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Living with HIV: Views through the Blog

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

by

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## Acknowledgment

Many people encouraged me along this journey and there are too many to name individually. I especially want to acknowledge Yvonne and Gregg, who listened daily, comforted me in times of stress and cheered with me in times of success. Each of them heard and read some passages many times. Gregg responded with amazing speed to cries for help when my computer was not working and spent many hours explaining the Internet and World Wide Web to me. I could not have completed this amazing journey without each of you at my side. My family provided love and constant support throughout this process. It was my family that first taught me to value education and I know my mother and other family members are quite proud to tell their friends that I have completed this portion of my educational journey. I am grateful to my colleagues at UVa, especially Dr. Cathy L. Campbell who kept me grounded and moving forward. I am also appreciative of the support I received from my peers and the patient guidance provided by my faculty here at VCU. I am grateful to my committee: Dr. JoLynne Robins, Dr. Nancy McCain, and Dr. Daniel Nixon. Finally, I want to thank Dr. Patty Gray for her guidance with this study.

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## Abstract

### LIVING WITH HIV: VIEWS THROUGH THE BLOG

By Linda A. Eastham, MSN

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2011.

Major Director: D. Patricia Gray, Ph.D., RN, Professor, School of Nursing

The purpose of this qualitative descriptive study was to develop a greater clarity of how HIV infected individuals live and work within the sphere of HIV infection as represented through unsolicited, personal narratives posted on blogs. Existing, single author, personal blogs were identified via a search engine. Blogs were defined as the blog author's postings and all responses, whether written by the blog author or a reader respondent. Inclusion and exclusion criteria were developed to respect indicators of bloggers' intentions for privacy, e.g., blogs which required a password were excluded. A total of 14 blogs met inclusion criteria. Actions to promote validity focused on the areas of credibility, authenticity, criticality, and integrity.

Throughout the blogs, online social connectedness formed the context for expression of the four themes identified to describe the experiences of the bloggers and their readers living with HIV infection. *Suffering* was the human experience of stigma related to living with HIV infection. This was primarily manifested in either self-imposed isolation or isolation resulting from rejection by others. *Relationships* addressed both the online and offline/in-person interactions experienced by the blog authors and their readers. These stories were predominantly

about receiving support from persons via online interactions. *Daily living with HIV dialogue* addressed the common experiences shared by various bloggers and their readers such as longing for normalcy. *A call to action* addressed a self-embraced sense of mission or purpose which was a contributing impetus to blog. Blog readers affirmed these missions in their responses. While these themes have been documented in prior qualitative research on living with HIV infection, the opportunities for online social connectedness altered the expression of these themes. Further research using unsolicited narrative blogs is warranted.



## Chapter 1: Introduction

More than one million adults and adolescents live with HIV infection in the U.S. today (CDC, 2008). Long term survivors have lived with the disease for over two decades and people infected at birth are now coming of age as young adults. Indeed, Healthy People 2020 recognizes the significance of HIV disease as a priority area (Federal Interagency Workgroup, 2011). Multiple prior studies of living with HIV infection have revealed the commonality of HIV-infected persons' experiences of isolation, whether due to actual or feared stigmatizing behaviors by others. Moreover, prior studies have documented the criticality of positive relationships with others to successful treatment adherence (Alfonso, Geller, Bermbach, Drummond, & Montaner, 2006; Remien & Mellins, 2007; Rajabiun et al, 2007).

Yet even as these prior studies were published, the Internet was evolving, yielding a greater prominence in people's everyday lives. Initially used only by those with computer programming skills, the social nature of the Internet exploded into every person's reality with the development of sites allowing anyone with Internet access to communicate from the privacy of their computer. This technology resulted in the formation of various types of virtual communities, each offering another avenue to establish human connectedness.

The purpose of this qualitative descriptive study was to develop a greater clarity of how HIV infected individuals represent living and working within the sphere of HIV infection through unsolicited personal narratives posted on public blogs. Experiences of living with HIV infection as shared in existing single author personal blogs posted in public sites were analyzed via conventional content analysis. Fourteen blogs met inclusion criteria; blogs were defined as

the individual entries and all comments for each entry. On-line blogging communities ameliorated the effects of stigma and isolation, facilitated activism, and generally offered an expanded sense of human connectedness.

Published qualitative studies examining illness experiences via unsolicited narratives in the form of public blogs are not common. Chapter 2 is a published article that addressed human subjects protection when using this novel methodology. Chapter 2 was published in *Research in Nursing & Health* earlier this year. Chapter 3 is the research study report and is ready for submission to a peer-reviewed nursing research journal. References for each chapter are included with the respective manuscripts.

# Research Using Blogs for Data: Public Documents or Private Musings?

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Accepted 28 April 2011

**Abstract:** Nursing and other health sciences researchers increasingly find blogs to be valuable sources of information for investigating illness and other human health experiences. When researchers use blogs as their exclusive data source, they must discern the public/private aspects inherent in the nature of blogs in order to plan for appropriate protection of the bloggers' identities. Approaches to the protection of human subjects are poorly addressed when the human subject is a blogger and the blog is used as an exclusive source of data. Researchers may be assisted to protect human subjects via a decisional framework for assessing a blog author's intended position on the public/private continuum. © 2011 Wiley Periodicals, Inc. Res Nurs Health 34:353–361, 2011

**Keywords:** blogs; internet research; illness experiences; human subjects protection

Over the past 15 years U.S. adults have consistently and impressively increased their Internet use (Rainie, 2010). Researchers now have access to textual and audiovisual digital data from these Internet sources. One type of Internet source, personal blogs, offers insights into everyday living experiences including illness experiences. Advantages of using blogs as a single source of data include decreased research costs and a wider geographic catchment area. The extensive catchment area offers researchers the ability to access greater numbers of individuals with specified health problems than would be possible in an off-line study with geographic constraints on recruitment and sampling. Although these advantages might encourage the researcher to consider using blogs as a single source of data, the public and private nature of blog content will affect research design with regard to protection of human

subjects, informed consent, and bloggers' rights to privacy.

Blogs are simultaneously private and yet quite public (Huffington Post, 2008). The private nature is reflected in the "intimate, often ferocious expression of the blogger's passions" (Huffington Post, 2008, p. 6), whereas the public nature is inherent in the very fact that anyone with Internet availability can access and read those intimate expressions. This public/private contradiction challenges the researcher to design studies with blog data that contain appropriate protections for human subjects. My purpose in this article is to provide researchers and those serving on human subjects review committees with a framework for assessing the blogger's intentions regarding privacy when blogs are used as the only data source.

Blogs are unsolicited narratives that offer a naturalistic entrée into the illness experience

The author would like to thank D. Patricia Gray, PhD, RN for recommending my journey into research using blogs and Gregory M. Kelley for his Internet expertise.

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Published online 27 May 2011 in Wiley Online Library  
(wileyonlinelibrary.com). DOI: 10.1002/nur.20443

unconstrained by time. Entries and responses might provide insight into advice shared among persons with the same illness but with varied experiences. When viewed as the voice of the author, blogs have the potential to clarify previously misunderstood perceptions of treatments, the impact of patient-provider interactions, and of living with potentially stigmatizing illnesses. For example, in a recent study using blogs as a single data source, Clarke and van Amerom (2008) delineated gender differences in the experience of depression. McCosker (2008) featured three powerful illness blogs wherein each author's illness journey was traced in his or her blog posts to recovery or demise. Blogs allow the option for an author to write under cover of a pseudonym and without the necessity of a personal encounter. The unsolicited narrative data from blogs is free from the influence of the research process itself, such as responses given to please the interviewer (Jones & Alony, 2008). As a result of the anonymity afforded by the pseudonym and lack of face-to-face encounter, authors may share feelings and experiences more openly than in a face-to-face interview. Winer (2003) stated that a blog is the "unedited voice of a single person." Researchers may have concerns regarding the veracity of anonymous and unsolicited narratives, but discussion of that concern is beyond the scope of this article.

### **Assessing the Public/Private Nature of Blogs**

When using blogs as the only data source, attention to elements in four domains will guide researchers to assess the public or private nature of the blog including: (a) blog attributes, (b) privacy attributes, (c) interaction influences, and (d) the U.S. Department of Health & Human Services (USDHHS) regulations concerning human subjects protections (2004) and USDHHS Code of Federal Regulations (2009) definitions of privacy.

#### **Blog Attributes**

Although exact definitions vary, blogs are generally viewed as having the following attributes: (a) posts organized in reverse chronological order, (b) readers are able to respond, (c) links to other sites are provided, and (d) some author information usually

accessible via a side-bar (Hookway, 2008; Rettberg, 2008). The majority of blogs have textual entries or posts, but videos, pictures of the blogger, or other images used to represent the blogger may also be part of the entry. Links to other blogs and comments from readers provide communication as well as documentation of the communication within the cyberspace social community.

There are various types of blogs, including corporate, professional, educational, team, and personal blogs. Personal blogs may offer descriptions of family outings, provide stories about the new dog, or serve as a lens through which to watch a baby grow up via posted pictures or video clips. A personal blog may be related to a specific topic of interest such as photography or living with a specific chronic illness. Personal blogs may be of greatest interest to nurse and other researchers interested in exploring health and illness. A cursory browsing expedition of the Internet reveals various personal chronic illness blogs on such illness topics as HIV/AIDS, breast cancer, fibromyalgia, arthritis, depression, inflammatory bowel disease, and living with an ostomy.

Although there are various types and appearances of blogs, blogs as a group are distinct from other Internet social applications. Understanding the differences between blogs and other social applications is important to researchers when evaluating data sources to determine methods of collection. The significance of these differences is illustrated in Zimmer's (2010) analysis of privacy violation that occurred in a study in which data from Facebook were used. Although hundreds of diverse types of social applications exist such as Facebook, chat rooms, Myspace, Yelp, Twitter, and You Tube, in this article, I compare blogs with two of the most commonly recognized social applications, Facebook and chat rooms.

Social networking sites (SNSs) provide mechanisms for registered members to search for and communicate with other registered members within that site. SNSs offer the ability to post or upload entries as do blogs. SNSs, however, have much greater communication potential than blogs, which are purely asynchronous applications. For example, people can "friend" someone on Facebook to read their "friend's" page, share their own page, send private messages, view photo albums, or even "poke" someone who hasn't been on Facebook or communicated recently. For those new to Facebook, finding someone else's posts showing

on your own page can be confusing. This is similar to technology known as Really Simple Syndication (RSS) feed, which allows a specific web page's readers to subscribe to or "pull" information from that web page when it indicates new updates are available (Rettberg, 2008). The difference between the RSS feed offered by a blog and the news feed on a SNS page is that anyone may subscribe to the RSS feed offered by the blog author, but SNSs require the individuals to be "friends" before the news feed can be activated. Additionally, many SNSs have a function that allows an individual to note when or if friends are on-line. Via this function, private conversations may occur in a synchronous mode. Synchronous activities are not part of the blog function.

Blogs and chat rooms are similar in that each offers researchers the ability either to participate in or to observe textual conversations. Blogs and chat rooms may both be found via search engines but are different in terms of access and communication. Some blog sites require readers to sign-in or register; other blogs may be read simply by clicking the link provided by the search engine. When accessing a chat room, however, individuals are required to sign in with a user name. Registering with a user name and possibly providing other information is required to participate in a chat room, whether that participation is as a lurker observing conversations or as a participant engaging in conversations with others in the chat room. Although blogs are primarily writings of the blog author (blogger), dialogue may develop between the blog author and the readers who choose to post, provided the blog author has set the parameters to allow readers to post. Blog dialogue is asynchronous, archived, and retrievable; chat room conversations are real-time synchronous textual conversations occurring between people. Although the text of the chat may be archived on the participants' computers and some chats may be archived by Internet Service Providers and Employers, the archived texts are not easy to obtain and are not considered to be public. Within larger chat rooms, private chats may occur between individuals who restrict comments to one another for a private conversation. The passive onlooker or lurker and others within the larger chat room would not be aware of or see the conversation. Thus, the archived conversation would be accessible only to those chatting and not to those others in the larger chat rooms, which is in contrast to blogs that are archived publicly and are retrievable by

anyone. The ability for anyone to retrieve the blog monologue/dialogue contributes to its public nature.

### Privacy and Bloggers

According to Altman (1975) privacy is a dynamic, dialectic process changing over time and across conditions. Individuals experience shifting needs to be alone or in contact with others at different times or in different circumstances. Altman did not visualize public/private as an "all or none" phenomenon, but rather a balancing of competing needs. Gal (2002) agreed with Altman that *private* and *public* are not a dichotomous, but rather a discursive phenomenon. She viewed private and public as negotiated concepts found within narrower and broader contexts. As the context changes, the concepts are redefined. Gal used the analogy of a house being private when viewed from the street, yet within the house, some rooms such as the kitchen or living room are more public when compared with other rooms such as the bedroom or bathroom. Privacy as a discursive process may be more difficult to recognize in on-line situations than in off-line situations. In off-line situations, a closed door indicates that one should knock to request entrance into a more private area. Likewise, seeing two people in a quiet conversation away from other guests at a social gathering indicates their desire for a private conversation within the public setting. In the on-line situation, researchers can find similar clues regarding a blogger's intended public or private writing.

