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Barriers to Implementation of a Continuity of Care Record (CCR) in HIV/ AIDS Care

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Abstract

This qualitative study was part of the pre-implementation formative evaluation of SelectHealth's Continuity of Care Record (CCR), an electronic health information network (EHI) for HIV/AIDS care in New York City (NYC). The purpose of the study was to explore case managers' perceptions of the barriers to adoption of the CCR. Focus group methodology was used to gather perceptions from 26 participants who provided direct case management services for persons living with HIV/AIDS (PLWHA) in NYC. Question development was guided by models of technology acceptance. Data about the barriers to implementation of the system were classified into four main themes: client capacity for system adoption, potential breech of confidentiality, information quality concerns, and training needs. The four identified themes can serve as focal points for developers seeking to create EHI networks for the provision of HIV care.

Keywords

Electronic Health Record; HIV/AIDS; Technology Adoption

1. Introduction

SelectHealth (SH), an HIV/AIDS Special Needs Plan provides health services to its members through a network of providers. Since HIV/AIDS care is complex and SH has a large network of care providers, highly coordinated care is necessary to achieve desired outcomes for the management of PLWHA. EHI networks offer a potential antidote for coordinating complex HIV/AIDS care. Records can be accessed from remote sites and providers can enter patient information locally and send the data securely via the Internet to a central server [1].

In 2008, SH will upgrade its existing EHI network and implement a CCR, an EHI exchange which includes core clinical, demographic and care coordination data. The CCR represents a comprehensive summary of a patient's relevant current and historical health care data at the time the CCR are generated. The project will aggregate SelectHealth's pertinent critical patient information and make it available via a secure Internet connection to PLWHA and their health care providers.

2. Objective

Numerous well-designed studies have illustrated the many benefits of EHI networks on the care of patients [2]. EHI networks promote access to critical patient data and enable provision of care which is less redundant, time intensive, and prone to error [3]. While some research has been done on patients' attitudes towards sharing personal health information

(PHI) using an EHI system, little is known about providers' experiences [4]. The objective of this study was to explore case managers' perceptions of the barriers to adoption of the CCR.

3. Methods

Focus group participants included two males and 24 females with multiethnic backgrounds, who provide direct case management to SH members. Each focus group had between six and eleven participants. The Technology Acceptance Model informed the development of a six question focus group guide [5]. The data reported reflect answers to two questions: "What do you perceive as barriers to implementation and use of the CCR in your case management activities?" and "What do you think PLWHAs will perceive as barriers to use of the CCR?"

The focus groups were conducted in a conference room at two clinics and a community health care center in NYC. The session was facilitated by a member of the research team; a second member recorded field notes. The focus group session, which was approximately one hour long, included food and drinks and reimbursement for time ($50). Following completion of the informed consent process, audio tape recording and field notes were used for data collection. Ground rules were introduced to improve the understanding of the purpose of the focus groups and to ensure the flow of the session. The audiotapes were transcribed verbatim and summarized thematically through an iterative process by a member of the research team (RS). The informants' words guided development of the codes. Categories were reviewed and commented on by a second researcher (SB) with expertise in informatics and HIV/AIDS care.

4. Results

The focus group utterances associated with barriers related to adoption of the CCR were summarized. Four major themes of barriers emerged from the data: client capacity for system adoption, potential breech of confidentiality, information quality concerns and training. The themes described below are patterns that were seen across the three sites. Quotations have been selected because they are representative of the themes and categories (Table 1).

4.1. Theme 1: Client capacity for system adoption

Client capacity for system adoption comprised five categories: willingness to change, psychological competence, physical competence, computer and reading literacy and access to a computer and the Internet. A primary barrier to adoption of the CCR was clients' willingness to change how they receive care. For example, a case manager explained, "…I mean you know they have one way of doing things…" Changing the way PHI is stored and delivered can be scary and so "some people will probably be a little frightened …" Another barrier to adoption of the CCR which was expressed was client's psychological competence. The focus group participants suggested that PLWHA often have co-morbid conditions including mental health disorders which make them unable to use the system. For instance one case manager questioned, "What happens when the patient is psychotic?" He was concerned that patients without mental competence should not have access to an electronic health system. In addition to psychological competence, physical ability to use the system was a barrier that was highlighted. Case managers expressed concern over whether the system was "going to be catered to someone who is visually impaired," or "for someone who is hearing impaired?" Additionally, there was concern over whether the kiosks, which would be set up in the clinics to allow patients to access their CCR would "be wheelchair accessible?" and whether there would be "a seat next to it for people who can't stand too long?" A further barrier to using the system is that there are patients who are not computer

literate, who “might not know how to use a computer.” To further intensify this barrier there are patients who “are illiterate all together…” These patients do not have high enough literacy skills to read and understand the information in the system and as a result as one case manager said, “if they can't read, they are going to have to rely on other people to access the information.” Case managers also expressed concerns about patients having computer and Internet access, more specifically, “Not every household is going to have a computer.” A participant stated that “I don't think they are going to travel,” to find a computer with free Internet access in a location such a public library.

