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Creating a paper-based personal health record for HIV-infected persons

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Abstract

A personal health record (PHR) contains information that a client believes is important to his/her health status; it can be either paper or Internet-based. The purposes of this action research were to determine the length of time an expert HIV nurse clinician needed to create a comprehensive PHR and determine how hard it is for the patient to understand different components of a PHR. The average respondent ($N = 9$) was older, female, completed high school, African American, diagnosed with AIDS, and taking HIV medications for 11 years. The HIV nurse expert spent an average of 79 minutes preparing the PHR. Clients had the greatest difficulty understanding laboratory tests, medications, medical history, and immunizations. PHR are evolving through the consumer empowerment movement, technology, and a growing awareness of the consequences of medical errors. Nurses need to assist clients to create and use the PHR as an important tool in self-care management.

Keywords

electronic health records; HIV; personal health records; self-care; self-management

Personal health records (PHRs) are evolving as a result of the consumer empowerment movement, increasing access to technology, and a growing awareness of the extent of the scope and consequences of medical errors. Chronically ill persons, including persons living with HIV (PLWH), interact frequently with health care providers and may benefit from creating and maintaining PHRs that can be stored in file folders, home computers, or on a

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Conflicts of interest
The authors report no real or perceived vested interests that relate to this article (including relationships with pharmaceutical companies, biomedical device manufacturers, grantors, or other entities whose products or services are related to topics covered in this manuscript) that could be construed as a conflict of interest.

reputable Web site (American Health Information Management Association [AHIMA], 2011). PHR do not replace the medical records held by the treating institutions or health care providers but rather contain summaries of information that clients believe are important to understand their health history and status. PHRs offer a different perspective from medical records, including the Electronic Health Record (EHR), because they can include all health-related information as well as information about exercise routines or use of community resources such as mental health and/or drug-treatment programs. While many consumers have a component of a personal health record (PHR; e.g., an advance directive or immunization record), a comprehensive folder that reflects the comprehensive health history is rare. Complete and accurate knowledge of a patient's history is essential for safe and effective health care delivery (Porter, Kohane, & Goldmann, 2005). Keeping PHR allows clients to offer health care providers valuable information that can help improve the quality of care received, reduce or eliminate duplicate tests and receive faster, safer treatment and care in an emergency. (MyPHR is a good Internet site for PHR, see http://myphr.com/).

But creation and maintenance of even paper-based PHRs can be overwhelming for PLWH and clients with other chronic physical and mental health issues because of the amount and complexity of the clinical data. Accessing copies of health records can be particularly challenging and, when obtained, it can be difficult for clients to identify which medical record information is pertinent to understanding their ongoing health conditions. Some chronically ill clients are given copies of complex medical records that contain disturbing information about their medical conditions in language that is difficult to comprehend. Although a widely adopted definition of PHR refers to them as software applications that patients can use to communicate with their clinicians, enter their own health data, and access information from their medical record (Reti, Feldman, Ross, & Safran, 2010), many PLWH receive care in publicly-funded clinics that are only now transitioning to EHR. Computer-based PHRs can be tethered to the health care organization's existing EHR, but some PLWH may have difficulty regularly accessing and using computer-based systems because of the digital divide (Yamin et al., 2011). In addition, some PLWH have been diagnosed for many years and have extensive and complex disease histories that are not easy to organize into existing PHR systems in a way that promotes self-care.

The first cycle of an action research process requires researchers to gather information about participants' experiences and perspectives. Ethnographic observations enable an observer to build a picture of the life world of those being observed and better understand the way people go about their everyday activities (Stringer, 2007). PLWH who were engaged in receiving regular HIV-related health care services were asked to participate in this research that addressed creation of a PHR.

