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Patient and Provider Perspectives on Cellular Phone Based Technology to Improve HIV Treatment Adherence

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Abstract

Innovative techniques, potentially using technology, to improve adherence to antiretroviral therapy (ART), may help patients with HIV who struggle with self-care. This qualitative study compared patient and provider participants' perspectives on ART adherence and text messaging as a tool to promote adherence. Thirteen providers and 14 HIV-infected patients identified four main themes: 1). facilitators and 2). barriers to using text message reminders as a medium for ART medication reminders; 3). framing of text message reminders; and 4). patient responsibility and autonomy in management of their health and wellness. Ease of use, access, convenience, and confidentiality were cited as benefits of a text message based adherence intervention; while access, cost, difficulty manipulating cellular phones, lack of knowledge/education, and confidentiality were cited as potential barriers. Providers, but not patients, also identified patient apathy and time burden as potential barriers to a text message based adherence reminder system. Patients and providers felt that personalization of messages, attention to timing, and confidentiality of messages were key factors for a successful text message based adherence reminder system. Both providers and patients felt that patient responsibility and autonomy over an individual's own health care is an important issue in adherence to medical care. The majority of

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patients and providers felt that a text message based adherence reminder system would be beneficial. While patients and providers had many similar views on factors influencing adherence with ART and the use of text messaging to improve adherence, there were some divergent views between the two groups.

Keywords

HIV; antiretroviral therapy; adherence; technology

INTRODUCTION

Antiretroviral therapy (ART) has transformed HIV from a fatal diagnosis to a chronic disease (Palella et al., 1998). Despite newer ART agents, high levels of adherence are still needed to maintain virologic suppression (Bajunirwe et al., 2009; Bangsberg, Moss, & Deeks, 2004); and therefore techniques to promote ART adherence are necessary. ART adherence can be challenging due to a variety of factors such as pill burden, forgetfulness, homelessness and substance use (Juday, Gupta, Grimm, Wagner, & Kim, 2011; Mills et al., 2006; Sullivan et al., 2007).

Cellular phones are ideally suited as a medication adherence tool due to accessibility and ease of text messaging. Text messaging has been shown to improve adherence in previous studies (Ammassari, Trotta, Shalev, & al., 2011; Hardy et al., 2011; Horvath, Azman, Kennedy, & Rutherford, 2012; Lewis et al., 2013). The objective of this study was to understand differences and similarities in patients' and providers' perspectives on cellular phone technologies to improve ART adherence.

METHODS

Participants and Procedures

This study was conducted at the Center for Infectious Diseases (CID) at Boston Medical Center (BMC) in Boston, Massachusetts. CID is an HIV clinic at an urban hospital which provides care to a socioeconomically disadvantaged population of ~1,500 patients. Qualitative interviews were conducted between March and April 2011. Interviews were recorded and transcribed verbatim. Participants provided written consent and received a \$25 incentive. Data were de-identified to preserve confidentiality and the protocol was reviewed by the BMC Institutional Review Board.

English-speaking, HIV-infected patients over 18 years of age on ART were eligible. Patients were recruited through direct referral from CID medical providers and through recruitment materials posted around the clinic. Medical providers directly involved in HIV care at CID were recruited via a purposive sampling technique (Maxwell, 1998).

Study Assessments

Following a brief demographic questionnaire, semi-structured interviews were conducted to explore perceived acceptability of cellular phone use to promote medication adherence.

Patients were asked about cellular phone use patterns and experiences taking ART. Providers discussed existing tools for adherence and factors influencing ART adherence.

Data Analysis

Interviews were analyzed using thematic content analysis. Initial themes based on the interview guide were identified to develop a codebook comprised of a label, definition, and illustrative quote (Silverman, 2010). Transcripts were coded by a trained staff member using NVivo software (v.8). The coded data were organized to fit the emergent themes relevant to the research questions. Staff members regularly met to draw connections between the research questions and raw data and further conceptualize codes. The group then agreed on final themes.

RESULTS

Descriptive Characteristics

Tables 1 and 2 provide demographic characteristics of the patient (n=14) and provider (n=13) participants. These qualitative data are organized according to four overarching topics related to text message reminders as a potential tool to promote ART adherence among HIV-infected patients. Table 3 provides verbatim quotations representing the specific themes found in the content analysis.

