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REVIEW

Article Detail

Prospecting SEHAT-Kader Project to Decrease Perceived Stigma and Improve Quality of Life People Living With HIV/AIDS at Kudus District, Central Java

Author: ERNAWATI ERNAWATI, NURSALAM NURSALAM, SHRIMARTI RUKMINI DEVY, SITI AMINAH, AHMAD FATHUROHMAN, TRI HARTITI, ARIEF YANTO, MACHMUDAH MACHMUDAH

Abstract: Background: People living with HIV/AIDS (PLWHA) experience various difficulties in life. Society gives them a strong stigma that causes poor quality of life. Although they had been gotten support from cadre, however the cadres themselves encountered many obstacles during accompaniment. This study aimed to explore the prospect of comprehensive HIV/AIDS care with the electronic system (SEHAT-Kader) as a personal health record in information systems for PLWHA and their special needs plan based on Web to decrease perceived stigma and improve quality of life PLWHA. Method: A qualitative research method was used to gather experiences of managing stigma and health condition status PLWHA and how are perceptions and barriers regarding challenges to designing SEHAT- Kader application at Kudus district, Central Java. The study had been carried out during February 2019-April 2020. The sample comprised PLWHA, cadre members, and case manager. We conducted 2 focus groups with members (n=12). Data were thematically analyzed. Results: The study revealed that mayor problems of HIV/AIDS's cadre in Kudus district, Central Java are: the extent of coverage area and accompaniment ratio is disproportionate (1 cadre:45 PLWHA); fear direct contact and being HIV infected; the manual data record system, so often error and lost; Cadres needed an information system to monitor the health conditions of PLWHA. The “SEHAT-Kader” app is designed as a personal health record for PLHIV information systems and information technology-based special needs plans to reduce perceived stigma and improve the quality of life of PLWHA. Conclusion: The features of SEHAT-Kader application designed to support routine operational activities of user groups, namely cadre companion, PLWHA, and case manager as care coordination or administration personal.

Keyword: HIV/AIDS Cadre, SEHAT-Kader application, PLWHA, Perceived Stigma, Quality of Life, mobile self-management

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Research Article

Prospecting SEHAT-Kader Project to Decrease Perceived Stigma and Improve Quality of Life People Living With HIV/AIDS at Kudus District, Central Java

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ABSTRACT

Background: People living with HIV/AIDS (PLWHA) experience various difficulties in life. Society gives them a strong stigma that causes poor quality of life. Although they had been gotten support from cadre, however the cadres themselves encountered many obstacles during accompaniment. This study aimed to explore the prospect of comprehensive HIV/AIDS care with the electronic system (SEHAT-Kader) as a personal health record in information systems for PLWHA and their special needs plan based on Web to decrease perceived stigma and improve quality of life PLWHA.

Method: A qualitative research method was used to gather experiences of managing stigma and health condition status PLWHA and how are perceptions and barriers regarding challenges to designing SEHAT-Kader application at Kudus district, Central Java. The study had been carried out during February 2019-April 2020. The sample comprised PLWHA, cadre members, and case manager. We conducted 2 focus groups with members (n=12). Data were thematically analyzed.

Results: The study revealed that mayor problems of HIV/AIDS's cadre in Kudus district, Central Java are: the extent of coverage area and accompaniment ratio is disproportionate (1 cadre:45 PLWHA); fear direct contact and being HIV infected; the manual data record system, so often error and lost; Cadres needed an information system to monitor the health conditions of PLWHA. The "SEHAT-Kader" app is designed as a personal health record for PLHIV information systems and information technology-based special needs plans to reduce perceived stigma and improve the quality of life of PLWHA.

Conclusion: The features of SEHAT-Kader application designed to support routine operational activities of user groups, namely cadre companion, PLWHA, and case manager as care coordination or administration personal.

