



# Qualitative investigation of the role of quality in online community support for people living with HIV and AIDS

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## ABSTRACT

This research advances a new P2PSNSQUAL model, a peer-to-peer (P2P) social networking site quality construct. This study derived its theoretical background from SNSQUAL, a social networking quality model, and qualitatively confirmed that two independent dimensions – perceived usefulness and information quality – influence the quality of P2P support groups on social media and continued user engagement. For people living with HIV and AIDS (PLHA), this study determined that perceived usefulness is based on five dimensions identified here: reduced felt stigma, reinforced safe space, critical life line, perceived social support, perceived material support. Information quality is determined for PLHA users by the availability of information critical to PLHA, access to which is facilitated by a social media-based health intervention. This study contributes to information systems (IS) research and practice by: 1) introducing a new quality construct, P2PSNS quality; 2) recognizing six required dimensions of P2PSNS quality for PLHA; 3) and creating the first P2P social media quality model (P2PSNSQUAL), contextualized for use within a unique user group; and 4) investigating the impact of P2PSNS quality on continued user engagement, and fills a gap in the IS literature. The new P2PSNSQUAL model identifies a need for further study of P2P SNS use by targeted user groups in the health intervention context.

## KEY WORDS

critical information; critical life line; P2PSNSQUAL; perceived usefulness; information quality; perceived social support; perceived material support; reduced felt stigma; reinforced safe space

## Introduction

Prior research suggests that services generated by online peer-to-peer (P2P) support groups have been used in health intervention programs. Groups like Alcoholics Anonymous (Kast, Meier, and Pomeranz 2012) or support groups for multiple sclerosis (MS), where participants are also the service consumers, are quite useful (Schwartz and Sendor 1999). People Living with HIV and AIDS (PLHA) must maintain relative anonymity due to the stigma associated with this illness, while interacting to gain support and needed advice and information (Gilbert and Walker 2010). As in the face-to-face (F2F) support group environment, online P2P support groups are formed in which services are generated and consumed at the same time by the participants (Solomon 2004). In communities of PLHA, a P2P online support group can offer its members the desired anonymity for group members to feel comfortable by ensuring a sense of privacy and trust, which fosters a perception of safe and secure social and emotional

support (Coursaris and Liu 2009). The authors believe the structure of service delivery in online P2P support groups can model an effective health intervention program for PLHA communities. However, there is not much research that examines online P2P support groups for PLHA. Furthermore, little research investigates the quality dimensions of P2P online support groups for people living with HIV and AIDS. The authors propose that the success of such an online P2P support group can be replicated to serve populations of diversified backgrounds and needs if the quality dimensions of the P2P online services are formalized and structured in the context of the specific needs of targeted groups of individuals, like people living with HIV and AIDS. This study seeks to fill this research gap by qualitatively investigating a community of people living with HIV and AIDS, who are geographically dispersed yet connected to each other through membership in a closed/secret Facebook group.

Prior research shows that web services comprise an interface between a database server and application

servers that create services for end users (Küster and Vila 2011). Websites satisfy the end user's needs (Prajogo and Sohal 2004) and enrich the end-user experience through exceptional service delivery (Madu and Madu 2002). Hence, website usefulness depends on the reason the website was created and its ability to accomplish the desired goal. A website's success depends on its perceived usefulness by the end user (Muhammad et al. 2009). A website is rated high quality if it generates traffic that reflects its utility and popularity (Sumaedi et al. 2016). Thus, understanding the parameters that make a website successful informs research relevant to its quality. The authors' literature review revealed that there is not much literature that explores the quality of online P2P support groups for PLHA. This research study examines the dimensions of web service quality that offer services to communities PLHA and addresses the gap in understanding the quality dimension required for such a service to be successful. This study investigates the use of a closed online Facebook group by a community of PLHA. Because the study applies to Web 2.0 platforms that enable content created by the users through a significant collaborative effort, the authors use a theoretical background drawn from SNSQUAL, a model developed by Phillips, Peak, and Prybutok (2016) that explains the quality of social networking sites (SNS). The authors also see a theoretical connection to behavioral decision theory (Elam, Jarvenpaa, and Schkade 1992; Simon 1959), which helps the authors to connect perceived benefits to the dimensions of SNSQUAL. The authors present a framework that offers deeper insights into behaviors that create the quality dimensions associated with services created and consumed by PLHA.

## Literature review

The healthcare industry includes a growing trend in applying online consumer health informatics (CHI) applications to deliver relevant health information to targeted populations, and to facilitate information exchange within such groups (Cleveland and Cleveland 2009). Since health behavior is a function of culture (Obregon 2000), it is possible to reach a population subgroup by understanding their unique culture and communicating with the members of that subset based on characteristics those members share (Kreuter and Wray 2003). Prior studies indicate that traditional print and interpersonal methods of health communication are still valid and provide relevant and useful health information to a significant segment

of the general population (Prybutok, Koh, and Prybutok 2014). However, these methods are not as effective in managing and influencing risky health behaviors or communicating preventive measures for younger audiences or stigmatized groups (Prybutok, Koh, and Prybutok 2014). Griffiths, Lindenmeyer, and Powell (2006) analyzed 38 interventions and reported the factors that explain why health interventions have progressed to online delivery. Advanced development in graphical user interfaces and related technologies have made technology user-friendly, affordable for both healthcare providers and patients to deploy and implement, reducing the cost for both. P2P health is a growing online health-related behavior of people who have capitalized on the development of Web 2.0 technologies or interactive technologies that facilitate real-time communication between people (Tennant et al. 2015). These techniques allow people to share their experiences, concerns, and treatment plans with trusted peers (Fox 2011; 2013). Face-to-face HIV/AIDS support groups offer unique challenges to participants.

