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Users' Continued Usage of Online Healthcare Virtual Communities: An Empirical Investigation in the Context of HIV Support Communities

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Completed Research

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Abstract

This study uses data from an online HIV/AIDS health support virtual community to examine whether users' emotional states and the social support they receive influence their continued usage. We adopt grief theory to conceptualize the negative emotions that people living with HIV/AIDS could experience. Linguistic analysis is used to measure the emotional states of the users and the informational and emotional support that they receive. Results show that users showing a higher level of disbelief and yearning are more likely to leave the community while those with a high level of anger and depression are more likely to stay on. Users who receive more informational support are more likely to leave once they have obtained the information they sought, but those who receive more emotional support are more likely to stay on. The findings of this study can help us better understand users' support seeking behavior in online support VCs.

Keywords

HIV/AIDS patients, grief, social support, emotional states, continued usage.

Introduction

Users' continued usage of online healthcare virtual communities (OHVCs) has received considerable attention in the IS field because users who stay longer are more likely to enjoy the full benefit and support provided by the communities (Coursaris and Liu 2009; Liu et al. 2018; Wang et al. 2015; Yan and Tan 2014). Continued usage allows users to stay engaged with other members and develop meaningful social ties. It is also critical for the success of the OHVC, because like other online communities, a large number of active members helps create activities, generates useful content, and serves as resources for other members (Butler 2001; Gupta and Kim 2004).

However, only a small number of studies have examined factors that influence users' continued usage in OHVCs. For example, Wang et al. (2015) have investigated how users' exposure to informational and emotional support affect their length of usage. Yang et al. (2017) find that the effect of informational and emotional support on users' commitment is different between new users and those with higher tenure. In this study, we aim to extend this body of research and examine the effect of users' emotional states on their continued usage in addition to the social support they receive. Health problems, especially chronic diseases, can be detrimental to an individual's social and personal life, including family, finance, and work (Megari 2013). Handling the negative emotions as a result of the disease is especially important for patients living with chronic diseases (De Ridder et al. 2008). The emotional state that they experience can shape the way they interact with others and how they seek support. Therefore, the key research question is to examine

whether users' emotional states can affect their continued usage of OHVCs in addition to the support that they receive.

The current study is conducted in the unique context of an HIV/AIDS support OHVC. Being diagnosed as HIV/AIDS positive is a shocking and devastating experience, making these users more susceptible to the influence of negative emotional states (Kalichman et al. 2003; Smith et al. 2008). In addition, due to the social stigma and potential discrimination against those with the disease, people living with HIV/AIDS are more willing to disclose their emotions and feelings in an online environment that they consider to be safe and private (Guo and Goh 2014). By modeling users' continued usage as support seekers based on their emotional states expressed through their posts and the support they receive, this study expands the literature on user continuance in OHVCs by bringing in users' emotional factors and focusing on the needs of the users. Improving users' willingness to continue to use OHVCs has been an important topic of research in the healthcare arena, the findings of this study can help us better understand users' support seeking behavior in OHVCs and provide better support to cater to their needs.

Background

Informational and emotional support as the two major types of social support has been studied extensively (Attai et al. 2015; Yan and Tan 2014). Informational support refers to providing factual information and advices related to care and treatment, whereas emotional support mainly includes encouragement, comforting, and sympathy. Yang et al. (2017) state that users evaluate the benefit of joining the OHVC by the amount of support they receive. In this paper, the support that support seekers receive is measured from two aspects: the breadth of the support by the number of replies, and the depth of the support by the amount of informational and emotional support provided.

