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Personas In Online Health Communities

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Abstract

Many researchers and practitioners use online health communities (OHCs) to influence health behavior and provide patients with social support. One of the biggest challenges in this approach, however, is the rate of attrition. OHCs face similar problems as other social media platforms where user migration happens unless tailored content and appropriate socialization is supported. To provide tailored support for each OHC user, we developed personas in OHCs illustrating user s' needs and requirements in OHC use. To develop OHC personas, we first interviewed 16 OHC users and administrators to qualitatively understand varying user needs in OHC. Based on their responses, we developed an online survey to systematically investigate OHC personas. We received 184 survey responses from OHC users, which informed their values and their OHC use patterns. We performed open coding analysis with the interview data and cluster analysis with the survey data and consolidated the analyses of the two datasets. Four personas emerged—Caretakers, Opportunists, Scientists, and Adventurers. The results inform users' interaction behavior and attitude patterns with OHCs. We discuss implications for how these personas inform OHCs in delivering personalized informational and emotional support.

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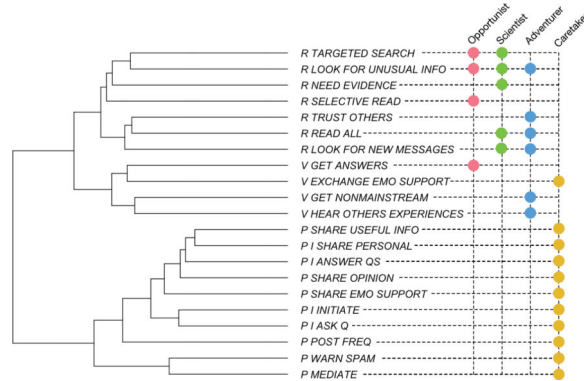
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Graphical abstract



Keywords

online health community; patient support; consumer health informatics; social support; persona; online health information seeking

1. INTRODUCTION

Studies demonstrated online health communities (OHCs) help patients improve both psychosocial and behavioral health aspects [19, 41]. However, some challenges with using OHCs as an intervention are retention and attraction [12, 52, 54]. Technology based health interventions often share these challenges. The key to improving retention is to address tailored needs of each user, provide tailored content, bring socialization support including peer influence [27, 54]. OHC based interventions need to understand the tailored needs of each user and address the kinds of support the user wishes to get out of the OHC.

Each patient has unique needs in using OHCs. Some want to get quick answers to their questions while others just need someone to talk to [23, 50]. OHCs have an abundance of information and members' experiences. These resources can be helpful, overwhelming, or even disturbing depending on the needs visitors have. OHC users have complex, serious—sometimes life threatening, health-related needs stemming from various aspects of their lives. Examples include: personal life, stages of illness (e.g., newly diagnosed vs. settled in managing illness), complications, and preferences and philosophies toward approaching the illness. These personal contexts result in unique and complex OHC user needs. Providing personalized informational and emotional support will further improve the experience of those visiting OHCs and providing the help they need.

The first step to developing retention strategies tailored for each user is to understand what kinds of user groups visit OHCs and what their needs are. In this paper, we identified these user groups by clustering characteristics of members in online health communities. We conducted interviews with 16 OHC users and administrators (14 and 2 respectively) and an online survey with 184 participants in varying stages of illness and online community use. Based on our findings, we present personas representing varying user needs in their interactions with OHCs and requirements for delivering personalized support in OHCs.

2. BACKGROUND

Persona

In the field of human-computer interaction, personas have been used to clarify user descriptions [3, 11, 33]. Personas help designers to focus on primary users, specifically around their behavior patterns to the interested system and their user needs. Personas have been used as a way to communicate with various stakeholders to guide design requirements and evaluate design [17, 34, 35]. There is no set approach to developing personas—personas can be created at the beginning of a design process or evolve throughout the design process [7]. Researchers have suggested personas to be developed from “sound field research” [17] and should be associated with methodological rigor and data [36]. However, at the same time, personas can come not just from user studies but also from the designers’ assumptions, experiences, and other possibilities such as ad hoc assumptions [31, 35]. Personas help when user study results require interpretation beyond its objective measure, such as the data of young children [1] or when the resources are limited [35]. As such, personas are a useful method to understand user types, behavior patterns, and needs, and communicate with the stakeholders in terms of design and research possibilities. Studying personas of online health communities can then give insights to what user types we should support for online health information environments and how.

Social types in online communities

Researchers developed a number of social types and roles online that can be considered as a persona, but are strongly data-driven. Fisher et al. [14] divided online community users into two categories—information providers and information users. Golder [16] described newbies, celebrities, elders, lurkers, flamers, trolls, and ranters. Kim [25] described how social types change over time as their participation with the communities increases: from visitors to novices, regulars, leaders, and elders. Turner et al. [47] described: answer [person, questioner, troll, spammer, binary poster, flame warrior and conversationalist]. All of these social types were defined by user s’ posting and participation behavior.

The distinctive nature of OHC users—psychosocial issues and values involved in illness management —adds complexity to how social types can be categorized. In addition to the personal context around having the illness, privacy issues, information quality, and legality emerge as new issues in understanding OHC users. Thus, posting and participation behavior should not be the only measure in which social typing occurs. Such existing models of social types and roles in online communities fall short in addressing psychosocial and informational aspects strongly tied to illness management. We should develop understanding about what personas are available, incorporating all aspects of information behavior — emotional, interpersonal, and psychosocial characteristics in user s’ interactions with OHCs.

Online social support

The literature on OHCs emphasized the crucial role of social support exchanged among the community users [32]. Self-help groups, such as Alcoholics Anonymous®, are established based on the fact that patients want to help others, which helps the patients themselves as well [28]. Numerous studies showed how psychosocial help in OHCs led to successful

illness management [38, 40, 53]. Interacting with peer as mentors significantly improved patients' diabetes conditions compared to receiving help from the nurse navigators [19].

Still, not only psychosocial support but also informational support plays a critical role in OHCs. The social support theory categorized both emotional and informational support as core constructs under social support [8]. Studies have shown that patients visit OHCs to ask questions on the illness, gain peer s' expertise, and educate themselves about daily management strategies [23].

As such, OHC users develop multifaceted needs, wanting both psychosocial and informational support. Furthermore, each individual with complex needs due to varying illnesses, complications, personal contexts, and learning styles will all have to be taken into account. Thus, the advanced interfaces developed towards large-scale online conversations might only partially address the OHC user s' needs because these interfaces were not intended to support such complex illness contexts. Whether users perceive current OHCs as useful, as a solution to their personal problems, is uncertain. Identifying what user types and needs there are would be an important next step.

