

A HEALTH INFORMATION SYSTEM FOR SCALABLE AND COMPREHENSIVE ASSESSMENT OF WELL-BEING: A MULTIDISCIPLINARY TEAM SOLUTION

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Abstract

To improve the health and well-being of the medically underserved in a free clinic in Pittsburgh, Pennsylvania, a multidisciplinary team representing several health information management and information technology (IT) professionals, including faculty, students, researchers, and clinicians, created a novel IT system called imHealthy. The imHealthy system includes four critical components: a multidomain well-being questionnaire, a mobile app for data collection and tracking, a customization of an open-source electronic health record (EHR), and a data integration and well-being evaluation program leading to recommendations for personalized interventions to caregivers serving the medically underserved. This multidisciplinary team has worked closely on this project and finished critical components of the imHealthy system. Evaluations of these components will be conducted, and factors facilitating the design and adoption of the imHealthy system will be presented. The results from this research can serve as a model for free clinics with similar needs that identified by the research team in Cleveland, Indianapolis, Minnesota, Motor City, Orange County, San Diego, and St. Louis.

Keywords: information technology system; questionnaire; mobile app; electronic health record (EHR); web portal; multidisciplinary team

Introduction

Millions of people in the United States live in medically underserved communities (MUCs). In these communities, many people do not have health insurance coverage, or do not have a primary doctor, or have financial or linguistic difficulties that hinder their access to healthcare services. Great effort goes into improving their health and well-being. However, this task can be very challenging because achieving well-being is complex, requiring medical, social, and financial interventions.

FOCUS Pittsburgh Free Health Center (FPFHC) is a free clinic with limited resources that serves the Hill District community in Pittsburgh, Pennsylvania. The staff consists of a volunteer physician, a psychiatrist, a nurse, a clinic administrator, and a chief operating officer. The clinic staff of FPFHC collected information from community leaders supporting their belief that in order to improve the well-being of their community, a comprehensive well-being assessment is needed and the interventions they provide to individuals in the MUCs must be personalized. Poverty, educational level, unemployment, chronic health issues, physical or psychological trauma experienced in childhood, posttraumatic stress disorder (PTSD), and substance abuse are major determinants to be considered in the comprehensive well-being assessment and the development of personalized interventions.

The clinic sought help from the authors to design a health information technology (IT) system that is user-friendly, is scalable, is simple to understand and use, and has the ability to guide laymen in the design of personalized interventions. The need was echoed by other free clinics located in Cleveland, Indianapolis, Minnesota, Motor City, Orange County, San Diego, and St. Louis. These clinics expressed needs similar to those of the Pittsburgh clinic for a comprehensive, well-being assessment to guide their intervention programs.

A multidisciplinary research team was formed in 2015 and involved the University of Pittsburgh's Department of Health Information Management, the university's School of Information Sciences, and FPFHC, which serves MUCs in Pittsburgh, PA. The research team assembled for this project included clinicians, industry researchers, faculty, and students.

The overarching goal of the project is to improve the well-being of individuals in MUCs by adopting technologies enabling the users to provide personalized interventions to community members or patients and potential patients in MUCs. To achieve this goal, we used a mixed-methods approach to perform stakeholder analysis and design a novel IT system, called imHealthy. The imHealthy system is designed to collect and integrate multidimensional data on well-being from multiple sources and perform statistical analysis and modeling, in order to generate quantitative and solid well-being assessment results. Personalized interventions can then be recommended by caregivers (e.g., clinicians) and delivered to people in MUCs. These personalized interventions may include clinical and behavioral healthcare, housing, job training, community activities, resilience training, educational workshops, and exercise programs. The imHealthy system will make it possible to perform a comprehensive well-being assessment on many people in MUCs easily. One can also perform this assessment multiple times over a period of time and observe changes in people's well-being over time, and thereby determine the effectiveness of the personalized interventions administered to this population.

The specific tasks to create this imHealthy system include the following:

1. Develop a well-being questionnaire that can be delivered via a mobile app;
2. Customize an existing open-source electronic health record (EHR) for the ambulatory clinic setting;
3. Develop an assessment algorithm that integrates and analyzes data from multiple sources;
4. Provide assessment results and personalized intervention recommendations to caregivers via a web portal; and
5. Facilitate the engagement of researchers in multiple disciplines, as well as graduate students, for the betterment of the imHealthy system.

Multidisciplinary Approach

To foster adoption, acceptance, and usability of the imHealthy system, a multidisciplinary research team was recruited in April 2015 and consisted of industry researchers, clinicians, and faculty and students with backgrounds in psychology, psychiatry, medicine, epidemiology, occupational therapy, health information management (HIM), information sciences (IS), computer science, statistics, social work, theology, and management. Each member of the research team was engaged in the design, implementation, and evaluation of the health IT system, contributing specialized knowledge and discipline-specific competencies and skills. Students contributed to the implementation of the imHealthy system. All researchers, clinicians, and faculty members of the team provided extensive mentoring and guidance for the students. [Table 1](#) shows the roles and responsibilities that were agreed upon by and for each discipline on the research team.