On the other hand, a growing number of studies have examined the social emotions expressed in online texts, particularly in the context of virtual interactions in online communities. Texts can indicate that an individual is feeling happy, sad, angry, or bored, and such emotions can shape the outcome of a conversation as people interpret the emotions and respond accordingly (Bao et al. 2012). In the context of this study that focuses primarily on the negative emotions experienced by HIV/AIDS patients, we adopt the Grief theory from psychology and social studies to understand how negative events such as HIV/ADIS diagnosis affects people so that better care can be provided to help the recovery. We review and synthesize theories from the work of Bowlby (1973) and Bowlby and Parkes (1970) (known as the Bowlby and Parkes Model) as well as the widely known Kübler-Ross (1969)'s five stages of grief. In principle, these different theories agree that people can go through several different emotional states after loss or trauma, the most prominent of them being disbelief, yearning, anger, and depression. The experience of these negative emotions are highly individualized: Some may experience them in a different sequence; some may move through a negative emotion relatively quickly, others more slowly. Some individuals do not experience one or more emotions at all, others can experience one emotion for more than once (such as on anniversaries or other memorable days since the event) (Maciejewski et al. 2007).

For people living with HIV/AIDS and the tremendous amount of pain, stigma, and psychological burden of the disease, we propose that knowing what kind of negative emotion that they are experiencing is vital to understanding their support seeking activities. Prior studies have pointed out the importance of recognizing the emotional fragility of HIV patients in support groups (Soskolne et al. 2003). Unlike other chronic disease such as cancer or diabetes, people living with HIV/ADIS are more sensitive and psychologically vulnerable, which can affect their willingness and openness to discussing their conditions and continuance in seeking support (Solomon et al. 2018). Based on their potential effect on an individual's support seeking behavior, we categorize the negative emotions into two groups: Disbelief/Yearning, and Anger/Depression.

Disbelief/yearning are common reactions to unexpected and shocking negative events. Individuals experiencing these emotional states often refuse to accept the event or see it as not real. Their expressions are usually mixed with confusion and disorientation. For example, most people have a hard time processing the fact that they have been infected or when their conditions suddenly deteriorate, such as *"...I don't know why we did it? ...How could I have been so stupid, how did it happened anyway..."* or *"...just got back from the latest ID doctor visit...CD4: 273 VL: +100,000 ... I just don't get how the percentage can be at an all time high"*. Others cling to false hopes that the event never happened, that they have been mistaken. Such

as "*I only wish things could go back before he tested POZ. I am not a religious person but I am willing to try anything...*".

On the other hand, Anger/Depression mark that the individual has somewhat accepted the event and has internalized the grief. People living with HIV/AIDS often suffer from unfair treatments and stereotyping from others, they are thus more prone to outbursts of emotions such as "*...for them to judge and say that gay men deserve to have HIV...*" or withdrawals into isolation and depression, such as "*...I feel very overwhelmed and extremely alone*". Emotions expressed through words in online interactions often signal different types of social support needs (Buis 2008). Therefore, capturing the semantics embedded within the text can offer us a glimpse into the dominant emotional state that the user is experiencing and help us better understand they usage of OHVCs.
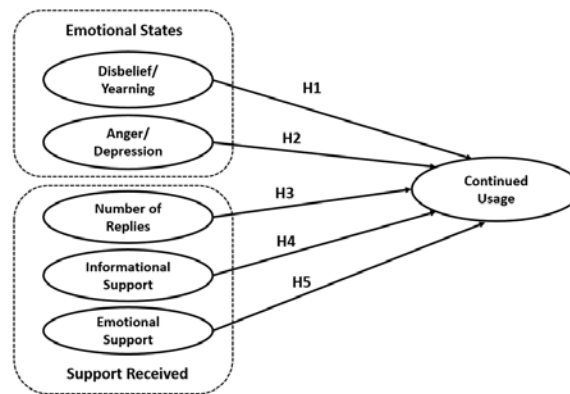
Conceptual Model