PLHA face many social challenges that are specific to their illness. People face discriminatory practices based on their HIV status. Lack of employment can lead to financial circumstances that prevent people from having reliable transportation. In some locations, public transportation is either unavailable or runs with very low frequency, rendering those services ineffective in meeting transportation needs in the context of HIV medical management. There are fewer resources that generate social support, as well as reduce discomfort caused by discrimination (Bozovich et al. 1992; D'Augelli 1989; Heckman et al. 1998; Heckman et al. 1996; Rounds 1988; Smith, Landau, and Bahr 1990; Wismer 1991). Many barriers have adverse effects on the quality of life of people living with HIV in rural areas, which can be mitigated when these people have access to the internet.

Facebook has been studied in the context of providing needed social support to PLHA. For instance, Nabi, Prestin, and So (2013) said that having many friends on Facebook is an essential predictor of perceived social support. People with many life stressors have been able to reduce their stress with social support, which leads to less physical illness and a greater sense of general well-being (Nabi, Prestin, and So 2013). Men who have sex with men (MSMs) seem to gravitate toward SNS in large scale (Smith et al. 2004). LGBT communities have adapted SNS to make new friends in hopes of forming new sexual relationships (Ramallo et al. 2015). Members who reported having

anxiety discussing HIV prevention topics via public postings within general SNS like Twitter and Facebook preferred using technology that facilitated more private forms of communication. Facebook offers such a medium, where an online closed or secret group of friends can communicate within the public domain of Facebook, under conditions of greater privacy and anonymity from the world at large (Ramallo et al. 2015). Designing and implementing a website to provide services that offer health interventions from the perspective of healthcare providers, and various resources that address the unique needs and challenges encountered by afflicted healthcare consumers, can ensure timely help and a better quality of life for PLHA (Wantland et al. 2004). Prior research indicates that website success is a function of dimensions that include credibility, content, the purpose of the website, hyperlinks, design, and interactivity (Ambre et al. 1997). Website features' design and access to specific information facilitate users' perceptions of the usefulness and ease of use that guarantees the success of the website and associated web services (Song and Zinkhan 2003). Similarly, prior research on perceived quality revealed that quality is the judgment of the consumer, who decides whether the entity under consideration is superior overall (Zeithaml 1987). Zeithaml et al. (2012) suggested that services are intangible, since they are not products but are more processes, acts, and performance of the activity (Wilson et al. 2012).

In their early works, Parasuraman, Zeithaml, and Berry (1988) developed the construct service quality, measured by SERVQUAL, with the dimensions of tangibility, reliability, responsiveness, assurance, and empathy (Parasuraman, Zeithaml, and Berry 1988). Another model, developed by Landrum et al. (2009) for information systems success in SERVQUAL, included seven dimensions: service quality, systems quality, information quality, user involvement, usefulness, user self-sufficiency, and user satisfaction (Delone and McLean 2003; Landrum et al. 2009; Song and Zinkhan 2003) proposed a model that considered "interactivity, usability, reliability, content quality, entertainment, privacy and security, and merchant brand image," which encapsulated website design, and access to the information that influenced consumers' perceptions of website quality (Song and Zinkhan 2003). Moreover, the Health Information Technology Institute (HITI) of Mitretek Systems developed protocols that influence website quality when providing health information (Ambre et al. 1997). They reported that credibility, content, the purpose of the websites,

hyperlinks, design, and interactivity are some of the criteria that website developers should factor in when considering quality during website development (Ambre et al. 1997). Understanding quality parameters in the context of designing websites that serve this special interest group are critical to the functionality and success of such websites.

### **Definition of quality**

Quality has been defined and described extensively by various researchers. Shewhart (1931), one of the pioneers of quality management, said that quality has two facets: objective and subjective. Quality as an objective reality is independent of the external influences of man (Shewhart 1931). Objective quality can be defined by a range of quality attributes, such as reliability, serviceability, maintainability, and attractiveness (Feigenbaum 1956). High quality is created by a group of quality attributes that provide the intended functions with the greatest overall optimization (Shewhart 1931). Alternatively, quality as subjective reality aligns with cognitive and affective attitudes of the user because of objective quality (Shewhart 1931).

