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# The Use of Online Forums by People Living with HIV for Help in Understanding Personal Health Information

Adrian Bussone, Simone Stumpf, Stephanie Wilson

Centre for HCI Design, School of Mathematics, Computer Science, and Engineering, City,  
University of London, Northampton Square, London EC1V 0HB, UK

## ABSTRACT

*Purpose:* Effective self-management of the human immunodeficiency virus / acquired immune deficiency virus (HIV/AIDS) requires constant vigilance over personal health information. Little is known about the contribution of online communities to this endeavour. This paper reports a study to investigate how people living with HIV/AIDS use an online community to try to understand their personal health information by analysing how health information is shared and asked about, and how the community responds to questions.

*Methods:* A webscraper was used to gather all messages in the 200 most recently active threads in an online forum for people living with HIV/AIDS, resulting in a total of 2455 messages. These were filtered for all instances of individuals sharing their personal health information and asking the community for help in understanding it. Thematic analysis was used to determine the types of questions asked, the personal health information shared and the information that was asked about. Messages from the community aiming to address the questions were analysed using a framework of social support.

*Results:* Approximately 10% of the 2455 messages were found to be involved in this activity: 60 messages contained questions, and 192 messages responded to address the questions. The most frequent type of question was about causation. While users shared a wide variety of information about their health, they most commonly asked about reactions, lab results,

and other conditions. Nearly all the messages from the community that aimed to answer the questions provided informational support, which is a type of social support, and the community shared their own personal experiences in these responses.

*Conclusions:* This study demonstrates that online forums are used by people living with HIV to ask specific questions as a means of understanding their personal health information. The analysis provides a better understanding of the questions that people living with HIV have about their health information, and the types of support they receive from the community. The results provide a basis for further research into community support and self-management and will enable improved tools to support self-management.

**KEYWORDS:**

HIV; Social support; Support group; Health information; Internet; Self-management.

**1. Introduction**

HIV is a global issue affecting an estimated 36.7 million people worldwide [1]. While HIV cannot yet be cured, the virus can be suppressed to an undetectable level through antiretroviral (ARV) drugs. Effective self-management enables people living with HIV, as well as other long-term health conditions, to improve health outcomes [2]. Recent research [3, 4] has shown that self-management of HIV requires constant vigilance in monitoring personal health information (such as viral loads, CD4 counts, and medication compliance). However, both the virus and the ARV drugs can cause significant changes to the bodies and minds of people living with HIV, and understanding these changes in personal health information can be challenging [3, 5].

Research has shown that people living with HIV look for health information from a variety of sources, including newsletters, magazines, personal physicians, and friends [6]. Recent

research on chronic conditions has also shown that online communities and forums are often beneficial to those who are in need of information or advice [7, 8], and that the sharing of experiences and information may promote patient empowerment [5]. For example, an analysis of the health information sharing website, PatientsLikeMe, found that users view information shared by others with similar conditions in order to inform their own care [9]. An investigation into the online information-seeking behaviour of people with diabetes and chronic migraine reported that individuals often wanted to determine whether their personal health information was typical, or 'normal', for someone with that condition [10] and they sought input from others to try to understand their personal health information. While researchers have shown that people living with a chronic disease, such as HIV, use the health information of others to understand their own health information, to our knowledge there has been no previous research examining what in particular they are trying to understand: what health information they ask about, what types of questions they have about this health information and what background information they share with others. In order to support HIV+ people in self-managing their health, this paper reports a study to address this gap.

People receive various types of social support when conversing in online communities; some types of support nurture the individual (emotional, esteem, and network support), while other types of support facilitate action or comprehension (tangible and informational support) [11]. The social support that people receive in an online community has been investigated in the case of caregivers of children with autism [8], people attempting to lose weight [12], and people living with HIV [5, 13]. These authors have shown that social support exists in online forums, including forums for HIV+ people, and they have detailed how much of different types of social support is provided. Others have shown that posts about personal experiences elicit more emotional responses from the community [14]. However, it is not known how online communities offer social support specifically when responding to questions about someone else's personal health information.