Figure 1. Model of Continued Usage

Figure 1 above shows the model of this study. The model posits that users' continued usage of an OHVC is predicted by two factors: the emotional state of the user and the social support the user received. As discussed above, users who are showing high level of disbelief and yearning often refuse to accept the reality. As a result, rather than getting an accurate assessment of the situation and seeking practical advices, these users are seeking confirmation of the alternative reality that they convinced themselves to believe in (MacWilliam 2017). These emotional states could be harmful to the grieving individuals because they are fixated on their own alternative realities instead of focusing on the present and taking necessary actions. With their heads still buried in the sand, as the idiom says, useful advice and constructive suggestions would be falling on deaf ears. When other members are trying to bring them back to reality and take proper actions to manage their conditions, users with high level of disbelief and yearning may even think these words are too harsh and not what they want to hear. Therefore, they are more likely to leave the community:

Hypothesis 1: Users showing high disbelief/yearning are less likely to continue to use the OHVC.

Prior studies have shown that people suffering from negative emotions such as anger and depression rarely explicitly ask for help. Ilardi (2009) notes in his book "*...that people often resist opportunities to lighten their burdens like this. Many times it's because they feel they don't deserve the help, and sometimes they're simply unwilling to ask for it...*". Angermeyer et al. (1999) have found that only about one fourth to one third of depressed individuals seek professional help. Therefore, the willingness to share their feelings of anger and depression indicates that the user trusts the members of the community and feels safe to share their emotional vulnerabilities. It also signals that they view the OHVC as a source of emotional sustenance and have developed a certain degree of emotional attachment to the community. An empathetic and understanding community can help these users to rebuild confidence in life and reconnect with others. Therefore, users who express their anger/depression in their posts are more likely to stay longer in the community and develop emotional bonds with other members.

Hypothesis 2: Users showing high anger/depression are more likely to continue to use the OHVC.

Posting questions and receiving replies is the most important method of obtaining social support in OHVCs. Users may join an OHVC seeking different types of social support. For users seeking for informational support, more replies mean that the chance of another member who possess the right knowledge is increased. On the other hand, for users seeking for emotional support, receiving replies from other people shows that other members value their presence, their needs are not ignored, and people are willing to listen to them. To sum up, the number of replies that users receive can promote the feeling of connectedness and companionship from a broad variety of conversations. Therefore, the number of replies, which represents the breadth of the support that users receive, positively affects users' likelihood to continue to use the community.

> Hypothesis 3: Users who receive more replies from other members are more likely to continue to use the OHVC.

Contrary to common belief that users would stay longer if they found useful information in the VCs, studies of similar OHVCs show that informational support can have a negative effect on users' continued usage (Wang et al. 2015; Yang et al. 2017). Because HIV/AIDS is a serious disease that requires professional medical care, OHVCs only serve as a supplement to doctors and other healthcare workers whom are the most reliable and accurate sources of information. This means that the informational needs of users are usually only sporadic and short-term. Similar to using search engines and dictionaries, users are less likely to return once they have obtained the informational support they need. Wang et al. (2015) also proposed the other possibility that users may become unsatisfied with the accuracy of the information provided by less professional and knowledgeable members, which also reduces the likelihood of future questions. Therefore, we hypothesize that:

> Hypothesis 4: Users who receive more informational support are less likely to continue to use the OHVC.

By contrast, emotional support is only obtainable through interpersonal interactions. Compared to the supplementary role in providing informational support, OHVCs are more important in providing emotional support. People living with HIV/AIDS have to endure years of distressing, painful, and stigmatizing experiences (Plattner and Meiring 2006). While patients of other chronic diseases can lean on their friends and families for emotional support, HIV/AIDS patients often prefer OHVCs to discuss issues they feel are sensitive or potentially stigmatizing (Guo and Goh 2014). Developing meaningful social ties with other members takes time, and once such ties are formed, the users become emotionally attached to the community. Therefore, receiving emotional support can increase users' likelihood of staying in the community:

> Hypothesis 5: Users who receive more emotional support are more likely to continue to use the OHVC.