Perspectives on the Potential Utility of Text Message Reminders

Nine of the 14 patients had previously used a cellular phone and eight were familiar with text messaging. Most patients thought text messages would be a powerful adherence tool, citing ease of use and the comparative confidentiality of text messages compared to other communication forms. Nine patients preferred text message reminders over an interactive voice response system (IVR) or live person. Over half of the providers thought that text messages had the potential to be a positive adherence tool due to their ease of use and access. Providers generally concluded that text message adherence reminders would be easily accessible for patients due to high rates of cellular phone use within the patient population.

Barriers to Use of Text Message Reminders

Several issues emerged as potential barriers to using text message reminders to promote ART adherence. Barriers most significant for patients and providers included: (1) access; (2) cost; (3) difficulty manipulating cellular phones; (4) lack of knowledge/education; and (5) confidentiality. Unique to the providers' perspectives were message fatigue and the potential time burden of responding to texts.

Framing of Text Message Reminders

According to several patients and providers, the content and framing of text messages was crucial to text messages to promote ART adherence. In particular, providers highlighted personalization and timing of messages; while patients and providers cited maintaining patient confidentiality. Five providers described customization of text message reminders to

patients' preferences; while four providers cited the importance of timing of text messages to ensure that they are sent at time when patients are comfortable receiving them.

Both providers (n=4) and patients (n=6) stressed the importance of ensuring confidentiality. They suggested that text messages avoid language which could disclose HIV sero-status. Some respondents suggested that messages use code words to deliver the reminder in an oblique way. A few participants also thought that a graphic text would be helpful. However, the majority of patients (n=9) and over a third (n=5) of providers suggested that messages should be simple reminders about taking their medication.

The Role of the Patient in Health Management

Providers and patients alike emphasized the importance of patient responsibility in ART adherence. A number of providers worried that an increased role in the management of their patients' health might stifle patient autonomy and ultimately discourage personal health management responsibility. A few providers raised concerns about the time and effort currently spent on improving adherence. From the viewpoint of these providers, there were very few options for improving adherence for certain patients who had continuously struggled with taking ART; and a few providers underscored the lack of sustainability in a text message reminder system. It was suggested that once the patient has acquired the tools to maintain adequate adherence, the text message reminders should be stopped. Similarly, some providers suggested that adequate knowledge and support would augment the role of text messages in promoting adherence.

DISCUSSION

The present study examined patient and provider perspectives on the use of cellular phones as an ART adherence tool. Despite the relatively limited use of cellular phones by some patients, both patients and providers were generally enthusiastic about a cellular-based system for adherence. Our results are consistent with existing data published on patients' perspectives about technology-based tools for adherence (Curioso et al., 2009; Curioso & Kurth, 2007).

Participants highlighted potential strategies for implementing text message based programs for ART adherence. While patients and providers identified many of the same implementation challenges, providers underscored the role of message fatigue and time constraints as potential barriers. Attention to personalized content and convenient timing of text messages would help to address these concerns. While confidentiality was identified as a potential problem for some patients, many other patients did not mention it. Both groups in our study felt confidentiality could be protected by avoiding certain phrases or using code words. This finding is aligned with a qualitative study of HIV-infected patients in Peru (Curioso et al., 2009). Personalized messages may help address the issue of confidentiality for those who are concerned. Cost was identified as a barrier for many of the patients but was only mentioned by two providers. Additionally, participants pointed to literacy and familiarity with cellular phone use as important issues to consider. Such barriers may be magnified for resource-poor patients, such as those at CID. Technology-based adherence

tools should be tailored to the unique social, educational, and economic profiles of the patients that will be utilizing the service.

Patient responsibility was stated as a necessary factor for success in medication adherence and the overall utility of text message reminders. Text message efficacy could be improved if patients view their medication adherence as a problem and cellular phone adherence programs as part of a comprehensive strategy including self-management of their HIV (Bodenheimer, Lorig, Holman, & Grumbach, 2002), rather than a quick fix. As cellular phone technology is utilized more in the clinical setting, providers should carefully consider their patients' self-efficacy levels and how text message-based ART adherence programs are framed for patients.

These findings should be considered in light of some limitations. Because patients were recruited from a single urban safety net HIV clinic, the extent to which these data can be generalized to other populations may be limited. However, these findings are representative of patients with a variety of text messaging and cell phone usage patterns. Also since this study was exploratory, the sample was small and non-random. A larger number of participants may have allowed us to clearly characterize distinctions between provider and patient perspectives.

