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The Internet and Care Initiation by People Living with HIV

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Abstract

Over the past 20 years, people increasingly use the Internet to obtain information, including information about health. Yet, we lack understanding of how people living with HIV (PLHIV) use the Internet in their care and treatment decisions. Interviews with 23 individuals who initiated HIV care at an urban, Midwestern medical center were analyzed to explore how they used the Internet during the process of initiating HIV care. The time frame of initiation of HIV care ranged from less than one month to a delay of three years post-diagnosis. Qualitative content analysis was conducted and revealed that the participants discussed the Internet as a source of information about their diagnosis that influenced their care and treatment decisions. Five predominate themes emerged: 1) The Internet Alerted me to the Possibility of HIV, 2) The Internet Showed me a Solution is Available, 3) The Internet Influenced my Decisions about Care, 4) The Internet Empowered me to Participate in my Treatment Decisions, and 5) The Internet Gave me Hope for my Future. The results suggest that the Internet has the potential to provide information that can profoundly influence PLHIVs acceptance of care and treatment decisions. Clinicians face a new reality in which patients use Internet resources to obtain information and shape opinions about HIV treatment and care initiation decision-making. Guiding PLHIV in their selection of online resources needs to be adopted as one approach to educating and empowering individuals as they cope with their diagnosis and contemplate decisions regarding HIV care and treatment.

The Internet is a widely leveraged medium that can be used to obtain information and connect with other people for health-related purposes (Perrin & Duggan, 2015). The Internet is particularly useful as a tool for traditionally disparate populations including older adults, and also low SES individuals increasingly through smartphone access (Blackstock et al., 2015; Odlum et al., 2013; Perrin & Duggan, 2015; Zickuhr & Madden, 2012). Researchers have established that people living with HIV (PLHIV) often use the Internet (Blackstock et al., 2015; Kalichman et al., 2005; Kalichman et al., 2002), but less is known about specific ways that the Internet influences their care and treatment decisions.

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In the US, more than 1.2 million people are living with HIV (Centers for Disease Control and Prevention [CDC], 2016). The advent of antiretroviral therapy (ART) marked the transition of HIV from a fatal disease to a chronic and manageable condition. Today, PLHIV can achieve longer life expectancy and have reported improvements in quality of life, but less than half of PLHIV are engaged in HIV care. Furthermore, only 30% achieve the optimal benefit of HIV treatment (Department of Health and Human Services [DHHS], 2015). Failure to engage in HIV care places PLHIV at risk for disease progression and development of acquired immunodeficiency syndrome (AIDS) (CDC, 2016; DHHS, 2016). Viral suppression (also known as an undetectable HIV viral load) is an indicator of optimal treatment outcomes that are achieved through consistent ART adherence (DHHS, 2016). We need a better understanding of factors that influence care and treatment-related decision-making among PLHIV.

The Pew Research Center (2015) surveyed more than 225,000 American adults of various racial and ethnic backgrounds, and found that 84% of US adults use the Internet, and have found that up to 81% have reported that they use the Internet to obtain health-related information (Pew Research Center, 2013). Online, individuals are able to access a wide variety of resources, including descriptions of diseases and their risk factors, treatment recommendations, personal experiences and testimonials of individuals living with diseases (e.g. blogs), social media sites to connect with similar others, and social/emotional support (Pew Research Center, 2013). PLHIV are no exception in their use of the Internet, as evidenced by the results of studies that have reported that individuals who are diagnosed with HIV use the Internet as a source of information about HIV and for social support (Horvath et al., 2009; Mo & Coulson, 2010; Rice, Monro, Barman-Adhikari, & Young, 2010; Walsh, Horvath, Fisher, & Courtenay-Quirk, 2012; Young & Jaganath, 2013).

