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Exploring Factors Related to the Adoption and Acceptance of an Internet-based Electronic Personal Health Management Tool (EPHMT) in a Low Income, Special Needs Population of People Living with HIV and AIDS in New York City

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Abstract. Access to personal health information assists efforts to improve health outcomes and creates a population of active and informed health consumers. Understanding this significance, Healthy People 2020 retained, as a Focus Area, the need for improved interactive Health Communication and HIT. Attainment of this goal includes increasing the use of Internet-based electronic personal health management tools (EPHMT). Health information management, essential for favorable health outcomes, can be problematic in low income, special needs populations with complex chronic illnesses such as HIV/AIDS. Furthermore, barriers to the adoption and acceptance of an EPHMT in such populations have not been well explored. The current study seeks to explore the usability of an EPHMT entitled MyHealthProfile and to identify perceived health information needs in a vulnerable population of people living with HIV and AIDS (PLWH) that have access to an EPHMT through their Medicaid Special Needs Plan.

Keywords. Health Information Technology, HIV/AIDS, special needs population

Introduction

Consumer access to personal health information has the potential to improve healthcare delivery in an assortment of ways [1]. Despite the powerful potential of EPHMTs, including personal health records (PHR) to facilitate this process, technology adoption and acceptance is an ongoing challenge. While the primary push is to provide consumers access to personal health records, efforts have been minimal in the area of identifying and addressing information needs and ensuring system usability, readability and information comprehension. Barriers to effective health information retrieval,

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access, comprehension and use exist [2]. These recognized gaps in knowledge that hinder desired outcomes; can be defined as information needs [17].

Information needs can be two-fold. Information seeking and viewing to satisfy questions or concerns can then lead to subsequent information needs. Difficulty with comprehension can have adverse effects including increased anxiety or suboptimal health outcomes [2]. Comprehension difficulties, including medical jargon [3; 4] diagnostics [3] and laboratory test results [3; 5]; have emerged as barriers to consumers who have viewed their electronic personal health information. Observational studies that have reported negative experiences from online health information seeking showed increased levels of confusion about illness and treatment [4]. Understanding health information can be challenging, even for consumers with high levels of educational attainment [2; 6]. Similarly, in a study with people living with HIV/AIDS (PLWH), difficulties in record comprehension persisted even with higher levels of education [3]. Health information comprehension, essential for effective self-care and health decision making, can be even more challenging for low income, special needs populations of PLWH with high burdens of HIV-related illnesses, thus presenting major barriers to optimal health [18].

1. Background and Purpose

Effective health information management can be extremely problematic in special needs populations of PLWH. Complex care regimens can present as barriers to improved health outcomes [7]. Understanding the issues, NewYork Presbyterian System SelectHealth (SH), a Medicaid Special Needs Plan for low income PLWH, designed, developed and evaluated a Continuity of Care Document (CCD) entitled MyHealthProfile (*MHP*). The CCD provided SH members access to view facets of their medical record via any standard Internet connection. The system was subsequently refined into *MHP-plus*, an enhanced Personal Health Record (PHR) version on a Regional Health Information Organization platform. SH's decision to grant access to its members was intended to increase retention in care, optimize treatment protocols, and improve health outcomes and quality of life. During the *MHP* and *MHP-plus* iterative development and refinement processes, several evaluation activities were conducted. The current study sought to use collected data to: 1) assess the ease of use and usefulness of *MHP* and 2) identify the actual information needs of MHP-users and perceived information needs of *MHP*-users and *MHP* non-users before *MHP-plus* roll out.

2. Methods

A convenience sample of SH members was recruited to participate in evaluation activities. Quantitative data was collected in the form of *MHP* System Usefulness surveys and qualitative data in the form of *MHP-plus* pre-implementation focus groups. English or Spanish speaking, active SH membership and the ability to provide informed consent were the main inclusion criterion for participation. Recruitment occurred through invitation letters, personal contact at clinical and ancillary care sites, in SH newsletters and in welcome packages for new members. Study activities began with a verbal delivery in English or Spanish of the study purpose. An information

sheets explaining the nature of the study and the informed, voluntary and confidential nature of participation was given to participants. The *MHP* System Usefulness survey was administered by team members that doubled as assistants for item clarification. Two team members also facilitated the *MHP-plus* pre-implementation focus groups with users and non-users of *MHP*, lasting approximately 60 minutes in duration. Focus groups included a *MHP-plus* demo that walked through the new and enhanced system features. Participants were incentivizes for their time.