3. METHODS

To identify complex and diverse characteristics of members in OHCs, we first conducted 16 interviews. Based on the interviews, we generated initial groupings of personas based on open coding [45] and affinity diagramming [4]. Based on initial findings, we constructed survey questions and distributed surveys (184 respondents) to finalize clusters of persona. Combining and cross-validating the results from both ends, we extracted distinctive personality traits, called Personas, and their behavioral characteristic and values sought in OHCs. All studies were approved by the Institutional Review Board of the authors' institutions, and the participants were given an informed consent to participate.

3.1. Interviews with OHC users

We conducted a total of 16 interviews. Among the interviewees, 14 OHC users were either diagnosed with diabetes (both type I and II), have concerns about diabetes or overall wellness. The two remaining participants were OHC administrators who shared their experiences overseeing multiple online health communities. We chose diabetes as our starting illness topic because it is a chronic illness where patients can benefit from both emotional and informational support [26]. We recruited participants at all stages of managing diabetes and OHC use. Accordingly, we included those who were undiagnosed but concerned with diabetes and those with varying levels of experience using OHCs. The recruiting sites were diabetes-related online communities and subgroups (7 participants from 3 online diabetes communities, 5 participants from reddit.com, and 1 from a diabetes Facebook group) and 3 from co-authors' social network (e.g., recruiting flyer disseminated through Facebook status). The age of the participants varied from 19 to late 60s. OHC user participants included 8 females and 6 males, 1 type I diabetes, 8 type II diabetes, and 5 undiagnosed but with concerns about diabetes. The two OHC administrators were male and one was a caregiver of a diabetes patient. Our OHC user participants' number of years since

diagnosis varied from undiagnosed to 2 weeks to 20 years. Also, their experience with OHCs varied from one-time users, lurkers, to regular users.

The semi-structured interviews took 1 to 1.5 hours for each participant. We asked OHC user participants to share their experiences and concerns around diabetes and using OHCs. For instance, we began with asking them “When was the last time you visited an OHC? Could you walk us through it?” We used Dervin’s Sense Making method [9] to first allow participants to walk through their experience and triangulate on critical events, such as not finding the information they wanted or starting participation in a new OHC. We then gave them a webpage we created, which contained 206 diabetes community threads on the Atkins diet downloaded from a publicly accessible online diabetes community. We did so to remove distracting links and advertisements. We chose the Atkins diet as the topic because it helps us to probe on factual as well as experiential knowledge (e.g., What were the experiences of Atkins diet users?), which is representative online community content. We asked our participants to find what they want to know further about the Atkins diet as if they are reading through community threads. During this process, we asked probing questions to further understand their choices of what to read and why. For the interview with the OHC administrators, we asked what types of patients they like to support in their communities. We then probed what different patients there might be and how they attempt to support them differently as administrators. We then shared our results to check whether the findings concur with their understanding of the OHC user types in their OHCs.

All interviews were transcribed. Using open coding analysis [44], all authors first analyzed one participant’s transcript together. We then shared our thoughts and initial codes. We negotiated and merged our codes, with which we further coded the rest of the interviews while allowing for new codes to be developed. At least two coders analyzed any one participant’s transcript. Through the affinity diagramming exercise [20], we identified emerging themes and personas, particularly around characterizing OHC use. As seen in the Figure 2, we lumped usage characteristics, patterns, and the values participants stated about using OHCs. We then developed survey questionnaires based on the themes and personas around OHC use (Table 1). The resulting preliminary findings are described in Section 4.

3.2. Online survey

The interview results gave us preliminary results on personas that helped us characterize values people have in OHCs and their usage patterns and preferences in reading and posting on OHCs. We used the findings to construct the survey questions on how much respondents agree with the values, reading, and posting patterns in using OHCs and the grouping of personas that we observed from the interviews (Table 1). We followed general rules in Likert scale on agreement with statements [10]. We added questions on demographics and experiences with the illness of interest, followed by questions on: (1) values in using OHCs, (2) posting behavior within OHCs, and (3) reading behavior within OHCs. We also included open-ended questions for each category (i.e., values, posting behavior, and reading behavior) to elicit respondents’ values and usage patterns not addressed by the Likert scale questions.

We recruited survey participants from two main sources: (1) online health communities and (2) online advertisements (Facebook Ad and Google Ad). From our interviews, we learned

that recruiting individuals with diabetes from online health communities resulted in an extremely low response rate (n=14 responded from three online communities, Reddit, and Facebook). To recruit a larger number of survey respondents, we widened the illness context to including all chronic illnesses: HIV, cancer, diabetes, weight management, heart disease, ADHD, Parkinsons disease, fibromyalgia, depression, and bipolar.

Recruiting from online health communities—We systematically searched on a search engine for online health communities using the keywords: “[illness name] online health community.” We identified a list of online health communities meeting the inclusion criteria, which are: (1) the community allows researchers to post recruitment flyers and (2) the community provides information on an email or message system to the community moderator. The exclusion criteria were: if the community had a policy that prohibited solicitation of research recruitment and that the community was listed outside the first page of the search results. For the 13 final communities that met the inclusion criteria, the first author sent an email to the moderators with the flyers or posted directly to the community depending on each community’s policy.

Recruiting from online advertisements—We also created a Facebook page with a link to the online survey. We registered the page to Facebook Ad, adding target populations as those related to the keywords listed above and recommended keywords from the Ad tools. Examples included: “diabetes support groups,” “community support groups,” “demential family support group.” We also created a website with the link to the online survey and registered the website to Google advertisements, specifying the list of keywords above as the target population. For the Facebook Ad, we received 164,952 total reach (showed up on their status) and 2,908 total clicks. Google Ad reached 362,587 users, out of which 1,997 clicks were made. The average position of the Ad was 1.61.

3.3. Analyzing the survey data with the interview findings

After the descriptive analysis of the overall survey results including non-response rates for each question, we performed imputation on missing data using the mean [21]. We then selected the core questions regarding personas: values, posting, and reading behavior for the cluster analysis. We performed a cluster analysis based on the Euclidean distance and visualized the results into a dendrogram (See Section 6, Figure 3). We compared the cluster analysis results against the initial interview findings on the group of personas. We used the R statistics software [6] to perform these analyses and the dendrogram visualization and wrote a D3 java script [5] for the cluster visual shown in Figure 4. We used the Google spreadsheet [24] for the affinity diagramming exercise.

Next, we describe how we developed the survey questions based on the interview findings around user patterns of posting, reading, and value seeking behaviors in OHCs. We then present personas that emerged from the cluster analysis of the survey results, linking back to the qualitative interview data.