Such findings demonstrate that the Internet can be a valuable resource for PLHIV. A qualitative analysis of online forum entries by Coursaris and Liu (2009) provided rich insight into how the Internet was a useful information tool, and as a means to meet other PLHIV to whom they can relate. The participants most often used web-based resources for information and emotional support. Courtenay-Quirk et al. (2010) conducted a mixed methods investigation into the perceptions of HIV-related websites from a sample of 63 individuals recently diagnosed with HIV. Study participants described using specific types of websites and content as important decision-making tools for PLHIV. The results of the study demonstrated that the Internet was used by people recently diagnosed with HIV to find treatment-related resources and gain insight into their diagnosis (Courtenay-Quirk et al., 2010). While the benefit of the Internet for obtaining medical information has been established, a gap in current knowledge is how the Internet influences care initiation by people initiating HIV care.

Method

The Parent Project

From April to December 2014, Perazzo, Martsolf, Pritchard, and Tehan (2015) conducted in-depth interviews with 30 adult women and men who participated in a grounded theory study entitled “Translating the News: A Grounded Theory of Care Initiation by People Living with

HIV” which provided the data for the current study. The purpose of the grounded theory study was to develop a theoretical framework to describe the psychosocial process of care initiation by PLHIV. Care initiation was conceptually defined as the time point on the HIV care continuum in which an individual first enters HIV-specific care. Participants shared their stories about finding out they had HIV, about their lives during the time between learning they had HIV and deciding to enter HIV care, and their experiences initiating HIV care. It is important to note that the focus of the study was on the entry into the care environment and not about the initiation of ART or other treatments related to HIV infection, which occur later in the HIV Care Continuum.

The results of the study indicated that PLHIV progress through a process of *receiving, interpreting, incorporating, acting upon, and moving beyond* the news of their HIV diagnosis. As participants shared their experiences of progressing through the process of care initiation, they discussed ways in which they sought out information about HIV and its implications for their lives as well as information about HIV care and treatment. These discussions often included the use of the Internet as a tool to gain information and help them make care and treatment-related decisions. Consistently, the outcome of such inquiry influenced their understanding of their HIV diagnosis, their expectations with regard to HIV care and treatment, and their decision of when, where, and with whom to pursue HIV care. The purpose of this article is to present the findings of a secondary analysis that was conducted to explore data on the use of the Internet in care and treatment decision-making in PLHIV. Specifically, we explored how PLHIV found meaning and conceptualized their new reality by using the Internet during the process of care initiation.

Participants

For the parent study, the research team leveraged a purposive sampling method to recruit individuals initiating care through an HIV New Intake Center at an urban, Midwestern medical center. In 2014, the majority of the 232 individuals who initiated HIV care through the new Intake Center were men (n=78%) with a primary risk factor of being men who have sex with men (MSM; 60%). The first author partnered with HIV care providers within the HIV treatment center to identify interested participants, and all individuals initiating HIV care through the New Intake Center were offered the opportunity to participate in the study. The first author met with interested participants and informed them about the scope and purpose of the study. If the participant chose to participate in the study, the first author obtained informed consent and scheduled a time that the individual could meet at the facility for a private interview. Participants were invited to participate if they met the following inclusion criteria: (a) at least 18 years of age, (b) had received a confirmed seropositive HIV test result prior to initiating care, (c) had not previously initiated HIV care (i.e. in and out of care), and (d) were able to speak and understand English. Participants were not eligible to participate if they were experiencing acute illness requiring inpatient hospitalization at the time of intake.

Racial and ethnic backgrounds of study participants included Caucasian, African American, Native American, Hispanic/Latino, or multi-racial identification. All participants had received confirmed HIV seropositive diagnoses prior to participation, and had received

initial testing in private practice encounters, local HIV testing centers, and with home HIV testing products. While the participants were initiating HIV care for the first time, they varied in the time that they had been diagnosed with HIV at the time of the interview—ranging from less than one month to three years since diagnosis.