The collaborative and participatory team agreed that each discipline would take the lead for each of the domains and agreed upon the areas of responsibility. This arrangement required commitment to weekly meetings, as well as to the inclusion of community members, because we recognized that no one discipline or stakeholder could achieve the desired outcomes alone. All disciplines were needed, engaged, and recognized equally.

Examples of collaborative research deliverables included new features for the open-source EHR to meet the needs of the MUC in a free clinic atmosphere, the mobile app for administering the wellness questionnaire, and a prototype web portal. So far, we have developed critical components of the imHealthy system (mobile app, comprehensive well-being scale, customized EHR, and a prototype of the web portal), engaging a multitude of disciplines and stakeholders and at the same time providing a wealth of knowledge and real-world problems for the students so that they will be able to use this experience when they graduate and work in their respective fields.

A mixed-methods research approach was conducted in phases for the imHealthy system and is described below.

Methodology

The novel imHealthy system collected data related to individual well-being from multiple sources, including the validated five-domain well-being questionnaire, data items stored in the EHR, and data collected from public surveys and research. The five domains of the wellness questionnaire included physical health, behavioral health, relational status, socioeconomic status, and spiritual status. The data items collected for these five domains were stored in relational databases and were analyzed using a statistical modeling approach for well-being assessment. The assessment results were summarized and presented graphically on a web-based portal for ease of use by clinicians. On the basis of the well-being assessment results (which continue to be updated over time), caregivers received personalized intervention recommendations.

Here is one simplified scenario to illustrate the process: The well-being questionnaire was completed by a community member via a mobile app with assistance from a social worker. The graphical results of the well-being assessment showed that the individual's scores were high on the physical health domain but low on the behavioral health domain. Therefore, behavioral health therapy, resilience training, and exercise programs might be recommended as a personalized intervention for this person based on these results.

The architecture of the imHealthy system is shown in [Figure 1](#). First, social workers use the custom-made mobile app to administer the validated well-being questionnaire to people in the MUCs who have agreed to participate in the study. These study participants might also see clinicians or have already seen clinicians at FPFHC and had their physical and behavioral health records stored in the custom-designed EHR system. The data from the EHR would be associated with specific questions in the well-being questionnaire and used to replace, enhance, or validate the answers to those questions. The validated answers from the members are statistically analyzed, and the assessment results are summarized and intervention recommendations provided to caregivers via a web portal. The caregivers of the FPFHC can then decide which interventions to use for each participant. A brief summary of the well-being assessment result will also be provided and explained to each participant.

Results

The results for each of the components of the imHealthy system are described below.

Well-being Questionnaire

A literature review was performed, and many well-being questionnaires were found. However, many of the well-being questionnaires were used to measure the effects of short- or long-term disabilities, or to measure one specific domain of well-being,¹⁻⁵ or to measure quality of life in people living with chronic illnesses or cancer.⁶⁻⁹ None of the questionnaires found in the literature were comprehensive in measuring the well-being of individuals in MUCs. The literature review also indicated that the five domains of physical health,¹⁰ behavioral health,^{11,12} socioeconomic status (SES),¹³ relationships,¹⁴⁻¹⁷ and spiritual life¹⁸⁻²⁰ are directly related to the well-being of an individual. The importance of these five domains was also confirmed by a focus group of community leaders and residents of a MUC in Pittsburgh. No well-being questionnaires included all five of these critical well-being domains. Therefore, a questionnaire was developed in this study to include these domains.

A number of questions in the well-being questionnaire were designed on the basis of on a

comprehensive evaluation of existing and well-validated questionnaires such as PROMIS,²¹⁻²³ Urban Poor Quality of Life, Friedman well-being scale, Adverse Childhood Experience (ACE) test,²⁴ the McGill Quality of Life Questionnaire,²⁵ a resilience questionnaire developed at Southern Kennebec Healthy Start, and survey questions created by the Western Pennsylvania Regional Data Center, to name just a few. The remaining questions on the well-being questionnaire, representing the majority of the new survey, were created by the research team with input from members of the MUC.

Expert focus groups were formed from members of the research team. Each selected or newly created question in the well-being questionnaire went through content analysis for relevance and clarity, and a content validity ratio and content validity index were determined by the focus group members. The well-being questionnaire was then reviewed by a group of stakeholders (community leaders and representatives of the community). The research team then made adjustments on the well-being questionnaire. The focus group of stakeholders performed another round of review and approved a final version of the well-being questionnaire.

