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HIV Patients' Willingness to Share Personal Health Information Electronically

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Abstract

Objective—To assess the attitudes of persons living with HIV/AIDS (PLWH) towards having their personal health information (PHI) stored and shared electronically.

Methods—PLWH (n=93) in New York City completed surveys using Audio Computer Assisted Self Interview (ACASI) that assessed willingness to share their PHI with various people and entities via a secure electronic network. The survey also included questions on satisfaction with and trust of healthcare providers, current health, HIV-associated stigma, and frequency of internet access. Data were analyzed with descriptive and multivariate statistical methods.

Results—The majority (84%) of individuals were willing to share their PHI with clinicians involved in their care. Fewer individuals (39%) were as willing to share with non-clinical staff. Willingness to share PHI was positively associated with trust and respect of clinicians.

Conclusion—PLWH accepted clinicians' need for access to accurate information. Patients' trust in their primary care providers highlights the importance of the clinician-patient relationship which can be used to engage patients support for health information exchange initiatives.

Practice Implications—As electronic storage and sharing of PHI is increasing, clinicians and PLWH should discuss patients' attitudes toward sharing PHI electronically.

Keywords

HIV; Continuity of Care Document; Personal Health Information; Health Information Exchange

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I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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1. Introduction

Electronic health information exchange has the potential to improve patient safety, clinical care and enhance health-related decision making by providing clinicians with timely access to accurate patient information at the point of care [1–5]. Having access to accurate health information is particularly important for patients with chronic diseases, such as persons living with HIV/AIDS (PLWH) [6,7]. However clinical data of PLWH, such as laboratory results and medications, may identify them as being HIV-infected and patients may therefore be reluctant to share their personal health information (PHI). Within the context of a larger project aimed at improving continuity of care for PLWH, we explored patients' attitudes about having their PHI stored and shared electronically and what factors might be associated with their willingness to share.

1.1 Background

PLWH often receive clinical care in a variety of settings where their PHI may be incomplete or not available. Health information exchange efforts can improve access to PHI, but raise privacy issues. When people were asked their attitudes towards health privacy, most were willing to share PHI, but ethnic and racial minorities and patients with chronic illnesses had the greatest concerns about sharing [8]. Reports of lost data and security breaches may make some people reluctant to having their PHI stored and shared electronically. The more sensitive the health information, such as HIV-related information, the less willing people were to share [9].

In this study, a continuity of care document (CCD) was implemented by SelectHealth, a Medicaid Special Needs Plan for PLWH in New York City. A CCD is an accepted health information exchange format, allowing aggregation and sharing of patient data [10]. It has defined sections such as medications and laboratory results, and may include structured data or narrative blocks of text [11]. The SelectHealth CCD is an electronic document that is web-accessible by clinicians, case managers, and patients and is written in extensible markup language (XML), allowing it to be read using any web browser. It is updated bimonthly and contains laboratory results and pharmacy refill data. Given this initiative, it was important to assess patients' willingness to share their PHI and to identify factors associated with willingness to share.

2. Methods

2.1 Participants

All SelectHealth members (i.e., patients) received a letter describing the overall CCD implementation project and the survey, inviting them to participate. Patients were also approached in care settings while waiting to see their clinician. A convenience sample of eligible patients (English or Spanish speaker, age 21 or older) was recruited. Patients received a \$20 gift card for their time.

2.2 Procedures

Survey data were collected on laptop computers in private offices using audio computer-assisted self interviewing (ACASI) technology, in either English or Spanish. Bilingual staff provided instructions on the ACASI interface and how to enter responses. The interviews took approximately 50 minutes on average to complete, including 6 practice questions.

2.3 Measures

Non-health related questions included sociodemographic characteristics and frequency of internet use. Patients self reported their most recent viral load results and medication

adherence. Current health and quality of life were rated on a 0 (worst possible health or quality of life) to 10 (best possible health or quality of life) scale [12]. Physical and mental health was assessed using the SF-12 [13,14]. Patients' ratings of willingness to share PHI with various recipients using a secure electronic network were obtained using a validated survey instrument [9]. Patient-provider communications were assessed by asking patients how often, ranging from never to always, did their doctors listen carefully to them, explain things in a way they could understand, show respect for what they had to say, and spend enough time with them [15]. Patients were asked how much they trust their HIV care team to offer high quality medical care and to put their medical needs above all other considerations when providing care [12]. Patients were also asked how strongly they agreed with the statements: my doctor will do whatever it takes to get me all the care I need, and my doctor only thinks about what is best for me [16]. HIV-associated stigma was assessed using a modified version of Sayles' Internalized HIV Stigma Measure [17].

