Entrust: Connecting Low-Income HIV+ Individuals with Health Care Providers

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Abstract
Individuals infected with Human Immunodeficiency Virus (HIV) face numerous stigmatizations and challenges, specifically with the maintenance and adherence to their medical regimen. This situation is further complicated when individuals lack monetary resources to maintain their overall wellbeing. This paper presents *Entrust*, a service that provides low-income HIV positive individuals (clients) with cellphones to communicate with their health care providers. The cellphone is used to foster consistent and effective communication between clients and case managers, and client compliance is motivated by free phone minutes. In this way, *Entrust* facilitates a higher quality of life for low-income HIV positive individuals.

Keywords
HIV/AIDS, Case Management, Cellphone, Communication, Low-Income, Ethnography

ACM Classification Keywords
H.5.2. User Interfaces (D2.2, H.1.2, I.3.6) Subjects: Graphical User Interfaces (GUI), Input Devices and Strategies, Prototyping, User-Centered Design.

General Terms
Design, Human Factors, Communication

Figure 1: *Entrust* branding

Introduction

Human Immunodeficiency Virus (HIV) is a chronic illness that affects around one million people in the United States with 56,300 new infections every year [1]. HIV concerns the infected and non-infected populations. Advancements in Highly Active Antiretroviral Therapy (HAART) only fight the HIV infection and the opportunistic infections associated with the virus: There is no cure. Although HIV positive (HIV+) individuals can live with the virus for many years, the general public is not adequately engaged or informed about HIV. Therefore, it is not alarming that one out of five (21%) people infected in the United States are unaware of their HIV status [1].

In addition to the medical needs associated with the treatment of a disease, (e.g.: financial needs and medications), the HIV stigma isolates this population, indicating the need for support and understanding [2]. Studies indicate the HIV+ community contends with many issues including: personalized stigmas, disclosure concerns, negative self-image, and concern with public attitudes toward people with HIV [3].

Problem Identification

Multiple sources were consulted to better understand potential problems within the HIV+ community, specifically the low-income subpopulation. Informal ethnographic studies were conducted on health care providers, case managers, and HIV+ individuals to understand the user groups and their needs. Peer-reviewed literature supplemented these interviews. It was found that conventional medical care could not meet all of the needs of the HIV+ community. In addition to medical care, low income HIV+ individuals need supplemental aid such as social services, transportation, home meal delivery, psychological counseling, housing, legal services, HIV risk reduction, substance abuse treatment, support groups, and disclosure help, among others [4, 5].

One method of helping HIV+ individuals through the difficulties associated with being HIV+ is case management. Case managers are professionals who meet with HIV+ clients to identify and meet their individual needs. Case management decreases the unmet needs of HIV+ clients, increases adherence to medications, and decreases risk behaviors [6, 7]. One of the main challenges of case management identified in the interview process is the lack of consistent and reliable communication with the client. The most frequent concern linked to the lack of communication is clients' lack of access to standard communication devices and services, such as a phone, the Internet or traditional mail.

A cellphone-based service provides means of communication, a sense of security, and reliable point of contact. Additionally, Douglas and Traugott [8] indicate cell phones and text messaging is used by all demographic populations.

Precedent

Cellphones have been used in general heath applications to aid in adherence, monitoring, diagnosis and data collection [9]. Cellphones have also been used specifically for HIV applications. For many years, cellphones have been used in developing countries to aid in the education of HIV and to help connect HIV+ individuals to healthcare [10]. One study tracked the use of cellphones to assist low-income HIV+ individuals to quit smoking. The research implemented cellphone-based counseling sessions as compared to regular counseling to aid in the cessation process. The study indicates participants in the cellphone intervention

User Group	HIV+ Clients	Case Managers
Education	All Levels	College Level
Income	Low	Medium/High
Technology Experience	Low/Medium	Medium/High

Table 1. The demographic comparison of HIV+ clients requiring assistance and Case Managers.

program are more likely to abstain from smoking than participants in regular counseling sessions. The cellphones also allow participants to overcome barriers commonly experienced by individuals living with HIV/AIDS such as geographic mobility, lack of transportation, and no phone service. Furthermore, this study establishes the feasibility of a cellphone intervention program [11].