Clues regarding bloggers' intentions come from knowing why bloggers blog, from the choices bloggers make in setting up their blogs, and from research addressing bloggers' perceptions of the privacy of their work. In three surveys of bloggers (Jones & Alony, 2008; Lenhart & Fox, 2006; Nardi, Schiano, Gumbrecht, & Swartz, 2004), a commonly cited reason for blogging was to document or share personal life experiences with others. In the Pew Internet & American Life Project survey (Lenhart & Fox, 2006) completed between July 2005 and February 2006, other reasons for blogging included (in descending order): to stay in touch with friends and family, to share practical knowledge, to motivate others, to entertain, to influence others, and to meet new people. Nearly 90% of bloggers allowed comments on their blogs. Although RSS feeds were not common at

that time, nearly 20% offered an RSS feed on their blogs. A little more than half of bloggers used a pseudonym (Lenhart & Fox, 2006).

Nardi et al. (2004) documented four additional major reasons for blogging including: “providing commentary and opinion; expressing deeply felt emotions; articulating ideas through writing; and forming and maintaining community forums” (Nardi et al., p. 43). Jones and Alony (2008) documented the need for social contact within both existing and new relationships. They identified additional blogging purposes including the need for self-expression, recognition, introspection, academic pursuit of knowledge, and artistic activity (Jones & Alony).

Many of these reasons for blogging (e.g., to share knowledge, motivate, entertain) require a public venue. A blogger cannot seek recognition or develop new relationships without a public from which to seek that recognition or with which to develop the new relationships. If the blog were only available to those persons the blog author already knew, there would be no recognition or relationships beyond those that already existed. This does not mean, though, that blog authors necessarily reveal their names or other identifying information. New relationships may develop between individuals using aliases or pseudonyms.

### **Bloggers’ Privacy Choices**

Indeed, to manage the paradox of personal intimacy in a publicly available location, blog authors may choose to use a pseudonym and thereby retain some level of anonymity. Although some blog authors might choose to use a particular pseudonym only for authorship of their own blogs, other authors might use that pseudonym consistently throughout all social activity on the web and thereby make that pseudonym their identity (Bruckman, 2002). An off-line analogy to this choice would be the use of a pen name as in the well-known case of Mark Twain/Samuel Clemens.

Blog authors might choose also to use an avatar: an actual picture of the author, graphic representation, or other picture to represent themselves. Using an avatar is like attending a masquerade party; others do not know who the person behind the mask is, but the costume and mask are recognizable throughout the evening as the same individual. A certain amount of personal privacy is upheld, yet the alternate image and identity become public.

Blog authors might further choose to limit readers and contributors to preselected individuals in an attempt to control their privacy. A blog created using these parameters might not be indexed and thus will not be located by a search engine. If researchers discover the blog despite its inaccessibility to search engines, then a password or registration might be required to read the blog. Such a requirement implies that the blogger desires privacy. Off-line, this could be analogous to keeping one’s diary in a private location, but choosing to share diary contents with specific individuals.

Another option for controlling a certain degree of privacy is for the blog author to allow any reader to open the blog, but deny those readers access to post any comments. This type of blog would be indexed and archived so the researcher would be able to find it via a search engine. The researcher would not need to register or provide a password to read the blog; there would be posts by the blog author, but no comments from readers. An off-line corollary would be keeping one’s diary at a publicly available location such as a library for anyone to read, but with no option for the reader to speak or respond to the writer of the diary.

Yet another privacy option for the blog author is to open the blog to any readers and to allow contributions from any readers. In most instances, readers may add entries on an individual’s personal blog to interact or converse asynchronously with the blog author or another contributor (Gaiser & Schreiner, 2009). In this situation, the researcher would find the blog via a search engine and be able to read the blog posts and responses without using a password or site registration. This is analogous to the off-line concept of newspaper editorials and letters to the editor. The selection of one or more of these privacy-settings indicates to the researcher the blogger’s privacy intentions for the blog content.

Finally, to establish privacy, a blog author may “remove” a blog from the Internet, although that blog may still be retrievable through web cache. Web cache is a temporarily stored version of the web page or parts of the web page that enables the web browser to connect the user to the blog web page link faster than if the page or components were not in cache. Because web cache is only temporary storage, it is possible that both a current and a prior version of a blog may be available. If a blog in current form is retrievable, an earlier version of that blog may also be



retrievable from cache. If a blog has been publicly available but is later removed, only the earlier, cached version will be available to the search engine. The question for the researcher then becomes: is that blog still in the public domain? The blog was initially posted in the public domain and continues to be indexed and archived or it would not have been found by the search engine. Yet because the only version of the web page is the cached version, the researcher may infer that the blogger's intention was to withdraw the page from public domain.

### **Bloggers' Perceptions of Blog Privacy**

Viégas (2005) explored 492 bloggers' perceptions of the public versus private nature of their work via an online survey. A majority of the responding blog authors acknowledged posting personal thoughts and giving consideration to whether some content may perhaps be too personal to post. About one-third of the respondents acknowledged experiencing trouble due to postings. Identified trouble ranged from more severely negative experiences such as loss of job to less severely negative experiences such as interpersonal difficulty with friends and family members named in blog entries. The surveyed bloggers believed the ability to control access to their blogs was important. One blogger had a private blog, protected by password or registration, but chose to blog in a public forum as well.

To summarize, private and public are not dichotomous states; rather, they exist in varying degrees along a continuum. Altman (1975) and Gal (2002) each identified privacy not as a static state of being, but as a dynamic and discursive process. Bloggers make conscious privacy choices that researchers then must discern and respect. The blog that is identified via a search engine and that is open to responses from others is clearly a public blog. The public nature of blogs is less evident in blogs that have been removed from the public domain (but that may remain available via web cache), blogs that require passwords to access, and blogs that restrict reader responses.

### **Interaction and the Public/Private Nature of Blogs**

According to *Cambridge Dictionaries Online* (2011), to interact is "to communicate with or react to" and *Oxford Dictionaries* (2011) stated that to interact is to "act in such a way as

to have an effect on each other." Within the context of research, direct involvement of researchers and study participants occurs via some form of communication (e.g., an intervention, a survey, or an interview). In general, participants freely agree to the designated research project interaction but are assured of identity protection through the informed consent procedure. When researching on-line, the researcher must determine if there is direct involvement or communication between the researcher and the participant(s). Surveys and interviews are obviously interactive, whether accomplished off-line or on-line, and informed consent is self-evident. Researching via other on-line applications may offer less clarity regarding interaction and therefore requires some understanding of computer-mediated communication (CMC).

CMC is either synchronous or asynchronous. Synchronous CMC is used in chat rooms and may be used in SNSs. Synchronous CMC allows a textual conversation to occur between two or more people in real time. An example is a private conversation between two or more people within a larger chat room context. This conversation is not visible to any others in the chat room and is not indexed or archived for search engine accessibility, although participants may archive their conversations on personal computers. For these reasons, synchronous CMC is generally associated with a greater expectation of privacy than asynchronous CMC.

Asynchronous CMC is generally not associated with privacy per se because this type of communication may be indexed and archived and thus be available for search engines. Yet, some asynchronous CMC is associated with privacy. E-mail is a form of asynchronous CMC that is usually protected from search engines and public access. Wikis, such as Wikipedia, are another type of application that uses asynchronous CMC and can be indexed and archived. Blogs are a form of asynchronous CMC that is commonly indexed and available for search engines if the blog author so chooses via the blog content management system (BCMS) privacy settings. Because blogs can be publicly accessed by search engines, blog posts invite conversations within public view or in a public "commons" (Quiggin, 2006). Posting a response to a blog post or comment is a form of interaction through asynchronous CMC. Merely reading a blog post offers no form of interaction between blogger and reader. The blogger has no ability to determine who is reading the blog

other than through written or verbal conversation with the reader. Lack of interaction meets one criterion for defining the public nature of the blog as defined by the USDHHS Code of Federal Regulations (2009).

### Human Subjects Definitions and Regulations, and Blogger Privacy

The definitions of *human subject* and *minimal risk* are particularly important to the researcher using blogs as a single data source. A human subject is defined as “a living individual about whom an investigator (whether professional or student) conducting research obtains data through intervention or interaction with the individual or identifiable private information” (USDHHS Code of Federal Regulations, 2009, p. 4). The juncture of human subjects and blogs as data source forces the researcher to assess the existence of an intervention or interaction with the blog author as well as whether the blog content is reasonably viewed as identifiable private information. Downloading, reading, and analyzing a blog does not serve as an intervention or an interaction with the blog author because there is no direct involvement or communication between the researcher and the blogger. Kitchin (2007, p. 15) referred to this type of research activity as “nonintrusive” and defined such nonintrusive activities as those that “do not interrupt the naturally occurring state of the site or cybercommunity, or interfere with premanufactured text.” She noted that a research subject is “produced” (p. 53) by contacting a person directly.

Continuing with the USDHHS definition of human subjects, the second and discrete component of defining a human subject is identifiable private information. Private information is “individually identifiable (i.e., the identity of the subject is or may readily be ascertained by the investigator or associated with the information; USDHHS Code of Federal Regulations, 2009, p. 4)”. In the off-line setting, human subjects are recruited through flyers and other advertising venues. Potential participants can then seek out the researcher or team member to discuss the study particulars and sign an informed consent indicating they understand the risk involved in study participation. Because there is clearly interaction in these off-line situations, researchers may determine the given identity of the subject. Thus, informed consent also identifies the researcher’s plan to avoid

undesired disclosure of participants’ private information. In a study in which data include both blogs and interactive data (e.g., interview) from those participants, the blog author participants may choose to negotiate citation of quotations from their blogs by name and URL, as would be done with quotations from any other published document. In a study in which blogs are used as the single source of data, the researcher must determine whether quotations from blogs reveal the identity of the blog author and whether the answer to this question changes if the blog author is writing under a pseudonym. Because a pseudonym may serve as an identity throughout the on-line arena, it is possible that the blogger’s identity may be revealed through use of direct quotations. The researcher can prevent or minimize the risk of identifying the blog author by avoiding direct quotations or using other disguises as noted below.

According to the USDHHS Code of Federal Regulations (2009, p. 4), minimal risk is defined as “the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.” In this instance, the risk to the blogger is to be identified via an Internet search engine seeking the direct quotation. Viégas (2005) delineated risks of blogging as significant as job loss and as minimal as the mild displeasure of family or friends. Although, Viégas was describing harm from content in blog postings, rather than harm for participating in research, the outcomes may be the same. Although the risk of having one’s blog discovered due to reading a quotation in a research report may be minimal, the possibility for more severe risk clearly exists. The researcher can minimize the risk by paraphrasing rather than using direct quotations, avoiding identification of the specific BCMS (e.g., Blogger.com) and implementing one of the three levels of disguise Bruckman (2002) identified including changing names, changing pseudonyms, and omitting proper names of cities, schools, or businesses that might identify the blog author.

### Discussion and Implications for Ethical Research

Informed by a clear understanding of the nature and characteristics of blogs, researchers who



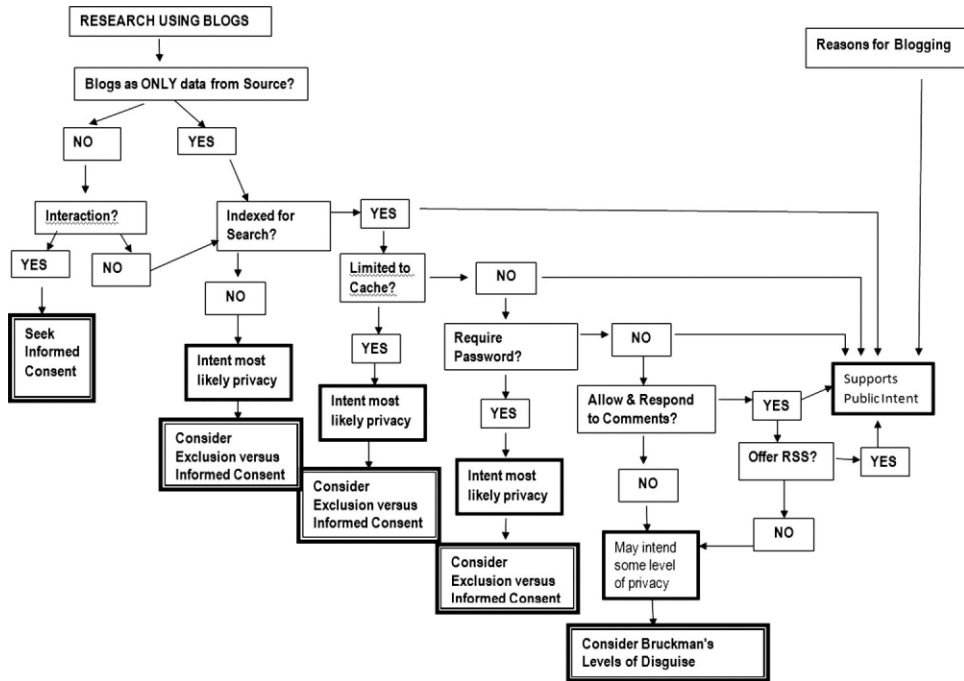


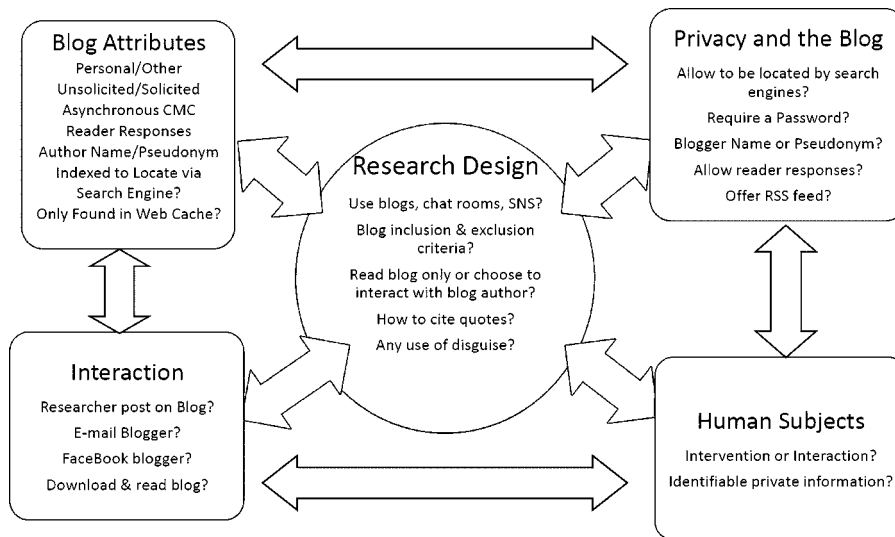
FIGURE 1. Essential elements and blog research design questions.

plan to use blogs as a single data source should consider the elements of privacy, interaction, and human subjects in their study designs to develop blog inclusion and exclusion criteria as illustrated in Figure 1. Understanding the role of interaction within the defining characteristics of human subjects clarifies the initial concern for informed consent. Yet, if blog researchers were to move forward with the research design based solely on the USDHHS criteria (2004), the process of negotiating privacy would be omitted. Researchers participate in this negotiation of privacy by observing the subtle distinctions inherent in the blog authors' choices when setting up their blogs. Subtle distinctions such as passwords or RSS feed provide clues for assessing the blogger's intentions regarding privacy. Researchers continue privacy negotiation by responding to those clues when making research design choices of blog selection and exclusion as well as the use of disguise when citing quotations.