Nie and Sundar (2013) investigated self-presentation in Facebook. Users engage in self-presentation when they upload content on their walls, creating an online profile. As time passes, users create a distinct online personality. As users continue to upload content on their walls, this creates richer and fuller profiles. Self-esteem directs self-presentation, is instrumental in a detailed and an enriched profile, and is responsible for the creation of personal identity. Conscious self-esteem makes users habitually monitor the content they upload on their online profile, customizing their wall frequently, resulting in the emergence of their social identity. The study said that users consider personal identity as a valued virtual-possession. This study suggested that personal identity is simply subjective quality, which is a part of user experience metrics, and can play a significant role in defining the objective quality or the way Web 2.0 websites should be designed (Nie and Sundar 2013). Herzberg's (1968) seminal work on motivation at the workplace describes hygiene and motivator factors, where hygiene is the factor that causes dissatisfaction at work and motivators are the factors that create satisfaction at work. Satisfaction and dissatisfaction are the attributes most highly correlated with defining quality (Lee, Lee, and Yoo 2000). Daft and Lengel (1986) suggested that the user's ability to perform tasks efficiently depends on the medium's capacity to

articulate the task specifications efficiently. They argued that the medium plays a critical role in the efficiency of the user's task performance during group interaction because the medium enables users to have a dialog dependent on media richness (Daft and Lengel 1986). Dennis and Valacich (1999) define three attributes of media richness. Variety is an attribute that allows a variety of natural languages to be translated. Multiplicity is an attribute that communicates the nuances of face-to-face communication during the online exchange of information. For example, different voice tones convey different meanings and so, different information. Personalization is an attribute that allows users to customize the features of the medium. Aligned with Herzberg (1968) and Lee et al.'s (2000) work that links motivation to quality, Dennis and Valacich (1999) developed the Theory of Media Synchronicity. This theory proposes that media richness has five other attributes. They are: ability to provide immediate feedback; symbol variety, or multiple ways of communicating information; parallelism, or the ability to handle a number of simultaneous conversations; rehearsability, or the ability to let users fine-tune the message or rehearse before sending it; and reprocessability, or the ability for users to retrieve information for analysis and processing. These factors facilitate task completion during group interaction (Dennis and Valacich 1999). These factors inform research that defines quality in the context of social media sites.

### **Service quality (SERVQUAL)**

A doctor's accurate diagnosis is dependent on the patient's accurate description of the symptoms. Similarly, users of services must articulate their needs and are often involved in the creation of services (Zeithaml 1981, 187). Services are thus characterized as intangible, unreliable, and inseparable. Therefore, consumers must use different signs and methods to evaluate services (Zeithaml 1981, 186). Zeithaml reports that the quality of many services depends on how well the consumer has defined or communicated the requirements to the service provider. The consumer may be dissatisfied with the service, either because he or she chose the wrong service provider, or because he or she did not articulate the task requirements to the service provider correctly. When Parasuraman, Zeithaml, and Berry (1985) investigated perceptions of service quality from the consumer's viewpoint and compared them to the understanding of service quality from the service provider's

viewpoint, they identified substantial gaps between the providers' and consumers' perceptions of service delivery. SERVQUAL is a widely utilized instrument in marketing research to measure the customers' expectations and perceptions of service quality (Kettinger and Lee 1997). Parasuraman, Zeithaml, and Berry (1985) developed a model of service quality and a definition of quality in services. Consider service quality provided by a server in a restaurant. Service is produced and consumed simultaneously when the server waits on the patron. Yet, there may be no consistency in the perception of service quality. A patron may perceive a difference in the quality of service provided by different servers. Hence, service quality is intangible, heterogeneous, and inseparable from the user's experience in the unique situation, as reported by Parasuraman, Zeithaml, and Berry (1985). Thus, the multidimensional nature of service quality is expressed and operationalized by the consumer's perception of service quality and is based on five dimensions: tangibility, reliability, responsiveness, assurance, and empathy (Devaraj, Fan, and Kohli 2002; Parasuraman, Zeithaml, and Berry 1988). Information systems (IS) researchers have extended this definition to gauge IS service quality, which investigates the gap between perceived service compared to expected service (van Dyke, Kappelman, and Prybutok 1997). Customers expect price value, and they seek convenience and are ready to pay for it (Reichheld and Scheffer 2000). The authors define e-business as businesses that utilize e-commerce as an important segment of their actions (Allison 2017). E-businesses enjoy customer loyalty and competitive edge through their superior e-services that differentiate them from their competitors (Phillips, Peak, and Prybutok 2016). Zhang and Prybutok (2005) focused on customer satisfaction rather than service performance. Their study reported that the risks associated with using websites are among the factors that influence user satisfaction with online services, which impacts their intention to use various websites. The authors developed an e-service satisfaction model (Zhang and Prybutok 2005). Service quality ensures continuous patronage of sites by users contributing to the website's success (Liu, Arnett, and Litecky 2000). Phillips, Peak, and Prybutok (2016) agree with Liu, Arnett, and Litecky (2000). They developed an SNS quality construct (SNSQUAL) that has five dimensions: trustworthiness, integration, personalization, reliability, and ease of use, and concluded that these SNS factors influence SNS quality. Moreover, it is this SNS quality that positively impacts the sustained intention to use the

chosen SNS (Phillips, Peak, and Prybutok 2016). SNSQUAL is especially applicable to Web 2.0 venues, which facilitate user-generated content and collaboration, and where site personalization and integration are essential antecedents to quality.

### **Website quality**

The essential and critical features that constitute the service itself are the quality features from the service viewpoint (Taylor n.d.). These features are recognized by analyzing the negative impact on the service offered in the absence of these features (Taylor n.d.). Business to consumer (B2C) websites consider information content and website design (including user-friendly navigation, security, and privacy) to be the key dimensions of B2C website quality (Ranganathan and Ganapathy 2002). Quality is assessed based on the design, navigation characteristics (Tarafdar and Zhang 2005), and usability of websites, which factor into perceived ease of use and usefulness (Agarwal and Venkatesh 2002). In 2001, von Dran, Zhang, and Small investigated the impact of a customer-centric focus on the development of websites by studying user perceptions, and reported that customers' quality expectations change over time, and that all factors do not have the same importance. What is ranked higher on one website may not be rated the same on other sites (von Dran, Zhang, and Small 1999).