Cell phones and Short Message Service (SMS) have been used as a persuasive technology, which is used to adapt and change medical-related behaviors [9, 11, 12]. Persuasive technology, specially through SMS, has been used for social campaigns, such as marketing political events or retail promotions [13].

The Federal HIV/AIDS Web Council (FHAWC) is currently addressing how technologies, such as SMS and Multimedia Messaging Service (MMS), can be implemented to promote coordination of new information delivery [14, 15]. This demonstrates mobile information systems are important issues for current HIV/AIDS campaigns.

Unlike previous programs, the proposed solution provides incentives for low-income HIV+ individuals to connect and communicate with specific health care professionals and personalized contacts.

User Groups

Two user groups are identified from the interviews: the clients and the case managers. Each group has a distinct user profile as described in Table 1.

Envisioned Solution

Entrust fosters a consistent and effective connection between case managers and low-income HIV+ clients through the principles of persuasive technology [12]. The service is cell-phone based: *Entrust* provides clients with entry-level cellphones. Clients are able to make free calls to the case manager and other designated *free contacts*, such as professional resources in the clients' life: a pharmacy, physician, or emergency contact. As the client adheres to the proposed action plan developed with the case manager, the client is rewarded with *incentive* cellphone minutes. Clients can use incentive minutes to call anyone they choose, such as friends, family, or an employer. Rewards are based upon the frequency of communication and maintenance of responsibilities established by an action plan.

The phones distributed through *Entrust* have basic calling functionality and the ability to store free contacts. Other features, such as Internet access and voicemail, are not required. Additionally, the price of entry-level phones reduces the overall cost of *Entrust*. Local case managers indicate that the use of less expensive phones reduces the temptation for clients to sell them. Eliminating reliance on a service provider allows for simplified distribution through the case manager while reducing the logistical issues of losing a phone.

Service Platforms

Entrust utilizes a case manager platform and a client platform. Both platforms are tailored to their specific user groups.

The client platform is designed for simplicity and functionality. The following use cases are presented:

Curtis is a low-income HIV+ individual who has fallen behind on his medication adherence. Furthermore, he lacks access to some basic amenities such as weather-appropriate clothing, consistent meals and has not communicated with family for a long time.

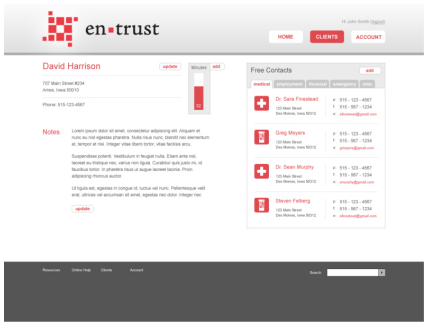

Figure 2. Entrust Management System (EMS). The organization and layout of the EMS provides a clean and streamlined interface that allows case managers to access client information at a glance.

Curtis decides to seek assistance through an HIV service provider, where he meets with a case manager. An action plan is discussed and developed to improve aspects of Curtis' life. He is enrolled in *Entrust* to ensure he can contact his physician and be contacted by his case manager. His free contacts include: a local food bank, pharmacy, and a source of local transportation.

After three weeks in *Entrust*, Curtis has adhered to his action plan, only missing a few calls. His life has benefited from *Entrust* in many ways. When talking with his case manager, Curtis was informed about a new local charity that could provide him with dinner once a week. Curtis has also called the pharmacy to refill his prescription and has started regularly taking his medication. Because he was able to comply with his action plan, his case manager rewards Curtis with 20 incentive minutes.

Rachel is a case manager who has difficulty keeping in touch with a client because they lack access to a phone, and cannot be reached by mail.

