Nutrition Telemonitoring for CKD-HD Patients: A Qualitative Study on Patients, Patients’ Families, Medical Teams, and Hospital Management

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Abstract

BACKGROUND: CKD-HD patients require a nutritional monitoring system to control the amount of protein, fluid, sodium, potassium, and phosphate intake to reduce readmission rates and to improve their life quality. The Nutrition Telemonitoring Application (NTA) has a potential to resolve this problem.

AIM: Therefore, this study aims to prepare NTA design materials conditioned to the needs of patients, families, medical teams, and hospital management.

METHODS: A qualitative study with semi-structured interviews was conducted on 16 informants consisting of patients, families, medical teams, and hospital management teams. Furthermore, a purposive sampling technique was used to recruit participants, and the thematic analysis of the audio recording was conducted.

RESULTS: Three main themes and seven sub-themes were identified. First, all participants in support of NTA will find it beneficial. Second, NTA implementation requires family, medical team, hospital management, and BPJS (Health Social Security Agency). Third, all participants demand an easy Indonesian language interface equipped with pictures of food portions, additional alarm features, exercise, food recipes, educational videos, and free of charge.

CONCLUSIONS: This study provides important insights considering the issues associated with the sustainability of NTA design and long-term benefits for CKD-HD patients.

Introduction

At present, there is an increase in the global incidence and prevalence of chronic kidney disease (CKD) [1, 2]. Terminal stage CKD requires patients to undergo lifelong renal replacement therapy, and the most widely used is hemodialysis (HD) [3]. Patients with end-stage CKD that are meant to experience routine HD are referred to as CKD-HD patients [4]. These patients require proper nutritional monitoring to control the amount of protein, fluid, salt (sodium), potassium, and phosphate intakes [5, 6]. The purpose of the monitoring system is to reduce the risk of complications and improve life quality [7, 8]. Furthermore, the rates of non-adherence to diet programs and treatment management have been associated with an increased risk of death, higher hospitalization rates, increased complications, and poor life quality [9]. Integrated nutrition monitoring with hospital information system will increase the convenience of health services, improve the quality of hospital, and existing services to increase patient satisfaction and loyalty [10].

Specific food and fluid composition restrictions can confuse and burden patients at all CKD stages. At present, the discrepancy between patient needs and the provision of clinical services considers alternative strategies to support patient dietary management [11]. Emerging evidence suggests that using technologies such as telemonitoring promotes dietary adherence and improves health-care quality. Furthermore, telehealth modalities can support the complex dietary changes in CKD-HD patients [11]. The Nutrition Telemonitoring Application (NTA) design is part of the modality with an integrated plan using a hospital information system installed in the patient’s cellphone application. It contains several menus for determining calorie limits, protein limits, daily intake targets, and daily activity targets of the management doctors. At present, no mobile application is designed explicitly for nutrition telemonitoring, especially for CKD-HD patients in Indonesia. Therefore, the purpose of this study was to describe the experiences of CKD-HD patients in managing dietary recommendations and to solicit suggestions for developing an NTA design according to their needs and desires.
Methods

Study design
A descriptive qualitative study was conducted using a list of questions developed based on the objectives, literature review, and information needed for the NTA design development. Semi-structured individual interviews with the patient, the patient’s family, the medical team, and the hospital management as the HD unit manager were then carried out. The HOT-Fit [12] and UTAUT [13] models developed the interview guide and data analysis. Subsequently, the HOT-Fit model consists of three interacting domains to accept new technology for behavior change. Human (individual), Organizational (Social), and Technological factors are the three main factors, in which performance expectations (benefits), business expectations (convenience), social influences, and facilitating conditions are studied as supporting factors in the same goal. The Research Ethics Committee approved this study of Aisyiyah University Yogyakarta No. 1382/KEP-UNISA/III/2021. The study was conducted between July and August 2021 at the Tugurejo Regional General Hospital, Semarang. It is the main referral hospital for patients throughout Central Java, under the direct control of the Central Java Provincial Government. This hospital has 20 HD machines with 90 active patients and 800 HD procedures per month.