Method

Sample

With permission from the administrators of a large online support VC for people affected by HIV/AIDS, we collected all the posts generated by users from May 2006 to March 2017. The OHVC consists of several different sub-forums hosting different topics such as "Am I Infected?", "I Just Tested Poz", "Treatment & Side Effects", and etc. For the purpose of this study, we excluded posts from two sub-forums: the first one "Am I Infected?" is for users who are concerned about their chance of infection after potentially risky exposures. However, most of their concerns only constitute minimal risk (e.g. cutting fingers, performing oral sex). As a result, most of users only post once and do not return. The second sub-forum, "Research News", is a bulletin board for news of related medical researches.

With the collected data, including the text of the posts, replies, and timestamp, we assign a unique numeric user id to each user and remove their usernames for privacy. We also remove users with top 5% number of total posts because they are most likely to be administrators and moderators (33 users, each with 3426 posts or more), their behavioral patterns are likely to differ significantly from ordinary users who are seeking support. The final dataset consists of 14,878 users who have started 27,103 threads and received 212,149 replies in total.

Measuring Continuance

We apply survival analysis in this study to models users' length of active use of the OHVC to seek support. Survival analysis is widely used to model the duration of time until a certain event happens that is defined as failure, such as dropping out of school, becoming unemployed, or malfunctions in machines. In this study, we define the survival timeline as the activities of an individual user until this individual stops using the OHVC. Because the focus is on usage of the OHVC to seek support, we track each user by the number of threads started by that user to ask questions and elicit replies from the community. Each user starts participating in the OHVC at the timestamp of his/her first post starting a thread. The timestamp of the last thread posted by the user is considered to be the point when the user stops using the OHVC. If a user's last thread is posted within 3 months to our data collection date (which is set to April 1 2018), we consider it to be right censored. Right censoring occurs when the failure event has not happened at the end of the observation period (i.e. still surviving), in the context of this study, it means that the user may post again in the near future and we are not certain if this user has truly left the OHVC.

Because we are only able to observe the emotional states of the users and measure the support they receive each time they write a post, we measure survival time by the number of thread-starting posts each user have written. It is possible that users can also obtain useful informational support by "lurking" in the OHVC, but their value and contribution to the community and other members is only materialized when there is actual activity. For example, between two users, user A posted 2 posts in a single day, whereas user B has a 3-month gap between the 2 posts. Although user B have stayed around much longer than A in terms of chronological time, but their activity level and contribution to the community is about the same. Therefore, in our measurement, both user A and B would have survived 2 time periods.

Measuring Emotional States

Due to the large sample size, it is unrealistic to rely on manual labeling to identify the emotions expressed in the posts. Therefore, we employ a combination of two widely used linguistic analysis methods to automate this process. In the first step, we use unsupervised machine learning to train a word2vec model to identify key words that are related to or used to express certain emotional states. Word2vec is a popular word embedding technique based on shallow neural network that can learn semantically meaningful representations for words from their co-occurrences in sentences (Mikolov et al. 2013a). It generates numeric vectors representing words in a multi-dimensional space and group vectors of similar words together while preserving the contextual meaning of the words. For example, the result of vector(Berlin) - vector(Germany) + vector(France) would be very close to the vector representation of the word "Paris" (Mikolov et al. 2013b). Because word2vec can preserve the contextual meaning of the words beyond simple synonyms and ontological similarities, prior studies have found that it can demonstrate human-like comprehension quality and outperform traditional linguistic analysis techniques (Levy and Goldberg 2014; Levy et al. 2015).

We use *nltk* package in Python 3.71 to prepare the document so that it can be correctly read and processed by the machine learning algorithm. Posts are broken into individual words and tokenized, then we remove stop words (e.g. you, we, the, of). Lastly, all words are converted to lower cases and lemmatized to remove inflectional endings to return the base stem (e.g. lemmatized, lemmatizing, lemmatization -> lemmati). Then we use the *gensim* package in Python to train the word2vec model. Although there are pre-trained word2vec models available based on corpus of words from Wikipedia and Google news, we choose to train our own word2vec model based on the posts collected from the OHVC so that the model can capture the relations of the words when used in the specific context of HIV/AIDS support. We set the minimal frequency of words to 3 to exclude extreme rare words and potential misspelling and typos. The final word2vec model contains 50,969 unique words.