4.2. Theme 2: Potential Breech of Confidentiality

The potential for a breech of confidentiality was a barrier emphasized by many of the case managers. As one participant highlighted, “I mean there is the whole of course confidentiality stigma around HIV.” There were three main themes which surrounded the theme of confidentiality: privacy, trust and loosing one's access code. Case managers emphasized that privacy would be a big concern because patients who use the system may be afraid that their PHI would not remain private because “if you know that your medical record is right there at the touch of a fingertip you have to admit how accessible your information is…” More specifically, PLWHA can be apprehensive that people will gain access to their PHI, and as one case manager explained “Many of our patients are guarded and quite paranoid about that kind of information being available.” Another barrier which was highlighted was patients not having trust in the CCR. “Trust is a big issues with a lot a client especially clients that are actively using the substance.” Moreover, patients have different levels of trust for different care providers. One participant explained, “I know there are certain things our clients will tell the providers that they wouldn't want case managers to know.” Specific concerns were expressed about particularly sensitive information like a patient's substance abuse history and “who makes decision as to what is appropriate” information to be shared with which provider? Case managers expressed concerns over confidentiality being jeopardized specifically “what if they lose their SH card or password?” and as a result a concern over who might gain access to confidential PHI.

4.3. Theme 3: Information Quality Concerns

Participants stated concerns over the quality of the information, specifically the efficiency in updating the system's data, the reliability of the data, and the stability of the system. For instance, a participant voiced concerns over the data quality “if providers aren't always entering stuff it won't be up to date.” An additional barrier is that it may not be reliable because “I have a concern if everybody is doing the input into the computer what if somebody makes a mistake…” The importance of the stability of the system and an assurance that system wouldn't “go down” was expressed.

4.4. Theme 4: Training

Multiple participants made recommendations for training sessions to introduce the providers and patients to the system. Case managers recommended “that in the orientation you know when they enroll or something to have some kind of short training,” which would facilitate use of the system.

5. Discussion

Case managers in this study highlighted barriers which should be managed before the implementation of the CCR. There are notable client characteristics which can be addressed pre-implementation which would help facilitate acceptance of the system. Namely, policies about patients' psychological competency should be established before a patient is given a password to access the CCR. Moreover, kiosks at clinics should be designed to

accommodate wheelchair accessibility and other physical disabilities, such as vision and hearing loss. Furthermore, barriers which can be addressed pre-implementation of the system include system stability and assurance of data integrity. Case managers were hesitant to use a system which they feared would crash on or would provide them with data which is not reliable. These issues related to the system need to be managed from the technical end before it is implemented. Finally, training courses may be exceedingly beneficial in promoting the system and teaching users how to access information.

The credibility of data collected is the main concern of focus group methodology. Case managers' perceptions were verbally summarized and reflected back to the participants to ensure that utterances were not misinterpreted.

6. Conclusion

The themes identified indicate that the barriers to implementation of this system for HIV/AIDS case managers and patients will be similar to problems of technology implementation in other fields. Data from this study suggests that training and accommodations for special needs may enhance adoption of the system.

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Table 1

Barriers to Implementation of a CCR

Theme1: Client capacity for system adoption
Category: Willingness to change
"*I could see them being fearful because I know that when I come across something new you know it is scary it is change*."
Category: Psychological competence
" *A person has this illness, they are an addict but has been living in a shelter for three years but you know what, they have been selling their bodies for a long time. So, how do you possibly give them access?* "
Category: Physical competence
"*I know those things are going to be barriers you know and especially those who are visually impaired or hearing impaired*."
Category: Computer and reading literacy
"*Patients themselves are not computer literate.*" "*We have clients that are illiterate all together who can't read or write*."
Category: Access to computer and Internet
"*I can count the patients who have a computer*."
Theme 2: Potential breech of confidentiality
Category: Privacy
" *How comfortable will the client be knowing that pretty much all of their business is there and up for grabs for people to read?* "
Category: Trust
"*Trust is a big issues with a lot a client especially clients that are actively using the substance*."
Category: Lose password/ access code
"*I don't know how they are going to get these temporary passwords but my biggest issue is that they are going to misplace it*."
Theme 3: Information quality concerns
Category: Reliability
"*I have a concern if everybody is doing the input into the computer what if somebody makes a mistake and how accurate would it be*."
Category: Efficiency
" *How long will it take to put that information in the system so you can access it?* "
Category: Stability
" *How it will affect the flow if the system would be down for an extended period of time?* "
Theme 4: Training
" *Is SelectHealth gonna run some type of training for these patients learn how to access their information?* "