Procedures

In-depth, audiotaped interviews with participants took place in a private office within the HIV treatment center. Using a semi-structured interview schedule individuals were asked a beginning general question: *'You were diagnosed with HIV on [Date], tell me your story about how you went from learning that you had HIV to coming here to receive care'* to elicit their stories about learning that they had HIV and the subsequent experiences they had during the time frame between receiving their HIV diagnosis and initiating HIV care. Participants were asked additional questions about phenomena they described during the interviews. Internet use was explored through follow-up probes when participants initiated discussion of going online to obtain information (e.g., *'Walk me through your online search, specifically what terms did you use? What results came up?'* *'Tell me about the information you read online. Did anything particular stand out to you?'*). Interviews lasted between 45 minutes to two hours. Following the completion of interviews, participants were compensated with a \$20.00 gift card for their time. The interviews were transcribed verbatim for data analysis by a professional transcription service, and were checked against the recorded interviews for accuracy by the first author. Once the transcripts were confirmed to be accurate, all were placed on an access-restricted research drive within the university.

Data Analysis

Two researchers independently reviewed all transcripts from the parent study to find content about Internet use. Through this process, the researchers identified 23 participants who discussed using the Internet in their narratives; these 23 participants became the data set for this analysis (Table 1), and included heterosexual men, MSM, and heterosexual women. The principles of conventional qualitative content analysis (Hsieh & Shannon, 2005) were used to guide the data analysis. The 23 interviews were reviewed in their entirety to gain an overall perspective of the participants' experiences, and to isolate sections of text in which Internet was discussed, along with contextual factors surrounding these discussions. The researchers independently reviewed the Internet data line-by-line to derive codes represented by key words and concepts in the data (e.g. 'symptoms', 'help', 'search terms'), which formed a preliminary coding scheme. Each researcher independently noted their impressions of each interview, the codes they had identified, and potentially emerging categories. The researchers met to review their independent findings, and collaborated to organize the codes into meaningful categories (e.g. 'treatment-related Internet use', 'disease-information Internet use'), resulting in nine initial categories. The researchers independently returned to the data and reanalyzed the data using this coding scheme. The researchers then met again to discuss their findings, and through discussion and consensus, were able to merge similar categories into more comprehensive themes that appeared consistently in the data. Finally, the researchers collaboratively identified data that exemplified each theme, and partnered with three independent researchers with expertise in HIV to review the findings. There was

unanimous agreement among the research team that the thematic structure accurately represented the coded meanings from the interviews.

Results

The analysis revealed that the Internet influenced individuals in five predominant ways with regard to their care and treatment decisions: 1) The Internet Alerted me to the Possibility of HIV, 2) The Internet Showed me a Solution is Available, 3) The Internet Influenced my Decisions about Care, 4) The Internet Empowered me to Participate in my Treatment Decisions, and 5) The Internet Gave me Hope for my Future.

The Internet Alerted me to the Possibility of HIV

It is not uncommon for people to be unaware that they have been infected with HIV. HIV can silently replicate for up to 10 years before an individual experiences symptoms. Even among people who experience primary HIV infection, often described as flu-like symptoms within two to four weeks of diagnosis (CDC, 2016) they may not attribute these symptoms to the possibility of HIV infection and may not seek help. All of the participants began their narratives by talking about events in their life preceding their HIV diagnosis, and in nearly half of these cases, these events included the onset of persistent symptoms. Symptoms described included rapid weight loss, severe flu-like symptoms, persistent mouth sores, petechiae, and thrush. Internet search results can present explanations and even potential remedies for symptoms, often setting a process of elimination in motion. Individuals may not approach an Internet search related to health with any information other than a symptom, and it is the subsequent information they find online that gives direction to further searching or actions related to their health. When participants saw HIV as a recurring repeatedly appear in their searches, it alerted them to the possibility of HIV to explain their symptoms. Whether they took action immediately, or sought out other explanations and remedies first, the participants described making a decision to get an HIV test based on the consistently seeing HIV in their Internet searches as a possible explanation for their symptoms.