Researchers must have an understanding of the characteristics of blogs to be included in the study. Requiring a password to access a blog, even a blog found on a BCMS that states the blogs are public, provides a clue to the researcher that the blogger may have an expectation of some level of privacy. Researchers

may choose to obtain informed consent, or use Bruckman's (2002) highest level of disguise, or simply exclude such blogs from their studies. Conversely, selecting a blog that is indexed and thus available to search engines, that does not require a password, and offers RSS feed strongly suggests a blog author's intention that the blog be considered public. The blogger's public intentions would obviate the need for informed consent, but the researcher may still consider some minimal level of disguise due to the potential for risk to the blog author if the blog were to be identified through direct quotations.

A blog author's use of a pseudonym does not by itself delineate privacy intentions. For example, an author writing under a pseudonym may allow the blog to be indexed for a search engine, offer readers RSS feed, provide the option for reader comments and forego a password requirement. These combined blogger choices would seem to imply a public blog, because the majority of privacy choices support that concept. Alternatively, another author writing under a pseudonym may also allow the blog to be indexed for a search engine, but instead require a password and not offer RSS feed. These alternate choices would suggest a blog author's intention for some level of



**FIGURE 2.** Decision tree: assessment of bloggers' privacy intentions.

privacy, despite the fact that the blog is indexed for search engine availability.

Researchers should note whether the blog exists only in cache. If so, the implication for intended privacy prevails, even though the web page may still actually remain in the public domain as evidenced by its availability to the search engine. Researchers may give consideration to excluding such blogs in response to the subtle hint of the blogger's desired level of privacy. Allowing readers to comment on a blog also hints at its intended public nature. Researchers should consider all attributes of the blog to assess the blogger's privacy intentions as summarized in Figure 2.

### Conclusion

U.S. adults have demonstrated a steady increase in blogging practice over the past decade. This persistent interest in blogging is evident in the marked increase in popular literature devoted to best practices for blogging, the increased numbers of blogs found on the Internet, and researchers' growing interest in textual and audiovisual digital data from these Internet mediated sources. Blogs offer an alternative avenue to examine illness experiences. When research designs include blogs in addition to interview or survey data from those blog authors, the need for informed consent is self-evident. However, when the research design uses blog data as the only data from a particular

source, ethical clarity blurs. The public/private tension inherent in blogging presents a challenge to the researcher to design studies with appropriate privacy protections. Combining knowledge of blogs with an assessment of the blogger's intended privacy level, researchers will be better able to design studies that entail minimal risk to blog authors.

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Blogging HIV: Anonymous Familiarity

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December 5, 2011

## Abstract

The purpose of this qualitative descriptive study was to develop a greater clarity of how HIV infected individuals represent living and working within the sphere of HIV infection through unsolicited personal narratives posted on public blogs. Experiences of living with HIV infection as shared in existing single author personal blogs posted in public sites were analyzed via conventional content analysis. Fourteen blogs met inclusion criteria; blogs were defined as the individual entries and all comments for each entry. Online blogging communities ameliorated the effects of stigma and isolation, facilitated activism, and generally offered an expanded sense of human connectedness. Blogging provided persons with HIV infection a sense of community in which support and guidance were both given and received without fear of stigma or rejection. Patients with HIV infection may benefit from HIV blog communities. Further research using unsolicited narrative blogs is warranted.

## **Blogging HIV: Anonymous Familiarity**

This year, 2011, marks the 30 year anniversary of the United States (U.S.) HIV epidemic. Prevalence continues to increase with approximately 1.1 million infected persons living in the U.S. (CDC, 2008). Long term survivors have lived with the disease for over two decades and people infected at birth are now adults.

Adults in the U.S. are also increasingly using the Internet to connect with others. Indeed, one national survey found that 74% of adults in America are using the Internet (Rainie, 2010) while another survey reported that about half of Internet users ages 50 to 64 are using social networking sites (Madden, 2010). A Pew Research Center survey found that eight out of ten adult Internet users have examined online sites for health information (Fox & Jones, 2009). They reported that "technology can help to enable the human connection in healthcare and the Internet is turning up the information network's volume" (Fox & Jones, 2009, pp. 11-12). Hawn (2009) provided specific illustrations demonstrating how various new social media tools such as blogs redesign patient interactions with providers and others.

The purpose of this qualitative descriptive study was to develop a greater clarity of how HIV infected individuals represent living and working within the sphere of HIV infection through personal narratives posted on public blogs. Typically employing face-to-face or group interviews, other researchers have obtained and analyzed stories of HIV-infected individuals' challenges, triumphs, and fears (Mallinson et al, 2005; Ware, Wyatt, & Tugenberg, 2006; Wrubel, Stumbo, & Johnson, 2008; Konkle-Parker, Erlen, & Dubbert, 2008; Buseh & Stevens, 2007; Emler, 2008; Polzer Casarez & Miles, 2008). What sets this study apart is the absence of the interviewer as mediator and the presence of a longitudinal perspective gained by the use of blogs as the primary data source. A secondary purpose was to document issues in accessing and

using blogs as a source of research data. This paper will focus on the experiences of living with HIV infection as revealed in public personal blogs.

## **Background**

This study is founded on the intersection of a modern day epidemic and the evolution of the Internet in daily living. In our society, we have been learning to live with HIV and with the Internet for about the same period of time. Blogs are the specific Internet-based applications used in this study; they reflect the social nature of the Internet that has evolved over the past decade. Background information is therefore provided regarding the significance of HIV, relevant prior research about living with HIV, and the concepts of blogs and blogging within the context of research. Additional background regarding blogs and privacy can be found elsewhere (Eastham, 2011).

### **Significance of HIV infection in the U.S.**

HIV infection is a priority area for Healthy People 2020 (<http://www.healthypeople.gov>). Approximately 1.1 million US adults and adolescents live with HIV while about 50,000 new infections occur per year, having remained stable from 2006 through 2009 (Prejean et al, 2011). The effectiveness of HIV therapy has diminished the progression of HIV to the advanced stage of AIDS for those in treatment. Consequently, prevalence continues to climb, while incidence overall has generally leveled (Moore, 2011; CDC, 2010). HIV infection occurs in all ages, races, and genders. According to the CDC, rates of both newly diagnosed HIV infection and AIDS in persons ages 15-24 increased between 2006 and 2009 (CDC, 2009, pp.6-7). Rates of HIV infection also increased in persons aged 55-59, though rates of AIDS remained stable in this age group. Overall, the numbers of persons age 50 and older diagnosed with HIV infection increased by 17% in the past decade (Moore, 2011). HIV and AIDS continue to disproportionately burden

people of color. In the U.S. population, blacks account for about 12% of the population, yet represent nearly half of all persons living with HIV (CDC, 2010). Women comprise approximately 27 % of those with newly diagnosed HIV infections and black women account for about 15 times more of those new infections than white women.

### **Prior Studies of Living with HIV**

Researchers have explored various aspects of living with HIV over the three decades of the US epidemic. Chu and Selwyn (2011) labeled these decades in order as the Opportunistic Era, the Antiretroviral Era and the Chronic Disease Era. Many studies examining these experiences from an emic perspective were completed in the first half of the 1990's or the early Antiretroviral Era. While a review and synthesis of all studies investigating living with HIV infection or components of living with HIV infection is beyond the scope of this paper, a review of relevant studies is presented.

In a metasynthesis of qualitative studies focused on persons living with HIV infection published from 1990 to 1995, Barroso and Powell-Cope (2000) distilled 6 overarching metaphors. These metaphors included: "a) finding meaning in HIV/AIDS, b) shattered meaning, c) human connectedness, d) focused on the self, e) negotiating health care, and f) dealing with stigma" (Barroso & Powell-Cope, 2000, p. 341). The most prominent metaphor in the metasynthesis was "finding meaning." In the studies examined by Barroso and Powell-Cope, participants found meaning in HIV/AIDS after accepting HIV as a terminal illness. Acceptance of the terminal diagnosis spurred the participants to reflect on and reevaluate their life priorities. Conversely, shattered meaning occurred when the participant felt an extreme loss and overwhelming fear (Barroso & Powell-Cope, 2000). Because these studies were completed and published prior to the implementation of highly active antiretroviral therapy (HAART), the



number of deaths due to HIV infection was significantly greater than in the following years (CDC, 2011). Currently in the US, HIV is no longer equated with a death sentence.

Barroso and Powell-Cope (2000) defined human connectedness as "the emotional support given and received and the sense of belonging that came from social interactions" (p.345). They identified two levels of human connectedness. The first level was a larger community and the second level was family and friends. The authors' examples of human connectedness also reflected experiences of rejection and stigma which then resulted in the formation of new relationships. They concluded that human connectedness served as a buffer to the myriad experiences of stigma described in the studies (Barroso & Powell-Cope, 2000).

More recent studies have addressed the relationship of human connection to sustained engagement in HIV care. Sustained engagement in HIV care is generally associated with better adherence to treatment regimen and thus to improved clinical outcomes. Mallinson and colleagues (2005) noted that, in addition to participants' social connectedness to family and friends, connectedness to HIV clinic staff and care providers was a critical prerequisite to attaining regular and persistent HIV primary care. Others found that social connections or positive relationships with family, friends, partners, or external groups were critical to HIV-infected individuals' ability to successfully adhere to treatment regimens (Alfonso, Geller, Bermbach, Drummond, & Montaner, 2006; Remien & Mellins, 2007; Rajabiun et al, 2007). Judith Wrubel and her team (2008) explored types of practical support offered by partners of people with HIV infection. They found three overarching types of practical support: reminding, hands-on helping, and coaching. Specific activities within this typology included reminding, monitoring medication, ordering, picking up, and organizing medications, and problem-solving (Wrubel et al, 2008).

Social connectedness is associated with better virological outcomes (Burgoyne, 2005). However, such connectedness requires some element of disclosure to elicit support for taking medications, keeping appointments, or other activities of living with HIV. When people desire social connection but have an even greater fear of disclosure, they make behavior choices which are not associated with better virological outcomes. Ware and colleagues (2006) revealed that participants' desires for social connections in combination with fears of rejection or anticipated stigma outweighed their needs for adherence. Participants in their study reported activities to avoid disclosure of HIV diagnosis such as seeking care in clinics far from their own neighborhoods, not being seen with medications, and not taking medications when others could observe. These activities facilitated both human connectedness and nondisclosure of an HIV diagnosis, but created barriers to adherence with regard to keeping appointments and taking medications as prescribed.

Stigma remains a significant challenge to those living with HIV infection, potentially necessitating strategic disclosure and inhibiting opportunities for social support (Buseh & Stevens, 2007). Moreover, the increasing incidence of criminalization of HIV transmission has the potential to persuade undiagnosed individuals to avoid HIV testing, hindering case finding, and perhaps being the most critical indicator of stigma (Cameron, Burris, & Clayton, 2008; Galletly & Pinkerton, 2006; Jurgens et al, 2009). Additionally, HIV stigma may be layered with stigma related to other conditions such as substance abuse, welfare, sexual orientation, incarceration, and homelessness (Ware, Wyatt, & Tugenberg, 2006). The HIV Stigma Framework was developed to illustrate the processes in which stigma affects outcomes of those infected with as well as those not infected with, but directly affected by HIV (Earnshaw & Chaudoir, 2009). According to the Earnshaw and Chaudoir, stigma is manifest through a variety

of mechanisms but predominantly via negative emotional responses, group beliefs, and actions, i.e., prejudice, stereotypes, and discrimination. In their model, potential harmful outcomes related to stigma ranged from a simple choice to not disclose one's HIV diagnosis to social isolation, substance use, depression, or risky sexual behavior (Earnshaw & Chaudoir, 2009).