Keywords: HIV/AIDS Cadre, SEHAT-Kader application, PLWHA, Perceived Stigma, Quality of Life, Mobile Self-Management

INTRODUCTION

People living with HIV/AIDS (PLWHA) experience various difficulties in their lives. Society gives them a strong stigma that causes poor quality of life. The stigmatization of PLHIV in Indonesia is still widespread (Chew & Cheong, 2014; Waluyo et al., 2014). Almost all components of the quality of life are low with a mean score of 0.38 (scale range 0-3, SD = 0.30) (Nyamathi et al., 2017). Efforts to deal with and reduce stigma determine the quality of life of PLWHA (Chidrawi et al., 2015). The proportion of PLWHA requiring complex care has increased. The case manager noted that the data on new HIV/AIDS case findings increased from year to year. In 2016, there were 102 cases, in 2017 there were 114 cases, while in 2018 there were 140 new cases of HIV sufferers. Currently, there are more than 400 people living with HIV in the Kudus district (KDS 'Kasih Kudus' data, 2019). Meanwhile, public awareness of the HIV/AIDS problem is still limited among sufferers and volunteers who are called upon by their human instincts.

Even though they have received support from cadres, cadres themselves encounter many obstacles in mentoring. The problem of outreach

in poor rural communities is complex. The study in South Africa found that some of the reasons for the limited effectiveness of cadres were the lack of understanding of facilitators and barriers to their involvement (Majee et al., 2020). The fear of being infected is one of the obstacles for people from being reluctant to be involved in HIV care (Lazuardi et al., 2018). Provision of health services to improve HIV care using mobile-based application technology is needed in developing countries with limited health human resources. Studies on the use of mobile-based technology for the treatment of vulnerable groups with chronic diseases have been widely carried out. Some of them are the application of tele-healthcare focused on home-based health monitoring for the elderly (Kao et al., 2014). The standard feature 'Mobile-based self-management system' is the result of an identified literature review consisting of 11 features and 6 demographic data elements designed to provide, evaluate and improve HIV care (Mehraeen et al., 2018). Mobile-based self-management is becoming a new strategic approach to slow the progression of HIV infection and improve quality of life (Mehraeen et al., 2019). This study aims to examine the prospects for comprehensive HIV/AIDS services with an electronic system (SEHAT-Kader) as personal health records in the PLWHA information system and a Web-based special needs plan to reduce perceived stigma and improve the quality of life of PLWHA.

Research Method

The qualitative research method was used to gather experiences managing the stigma and health status of PLWHA and how the perceptions and barriers related to the challenges of designing PLWHA data management application software were used as a source of educational materials for assisting HIV/AIDS cadres.

Research Area and Period

This research is the initial stage of a project to reduce stigma and improve the quality of life of PLWHA through community advocacy in the Kudus district. Implementation of developing PLWHA data management application software during February 2019-April 2020.

Participants

The data sources of this research are primary and secondary data. Primary data were obtained from 12 participants including 6 PLWHA and 6 HIV/AIDS cadre members from peer support groups (KDS) to get a more complete picture of mentoring and problems with stigma and the quality of life of PLWHA. Meanwhile, secondary data were obtained from the documentation of PLHIV data, case managers and literature review results to help understand and analyze more comprehensively.

Sampling by purposive sampling. Participants living with HIV/AIDS were selected according to the inclusion criteria of male or female adults (20 years> age <60 years) who were diagnosed with HIV, could communicate fluently verbally, were in good general health. Meanwhile, the cadres who are included are volunteers in the community, live in the Kudus district, actively assist PLWHA for at least the last 3 months.

Data collection and analysis

Collecting research data through focus group discussions (FGD), observation, documentation and triangulation. We conducted FGD with 2 groups, each consisting of 6 people (n = 12). All participants attended and followed through to completion. The average FGD lasted 60 minutes.

Manually documenting PLWHA data in the cadres' notebooks has identified its scope as an element of PLWHA demographic/biodata and clinical data. Triangulation was carried out for HIV/AIDS case managers to check the correctness of data or information obtained by researchers from different perspectives. Data collection by triangulation is useful as well as testing the credibility of the data with various data sources (Denzin & Lincoln, 2011).

All the discussion data were recorded with MP4 audio then transcribed, reviewed for accuracy, read over and over by the research team and coded. Data were analyzed manually using the 'thematic analysis' method. Themes result from the interpretation and exploration of various statements and situations, then color coded, cut and pasted. Themes emerging from field notes were included in the analysis. A list of combined themes was developed from the sub-themes and then combined to show the relationship between the themes.