4. FINDINGS 1 : SURVEY QUESTION CONSTRUCTION AND OVERALL SURVEY INFORMATION

From the interviews, we identified three themes that corresponded to usage patterns which distinguish user s' needs in OHCs: Reading, Posting, and Values sought.

The *reading* category involved their knowledge-seeking attitude, information seeking methods, and the amount of reading per visit. Some participants fully trusted what others posted and valued hearing about others' personal experiences, whereas others looked for scientific evidence. Some performed targeted search and selectively read certain posts, rather than reading all posts. Others had to read new messages as they came up so that they could keep up with the forum.

The *posting* category involved their frequency of posting, how often have they asked questions to others, whether they tend to initiate threads or answer other people's posts, or both. They also posted varying information—from useful information that others could benefit from sharing their own personal experiences. Some preferred not to share their own stories because they felt the story was not validated.

The *values sought* category involved reasons why the participants visited OHCs. Some valued emotional support they could receive from others and build a community together. Others did not want to socially interact with other community members. These participants wanted to get the information they needed and leave. Some used OHCs as a place to get answers to their questions or get non-mainstream information that their doctors would not provide.

Preliminary findings on personas

From the affinity diagramming exercise (Figure 2), we identified 4 personas that grouped together: Caretakers, Opportunists, Scientists, and Adventurers. These personas were not mutually exclusive; instead an individual can possess a few traits from each persona, or transition from one persona to another.

The main motivation to participate in OHCs for *Caretakers* is altruistically oriented. Caretakers desire emotional support exchanges more than information seeking. Caretakers would be experienced OHC users who want to take care of the community as their own. Thus, their visiting and posting activities would be higher than others.

On the other hand, *Opportunists* opportunistically find information from OHCs and are not necessarily interested in interacting with other members. For instance, they come to OHCs because a web search portal brought them to one conversation thread in the OHC site. They would not necessarily create memberships with the OHC, since they moved onto another website after receiving the information they needed from the OHC.

Scientists illustrate characteristics of the kinds of information OHC users value. Scientists care about the scientifically accepted evidence—it has to have numbers and citations back to its original source. These users might not trust other members' experiences. They can refrain

from posting about their experiences and opinions because they feel their personal experiences are not validated.

Adventurers, on the other hand, value personal experiences and information not available from their providers. They seek new information that might not have been approved by the scientific community.

These four personas illustrate various values OHC users have in using OHCs and their OHC use patterns. Because personas are transitional and one person can have multiple personas, a larger scale survey can explain how these personas cluster around OHC use patterns and sought values.

We translated these findings into a questionnaire, asking about demographics, reading and posting behavior, and values sought from OHCs. The questions in conjunction with descriptive findings are shown in Table 1.

OHC administrators' reactions to the findings

According to the OHC administrators we talked to, the goal in managing online health communities is to ensure: (1) those who need help get help, (2) to monitor conversations that can be destructive to the community, (3) to understand patients' illness stage and provide appropriate help accordingly, and (4) to provide personalized help to the OHC members. OHC administrators perform these four tasks manually by reading the community threads everyday and monitoring them closely. Accordingly, some automated ways to detect these notable activities would be helpful for them. When presented with the potential personas and their illness contexts, the OHC administrators agreed that the personas aptly described the patient profiles they had in mind as they moderated their OHCs. Furthermore, the OHC administrator noted that the majority of the community members would fall into the category of Opportunists—the lurkers—many of whom might need help, due to their newly diagnosed state.

5. FINDINGS 2 : OVERALL SURVEY RESULTS

In Table 1, we show the overall survey results. We found the majority of the survey responders were in their ages between 30s and 60s (AGE¹), Female (GENDER), and have at least some college education (EDUCATION). The majority of the survey respondents were White (RACE AND ETHNICITY), married or divorced (MARITAL STATUS), and working (EMPLOYMENT). The respondents were interested in diabetes and weight management, and were mostly diagnosed between 1 and 5 years.

The majority of the responders never posted on OHCs (P_POST_FREQ). The responders' situations did not pertain to the questions on why and how they post in OHCs (POSTING BEHAVIOR). The responders also mostly did not have strong opinions for what kinds of posts they read (READING BEHAVIOR). However, their agreement to our suggested reasons for visiting OHCs (VALUES SOUGHT) was higher than for our questions around

¹This label refers to the survey question labels described in Table 1.

reading and posting. The highest motivation for visiting OHCs, according to the average responses, was to hear about others' experiences, followed by being able to get non-mainstream information. When we qualitatively analyzed the "other" category, we did not find any new motivations for reading, posting, and values sought from OHCs. About a third of the participants responded to the open-ended questions. After excluding uninterpretable responses (e.g., "N/A" and "...?"), we found the majority of the responses concurred with the existing answers in the Likert scale questions. For example, for the "other" category for the reading behavior, we filtered out the answer of "... I pick the individuals I know are reliable and know what their talking about" because this answer was in line with the Likert scale question of R_TRUST_OTHERS.

The open ended responses of the "other" category, however, gave us a better context for how participants interpreted what their values were and how they would read and post in OHCs. We found a number of insightful answers, although they came from a small number of respondents. Some respondents scanned all messages instead of reading and one respondent selected and read unanswered messages to see whether he or she could help other OHC users. Some respondents wanted to get or provide public support for their ways of managing illness by posting messages on OHCs. A respondent simply wanted to share everyday life with the group members. Some respondents answered that generating personal, private connections was the value what they received from OHCs.

These results show the majority of OHC users who were also responders of our surveys were casual visitors rather than committed members who have strong opinions for what kinds of posts they make and what kinds of posts they desire to read.

6. FINDINGS 3: CLUSTER ANALYSIS AND PERSONAS

From the cluster analysis, we discovered largely two distinct clusters. The first half of the dendrogram illustrated the characteristics of "Receivers" in OHCs. Depending on members' values sought and behavioral characteristics, the receivers categorized as (1) Opportunists, who aim to learn about specific questions, (2) Scientists, who aim to find scientific evidence, and (3) Adventurers, who seek alternative and novel approaches for disease treatment. These clusters reinforced our preliminary findings from the interviews. The second half of the dendrogram represented the characteristics of the "Givers" in OHCs, who willingly share knowledge and emotional support and help other people. We labeled this altruistic behavior as Caretakers (shown as yellow circles in Figure 3), which derived from one of the interviewees' description of the altruistic activity (e.g., coddling) of providing emotional support to one another in OHCs.

At any given time, one individual can have characteristics of more than one of the personas, while possessing a dominant persona. This individual can also move from having one persona to another over time as the individual's personal contexts and needs change. Accordingly, our survey results as well as interview results show that the three personas (e.g., opportunists, scientist, adventurers) are not mutually exclusive. People can have a mixture of personas with varying levels in each, as we will discuss later in Section 6.6.