Second, we identify the words that are closest in meaning and context to the emotional states of disbelief/yearning and anger/depression based on cosine similarity. Results in Table 1 below show that the model can accurately understand expressions of emotions. For example, words expressing doubt, incredulity, guilt, and regret are correctly identified to approximate emotions of disbelief/yearning. For anger/depression, the model was able to capture expressions, causes, symptoms, and medications related to them. We select the top 600 words for each set of emotional states and construct a custom lexicon. Next we use the custom lexicon in Linguistic Analysis and Word Count (LIWC), a widely used linguistic analysis

program, to analyze the emotional states of the users based on the text of the thread-starting post that they wrote when seeking support.

Emotional States	Lemmatized Word Examples
Disbelief/ Yearning	disprov(e), guarante(e), assert, odd evid(ence), factual, likelihood, certainti(-y), flaw, dubiou(s) zero, nonexist, insignific(ant), improb(able), rare, neglig(ible), stupid, dumb, foolish, careless, fault, guilti(-y), regret, fate, karma, deserv(e)
Anger/ Depression	angeri(ly), moodi(-y), suicide(e), exhaust(ed), unbear(able), heartbreak, loath, offend, resent, hate betray, judgement, homophob(ia), confront, victim, bulli(-y), cheat, assault, hypocrit(e), bigot insomnia, bipolar, disorder, adhd, dysphor(ia) prozac, ssri, alprazolam, seroquel, citalopram

*Letters in parentheses give example of full words.

Table 1. Lexicon for Emotional States

Measuring Support

We assume that users read all the replies in their previous thread before they start a new thread. Therefore, the social support a user receives in each time period is the sum of the social support provided under the last thread initiated by this user. The breadth of the support that users receive is calculated by the total n*umber of replies* received in their threads.

Informational support and emotional support, however, are much more complicated expressions and cannot be measured by a single category of words, unlike the emotional states. Therefore, we adopt Latent Dirichlet Allocation (LDA) (Blei et al. 2003), a popular technique in topic modeling that can extract latent topics from large passages of texts. LDA uses sparse Dirichlet priors and assumes that normal conversations are more likely to focus on a handful of topics instead of spanning across a variety of topics. Therefore, words belonging to the same topic should co-occur frequently within one document but relatively sparse across different documents (Girolami and Kabán 2003; Wei and Croft 2006).

To determine the optimal number of latent topics that should be extracted from the corpus of posts, we plotted coherence score against the number of topics extracted (Bao and Datta 2014). Coherence score assesses the quality of the extracted topics by evaluagiroting the pair-wise similarities between words in the same topic, adjusting for the frequency they appear in different documents (Newman et al. 2010). Figure 2 below shows that maximum topic coherence is achieved with around 28 topics.
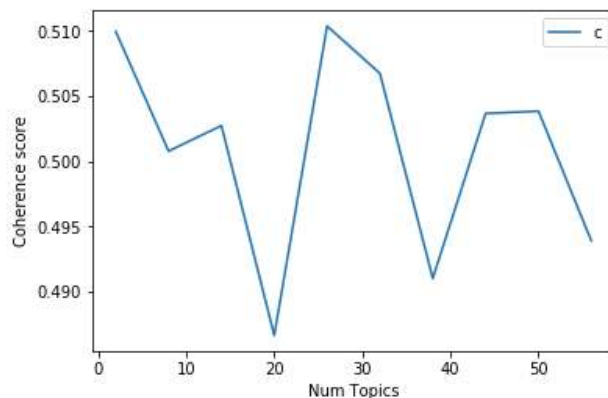

Figure 2. Coherence Score for Number of Topics

Out of the 28 topics extracted from the text corpus of all replies, we remove several topics that contain mostly general daily chatting and conversations such as dates and locations, and identify the following topics as relevant to providing informational or emotional support as shown in Table 2. We extract the top

50 keywords from each of these topics to construct the lexicons that represent informational and emotional support. Then we use the lexicon in LIWC to analyze the text of the replies each user received and calculated scores for both informational and emotional support.