To summarize, HIV is a chronic illness that infects an increasing number of adults in the U.S. Previous studies of living with HIV have documented the significance of social connectedness with regard to successful personal management of HIV and other potential co-morbidities such as depression or substance use. Issues of disclosure and fear of disclosure have been explored, albeit only within an offline/in-person environment. Although studies have been done throughout the prior decade, no published studies viewing the experiences of living with HIV from the perspective of Internet social applications such as blogging have been published.

### **Blogs and Blogging in the Context of Research**

According to the Pew Internet and American Life Project, the number of adults in the US who kept a blog in 2005 and 2006 was about 12 million and about 57 million American adults read blogs (Lenhart & Fox, 2006). The surveyed bloggers reported their central focus for blogging was writing about their life experiences but additional reasons included sharing practical knowledge, motivating others, and documenting one's own experiences. The majority of adult bloggers were 30 years old or less and equally divided between genders. When examining the demographics of bloggers and the demographics of those infected with HIV, it becomes apparent that there is a large number of young adult persons within each group.

Blogs, a shortened version of the term web-logs, are also known as online journals or diaries (Grassley & Bartoletti, 2009). Specific attributes are associated with blogs: entries in reverse chronological order, options for reader responses, some information about the author,

and potentially links to other blogs or web sites (Hookway, 2008; Rettberg, 2008). Blogs usually have a title for the entire blog as well as titles for each individual post or entry. A posting or entry generally consists of a title, the content of the entry itself, and optional links (Winer, 2003). Reader responses then follow the post, also in reverse chronological order. Multiple sites on the Internet offer blog content management services that provide anyone with Internet access the ability to blog. Some sites offer only content management for blog authors, while others provide additional services. These latter sites are generally organized around a specific topic, (e.g., breast cancer or HIV) and may include informational services or news feed about the specified site topic.

While there are many types of blogs, personal blogs have the greatest potential to offer an emic view of illness experiences (Eastham, 2011). In these unsolicited narratives, people share their journeys, seek advice, and offer wisdom from their lived experiences. Rather than the cross-sectional perspectives offered by interviews or focus groups, blogs have the potential to provide a longitudinal perspective, documenting the blogger's illness journey over time. Illness stories may include reader-author or reader-reader conversations, albeit asynchronous textual conversation. Because the blog narrative is unsolicited, it remains free from bias of the research process (Jones & Alony, 2008).

Use of blogs as a primary source of data for the purposes of research is not without concern. Issues surrounding use of blogs primarily concern veracity and autonomy. Rosenberg (2009) described two types of bloggers: sincere and authentic. Sincere bloggers' posts are in harmony with their offline activities and opinions, i.e., there is continuity between the online and offline personae. In contrast, authentic bloggers use their posts as an outlet for their "true" self, a persona that is in contradiction to the repressed or artificial offline self (Rosenberg, 2009, p.

258). Others point out the potential for online deceit and creation of blogs based on fictitious or imagined experiences (Jones & Alony, 2008; Hookway, 2008). While online deceit is possible, the researcher is cautioned against viewing online data as less authentic than offline data (Orgad, 2009). Hookway offered two questions to consider when exploring the trustworthiness of blogs: "does it really matter if the bloggers are not telling the truth?" and "how can the truth be ensured in any research scenario?" (2008, p. 97).

The public versus the private nature of a blog is the underpinning of blogger autonomy to participate in a study. Rather than a simple dichotomy, the concepts of public versus private are negotiated states achieved via a dialectic process within changing contexts (Altman, 1980; Gal, 2002). Careful evaluation of specific attributes of each blog to be used enables the researcher to make a reasonable judgment regarding the blogger's public or private intent and to subsequently act in response to that perceived public/private intent. Blog attributes such as requiring a password to access the blog or prohibiting reader comments would support a more private intent while attributes such as being indexed for a search engine or offering RSS feed would lend support to a blog author's more public intent (Eastham, 2011). Any interaction between the researcher and the blog author would yield a research subject and informed consent to participate in a study would then be required to ensure autonomy (Kitchin, 2007).

While many studies have been done using the Internet, research seeking an emic perspective of illness experiences via personal blogs as a single source of data are uncommon. Clarke and van Amerom (2008) used blogs to reveal gender differences in the experiences of depression. In an unpublished study, McNamara (2007) studied blogs from women who wrote specifically about experiences with breast cancer. Search engines were used to find blogs in both of these studies. McNamara gathered additional blogs via hyperlinks from selected blogs. Shah

and Robinson (2011) used data mining software to collect and analyze individual blog postings to describe patients' experiences of home-testing blood for anticoagulation therapy. Data mining looks for patterns in data. All researchers described the blogs/blog postings as public. Only McNamara chose to cite quotations providing the URLs and online names of the authors.

Online conversations about health related problems have developed and grown over the past decade. According to a 2009 Pew survey, 83% of Internet users or 61% of American adults seek health related information online (Fox & Jones, 2009). Additionally, uploading a post to a blog, responding to a post, or reading a blog has never been easier given the proliferation of wifi and mobile devices such as smart phones and tablet computers. Mobile devices enable conversations about health to occur as easily as search engines enable research (Fox & Jones, 2009, p. 10).

To summarize, blogs are a common form of CMC. Personal blogs offer a new lens through which to gain an emic perspective of illness experiences. Using blogs as the only source of data offers the advantages of a longitudinal context as well as freedom from the biases inherent in a traditional interviewing process. Individual blog attributes provide clues to each blog author's public/private intent. Although some studies exploring illness experiences via unsolicited narratives from the Internet have been done, they are rare. This study assumes that a realistic portrayal of living with HIV is found in blog writings, reflecting life with HIV in the 21st century. Moreover, because blogging in general and online conversations about health specific experiences have rapidly expanded over the past decade, studies using blogs to explore living with HIV are needed.

### **Research Design**

This qualitative descriptive study was designed to examine experiences of those living with HIV infection as shared in existing personal web logs/blogs posted in public sites. The appropriate institutional review board approved the study. The design was consistent with the qualitative descriptive approach described by Sandelowski (2000). Conventional content analysis was used as the method for data analysis.

Strategies for validity focused on the four primary criteria of credibility, authenticity, criticality, and integrity as described by Whitemore and colleagues (2001). Credibility and authenticity were supported by a research design which promoted participant-driven data; bloggers decided what was important and no interviewer existed to influence the bloggers' stories. Up to two years of blog data were analyzed if available, thus preserving context and supporting credibility. Concern for transcription errors was obviated by study design, further supporting authenticity. The first author maintained a reflexive research blog in which assumptions were identified and research decisions throughout the process were recorded, thus promoting both criticality and integrity of the study. Finally, further support for study integrity occurred via periodic review of study procedures and data analysis with a qualitative expert.

### **Sample/Data collection**

Data were collected following the procedures delineated by Clarke and van Amerom (2008). The process for identifying and evaluating blogs for inclusion is summarized in Figure 1. Blogs meeting inclusion criteria and containing engaging entries about events which could easily be defined as "living" with HIV were selected. Examples of such events include: experience of learning HIV diagnosis, switching to a new provider, experiencing a change in medications, or changes in lab values such as a viral load becoming undetectable. Examples of unacceptable search results included "Botswana Blogs", [HIVthisweek.unaids.org/](http://HIVthisweek.unaids.org/), CNN

newsroom blog archive, blog.AIDS.gov. and a video "Emma's story Aids Day". Emma's story was a video made in a prior year for World AIDS day, but was not a blog.

Searches were conducted on two different days, approximately one month apart. Ten blogs that met all criteria were identified on the first day and four additional blogs were identified during the second search. A total of 14 blogs served as the data for this study. Blogs included both the postings of the blog authors and reader comments. All blogs except one had reader comments. The blog without reader comments had a hyperlink to upload reader comments at the end of each entry, so that the option was available but unused by readers.

### **Data Analysis**

Blog web pages were downloaded and saved in HTML format. Blogs were analyzed by the first author using conventional content analysis. As described by Hsieh and Shannon (2005), analysis began with repeated reading of each blog to gain a sense of the whole. Following this, data were analyzed line by line, highlighting words or phrases that captured principal concepts. Avatars, emoticons, pictures, or video clips were included as data if they were part of a blog. The investigator recorded observations regarding visual cues from these data and incorporated them into the analysis. Coding was discussed and validated with the second author; no disagreements in coding were identified. Data were initially organized by blog and a profile was made of the "stories" of living with HIV within each blog. To protect the privacy of bloggers and their reader-responders, pseudonyms used by bloggers were avoided and some quotations were paraphrased if an electronic search for the actual quotation could reveal the blog author.

### **Findings**

#### **Description of Sample**



The data for this study consisted of 14 blogs. It was difficult to determine the characteristics of all reader responders; the following describes the blog authors, also referred to as "bloggers". Ten bloggers were men and four were women. Exact ages were disclosed by few blog authors; others stated or implied age ranges from their 20's to 50's. Ten of 14 bloggers indicated the time since their initial diagnoses of HIV infection ranging from a few months to more than 25 years. Eight of the 14 bloggers referred to a partner or spouse in their writings, while five clearly indicated they were either single or divorced, and dating or hoping to date. Eight blog authors referred to a job or career, one blog author was disabled, and the remaining five did not identify a job or career. Twelve of the blog authors were living in the US with the remaining two living in Canada. Six blog authors used first and last names in their blogs. Five blog authors used obvious pseudonyms, e.g., SunnyState or Perry Mason. Of these five, one also provided his full name in an attached profile. A search for another blogger's pseudonym revealed multiple hits indicating the pseudonym was used as an identity. Two blog authors used a common American first name with another word or alphanumeric number, e.g., "David's Diary" or "Meredith 21."

### **Blog Communities**

Blogs included in the analysis were located on one of four blogging content management sites (BCMS) or communities as diagramed in Figure 2. One BCMS offered only blog content management services while others offered additional services such as news feeds, information about HIV, or links to Facebook and Twitter. Reader comments within the sampled blogs included a subgroup of the same readers commenting across these blogs. Some of these reader commentators also hosted their own blogs within the BCMS site. Dialogue occurred frequently between readers as well as between readers and blog authors within a BCMS. Communication

between BCMS occurred, but was rarer than communication within a site. An example was the blogger on one BCMS who posted a link to a blog on another BCMS and queried his readers as to whether they had similar experiences to that blogger's post (See Figure2, Landscape).

Comments such as "Hi Family", "I'm so excited about your upcoming event", or "I'm so glad you're here" reflected a sense of community within BCMS.

Blogging communities had different appearances, but many commonalities. Community home pages were colorful and engaging. News feeds were located on Community home pages while RSS feeds, links to Facebook and Twitter, and pictures of bloggers were found only after clicking on the link to the blogging site home page. Individual blog pages were generally plain with occasional pictures. However, some reader commentators provided signatures with clip art style pictures or word art.

Although blog authors wrote about similar experiences, their use of language was variable. Some had somewhat more frequent spelling or grammar errors, while others had fewer spelling or grammar errors. One author used colorful vernacular or font changes to indicate emotions such as the use of all caps or multiple exclamation points or question marks. No emoticons were noted other than an occasional smiley face.

## **Themes**

Four themes were generated from the data: (a) suffering, (b) relationships and support, (c) daily living with HIV, and (d) a call to action. Table 1 displays the categorical components of each theme. While these themes are similar to those of prior studies, each of these themes was constructed in unique ways within the context of blogging communities.

**Suffering.** Suffering was ubiquitous and multifaceted among the blog sample. A primary modifying factor of this suffering was nondisclosure of HIV infection as evidenced in this

reader's comment: "Am I suffering more because I hide my HIV infection to avoid stigma? Am I suffering more because I keep HIV as my top secret?" While a few blog authors or reader commentators described offline disclosure with warm support from loved ones, others wrote about negative offline experiences after disclosure such as verbal assault. One blog author wrote about changes in her interactions with her obstetrician subsequent to her initial diagnosis of HIV. She reported the obstetrician "seemed to avoid me like the plague. The visit was beyond weird." However, most bloggers or reader commentators expressed fear of potential marginalizing behaviors rather than recounting actual experiences. One blogger wrote "Disclosure of HIV infection is like committing suicide. You only invite stigma." The common outcome of actual or feared rejection was a self-imposed offline/in-person isolation. The online blogging communities permitted reader commentators and blog authors the opportunity to disclose online yet maintain offline nondisclosure, thus minimizing suffering.

Bloggers described two consequences of offline isolation: interference with self-care/disease management and loneliness. One reader spoke of postponing HIV medical care appointments due to fear of inadvertent disclosure, while another writer described panic attacks due to fear of disclosure and "keeping my head down" when attending HIV care appointments to avoid recognition and unintended disclosure. Moreover, writers told of being counseled by HIV-care providers to carefully evaluate their situations before considering disclosure due to the potential of violent reactions. Self-imposed isolation also impeded management of comorbidities such as substance use. For example, some bloggers spoke of the need, but inability, to disclose in offline/in-person situations such as N.A. meetings, because "stigma, fear, and ignorance still exist".