David Mercer (2010) identified 10 critical features of good websites. They are: intuitive, easy to use, flexible, useful, integrated, geared, should provide media support so that users can upload videos, pictures, and so on. Websites should exhibit high performance, should have strong administrative support, and should have traffic, which is the most significant feature of a website. Mercer reports that what differentiates a great website from a good website is its responsiveness or its adaptability for accessibility by computers and handheld devices. Mercer also reports that website features are subjective, and a feature that may make one website successful may kill the success of another website (Mercer 2010).

Website users are also the consumers, as they engage in various activities like surfing the Internet; accessing, retrieving, and sharing knowledge; and interacting with each other, either socially or formally. In essence, specific websites are designed so they fulfill the specific needs of their users/consumers (von Dran, Zhang, and Small 1999). Gwinner, Gremler, and Bitner (1998) define relational benefits as benefits users receive from their long-term use of a specific

website, in addition to benefiting from the primary services promised (Gwinner, Gremler, and Bitner 1998). As users continue to perceive benefits from the services derived from using the websites, users begin to develop confidence and begin to trust the services. This attribute hints at yet another dimension of the quality of core services (Morgan and Hunt 1994).

### **SNSQUAL**

Phillips, Peak, and Prybutok (2016) extended the Technology Acceptance Model (TAM) to explain SNS quality (Davis 1989; Doll, Hendrickson, and Deng 1998; Zhang and Prybutok 2005). They argued that, as users find SNS easy to use, they will perceive SNS to have quality attributes such as being compelling and trustworthy. Thus, there exists a correlation between SNS quality and ease of use (Phillips, Peak, and Prybutok 2016). This study reports that SNSQUAL is composed of five independent dimensions: ease of use, trustworthiness, personalization, integration, and reliability (Phillips, Peak, and Prybutok 2016).

### **Methodology**

In this exploratory study, the authors take a qualitative approach that draws its framework from grounded theory (Glaser and Strauss 1998). Corbin and Strauss (2008) employed grounded theory in their qualitative studies to reveal specific constructs (Corbin and Strauss 2008). Grounded theory can be revised with constructivist ideology to develop an approach that applies to a particular population in the context of some specific concerns (Charmaz 1995; Corbin and Strauss 1990; Strauss and Corbin 1998). It is a methodological approach that helps to develop a research model to explain the phenomenon revealed in empirical data (Glaser and Strauss 1967). Quantitative investigations like these can be challenging for two reasons. First, such an approach would be inadequate to reveal more profound insights due to the sensitivity and anonymity associated with issues resulting from disclosure of HIV status and subsequent social exclusion. Second, appropriation of social media to deliver health interventions and promote the well-being of people living with HIV is still an emerging area of study. Yin (2003) provides a solution to these challenges by suggesting that qualitatively studied individual cases can be a useful strategy to investigate complex issues by deriving substance and meaning from the life events within a single realm of research (Yin 2003).

## Data collection

The authors focused on their selection method and concentrated on selecting information intense cases that offer more profound insights into the observed behavioral phenomenon (Patton 2002). Accordingly, the authors approached various organizations that provided services to people living with HIV in the hopes of gaining access to HIV positive individuals who use social media for health and social interventions. The authors engaged in semi-structured interviews with 32 HIV positive respondents as their primary data source. To recruit their respondents, they approached several health organizations based in the Dallas-Fort Worth area. Their efforts resulted in access to a closed online network of HIV positive individuals interacting on Facebook to facilitate information exchange within it for people living with HIV. To maintain the anonymity of the subjects, and for the sake of simplicity, this research study will refer to this secret Facebook group as PLHA-FB group. Authors of this study made initial contact with the group members by using the group chat features of Facebook Messenger. Authors could explain the importance of this research study, and through word-of-mouth referrals were able to recruit 32 subjects for semi-structured interviews after validating that all the selected respondents are existing users of the PLHA-FB group. Authors scheduled online meetings at a time convenient for the individual subjects. To record the interviews for later transcription, the authors used GoToMeeting software (Perron 2011). They obtained informed consent from each of their respondents before the interviews. The primary investigator initially transcribed the recording. Another author verified that transcriptions were accurate and reflected accurate information as recorded during the interviews.

## Data analysis procedure

The most important principle of grounded theory is that coding should evolve from the data. Data should drive the development of concepts. Strauss and Corbin (1990; 1998) describe the criteria used to assess the process of qualitative research. These criteria describe the process of creating categories and establishing links between the categories. Several researchers have described the use of NVIVO in qualitative analysis (Bazeley and Jackson 2013; Bringer, Johnston, and Brackenridge 2006; Johnston 2006; Richards and Morse 2012). For the authors' use, NVIVO allowed them to perform open coding as well as axial coding (creating connections between the nodes). Through axial coding, they can transform

descriptive text into theories about the cause of the phenomenon under investigation (Bringer, Johnston, and Brackenridge 2006). They also used a conditional/consequential matrix (Strauss and Corbin 1998) to identify relationships between the categories or nodes as is used in NVIVO. NVIVO does not complete the analysis on its own. Researchers must interpret the relevant themes and conclude this analysis (Bringer, Johnston, and Brackenridge 2006).