Both patients and providers play a central role in the successful implementation of technology-based programs to improve ART adherence. This study aimed to characterize both overlapping and distinct perspectives about text messaging as an adherence tool among patients and providers in a resource-limited health care setting. Addressing the shared concerns of confidentiality, message content, and timing is an important step in the development of technology-based tools that adequately address the unique needs of the patient population. Future research should focus on identifying strategies that integrate text message reminders for adherence within a broader health promotion framework for HIV-infected adults.

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Table 1

Demographics of Participating Healthcare Providers

Characteristics		Number (n = 13)
Gender (Female/Male)		(9/4)
Race/Ethnicity	Asian	2
	Black	2
	White	9
Type of provider	Nurse	1
	Physician	11
	Pharmacist	1
Years of experience in HIV care	Less than 1 year	2
	1 to 5 years	3
	6 to 10 years	3
	More than 10 years	5
Percent of patient practice with HIV infection	10% to 25%	3
	25% to 50%	2
	50% to 75%	2
	Greater than 75%	6
Proportion of HIV-infected patients perceived to have antiretroviral therapy adherence problems	10% to 25%	3
	25% to 50%	5
	50% to 75%	4
	Greater than 75%	1

Table 2

Demographics of Participating HIV-infected Patients

Characteristics		Number (n = 14)
Gender (Female/Male)		(5/9)
Age distribution, years (Mean $\pm$ S.D. ^a)		46.5 (9.8)
Ethnicity	Black	5
	White	6
	Other	3
Education	Junior high or less	2
	Some high school/GED	7
	Some college	2
	College degree or higher	3
Employment status	Unemployed	12
	Part-time	1
	Full-time	1
Own a cellular phone (Yes/No)		(10/4)
Frequency of cellular phone use	Several times a day	9
	Once a day	4
	Once a week	1
Frequency of text messaging	Several times a day	6
	Once a week	1
	Never	5
	Missing	2

^a S.D., standard deviation

Table 3

Patient and Provider Themes Identified for Using Text Message Reminders as an Adherence Tool

Theme	Representative quote	Subject Group	Patient Age/ Provider Years of Practice (years)	Gender
Facilitators				
Ease of use / Convenience / Ease of access	1. Because it's [texting is] quick, and it's easy, I guess. And I know they'd come through on my phone.	Patient	32	Male
	2. It's [A cell phone is] not one more thing that I have to put in my pocket, or bring with me, or whatever. I already have it with me. It's already there.	Patient	47	Male
	3. Yeah, I think that [text message reminders] would be the best way. Because everybody has a cell phone today, you know. So that's the best way to get through to everybody.	Patient	53	Male
	4. There's pretty high penetration of cell phones here; I think even among the homeless people.	Provider	>10	Male
	5. It [Texting] doesn't take a lot of their time, and yet it's a medium that people are using a lot these days.	Provider	1–5	Female
Confidentiality	6. Yeah, I'd rather have the texting. So, like, if I'm around people-- Because everybody doesn't know my medical status.	Patient	40	Female
	7. Just keeping confidentiality in mind while you do it [sending text message reminders]. Because in case somebody else looks at it.	Provider	>10	Male
Barriers				
Access	8. Most people I know, they don't have their phones on them all the time. Even if they do, they don't take it every minute. So, maybe the text message would be sent, but maybe it's going to be received an hour later or 30 minutes later.	Patient	32	Female
	9. But people are going to lose, or trade, or give away their cell phones, especially if you're going to give them their second cell phone, rather than rig their current cell phone with the program.	Provider	6–10	Male
Cost	10. Yeah. It [a cell phone] costs money every month and I'm on social security, so I only get enough for the rent and the bills.	Patient	46	Female
	11. So one thing we have to be sure that the patient doesn't have to pay for each text. So they have to have the texting program, because they definitely will not do that.	Provider	1–5	Female
Difficulties with mechanical manipulation of cell phones	12. Couldn't text. The numbers were very small. That even though I had the one [phone] with the keyboard, my thumb was too big and I hit the wrong button.	Patient	47	Male
	13. But, if it's like how my phone is made, that's kind of like frustrating, because the alphabets are not on single keys.	Patient	40	Female
	14. I would check their dexterity; are they able to text?	Provider	6–10	Female
Lack of knowledge / education	15. It's hard for me to spell. I can't-- Hard for me to spell. It's like a block. I can't.	Patient	57	Male
	16. No. I guess it [my phone] texts, but I don't know how to text.	Patient	54	Female