Review of the Literature

Self-care has been described as a naturalistic decision-making process used in choosing health-promoting behaviors and symptom self-management (Riegel et al., 2011). PHRs can promote self-care behaviors by organizing health-related information in a systematic fashion that can be interpreted and manipulated by the client. PHRs help to empower consumers through improved patient safety, access to personal health information and general health information, communication with health care providers, and informed decision-making about their own care (Weaver & Zielstorff, 2011). PHRs are relatively new innovations in a rapidly evolving industry. The five most common types of information kept in a PHR are: (a) insurance information, (b) primary and specialist provider information, (c) personal information such as contact and social security numbers, (d) prescribed medications, and (e) history of insurance claims, payments, and health expenses (Weaver & Zielstorff, 2011). This information can be kept in either a paper or computer-based format.

In 2003, the U.S. Department of Veterans Affairs (VA) introduced web-based PHRs, MY Health-eVet, to empower patients and their families to play a more active role in care management (Nazi, 2010). Veterans self-register at the My HealtheVet website (http://www.myhealth.va.gov) to create accounts and develop customized PHRs that are accessible from any computer via the Internet. Veterans receiving care at a VA facility can complete an additional one-time, in-person authentication at a local VA facility; this service provides additional resources, including the ability to extract information from their EHRs into their PHRs. As of October 2009, 16% of the veterans receiving health care services had been served by My HealtheVet (*n* = 850,000) and about 150,000 had authenticated their accounts. Veterans who used My HealtheVet were found to be highly satisfied, highly likely to recommend the site to other veterans, and highly likely to return to the site (Nazi, 2010). What is curious is why fewer than 20% of the veterans chose to set up PHR accounts and why only 18% of those with accounts chose to take the next step, which would allow their PHRs to interface with their EHRs.

To address the concern that patients in safety net settings with poor Internet access and limited health literacy would not have access to PHRs, myHERO was set up for PLWH receiving health care at the University of California San Francisco AIDS clinic (https://myhero.sfdph.org). Data in PHRs were automatically populated from EHRs used in the clinic; information included laboratory values, medications, appointments, and tools to promote health care maintenance (Kahn et al., 2010). Patients can enter blood pressure, glucose, weight, and private notes into myHERO. Approximately 6% of the eligible patients (*n* = 211) registered and activated an account. Those clients were more likely to be younger, male, and Caucasian. While overall, users found myHERO helpful, the lack of uptake is troubling.

SelectHealth is a Medicaid Special Needs Plan in New York City that supports a continuity of care EHR that includes medications, laboratory results, and structured data and narrative blocks of text. Teixeira, Gordon, Camhi, and Bakken (2011) found that PLWH were willing to have personal health information shared electronically through the continuity of care document with their primary care providers and clinicians in other settings where they were receiving health care. This was in contrast to the perception of case managers in the same settings who thought that the clients might be frightened to change how they received care (Schnall, Odlum, Gordon, & Bakken, 2009).

Yamin and colleagues (2011) described the characteristics of patients using the PHR Patient Gateway system developed by Partners HealthCare Network that included approximately 8,000 physicians and 8 hospitals in the Northeast. These researchers found that racial/ethnic minorities and patients with the lowest annual incomes were less likely to create computer-based PHR. Their findings suggested that the key gap was related to adoption or creation of the PHR. This research also examined factors in the PHR adoption phase from a clinician perspective in order to identify potential barriers and sections that PLWH might find difficult to understand.

The first PHRs were paper-based and many people still maintain PHRs in print (Jones, Shipman, Plaut, & Selden, 2010). Our research used paper-based forms developed by the AHIMA to create a PHR form. The adult PHR form in English was downloaded from the myPHR site (http://www.myphr.com/resources/choose.aspx), and the different sections of the paper-based record were organized in a binder. Table 2 includes descriptions of the different sections of the AHIMA record along with sample field notes to illustrate specifics related to each section of the record.