3. Instruments

The 37-item System Usefulness survey gathered the perceptions of *MHP* users. The survey, a combination of two scales, was informed by the Technology Acceptance Model (TAM) Davis (1989) and the Ease of Use scale, created by Gadd and colleagues (1998) was adapted to fit and assess the functionality of the system. The reliability and validity of the above mentioned scales has been previously established [8; 9]. Focus group guides followed a structured protocol informed by the Precede-Proceed framework [10]. Open-ended questions were asked to elicit the perspective of participants to identify actual and unrecognized information needs.

4. Data Analysis

Summary statistics for the domains of the *MHP* System Usefulness survey was generated. Internal consistency reliabilities and means and standard deviations were computed for the Ease of Use and Usefulness scales. Pearson Product Moment Correlations (PPMCs) were calculated to determine the relationship between reported Ease of Use and Usefulness across selected patient-level characteristics, *MHP* data elements and system functionality. Data was analyzed using SPSS 21.0. Focus group audiotapes were transcribed verbatim. Data was analyzed, coded and organized using the NVivo 8.0 software. Data analysis occurred inductively based on emerging themes. The coding scheme was reviewed by a team member with expertise in informatics and HIV/AIDS.

5. Results

Quantitative: MHP System Usefulness Survey. Forty-two System Usefulness surveys were completed, by 27 males (64.3%) and14 females (33.3%). Participants were approximately 47 years of age (M= 46.6±9.2), with age range of 24-63 years. The sample mostly consisted of Black /African American (N=27, 64.3%), followed by Other/Mixed race (N=11, 26.2%). Hispanic comprised 23.8% (N=10) of the sample. The majority were born in the United States N=36, 85.7%) with English (N=40, 95.2%) as the primary language spoken. Combined household incomes for participants ranged from no income to $10,000 per annum (N=34, 80.9%). Levels of educational attainment was reported as mainly high school diploma/GED or less (N=35, 83.0%), followed by Associate degrees 9.5% (N=4) and Bachelor's degrees (N= 2, 4.8%). The

internal consistency reliability for Survey scales were assessed by calculating Cronbach's alpha (Ease of Use= 0.7 and Usefulness=0.9).

***MHP* Ease of Use** was assessed using a 10-item scale. Values ranged from 1 to 5 (lower scores representing stronger agreement that the system was easy to use. The mean total score of Ease of Use was 2.4±0.5, item scores ranged from 2.4 to 3.5. ***MHP* Usefulness** was assessed using a 7-item scale. Values ranged from 1 to 5, with lower scores representing stronger agreement that the system was useful. The mean total score of Usefulness was 2.0±0.8, item scores ranged from 1.6 to 1.8. **Usefulness of *MHP* Components** were assessed with a 6-item scale. Values ranged from 1 to 3, with lower scores representing higher levels of component usefulness. The mean total score was 1.86±1.3, item scores ranged from 1.2 to 1.3.

Significant associations were observed for higher reported *MHP* Usefulness total score with shorter time living with HIV, higher educational attainment and higher willingness to share health information with non-clinicians via a secure electronic network. Significant associations were also observed for *MHP* Ease of Use and Usefulness total scores with the perceived usefulness of specific *MHP* data elements and functionality, (Table 1).

Table 1. Correlations: Variables Associated with *MHP* Usefulness and Ease of Use

	USEFUL_TOT		EASE_TOT	
Time living with HIV	-0.55	*		
Educational Attainment	0.35	*		
Willingness to share health data via ENS:				
Pharmacists	0.43	**		
HIV Support Organizations	0.31	*		
Government Health Insurers	0.33	*		
Local Health Departments	0.39	*		
Usefulness MHP Components:				
Data: Demographics	0.77	**		
Data: Medical Problem List	0.37	*	0.35	*
Data: Prescriptions Filled/Refilled	0.59	**	0.35	*
Data: Laboratory Results	0.59	**		
Data: Documentation of HIV/AIDS status	0.45	**	0.31	*
Data: Emergency contact	0.67	**		
Data: Health Services Utilization (ER Visits, Referrals)	0.44	*		
Function: *MHP* access via remote Internet access	0.53	**		
Function: Temporary *MHP* access for emergency	0.53	**		