Pre-pilot testing of the wellness questionnaire with five members of the MUC determined that the questionnaire was too long, some questions were too sensitive in nature, and some questions were vague. Changes were made to the wellness questionnaire on the basis of this feedback.

The final version included 25 demographic questions (such as age, race, sex, job, insurance, income level, driver's license status, criminal history, marital status, children, housing, financial situation, and church attendance) and 101 questions in five domains. The questionnaire had 28 questions in the physical domain, 40 questions in the behavioral domain, 16 questions in the social economic domain, 11 questions in the relational domain, and 6 questions in the spiritual domain. It also included several subdomains under the larger domains. Some questions can be bypassed if they are not applicable to the individual, which will decrease the total number of questions asked per person.

Examples of questions in each of the domains include the following:

- Physical: *How would you rate your overall health on a scale of 1-4, where 1 = poor health, 2 = fair health, 3 = good health, 4 = excellent health?*
- Behavioral: *Did you ever feel that your life is in danger?*
- Relational: *How satisfied are you with your personal or work relationships?*
- Spiritual: *To what extent does spirituality help you to accept your life circumstances?*
- Socioeconomic: *How satisfied are you with your financial situation?*

Responses for the four domains above were on a scale from "Not at all" to "An extreme amount."

This version of the wellness questionnaire underwent pilot testing for validity and reliability by 28 community members in two rounds. The correlation between the physical domain in this questionnaire and one well-established physical well-being questionnaire (Short Form-12, or SF-12)

was strong (0.879). The correlation between the behavioral domain in this questionnaire and SF-12 was also good (0.549). In other words, this newly constructed physical and behavioral health assessment measures the same thing as the SF-12. The intraclass correlation coefficient was used to measure test-retest correlation. In this study, two identical tests were conducted in a two-week interval. If the answers from the study participants are consistent in these two tests, the intraclass correlation coefficient should be high. Generally, 0.7 is an acceptable value for this correlation, and the value obtained in this study was 0.83. The reliability was measured by Cronbach's alpha.²⁶ If this value is 0.7 or higher, the questionnaire is considered adequately reliable.²⁷ A lenient cutoff of 0.6 is common in exploratory research. The Cronbach's alpha values for the five domains (physical, behavioral, relational, spiritual, and socioeconomic) were 0.84, 0.85, 0.79, 0.85, and 0.75. In other words, this newly created well-being assessment questionnaire is highly consistent, is reliable, and measures the desired aspects of well-being.

Mobile App for Survey Administration

A mobile app was created to collect answers to the questions on the well-being questionnaire. Questions were categorized by their domain (physical, behavioral, relational, spiritual, socioeconomic). Social workers will use this mobile app when they interview members of the community on their well-being. Extensive review and feedback on the design and implementation of the mobile app was received from research team members on a weekly basis, using student demonstrations of the mobile app to the entire research team.

Each study participant had one unique ID, and only the clinic administrator from FPFHC was able to associate the unique ID with the corresponding person. No other personal identifiers were accessed by the mobile app.

All data collected on the mobile app were uploaded to a central server for secure storage and further analysis. All mobile devices (tablets) distributed to social workers required user authentication before they could use the app for the study purpose. All of the distributed mobile devices had data services included. If any mobile device were lost or stolen, the data on the device would be remotely deleted, while the collected data would remain stored in the secure server.

A usability study was conducted with seven social workers as they used the mobile app. Tasks related to ease of use, navigation, and overall appearance (e.g., color, font size) were performed by the seven participants. Results of the usability study indicated that these social workers were able to finish the assigned tasks easily and were satisfied with the design and implementation of the mobile app.

Customization of an Open-Source EHR

The main purpose of the EHR is to collect physical and behavioral health information from clients. This custom-designed EHR was based on a well-known and widely used open-source EHR system, OpenEMR (<http://www.open-emr.org/>). OpenEMR is certified by the Office of the National Coordinator for Health Information Technology (ONC) and already has the basic features of a typical EHR system. However, the EHR needed extensive changes in order to meet the needs of the FPFHC. Students and the research team spent more than one year programming and reconfiguring the EHR system to meet the specifications of the FPFHC. Changes included the following:

1. Modulating a number of typical steps in patient communications;
2. Making all documented data and lab test results convenient for query purposes;
3. Expanding the fields stored in the demographic area to collect data on employment, housing situation (socioeconomic status), and spirituality;
4. Itemizing certain fields needed in the information integration step, such as doctor's diagnosis, treatment plan, and medications in the prescription section;
5. Creating reminders and alerts specific to the patient community; and
6. Formatting the history and physical examination section with specific tabs for ease of use in documentation.

During the implementation of these features, we worked closely with three physicians at the clinic because they will be the primary users of this EHR. Most of their requirements for the system have been implemented, and multiple EHR system demo sessions have been conducted on a weekly basis. We will conduct a usability study on the EHR system including three to five physicians.