Purpose

PHRs are relatively new tools available to consumers and uptake has been low. The purpose of our research was to examine processes involved in creating paper-based PHRs for PLWH receiving routine health care in a clinical trials unit in a private not-for-profit health care setting in New York City. The overall goals were to (a) determine the length of time needed by an expert HIV nurse clinician to create a comprehensive PHR for a person living with HIV, (b) determine the level of difficulty in creating different sections of a PHR for a person living with HIV using AHIMA health forms, and c) assess feedback from PLWH about PHRs created for them. AHIMA forms were used rather than forms offered by a specific health care facility because they were easily accessible on the Internet and offered a standardized system of organizing health information for consumers.

Method

The qualitative method of action research was used as the organizing framework. In action research, solutions are implemented as part of the research process (Nieswiadomy, 2008); participants each left with a binder containing the paper-based PHR that had been created by the HIV nurse expert and reviewed with them for accuracy. Three participants took part in each interaction: the HIV-infected patient; the HIV nurse expert who created the PHR and presented the prepared binder to the patient during a one-to-one interview; and the nurse observer who documented the interaction between the HIV nurse expert and the patient. The nurse observer kept comprehensive field notes to create written records of the observational data (Montgomery & Bailey, 2007). Field notes represent the participant observer’s efforts to record information along with synthesizing and trying to understand the data (Polit & Beck, 2012). Anderson (1987) described five types of records for field notes: (a) general field notes, (b) interview notes, (c) informant notes, (d) observation notes, and (e) interaction notes. Because there is no one universally accepted way to do field noting, we decided to create a worksheet to promote more descriptive and logical entries. The worksheet consisted of a section for time started/finished and a table with columns for each AHIMA section, observations, Association of Nurses in AIDS Care (ANAC) nursing standard being implemented (2007), time in minutes, and level of apparent difficulty. After each visit, the nurse observer completed field notes that were submitted to the principal investigator who read them and made suggestions or asked questions about the observation. Sample illustrations are provided in Table 1. Descriptive statistics such as mean and range of scores were calculated to describe the quantitative data.

Ethical Considerations

This study was approved by the Weill Cornell Medical College Institutional Review Board. Access to the EHR and other Health Insurance Portability and Accountability Act (HIPAA)-protected information was given only to members of the research team, who were also employees of the health care setting. All participants gave written informed consent.

Sample

Nine PLWH who had received health/medical care during the previous 6 months and who were known to the clinical trials unit at New York Presbyterian hospital participated. Sample characteristics are presented in Table 2. The average participant was a 52-year-old, African American woman, who had completed 12th grade, had been infected through unprotected sex with an opposite sex partner, had lived 15 years with HIV, had a CD4+ T cell count of 461 cells/mL and an undetectable viral load, was diagnosed with AIDS, had taken HIV medications for 11 years, and was taking 15 different medications.

Procedure

A recruitment flyer was posted in the waiting room of the clinic and potential subjects approached the HIV nurse expert about their interest in participating in the research. The HIV nurse expert also suggested the research to clients known to have participated in other research studies. At the first visit, participants gave informed consent and were advised that the HIV nurse expert would be using their medical records to create PHRs using the AHIMA forms. Participants were asked to bring any health-related forms that they had at home to the next visit.

During the second visit, the client and HIV nurse expert reviewed the prepared PHR in the presence of a registered nurse who was completing graduate nursing education and who was also an expert in HIV care and an employee of the health care setting (nurse observer). The nurse observer recorded: (a) the time of the beginning and end of each visit, (b) the level of difficulty clients seemed to have in discussing specific sections of the AHIMA form, and (c) scored the number of minutes spent in each ANAC standard by the HIV nurse expert. The nurse observer used the ANAC *HIV/AIDS Nursing Scope and Standards of Practice* (2007) to identify the standard of practice being used by the HIV expert nurse as each AHIMA section was discussed. The level of difficulty was the nurse observer’s subjective perception based on how quickly the client answered the questions, whether they instantaneously "got" or understood the questions, if they asked for further explanations, or if they required cues to answer the questions. The field notes created by the nurse observer included specific comments related to each section of the AHIMA record. The HIV nurse expert and the nurse observer completed all data collection from the nine participants over a 13-month period from June 9, 2009 through July 23, 2010. Participants received a total of $50.00 to cover transportation and other study-related costs. All of the clients were known to the health care setting and had been receiving HIV care at the clinic for a number of years. Providing a health history was not an unusual activity for these chronically ill clients and so sampling continued until data saturation was achieved.