Note. **p < 0.01, *p < 0.05

Qualitative: MHP-plus Pre-implementation focus groups/participant observations. ***MHP-plus* pre-implementation focus groups** were conducted (N=15): one group with current *MHP* users (N=8) and the second group with non-*MHP* users (N=7), (Table 2). These focus groups included a demonstration of the new system *MHP-plus*, allowing participant to have a more interactive discussion about experiences and information needs, outside of the structured protocol of the focus group (Figure 1).

Table 2. Basic Demographic Profile of MHP-plus Focus Groups (N=15)

	Gender		Race/Ethnicity			
	Female	Male	Black/ A.A.	Latino	Caucasian	Asian
MHP users	6	2	7	1	N/A	N/A
MHP non-users	2	5	6	N/A	1	N/A

Perceived Information Needs: *MHP-plus* pre-implementation focus groups. ***MHP* System Use:** *MHP* User Themes. Actual information needs, based on *MHP* use, were identified. ***MHP* user** identified themes: 1) incomplete health information in *MHP*; 2) information display confusion in *MHP*. Participants expressed frustrations with *MHP* regarding ***incomplete health information***, wanting more than medication information, an *MHP* user stated "when I checked it [*MHP*] only had medications that were given to me, that's it! I am surprised the hospital didn't put in anything else". Another *MHP* user discussed specific health information they desired to have access to, "What I don't see is a thing for your allergies …" Other information requested for *MHP*-plus by *MHP* users included vaccinations and diagnostic test results, indicating missing health data. One *MHP* user stated, "I don't remember [*MHP*] having x-rays, and immunizations. ***Information display confusion*** One *MHP* user simply stated, "it's a little all over the place [*MHP*]… medications should be there coinciding with your CD4 counts and stuff like that". Another *MHP* user, not realizing that laboratory results were in *MHP* stated, "You know what, I don't think they have mine on there [CD4 cell count]…viral load? I didn't even remember seeing that in there".

***MHP-plus* System Demo Viewing:** MHP user and MHP non-User Themes. Unrecognized information needs emerge upon *MHP-plus* viewing. ***MHP* user** and ***MHP* non-user** identified themes: 3) information to better facilitate provider visits; 4) data retrieval confusion; and 5) ability to input health history to promote self-care.

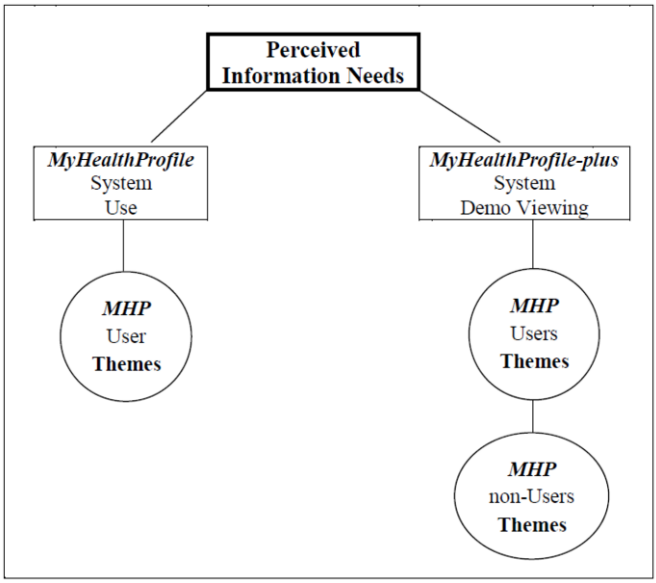

Figure 1. *MyHealthProfile* (*MHP*) Focus Group Themes

During the *MHP-plus* system demonstration, unrecognized information needs emerged in both the MPH user and *MHP* non-user groups. Participants expressed the need for health information to ***better facilitate provider visits***. One ***MHP* non-user** stated, "Once I get out of the ER and [go to] see a real doctor, [I will use *MHP-plus*] so I don't have to listen to 3 or 4 doctors. One doctor comes, he leaves, another doctor comes, he leaves and they always asking me the same thing". Simple system access by *MHP* user was also expressed during *MHP*-plus demo. The ***MHP* user** indicated being unclear in how to grant providers access, recalling an instance where MHP did not facilitate visit, "…ER little disoriented when I came in … gave the nurse my card with my password and she didn't know how to log into the system that made it a little frustration because I would assume that the providers would know how to get into the system to help you and they didn't".