Below, we walk through each persona, supplementing the results using the qualitative interview data together with the survey data.

6.1. Receivers

78 out of 184 (42%) survey participants on average scored at least 4 (Agree) or higher (Strongly Agree) to the questions in the Receiver cluster. Main activities of Receivers are to read rather than to post (²Receivers x P_POST_FREQ x Never| A few times a year| A few times a month: 69%), and they considered information from OHCs as a useful resource (Receivers x V_GET_ANSWERS x True| Very True: 76%). The Receivers amongst themselves might disagree on the types of information they trust, the kinds of information they seek, and the degree to which they consider OHCs as a regular place to visit. However, over time, such preferences change based on the needs of their illnesses and their developing relationships with other members in the community. Largely, we saw three characteristics under the Receivers that explain these varying perspectives— Opportunists, Scientists, and Adventurers.

6.2. Opportunists: OHC as a place to opportunistically find information

39% (71/184) of all survey participants on average responded 4 (Agree) or higher on the Opportunist cluster questions.

Landing user, lurkers—Opportunists are not necessarily regulars or frequent visitors of an OHC like Caretakers might be (as will be later discussed). Newly diagnosed patients have many questions that they do not know where to find answers to. They can be Opportunists, who land on a thread of OHCs from a search portal. Opportunists are not registered in any forum (P8, P9³). Extreme opportunists get what they need from the thread and leave (P8). They rarely stay to browse the community further; but if they do, they lurk or post one post at best (P8; Opportunist x P_POST_FREQ x Never| A few times a year| A few times a month: 68%). Opportunists consider OHCs as a place to get people's experiences (Opportunist x V_HEAR_OTHERS_EXPERIENCES x True| Very True: 89%) for triangulating with other Web search results and gaining information that only OHCs can provide. Examples of such unique information OHC provides included obtaining information on new innovative treatments that their providers might not readily give (Opportunist x V_GET_NONMAINSTREAM x True| Very True: 73%). Such opportunistic OHC use is reflected in both Scientists and Adventurers.

Opportunists do not go to other threads within the community after reading the thread—they come back to the list of search results (P6, P9, P12). Thus, Opportunists feel neutral about ownership or social linkage with other community members (Opportunist x P_SHARE_EMO_SUPPORT x Never| Rarely| Sometimes: 55%). Opportunists browse through many search or curated search results to get to an OHC. When asked how the participant found the OHC thread she mentioned, P4 could not remember:

²To describe survey results of a group of people on specific questions, we will use the following notation: (Group name x SURVEY QUESTION / CATEGORY LABEL x RESPONSE CATEGORY 1| RESPONSE CATEGORY 2| ...: Proportion of the response categories over all responses).

³These are the references to the interviewees.

Oh, Jeez. How do you ever get to anything on reddit? Seeing it cross-posted or hearing people talk about it in a different sub reddit... Just browsing through, I guess (P4).

Since Opportunists are not bound to one community, unlike Caretakers who find “everything under the sun” (P9) from one OHC, Opportunists like to triangulate the information found from an OHC with other information sources:

Once I make sure the information’s correct, then I go back to the search results and then I just look for some blog or some online community that talks about the diet [from the] people who tried to do that diet (P9).

Skim and move on—Opportunists do not necessarily read all posts in depth (Opportunist x R_READ_ALL x Agree| Strongly Agree: 55%). They get what they need and leave. They skim not only OHCs but also other websites as part of their information gathering process. P9 described a representative way of Opportunists’ information search in general:

I go for a news article and see how many weights have he (a celebrity) lost, for how long, how many days or months. [...] I will jump to the next [search] results and see if it’s more related to me (P9).

During P9’s information search process, OHCs might or might not be included. For instance, P8 described how she travels in and out of OHCs through unguided browsing:

a friend will put something on Facebook “I just ran a marathon, read about it on my blog,” And then I’ll go to her blog, and then someone on the blog will comment about, “Oh, I had a similar experience. Come read about this at my Tumblr page or at this group on this website”. And so, I’ll just follow the electronic breadcrumbs and end up reading about other people’s experiences (P8).

In favor of fast browsing, they also care about the cost of reading, such as time and effort, when opening up a thread. They look for specific things in the posts:

I don’t want to read all the texts and stuff. I’m looking for intersections of specific things. I don’t want to spend a lot of times reading posts and see which posts will fit for me (P9).

Opportunists look for numbers, signaling words, or pictures (P8) to skim and read only those posts that catch their interests or are relevant to them. P4 described her recommendations on how to make skimming efficient:

I think that maybe two lines of information in the search result to further read more would be more useful, so that you could have a better idea of whether the rest of the post is going to be pertinent (P4).

Value product reviews and experiences—Although Opportunists find it difficult to efficiently find factual, practical information, they see OHCs as a place to hear about others’ experiences (Opportunist x V_HEAR_OTHERS_EXPERIENCES x True| Very True: 89%). For instance, P12 saw OHCs as not offering practical advice:

[One site I found] was a bunch of people talking back and forth and not really offering any real advice, I guess (P12).

They find OHCs as a place to get “reviews,” similar to Amazon product reviews (P6). For instance, P6 and P9 described what they would use OHCs for—as a place to get individuals’ experiences on a regimen:

The only time I would consider reading [OHCs] would be after I feel I have a background [from] diabetics associations or whatever, and then consider reading this for individual people’s experiences (P6); I Google-ed their diet and the forum to see if normal people like me did this and was working for them (P9).

Similarly, P7 described how she would compare resources from the Google search results against the answers retrieved from OHCs (Opportunist x P_I_ASK_Q x Sometimes| Often| Always: 64%):

if I can’t find anybody on the forum that tried it, I can ask, “Has anybody tried this? What were your experiences with it? How did you like it?” (P7)

6.3.Scientists: A transitioning patient--Skeptically, OHC as a place to gain information

35% (65/184) of all survey participants on average responded 4 (Agree) or higher on the Scientist cluster questions.

Either an active moderator or a silent researcher—Depending on their level of participation, Scientists can be active moderators or silent researchers (Scientist x P_POST_FREQ x A few times a week| Everyday: 43%; Scientist x P_POST_FREQ x Never| A few times a year: 43%). One important characteristic that distinguishes Scientists from others is that they like to verify information shared in OHCs. Scientists continue to test and look for strong evidence from the information shared around OHCs (Scientist x R_NEED_EVIDENCE x Agree| Strongly Agree: 65%).