## Results

In this developmental research, the authors propose a new peer-to-peer (P2P) SNS quality model, P2PSNSQUAL, with six dimensions that determine perceived usefulness and information quality, and that influence continued intention to use for this unique user group in the healthcare arena, people living with HIV and AIDS (PLHA). Five dimensions that include reduced felt stigma, reinforced safe space, critical life line, perceived social support, and perceived material support determine perceived usefulness. Information critical to PLHA, which is facilitated by a social media-based health intervention, determines information quality. The authors qualitatively identified the benefits of membership in the closed online Facebook support group for PLHA. Based on their interviews they categorized the benefits identified by participants during semi-structured interviews, which are reported in Table 1.

### Perceived usefulness

The TAM says that perceived ease of use directly impacts perceived usefulness (Davis 1989). In the context of technology acceptance, Davis defines perceived usefulness as the perceived benefits of improved job performance achieved by using the technology (Davis 1989). Davis (1989) argues that according to behavior decision theory (Beach and Mitchell 1978; Elam,

**Table 1** Thematic observations.

Category	Sub-category	Sources	References
Helps reduce felt stigma		8	18
Safe zone		6	15
HIV management		5	11
Social support		7	17
	Friendships	6	10
	Emotional support	5	7
	Offline social life	7	12
	Material support	5	11
Information sharing	New Information	12	28
	Nutrition	4	14
	Motivation to engage in HIV disclosure	6	14
	HIV disclosure on Facebook	5	8

Jarvenpaa, and Schkade 1992; Johnson and Payne 1985), the decision-making process relies heavily on perceived benefits in the determination of usefulness and decision making. If users perceive benefits, it leads to the perception of perceived usefulness, resulting in the determination of the dimensions of quality, which explains why people make different choices in their decision-making process (Davis 1989).

### **Reduction of felt stigma**

Researchers have extensively documented stigma investigations in various contexts. Goffman describes stigma as an attribute that brings deep dishonor (Goffman 1963) and emphasizes that is deep-rooted in any given society and is interactive in nature (Gray 2002). If such an incident occurs and public knowledge of that event leads to shame and embarrassment, people generally tend to not share such knowledge with others in the society for fear of being judged and subjected to either censure or outright discrimination. This prevents them from seeking external help in dealing with stigma-related events. They hesitate to share information about these events as they experience guilt, shame, and fear that they are the victims of such treatment. Literature in psychology refers to this state of mind as “felt stigma, internal stigma, or self-stigmatization” (Scambler 1998). When the society subjects an individual to unfair treatment, it is called “enacted stigma” (Scambler 1998). Bogart et al. (2008) describes the damage caused by the experience of felt stigma endured by PLHA. The authors of that study revealed that “felt stigma” is one of the main reasons for non-disclosure of HIV status even to the individual’s primary physician, despite patient-doctor confidentiality. This can lead to severe consequences (Bogart et al. 2008). When family members of PLHA mistreat the person, or banish the person from home and the family, this discrimination takes the form of interpersonal discrimination. Close family members such as parents, spouses, siblings, and children inflict enacted stigma of an interpersonal nature. When family members of PLHA experience enacted stigma or face discrimination from other members in the society, it is called “courtesy stigma.” The effects of this stigma have been documented to result in suffering and pain (Bennett et al. 2016; Bogart et al. 2008; Florom-Smith and De Santis 2012; Logie and Gadalla 2009; Takada et al. 2014). Most of the discrimination directed at PLHA stems from ignorance about the illness and fear of getting infected just by close physical proximity (Parker et al. 2003; Gilbert and Walker 2010; Florom-Smith and De Santis 2012b; Logie and Gadalla 2009b;

Takada et al. 2014b). According to Bogart et al. (2008), people fear the risk of contracting HIV from a person who is living with HIV, and this fear of contagion leads them to discriminate against PLHA individuals. The Bogart study concluded families of all of the respondents of the study experienced stigma, including 100 percent of mothers, 88 percent of fathers, 52 percent of children, 79 percent of adult children, and 60 percent of caregivers. About 97 percent of families described fear of discrimination, 79 percent of families experienced actual discrimination, and 10 percent of uninfected family members experienced stigma from association. The HIV felt stigma experienced by the respondents lead to non-disclosure of their HIV status (Bogart et al. 2008). One of the most discussed themes in the semi-structured interviews revealed the strong influence of felt stigma within the consciousness of the respondents. One respondent shares the memory of rejection that came with that experience.

“I mean I have had people that when I have told them that I was positive you know the relationship stopped and some people that I have told that I was positive, it did not bother them and they were negative and we have been friends till today with some of those people, and we have had intimate situations and then there are some, a few times when you told someone that I was positive just to reveal it before it got any further, the relationship just stopped. They disappeared and what not and that hurt.”

Another respondent refers to the stigma that people must live with in many countries.

“Because in that you have many of the countries that have HIV as a stigma, and being gay is a stigma as well, so you have a double negative.”

Another respondent referred to the enacted stigma that affected his ability to retain gainful employment.

“There could be issues with uneducated people who would say that well if the customers do not like services from HIV positive people, they would not hire you.”