Results

Only one client brought any health-related forms to the second visit; the remainder relied on the HIV nurse expert to use their EHR to create the PHR and did not bring any materials from home or other health care settings. The HIV nurse expert spent an average of 79 minutes to prepare the PHR (range = 52–102 minutes). Table 1 describes the AHIMA section along with the level of difficulty. During the HIV nurse expert/participant meeting, most time was spent on the following sections: M. Medications (4.25 minutes), F. Medical History (4.22 minutes), and J. Family member history (3.44 minutes). The nurse observer rated the highest level of difficulty about the clients’ perceptions in understanding the concept in the Q. Lab or imaging (1.88), M. Medications (1.55), F. Medical History (1.55), and H. Immunizations (1.44) sections of the AHIMA PHR.

The purpose of this research was to examine processes involved in creating paper-based PHR and some of the general comments made by the PLWH reflected satisfaction with the PHRs that were created. The field notes written by the nurse observer gave additional insights about the clients’ perceptions on working with the HIV nurse expert to ensure that the PHRs were comprehensive and accurate. During the visit, the nurse observer made notes about each of the different sections of the PHR. To illustrate, under section K. Lifestyle, one note stated: “proudly reported that she quit smoking 6 months ago and is involved in exercise activities 3X a week”; another note under that section for a different client stated: “client sadly reported smoking 2 cigarettes per day but proudly denies alcohol or illegal drug use.” Additional illustrations are provided in Table 1. The nurse observer noted the time spent addressing each section of the PHR and made summary notes of the total interaction including comments such as “During the entire session, the client seemed relaxed and focused and sincere.” and “That’s a beautiful folder.” Another client asked that her home health aide (HHA) not be present during the interview because the HHA did not know of her HIV status and the client did not want to disclose; she complimented the HIV nurse clinician for “doing a very good job” in organizing the PHR binder.

Discussion

The PHR is seen by health policymakers as an essential tool in accomplishing the goal of an empowered and informed consumer society (Weaver & Zielstorff, 2011). Although the trend is to use computer-based PHRs and to link the PHRs with the EHRs, our research explored the amount of time it would take for an HIV nurse expert to create paper-based PHRs for a sample of PLWH. Although the HIV nurse expert had worked with some of the participants on other research, it took her an average of 79 minutes to organize each PHR binder using data from the EHR in the health care setting. Considering an average hourly rate for advanced nursing staff of $51.91/hour for a nurse practitioner in this setting, the average cost of salary and fringe benefits would be approximately $100.00 for one PHR-development session, which would be reasonable if the HIV-infected client agreed to maintain and use the PHR. All of the participants were pleased with the PHR binder; one reported that “he had a medical bag at home which contains all types of medical records, mixed together.” He thought that the PHR binder was more helpful because each section was organized with easily identified tabs. Another client decided to leave the PHR in the HIV nurse expert’s office and to update it during subsequent visits. The cost of the binders and dividers was approximately $15.00 per client.

Chronically ill PLWH with complex diseases welcomed the opportunity to receive paper-based PHRs that reflected their unique histories. Further research is needed to evaluate whether PLWH use the PHRs in subsequent visits with other health care providers, integrate health-related information from other sources, and update their PHRs regularly. Research with veterans and at a safety-net setting in San Francisco has shown that fewer than 20% of PLWH create readily accessible Internet-based PHRs that are tethered to their EHRs (Kahn et al., 2010).