Participants
The purposive sampling was applied to select informants, subsequently, a qualitative study was conducted on 16 informants consisting of four CKD-HD patients, four families of CKD-HD patients, and eight HD unit teams comprised two nurses, two general practitioners, two internal medicine specialists, and two hospital management teams. They were selected with the inclusion criteria: Have been or accompanied CKD-HD patients for at least 6 months, are managers of CKD-HD patients, aged 16–60 years old, able to communicate in two directions, and are accustomed to using smartphones.

Data collection
All data were taken through semi-structured interviews with 16 predetermined informants. Twelve informants were interviewed online through zoom, and four were interviewed directly with strict health protocols. However, some informants were interviewed online because there were restrictions and recommendations from the hospital medical committee to minimize direct contact with informants due to the COVID-19 pandemic.

The interview used an open-ended guideline consisting of questions to explore patient knowledge and adherence to the HD diet, experience in managing existing HD diet monitoring, perceptions of the NTA development plan, support for NTA implementation, and suggestions for NTA design according to the needs of all parties. Before being used, the question guide was piloted on subjects with the same characteristics as the study informants.

Each interview took about 20–60 min, using a combination of Indonesian and Javanese recorded using video and audio. Different approaches ensured the credibility of the data during the interview process. Triangulation of sources and data was used, and repeated questions were requested to confirm the informants’ answers. All three authors have qualitative research backgrounds and practices.

Data transcription and analysis
The recorded interviews were transcribed verbatim and identified before analysis. Furthermore, all audio recordings and interviewer field notes were also studied as the basis of the study. Thematic analyzes were performed on the transcripts by three investigators. Quotations by participants were edited on a limited basis to remove content that does not convey meaning (repeated words and stuttering) and correct grammar. Moreover, the ellipsis records the removal of unrelated content. Finally, square brackets are used in quotations to provide comments that the speaker omitted or to replace sensitive information involving names.

Results
Characteristics of informants
Around 64% of the informants are female, with an average of 41.8 years old. The duration of the HD patient and the accompanying patient’s family was 5.38 years. The team worked to manage HD units on average for 8.5 years. The educational background of the patient and the patient’s family showed 12.5% from Junior High School, 75% from Senior High School, and 12.5% from bachelor’s degree. Meanwhile, the HD patient management team has a minimum of bachelor’s degree education. All informants are also accustomed to using smartphones in their daily activities.

Data analysis results
The results of the analysis obtained three significant themes, where theme 1 represents individual factors related to NTA which consists of three sub-themes and eight categories. Meanwhile, the theme of NTA comprises social and organizational factors facilitating
NTA which is further developed into three sub-themes and seven classes. Theme 3 describes suggestions related to NTA design development technology, divided into three categories (Table 1).

Table 1: List of categories, sub-themes, and themes of study results

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Sub-theme of compliance with the HD diet

Low patient self control

Low nutritional knowledge reduces self-control, and patients tend to judge from the physical condition and symptoms that are felt. As long as the body feels fine, the diet that is followed is safe even though it violates the HD nutrition guidelines.

"... I'm still eating everything.... yeah, I'm limiting myself, but I don't abstain." (P1)

"... My father is fat.... it is hard to limit him to eating outside. It feels like he is always hungry." (KP1)

Routine nutrition evaluation not working

An evaluation is required to determine how to implement the nutritional guidelines and programs provided. Finally, there are clinical and laboratory indicators to measure the success of the nutrition program.

"... the problem is that there is no nutrition team here, nutrition doctors and nutritionists are not on standby or regular duty here...." (DS2)

"There is no routine nutritional evaluation .... initial screening is available when the patient is first treated...." (D1)

Theme 1: Individual Factors Related to NTA

This theme is formed from 4 sub-themes: Knowledge of the HD diet, individual adherence to the HD diet, and the expectations of NTA performance and efforts to use NTA.

HD diet knowledge subtheme

Lack of nutrition knowledge

The interviews conducted on patient informants, families, and medical staff (nurses and doctors) showed that the nutritional management with kidney disorders that were not HD cannot be differentiated from CKD-HD patients. Therefore, the patient believes that healthy regulation in kidney disease applies to both.