In this context, interacting with a closed Facebook group for “like-conditioned” (like-minded) people is a therapeutic experience for most of the users. People share their experiences related to the stigma, and experience that this interaction has healing effects. The camaraderie created by sharing the memories of shame, guilt, and pain diminishes the damaging effects of experienced felt and enacted stigma. One interviewee said:

“I think it lowers the stigma of the discrimination that we are dealing with a group of people in the same category.”

Another interviewee reveals:

“... And it does promote that because of the fear of the stigma, you do away with the stigma you do away with the fear, you do away with the fear then you do not have those problems and PLHA-FB they were one of those, not I am HIV and proud, but teaching people that it is OK to disclose your ... because now it is so accepted. Just because one individual is HIV negative and the other one is positive does not mean there cannot be a romantic clause, trust me it happens all the time.”

### **Reinforced safe space or safe zone**

Interestingly, this line of discussion revealed another benefit- provision of a “safe zone.” The respondents report a feeling of security created in this closed Facebook group:

“As I said, I think it is a safe zone for people because they are still ... the culture and society today still frowns upon a lot of you know ... a lot of it. They have been drilled into their head that it is like a life sentence but not necessarily anymore because it is maintainable. On PLHA-FB and I would feel safer there than I would be on some Yahoo group or whatever group that is just “gay” because you never know who is doing that Craigslist or whatever, so but if it is a bona fide group that has got a reputation that is there for the gay community and more specifically the HIV gay community then I think it would be a lot safer.”

Another respondent affirms:

“A forum like PLHA-FB is extremely important because they have created an environment where people can be honest, ... if I have got something going on and I need advice or I want to share a situation, you know, I feel like it is a very safe forum to be able to do that and I feel it is very important for anyone who is being honest about their status in their life.”

One benefit people perceived is the bonding that creates a safe environment as one respondent reveals:

“It is more of a bonding thing. It is like birds of a feather sort of ... because you feel more comfortable. You do not feel like you know that person is not going to judge you, so you feel more ... more comfortable in open discussion. As I said, I think it is a safe zone for people because they are still ... the culture and society today still frowns upon a lot of you know ... a lot of it. They have been drilled into their head that it is like a life sentence but not necessarily anymore because it is maintainable.”

“As I said, I think it is a safe zone for people because they are still ... the culture and society today still frowns upon a lot of you know ... a lot of it ... they

have been drilled into their head that it is like a life sentence but not necessarily anymore because it is maintainable. Anyway, the biggest thing is the freedom to speak freely because you it is a no judgments zone ... is what I call it. This group, to me, is a ‘no judgment type’ zone because I have the freedom to discuss anything usually about how I maintain and live with HIV.”

### **Perceived social support**

Prior research indicates that use of online platforms such as the internet makes it possible for people to access more social groups than is possible from the contacts made through their offline networking (Chan and Ghose 2014). Prior research has also indicated that usability, which includes usefulness and reliability, and an invasive nature that facilitates anonymous connectivity have made information and communication technologies prolific and ubiquitous (Ayyagari, Grover, and Purvis 2011). Respondents of this study agree that the PLHA-FB closed group affords anonymity yet connectivity, and allows a far greater number of people living with HIV to connect and remain to connect continuously. A respondent says:

“The kind of support I get is more a sense of being a part of the community, which has the shared experience of dealing with HIV and a shared interest in combating the disease in various ways.

It is evident that people like to connect with people who are going through similar experiences.”

A respondent affirms:

“I think what I would be looking for is to be around people who are the same status as me where, that is not an issue and for social gatherings and what not, that is what I would be looking for.”

The need for social support is evident as another respondent reveals:

“I think there are people that need support and I know I did when I first found out and I went to a support group, and if it was not for that, I do not know what I would have done. Social support can be in the form of emotional support. Some people express fears about the future. Whether it has got something to do with getting older, or the effect of political changes on the environment in which we all live, about getting medications.”

Another respondent equates the feeling of empowerment offered here. He says:

“I think it is important to empower people and to have that knowledge so that there is more of a comfort.”



Another respondent describes the role of the PLHA-FB group in empowering him against other people's malicious intentions. He says:

"Since I am out there with it, that is why I am out there with it, is that it totally disarms anybody who tries to use it against me. It does not give them the power to be able to do so because I have empowered myself in that."

Respondents of this group derive social support from friends they made in this group who are then integrated into respondents' everyday life. This reveals that this group allows people to connect, and the emotional bonding generated through shared pain gives them a source of friendship.

Another theme that evolved from discussion of social support is the ability of this group to reduce loneliness. Prior research indicates that user engagement in social media reduces feelings of isolation and loneliness (Braa et al. 2007; Glass, Li, and Pan 2014; Kisilevich, Ang, and Last 2012; Matook, Cummings, and Bala 2015; Turel and Serenko 2012; Wang and Chang 2008). These results find evidence to support that PLHA experience more relief online since it is difficult for them to share experiences related to their life and living with HIV with other members of society. A respondent revealed:

"I think that really helps build the sense of security when somebody newly diagnosed realizes that they are not alone and that is a huge thing. So yes, it has definitely counteracted the feeling of being alone. I do live alone; I am not a social butterfly, so I am one of those people who are at risk of isolation."