Some of the most poignant descriptions of suffering related to offline isolation were those of loneliness or the absence of a partner with whom to share life's journey. A reader commented "Thank you...for letting me into your world a little bit, so I can remind myself that I am not as alone as I feel most of the time." Another author wrote, "Will anyone ever hold this shriveled bony hand with the gentle affection I crave? Will I ever know that the person snoring quietly by my side loves me for exactly who I am, virus and all?"

**Relationships.** Online relationships evolved over time, via textual conversations between readers or between blog author and readers. The overarching characteristic of the theme "relationships" was the support gleaned from the online community. Many readers wrote to thank blog authors for sharing their stories. Some wrote to share how the blog author gave them comfort, hope, inspiration, or strength to continue their journeys or to begin medications. This appreciation and support was bidirectional, with blog authors thanking readers for supporting them during difficult times and readers writing to express appreciation for the support and inspiration received from the blog authors' postings. Statements such as "What would I do without this site? I can't imagine how I would be feeling now" or "this site is a lifeline for me" exemplify the perceived support from online relationships.

Online support was not limited to experiences associated with HIV infection. Some blog authors wrote about personal losses such as the unexpected death of a loved one and received multiple supportive comments in response. In general, online friendships appeared to be experienced very similarly to offline friendships as documented by one reader who wrote, "although we've never physically met...I consider you a very dear friend."

Some online relationships grew to include an offline/in-person component. One blogger met online a person from a different web site and eventually developed an offline/in-person

friendship. Another blog author set up a face-to-face social function for anyone within the blogging community to which he belonged. Other writers discussed attempts at dating people they met online. Although some writers successfully took their relationships offline, others simply wrote of their need for actual human contact: "talking here is wonderful, but if I could meet someone in person and hug them, it would make a world of difference." Only one reference was made about offline/in-person relationships moving into the online arena. In this instance, the blog author described negative online experiences, "I was being bashed", created by "flesh and blood" friends, known to the blog author originally in an offline/in-person relationship. While no specifics were provided, the writer noted that these individuals had timed the online negative comments to coincide with an especially difficult time in the writer's personal life.

**Daily living with HIV dialogue.** Daily experiences of life were shaped by the framework of HIV infection. One blogger described a longing for normalcy, stating " I just want to get through one day where this disease is not on my mind. I also haven't shed that feeling where I feel dirty. I just want to feel normal again." Another writer commented on wanting to "add life" to his years, rather than "add years" to his life and questioned if a return to "normal" was perhaps not a desirable goal. Several opined appreciation for being diagnosed in the time of ART. "Let's rejoice at the life we have been given through the sacrifices of the men and women who came before us." Still others viewed HIV as a gift, allowing them to "live each day more fully". One writer noted that "HIV saved my life."

Online dialogue offered a unique view of the willingness of individuals to provide reassurance or share knowledge about HIV infection. One blogger, frustrated about not being told lab results over the phone, wrote about his fears of starting medications and then dying from

resistance. Respondents quickly wrote to explain his responsibility to make an appointment and discuss a treatment plan with the doctor; others offered reassurance about the effectiveness of medications.

**A call to action.** Many wrote of a mission or purpose as the driving force in initiating and maintaining their blogs. This idea of a mission or purpose is reflected in statements such as: "...if just one person gets to read this and it touches them in some way, then I am accomplishing what I set out to do." Another author noted that "you cannot pay for the kind of education learned by experience...I must use all of these experiences to help some poor young person from making those choices." Reader respondents validated this mission stating "it is important for me to know that I'm not alone." Blog authors also used the blogging community's amplification of their voices to pass along news of advances in HIV treatment or magnify awareness of political causes such as gay rights, health care reform, or Ryan White funding.

### **Discussion**

Blogs are a form of social media. By definition, social media provide opportunities for people to interact with one another (Eckler, Worsowicz, & Rayburn, 2010). The social interaction within and across the blogging sites frames the sense of community bloggers acknowledge in their postings. Stories of living with HIV infection as described by the blog authors and reader respondents in these publicly available blogs were similar to findings of prior qualitative studies conducted via traditional research interviews. The unique aspect found within the descriptions of living with HIV while actively engaged in either reading or writing a blog were related to the sense of community perceived by the blog authors and their readers. This sense of community ameliorated the negative outcomes of some aspects of suffering associated with HIV infection. Specifically, online blogging communities provide an alternative social

outlet for gathering support, sharing concerns, and learning about HIV infection. Miles and colleagues (2011) have noted the secrecy-disclosure dilemma faced by persons living with HIV infection (PLWH). If the secret is revealed, rejection and enforced isolation may occur. If the secret is kept, isolation is self-imposed. In a face-to-face, geographically based community there is no satisfactory resolution of the secrecy-disclosure dilemma and the community contributes to the suffering (Miles, Isler, Banks, Sengupta, & Corbie-Smith, 2011). However, in this study, blogging communities provided an alternative option for disclosure thus alleviating the secrecy-disclosure dilemma and mitigating the related suffering.

Additionally, the virtual setting amplified the voice of the writer to areas beyond the local, geographically-bound community and thereby provided an opportunity, recognized and valued by participants, to share information and engage in a self-embraced mission of education about living with HIV. The offline/online dichotomy allowed the blog authors and reader respondents to be secretive offline, yet seek and receive support and guidance within the online blogging community. For the blog authors and readers in this study, online disclosure did not incur marginalizing responses from online community members, though one blog author described negative online actions committed by offline "friends". Although bloggers repeatedly cited appreciation of the online support and guidance, and acknowledged the significant contribution of their blogging communities to their abilities to cope with the illness, the longing for physically intimate relationship could not be mediated by the online community.

Limitations of this study include the restriction to use of public blogs and the inability to validate understanding with the blog authors and reader respondents. Many public blog authors used both first and last names which may have been due to a greater level of comfort with both online and offline disclosure than bloggers who used a pseudonym or provided only a first name.

Authors of blogs with privacy setting such as the requirement of a password may have variable views regarding the freedom of online disclosure. Finally, a larger number of blogs would have been preferable for a potentially broader perspective of living with HIV.

### **Conclusions**

In this study we have documented the ameliorating effects of blogging communities on the suffering associated with social isolation in the experiences of PLWH. Social isolation is associated with poorer adherence to treatment, lack of persistent engagement in care, and poorer clinical outcomes (Burgoyne, 2005; Mallinson et al, 2005; Ware et al, 2006). Connecting socially via CMC allows persons to disclose their HIV infection, yet remain anonymous to those others also participating in the online communities and to whom they disclose. Thus, physical geographical boundaries as well as face-time are no longer prerequisites to social connectedness. Social connectedness can be as close as one's computer. Patients with HIV infection may benefit from HIV blog communities. Further research using unsolicited narrative blogs is warranted.



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Figure 1. Blog Sampling Process

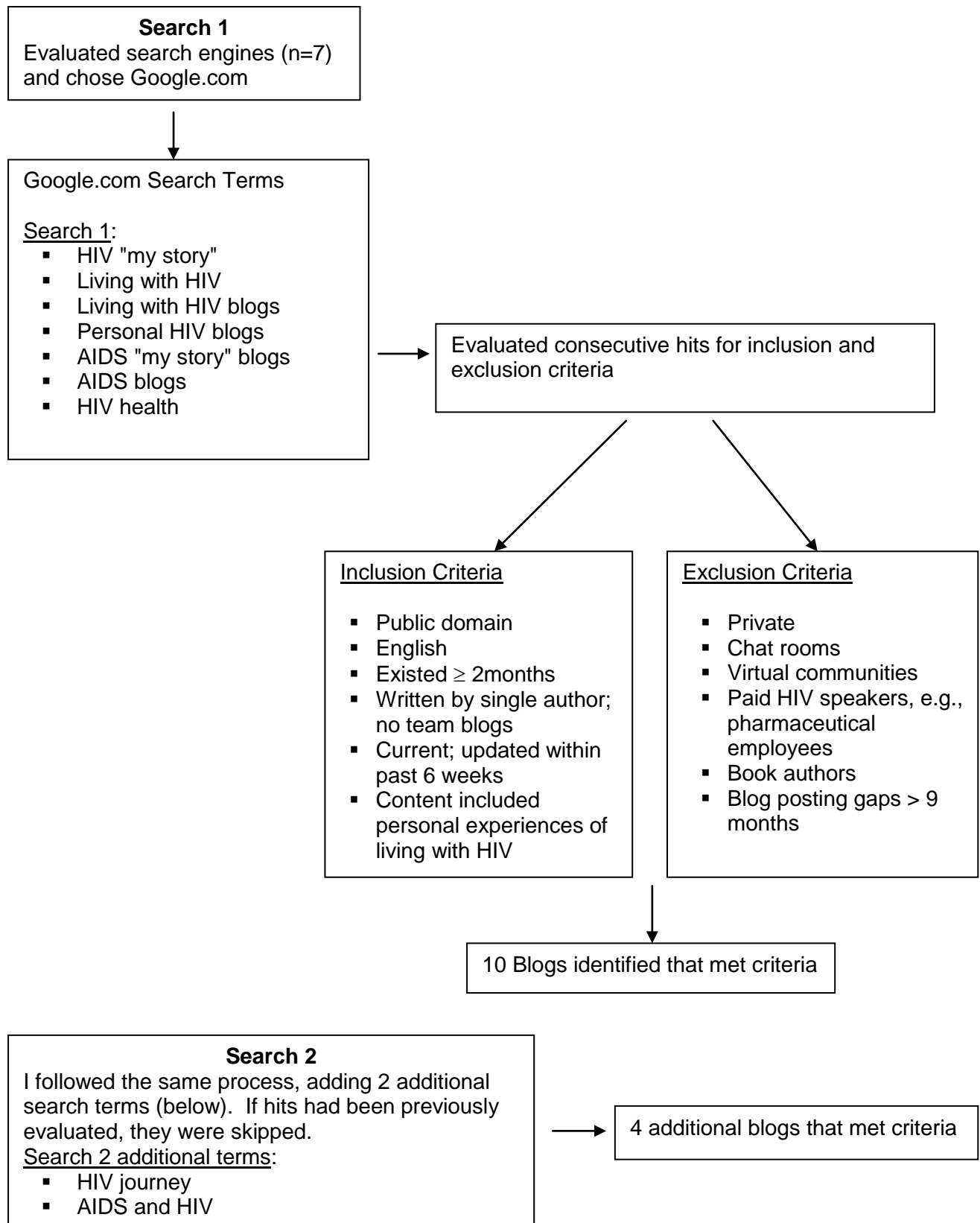
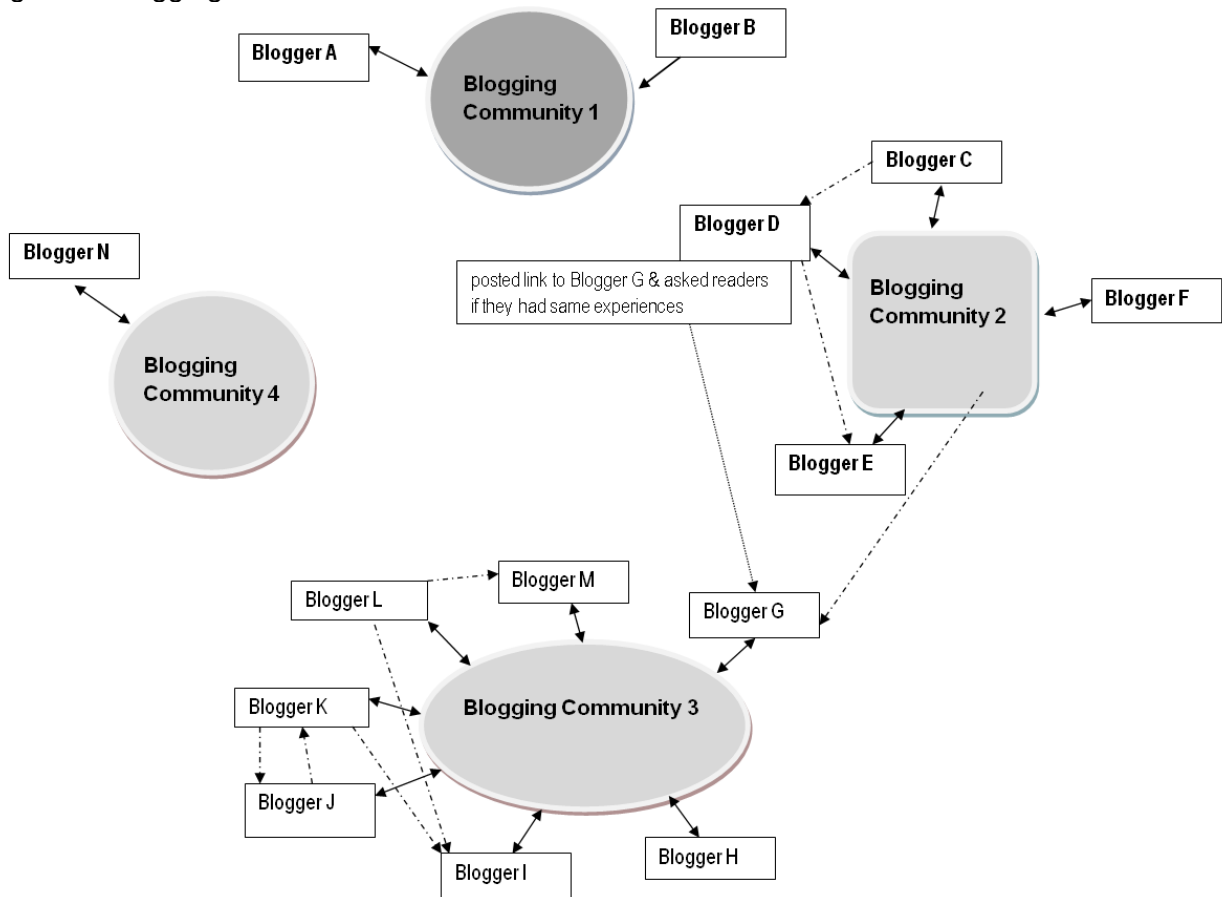


Figure 2. Blogging Communities



**Key**

Blue (Blogging Community 1) = generic blog content management system; not focused on any group, topic, etc.