Theme	Representative quote	Subject Group	Patient Age/ Provider Years of Practice (years)	Gender
	17. They're [The patients are] illiterate. The text message is in English, and they speak Spanish.	Provider	>10	Female
Confidentiality	18. Concern? It's [Confidentiality is] not a concern. It's a negative right there. You know? If it's not my doctor calling, I'm not going to give out any information. It's no one's business.	Patient	57	Male
Message fatigue ^a	19. Somebody that's real confidential, they ... might be scared of the phone situation. They don't know if the phone message is going to go somewhere else or somebody else is going to pick their phone up.	Patient	41	Male
	20. It [Text message reminders] will cause them to have to disclose their status because they're with somebody who doesn't know, and they may be looking at their phone.	Provider	6–10	Male
	21. I'm afraid that if they [patients] get it [a text] every day, twice a day, if they're on twice a day regimen, I hope that they'll take it seriously and not after ten days be like okay, it's the same message, delete and forget.	Provider	1–5	Female
Time burden ^a	22. They [The patients] just may not, you know, want to do it [respond to text message reminders] because they're busy or involved in other activities depending on the timing when the reminder arrives.	Provider	>10	Male
	23. Again, I just think of my female patients who are usually mothers, often single mothers and working....they're trying to do a million things all day that they may not kind of see the priority of answering it [text message]. 7	Provider	>10	Female
Framing of Text Message Reminders				
Personalization of messages	24. I think that you really should try to tailor them [text messages] to, not only the patients' needs, you know based on whatever assessments you do, but also to their preferences.....So I told you sort of my skepticism about that. I think though that the outgoing text messaging—I think that they said that it should be tailored based on your assessments. And then it also should be tailored based on the preferences. So I think you do need to assess what the patient's individual preferences are as far as time frequency of messages...	Provider	6–10	Male
Timing of messages	25. I think the one thing will have to be definitely like you said, send it maybe of the time when they have to take the medicine. Because if it's an hour before, they're probably going to forget. Some of these patients are very busy, and they work, and they have kids. So it really has to be at that time, after work.	Provider	1–5	Female
Confidentiality of messages	26. [The message should be] as vague as possible, but only I would know what it means. Because in this virus, the word 'meds' is so well known. You mention the word 'meds', they automatically know what you're talking about.....everyone knows that that means HIV.	Patient	47	Male
	27. [Using a code such as] 'Did you take your power juice today?' ...So, when you call with that code, I would know what you're talking about.	Patient	40	Female
	28. For [patient] privacy, medications, it should definitely not [say] HIV. But...it shouldn't [even] say the word 'medications'."	Provider	1–5	Female

Theme	Representative quote	Subject Group	Patient Age/ Provider Years of Practice (years)	Gender
	29. Maybe come up with whatever the codes are, whatever the clues are for the patient. [Such as] 'Time to drink your juice.'	Provider	6–10	Female
The Role of the Patient in Health Management				
Patient responsibility	30. Any amount of texts is not going to do it. All they [patients] need is someone professional to sit down with them and explain that if they don't take them [the medications], they die. Simple as that. You know? Everything else is secondary. Your medication is what comes first.	Patient	57	Male
	31. I think it's just thinking about myself and what I need to do in my life that keeps me going. Because I know they [HIV medications] are effective. They are helping. I [have] never been sick in my whole life. So I'm not going to start being sick because [I'm] not taking the medication.	Patient	32	Female
	32. Giving them [patients] sort of the autonomy at some point that, 'Okay, yes, you're doing a great job,' and giving them that sort of self-efficacy, 'you can do it on your own' and not calling all the time, but letting them sort of show you that, yes, they can do it.	Provider	6–10	Female
	33. Well, we go through the whole thing with them. But I mean, you can't force somebody to take their meds.....And you can't force them not to do cocaine.	Provider	>10	Male
	34. I guess you have to buy into 'I need to do this for my health'. But there's a whole group of patients who say 'I have to do this to take care of myself, it's the best thing I can do for me'. And they believe what the physician has told them. And so they buy in. And because they buy in they'll do what it takes.	Provider	6–10	Female

^a No patient participants brought up this theme.