To keep updated with her client's condition, she enrolls her client in *Entrust*. Rachel and her client discuss an appropriate action plan. The action plan agreed upon includes Rachel's client calling her twice weekly for health and well-being updates with the *Entrust* cellphone she provides. Rachel will also send out SMS messages through the *Entrust* interface to remind Curtis of any upcoming appointments.

Rachel then explains whom her client can call for free: herself, the client's physician, and pharmacy. She also informs Curtis that his text messages will be used to track his adherence behavior and various appointments.

On a follow up conversation, Rachel observes her client has been adherent to their action plan and rewards them with 30 incentive minutes. Additionally, her client informs her that they are struggling with depression. Rachel programs the contact information of a mental health provider in the cellphone.

These use cases demonstrate *Entrust* from both a client and case manager's perspective.

The case manager platform is the *Entrust Management System* (EMS). EMS is an interface (See Figure 2) designed to easily and effectively manage the client's platform. EMS is built using web technologies and is located on local servers.

Through EMS the case manager can: send, receive, and track SMS messages, set and change the client's free contacts, add incentive minutes, add client-specific notes, register new cellphones, and monitor phone statistics.

While managing the details of each client's platform increases the workload for the case manager, the customization benefits are apparent. For example, a client may need to have daily communication with the case manager while going through a medical crisis. The case manager can add free contacts, such as a psychiatrist, then reward the client for their daily contact with incentive minutes.

Implications

Entrust has positive implications for both user groups. For case managers, *Entrust* can make communication between clients more reliable and consistent. When clients possess cellphones, case managers no longer have to spend time calling peripheral contacts, sending notifications through the mail, or physically visiting last known addresses. This allows case managers to spend

more time addressing their clients' needs. Frequent communication, motivated by the incentive system, makes it easier for the case manager to stay informed of clients' needs, and quickly address any problems that arise. Furthermore, the EMS phone statistics can be used as a metric for client evaluation.

One of the main goals of *Entrust* is to more effectively connect the case manager and client. As previously discussed in the problem identification, case management has several positive implications on a client's life [6, 7]. Case management is crucial for clients as it can assist them in reaching out for emotional, communal, medical, financial, or psychological support. It also aids clients in establishing a sense of independence, gaining self-esteem, and maintaining a healthy lifestyle.

Entrust's reward system allows the client to gain incentive minutes. When incentive minutes are earned, the client can call individuals other than their free contacts. This provides social benefits such as "security, coordination, and expressiveness" [16]. Additionally, clients will be able to stay in touch with family, friends, and practical contacts such as employers, landlords, or utility providers. Cellphones also make it possible for clients to contact and be contacted by new friends, thereby increasing their social support network.

Future Work

The next step for *Entrust* is to develop a functional prototype of the service. This would involve: securing mobile phones, deciding the best phone to use, and developing and implementing EMS. A pilot study will be conducted once a functional prototype is developed. The pilot study will consist of: (a) implementing *Entrust* with local case managers, and (b) performing usability studies for evaluation and feedback. Local service organizations express significant interest in being involved with the pilot study. One organization acknowledges the potential for *Entrust* and expresses a willingness to participate.

A case manager must keep good documentation of correspondence with clients. To allow for maximum utility *Entrust* will be fully integrated into the case manager's documentation process. The case manager will benefit if communication data from EMS (e.g.: time, duration, number of calls) and SMS information is recorded and integrated with the client's current records. This would effectively streamline the case management process.

Entrust's underlying reward system is effective in promoting communication in numerous user groups. An *Entrust*-like system could be implemented for other low-income individuals struggling with chronic illnesses, such as diabetes, epilepsy, or Crohn's disease.

Conclusions

Low-income HIV+ individuals face numerous challenges; many of which can be resolved by having means to connect with those who can help.

In accordance with a user-centered design process, *Entrust* was conceived by focusing on the needs of both case managers and clients. Interviewing local sources and conducting background research informed our decisions on: problem identification, user group selection, user group needs and platform development.

Entrust joins low-income HIV+ clients and their health care providers by furnishing cellphones and an incentive program. The result of this connection is the

betterment of the health, safety, and welfare of the low-income HIV+ individual.

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