Red = HIV-related site that also offers blogging

- Community 2 = HIV/AIDS Tribe
- Community 3 = thebody.com
- Community 4 = whospositive.org

↔ Means blog author allowed readers to comment

→ Means blog author had no comments on any post from any reader; I am currently assuming that the author simply did not allow comments

- - - - - → Means person commented on a blog



Table 1  
Categorical Composition of Themes

| <b>Suffering</b> | <b>Relationships and Support</b>         | <b>Daily Living with HIV</b>            | <b>A Call to Action</b>                       |
|------------------|--|---|---|
| Isolation/Alone  | Online relationships                     | Finding out                             | Perceived mission or purpose                  |
| Secrecy          | In-person relationships                  | My story                                | Sharing HIV treatment or research information |
| Stigma           | Online support                           | Living with HIV                         | Get tested                                    |
| Disclosing       | In-person support                        | Experiences of HIV illness or treatment | Being gay                                     |
|                  | Relationships with HIV-related Providers | Journey                                 | Political/legal issues                        |
|                  | Coping                                   | Good outcomes                           | HIV education                                 |
|                  |  | Future plans                            |   |

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**VCU RESEARCH PLAN TEMPLATE**

Use of this template is required to provide your VCU Research Plan to the IRB. Your responses should be written in terms for the non-scientist to understand. If a detailed research protocol (e.g., sponsor’s protocol) exists, you may reference that protocol. **NOTE: If that protocol does not address all of the issues outlined in each Section Heading, you must address the remaining issues in this Plan. It is NOT acceptable to reference a research funding proposal.**

**ALL Sections of the Human Subjects Instructions must be completed with the exception of the Section entitled “Special Consent Provisions.”** Complete that Section if applicable. When other Sections are not applicable, list the Section Heading and indicate “N/A.”

**NOTE: The Research Plan is required with ALL submissions and MUST follow the template, and include version number or date, and page numbers.**

**DO NOT DELETE SECTION HEADINGS OR THE INSTRUCTIONS.**

**I. TITLE**

Living with HIV: Views through the Blog

**II. STAFFING**

**A. In the table below (add additional rows as needed), indicate: (1) key project personnel including the principal investigator and individuals from other institutions, (2) their qualifications, and (3) a brief description of their responsibilities.**

| NAME OF INDIVIDUAL | QUALIFICATIONS | RESPONSIBILITIES  |
|--------------------|----------------|---|
| D. Patricia Gray   | PhD, RN        | Principal Investigator (responsible for research and will serve as primary contact) |
| Linda Eastham      | MSN, RN        | Student Researcher  |

**B. Describe the process that you will use to ensure that all persons assisting with the research are adequately informed about the protocol and their research-related duties and functions.**

The Student Researcher (Linda Eastham) has completed all requisites for doctoral course work including research courses. She has received additional individual mentoring in the conduct of qualitative inquiry. Ms. Eastham was involved in every aspect of development of the research protocol and will be responsible for the overall execution of the study with oversight from Dr. Gray. Ms. Eastham will 1) ensure the scientific quality and integrity of the project; 2) identify and select the blogs to be analyzed; 3) conduct all analysis; and 4) assume primary responsibility for reports, manuscripts and presentations that are an outcome of the project. The study

procedures for ongoing and regular oversight of Ms. Eastham's work are described in the section on rigor (see below).

### III. CONFLICT OF INTEREST

Describe how the principal investigator and sub/co-investigators might benefit from the subject's participation in this project or completion of the project in general. Do not describe (1) academic recognition such as publications or (2) grant or contract based support of VCU salary commensurate with the professional effort required for the conduct of the project

The investigators will not benefit from subjects' participation or completion of this project.

### IV. RESOURCES

Briefly describe the resources committed to this project including: (1) time available to conduct and complete the research, (2) facilities where you will conduct the research, (3) availability of medical or psychological resources that participants might require as a consequence of the research (if applicable), and (4) financial support.

1. Twenty percent of the student researcher's time will be available at no cost to conduct and complete the research.
2. Personal public web logs (blogs) will be accessed from the student researcher's computer. Data analysis will be completed at the student researcher's home.
3. NA; only existing blogs from a public site will be analyzed.
4. No financial support is available

### V. HYPOTHESIS

Briefly state the problem, background, importance of the research, and goals of the proposed project.

A qualitative descriptive design will be used to develop a greater clarity of how HIV infected individuals live and work within the sphere of HIV infection as represented through personal narratives posted on blogs. Since hypotheses are not appropriate for qualitative research designs, the research questions are: 1) "What is revealed about experiences of living with HIV infection through personal blogs of those who represent themselves as HIV infected?" 2) "In what ways do issues in accessing and using blogs as a source of research data affect the researcher's ability to examine experiences of those living with HIV infection?"

This research is significant because web logs or "blogs" are a relatively new and untapped research resource that will allow exploration of current experiences of living with HIV. On-line personal narratives have evolved into public diaries in which personal experiences are made visible and public. These experiences as described in the on-line personal narratives may reveal previously unidentified and/or unmet needs. Identification of previously unidentified or unmet needs may illuminate new pathways to provide more effective and relevant care to those living with HIV.

### VI. SPECIFIC AIMS

The aims of the qualitative descriptive study are:

1. To describe experiences of living with HIV infection by individuals as revealed in their blog narratives; and
2. To document issues in accessing and using blogs as a source of research data.

## VII. BACKGROUND AND SIGNIFICANCE

**Include information regarding pre-clinical and early human studies. Attach appropriate citations.**

Human Immunodeficiency Virus (HIV) infection is a priority area for Healthy People 2010 (<http://www.healthypeople.gov>). While initially a terminal disease, the advent of highly active antiretroviral therapy (HAART) in the latter 90's ushered in a new paradigm of experiences, and a renewed interest in examining living with HIV. Many individuals who previously had expected to die found they were now unexpectedly living and regaining immune system stability.

Now, a little more than a decade later, HIV is widely viewed as a chronic illness with approximately 1 million infected persons living in the United States (CDC, 2008). The majority of newly diagnosed individuals with HIV in the United States (U.S.) are between the ages of 13 and 29 years of age. The greatest rate of newly acquired infection is in those individuals age 30 – 39 years at a rate of 42.6 per 100,000 (Hall et al, 2008). Seventy-five percent of individuals affected by this disease range in age from 13 to 49 years of age (CDC, 2008).

According to the Pew Internet and American Life Project, the number of adults in the US who kept a blog in 2005 and 2006 was about 12 million and about 57 million American adults read blogs (2006). The surveyed bloggers reported their central focus for blogging was writing about their life experiences. The report revealed the majority of adult bloggers to be young (30 years old or less), and equally divided between genders. Reasons for blogging included sharing practical knowledge, motivating others, and documenting one's own experiences (2006). Kumar and colleagues (2004) found that while bloggers exist globally, the majority are found in the US. When examining the demographics of bloggers and the demographics of those infected with HIV, it becomes apparent that there is a large number of young adult persons within each group.

Blogs are public, archived, retrievable journals published on the internet. There are various types of blogs, for example corporate blogs, professional blogs, and personal blogs. Corporate blogs are useful for businesses to assist teams in disparate geographical locations to work together or to increase productivity through online interaction. Potential consumers may read a corporate blog to help determine if that business is the business with whom they want to work. Professional blogs may be written by various individuals for the purposes of sharing information from their areas of expertise. For example, in the health care field, a health care provider might have a professional blog to provide information about particular health-related

problems common among individuals experiencing an illness within that provider's area of expertise. Personal blogs may describe family outings or regale readers with stories about the new dog or serve as a lens through which to watch baby grow up via posted pictures or video clips. Alternatively, a personal blog may be related to a specific topic of interest such as photography or living with a specific chronic illness. A cursory browsing expedition of the internet reveals various personal blogs on Human Immunodeficiency Virus (HIV), breast cancer, fibromyalgia, depression, inflammatory bowel disease, living with an ostomy, arthritis, and more. Writing in the blogosphere enables the blogger to share intimate thoughts and feelings without doing so in a "face-to-face" situation.

Blogs are simultaneously personal and yet quite public (Huffington Post, 2008). The personal nature is reflected in "an intimate, often ferocious expression of the blogger's passions" (Huffington Post, 2008, p.6), while the public nature means that anyone with access to a computer has the potential to locate and read a blogger's expressions of passion. To compensate for this paradoxical discord of personal intimacy in a publically available location, blog authors may employ various mechanisms to assure some level of control over the public nature of their blog. Mechanisms available include the establishment of various identity and privacy parameters. To control identity, a blog author may choose to use a pseudonym and thereby retain some level of anonymity. While some may choose to use a particular pseudonym for authorship of their own blog, other authors may choose to also use that pseudonym consistently throughout all social activity on the web. In that way, the pseudonym becomes an identity (Bruckman, 2002). A blog author could also choose to use an actual picture of him or herself or alternatively select a graphic representation or other picture to represent self. To control for privacy, a blog author may choose to limit readers and contributors to certain, pre-identified individuals. Alternatively, a blog author may choose to open the blog to any readers, but deny readers access to comment. Another choice could be to open the blog to any readers and to allow contributions from any readers. In most instances, blog settings allow readers to add entries on an individual's personal blog and converse with the blog author or another contributor (Gaiser and Schreiner, 2009). In that way, personal blogs provide a channel for interactive communication within a community framework, albeit an online or virtual community. Finally, to establish privacy, a blog author may "remove" a blog from the internet, although that blog may still be retrievable through web cache.

For the purposes of the proposed research, only personal web logs will be considered sources of data for analysis. Personal blogs are a largely untapped source of qualitative data, currently beginning to be studied primarily by marketing analysts, sociologists, and educational researchers.

Other researchers have obtained and analyzed stories of HIV-infected individuals' challenges, triumphs, and fears, generally based on face-to-face or group interviews (Mallinson et al, 2005; Ware, Wyatt, and Tugenberg, 2006; Wrubel, Stumbo, and Johnson, 2008; Konkle-Parker, Erlen, and Dubbert, 2008; Buseh and

Stevens, 2007; Emler, 2008; Casarez and Miles, 2008; Groft and Vollman, 2007). What sets this study apart is the use of blogs as the primary data source.

### VIII. PRELIMINARY PROGRESS/DATA REPORT

If available.

NA

### IX. RESEARCH METHOD AND DESIGN

Include a brief description of the project design including the setting in which the research will be conducted and procedures. If applicable, include a description of procedures being performed already for diagnostic or treatment purposes.

#### Research Design:

This qualitative descriptive study was designed to examine experiences of those living with HIV infection using existing personal web logs/blogs posted in public sites as sources of data. In addition, issues in accessing and using blogs as a source of research data will be documented, summarized and analyzed to address the extent to which the researcher's ability to examine experiences of those living with HIV may have been enhanced or limited.

#### Research Questions:

The aims of the qualitative descriptive study are:

1. To describe experiences of living with HIV infection by individuals as revealed in their blog narratives; and
2. To document issues in accessing and using blogs as a source of research data.

#### Sampling:

Up to 25 existing, public-domain, personal blogs written or video-recorded will be accessed and analyzed. For the purposes of this study, a personal blog is one written by a single author who self-identifies as HIV-infected and which may have posts from readers as well as potential subsequent responses. Blogs will have many entries. Entries that mention HIV/AIDS or address issues clearly associated with HIV/AIDS will be included in the analysis. Examples include medications, diet, exercise, transportation to medical appointments, employment, seeking employment and financial issues regarding medications or medical care. Entries unrelated to living with HIV will be categorized or tagged as part of the credibility procedures but will not be analyzed.

An initial search for existing, public-domain, personal, HIV-related blogs either written or video-recorded will be done via blog search engines such as Technorati, Google Blogsearch, and Blogdigger. Public domain blogs are defined as: a) not requiring a password and b) current page accessible via a search engine. Each blog retrieved by the search engines will be evaluated to determine if the blog:

- Addresses living with HIV;



- Has been maintained for at least two months;
- Has current activity, i.e, a blog entry or posting by the blog author within the prior six weeks
- Is engaging, i.e., provides an authentic perspective.

Criteria for inclusion and exclusion:

- Inclusion characteristics of blogs: public-domain blog; Blog Content Management System (BCMS); English language; topical entries related to living with HIV infection; blog must have existed for at least two months; been written by a single author although may have postings from readers; and, updated within the past 6 weeks by the blog author.
- Exclusion characteristics of blogs: private; chat rooms; virtual communities

Data collection:

Data will be collected following the procedures delineated by Clarke and van Amerom (2008).