Realizing the need for effective ***data retrieval*** and the simple *MHP-plus* display, a ***MHP* user** commented, "Everything is in its place [sections] instead of going through the whole thing you just click on something [tab], Bamb!; and its right there. It is very convenient". Echoing the same convenience, a ***MHP* non-user** inquiring on the retrieval of entered data stated," pain management …I can put that kind of comment?…doctor …can see it when he goes on [to the record]". Participants were also excited about the ability to ***enter their own health history*** into the system. Storing self-reported health information in a secure and organized manner arose as an important information need. A ***MHP* user** stated, "The system [*MHP-plus*] is convenient… put your own information in and use it, makes it convenient ". In fact, another ***MHP* user** comparing the two systems stated, "It's very proactive [*MHP-plus*] because you are able to, instead of going on to the old *MHP* and just looking at something you, know you are able to add". A ***MHP* non-user** commenting on his health problems stated, "I have 5 different major problems and I can't remember them all… [*MHP-plus*] is gonna help me a lot because I can't get them all up in here [brain]. When I get the information into the system, I can remember what is what".

6. Conclusions

Health Information Technology (HIT) has provided consumers with effective ways of gaining personal health information via EPHMTs including CCDs and PHRs. In spite of the identified need for health information access, the literature on perceived and actual consumer health information needs and system functionality remains sparse. The literature is even more deficient for low income, special needs populations of chronically ill, such as PLWH. The current study provides insight, as it aims to capture the SH member populations' actual and unrecognized health information needs and their perceptions of the ease of use and usefulness of the *MHP* system.

The System Usefulness survey, capturing perceptions of the *MHP* ease of use and usefulness, demonstrated strong psychometric properties, with alpha coefficients of 0.7 and 0.9 respectively as reflected in the literature [11]. Users of *MHP* found the system easy to use and perceived the system to be useful for care support. Studies of PHR use have indicate that users found these system similarly useful [3; 12; 15]. In fact, a study to capture the experiences of the chronically ill using a PHR showed that in spite of system functional barriers, great benefit with use was observed [3]. *MHP* data were also perceived to be useful, with demographics, laboratory results, prescription data and emergency contacts considered most useful. The few studies conducted on

information needs have shown that consumers desire primarily to view test results such as laboratory and radiology reports, supporting the results of the current study [13; 14]. An observational study on a PHR entitled *My Hero*, identified laboratory test results as the most commonly viewed feature [17].

The current study also captured perceived and actual information needs of SH members when viewing a demo of the *MHP-plus* PHR. Information needs identified were generally around obtaining and retrieving health information, overcoming functional barriers to system use, and to eliminating complexities in care. Participants were encouraged by *MHP-plus*'s ability to overcome identified barriers. A needs assessment in a population of malignant hematoma patients revealed similar results as participants were eager to keep track of vital health information and ensure accuracy in health records to potentially reduce the time spent waiting for test results and improving satisfaction with care [1]. A few limitations existed. Our study relied on a convenience sample, limiting generalizability. The System Usefulness survey, with a sample size of 42, limited the types of analyses. Focus group themes were robust, yet SH members that were eager to participate in study activities may not reflect the overall SH population.

Our study has provided insight into the information needs and system perceptions of a low income, special need population of PLWH. Developers of EPHMTs such as PHRs and similar applications should take the above mentioned factors into consideration. Ways to facilitate ongoing system use to ensure technology adoption and acceptance must be explored and promoted in the context of providing tools to effectively address information needs. Enhancements of existing systems have included consumer friendly interface designs, terminology support, education-related documents and infobuttons [2; 3]. In fact, the use of infobuttons has resulted in less time spent seeking supplemental information and ensuring data comprehension [16]. It is important to note that when population-specific information needs are addressed and systems enhanced, all healthcare consumers will find optimal value in PHRs.

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