Such a characteristic is helpful to have as a moderator, who monitors inappropriate information exchanges among members. Also, for those looking for a new regimen because they are having problems with an old one, gathering valid information on the new regimen would be critical. P2, with experiences in moderating general online forums, wanted to make sure that no misinformation is being shared, especially for information which does not pertain to every individual. P13, who also has been a moderator for multiple online forums, makes sure the community is free of any arguments or inappropriate posts:

Mainly I’m looking for any flagged posts, any arguments, people getting rude. Sometimes you get spammers (P13).

Survey respondents who on average agree to the Scientist cluster questions did not strongly agree to seeing themselves as playing moderator roles (Scientist x {P_MEDIATE, P_WARN_SPAM} x Often| Always: {16%, 26%}). This finding is consistent with the fact that only a handful of people become moderators or informal leaders of the communities [25]. In the interviews as well, other participants with the characteristics of Scientists showed an opposite behavior in terms of community involvement. Since Scientists believe

that they should have an actual experience or evidence of a success or failure in managing diabetes to post anything, Scientists remained as silent researchers for many years as P8 did:

I don't really feel like I've made any weight loss progress, so I don't really feel like I have reason to make a post (P8).

Information scent for judging quality and relevance—Scientists can be skeptical about information shared online. Thus, Scientists look for all possible indicators about how valid the shared information is. Scientists search for specific information. Thus, they do not embrace, like Caretakers do, irrelevant conversations, such as sidetracked conversations or personal chats. Some participants were skeptical about certain information being shared in OHCs:

I don't know if I can trust these online forums. It's people who just say, "Oh, I've tried this diet, it's not working for me." But how do you know they did it 100%, or if they are doing it wrong? (P9)

Accordingly, Scientists need to see strong evidence to trust what other members are sharing. P4 noted the importance of "science-based" information that relates to generalizability over anecdotal evidence:

[I need] something that's more science based and relatable to the general public than just one person. [...] you often get a lot of things that aren't very reputable and are not really backed up by any science (P4).

As cues for credibility, Scientists look for references, numbers, and recent postings (P8). They will also cross-validate multiple forums to validate information (P9). P9 did not trust posts with URLs in the end, because it might be a link for a promotion page to a product. Scientists will also look at whether a post is paragraphed or just a "giant wall of text" to assess the quality of the post. P9 saw that "hot necessarily people who wrote long text replies are good."

Although these simple cues can serve as the "scent" for detecting quality, often Scientists have to read further to get a good sense of how valid the information being shared is. Scientists need to closely check who the posters are so that they can judge if the person is "flagged somewhere else working for whatever company" (P5). Also, when members present information "moderately, not extreme" (P8), those members would gain readers' trust.

Unlike Caretakers, who read all the posts whenever possible, Scientists would stop reading the thread when members start to veer away from the main topic and become irrelevant (P6, P8).

Finding others' experiences within spheres—As they make sure information is accurate, Scientists want to retrieve relevant information for their needs. They value others' experiences shared in OHCs (Scientist x V_HEAR_OTHERS_EXPERIENCES x True| Very True: 97%). However, for these experiences to work for Scientists, they need to verify that these experiences are applicable to them. Scientists have specific "spheres" they consider as important in finding the information they need. Spheres refer to areas of interest or

constraints, such as money or primary health interests (e.g., losing weight or being heart-healthy) (P8). For instance, patients with type I diabetes will not want to read experiences of type II diabetes patients (P7). Similarly, for Scientists, it is important to know the posters and their profile in depth so that they find others who have similar concerns:

“This is what you need. You just need to eat that vs. this and this.” But who did that? And what is that person’s condition? And why didn’t he do that? I need to learn more about why they did that and how did they do that (P9).

P5 also looked for a similar demographical profile when trying to learn about post-surgery management.

6.4. Adventurers: An exploring patient—OHC as a place to explore new and alternative ideas

41% (75/184) of all survey participants on average responded 4 (Agree) or higher on the Adventurer cluster questions.

Unlike Scientists, Adventurers do not seek scientific evidence (Adventurer x R_NEED_EVIDENCE x Agree| Strongly Agree: 52%). They want to be challenged and are curious about how others talk about managing illness regardless of whether evidence exists. While Scientists frown upon information not validated by the scientific community, Adventurers value cutting-edge information on radical approaches with potentially better results that members discuss, which might not be embraced by the mainstream, conservative medical community (Adventurer x R_LOOK_FOR_UNUSUAL_INFO x Agree| Strongly Agree: 59%). To be an Adventurer, one needs to have substantial knowledge as a diabetes patient. Accordingly, Adventurers tend to be experienced patients with relatively controlled diabetes, they are always open to exploring new and novel ways of managing the illness.

Messengers or steady observers—Similar to Scientists, Adventurers do not have a common participation pattern. Adventurers rarely share useful information, although it might vary by person (Adventurer x P_SHARE_USEFUL_INFO x {Often| Always, Never| Rarely}): {46%,31%}). Adventurers might share their own unique results. Because Adventurers are open to new ways of managing illness, sharing what worked for them, especially a new regimen, is a good way to mutually benefit from participating in OHCs:

I try to share my results. This is what works for me, this is what I find that’s beneficial to me. [...] I like being helped by other people that may have had similar instances. How to use supplements? What supplements they’ve used that have worked, that don’t work (P2).

Adventurers also value hearing others’ experiences (Adventurers x V_HEAR_OTHERS_EXPERIENCES x True| Very True: 93%).

Open exploration with curiosity—When browsing through OHCs, Adventurers do not necessarily know what they are looking for. Adventurers are curious and open to exploration. Most of the time they do not know what they are looking for. They do not care about finding relevant information. They want to be surprised and let unusual information catch their attention (Adventurers x R_LOOK_FOR_UNUSUAL_INFO x True| Very True:

59%). For instance, P2 described himself as a person who says a lot of “unpopular things.” In a way, Adventurers consider themselves as outsiders who are into extreme things:

I would be curious as to what somebody was saying that was so unpopular, because odds are pretty good they may be saying what I’m saying, because I say a lot of unpopular things (P2).

Adventurers get excited when seeing individual differences:

Wow. Wow. That would be, that’s an interesting post. It’s really definitely one of those, ‘What works for me doesn’t work for you’ (P2).

This view of an Adventurer contrasts with Caretakers who feel uncomfortable when they see disagreeing facts (P10). P2 found disagreeing posts to be useful unlike the “cheerleading” posts:

I’m looking for someone who goes, “This is a bunch of baloney, and I tried this and it didn’t work.” Sometimes you can find more information from the negative reviews or negative comments than you can from the cheerleaders. (P2)

Adventurers’ practice of consuming information in OHCs is exploratory. Adventurers rarely have a focus while browsing through OHCs. P11 found suggested keywords during search to be helpful when he does not know what he wants. Adventurers want to encounter unusual information that is out of the ordinary:

Things that are interesting are generally things that either pertinent to me or are sort of out of the ordinary (P4).