This paper reports a study to address these two issues. The study entailed a detailed analysis of messages posted in an online forum for people living with HIV. The research questions were:

1. What types of questions do people living with HIV ask the community about their health information?
2. What types of personal health information are people trying to understand with these questions?
3. What types of personal health information do they share alongside these questions?
4. What types of support are offered by the community to address the questions?

The findings reported here demonstrate that online communities are used by people living with HIV as a means of trying to understand their health and reveal the specific ways in which this occurs. These results contribute a deeper understanding of the questions that people living with HIV have, the information they share and ask about, and the patterns of social support responses from the community. These details can be used as grounding for further research into community support and self-management and to improve tools that support and empower people in self-managing their health.

## **2. Methods**

### ***2.1 Data collection***

A well-known, internationally available forum associated with an established organization in the HIV/AIDS community was selected for analysis. In keeping with recommendations on ethical considerations when researching online communities [15], the forum is not named here. The forum is intended for people living with HIV, and is popular within that community. It hosts a variety of conversations related to the disease, ranging from

discussions about nutrition to updates on progress. The forum is self-policing: the community generates and moderates the content – no healthcare professionals check the quality or veracity of the information discussed. It is a public forum: no registration is required to view the messages, and all potential users are informed that the forum is fully searchable and are given a strong privacy warning. Thus, this forum is considered a ‘public’ place and it was not necessary to obtain informed consent from individual users [13, 15]. Ethical approval to conduct the investigation was granted by the Department of Computer Science Research Ethics Committee at City, University of London.

Import.io, a webscraper that goes through a website and automatically downloads its content, was used to gather the 200 most recently active threads on the forum and all messages within these threads as of 25 July 2016. Some threads had been created recently while others had been created over a year prior to the scraping. In total, the 200 threads contained 2455 messages posted by 389 unique user names. All user names were anonymized prior to analysis, by replacing them with numeric IDs.

## ***2.2 Data analysis***

A multi-step approach was taken to analyse the data set. Initially, every message was examined to determine if it contained a question asking others for help in understanding an aspect of personal health information, or if it contained a response from a community member aiming to address a question. Of the 2455 messages, a total of 252 were involved in asking or responding to questions about personal health information (10.2%); 60 messages contained questions and 192 messages aimed to address the questions. The questions were asked by 46 unique users, while 76 unique users posted messages aiming to address the questions.

All 60 messages containing questions were then examined. It was found that 11 of the 60 messages contained more than one question, resulting in a total of 77 different questions. A thematic analysis was conducted to determine the types of questions asked. As described by [16], thematic analysis involves a researcher manually exploring data to find instances of themes, also known as codes. The thematic analysis in this study drew partly on a set of previously defined codes for information-seeking [10], and also developed new codes from themes in the data. This resulted in the identification of five question types: *Did that cause this?*, *What caused this?*, *Is this normal?*, *Is this normal at this point in time?* and *What's going to happen?*.

Following the analysis of question types, the 60 messages containing questions were analysed for the health information that was being shared and the health information that was being asked about. An existing framework of 7 information types used in personal health information tracking of HIV [3] was used as a starting point for this analysis, with new information types added as necessary through open coding of the data. In total, 11 personal health information types were identified, four of which were not in the previous framework: *sexual activity*, *diagnosis* (date or time since being diagnosed with HIV), *start of ARV* (date or time since starting ARV drugs), and *reactions* (potential medication side effects or reactions caused by the virus).

Finally, thematic analysis was applied to the 192 messages aiming to address the questions, using the social support codes described by [13]. The 176 messages identified as providing informational support were further analysed to determine sub-types of informational support, as outlined by [13].