The Internet was involved in other aspects of the early stages of confronting the possibility of HIV infection. Two participants learned that they tested positive for HIV for the first time through an Internet-based healthcare portal after being tested by their primary care providers. In both cases, these participants shared that they immediately contacted their healthcare providers who told them that the availability of the test result online prior to consultation was a system-level mistake, and not the ideal way they'd hoped to share a positive HIV test result with their patients. In both cases, care was immediately established. However, not everyone who received a positive HIV test believed that the results were accurate. Six of the participants shared that they questioned whether there was a possibility that their positive test was a mistake, and again, turned to the Internet for information about false-positive HIV tests. Such information seeking included searches for foods, drinks, and medicines that can result in a false-positive HIV test, as well as general inquiry about the likelihood of false-positives. The participants described learning that false-positive HIV tests are not common and received messages about the importance of contacting a provider and getting confirmatory testing done (in all cases, an HIV positive test result was confirmed).

The Internet may be what ultimately leads to HIV testing and subsequent care, even when the initial searches are not HIV-specific. Exemplifying this theme, one participant who presented to care with advanced HIV shared about a persistent oral infection he had been trying to get rid of for months, and how looking up his symptoms on the Internet led him to his decision to get tested for HIV:

I looked up online what causes [mouth sores], and HIV was one of the [conditions] that causes them. So I said let me just make sure because it's been a while since I've been tested.

The Internet Showed me that a Solution is Available

All of the participants shared about receiving their HIV diagnosis. The stories varied depending on the level of preexisting knowledge about HIV they possessed, whether they knew other people living with or who had died from HIV infection, as well as other personal perceptions of HIV illness. Four participants shared that they believed their lives were over because of HIV infection, often citing media images and stories of people they knew who died from HIV. The other participants varied in their knowledge about HIV, but were generally aware that advancements in HIV treatment have been made since the beginning of the epidemic. However, even these people expressed that they had concerns about how difficult the medication regimens were going to be and what their lives were going to be like from now on. Participants described using the Internet during the immediate post-diagnosis time period in an attempt to find out what they should expect is going to happen to them, and described privately searching the Internet on their phones and computers, using search phrases such as “I have HIV”, “AIDS”, “HIV help”, and “HIV what now”. Participants learned online about the current state of HIV treatment, that new treatments may be available that promote health and longevity in PLHIV, and that today's treatment regimens are not like those taken by PLHIV in the early days of the epidemic (i.e. high pill burden, high side-effect regimens). The information gathered from these searches often brought a sense of relief and helped them realize the potential for a healthy future and to take action about their health.

Participants also shared that they used the Internet to locate a treatment facility and choose a healthcare provider. Participants were often referred to specific locations for HIV care, primarily using the Internet to get directions, phone numbers, and to arrange public transportation, thereby helping them to locate and establish their initial contact with HIV care. Among those who chose to seek out care providers on their own, choices were sometimes made based on geographic or transportation constraints, and sometimes made in an effort to choose a provider they believed was right for them. The Internet was a source of information that could answer a variety of questions about HIV treatment facilities and the providers available for care. This information often came from the personal and professional websites of providers and the institutions for whom they worked. These searches led to feelings that they were making more informed decisions regarding their care by doing their own online research first to read about providers' backgrounds, training, HIV specialties and the institutions where they worked (e.g. location, history, patient population, etc.). One participant shared an experience that exemplifies the role of the Internet in realizing that there was a solution for PLHIV despite his preconception:

Deep down in my mind, I thought “God, if you get HIV, your life’s going to end. It’s going to control your life. It’s going to end up killing you.” So it was a relief to find out [from researching online] that with proper medication, you can still live a normal life. You can still live to be 60, 70 years old.

Information Online Influenced my Decisions about Care

When an individual is not experiencing an acute health crisis related to HIV, the process of initiating HIV care requires initial assessments of disease progression, genotyping to identify an appropriate ART regimen, and assessment of psychosocial factors that may diminish an individual’s ability to adhere to ART before pharmacological therapy is implemented. Participants described their first encounters with health care professionals following care initiation as mostly helpful and positive interactions. Participants were not all immediately started on HIV treatment, but rather had new intake counseling with providers and laboratory analyses completed for genotyping and assessment of disease progression at their first visit(s). Participants shared about their experiences with learning about their ‘numbers’ (a term they often used to describe HIV-specific biomarkers) and using the Internet to help them interpret their results. Participants sometimes received laboratory results prior to follow-up with their provider when laboratory results were posted to an online medical record prior to follow-up, and used the Internet to understand their laboratory results. Often, providers were described as discussing HIV disease progression biomarkers during the initial consultation and follow-up, but participants still used the Internet to gain further information.