2.4 Data Analysis

Descriptive statistics of patient demographic characteristics were analyzed using Stata 9.2 [18]. Bivariate analyses (t-test, χ^2) were used to examine differences by patient characteristics and willingness to share PHI. Variables in the multivariate analyses were identified using Spearman correlations of willingness to share PHI with trust in providers and assessment of patient-provider communications. Three multivariate linear regression models were created to estimate the relationship between a patient's willingness to share PHI with: 1) primary care providers; 2) other clinicians at their clinic; and 3) non-clinical staff. Independent variables included trust in their HIV care team, satisfaction with provider communications, HIV-associated stigma, age, race, Hispanic ethnicity, education, and internet use. Primary clinic staff were selected because of the growing effort to get HIV patients into managed care programs, such as SelectHealth, and to have primary care providers and medical homes.

3. Results

Demographics and other characteristics of the sample (n=93) are shown in Table 1. Self-reported current health is comparable to what other studies of similar patient populations have reported [19–21]. Just over half (52%) of the patients reported having received an AIDS diagnosis at some point in time. Sixty (65%) patients reported having an undetectable viral load. Ten of the 33 patients reporting detectable viremia were not on ART at the time of the survey.

Although patients had received care for their HIV infection an average of 10 years, they still reported relatively high levels of HIV-associated stigma. When asked how often they felt that "Society looks down on people living with HIV/AIDS" the majority (96%) reported feeling this way some of the time or more, and nearly half (49%) felt that way most or all of the time. In multivariate analyses race and education were both statistically significant predictors of HIV-associated stigma.

Patient's willingness to share PHI is shown in Table 2 as a collapsed, 3-point scale. The majority of patients were willing to share PHI with their primary care provider and with other clinicians at their clinic. However patients were much less willing to share PHI with non-clinical staff at their clinic.

Patients reported having a great deal of trust in their HIV care team. Trust in their care team to deliver high-quality medical care and feeling that providers spent enough time with them were each associated with patients' willingness to share PHI with both clinical and non-clinical staff at their primary clinic (Table 3). Trusting the care team to place one's needs

above other considerations and respect for patients' comments were each associated with willingness to share PHI with non-clinical staff.

Three multivariate regression models examined patients' willingness to share PHI with their primary care provider, other clinical and non-clinical staff at their primary clinic (Table 4). Education and Hispanic ethnicity were statistically significant predictors of increased willingness to share PHI with a primary care provider. No significant predictors were observed for willingness to share with other providers at one's primary clinic. Trusting their care team to deliver high quality care and having the doctor spend enough time with them were significant predictors of willingness to share PHI with non-clinical staff.

4. Discussion and Conclusion

4.1 Discussion

Patients in our study reported high levels of trust for their primary care providers and HIV care team and most were satisfied with communications with their providers, both of which were correlated with willingness to share PHI. We observed only a modest difference in trust by race or ethnicity, in contrast to other studies which found Blacks and Hispanics to have lower levels of respect and satisfaction with their providers [22,23]. Patient's sense of trust in their care team had the strongest influence on willingness to share PHI. Understanding this influence and the relationships impacted by it can be beneficial to other non-care related activities such as providing patient education, and engaging and retaining patients in care.

4.2 Conclusions

The majority of PLWH in our study were willing to share their PHI electronically, despite their feelings of HIV-associated stigma. We believe this is because most patients understand the importance of giving providers access to accurate information. However, we were limited by our inability to disaggregate distrust of sharing PHI over electronic networks from distrust in providers. Our study lends support to this and other health information exchange efforts where personal and potentially sensitive health information will be stored and shared electronically. Understanding PLWH's attitudes towards having their PHI stored and shared electronically will become increasingly important as more health information is stored and shared electronically.

4.3 Practice Implications

Patients with stigmatizing diseases, such as PLWH, should not be excluded from health information exchange efforts. However more research is needed assessing actual patients' attitudes, rather than obtaining responses to hypothetical situations of health information sharing from non-patients. Equally important is providing clear and understandable privacy policies describing who may access the information and under what circumstances.