### **2.3 Reliability**

All coding of question types and social support was checked for reliability. Inter-rater reliability was calculated as the overlap of agreements [8]: a second, independent coder was provided with definitions for the question type codes and the social support codes, and asked to apply these codes to a subset of the 252 messages. Agreement for the question type codes reached 0.92, agreement for the social support main codes reached 0.95, and agreement for the sub-types of informational support reached 0.96. This indicates very high reliability [8]. Coding of information types was not checked for reliability as this involved a straightforward categorisation of specific health information rather than a judgement on the part of the coder; for example, “Egrifta” was coded as *medication*.

## **3. Results**

Each research question is addressed in turn: first, the types of questions asked in the forum are reported, then the personal health information that people with HIV were trying to understand and were sharing alongside these questions, and finally the types of social support that members of the community provided in response to the questions.

### **3.1 What types of questions do people living with HIV ask the community about their health information?**

The coding identified 5 types of question (Table I), grouped into 3 main themes: causation, normalcy and future. Two types of questions were about causation, two were about normalcy, and one was about expectations for the future. We report these questions in detail, in order of frequency of occurrence, which gives a rough indication of how important they seem to be to people living with HIV.

<i>Question theme</i>	<i>Question type</i>	<i>No. of questions</i>	<i>% of total questions</i>	<i>% of total questions, by theme</i>
Causation	Did that cause this?	27	35.06	53.24
	What caused this?	14	18.18	
Normalcy	Is this normal?	16	20.78	31.17
	Is this normal at this point in time?	8	10.39	
Future	What's going to happen?	12	15.58	15.58

**Table I: Question themes and types**

### **3.1.1 Questions about causation**

Questions about possible causation – *'Did that cause this?'* and *'What caused this?'* – were the most frequent overall in the corpus of data. These questions were often associated with changes in health. Most frequently, the person asking the question already suspected a causal relationship and was seeking input to confirm it:

*"Is HIV or treatment a factor of why my cholesterol is high?"* – User011

*'What caused this?'* was asked when the user had no hypothesis, or when they were open to other ideas regarding what may have affected their health:

*"Obviously, my medication has worked if I went from 440,000 down to 82 so quickly, but why am I hovering around 82-126?"* – User040

### **3.1.2 Questions about normalcy**

Two question types were used to enquire whether health information was 'normal' – *'Is this normal?'* and *'Is this normal at this point in time?'*. Similar to findings for people living with

diabetes or suffering from migraines [10], these questions were asked when users sought to determine if their health information was normal for someone living with the condition.

'*Is this normal?*' was the second most frequent of all the question types. Many of these questions were accompanied with a request for personal experiences, likely as a strategy for gauging the 'commonness' of health information as a substitute measure for normalcy:

*"I have been living with HIV for about a year and I have had warts running rampant throughout my body and it is taking its toll on me. I am wondering if anyone else has had experience with this? [...]"* – User016

The other question in this theme, '*Is this normal at this point in time?*', focused on the normalcy of a change, or changes, over time:

*"Results are cd4: 16! Viral load 13,027. I almost pissed my pants when the hiv specialist doc was telling me the results. That could not be right! Could I really progressed that quickly esp the fact that I was tested negative around 2 years ago?"*  
– User016

### **3.1.3 Questions about the future**

People also wanted to know '*What's going to happen?*', particularly *when* or *if* a health concern would disappear or improve over time. By asking the community to respond to this question, individuals were trying to get an understanding of a timeline for their personal information, based on the experiences of others who had lived through similar changes:

*"[...] I'm having difficulty accepting my changed body image and need to lose about 40 pounds. Can any long term users of Egriffta share their experiences? [...]"* -  
User349

However, there were also more emotional aspects to some of these messages, especially when people wanted to ascertain whether fighting against a change in health was fruitless due to the disease or ARVs:

*"[...] But one problem I'm having is somewhere about 5 to 6 years ago I began to gain belly fat. [...] I've recently started trying to watch what I eat and I'm trying to get more exercise. But I need to know if this hopeless due to the meds? [...]" -*

User351

**3.2 What types of personal health information are people trying to understand with these questions? What types of personal health information do they share alongside these questions?**

Each of the 77 questions was coded for the type of personal health information that the user was trying to understand. The coding revealed that people asked about only 5 types of information. Three of these, *lab results*, *reactions*, and *other conditions*, were more frequent than the others, occurring in 83% of all questions asked. A matrix (Table II) was constructed to show the relationship between question types and information asked about.