Although it was unclear how well participants conceptually understood HIV disease progression biomarkers (e.g., CD4+ T cell count, viral load), participants described comparing their own laboratory results to information they read online. Participants visited websites ranging from personal blogs to more official websites run by government agencies, and searched for comparisons between their laboratory results and what was “normal” or what other peoples’ laboratory results were when they were diagnosed. Participants varied in their reactions to learning this information, particularly when they saw that their laboratory results were associated with AIDS (e.g., CD4+ T cell counts less than 200). Participants varied in their reactions to this type of information, with some participants reporting feelings of distress, while others described it as a motivating factor to continue their engagement in care and begin an ART regimen.

While the Internet is an invaluable source of information, it is important to mention the ever-present concern for misinformation that accompanies Internet searching: misinformation that may have as strong an impact on decision-making in PLHIV as accurate information. It is possible that an individual may make the choice to delay care due to obtaining outdated information or encountering personal anecdotes online that suggest care is unnecessary or unimportant. One participant, for example, shared about his decision to delay HIV care after being diagnosed, despite recommendations from his provider. Believing he did not have the financial ability to pay for medicine every month, he searched the Internet to determine how urgent his case truly was based on his laboratory results. After further probing about the specific searches and websites that influenced his decision, it was revealed that he had

referenced a PDF document available in a basic Internet search of “HIV treatment” that contained outdated HIV treatment guidelines. This participant interpreted the document as recommending treatment ‘when CD4+ T cells fall below 300’. He went on to share that he looked at his laboratory results and saw that his ‘CD4 number’ was above 300 and decided treatment “was not a priority at that time”. This resulted in a delay of seeking care for approximately one year, at which point he was hospitalized for an intestinal infection and advanced HIV disease. He initiated HIV care upon discharge from the hospital.

Information sources online are not limited to official websites of health authorities, or HIV-specific websites dedicated to discussion of the disease and its treatment. Personal blogs and social media websites designed for PLHIV are also available, and allow PLHIV to learn about HIV from people who are living with it. Participants also visited these websites and described them as having a very positive impact on their perception of their HIV diagnosis. The websites provided personal experiences and insight into early post-diagnosis anxieties—including those specific to all of the new healthcare encounters they were experiencing. HIV discussion boards and blogs can provide PLHIV with the comfort of relatable personal experiences with being diagnosed with HIV. For example, several participants visited a popular website designed for PLHIV and read about people who had similar stories and fears as they were having, but the stories described an upward trajectory in which they ultimately achieved health. Participants expressed that such stories provided them with hope and motivated them to seek treatment. Participants gave insight into the ways the Internet provided them with information and influenced their decisions regarding care. A statement by one participant exemplified the use of the Internet to help inform his next steps following diagnosis:

I needed to take in as much knowledge as possible so that I’m educated about the subject... to know what to expect when my appointment happens... what questions I should ask... I want to know what route to take next.

The Internet Empowered me to Participate in my Treatment Decisions

In the early stages of HIV care, an individual is confronted with the reality that to achieve and maintain viral suppression, there is a requirement for adherence to lifelong medical therapy. In the case of the participants in the study, the new intake appointments included one-one-on counseling about the nature of HIV treatment and the importance of adherence to medications. All participants were given new intake packets that included comprehensive plain language material that included a list of currently prescribed HIV medications. The Internet was commonly used to explore these medication options. Participants explained that they wanted to know more about HIV treatment so that they would know what side effects to expect and be able to actively participate in discussions with providers regarding their care and treatment. Participants used Internet search engines for general information about HIV medications, and explored a variety of websites to learn about specific medications. In addition to information-based websites, participants also visited blogs, discussion boards, and social media websites to learn about medications from the people who take them.