This research follows ethical principles such as confidentiality, beneficence and non-maleficence, respect for people, and fairness. The research permit was granted by the Kudus Regency National and Political Unity Office (Kesbangpol), and the data collection permit was granted by the peer support group coordinator (KDS 'Kasih' Kudus). All participants received information about the aims and objectives of the study in advance and the subject had the right to accept or refuse to be involved in this study by providing informed consent.

RESULTS

Comprehensive HIV/AIDS services with an integrated HIV/AIDS Electronic System by cadres

are named "SEHAT-Kader" the app is designed as a personal health record in the PLWHA information system and information technology-based special needs plans to reduce the perceived stigma and improve the quality of life of PLWHA. This mobile system can be accessed within 24 hours, via an Android smartphone or laptop/computer connected to the internet so that information can be viewed anytime and anywhere. The system architecture of the SEHAT-Kader application includes application software that is connected to a PC or android smartphone through the cloud-based network server of the Universitas Muhammadiyah Semarang. A simple framework for recording and interaction between cadres and PLWHA is shown in Figure 1.

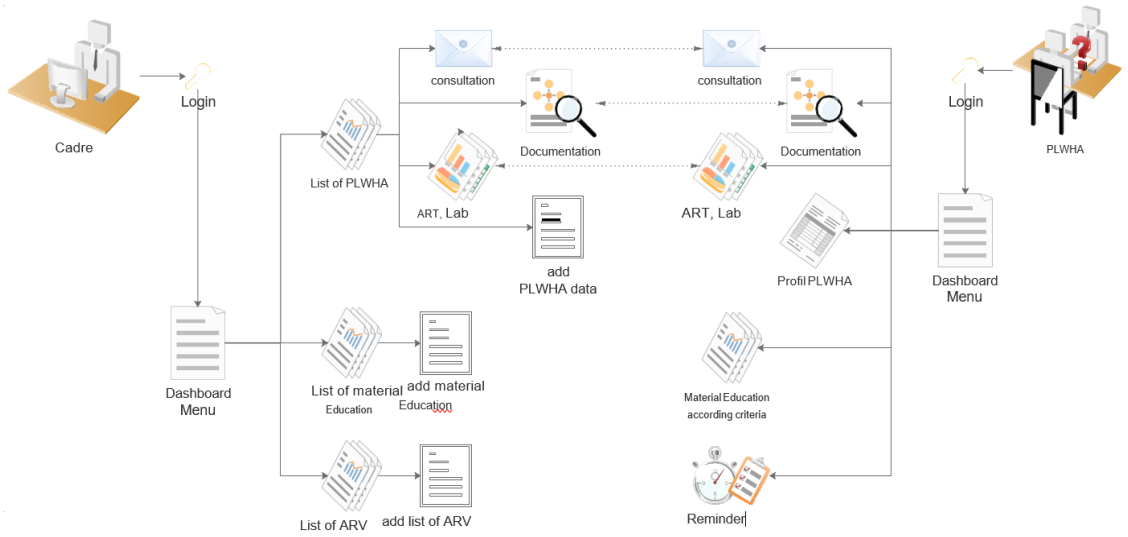

Fig.1: Flow diagram of aplication of SEHAT-Kader

This system is designed to have 5 elements as shown in Table 1.

Table 1: Data elements for the SEHAT-Kader application

1) Need assessment	The 8 features of need assessment filled by PLWHA are problems felt by PLWHA such as physical needs, emotional needs, spiritual needs, social needs, perceived stigma, quality of life, knowledge and assessing the ability of cadre mentoring.
2) PLWHA Biodata	The 17 features in the PLWHA biodata filled by cadres include name, NIK, place/date of birth, address of RT/RW Village, sub-district, Religion, marital status, occupation, No. HP, No. National Registration, No.KK, No.BPJS, No.CM (RSU), No.CM (RSDK/Referral), Time to start mentoring, Name of Spouse (Husband/Wife), Time known to be HIV Positive, Place known to be HIV Positive.
3) Educational materials	15 features for educational materials containing HIV transmission prevention, ARV therapy, adherence, side effects of ARV drugs, HIV & TB, diarrhea, candidiasis, skin rashes, safe sexual intercourse, diarrhea/nutrition, physical exercise, special needs of HIV women, special needs of HIV children, Strengthening Islamic spirituality, Psychoeducation therapy.
4) Clinical condition update	3 features for updating PLWHA conditions containing ARV drugs: The line of ARV drugs obtained, the name of the drug, and the dose obtained; Laboratory tests: CD4, Viral load, Hematology tests, Urinology tests; and BMI (BW/TB^2)
5) Remainder	3 features in the PLWHA reminder containing 30 minutes before taking medication; Days-3 control to health services; and complete a re-assessment every 30 days.