Informational Support			Emotional Support		
Topic	Latent Topic	Example Words	Topic	Latent Topic	Example Words
1	Disease Management	med(icine), take, atripla, pill, lab, viral, normal, chang(e), truvada, kaletra, dose, doctor	2	Encouragement	good, luck, congrat, best, love, sorri(-y), cheer, hope, mark, wish, success, futur, resist
3	Symptoms	hiv, sympton, caus(e), risk, discuss, problem, infect, diagnos(e), syphilis, statu(s), rash	5	Comforting	mind, peac(e), trust, exam, crisi(s), survivor, fan, dig, best, accus(e), dump, honesti(-y)
4	Treatments	treatment, studi(-y), diseas(e), haart(HAART), immune, research, improve, cure, cancer, report, increas(e), cell, percentage	13	Anecdotes	depress, problem, health, medic, mental, stress, anxieti(-y), therapist, care, emot(ion), seek, counsel, suffer, better, advic(e)
19	External Information	http, www, com, adap(t), list, prescript, link, watch, info, check, pharmaci(-y), search, updat(e), blog, websit(e), onlin(e), googl(e)	14	Feelings	peopl(e), think, know, person, like, want, friend, gay, family(-y), understand, right, believ(e), tell, need, ignor(e)
24	Testing Results	test, neg(ative), result, posit(ive), week, month, confirm, conclus(ion), antibodi(-y), seroconvers(ion), window, period, accur(ate)	15	Companionship	welcom(e), read, post, forum, thank, help, member, answer, thought, repli(-y), ask, thread, question, link
25	Cause Analysis	viru(s), bodi(-y), cell, damag(e), level, human, blood, fluid, semen, bacteria, protein, expos, saliva, enzyme, contact, fight	20	Living with HIV	issu(e), time, like, day, go, work, night, year, sleep, bad, good, away, week, rememb(er), mayb(e), month, hard, life, home, bed
26	Sexual Activities	condom, intercours(e), infect, sexual, transmit, anal, unprotected, vagin(al), sti, risk			

*Letters in parentheses give example of full words.
Table 2. Topics Related to Informational Support and Emotional Support

Other Predictors and Control Variables

Word count is the number of words that a user has written in the thread-starting post. It shows how much effort the user has invested in describing the problem and elicit support from other members.

Degree centrality is the total number of social ties the user has made in the OHVC. It includes in-degrees - receiving replies from other members, and out-degrees - replies that the user provided to others.

Disclosure is the sum of 3 dummy variables for user profile. Users can choose whether or not to disclose their gender, age, and location when creating their profile. We assign 1 for disclosure and 0 for nondisclosure. So disclosure ranges from 0 to 3.

Results

We conduct the survival analysis using Stata 14.1. Because prior studies indicate that users are more likely to leave a community at early stages of joining (failure event), we assume a Weibull distribution of the survival time. We first plot the survival function using nonparametric estimation without any predictors. The Kaplan-Meier survival curve shown below in Figure 3 confirms our assumption: a large number of users stop using the OHVC just after one or two threads, and the curve flattens out after around 10 threads, indicating that users are more active in the OHVC tend to stay longer.
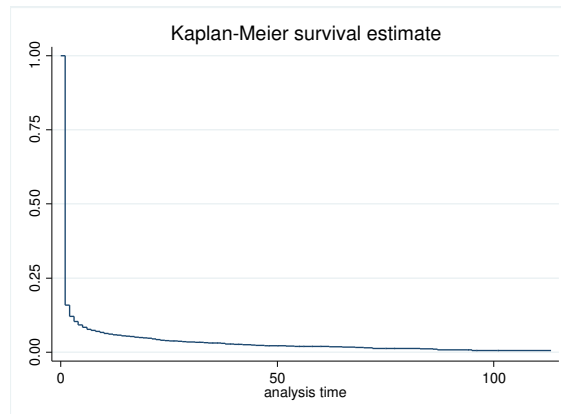