Considering the complexity of the course of HIV disease and the treatment options, PHRs could help empower clients and increase competency in self-care management. PHRs are a new tool available to clinicians and consumers who are interested in creating more engaged relationships characterized by shared decision-making. Self-care has been described as a naturalistic decision-making process used in choosing health-promoting behaviors and symptom self-management (Riegel et al., 2011). PHRs can promote self-care behaviors by organizing health-related information in an organized fashion that can be interpreted and manipulated by clients.

Limitations

Participants were engaged in receiving regular health care in a not-for-profit setting and their experiences would not necessarily reflect PLWH who were not engaged in health care or who were receiving services in a publicly funded setting. The use of PHRs is linked to health literacy skills (Weaver & Zielstorff, 2011) and so participants needed to have minimal literacy skills in order to understand how health-related information was being organized.

Conclusion

Our research showed that the cost involved in starting PHRs for a diverse population with minimum educational literacy is relatively low and could be worth the effort to ensure more accurate histories that providers can use to develop and implement plans of care. Many questions remain about cost and creation of PHRs for chronically ill clients. Will the time involved in creating PHRs be billable hours? Will health care settings offer classes to help clients create PHRs? Who will help clients interpret existing health-related information in their EHRs and import that information into their PHRs? And, most importantly, will PHRs help clients become more informed and engaged consumers?

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Clinical Considerations

- Persons with limited educational attainment may have difficulty understanding complex health-related information and using the Internet to access and interpret relevant information.
- Paper-based personal health records can be an intermediary step in assisting persons living with HIV to organize and understand their chronic health conditions.
- Personal health records are maintained by clients and contain more than medical information, thus providing a more holistic platform because many persons with HIV see multiple providers including substance use counselors, nutritionists, and other therapists outside of the primary care setting.
- Creation and maintenance of a personal health record may assist in self-care, self-management, and create more informed and engaged consumers.

Table 1

AHIMA PHR Component, ANAC Standard, Discussion Time, Nurse Observer Perception of Level of Difficulty, and Sample Field Note

AHIMA components	ANAC Standard (2007)*	Minutes	Difficulty level **	Sample field note by Nurse Observer
A. Identification	#1	1.11	1	“Client updated new address and phone number. Old data was in the computer record.”
B. Emergency contacts	#1	1.44	1	“Client has her psychiatrist as the contact person because, ‘She knows me for a long time, for over 15 years.’ Client unsure whether to include next-door neighbor but ultimately decided not to.”
C. Health care providers	#1	1.58	1	“Client identified Dr. X as primary medical doctor. She also included names and phone numbers of social worker, dentist, eye doctor.”
D. Insurance providers	#1	1.30	1	“Client brought in copies of ADAP card and Medicaid card, which HIV nurse expert attached to the binder.”
E. Legal documents/ medical directives	#1	1.61	1.22	“Client stated that he has to re-do current advance directive document because original agent is ‘no longer accessible’.”
F. Medical History	#2	4.22	1.55	“Client impressively narrated extensive medical history, including co-morbidities. She affirmed all medical conditions that were listed in her electronic record except for ‘heart problem’ that she claimed was resolved since she started dialysis.”
G. Infectious diseases	#1	2.63	1.33	“Chicken pox at 7 years, measles 7 years, syphilis at age 17. Denied hepatitis infection”
H. Immunizations	#1	1.52	1.44	“Client expressed that she is up to date with immunizations including hepatitis B, flu, and pneumovax. HIV nurse expert checked computer for confirmation.”
I. Allergies/drug sensitivities	#1	0.72	1	“Gets severe yeast infection from Ziagen. Latex hypersensitivity—rash.”
J. Family member history	#1	3.44	1	“Client narrated monotonously her family history with a flat affect. Mother died of heart attack (60 years), father was murdered, one brother is alive with DM, another one is epileptic, and a 3rd brother is HIV+. One sister has heart valve repair, another has colon cancer.”
K. Lifestyle	#5B	1.88	1.11	“Expressed intention to engage in healthier lifestyle. Quit alcohol since 06/09 but still smokes 5 cigarettes/day. HIV nurse expert suggested methods of smoking cessation.”
L. Health log	#5A	2.02	1.33	“HIV nurse expert explained what kind of information to put in the future such as colonoscopy results, etc. Client seemed excited and said. ‘I love this…it’s good to have your own medical history, all in one place.’”
M. Medications	#5B	4.25	1.55	“Client brought in medication sheet from the clinic. Medication reconciliation performed by HIV nurse expert who discovered that only 23 out of 30 meds were accurate.”
N. Physician visits	#5A	0.86	1	“Client has own way of organizing doctors’ appointments, using a ‘personalized calendar’ and would like to keep using it instead.”
O. Hospitalizations	#1	0.80	1	“Client had multiple hospitalizations last year due to fractures from a fall, DVT, UTIs. Stated the form will make his personal records more organized.”
P. Surgeries	#1	1.0	1.11	“C-section 3 years ago, hip surgery, and cholecystectomy.”
Q. Lab or imaging	#5B	2.47	1.88	“Client seemed excited about this section. She stated. ‘I have so many lab reports, now I have a place to put them.’ HIV nurse expert explained which ones were the most important and instructed to sort out old reports (> 3 years) and keep them in a box.”