*PLWHA = people living with HIV/AIDS; NIK = population identification number; RT = neighborhood unit; RW = community unit; No. = number; No.KK = family card number, No.CM = medical record number; No.BPJS = number of health insurance ownership; RSU = public hospital; RSDK = Kariadi doctor's hospital; HIV = human immunodeficiency virus; TB = tuberculosis; CD4 = cluster differentiation; BMI = body mass index; BB = body weight; TB = height; ARV = antiretroviral

Application users consist of 3 levels, namely (1) admin; (2) cadres; (3) PLWHA. Each of them has the access rights (Table 2).

Table 2: Access rights of SEHAT-Kader application users

No	Level	Part	Access rights
1	Level 1	Admin	All in-app features
2	Level 2	HIV/AIDS cadres	Edit features inputted by the cadres themselves, such as demographic data of PLWHA, up-to-date clinical conditions, educational materials, remainder.
3	Level 3	PLWHA *	Inputting the problems experienced, filling out a questionnaire about HIV/AIDS, stigma, quality of life, writing in the consultation column with the accompanying cadre, and assessing the ability of the cadre who accompanied them.

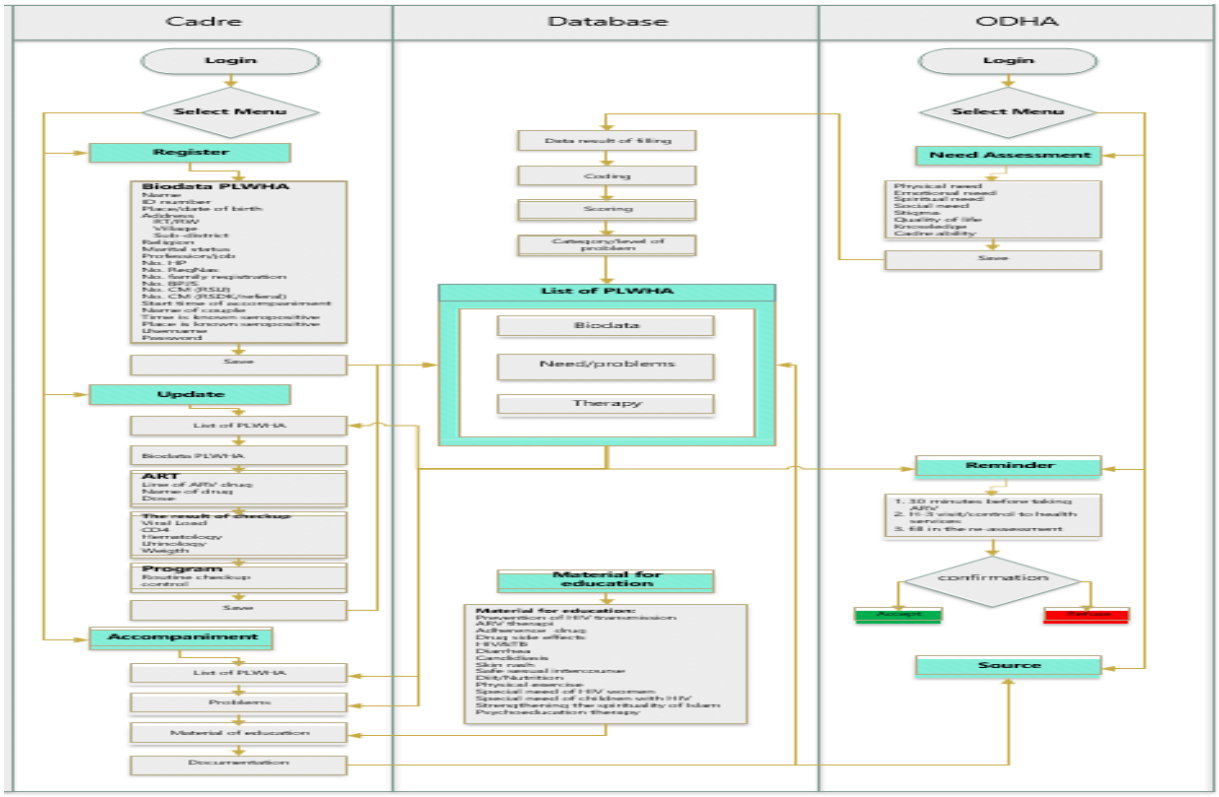

Fig.2: The SEHAT-Kader data management program

DISCUSSION

The application of "Integrated HIV/AIDS Electronic System for cadres" is named SEHAT-Kader. Features and design of software based on practical experience of community settings by cadres in providing assistance and identification of educational needs of problems often experienced by PLHIV. Its features are designed to facilitate daily operations.

The features in the SEHAT-Kader application are different from the mobile-based applications used in previous HIV/AIDS programs. However, the concept of architecture and software development is almost the same as mobile-based applications in tele-healthcare, which basically connects home boxes to BP devices, android smartphones related to pervasive computing, human computing

interfacing on smartphones and cloud-based information systems (Kao et al., 2014).

This system is able to input and manage PLWHA data, realizing effective interaction between HIV/AIDS cadres and assisted PLWHA from a distance. So that it becomes a solution to the problem of disproportionate number of assistance and the extent of the outreach area. In dealing with malnutrition in West Java, the information system for medical records and monitoring of malnutrition based on cloud computing is a solution for recording and reporting periodically every month (Putra, 2017).