Adventurers find it helpful to read those that challenge what they already know:

Because it doesn’t fit in my mind of how it should work. I mean that doesn’t mean that my mind is right, but it creates a conflict in my mind that I wanna try to figure out (P3).

Similarly, P1 often wants to “mix it up for a change” by randomly choosing different pages to read:

Or sometimes, I would do page, maybe one, two and three, and then go to page 10, 11, 12, something like that just to kind of mix it up and get further away from something just for a change (P1).

Avoiding the mainstream—Adventurers value OHCs for their potential to expose resources that doctors might have missed or refused to give. For Adventurers, OHCs are a place that provides diverse and cutting-edge information (Adventurers x V_GET_NONMAINSTREAM x True| Very True: 79%). Adventurers seek information that the medical community does not embrace due to its extremity. P2 believed that “most of the information that the established medical and diabetes community puts out there is very middle of the road.” Thus, P2 valued OHCs for their exposures to “things on conversation groups that are outside the norm that are being provided by the established medical and diabetes community.” Adventurers feel doctors do not share enough information with them or provide the information they want:

I am so frustrated that my doctor is no help, don't think seeing a diabetes educator is helpful (P14).

Patients' stories and experiences are another example information that doctors cannot give to patients:

[The community has] mostly people who [has experiences with] either pre-surgery or post-surgery talking about their different experiences. You have a lot of stories on that forum (P5).

Some Adventurers do not necessarily choose to be an Adventurer but their personal context makes them become one:

online is the only place I can get any info. I also live in a very rural area, so going to the library is out of the question (P14).

Adventurers, contrary to Scientists, appreciate contradictory, conflicting information. They care less about credibility as long as the information is novel and perceived as useful.

6.5.Caretakers: Experienced patients—OHCs as a social space

20% (37/184) of all survey participants on average responded 4 (Agree) or higher on the Caretaker cluster questions.

Caretakers possessed the most distinctive persona away from other personas. For Caretakers, OHCs are a social space where they altruistically engage by helping others and growing emotional bond with peer users. Accordingly, using OHCs is part of their daily routine. They have been participating in the community for many years, and they gain value from interacting with others and exchanging encouragements and stories as an experienced diabetes patient.

Community building through regular, loyal, and altruistic participation—

Caretakers are regular visitors of OHCs, mostly loyal to a single OHC. They tend to be old-timers. Accordingly, they tend to be more experienced with their illnesses than other members. Their illness management regimes are settled. Thus, they now have the ability to help others, given what they have learned from their own years-long experience. These participants developed a sense of ownership with the communities, referring to the communities as “we” (P3). Accordingly, when Caretakers read conversation threads, they find places to help whenever they can and attempt to help with newcomers and others who tend to be new to the community as well as in managing diabetes:

Yeah, I usually read all the responses, you know, especially in the new questions. And then, [see] if I feel like I can contribute (P3); [I would say] ‘Yes, it happens, pick yourself up, move on.’ And hopefully, I help other people. (P13).

Furthermore, P13 stated how helping others “also helps himself,” emphasizing the benefit of mutual help exchange in OHCs (Caretakers x V_EXCHANGE_EMO_SUPPORT x True|Very True: 95%). For instance, Scientists (M=3.00, SD=1.61) and Caretakers (M=4.16, SD=0.69) clusters had a significant difference in how much they share emotional support with others (P_SHARE_EMO_SUPPORT); $t(94.36)=5.06$, $p < 0.0001$.

Caretakers' goal in participating in OHCs is less about practical information seeking, but more about community building. They consider posting (Caretakers x P_POST_FREQ x A few times a week| Everyday: 85%) as a way to keep up with the community and help others. For instance, P1 said that posting not just about diabetes but also about “the personal side of things” can help build a community together (Caretakers x P_SHARE_EMO_SUPPORT x Often| Always: 84%). Because Caretakers' primary goal in responding to threads is interacting with other community members, when choosing which threads to read and respond to, how recent a post was posted is important. In this manner, Caretakers can have a better chance of getting a response back from the posters of the thread (P3). Not only when posting in the communities, but also when consuming information, Caretakers engage with other community members.

Getting into the weeds while allowing accidental information discovery—As regulars of the community, Caretakers' visiting routines mostly consist of checking for new threads or new comments since their last visit (Caretakers x R_LOOK_FOR_NEW_MESSAGES x Agree| Strongly Agree: 95%). This characteristic of Caretakers is significantly unique compared to Opportunists ($M=3.67$, $SD=1.22$); $t(105.69)=4.03$, $p=0.0001$. They like to discover new information as they browse through the threads. They rely on other community members to assess the quality of the information posted (Caretakers x V_HEAR_OTHERS_EXPERIENCES x True| Very True: 97%), rather than looking for scientific evidence.

Accordingly, they read or at least skim all unread threads (Caretaker x R_READ_ALL x Agree| Strongly Agree: 68%). During this process, they would often “get into the weeds,” (P2) while attempting to fully understand the context of the conversation (P10). The participants who showed this particular characteristic of a Caretaker—reading all threads instead of selectively choosing what to read—found original threads with all replies to be more useful than any summarized version of the threads (P10). The nuance would be lost in how posters portray their personal situations and opinions if the threads were somehow summarized or edited with an automated process (e.g., showing extracted quotes or aggregated responses).

Caretakers consider visiting OHCs as part of a daily routine, socializing with other community members and gaining additional information as a bonus. Thus, when reading the threads, Caretakers go with the flow, consuming information as they come up. P3 expressed how her needs at the moment influence her to choose specific posts in further detail. For P10, he would find useful information unexpectedly as he reads all comments in detail, such as finding out about stressing muscles during exercise:

I had started exercises using a stationary bike and just wasn't paying attention that I was stressing my muscles out that hadn't been working for years, [chuckle] It was just good information for me and I was happy to utilize it and use it (P10).

When Caretakers want to evaluate the information quality of a post, they rely on other community members' confirmations or opinions about the validity of the post:

“Oh, it happens to me, the same thing.” If I see more people confirming the earlier posts, then I start to have some kind of comfortable feeling (P10).

Similarly, P8 would check on people’s comments before visiting the posted link to evaluate the content.

Caretakers trust their community members’ opinions and consider a forum as more reliable than other information resources because of the interactions with others (P9). Caretakers consider OHCs to be sufficient as an information source. OHCs provide “everything under the sun”:

There’s recipes, discussions, just about everything under the sun, that I probably had wondered about when I was early diagnosed, that I wished I had known then (P10).