Participants consistently reported feeling more informed about medications going into post-intake appointments with providers because of their online research, and used this

information to formulate perceptions, evaluations, and decisions regarding specific medications. One participant shared that while searching for a specific medication in a general search engine, a pre-populated search ‘popped up’ that said “[Medication] not good for HIV”. He explained that this caused him great concern but he was glad he did the online search so he could tell his provider that he refused to take this specific medication because he believed that it would not be good for him.

Participants shared that they found comfort in reading about other peoples’ successes with ART and even identified specific medications to ask their provider about. They described identifying with the author of a post or a blog when they believed that their stories were very similar. This often led to evaluations that if a medication worked for this individual, it could possibly work for them. Reading about potential side effects or long-term consequences of specific HIV medications armed participants with questions and concerns that they could take to their provider. Preferences for a specific type of regimen (e.g. one pill per day) or regimens known to have fewer side effects were developed during their online searches. It is important to note that participants were quick to concede that ultimately they are not HIV experts and would yield to provider recommendations if their own ideas turned out to be suboptimal. However, the ability to participate in provider discussions regarding medication was empowering, and often made participants feel more in control at a time when they were facing a number of unknowns with regard to their health. One participant shared an experience that exemplified the desire of many participants to be able to take part in making decisions about their care (e.g. medications). He described a desire to look beyond basic information available about medications and learn about the experiences of the people who took them, and believed this would arm him with greater knowledge in discussions with his provider:

I sat at my computer for hours looking up medications....I want to know long-term side effects. I wanted to know about personal experiences from people. How has it affected you? What were your side effects?...I want to know from the real people what did you deal with on this medication? I did that on every medication that was on that list [his list of prescribed HIV medications].

The Internet Gave me Hope about my Future

The Internet provides a space in which people can seek out information privately. During the early days following diagnosis, PLHIV may not be ready to disclose their HIV status to or seek out counsel from friends and loved ones. A common finding in the parent study was a decision to hold off on disclosing HIV status to friends and loved ones until they had an established treatment regimen and the HIV was under control. The Internet provided what was perceived as a private venue for seeking information and asking questions. The overwhelmingly positive stories and advice that they found online commonly gave participants hope to continue adhering to appointments, begin ART, and stay in care. Participants visited HIV websites created and maintained by health authorities with strong messages about the importance of linkage with care, new and effective medical treatments, the potential for long-term survival while living with HIV, and the importance of getting into and staying in care.

Participants reported being motivated by personal stories of recovery and achievement of an undetectable HIV viral load, recommendations from PLHIV to prevent or mitigate the impact of side effects, adverse reactions to medications, how to live healthy with HIV (e.g. healthy diets), and the ability to maintain normalcy in their personal and social lives. These stories brought a sense of relief and hope to participants; particularly those who were seeking experiences and advice that they wanted from people who had lived a similar experience. Participants shared that they wanted to have the same positive outcomes as the people they were reading about, and that treatment was a route to “get back to normal” or to “have a better life” than they felt they were living. In this way, the information obtained online brought participants to a cross-roads, where they could choose to live a healthy life. These online resources sent strong messages in line with the goals of HIV treatment. One participant shared an overall message that exemplifies the theme of finding hope from the Internet search:

The biggest thing that I took away [from the internet search] was...most of the websites said you can live a normal life expectancy once it's under control, and once you're on medication. That's what I remember, and that's what I was looking for...you keep on the medication, you can live a pretty normal active life expectancy...That was my big relief.