Remainder is set according to the needs of PLWHA, namely 30 minutes before taking medication, 3 days before the time of control to health services, and filling out a re-assessment every 30 days. Another study suggests that for the design of an attractive mobile health application it is necessary to provide a remainder and instructions, goal setting, motivational messages, problem solving and feedback. The addition of a location-based time reminder is important to maintain medication adherence (Ramanathan et al., 2013). The benefits of the remainder alarm on self-monitoring, especially for medication adherence as a signal to act and strengthening the routine of taking medication (Swendeman et al., 2015).

Educational material features are provided to facilitate the needs for handling physical, psychological, social and spiritual complaints of PLWHA, including prevention of HIV transmission, ARV therapy, adherence, side effects of ARV drugs, HIV & TB, diarrhea, candidiasis, skin rashes, safe sexual intercourse, diet/nutrition, physical exercise, special needs of HIV women, special needs of HIV children, strengthening of Islamic spirituality, psychoeducation therapy. Studies on the impact of using self-management education programs on PLHIV resulted in short-term improvements in physical, psychosocial, health and behavioral outcomes (Millard et al., 2013).

Studies on the use of similar programs have been carried out, the results have been able to improve the quality of care, user satisfaction and operational efficiency. The application also allows users to collect and represent data from devices for self-management (Kao et al., 2014). Improving the quality of life appears as one of the themes related to reinforcing factors of the user experience of an HIV self-management app (Cho et al., 2018).

CONCLUSION

The scope of biodata, clinical conditions, need assessment, educational materials, and remainder are various elements of the data input system for PLWHA data management information which were developed into features of the SEHAT-Kader application software. The innovation of SEHAT-Kader based on Web is very prospective in improving the quality of life of PLWHA. This application was created to support the routine operational activities of user groups, namely companion cadres, PLWHA, and case managers as administrative personnel or community nurses as client care coordinators.

Acknowledgments

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Ethical statement

The research permit was granted by the Kudus Regency National and Political Unity Office (Kesbangpol), and the data collection permit was granted by the peer support group coordinator (KDS 'Kasih' Kudus). All participants received information about the aims and objectives of the study in advance and the subject had the right to accept or refuse to be involved in this study by providing informed consent.

Conflict of interest

There are no conflict of interest.

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