The sense of community—The sense of community and emotional support is the crucial value that Caretakers believe to be the key in OHCs. Caretakers prefer that the members of the community do not have to face the reality in a harsh way, especially for newcomers, who tend to already experience challenges dealing with a new diagnosis. Caretakers consider a post “useful” and “complete” if the poster adds encouragement to information:

Very useful post. First, it praises the person and encourages them about what they are actually doing. So it’s giving them some motivation. [...] some posts would say, “Don’t do that.” But this is a complete post. They actually praised them, encouraged them about what they actually are doing, so they don’t just make them feel down (P9).

Caretakers bond with other members through real-time chatting or private messages (PM):

There is a new person that came on the forum not too long ago and it was obvious she was struggling [in getting diabetes under control]. [...] So, she was going by what the doctors have told her, what her family tells her, and what little bit she’s gleaned from discussions. And I felt we’ve kind of bonded and we PM each other and we exchange a lot of information (P1).

It is not just about exchanging information, but the chat becomes a personal conversation or emotional support (P3). P1 also agreed that members bond with each other further through other personal contexts outside the illness, exchanging topics irrelevant to diabetes, such as, “Hey, you’re from the west, so am I.”

For Caretakers, even as an experienced diabetes patient, the emotional support and the sense of community are as important as helping members manage the disease:

I don’t know. It feels good to just reach out to somebody who I have diabetes in common with. I like people so I don’t want to be an island and isolate myself, because I feel like in the past, I’ve done that enough (P1).

Summary—Table 2 shows representative characteristics of the four personas presented so far in terms of their reading and posting behavior and the values they sought. Next, we

describe how these personas should be considered as less static but more dynamic, mutually inclusive, and transitory personas.

6.6. Multiple and transitioning nature of personas, intertwined with illness

The four personas described so far might be somewhat artificial, stereotyping, and simplifying the behaviors and the views of our participants regarding OHC use. Rather than mutually exclusive personas, these personas should be viewed as types of participation that OHC users could engage in depending on their illness stage, personality, or support needs at any given time. Accordingly, at any point, an OHC user could possess multiple personas and move from one persona to another over time. Persona development generally can follow their illness trajectory, starting with newly diagnosed, to exploring patient, and to experienced patient. However, based on the needs at the time, the stage of illness the user is in will not immediately categorize an OHC user to one persona, due to the complex, situational factors that all play in their support needs at the moment.

Multiple nature of personas—As shown from the mixed survey results among Scientists, Adventurers, and Opportunists, most of our interview participants showed multiple personas with one or two main personas. For instance, P2 was an experienced diabetes patient who possessed the characteristic of a Scientist needing scientific evidence for information he gathers. At the same time, he was also an Adventurer in that he wanted to explore a new regimen whenever available. He showed a partial characteristic of a Caretaker, in that he was altruistic to other community members but was against “coddling” in OHCs. He believed people need to face the hard facts:

This is my complaint on discussion groups. People tend to coddle diabetics a lot because we have emotional issues, and we can be somewhat fragile (P2).

At the same time, he liked to share his experiences with other people who are struggling, which is a characteristic of a Caretaker. Another example is P3, who was a Caretaker, a Scientist, and a little bit of an Adventurer. She regularly visited an OHC to interact with other people. She also liked to validate what other members had posted. She was adventurous in that she was interested in seeing posts in conflict with her knowledge.

Transitional nature of personas—The participants who were old-timers in OHCs and those who have had diabetes for a long time shared how their perspectives towards OHCs changed over time. These changing perspectives meant that their personas also moved from one to another. For instance, the participants we described as Caretakers all started out as landing users, meaning that they were opportunistically using OHCs at first:

I didn't even start talking to anybody until about two years ago, or responding to any discussions (P10).

Over time, P10 started talking with other members and began socializing in the community as she began to regularly visit the community, similar to P3. P1 also confessed, as a consequence, she never considered herself as being able to mutually exchange social support with others online and maintain healthier lifestyle:

I didn't think I ever, ever could. I never thought I would be one of those people (P1).

We did not see clear patterns for such evolutionary behavior towards approaching OHC use from the survey, where the list of Opportunists and Caretakers did not have significant differences in the length of time since diagnosis. The number of years since diagnosis was on average 13 years for Caretakers and 12 years and 10 months for the Opportunists. 43% of the Caretakers were diagnosed for less than 5 years, and 48% of the Opportunists were diagnosed for less than 5 years. However, the potential reason to this finding is that most of our survey respondents have been diagnosed between 1 to 5 years, and these respondents did not show strong tendency toward one or more personas at that point.

Personas intertwined with illness—Most of our participants did not consider the diagnosis as serious. Thus, the participants waited for many years until they finally encountered life-threatening events (P1), such as a stroke (P2, P10) or frequent hospital visits leading to expensive medical bills (P3, P7, P14). They then began visiting and participating in OHCs to be surrounded by similar others (P9), gain education on their own (P3) and moved forward. An Opportunist can begin to stay in the community, participate as a moderator, and continue to do further research on what illness management regimen can be improved, evolving into a Scientist (P2).

Depending on their illness stages, user needs will be different. At the time of the diagnosis, patients have big questions (P9), exploring options as they attempt to find their own strategies that work best for them. P11 showed frustrations for not being able to get “straight up” answers. Similarly, P6 did not feel OHCs addressed the “facts well.” P9 initially was only interested in learning about medical facts from OHCs. Over time, however, P9 started to socialize with others and found value in mutual support in the communities. As patients get settled into their routines, they might become more skeptical or more open to new kinds of information. They could develop frustration toward an existing regimen as it no longer works. Thus, they might turn to alternative ways of managing illness like Adventurers.

We also broke down illness interests by personas in the survey participants (Table 1). In general, our data included a low proportion of Caretakers, which reflected the low proportion of Caretakers in general. Even so, participants who showed HIV as their interest showed equal tendency towards all four personas. Participants interested in cancer, diabetes and weight loss, multiple sclerosis, and depression were often categorized as Opportunists. Participants interested in cancer were also often categorized as Scientists together with Opportunists. Participants interested in Heart disease, Parkinsons, Depression, and Fibromyalgia were most represented as Adventurers.

Our data heavily represented participants interested in Diabetes and Weight loss because of our recruiting effort, where we had better access to the moderators of diabetes forums compared to other illness topics. The moderators helped to recruit participants for the survey. Also diabetes and weight loss as a topic has a large presence in online health social networks, which could have led to our result shown.