Discussion

The results of this study highlight the specific ways in which PLHIV report using the Internet following diagnosis to obtain information and make decisions about initiating care and treatment. Consistent with recent literature, individuals in this study used the Internet to seek out health-related information (Coursaris & Liu, 2009; Courtenay-Quirk et al., 2010; Mo & Coulson, 2010; Rice et al., 2010; Walsh et al., 2012). Participants described the Internet as an informational tool they used when they had symptoms that often alerted them to the possibility of HIV infection and led, in time, to their decision to get tested for HIV. The Internet was also used to obtain information about HIV and its implications for their lives. Participants also located HIV facilities and health care providers online.

The information online helped participants see that a solution was available to them and helped them make decisions regarding their care and treatment. The information participants learned online was also described as being used to self-advocate in discussions with providers about concerns, questions, and in making decisions regarding specific treatment options (Brashers, Haas, & Neidig, 1999; Brashers et al., 2000). Participants described enacting Brashers et al.'s three patient self-advocacy strategies of 1) increasing their health literacy, 2) increasing their interpersonal assertiveness with providers, and 3) increasing their willingness to question providers' recommendations as part of becoming more participative in their health care decision-making (Brashers et al., 1999). Thus, the Internet is emerging as an important tool that enables patients to enact a patient-centered care perspective. Finally, participants used the Internet to learn from other PLHIV, describing the Internet as a resource that was not only informative, but that also gave them optimism for the future. Increasing HIV medication adherence to aid PLHIV maintain undetectable viral loads continues to be a top priority in improving the health of PLHIV, and in reducing

transmission though HIV prevention efforts (CDC, 2016). Access to online social support from other PLHIV may play an important role in success of these efforts.

While previous studies have demonstrated the impact that online resources can have on the ability of PLHIV to obtain HIV-related information (Courtenay-Quirk et al., 2010; Samal et al., 2011) and receive emotional support (Coursaris & Liu, 2009; Rice et al., 2010; Walsh et al., 2012; Young & Jaganath, 2013), our results indicate how the Internet may be used by PLHIV following diagnosis in the process of care initiation to make sense of their diagnosis and make decisions related to care and treatment. The evidence generated in this study carries both clinical implications and directions for future inquiry.

Clinical Implications

Healthcare workers, particularly those who work with PLHIV, will benefit from understanding clinical implications of the use of the Internet in HIV-related care and treatment decision-making. Understanding the influence that Internet information can have on PLHIV, their HIV knowledge, and interpretation of their own HIV test results is of great importance. The current study underscores the importance of post-diagnosis counseling and appropriate clinical follow-up after HIV testing occurs. If the test is completed outside of the clinical setting (e.g., testing at a non-profit community facility), individuals who doubt their test results should be encouraged to seek clinical consultation to obtain confirmatory testing. Failure to address these sorts of doubts or distrust of test results could lead to decisions to delay HIV care.

Participants' experiences reported here also shed light on areas of concern with regard to Internet use by those who are newly HIV diagnosed. Two participants described receiving their HIV test results through a website patient portal available to them prior to consultation with a provider. As the option for access to online medical records becomes more common, clinicians must develop comprehensive policies regarding how sensitive or distressing information should be released to patients. Clinicians would benefit from the development of protocols that specify how and when information is released (e.g., in-person, by phone, online) taking patient-centered preferences into account. Another issue that arose was the potential patient consequences of outdated websites and web resources. Outdated online information can mislead PLHIV's understanding of their disease and may influence decisions to delay care.

Healthcare systems should maximize the use of the Internet to provide up-to-date and accurate information about their facilities and providers, as the data from this study suggest that individuals may make care decisions based on information they obtain online. Participants shared that when they learned information online about HIV, particularly disease progression biomarkers, that they compared their own results to online information as baselines. Regardless of the accuracy of their interpretations, individuals who observe that they have biomarkers that are different, particularly lower or higher than normal range values found in their online research may experience unnecessary distress. Conversely, participants who see that their biomarkers are within a normal range may lack a sense of urgency regarding care initiation and when to connect with a healthcare provider. Clinicians should continue to provide critical patient education regarding HIV illness, but also should

leverage and provide guidance toward credible HIV Internet resources deemed reliable, safe, and understandable. While it is certainly possible that an individual will encounter misinformation online, there are reliable, evidence-based resources that clinicians can direct patients to in the event that the patient wants to seek additional HIV information online which our data and prior research suggests can empower patients (Brashers et al., 1999).