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References

1. Kaelber DC, Bates DW. Health information exchange and patient safety. *J Biomed Inform.* 2007; 40(6 Suppl):S40–5. [PubMed: 17950041]
2. Chaudhry B, et al. Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. *Ann Intern Med.* 2006; 144(10):742–52. [PubMed: 16702590]
3. DesRoches CM, et al. Electronic health records in ambulatory care—a national survey of physicians. *N Engl J Med.* 2008; 359(1):50–60. [PubMed: 18565855]
4. Middleton B, et al. Accelerating U.S. EHR adoption: how to get there from here. recommendations based on the 2004 ACMI retreat. *J Am Med Inform Assoc.* 2005; 12(1):13–9. [PubMed: 15492028]
5. Hillestad R, et al. Can electronic medical record systems transform health care? Potential health benefits, savings, and costs. *Health Aff (Millwood).* 2005; 24(5):1103–17. [PubMed: 16162551]
6. Robbins GK, et al. Predictors of antiretroviral treatment failure in an urban HIV clinic. *J Acquir Immune Defic Syndr.* 2007; 44(1):30–7. [PubMed: 17106280]
7. Nader CM, et al. Development of an electronic medical record-based clinical decision support tool to improve HIV symptom management. *AIDS Patient Care STDS.* 2009; 23(7):521–9. [PubMed: 19538046]
8. Bishop, L.; Holmes, B. National Consumer Health Privacy Survey. California HealthCare Foundation; Oakland, CA: 2005.
9. Whiddett R, et al. Patients' attitudes towards sharing their health information. *Int J Med Inform.* 2006; 75(7):530–41. [PubMed: 16198142]
10. Dolin RH, et al. The HL7 Clinical Document Architecture. *J Am Med Inform Assoc.* 2001; 8(6): 552–69. [PubMed: 11687563]
11. Ferranti JM, et al. The clinical document architecture and the continuity of care record: a critical analysis. *J Am Med Inform Assoc.* 2006; 13(3):245–52. [PubMed: 16501180]
12. Hays, RD., et al. The HIV Cost and Services Utilization Study (HCSUS) Measures of Health-Related Quality of Life. RAND; 1998.
13. Ware J Jr, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care.* 1996; 34(3):220–33. [PubMed: 8628042]
14. Revicki DA, Sorensen S, Wu AW. Reliability and Validity of Physical and Mental Health Summary Scores from the Medical Outcomes Study HIV Health Survey. *Medical Care.* 1998; 36(2):126–137. [PubMed: 9475468]
15. Hargraves JL, Hays RD, Cleary PD. Psychometric properties of the Consumer Assessment of Health Plans Study (CAHPS) 2.0 adult core survey. *Health Serv Res.* 2003; 38(6 Pt 1):1509–27. [PubMed: 14727785]
16. Hall MA, et al. Measuring Patients' Trust in Their Primary Care Providers. *Medical Care Research and Review.* 2002; 59(3):293–318. [PubMed: 12205830]
17. Sayles JN, et al. Development and psychometric assessment of a multidimensional measure of internalized HIV stigma in a sample of HIV-positive adults. *AIDS Behav.* 2008; 12(5):748–58. [PubMed: 18389363]
18. Stata, Version 9.2. Stata Corp; College Station, TX: 2007.
19. Hays RD, et al. Health-related quality of life in patients with human immunodeficiency virus infection in the United States: results from the HIV Cost and Services Utilization Study. *Am J Med.* 2000; 108(9):714–22. [PubMed: 10924648]
20. Mrus JM, et al. Variations in self-rated health among patients with HIV infection. *Qual Life Res.* 2006; 15(3):503–14. [PubMed: 16547789]
21. Mrus JM, et al. Utilities derived from visual analog scale scores in patients with HIV/AIDS. *Med Decis Making.* 2003; 23(5):414–21. [PubMed: 14570299]
22. Merrill RM, Allen EW. Racial and ethnic disparities in satisfaction with doctors and health providers in the United States. *Ethn Dis.* 2003; 13(4):492–8. [PubMed: 14632269]
23. Saha S, Arbelaez JJ, Cooper LA. Patient-physician relationships and racial disparities in the quality of health care. *Am J Public Health.* 2003; 93(10):1713–9. [PubMed: 14534227]