"Yes, basically, at the beginning of the illness, I was told, if I can’t eat red meat, then ....I cannot eat vegetables and fruit. Even Tofu and tempeh. Therefore, I stopped eating..." (P4)

"... hmmm. I eat all kinds of food, doc.... (....). I just eat a little bit like that... is it okay to get skinny or not, it is important to be healthy. hehe"... (P4)

Less Optimal Nutrition Education

The interview results showed that the patient’s nutritional knowledge was not optimal because the educational process from the beginning was not optimal, and there was no repetition or programmatic evaluation of nutrition. Patients and their families seek information according to their wishes and beliefs.

"..... the long explanation is given when the illness starts, or it is the first time to start HD...... “ (P1)

High patient readmission

High patient readmission was caused by ignorance and non-compliance with nutrition programs. As a result, the patients were hospitalized due to complications caused by electrolyte disturbances, uremia, and anemia.

".... I underwent HD for nine years and have been hospitalized six times doc......” (P3)

".... my husband since the first HD has been hospitalized eight times....” (KP1)

Patients’ knowledge and experience regarding nutrition affect their adherence to proper nutrition guidelines. Low compliance causes patients to often fall into malnutrition complications, fluid imbalance, electrolyte disturbances, and anemia. Meanwhile, innovation and strategy are needed as a solution to this problem. The development of technology as a health monitoring tool has been widely conducted, but the design should certainly be adapted to the target user of the tool. A preliminary study is needed to understand the core problems and desires of the users, therefore ensuring the sustainability of the application. NTA was formed as an alternative intended to solve the high rate of nutritional non-compliance in CKD-HD patients.
NYA performance expectations subtheme

Expected benefits from NTA

After explaining the NTA concept, the informants all supported and welcomed the idea. Furthermore, patients, patient families, nurses, and doctors stated that the idea will obtain the optimal benefit. Some of their statements are as follows:

“...well, it is perfect when there is an application like that, it can help make food menus... every time I want to eat what kind of side dish, I am easy to get confused... in the end, I just eat the available food....” (P2)

“... excellent doc. it can replace washed or lost watch books....” (N2)

Expected results from NTA

The interview was continued with questions concerning the expected result when the informants had used NTA in their daily lives. For example, patient informants expect their body condition to improve when using NTA. Moreover, patients’ family informants wish to prevent confusion on menu preparation to regulate diet. Nurses and doctors as informants expect the level of compliance and patient care to increase after using NTA. Statements that support this description are:

“This aims to make me obedient, doc... hence, I don’t often eat snacks arbitrarily...” (KP3)

“.. I hope that fewer patients will eat as they please.. and there will be fewer complications for patients...” (D1)

Expectations of NTA can help work

The informant’s perception stated that NTA could act as a tool to relieve or assist in daily work and activities. Just like the family informant, medical personnel informants said that they would be helped by the NTA, and the following statement supports this:

“..... when I think it is beneficial... my imagination that it can later be linked, for example about why is it anemia, and then it is because I just eat like this...” (D1)

“Education to patients is more practical, doc... because patients will be freer to choose the menu and the portion can then be checked through the application...” (D2)

Sub-theme of business expectations using NTA

Encouragement for NTA usage

Each informant contributed to the benefits of using the NTA through the provision of accessible, simple, and free applications. Their contributions are as follows:

“...... I need an easy one, doc.... simple, do not contain too many words.... “ (P4)

“.. I want to be able to connect to the hospital information system; therefore, I can take data directly.....” (DS2)

Constraints to use NTA

Informants stated several things that became objections in the NTA implementation. For example, it was not easy to weigh every meal, report for an extended period, and visit the nutrition poly.