	<i>Causation</i>		<i>Normalcy</i>		<i>Future</i>
<i>Information type asked about</i>	<i>Did that cause this?</i>	<i>What caused this?</i>	<i>Is this normal?</i>	<i>Is this normal at this point in time?</i>	<i>What's going to happen?</i>
	<i>N=27</i>	<i>N=14</i>	<i>N=16</i>	<i>N=8</i>	<i>N=12</i>
	<i>n</i> <i>%</i>	<i>n</i> <i>%</i>	<i>n</i> <i>%</i>	<i>n</i> <i>%</i>	<i>n</i> <i>%</i>
Medication	-    -	-    -	-    -	-    -	-    -
Diagnosis	-    -	-    -	-    -	-    -	-    -

Lab Results	-	-	10	71.4	8	50.0	8	100.0	3	25.0
Reactions	8	29.6	-	-	5	31.3	-	-	6	50.0
Other	11	40.7	3	21.4	2	12.5	-	-	-	-
Conditions	-	-	-	-	-	-	-	-	-	-
Start of ARV	-	-	-	-	-	-	-	-	-	-
Weight	6	22.2	-	-	1	6.3	-	-	2	16.7
Food	-	-	-	-	-	-	-	-	-	-
Emotions	2	7.4	1	7.1	-	-	-	-	1	8.3
Exercise	-	-	-	-	-	-	-	-	-	-
Sexual Activity	-	-	-	-	-	-	-	-	-	-

**Table II: Information types asked about**

Overall, 196 pieces of personal health information were shared within the 60 messages that contained questions, with multiple pieces of information shared in each message (Table III). Because some messages contained more than one question, we were unable to divide the information shared by question type. The information that was shared ranged across multiple aspects of health and wellbeing, not all of which are obvious in their relation to HIV (e.g. *exercise, emotions, food* and *weight*). This finding demonstrates that individuals attend to and share personal health information in order to provide a wide breadth of context for the questions they asked. Some information types were shared far more frequently than others, and therefore seemed particularly at the forefront of people's thoughts when describing their situation. In particular, information about *medication* and the date of, or time since, *diagnosis* was shared in over half of the messages.

<i>Information type</i>	<i>No. of messages</i>	<i>% of total messages</i>
Medication	36	60.00

Diagnosis*	30	50.00
Lab Results	29	48.33
Reactions*	25	41.67
Other Conditions	20	33.33
Start of ARV*	16	26.67
Weight	11	18.33
Food	11	18.33
Emotions	8	13.33
Exercise	5	8.33
Sexual Activity*	5	8.33
<b>Total:</b>	<b>196</b>	

**Table III: Information types shared (newly developed codes indicated with \*)**

A more detailed description of personal health information asked about and shared will now be given by question type.

### **3.2.1 Personal health information in questions about causation**

When asking ‘*Did that cause this?*’, users were mainly asking about *other conditions*, followed by *reactions*, and sharing what they believed to be the cause – their *medication*:

*“I was on [Egrifta] for about 3 months and my tongue started turning yellow I didn't have any [side effects] any change that is before my copay went up to 700 and some odd dollars but I couldn't afford it anymore but when I stop taking the [Egrifta] the yellow and my tongue went away I think it might have been having effect on my kidney I did want to try it again but I'm afraid. Anyone ever have this problem with the yellowing of the tongue” – User359*

In contrast, *'What caused this'* questions were typically asking about *lab results*:

*"need you experts on here as i am waiting to hear from nurse.....CD4 count went from 570 to 522 (im now 6 weeks on med)....now ya'll know me and I am freaking out- WHY did it drop??? I dont have the VL back yet but shouldn't CD4 be rising? I did lab first thing in the morning. help!!!!!!!"* – User049