AHIMA components	**ANAC Standard (2007)***	**Minutes**	**Difficulty level ****	**Sample field note by Nurse Observer**
R. Medical devices	#1	0.38	1	“Client uses a rolling walker.”
S. Physical/ occupational therapy	#1	0.41	1	“Client receives PT 4 times a week.”
T. Vision	#4	0.52	1	“Client reported last appointment was 12/08. Has upcoming appointment on Friday.”
U. Dental	#1	0.44	1	“Gets annual checkups. Will use form for future appointments.”

Note. AHIMA = American Health Information Management Association; ANAC = Association of Nurses in AIDS Care; PHR = personal health records; DM = diabetes mellitus; DVT = deep vein thrombosis; UTI = urinary track infection; PT = physical therapy

[*] ANAC Standards applied during the 1:1 PHR visit (Association of Nurses in AIDS Care, 2007).

ANAC Standard #1 The HIV/AIDS nurse collects comprehensive data pertinent to the patient’s health or the situation.
ANAC Standard #2. The HIV/AIDS nurse analyzes the assessment data to determine diagnosis.
ANAC Standard #4. The HIV/AIDS nurse develops a plan of care that prescribes interventions to attain expected outcomes for individuals with HIV infection.
ANAC Standard #5A. The HIV/AIDS nurse coordinates care delivery.
ANAC Standard #5B. The HIV/AIDS nurse employs strategies to promote health and a safe environment.

[**] The level of difficulty was based on the Nurse Observer’s subjective perception based on how quickly the client answered the questions, did they instantaneously "get" or understood the questions, did they ask for further explanations, or did they require cues for answering the questions.

Table 2

Sample Characteristics (*N* = 9)

Age	Mean = 51.8 Range = 44–65 years
Gender	Male = 1 Female = 6 Transgender = 2
Educational grade level	Mean = 12th grade Range = grades 8 through 16
Race	African American = 9
Ethnicity	Hispanic = 1 Non-Hispanic = 8
HIV-related risk	Sex with opposite sex = 7 Sex with same sex (male) = 1 IDU = 1
CD4+ T cell count	Mean = 461 cells/mm^3 Range = 9–1005 cells/mm^3
Viral Load	Undetectable = 7 Detectable = 2 51,111 copies/mL = 1 95,933 copies/mL = 1
Length of time with diagnosis of HIV infection	Mean = 14.8 years Range = 4–21 years
Diagnosed with AIDS	Yes = 8 No = 1
Length of time on HIV medications	Mean = 11.2 years Range = 4–16 years
Total # of medications being taken	Mean = 15.2 Range = 7–27 medications