“..... huh (surprised)... have to weigh every meal? Wow, what a hassle, doc.... am I just taking care of the patient?.....” (KP1)

“I have a forgetful character... if someone helps me, it is easy... all my children work... when they come home late at night, they are tired...” (P1)

“It is a hassle, Doc, if I have to go to the nutrition doctor’s clinic.....” (KP4)

Theme 2: Social and Organizational Factors that Facilitate NTA

Sub-theme of social influence on NTA acceptance

Requirement To Use NTA by hospital

The opinion of informants was asked when CKD-HD patients at Tugurejo Hospital were required to use NTA and fill out daily food monitoring. Several informants were willing to use it, while some were still hesitant because they were not used to using the application on a cellphone. Some can use it when assistance is received from family members, and the supporting statements are as follows:

“Okay doc... I want to use it.. I hope it is fast, doc......” (P2)

“My eyes are blurry when I look at my cellphone for a long time... later maybe my child will have to study first... I will let him use it later...” (P3)

NTA user community

The informants’ opinions are needed since all CKD-HD patients can use NTA. The response turns out to feel more comfortable when many friends use it. Furthermore, they are freer to propose questions and ask their friends to teach them instead of health officials. This statement is supported by the opinion of the informants as follows:

“...if my friend uses it, I will use it too...” (P4)

“...it’s good if many people use the application... I can ask my friends...” (KP2)
Sub-theme of social support for NTA

Family support

This category collects the form and amount of family support for illness, medication, and diet management. The results of interviews with patients and their families illustrate that patients are involved in the diet management and medication process. Some patients stated that their families were busy working, but they cared about their needs in the deepening of the interviews. Likewise, even though the patients often complain, they will obey and follow the family after a good explanation. From the side of the medical management team, patients doubt each family’s care level since the proportion of uncaring people is high. Lack of care is possibly caused by busywork, many family members to take care of, low level of education, and socioeconomic conditions; therefore, it is challenging to meet the patient needs.

“...Yes, my family knows that I have to eat less of this, but it is all up to me...” (P1)
“But it is a bit of a hassle for me, I mean, I am not at home just taking care of my father, right...” (KP1)

Patient management medical team support

Medical officers managing CKD-HD patients at Tugurejo Hospital consisting of nurses, doctors, and specialists expressed support for the NTA implementation. Patients also have a good perception of the medical team’s support to help them use NTA if it is later applied. The following statement supports this conclusion:

“...all the staff are good, doc... the nurses and doctors are all friendly...” (KP1)
“...the principle is that if you practice it until you can, it feels like everything can be done, right... for the good of each one of them” (D1)

Sub-theme of hospital management and BPJS support

Nutrition medical team in HD

The nutrition team was not involved in HD outpatient services considering the narrow unit cost and claim value. The new nutrition team is engaged with only new patients or inpatients. Most patients and their families refuse to visit the nutritionist polyclinic because they queue and wait. Furthermore, the patients did not pay the consultation fee but hoped that the implementation of NTA can hasten the setting up of nutrition programs in the HD unit. The following information supports this statement:

“It is a hassle when I have to go to the poly because of the long queue... Mom's condition is not good... It is a hassle when my mother has to go back and forth to the hospital again, and it is already hard for HD...” (KP4)

“...That includes drugs, injections, etc. Yesterday, it was suggested whether patients can be referred through the internal medicine poly to the nutrition poly. From BPJS, it does not allow that the patient has to go to the poly just for nutritional control like that...” (N2)
“...Maybe when the claim value from BPJS was increased, a nutritionist can be included in the routine HD Team.” (M2)

Theme 3 Suggestion on NTA Design Development Technology

Suggestions for NTA interface

All patient informants and families demand to use the Indonesian language and minimize medical
terms that risk misperceptions. The informant also mentioned the need to use keywords when inputting the names of food and beverages. Therefore, keywords can be typed with many clickable options and clear writing. Furthermore, informants expected the application page to be colorful and attractive. At the time of portion selection, it also included a picture of the portion, measured in an adults' palm or placed in a standard size spoon, glass, or plate used. This is supported by the statement of the informant as follows:

"...I want it in Indonesian, doc... it is confusing using English, I do not know what it means..." (KP1)
"The food will be Indonesian, right... for example; there will be getuk input options, doc... hahahaha...." (P2)
"...I want when I choose food, there are options that appear, for example, when typing tempeh, there will be a choice of fried, boiled, etc... then it has been selected for the portion using a picture, doc... for example a piece or 2 pieces.... " (KP2)

Suggestions for NTA menu/features

Apart from the main menu, the informants proposed additional menus that are expected to be input for daily food in SMS or sound. They also demanded a healthy food processing recipe menu for CKD-HD sufferers, a sports menu or video links, and an engaging educational menu in the form of videos. The following informants support this statement:

"...you can add a medicine alarm menu, doc... if my mother is not reminded to take medicine, she is forgotten, doc..." (P4)
"....my suggestion is to add an example of the food menu doc... I am often confused about what other menus are good and healthy for my husband..." (KP3)
"...there is a menu for recipes and cooking methods, doc....." (KP1)
"The educational menu is good... but maybe it is just a video because I am not sure if the patient wants to read it..." (DS2)
"I suggest an exercise menu, doc... maybe a video that we can practice in the morning..." (P2)

Suggestions for NTA sustainability

The informants explained several suggestions concerning users' sustainability and continuity of daily usage for an extended period. They wanted a simple and easy manual for using NTA without cost, easy and fast to be downloaded. The application should be installed on a cellphone with low specs, login quickly (not much verification), be used offline, do quick result analysis, and ensure communication with the nurse/doctor. These things are supported by the statements of the informants as follows:

"...there is a guide in Indonesian, right?" (KP4)
"...how about free fees, doc...I do not understand how to pay using cellphones..." (KP1)
"How about when the quota runs out, doc... can it still be used?...it should still work since the network does not block it... except when you have to send a report..." (DS1)

Discussion

Nutritional non-compliance is one of the main factors in the high readmission rate and decreased life quality of CKD-HD patients at Tugurejo Hospital. It is caused by the low level of knowledge about the HD diet and the absence of a programmable nutritional evaluation for patients in the HD unit of Tugurejo Hospital. This is consistent with the study conducted by Lim et al., where a significant relationship between the knowledge and literacy level of CKD-HD patients on the rate of non-compliance to the therapy program was stated [14]. The NTA concept is an independent monitoring tool for nutrition that contains eating and drinking targets personalized by a nutritionist according to each patient's conditions and daily needs. Furthermore, this application should be used to control the daily intake and as a report to monitor the patient's nutritional adequacy rate. Previously, concepts such as NTA have been conducted but not in CKD-HD patients, which are more complex and complicated to manage nutrition programs and control complications. Assessment and monitoring of food intake can measure nutritional adequacy and provide appropriate advice to patients [15]. Furthermore, the manual diet evaluation currently used has limitations, such as dependence on memory, the time-consuming conceptualization of portion sizes, literacy requirements, level of knowledge about food, and the specific time required [16]. In recent years, several studies have explored that mobile technology can improve real-time assessment of individual and group diets by incorporating their daily dietary routines [17]. A systematic review of 21 articles evaluating mobile health applications for diabetes management reported that 76% of studies had shown improved clinical outcomes after using mobile applications [18]. The widespread use of smartphones and mobile devices is expected to contribute to the critical role of information technology in healthcare [16].

The design of a technology-based application system requires many considerations and background considerations. The theoretical model used combines the UTAUT and HOT-Fit concepts developed by Yusof et al. in 2008. This model consists of three factors that play a role in accepting new technology, such as individuals, organizations, and technology [12]. In
the concept of individual factors, this study explores the performance and business expectations of NTA from the perspective of individual target users, such as patients, their families, and the medical team. The performance expectations are viewed as the extent to which an individual believes that the availability and use of NTA functions and features can assist in nutrition management [13].

This study found that almost all informants supported the NTA implementation plan to provide results and ease their daily work. Furthermore, the medical team expects that the use of NTA will improve the nutritional compliance of CKD-HD patients. They also facilitate the team to conduct nutritional evaluation and education even though this implementation requires training and habituation. This condition is consistent with Tout and Boulware, which states that a telehealth application should provide a flexible and customizable platform to increase knowledge through various modalities. It should reach all individuals with different learning styles and preferences to promote behavior change through engagement (guidance), repeated self-reflection (evaluation), and habituation [19].

The business expectation is simplicity in the application; therefore, it is not difficult to learn and use daily [13]. The study found several things that can promote potential users to accept and use NTA, such as simple, easy, and accessible design. Furthermore, several factors with the potential of becoming obstacles in the acceptance of NTA were reported. These include users’ objections to weighing food every eating period and carrying out continuous or long-term daily eating reports. Some patients have a low socioeconomic level due to unfamiliarity with cell phones. Therefore, NTA was suggested for a limited period to check the daily diet composition made independently by the patient and his family.