Usually, when asking a question about a cause for their lab results, users shared their date of *diagnosis*, either by exact date or more generally. By sharing their diagnosis as well as other health information, users were providing the community with a timeline for their lab results, giving the context for their question:

*"Hey people, am new to this and looking for support. I got diagonised [sic] recently. I did both rapid and 2 blood tests and they were positive. My CD4 count was 700 and Viral load undetectable. How possible is it to be undetectable yet not on drugs? Thank you"* – User063

### **3.2.2 Personal health information in questions about normalcy**

The majority of *'Is this normal'* questions were about *lab results*, followed by *reactions*. For both kinds of health information, users were surprised by a change in their health and wanted to determine if it was a 'normal' thing to happen. For example, users like User080 asked the community to share experiences in order to determine if theirs were normal:

*"[...] I have been on my medication for the full 3 months since my last blood test, so I thought I would be undetectable and my normal tcell level is 750 (highest ever was 780). I got my test results back last week and I am surprised and confused. My VL was 26 and my tcells were 1006. [...] Anyone ever have something like this happen?"* – User080

When asking about *reactions*, users usually thought their health concern was linked either to their *medication* or HIV. Sharing the precise name of the medication was important here; different medications cause different side effects, and so only community members who had taken that medication would be able to respond:

*"Hi Ladies, I was wondering if anyone had any changes in their periods? This is the 2<sup>nd</sup> month on meds and im pretty newly [diagnosed] – my 1<sup>st</sup> month I was right [on] time. The second month now I am 23 days late....and there is NO chance of pregnancy as my husband left us months ago. Im on Triumeq"* – User049

'Is this normal at this point in time' was always asked about *lab results* and in all of these questions users shared their *start of ARV* or date of *diagnosis*. By asking for the community's feedback, they were aiming to gain an understanding of how the changes in their lab results compared to what others had seen:

*"Hi everyone! I'm in treatment since March and my CD4 are increased from 5 to 103, that is a good signal or still a low increasement? And my VL went to 10.000 to undetectable, I never thought it would be so fast. Thanks!"* – User091

*"[...] Also, why is my CD4 this low ? Shouldn't this happen with many years of being positive? [...]"* – User028

### **3.2.3 Personal health information in questions about the future**

In 'What's going to happen' questions, users mainly asked about *reactions*. Here, users were trying to determine if a *reaction* would go away and when:

*"I've read about anxiety issues but not much about others with sleeping issues and if and how long it took to pass."* - User388



With these questions, *medication* was frequently shared, as people thought it was linked to their health, and so sharing the name of the medication, as well as how long they had been taking it (*start of ARV*), was common:

*"I found out I was positive just this January. My CD4 was pretty good (750) and my VL not too elevated (150,000). [...] I am on my sixth week on Truvada+Atazanavir(Norvir)+Reyataz. Overall I haven't had significant side effects except yellowing in my eyes, mostly on the parts covered by my eyelids so not too bad. [...] I'd like to know if anyone has had similar symptoms and if they went away at some point or if they continued as long as on that combo and if it is a determining cause to switch meds. [...] It would be great to read from someone that it will go away but if it doesn't then I might talk about switching? but what if another combo does have significant side effects? I'm a bit torn on it." – User026*

### **3.3 What types of support are offered by the community to address the questions?**

Informational support was present in 91.7% of the messages responding to questions about health information (Table IV). This suggests that the community aimed to facilitate understanding and knowledge by providing suggestions, alternative view points, or related information [11], rather than simply nurturing and comforting the person who asked the question. This points to the role of the community as an important information source for answering these types of questions.