Table 1

Sociodemographic, Disease-related, and Functional and Quality of Life Characteristics (n=93)

Characteristic	N	%
Black	62	67%
White	10	11%
Hispanic	30	32%
Female	42	45%
Heterosexual	63	68%
Aged 40+	80	86%
<High School (HS)	28	30%
HS Grad/GED	33	35%
Income <\$5k	40	43%
Income \$5–10k	40	43%
Use Internet*	37	40%
AIDS diagnosis	48	52%
Undetectable VL	60	65%
	M (SD)	
Current Health (1=worst-10=best)	7.66	(1.78)
Quality of Life (1=worst-10=best)	7.91	(1.80)
SF-12 – Physical Composite Score**	40.42	(7.88)
SF-12 – Mental Composite Score**	45.49	(13.50)
HIV-Associated Stigma	2.46	(0.72)

* Defined as accessing the internet at least once a week or more.

** Each composite score has a standardized mean score=50, SD=10.

Table 2**Willingness to Share Personal Health Information**

I am willing to allow my personal health information to be shared with the following using a secure electronic network.	Strongly Agree or Agree	Neither Agree nor Disagree	Disagree or Strongly Disagree
My primary HIV care provider (e.g., physician, NP, PA)	86%	9%	5%
Other clinicians in the clinic of my primary HIV care provider (e.g. nurses)	78%	10%	12%
Other health care providers (e.g. emergency or hospital personnel)	78%	11%	11%
Non-HIV specialists (e.g. cardiologists, ob/gyn)	72%	9%	19%
Other health care providers (e.g. emergency or hospital personnel)	78%	11%	11%
Pharmacists	63%	22%	15%
HIV support service organizations (e.g., case managers)	74%	14%	12%
Other, non HIV-specific support service organizations (e.g., drug treatment programs, mental health services)	51%	32%	17%
Private health insurers	40%	31%	19%
Government health insurers (Ryan White funding; ADAP; Medicare; Medicaid)	63%	22%	15%
The local health department	53%	29%	18%
Other non-clinical staff in the clinic of my primary HIV care provider (e.g. receptionist/manager)	39%	13%	48%

Table 3

Correlations for Trust, Provider Communications, and Willingness to Share PHI

	Rho (p)	Rho (p)	Rho (p)
Willing to share PHI with:	PCP	Other Clinician	Non-clinical
Trust Care Team:			
<i>High Quality Care</i> *	0.241 (0.019)	0.280 (0.006)	0.309 (0.002)
<i>My Needs First</i>	0.198 (0.056)	0.200 (0.054)	0.255 (0.013)
Provider Communications:			
<i>Respect for Patients</i>	0.117 (0.261)	0.184 (0.076)	0.285 (0.005)
<i>Time with Patients</i> *	0.243 (0.018)	0.269 (0.009)	0.241 (0.019)

* Variables selected to be included in multivariate regression analysis

Table 4
Multivariate Regression Models for Willingness to Share Personal Health Information, n=93.

	Primary Provider			Other Providers			Non-Clinical Staff		
	β	t	p-value	β	t	p-value	β	t	p-value
Education	0.265	2.53	0.01	0.098	0.78	0.43	-0.028	-0.19	0.84
Age	0.006	0.55	0.58	0.001	0.06	0.95	0.025	1.38	0.17
Annual Income	-0.054	-0.71	0.48	-0.083	-0.91	0.36	0.184	1.71	0.09
Race	-0.051	-0.26	0.79	-0.007	-0.03	0.97	0.281	1.02	0.31
Hispanic	0.652	2.54	0.01	0.296	0.97	0.33	-0.17	-0.48	0.63
High – Quality Care	0.085	0.75	0.45	0.093	0.69	0.49	0.488	3.06	0.003
Time with Patients	-0.138	-0.76	0.45	0.027	0.13	0.90	0.772	2.98	0.004
Stigma	0.127	0.82	0.41	0.159	0.86	0.39	-0.416	-1.98	0.06
Use the Internet	-0.019	-0.08	0.93	-0.061	-0.22	0.82	-0.216	-0.67	0.50
	Rsq=0.125, p= 0.24			Rsq= 0.05, p= 0.86			Rsq=0.25, p= 0.003		