Another reported:

"I think it is important to empower people and to have that knowledge so that there is more of a comfort, so that they can live a healthy life because when people are scared, and it is traumatic, it can be very destructive and it is important to maintain a healthy mind and stability as well, so...I think the support group is very good with that, takes that fear away."

Another respondent spoke about how this group helps to mitigate the anger, disappointment, and bitterness associated with having HIV. He said:

"I mean, because there are some people who are just really...you know...have not really dealt with the whole process of their status and so they are kind of angry at the world, and so they tend to lash out. It would be probably easier because you know that we all know that we are in the same boat, I feel that there would be less judgment here. It's easier to deal with these emotions when you know you are not alone and that it has probably happened with other people. That God did not choose to dish this out for you only."

### **Perceived material support**

Various themes evolved in the category of HIV management and material support. Group members perceived material support to be one of the benefits that group members enjoy. One respondent reveals:

"I have seen instances of where people post that because they are sick, they have lost their jobs, and they do not have a car, and they need to go to a clinic, and I have seen people offering them to help in going to clinics, grocery shopping, etc. I have seen in Dallas and Houston, where people have posted that they cannot get to the PLHA-FB GROUP social events, they need a pickup and drop off, and people respond likewise offering help to go to these events."

Another respondent said:

"Occasionally people will say, I don't have meds and does anybody have five pills of Atripla or something, and people will offer medicines."

And another respondent revealed his response when he reads a post about someone who is drained of energy and living alone:

"Yeah... or maybe even go over there and maybe cook him something you know... just to... because it is easy to bring somebody something and drop it off and be like, 'hey, here is a casserole'..."

Another said:

"Group members will also occasionally point out resources in the group chat and providing them information with resources that can get that done for them. You see I am a little bit on the other side because I am also a healthcare provider..."

I was shocked that many of them were just thrown literature and was not explained what was available from any type of social worker, so I had the ability to you know...give them literally, call this number, these people will help and not just me because some of them knew of things."

### **Critical life line**

Based on the authors' interviews with their respondents, they found that they reported that trust was built among the users of this closed Facebook group. This aligned with prior research that indicated that users' belief in the perceived usefulness of technology influences their trust in technology (Gefen 2000). As the users continue to trust specific websites, this translates to quality, as users will then continue to use the websites (Loiacono, Watson, and Goodhue 2007). In the authors' research users have expressed their trust in this closed Facebook group, and various themes have emerged that contribute to the quality of such

services, fostering continued use intentions. Group members view this group as a lifeline. A respondent described an incident where members in despair have reached out to the online group as a lifeline extender.

“Actually, one young man was saved from suicide... Literally, in that mode and another individual saved him, and that group saved... you could pretty much say that that group saved his life because if that group had not been available and he could not have reached out to one of the individuals from PLHA FB, that individual I know for sure was suicidal and I think... he owed his life to that group though I would say it is monumental, it is absolutely necessary.”

### **Information quality**

Philips et al's (2016) SNSQUAL described personalization as a key dimension. Zhou, Li, and Liu (2010) report that there is a direct correlation between personalization and information quality. In a prior study, user's feelings and emotions as they engage entirely in any activity have been described as a flow experience (Csikszentmihalyi and Csikszentmihalyi 1992). Zhou, Li, and Liu (2010) further examined the effects of information quality on SNS user loyalty toward their preferred SNS and reported that information quality influences users' trust and flow experience. The higher the perceived quality of information, the higher their loyalty and intention to use the SNS (Zhou, Li, and Liu 2010). Prior research has shown that when users customize their interface, as they can on Facebook through the Privacy Settings function, or in setting the elements that they can see or hide, will increase user traffic and result in higher user engagement with the website (Sigala 2009). In the context of PLHA interacting with a closed Facebook group, users customize their Facebook page to display information of interest via features such as notification and privacy settings. Information quality influence user traffic and time spent on this closed Facebook group, as previously noted. Interviews with respondents revealed that users engage in information-sharing behaviors like exchanging new information related to the development of new lines of treatments, relevant information about resources for PLHA, or information sharing about legal rights. A respondent says:

“What I disclose or what I would try to help out with is things that normally people should be doing to keep themselves healthy, looking into other things but always not giving medical advice, things that I would do of making sure that you sleep well, that you are eating well that you also make your doctor work for you and disclose all of your blood work, not just

because it is in an average or normal range but to look at everything... you know where any deficiencies, any vitamin deficiencies because... you should be supplementing that so that everything is in a good range all the way across and including rest and exercise and things like that have kept me healthy for many years, so... many times people post about their symptoms... reactions to a certain medicine and many people also then you know take that information and the discussion grows from there, you know... so something like that... what is your take on this kind of information sharing... If it has to do with maybe a nutritional thing or maybe a sleep aid or a nutritional thing, a lot of times I can make suggestions but you know what I always tell people... you can try this, it is not a guarantee, it is not a medical advice but this thing seems to work for me, or I have heard that this might be helpful.”

Group members often share sensitive personal information, which gives other group members a sense of the issues and complications that can arise in future. They referred this to as “learning from other peoples' mistakes.”