<i>Social Support Types</i>	<i>No. of messages</i>	<i>% of total messages</i>
Informational	176	91.7
Emotional	56	29.2
Esteem	15	7.8

Network	15	7.8
Tangible	1	0.5

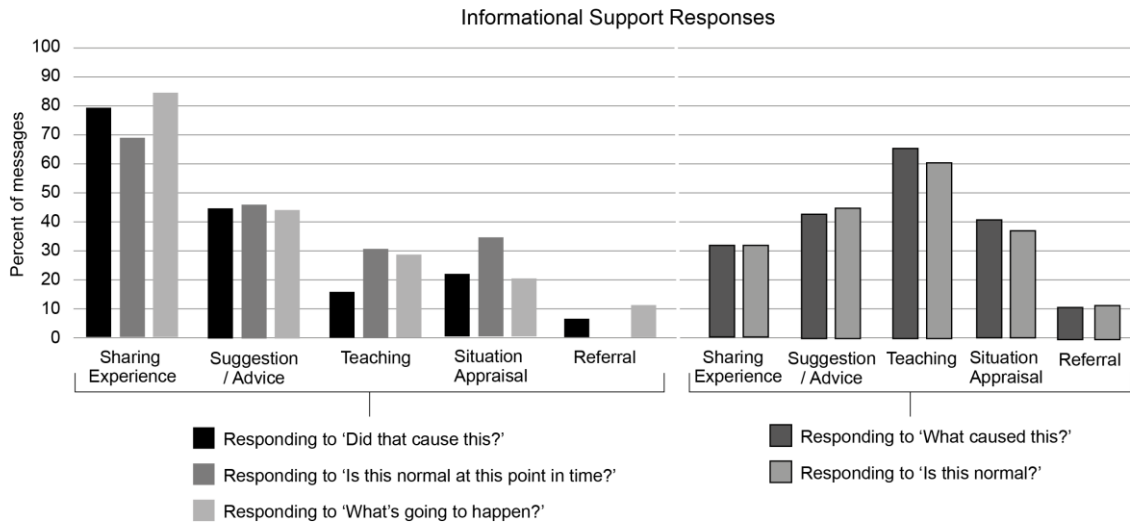
**Table IV: Social Support types**

Given the dominance of informational support in the responses, the kind of information provided was further analysed by applying the five informational sub-types defined by [13] (Table V). The three most common sub-types across all question types were *sharing own experience*, followed by *suggestion / advice* and *teaching*. While the latter two sub-types provided more general information about health and HIV, by sharing their own experience community members provided their own specific personal health information back to the individual posing the question.

<i>Informational sub-types</i>	<i>No. of messages</i>	<i>% of total messages</i>
Sharing Own Experience	105	54.7
Suggestion / Advice	81	42.2
Teaching	62	32.3
Situation Appraisal	48	25.0
Referral	20	10.4

**Table V: Informational sub-types**

The different ways in which information was offered in response to each question type were further investigated (Figure 1). It was found that for responses to *'What caused this?'* and *'Is this normal?'*, the frequency of the three most common informational sub-types was opposite to those received by the other three question types; *Teaching* and *Suggestion/Advice* were more common than *Sharing Own Experience*. Examples of the differences in these responses follow.



**Figure 1: Informational Support responses to 'Did that cause this?', 'Is this normal at this point in time?', 'What's going to happen?' (left), and 'What caused this?', 'Is this normal?' (right)**

The informational support in response to questions about *'Did that cause this'*, *'What's going to happen'* and *'Is this normal at this point in time'* frequently involved a community member's own experience, often providing a timeline or sharing their own personal health information in response. For example:

*"Hi, When started Triumeq I had trouble sleeping and vivid dreams when I did sleep, however this passed. I just stuck with it. [...]"* – User002, responding to a question about insomnia as a reaction to Triumeq

*"[...] I had jaundice again when I first started Reyataz. my eyes were just a little yellow tinged. I called the doc and he took a look. he agreed it was mild, warned me of other side effects or worsening side effects to keep an eye out for. My eyes cleared up a short time (a week?) later and I had no other effects. [...]"* – User007, responding to a question about jaundice as a reaction

*"ojo Hello user004 and user065, be patient, eventually you guys will get to UD level...you want to know how long it took me to get an UD level?...from November*