Another common finding in the data was the influence that the Internet had on treatment-specific decisions. Recent literature has indicated that web-based resources geared toward medical treatment options are considered both important and useful to PLHIV (Coursaris & Liu, 2009; Courtenay-Quirk et al., 2010; Mo & Coulson, 2010; Rice et al., 2010; Walsh et al., 2012). Participants in the present study reported using both information-based websites and social media to learn technical information about medicines (e.g., side effects), and to read about other peoples' personal experiences with specific treatments. Clinicians should actively seek out opportunities to answer patient questions about specific treatments, and also provide patients with direction toward useful and reliable web-based resources (Horvath et al., 2009).

Future Directions

The findings reported in this study suggest many avenues for future research. Online searches were initiated to find explanations of symptoms, and to try to eliminate a variety of potential causes for their symptoms, before self-determining that HIV may be the cause. Researchers should partner with PLHIV to explore further the psychological processes that individuals use to seek out symptom-specific information online prior to diagnosis, and use to determine what factors ultimately lead to a decision to be tested for HIV. Since participants reached a wide range of conclusions based on their Internet searches, future research should evaluate the impact of health literacy and e-Health literacy on the interpretations of information obtained online.

Participants also shared that the Internet often was used to collect information about HIV treatment locations and about HIV providers. Future research should examine specific attributes of facility-specific web resources that are most useful to individuals initiating HIV care, and determine what information about providers is useful and important to individuals preparing to seek care. Future research also should evaluate the quality of web-based resources regarding medication, side effects, and develop web-based interventions aimed at educating PLHIV about treatment options.

Finally, participants reported that they felt encouraged when reading the experiences of individuals who were successfully engaged in treatment. Such individuals shared about their experiences initiating care and starting treatment, and included valuable feedback that participants expressed a desire to learn. Researchers can partner with clinicians and patients in the creative development of evidence-based, patient-centered web resources at the microsystem level (e.g., information portal on the institution's website). PLHIV should be instrumental in the development of such resources in order gain crucial insight and to impact this target population.

Limitations

The study sample included a demographically high-risk group (MSM), but had limited representation of women and racial/ethnic minorities. As such, we could make few comparisons between the groups in the study. Few studies examining Internet use have focused on women and minorities (Coursaris & Liu, 2009; Walsh et al., 2012). Future research into Internet use by PLHIV who are initiating care should seek greater diversity from underrepresented groups in the HIV population. Further research also is needed to gain a greater understanding of the impact of limited Internet access, limited health literacy, and the wide range of interpretations of HIV information available online. We encourage researchers to take up this call.

Conclusion

PLHIV encounter many challenges following diagnosis. The Internet is a means of gaining information and empowering people diagnosed with HIV in the care initiation process. In addition, care and treatment-related decisions following diagnosis may be influenced by information discovered online. Clinicians and researchers should capitalize on every opportunity to use this powerful resource to provide education, direction, and support to PLHIV.

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Table 1

Demographic and HIV-Specific Characteristics of Internet Sample (n=23)

Characteristic	N (%)
Demographic Characteristics	
Age:	(Range)18–51
18–24	8 (35%)
25–34	11 (48%)
35–44	3 (13%)
45–54	1 (4%)
Gender	
Male	21 (91%)
Female	2 (9%)
Race	
African American	5 (22%)
White	14 (61%)
Native American	1 (4%)
Hispanic/Latino	2 (9%)
Multiracial	1 (4%)
HIV-Specific Characteristics	
HIV Exposure Category	
MSM	18 (78%)
Heterosexual Contact	4 (17%)
Injection Drug Use	1 (4%)
Time Since Diagnosis N (%)	
<30 days	6 (26%)
1–3 months	13 (57%)
4–6 months	1 (4%)
7–12 months	2 (9%)
>12 months	1 (4%)