The second concept of the HOT-Fit model is an organizational factor [12]. Patients and families want practical manual support and guidance from the medical team when NTA is applied to all patients. Patients and families are increasing in interest in using NTA when this application has been widely used in the CKD-HD community. This is because more comfort is felt when asking questions and being guided by their friends. CKD-HD patients who have limitations in mobile phones need the support of their closest family to help them use NTA. The medical team managing CKD-HD patients stated that they were ready to carry out socialization, training, and guidance to implement NTA.

The hospital management support expected in the NTA implementation project is the assignment of the nutrition team to be actively involved in the HD outpatient management team. As a trained and experienced party, the team should be responsible for the education and monitoring program. It is also necessary to provide bridging facilities that connect the application with the hospital information system. Tugurejo Hospital already has an E-Patient framework where NTA can be entered as part of the E-Patient menu. The medical team prefers this integration to replace the patient monitoring book that is often damaged and lost. Building this system is undoubtedly full of complexity later. The systematic review by Setyonugroho (2020) identified the complexity of development and obstacles in applying an information system.

This study reported a complex information system due to the connections within the hospital, which can affect the costs of development and implementation [20]. The performance of an information system should be planned to cover the aspects of hardware-software, data, users, and policies [20]. Furthermore, hospital and BPJS policies as funders for CKD-HD patients should provide support by submitting claims for outpatient nutrition. This is because nutrition supports patients who cannot make claims on the same day of HD treatment.

The study found several suggestions and inputs related to technology for developing NTA designs, including interface, primary and additional menus/features, and the continuity of using NTA consistently and in the long term. All patient informants and their families wanted to use the Indonesian language, minimize medical terms that risk misperceptions among patients, and use the Indonesian food and beverage database, especially those often consumed daily. The need to use keywords when entering the names of food and beverages was also stated. Therefore, many clickable options appeared by simply typing the keywords with clear writing. The informants also wanted colorful and attractive application pages. At the time of portion selection, they wanted a picture of the portion, where food is placed in the hands of an adult or on a spoon, glass, and standard size plate. Subsequently, they also proposed other menus as daily food input in the form of SMS or sound/vibration as a reminder of an event. A menu of healthy food processing recipes for CKD-HD sufferers was required with sport video links and an exciting education menu in the form of videos. The informants explained several suggestions about supporting users’ sustainability for an extended period. They wanted a simple and easy manual for using NTA, free of charge, and easy and fast to be downloaded, can be installed on a cellphone with not too high specs, login quickly (not much verification), can be used offline, can analyze the results quickly, and ensure communication with the nurse/doctor.

**Research limitations**

Most of the data were collected online using the zoom meeting application in the HD room (during the action), and informants used masks and PPE. Therefore, the challenges and body movements of the
Informants were not recognized since the entire body was not shown in the zoom.

**Conclusion**

Nutritional non-compliance causes high readmission rates and decreases the life quality of CKD-HD patients. Furthermore, it is fuelled by insufficient knowledge on HD nutrition and education program. The concept of NTA as a nutrition monitoring tool has full support from patients, their families, the medical team, and hospital management. The application helped manage diet and create daily meal portions. Prospective NTA users want a simple application, easy to be learned, uses Indonesian language and a list of Indonesian foods, uses keywords in food searches, and includes images of food portions. Additional medication reminders, daily meal menus, food processing recipes, sports, and educational videos are also preferred. Furthermore, they demand an NTA user manual that is easy, free of charge, fast to be downloaded, can be installed on a cellphone with not too high specs, easy login, used offline, analyze results quickly, and interact with nurses/doctors. Hospital management is ready to bridge NTA with the hospital information system provided by MoU and program compliance. Since prospective users request the involvement of the nutrition team regularly in the HD team, BPJS support is needed to consider a nutritional specialist consultation claim at the Hospital Nutrition Poly and Hemodialysis Outpatients.

**Suggestion**

After NTA implementation, further study is needed to determine the success and inhibition factors as well as the effectiveness in the field. It is also necessary to conduct other studies in different populations and units besides CKD-HD patients.

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