Figure 3. Nonparametric Survival Estimates

Next, we include our predictors and control variables in the parametric model. All predictors are standardized except for Disclosure. So the hazard ratio is comparing the risk of discontinued usage against a user who shows an average level of disbelief/yearning and anger/depression emotion, receives an average amount of replies and informational/emotional support, writes with average amount of words and connect with an average amount of members, and discloses no personal information in the profile. Hazard ratio is interpreted as likelihood to survival by 100% - (100%*hazard ratio). In Table 3 below, we can see that for users who shows a standard deviation higher level of disbelief/yearning, they are -192% less likely to survive, or conversely, 192% more likely to discontinue using the OHVC, when all other variables are at average level. On the other hand, users who show a standard deviation higher level of anger/depression are 31.3% more likely to continue usage.

Predictors	Hazard Ratio	SE	*P*
Disbelief/Yearning (standardized)	2.921	0.182	<0.000
Anger/Depression (standardized)	0.687	0.041	<0.000
Informational Support (standardized)	2.389	0.300	<0.000
Emotional Support (standardized)	0.399	0.063	<0.000
Number of Replies (standardized)	0.397	0.041	<0.000
Word Count (standardized)	0.112	0.010	<0.000
Degree Centrality (standardized)	0.062	0.005	<0.000
Disclosure	0.774	0.010	<0.000

Number of subjects = 14,878   Log likelihood = -7194.109
Number of failures = 13,659   LR chi^2(8) = 28473.07
Prob > chi^2 = 0.000

Table 3. Result of Parametric Survival Analysis (Weibull Distribution)

In terms of support received, users who receive a standard deviation more replies are 60.3% percent more likely to stay in the OHVC, but receiving a standard deviation over average of informational support will lead to 138.9% likelihood to leave the community, whereas receiving a standard deviation over average of

emotional support make users 60.1% more likely to stay. The control variables show that users who write longer and more elaborate posts are 88.8% more likely to stay, and those who make more connections are 93.8% more likely to stay. Lastly, users who disclose their personal information are 32.6% more likely to continue using the OHVC.

Conclusion

This study expands the literature on users' continued usage in OHVCs. We show that users' own emotional states can shape their support seeking behavior and affect their continued usage of OHVCs. These emotions are important signals of their needs and should not be ignored by other members of the community. Special consideration should be given when the user is showing high level of disbelief/yearning. These users often need more time to adjust and adapt to the facts. Forcing them to accept the facts would overwhelm the users and cause them to resist or even drop out. On the other hand, users showing anger/depression is a sign that they are reaching out and trying to share their feelings. Friendly support from other members can help these users feel welcomed and accepted and lead to long term usage. The results also confirm and provide support to previous findings that informational support only serves as a means to an end, building meaningful social ties and exchanging emotional support is the key in ensuring continued usage of users.

Limitations and Future Research

One potential limitation of this study is that "lurkers" – users who continue to use the forum without posting, are not included in the analysis. Leveraging system level data such as system logs that track user activities can effectively overcome this limitation, but dramatically increases privacy concerns due to the sensitivity of the nature of the disease. Other than system logs, there is no way to measure the unobservable activities of lurkers. However, since lurkers do not participate in the OHVC and thus do not contribute to the richness of contents and the longevity of the OHVC, it can be argued that "lurking" does not affect the goal of this study and does not pose as a critical limitation.

This study opens up potential research avenues to explore how users' emotional states can influence their perceived value of the support they receive. Users' desire for information and emotional support may be influenced by their emotional states, and they may benefit more from a certain type of social support. These research questions would no doubt further improve our understanding of the needs of the support seekers and the quality of support that online health support communities can provide.

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