- An initial sample of ten to fifteen blogs will be collected on a specific date
- The student researcher will evaluate the search engine results (hits) to determine if the entries are "rich" enough to provide an authentic voice of living with HIV
- Selection of specific blogs with sufficiently "rich" entries will occur based on the story timeline and events, e.g., just diagnosed with HIV versus known diagnosis for some period of time, switching to a new provider, experiencing a change in medications, or viral load becoming undetectable, etc. Such topics are easily defined as "living" with HIV and reflect variable experiences within the overall timeline of living with the disease.
- A second sample of five to ten additional blogs will be collected on a later specified date following the above procedure for a total of no more than 25 blogs.
- All data will be obtained from personal, existing, public journals (blogs) written or videoed by single authors found on the internet via search engines. Data includes postings by blog readers.

Data:

- Data includes:
  1. Blog author entries and responses to reader postings related to living with HIV
  2. Reader posted responses to the blog author's comments to provide for further elaboration of the experience(s) being considered
  3. Observational data resulting from use of avatars, visual appearance of blogs, emoticons, and pictures or video clips.
  4. Records of blog-search process including search engines, search words, and numbers retrieved.
  5. Research journal/blog entries related to ethical concerns, language issues or lack of interaction with blog author

Data collection and analysis will proceed using an iterative process described below.

Findings will be reported using themes and supportive quotes to answer the first



research question. Supportive quotes will be chosen that may be found in several blogs or quotes which may be found through a search will be disguised by changing pronouns and proper nouns as needed.

Limitations of the Study:

- Only reflects experiences of those who choose to share their experiences via a blog
- No communication with blog authors of any kind: no face-to-face exposure or interviews to assist in interpretation/understanding intended meanings of written blogs; no opportunities for the researcher to obtain feedback, probe areas of interest to the researcher nor to explore areas where the researcher may be unclear on what the blog was intended to convey.

**X. PLAN FOR CONTROL OF INVESTIGATIONAL DRUGS, BIOLOGICS, AND DEVICES.**

**For investigational drugs and biologics: IF IDS is not being used, attach the IDS confirmation of receipt of the management plan.. See item #11 on Initial Review form.**

**For investigational and humanitarian use devices (HUDs): Describe your plans for the control of investigational devices and HUDs including: (1) how you will maintain records of the product's delivery to the trial site, the inventory at the site, the use by each subject, and the return to the sponsor or alternative disposition of unused product(s); (2) plan for storing the investigational product(s)/ HUD as specified by the sponsor (if any) and in accordance with applicable regulatory requirements; (3) plan for ensuring that the investigational product(s)/HUDs are used only in accordance with the approved protocol; and (4) how you will ensure that each subject understands the correct use of the investigational product(s)/HUDs (if applicable) and check that each subject is following the instructions properly (on an ongoing basis).**

NA

**XI. DATA ANALYSIS PLAN**

**For investigator-initiated studies.**

The data will be analyzed via conventional qualitative content analysis as described by Hsieh & Shannon (2005). Content analysis focuses attention on the content or contextual meaning of the language with an overall focus on the ways in which language is used for the purpose of communication (p. 1278). Both textual and visual data will be included with the goal to provide greater understanding of the phenomenon of living with HIV as it is currently experienced. Prior to beginning data collection and throughout the data collection and analysis processes, the student researcher will identify and reflect on personal expectations and assumptions related to living with HIV infection and research processes such as data acquisition and analysis. The student researcher will begin data collection without a preconceived theory or framework to guide analysis so as to minimize bias.

No transcription will be required for written blogs because they are in textual format. If the video clip is of the participant talking about living with HIV, the student

researcher will transcribe the content verbatim. Analysis of textual data will begin with the student researcher reading and re-reading each blog as a whole, “immersing” in the data to obtain a sense of the whole. Data analysis of any video clips will begin with transcribing the video clip and then reading and re-reading that content and viewing the video to fully appreciate meaning conveyed by tone of voice, facial expressions, and body language.

Additional data will include the student researcher's observations of the blog appearance, use of pictures, and emoticons. Analysis of additional data will begin with the student researcher recording notes regarding appearance, pictures, emoticons, and other visual cues. These observations will then contribute to the overall understanding of the blog messages similar to the use of field notes. Data regarding frequency of use of avatars, emoticons, or other visual cues will be collected. Additionally, observations regarding visual cues from the video will be recorded.

Following immersion in the data, the student researcher will read the data word-by-word, identifying significant words or short phrases to derive key concepts in each data set (blog). Throughout the data analysis process, the student researcher will make reflective memos and notes regarding her impressions and ideas about these essential words or phrases within the data. She will also note specific descriptions or definitions of the key concepts. The student researcher will incorporate ongoing analysis, including her notes regarding visual data, to modify or refine key concepts throughout data collection. After individual blog analysis, the student researcher will compare data from all blogs to identify common key concepts across blogs. Common elements that characterize the experiences of the participants as conveyed in the blogs will emerge from the key concepts. The identified common elements will be used to construct categories; categories will be used to construct broader themes which typically incorporate several categories.

Interpretation of meanings within the text data will occur by using an iterative reflective process of reading and reflection. The student researcher will use themes to tell the stories, supporting the findings with quotes. When a direct quote from a blog is used, the blog author will be disguised so that he or she will not be recognizable. Possible methods of telling the stories include organizing by time (chronological storytelling) or theme (most common to least common themes) (Sandalowski, 2000). Findings will be reported in scientific journals and at scientific meetings.

The second research question will be addressed through the student researcher's journal/blog entries regarding all aspects of experiences related to blog searches, reading blogs, and analyzing blogs. Unanticipated events and experiences will be recorded as well.

#### Rigor

Various activities will occur to ensure the rigor of the process and outcomes of the study:

1. Prior to beginning data collection and throughout the data collection and analysis process, the student researcher will identify and reflect on personal expectations and assumptions related to living with HIV infection and research processes such as data acquisition and analysis.
2. Detailed documentation to validate the study procedures and outcomes will be maintained. For example, detailed documentation will include researcher notes and records of blog searches, information on decision processes regarding achievement of saturation and other key decisions in the data collection and analysis process, hard copies of coding notes and the researcher's research journal. Such materials will be used to provide contextual background when reporting the study and will be available to address potential questions regarding the integrity of study procedures and outcomes.
3. Ongoing meetings with dissertation advisor and committee will be conducted in order to review study progress, discuss issues or concerns that may arise during data collection or analysis, discuss relevant entries in reflexive journal, review interpretations of blog data, and ensure adherence to standards of rigor.
4. Peer debriefing (using de-identified data) will be completed during data analysis and descriptive phases with a minimum of two selected professional nursing colleagues who have extensive expertise in nursing and/or HIV care. Peer debriefing will provide the opportunity for ongoing response and feedback regarding the student researcher's interpretation of data and will facilitate identification of as yet unarticulated assumptions and/or the consequences of assumptions in the data analysis process.

## **XII. DATA AND SAFETY MONITORING**

- **If the research involves greater than minimal risk and there is no provision made for data and safety monitoring by any sponsor, include a data and safety-monitoring plan that is suitable for the level of risk to be faced by subjects and the nature of the research involved.**
- **If the research involves greater than minimal risk, and there is a provision made for data and safety monitoring by any sponsor, describe the sponsor's plan.**
- **If you are serving as a Sponsor-Investigator, identify the Contract Research Organization (CRO) that you will be using and describe the provisions made for data and safety monitoring by the CRO. Guidance on additional requirements for Sponsor-Investigators is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#X-2.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#X-2.htm)**

The proposed research studies the works (public-domain, personal web logs) of living authors (archival data). According to Bruckman (2002), studying the "works of authors is not human subjects research unless you actually interact with the person in the course of your research" (p. 223). In the proposed study, the student researcher will not interact with any blog author via any form of communication, including but not limited to e-mail and posting on blogs which serve as data for data analysis. Though unlikely, the only identifiable risk is blog identification and therefore potential secondary identification of the blog author. To prevent blog identification, data will be de-identified as noted below (and in XVI - Part F):

1. Use disguises for individual and community names.
2. Delete or mask compromising details as much as possible (e.g., institution

- names, geographic details, organizational affiliations, if mentioned)
3. Create composite characters or break identifiable characters into multiple characters to make them less identifiable (Gaiser & Schreiner, 2009, p. 30)

Data safety measures include (See XVI – Part H):

1. Blogs will be accessed from the student researcher’s private, home computer.
2. Downloaded data will be stored on the student researcher’s private desktop home computer.
3. The student researcher will always close the browser after accessing blogs.
4. Data will be backed up on a password protected external drive
5. Electronic files will be password protected and, along with any hard copy files, will be maintained in a locked file cabinet when not in use.
6. The list of blog URLs will be stored separately in a password protected file and, along with a hard copy file, will be maintained in a locked file cabinet when not in use.
7. All data generated from this study will be maintained and destroyed according to the policies and guidelines of Virginia Commonwealth University Office of Research.
8. Blog authors and their URLs will be assigned an alphanumeric code.

### **XIII. MULTI-CENTER STUDIES**

**If VCU is the lead site in a multi-center project or the VCU PI is the lead investigator in a multi-center project, describe the plan for management of information that may be relevant to the protection of subjects, such as reporting of unexpected problems, project modifications, and interim results.**

NA

### **XIV. INVOLVEMENT OF NON-VCU INSTITUTIONS/SITES (DOMESTIC AND FOREIGN)**

**1. Provide the following information for each non-VCU institution/site (domestic and foreign) that has agreed to participate:**

- Name of institution/site
- Contact information for institution/site

NA

**2. For each institution, indicate whether or not it is “engaged” in the research (see OHRP’s guidance on “Engagement of Institutions in Research” at <http://www.hhs.gov/ohrp/humansubjects/assurance/engage.htm>.)**

NA

3. Provide a description of each institution’s role (whether engaged or not) in the human subjects research, adequacy of the facility (in order to ensure human subject safety in the case of an unanticipated emergency), responsibilities of its agents/employees, and oversight that you will be providing in order to ensure adequate and ongoing protection of the human subjects. You should only identify institutions that have agreed to participate. If additional institutions agree to participate at a later time, they must be added by amendment to the protocol.

NA

4. For each institution that is “engaged” provide an OHRP Federalwide Assurance (FWA) # if: (1) the research is not exempt, AND (2) the research involves a DIRECT FEDERAL award made to VCU (or application for such).

**NOTE:** Additional guidance at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XVII-6.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XVII-6.htm), and [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XVII-11.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XVII-11.htm).

NA

#### XV. INVOLVEMENT OF INDEPENDENT INVESTIGATORS

**INDEPENDENT INVESTIGATOR:** an individual who is acting independently and not acting as an agent or employee of any institution or facility while carrying out his or her duties in the research protocol. Additional guidance at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XVII-15.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XVII-15.htm).

**ENGAGEMENT IN RESEARCH:** An independent investigator becomes "engaged" in human subjects research when he/she (i) intervenes or interacts with living individuals for research purposes; or (ii) obtains individually identifiable private information for research purposes [45 CFR 46.102(d)-(f)]. See OHRP’s guidance on “Engagement of Institutions in Research” at <http://www.hhs.gov/ohrp/humansubjects/assurance/engage.htm>.

1. Provide a list of independent investigators.
2. For each independent investigator indicate whether or not he/she is “engaged” or “not engaged” in the research
3. For each independent investigator who is “engaged”: (1) describe his/her role with human subjects/identifiable human data, AND (2) describe YOUR oversight of his/her involvement.

NA

**NOTE:** If an independent investigator is “engaged,” and the research is (1) not exempt AND (2) involves a DIRECT FEDERAL award made to VCU (or application for such), the independent investigator must sign a formal written agreement with VCU certifying terms for the protection of human subjects. For an agreement to be approved: (1) the PI must directly supervise all of the research activities, (2) agreement must follow the ORSP template, (3) IRB must agree to the involvement of the independent investigator, AND (4) agreement must be in effect prior to final IRB approval.

**XVI. HUMAN SUBJECTS INSTRUCTIONS (Be sure to use the sub-headings under A-I)**

**ALL** sections of the Human Subjects Instructions must be completed with the exception of the section entitled “Special Consent Provisions.” Complete that section if applicable.

**A. DESCRIPTION**

Provide a detailed description of the proposed involvement of human subjects or their private identifiable data in the work.

Up to 25 existing, public-domain blogs will be accessed and analyzed. An initial search for existing, public-domain, personal, HIV-related blogs will be done via blog search engines such as Technorati, Google Blogsearch, and Blogdigger or blog links). The search engine results will be evaluated for the topical content (living with HIV) and current activity (last entry within prior 6 weeks). Only public blogs will be used (those retrieved by a search engine and not requiring a password). No communication will occur between the student investigator and any blog author. The student researcher will not post on any blogs included for data analysis.

**B. SUBJECT POPULATION**

Describe the subject population in terms of sex, race, ethnicity, age, etc., and your access to the population that will allow recruitment of the necessary number of participants. Identify the criteria for inclusion or exclusion of any subpopulation and include a justification for any exclusion. Explain the rationale for the involvement of special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable. If you plan to allow for the enrollment of Wards of the State (or any other agency, institution, or entity), you must specifically request their inclusion and follow guidance on Wards and Emancipated Minors in the VCU IRB Written Policies and Procedures (specifically WPP#: XV-3) available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XV-3.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XV-3.htm).

Existing, public-domain blogs written or video-recorded by a self-identified HIV-infected adult will be accessed via blog search engines such as Technorati, Google blogsearch, or blogdigger.