Data Integration and Analysis

Answers to each question in the well-being questionnaire are scored and weighted according to the importance of factors in the five domains. For instance, physical activities²⁸ and income status²⁹ were known to be directly associated with an individual's behavioral well-being. Therefore, a higher weight can be assigned to these factors. The data from the EHR and some public data (other survey results, published research results, and data from government websites) will then be associated with each corresponding question in the well-being questionnaire to support or reject the answer to those questions.

An overall weighted well-being score and five subscores for each domain will be tabulated for each individual. Summary reports will include statistics (average, standard deviation, correlation, regression) and data visualization (such as histograms, scatterplots, regression curves) in an easy-to-read format (see [Figure 2](#)). Further analysis will be performed to determine whether the subscore for each domain and the overall well-being score can sensitively reflect the true needs of individuals

and ultimately enable care providers to meet these needs in appropriate interventions. The relationship between subscore for each domain and the overall well-being score can be determined with statistical modeling techniques such as structural equation modeling.³⁰⁻³² All of the statistical modeling will then lead to recommendations for personalized interventions that will be provided to caregivers as part of the summary reports.

Web Portal

A prototype of a web-based portal was created to visually display the results of the well-being assessment. The portal shows individual answers (displayed by ID only, with no personal identifiers) to each question on the wellness questionnaire as well as a domain score and an overall score. The caregivers are able to access all these details so that they can design proper interventions for each study participant (people in the MUC). The study participants will be able to access the web portal to view their own summary data, such as the overall well-being score and their well-being scores in the five domains. Figure 2 shows an example of the result that a study participant will see on the web portal, and the caregivers will explain the meaning of these numbers to the study participant. In this specific example, the study participant's overall well-being score was 70; his or her physical health is good (80); he or she has serious problems in the behavioral health domain (40); his or her relationship with family members, co-workers/classmates, friends, and others is OK (65); he or she does not have a high socioeconomic status; and his or her spiritual health is above average. Therefore, the most urgent need of this study participant is behavioral intervention, followed by efforts to improve his or her socioeconomic situation.

Some aggregated data, such as the assessment score for one family, one block, or the whole community, can also be visually shown on the web portal, as an interactive map of a city with different colors for different overall scores in different communities. Weekly meetings have been conducted to build the web portal and test its content. Feedback from community stakeholders will be continuous, and adjustments will be made to the web portal on the basis of the feedback received.

Caregivers will use the mobile app (along with the well-being scale), the EHR system, and the web portal to collect and process the data from study participants. Study participants will provide data to caregivers, and the only part that the participants can directly access is the web portal, to view their own well-being evaluation results.

Evaluation Plan

An overall system evaluation will be conducted on the imHealthy system. This evaluation will be performed after all of the separate components are extensively tested. The steps in our formal evaluation plan include engaging stakeholders, introducing imHealthy to stakeholders, developing

evaluation questions, gathering data, summarizing results, and making changes to imHealthy. This evaluation plan will be cyclical so that continuous evaluation and planning will be performed on the imHealthy system.

Information Assurance: Confidentiality, Integrity, and Availability

The research team understands that the data collected and processed in this project are highly sensitive, and therefore the HIM team has and will continue to provide the utmost protection of the users and their information. All state and federal regulations for privacy and security are followed and maintained. Institutional review board (IRB) approval has been obtained for sections of the imHealthy system (the well-being questionnaire and the usability study of the mobile app). As the imHealthy system progresses, additional IRB approvals will be obtained if needed. The custom-designed EHR system, the mobile app, the web portal, and the data analysis system (including the databases) are hosted in a secure, HIPAA-compliant server. A backup server will contain the same contents. Backups will be performed regularly, and three copies will be created and stored in different places, one in the same room of the server, one in the same building but a different room, and one in a physically remote place. Data in the database will be encrypted. The network will be scanned regularly to determine vulnerabilities, and solutions will be created to fix the identified problems. All users will be authenticated before they can access any part of the system. The data collected with the mobile app will be encrypted and transmitted to the server for storage. The mobile app will only access data on the server (the IDs of study participants) and upload data to the server. The app does not store data on the mobile device. Even if the mobile device is lost or stolen, unauthorized persons will not be able to access the data on the server because they will not have an authorized user's authentication information.

Conclusion

The imHealthy system was designed in order to meet a significant need expressed by the FPFHC. A fundamental underpinning of our approach is engaging community leaders, residents, and clinic staff, as well as assembling a multidisciplinary research team including faculty, students, industry researchers, and clinicians. Professional boundaries became permeable, and each team member took the lead in the agreed-upon areas of expertise. The students gained real-world experience and contributed to the imHealthy system. These factors have led to the achievement of the aims for the research project and acceptance of the imHealthy system by our stakeholders.

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There are no comments yet.