings suggest incorporating simplified explanations of HIV progression—supported by visual aids—and providing multilingual support in Bahasa Indonesia, Javanese, and Madurese. Furthermore, participants identified robust privacy and data security measures as a prerequisite for fostering patient trust and encouraging consistent app engagement. Finally, logistical enhancements were recommended to support mobile populations, including a barcode system for streamlined access during health visits and location tracking to assist users in finding ARV medication sources while working outside the city.

Application Database Design

The context diagram illustrates the relationships between various entities and the PLWHA assistance application (Figure 1). The primary source entity is the HIV/AIDS patient, who can access their personalized application. Patients can log into the application, where their entered data is securely stored. This data can be accessed by their peer supports, including NGOs, Primary Healthcare (PHCs), and health offices. Additionally, the assistance team, which includes application developers, can monitor the application's usage. While the context diagram is presented here, the detailed Data Flow Diagrams (DFD) and Entity-Relationship Diagrams (ERD) that illustrate the system's internal processes and data structure will be provided in future publications to offer a more comprehensive view of the application's architecture and functionality.

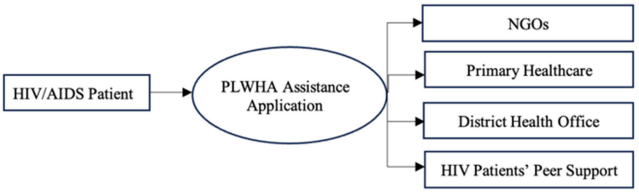

Figure 1: Context Diagram of PLWHA Assistance

DISCUSSION

The findings from this study showed the urgent need for a self-management information application tailored for people living with HIV/AIDS (PLWHA). Such an application, designed for Android devices, would significantly enhance the ability of HIV patients to manage their health effectively. By incorporating features that focus on clinical symptom control, adherence to antiretroviral (ARV) therapy, and access to health education, the application can play a pivotal role in improving treatment adherence and facilitating timely initiation of care at health services (3,5,6). Previous studies stated that evidence is sufficient to infer that self-management programs for people living with HIV/AIDS result in short-term improvements in physical, psychosocial, and health knowledge and behavioral outcomes (9,10). Another study indicated that the weighted matrix scores (WMS) for various aspects of self-care management were significantly above average, suggesting that PLHIV attending the antiretroviral clinic at the University of Abuja Teaching Hospital exhibit good self-care practices. However, psychological and workplace self-care requires some strengthening (11).

One of the critical components of the proposed application is the ability for users to maintain a daily record of their symptoms. This feature would empower patients to actively monitor their health, enabling them to identify any changes that may require medical attention. Study indicates that regular self-monitoring can lead to improved health outcomes, as patients become more engaged in their treatment processes (3,12). Self-monitoring is a potentially efficacious disruptive innovation for supporting self-management by PLWHA and for complementing other interventions (13). Additionally, the application should provide simple explanations of HIV progression, accompanied by visual

aids, to enhance understanding and promote informed decision-making among patients. This educational aspect is crucial, especially for individuals with limited health literacy, as it can simplify the complexities of HIV and encourage adherence to treatment protocols (14) (15).

Moreover, the application must facilitate appointment arrangements and send reminders for ARV therapy. Many patients face logistical challenges in accessing healthcare services, and by streamlining appointment scheduling, the application can help ensure that patients do not miss critical visits. Reminders for medication adherence are particularly important, as they can mitigate the tendency for patients to neglect their regimens, especially when they do not perceive themselves as ill (16). A previous study stated that a practical reminder system can significantly increase patient attendance at medical outpatient clinics (17)(18). An intervention focused on specific patient characteristics could further increase the effectiveness of appointment reminders. Moreover, expanding self-management support options is crucial for healthy aging and multimorbidity management in people living with HIV, addressing stigma, and addressing social needs (19). A previous study also stated that Self-management was positively significantly correlated with social support (20).

The inclusion of local languages, such as Madurese, Bahasa Indonesia, and Javanese, within the application is essential to cater to the diverse linguistic needs of the patient population in Jember Regency. Language accessibility can significantly enhance communication and understanding, leading to better health outcomes (21)(22). Furthermore, the application must prioritize patient privacy and data security, as these factors are crucial for fostering trust and encouraging more individuals to utilize the application (23). Concerns about data privacy are also important considerations for PLWHA, for example, when the app issues a warning message. This is aligned with a previous study that has shown that people living with HIV have a high level of awareness about the privacy and security of their health development data (24). The design and implementation of the app must ensure that patients who use the app in their daily lives cannot be identified by others as being HIV-infected. The advantages offered by this Android app for HIV patients are process improvements, such as treating more patients and avoiding unnecessary visits.

From the perspective of PLWHA, there is a strong demand for a tool that facilitates communication and support. The application should enable users to share their experiences and needs directly with healthcare providers, thereby enhancing the support network available to them. Designing of self-management system architecture will be possible. Self-management skills of PLWH and their communication with healthcare providers will improve by using this system (25). NGO representatives have emphasized the importance of having an application that allows for tracking patient locations and providing information on where to access ARV medications, particularly for those who work outside the city (26).

Additionally, incorporating a barcode system into the application would streamline access for patients during health center visits, making it easier for them to engage with health services. Monitoring the treatment progress of PLWHA through the application will also be vital for ensuring that individuals receive the necessary support throughout their treatment journey (27). It also meets their psychological and social demands (3).

In the next development steps how the system can technically be linked to the patient's medical record, we will involve people living with HIV to be included in our discussions about the initial app design and to test its usability. The response from PLHIV to the application initiative has been positive. A previous study stated that HIV-related Android apps should be simple and accessible even to people aged 60 and above. 85.2% of patients found the app useful in improving their healthcare, and 91.4% would recommend the app to friends or relatives (28).

Although this was action research, our approach was qualitative to explore the needs of the app. As with other qualitative approaches, the results are not generalizable or representative. We made a conscious decision regarding the number of participants, as we found appropriate information saturation in the analysis data. This is supported by a systematic review by Hennink et al., which states that qualitative studies can reach saturation at relatively small sample sizes (29). We identified other studies that used small sample sizes to gather initial requirements for developing an app. Although the sample size was small, this study represented all parties directly or indirectly involved in HIV treatment with a variety of experiences. In-depth interviews regarding care and information needs are a suitable way to obtain accurate information at an early stage of development, as many other studies have shown in the past. This method allows for enriching perspectives with a small group of participants and produces more convincing data than quantitative research (30,31). However, while qualitative research can reach data saturation with small samples, the limited patient input may restrict the comprehensiveness of understanding PLWHA needs. Future studies should involve larger, more diverse patient samples to validate and expand upon these findings.

CONCLUSION

This study underscores the critical need for a mobile application designed to enhance HIV self-management and treatment adherence among PLWHA. It revealed

significant challenges in the current support systems, including communication difficulties, treatment adherence barriers, and the limitations of existing patient monitoring methods. The study's findings highlight the essential features required for a successful application, including symptom tracking, medication reminders, health education resources, multilingual support (Bahasa Indonesia, Javanese, Madurese), and robust privacy and security measures. The application's design, informed by these identified needs, aims to facilitate improved communication between patients and healthcare providers, empower patients to actively manage their health, and ultimately enhance treatment initiation and adherence. The intended application represents a vital step toward improving the quality of life for PLWHA in Jember Regency. Future research should focus on evaluating the application's long-term impact on patient outcomes, its sustainability, and its seamless integration into existing healthcare systems. This will ensure comprehensive support for PLWHA, contributing to better management of HIV in the region and potentially serving as a model for similar interventions.

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