“I have seen it teeter on the topic, I have never seen the topics out there completely bold and blunt in someone's face, but you know when someone is talking about their stories or trying to encourage somebody for what they have posted, there is a lot out there about substance abuse and just hitting on it for about continuing to not use condoms or have safe sex and things like that and those are all disconcerting sometimes especially when you look at the context of some of them but for the most part again I think these are honest people being honest about their experience and the best way that they can explain that to somebody is helping them understand that you know I was on cocaine when I got positive, and I think... I have never seen

HIV Disclosure is sometimes legally mandatory in the context of physical intimacy with multiple sexual partners. However, the same disclosure is not mandatory in the context of housing, or employment based situations.”

Another respondent revealed that most PLHA are not aware of their legal rights, especially when it comes to facing discriminatory practices against them by their employers. PLHA-FB group addresses such issues. A respondent said:

“Yeah, from PLHA-FB, individuals will discuss medications, side effects, social stigmas, the ability to speak freely and when they develop the ability to not communicate with their jobs in the fear that they would be terminated and how to go about that, what their rights are, what they are not, the spread of the disease, which ones said they would not absolutely not use protection and ones that said they would

disclose and ones that would not and it would allow communicate ... allow people to communicate.”

Another respondent said that this group motivates people to behave responsibly. He said:

“I feel it is very important for anyone who is being honest about their status in their life.”

Another respondent described the feeling of betrayal experienced after diagnosis of his HIV status:

“You would have one person who was just anal about contraception and being very, very careful about what you did versus somebody who was ... well, somebody who did it to me, so I do not care. And so that one individual can say well that was a terrible thing that happened to you, so do you think that it is fair to take that risk.”

## Discussion and conclusions

### Assumptions

There are four philosophical assumptions (ontological, epistemological, axiological, and methodology) within the framework of qualitative research methodology (Creswell and Creswell 2012). Ontologically, this study acknowledges that multiple realities exist and investigated one of the many existing evidences of the P2PSNSQUAL phenomenon. During the research process, the authors became very close to their participants, which allowed them to interpret and verify the existence of P2PSNSQUAL, thus embracing epistemological assumptions. Their methodology assumption (semi-structured interviews), and prior experience collecting and analyzing data from people living with stigmatized illness and under related special circumstances, supports the discovery of new information.

### Contribution to research

This study contributes to the identification of benefits derived by members through the creation of closed P2P support groups based on health considerations. These benefits are unique because they expose the needs of specific minority populations. This study offers deep insights into essential quality parameters critical to the design of effective web-based health applications.

The findings from this research also provide a foundation for future research because no prior study has investigated quality in the context of web applications where the consumers engage in co-creation (Hatch and Schultz 2010). Co-creation is a research area where the consumers of the services are also

potential providers of the services (Davidson et al. 2006; Meehan et al. 2002; Repper and Carter 2011). Furthermore, in this research, co-creation is examined in the unique context of P2P SNS health intervention groups.

### Contribution to practitioners

This study qualitatively investigates the quality parameters of websites that offer products, services, or health interventions to PLHA. In the context of using a technology-based social media platform for P2P health exchanges, this study is unique. This research informs practitioners of the specific needs and requirements of PLHA, and will help them to design websites that cater to specific health-related user groups. This research provides more profound insights that confirm the need to incorporate essential attributes like personalization, design characteristics, and the ability to cater to the customized information requirements of specific groups of users. In the context of an online website that provided a support group for people living with HIV, this research informs development and helps designers to create websites capable of catering to the specific information needs of PLHA. Similarly, the authors detail the customization and personalization requirements so a dynamic home page can display links to all information relevant to the members of the HIV positive community.

### Limitations and directions for future research

This study investigated P2PSNSQuality in the context of a marginalized minority population. In this context, this study has reported on only one of the many existing evidences of the observed phenomenon of P2PSNSQuality. Future research can investigate multiple realities that would define P2PSNSQuality. Also, this study explores one of the many dimensions of P2PSNSQUAL: the perceived benefits of the closed or secret support group for people living with HIV and AIDS on a Facebook SNS. In this context, the authors suggest that future research efforts can investigate perceived risks or perceived lack of risk in the context of peer-to-peer SNS support groups (P2PSNS). While the authors have investigated populations living with HIV and AIDS, further research can investigate other populations such as Alcoholics Anonymous, or people living with leprosy or post-traumatic stress disorder (PTSD) to investigate the perceived benefits and perceived risks as dimensions of P2PSNSQUAL of such

support groups. An additional limitation of the authors' study focuses only on one SNS, Facebook. The authors suggest that further research should investigate this phenomenon on other SNS. Also, all the respondents in this study belonged to western civilization from DFW area. The authors believe cultural diversity will influence the lifestyle of populations, and will also influence the way people use coping strategies to address their unique concerns. Future research should investigate P2PSNSQuality in populations belonging to different parts of the world that are culturally diverse from one another.

## Conclusions

This study, which is theoretically based on the social networking quality model (SNSQUAL), qualitatively identifies six dimensions that contribute to the perceived benefits and user determination of quality associated with using PLHA-FB, a closed online group for people living with HIV and AIDS (PLHA), a unique user group in the health arena. This study identified five essential quality dimensions that drive the perceived benefits (perceived usefulness) that improve HIV management and quality of life for PLHA. These quality dimensions are: reduced felt stigma, reinforced safe space, critical life line, perceived social support, and perceived material support facilitated by a social media-based health intervention. Additionally, information quality is determined for PLHA users by the sixth dimension, information critical to PLHA, access to which is facilitated by a social media-based health intervention.

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