*1994 (dx) to March 2007...do the math, I have just ten fingers, and this happened because of treatment failures, my meds didn't work, resistance to all kind of meds, in your case, your med is working, so, relax and you will get there...hugs ojo” – User008*

In contrast, the responses to questions about '*What caused this*' and '*Is this normal*' mostly involved *teaching* informational support. Most of these questions asked about lab results, and thus general help in understanding and interpreting this type of health information seemed to suffice:

*“CD4s fluctuate throughout the day by as many as one hundred points or so. [...] Your CD4's are above 50, so [you] are in a “normalish” range.” – User059*

#### **4 Discussion and Conclusions**

This work contributes a deeper understanding of the role of an online community in helping people living with HIV make sense of their personal health information. The results showed that causation and normalcy of their health information, mainly involving lab results, reactions and other conditions, were the most common focus of questions by people with HIV. To provide context for their questions, people shared a wide range of personal health information, with medication taken and date of diagnosis featuring most frequently. In turn, the community responded to such questions with informational support, largely drawing on their own personal health experiences. The results confirm that people living with HIV are active in self-managing their disease and that the online community plays an important role when they try to understand personal health information.

These findings show that, like those living other chronic conditions such as diabetes, people living with HIV take an active role in self-managing their health. They pay attention to a wide variety of information types, including those that are not necessarily obvious in their relation to HIV, showing the far-reaching effects that the disease and ARVs have on the body and

mind of HIV+ people. The findings also show that HIV+ people seek to understand their health information by turning to their communities, again like those living with chronic migraines or diabetes [10]. This study, additionally, has built upon previous research by detailing how communities aim to address these questions: online communities provide informational support mainly based on their own health experiences to help individuals understand their health information. Looking at the accuracy and usefulness of the information that was shared was outside the scope of this study, but further research is warranted on this topic. While this study focused on people living with HIV, the approach could be applied to other chronic diseases in order to determine if the question or response types seen here are generalizable.

The results reported here can drive the development of much-needed tools to support HIV self-management. While there are a plethora of tools available for the self-management of other chronic conditions (e.g. measurement and tracking applications for hypertension or diabetes), there is a notable lack of tools tailored to HIV. These findings show that people living with HIV are interested in tracking information such as their emotions, food, weight, and exercise in addition to those information types directly related to the disease. This supports previous research by [3]. Current tools, such as BeYou+ [17], only allow HIV+ users to track their lab results, medication compliance, and consultation appointments [18]. Based on these results, self-management tools for HIV should allow users to track more types of personal health information. Additionally, these findings highlight the importance of using the health information of others in trying to understand personal health information. Tools like PatientsLikeMe currently facilitate viewing the information of others [9]. However, they do not enable users to examine both their personal health information *and* the information of others in the same visualization. We believe that such tools could better support individuals in understanding their own health information by providing better scaffolding for the socially-mediated reflection that is already occurring in online forums. With these

changes, tools for self-management will enhance conversations about health information and enable understanding of health experiences.

Finally, the results of this study indicate a need for further research into informational support in order to fully understand the role of community in making sense of health information. Throughout their lives, people with HIV can find themselves uncertain about their health information. The results reported here provide details about how an online community is used to ask and address questions about health information, but there are many other settings in which conversations like these may take place. Additional work should examine in-person settings, such as support groups and consultations with healthcare professionals, to determine whether more types of questions are also being asked. Moreover, the process of healthcare is changing with the push for patient self-management, and the roles of both patients and professionals along with it. The research reported here explicates one way in which this change is challenging the healthcare professional's traditional role as the knowledge broker, and sheds light on the need to re-examine this role and find new ways of ensuring patients receive appropriate and factual information outside of the clinical setting. This would contribute to a deeper understanding of how the interactions focused on in this study weave in to the larger healthcare process each individual goes through, and how it may empower them in taking charge of their health.

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### **Conflicts of Interest**

None.

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