Criteria for inclusion and exclusion:

- Inclusion characteristics of blogs: public-domain blog; Blog Content Management System (BCMS); English language; topical entries related to living with HIV infection; blog must have existed for at least two months; been written by a single author although may have postings from readers; and, updated within the past 6 weeks by the blog author.
- Exclusion characteristics of blogs: private; chat rooms; virtual communities

**C. RESEARCH MATERIAL**

Identify the sources of research material obtained from individually identifiable living human subjects in the form of specimens, records, or data. Indicate whether the material or data will be obtained specifically for research purposes or whether use will be made of existing specimens, records, or data.

All raw data will be obtained from personal, existing, public journals (blogs) or videos by single authors and posted on the internet; such postings will be located via



blog search engines or snowballing through links to additional public blogs

Data for analysis will include:

1. Blog author entries and responses to reader postings related to living with HIV
2. Reader posted responses to the blog author's comments to provide for further elaboration of the experience(s) being considered
3. Observational data resulting from use of avatars, visual appearance of blogs, emoticons, and pictures or video clips.
4. Records of blog-search process including search engines, search words, and numbers retrieved.
5. Student researcher journal/blog entries

#### **D. RECRUITMENT PLAN**

**Describe in detail your plans for the recruitment of subjects including: (1) how potential subjects will be identified (e.g., school personnel, health care professionals, etc), (2) how you will get the names and contact information for potential subjects, and (3) who will make initial contact with these individuals (if relevant) and how that contact will be done. If you plan to involve special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable, describe any special recruitment procedures for these populations.**

Up to 25 existing, public-domain, personal blogs written or video-recorded will be accessed and analyzed. For the purposes of this study, a personal blog is one written by a single author who self-identifies as HIV-infected and which may have posts from readers as well as potential subsequent responses. Blogs will have many entries. Entries that mention HIV/AIDS or address issues clearly associated with HIV/AIDS will be included in the analysis. Examples include medications, diet, exercise, transportation to medical appointments, employment, seeking employment and financial issues regarding medications or medical care. Entries unrelated to living with HIV will be categorized or tagged as part of the credibility procedures but will not be analyzed.

An initial search for existing, public-domain, personal, HIV-related blogs either written or video-recorded will be done via blog search engines such as Technorati, Google Blogsearch, and Blogdigger. Public domain blogs are defined as: a) not requiring a password and b) current page accessible via a search engine. Each blog retrieved by the search engines will be evaluated to determine if the blog:

- Addresses living with HIV;
- Has been maintained for at least two months;
- Has current activity, i.e, a blog entry or posting by the blog author within the prior six weeks
- Is engaging, i.e., provides an authentic perspective.

Criteria for inclusion and exclusion:

- Inclusion characteristics of blogs: public-domain blog; Blog Content Management System (BCMS); English language; topical entries related to living with HIV

infection; blog must have existed for at least two months; been written by a single author although may have postings from readers; and, updated within the past 6 weeks by the blog author.

- Exclusion characteristics of blogs: private; chat rooms; virtual communities

#### **E. POTENTIAL RISKS**

Describe potential risks whether physical, psychological, social, legal, or other and assess their likelihood and seriousness. Where appropriate, describe alternative treatments and procedures that might be advantageous to the subjects.

The student researcher will not have direct contact with blog authors or those who comment on blogs. Therefore, minimal potential risk is anticipated as blogs to be analyzed are both public and existing. Though unlikely, the only risk to blog authors would be the potential loss of privacy.

#### **F. RISK REDUCTION**

Describe the procedures for protecting against or minimizing potential risk. Where appropriate, discuss provisions for ensuring necessary medical or professional intervention in the event of adverse events to the subjects. Also, where appropriate, describe the provisions for monitoring the data collected to ensure the safety of subjects.

1. Use disguises for names and communities
2. Delete or mask compromising details as much as possible
3. Create composite characters or break identifiable characters into multiple characters to make them less identifiable (Gaiser & Schreiner, 2009, p. 30)

#### **G. ADDITIONAL SAFEGUARDS IF ANY PARTICIPANTS WILL BE VULNERABLE**

Describe any additional safeguards to protect the rights and welfare of participants if you plan to involve special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable. Safeguards to protect the rights and welfare of participants might relate to Inclusion/Exclusion Criteria: (“Adults with moderate to severe cognitive impairment will be excluded.” “Children must have diabetes. No normal controls who are children will be used.”) Consent: (“Participants must have an adult care giver who agrees to the participant taking part in the research and will make sure the participant complies with research procedures.” “Adults must be able to assent. Any dissent by the participant will end the research procedures.”) Benefit: (“Individuals who have not shown benefit to this type of drug in the past will be excluded.”).

NA

#### **H. CONFIDENTIALITY**

Describe how the confidentiality of data collected as part of this project will be protected including pre-screening data (e.g., physical controls on the data; access controls to the data; coding of data; legal controls, such as a Federal Certificate of Confidentiality; statistical methods; or reporting



methods).

1. Blogs will be accessed from the student researcher's private, home computer.
2. Downloaded data will be stored on the student researcher's private desk-top home computer.
3. The student researcher will always close the browser after accessing blogs.
4. Data will be backed up on a password protected external drive
5. Electronic files will be password protected and, along with any hard copy files, will be maintained in a locked file cabinet when not in use.
6. The list of blog URLs will be stored separately in a password protected file and, along with a hard copy file, will be maintained in a locked file cabinet when not in use.
7. All data generated from this study will be destroyed within 12 months according to the policies and guidelines of Virginia Commonwealth University Office of Research.
8. Blog authors and their URLs will be assigned an alphanumeric code.

#### **I. PRIVACY**

**Describe how the privacy interests of subjects will be protected where privacy refers to persons and their interests in controlling access to themselves, and assess their likely effectiveness. Identify what steps you will take for subjects to be comfortable: (1) in the research setting and (2) with the information being sought and the way it is sought.**

1. This study is analyzing archival data of existing public journals (blogs) on the internet. Therefore, no researcher interaction with human subjects will occur.
2. Public, existing blog entries (archival data) will be copied and pasted into working documents and stored digitally in a password protected format.
3. The student researcher will provide moderate disguise as defined by Bruckman (p. 230): disguise all on-line pseudonyms; change identifying details such as names of institutions; omit sensitive details which could aid in the online search for the blog author; and omit the names of any BCMS or groups within which blogs were found.

#### **J. RISK/BENEFIT**

**Discuss why the risks to subjects are reasonable in relation to the anticipated benefits to subjects and in relation to the importance of the knowledge that may reasonably be expected to result. If a test article (investigational new drug, device, or biologic) is involved, name the test article and supply the FDA approval letter.**

This study is analyzing archival data of existing public journals (blogs) on the internet. Therefore, there are no human subjects. The student researcher will not have direct contact with blog authors. Though unlikely, the only risk to blog authors would be the potential loss of privacy.

#### **K. COMPENSATION PLAN**

Compensation for subjects (if applicable) should be described, including possible total compensation, any proposed bonus, and any proposed reductions or penalties for not completing the project.

NA; existing public-domain blogs will be obtained.

## L. CONSENT ISSUES

### 1. CONSENT PROCESS

Indicate who will be asked to provide consent/assent, who will obtain consent/assent, what language (e.g., English, Spanish) will be used by those obtaining consent/assent, where and when will consent/assent be obtained, what steps will be taken to minimize the possibility of coercion or undue influence, and how much time will subjects be afforded to make a decision to participate.

Consent to have blogs included in the analysis will not be obtained since blogs are public. The student researcher will not link any blog entries and the blog author (see part I, subset #3). Only existing, publicly available blogs (archival data) will be included in the study.

For example, one site, HIV Forums, advertises itself as having over 500,000 members. Another site, HealthBoards, advertises that it offers “one-stop peer support” and has 200,000 members. This site has a wide range of health-topic blogs, including HIV/AIDS blogs. People who want to post must register, but the site clearly states that blogs posted within their site are available to external search engines. Members are instructed to avoid using real names or any part of an e-mail address that would make them identifiable.

### 2. SPECIAL CONSENT PROVISIONS

If some or all subjects will be cognitively impaired, or have language/hearing difficulties, describe how capacity for consent will be determined. Please consider using the VCU Informed Consent Evaluation Instrument available at <http://www.research.vcu.edu/irb/guidance.htm>. If you anticipate the need to obtain informed consent from legally authorized representatives (LARs), please describe how you will identify an appropriate representative and ensure that their consent is obtained. Guidance on LAR is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XI-3.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XI-3.htm).

NA

3. If request is being made to WAIVE SOME OR ALL ELEMENTS OF INFORMED CONSENT FROM SUBJECTS OR PERMISSION FROM PARENTS, explain why: (1) the research involves no more than minimal risk to the subjects, (2) the waiver or alteration will not adversely affect the rights and welfare of the subjects, (3) the research could not practicably be carried out without the waiver or alteration; AND (4) whether or not subjects will be debriefed after their participation. Guidance is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XI-1.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XI-1.htm). **NOTE:** Waiver is not allowed for FDA-regulated research unless it meets FDA requirements for Waiver of Consent for Emergency Research (see below).

This research is studying the works (personal web logs) of living authors. According to Bruckman (2002), studying the “works of authors is not human subjects research unless you actually interact with the person in the course of your research” (p. 223). In the proposed study, the student researcher will not interact with any blog author via any form of communication, including but not limited to e-mail and posting on blogs which serve as data for data analysis. The only risk to blog authors would be the potential loss of privacy, though the sites where blogs are posted make it clear that the site is public; privacy protection is provided in the study protocol as noted below.

To protect blog authors from the potential loss of privacy, the student researcher will provide moderate disguise as defined by Bruckman (p. 230). Therefore, the student researcher will disguise all on-line pseudonyms, change identifying details such as names of institutions, omit sensitive details which could aid in the online search for the blog author, and omit the names of any BCMS or groups within which blogs were found. Only existing, public web logs (archival data) will be analyzed. Findings will be reported using themes and supportive quotes to answer the research question. Supportive quotes will be chosen that may be found in several blogs or quotes which may be found through a search will be disguised by changing pronouns and proper nouns as needed.

**4. If request is being made to WAIVE DOCUMENTATION OF CONSENT, provide a justification for waiver based on one of the following two elements AND include a description of the information that will be provided to participants: (1) the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Subject will be asked whether they want documentation linking them with the research, and each subject’s wishes will govern; or (2) the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context. Guidance is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XI-2.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XI-2.htm)**

NA

**5. If applicable, explain the ASSENT PROCESS for children or decisionally impaired subjects. Describe the procedures, if any, for re-consenting children upon attainment of adulthood. Describe procedures, if any, for consenting subjects who are no longer decisionally impaired. Guidance is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XV-2.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XV-2.htm), and [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XVII-7.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XVII-7.htm).**

NA

**6. If request is being made to WAIVE THE REQUIREMENT TO OBTAIN ASSENT from children age 7 or higher, or decisionally impaired subjects, explain why: (1) why some or all of the individuals age 7 or higher will not be capable of providing assent based on their developmental status or impact of**

illness; (2) the research holds out a prospect of direct benefit not available outside of the research; AND/OR (3) [a] the research involves no more than minimal risk to the subjects, [b] the waiver or alteration will not adversely affect the rights and welfare of the subjects, [c] the research could not practicably be carried out without the waiver or alteration; AND [d] whether or not subjects will be debriefed after their participation. Guidance is available at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XV-2.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XV-2.htm)

NA

7. If request is being made to waive consent for emergency research, see guidance at [http://www.research.vcu.edu/irb/wpp/flash/wpp\\_guide.htm#XVII-16.htm](http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XVII-16.htm).

NA

8. If applicable, address the following issues related to **GENETIC TESTING**:

**a. FUTURE CONTACT CONCERNING FURTHER GENETIC TESTING RESEARCH**

Describe the circumstances under which the subject might be contacted in the future concerning further participation in this or related genetic testing research.

NA

**b. FUTURE CONTACT CONCERNING GENETIC TESTING RESULTS**

If planned or possible future genetic testing results are unlikely to have clinical implications, then a statement that the results will not be made available to subjects may be appropriate. If results might be of clinical significance, then describe the circumstances and procedures by which subjects would receive results. Describe how subjects might access genetic counseling for assistance in understanding the implications of genetic testing results, and whether this might involve costs to subjects. Investigators should be aware that federal regulations, in general, require that testing results used in clinical management must have been obtained in a CLIA-certified laboratory.

NA

**c. WITHDRAWAL OF GENETIC TESTING CONSENT**

Describe whether and how subjects might, in the future, request to have test results and/or samples withdrawn in order to prevent further analysis, reporting, and/or testing.

NA

**d. GENETIC TESTING INVOLVING CHILDREN OR DECISIONALLY IMPAIRED SUBJECTS**

Describe procedures, if any, for consenting children upon the attainment of adulthood. Describe procedures, if any, for consenting subjects who are no longer decisionally impaired.

NA

e. **CONFIDENTIALITY**

Describe the extent to which genetic testing results will remain confidential and special precautions, if any, to protect confidentiality.

NA

## Vita

Linda A. Eastham was born on September 10, 1955 in Wetzel County, West Virginia and is an American citizen. She received her Bachelor of Science in Nursing in 1978 from West Virginia University and her Master of Science in Nursing in 1982 from the University of Virginia. Linda worked as a Family Nurse Practitioner for more than a decade with patients infected with HIV and their loved ones who were affected by the disease. She subsequently began teaching nursing at the University of Virginia.