6.7. Mapping multiple OHC Personas of the survey participants

So far, we discussed the multiple, dynamic nature of persona. To map the distribution and overlap among personas of our survey participants, we generated four persona scores for each participant. Each persona has a related question group as shown in the dendrogram (Figure 3) and as described in the findings so far. For each individual, we calculated their average rating from 1 to 5 about each persona question group, where 1 is Strongly Disagree or Very Rarely and 5 is Strongly Agree or Very Frequently. For instance, the Opportunist's group of related questions consisted of R_TARGETED_SEARCH, R_LOOK_FOR_UNUSUAL_INFO, R_SELECTIVE_READ, and V_GET_ANSWERS. For each participant, we calculated their average rating of all five of these questions. The questions with no responses were excluded from the average calculation of the question group.

We plotted individual users on a two dimensional scatter plot to show similarities and differences between users based on the four persona scores, as shown in Figure 4. Figure 4 (a) shows the majority of participants with overall high scores on all four persona scores. We interpreted these groups represent active users, who are both Givers and Receivers. Figure 4 (b) shows those who are Opportunists and Scientists but not Adventurers and Caretakers. What this means is that the (b) group seeks scientific information from the community but rarely provides emotional support. Figure 4 (c) and (d) show participants who did not respond to any of the questions under any persona groups. In the center, Figure 4 e) shows participants without strong indications for any of the four personas.

7. DISCUSSION

In this section, we discuss our findings around how people use OHCs and what provisions should take place to further facilitate OHCs as a sustainable, high quality social and informational environment.

7.1. Supporting individualized needs of the personas

The majority of the participants came to OHCs to read what other people say. Only a small subset of participants actively posted and visited OHCs regularly. This phenomenon shows challenges around information imbalance in supply and demand, where there is much demand for high quality, personal experiences, but minimal supply of personal experiences is provided in OHCs.

To increase the supply of personal experiences, classic challenges around commitment and members' willingness to share personal experiences should be addressed. Effective commitment can be achieved through encouraging identity-based commitment or bonds-based commitment [37]. To achieve identity-based commitment, the illness of interest should align with how people think about themselves, and people should perceive others in the group as interchangeable [46]. For instance, breast cancer survivors can have a strong social identity due to the sense of empowerment associated with the "survivorship" [48]. Other illnesses, such as Inflammatory Bowel Syndrome, might not have such a strong empowering identity involved in being part of the group.

In the case of identity-based commitment not playing a useful role, bond-based commitment can work. This point illustrates the critical role of Caretakers, who can help members to sustain their engagement with OHCs through establishing social ties. The sense of membership, social network, and receiving emotional support allowed people to stay in OHCs longer [27]. Caretakers can provide such emotional support, which can help the members feel supported, hence staying in the OHC longer. Ideally, Caretakers should possess the characteristics that generate interpersonal attraction with the connecting member. Because of the online group environment, physical proximity, which is known as a strong factor for interpersonal attraction [2], is not feasible. Some alternative strategies can include creating a hypothetical space that each member is assigned to and showing where other members are located.

Visually exposing members to other people's activities and identities will help increase personal attachment among the members [49, 55]. Other members' activities can be illustrated through pictures, avatars, and personal stories. Facebook is a good example of seeing what other friends are doing, which in turn promotes personal attachment [27]. This kind of strategy would need to be sensitive to the culture of the illness, perceived privacy of the members, and members' willingness to create bond-based commitment.

Some participants who had the Scientist persona noted that they felt uneasy sharing personal experiences because they did not feel it was a validated source of information. OHCs should help members to be explicit about how their experiences pertain to themselves. Other OHC members should not interpret wrongly one's experience is generalizable to everyone. For instance, OHCs can provide icons for members to add to their posts when they want to claim that it was their personal experience, thus the information contained in that post should be taken as a grain of salt.

If the Caretaker's altruistic, actively posting characteristics can be combined with Scientists and Adventurers, it will bring more fruitful conversations to OHCs. For example, Scientists can turn into active moderators who seek and moderate conversations about controversial topics. In addition, Adventurers can feed OHCs with undocumented but novel ideas (e.g., ways to consume Vitamin without medication). We need to think about ways to grow more Scientific Caretakers and Adventurous Caretakers, who can add new values to the community. OHCs can explicitly value the Caretakers with ratings, points, or other types of reputation scores to award the "Giving" behaviors. We can make members' contributions more visible and offload their contribution efforts.

7.2. The personas in various illness contexts

We showed, depending on the illness, certain personas were more popular than others. However, considering the small sample, we cannot make generalizable conclusions on correlating illnesses with the personas. Additionally, the behavioral characteristics grouped into the four personas might not be the same for other illness contexts and in other online health social network contexts. The Youtube users with cancer and those with diabetes from the Health Vloggers study [22] were Caretakers because of their willingness to share their private stories with others to help others. However, Youtube users with cancer exchanged more emotional support than those with diabetes, who exchanged mainly informational

support. At the same time, our survey showed high percentages of Adventurers and Opportunists in participants with interests in cancer. Furthermore, we cannot simplify cancer as one group of individuals. One kind of cancer might have more characteristics of Adventurers in them than others—certain cancers do not have known effective treatments, and thus, people turn to alternative ways of finding appropriate remedies. A similar explanation can apply to participants interested in Parkinsons and Fibromyalgia showing highest tendency to be Adventurers. Conclusively, OHC personas should be used less as a definitive purpose but as a language to describe and compare diverging needs in online health social network users.

7.3. Connecting to online communities and information behavior literature

Our work showed that OHC personas are fluid, complex, and boundless, challenging existing static and deterministic models towards social types in online communities and information seeking literature. We saw how Caretakers vs. Adventurers show differences in their attitudes in dealing with conflicting information. Caretakers tend to turn away or ignore extreme, contradictory information. On the other hand, Adventurers look for the information that could challenge them. Such attitude differences resonate with what Steptoe and O’Sullivan [43] described as blunters and monitors. Blunters turn away from, but monitors face any conflicting information. However, our personas describe how blunting and monitoring are fleeting activities. Depending on the context of the illness and how other community members interact with each other, such activities can readily be removed. After all, both blunting and monitoring are ways to ameliorate cognitive dissonance [13] and selective exposure [39] one way or the other.

Kim [25] described social types according to how one gains participation level with the community over time. We observed some of our participants walking that path that Kim had described—and eventually transitioning their personas from Opportunists to Caretakers. However, such transitions are not simply based on a participation level with the community. The transition involves moving forward with their illness management, stages of behavioral change, and evolution of interpersonal relationships with other community members over time. Accordingly, to keep retention of the OHC participants, we need to be sensitive to their evolving information needs around their illness stages and their relationships with other members.

We do not see that our personas are complete or sufficiently explaining all OHC users’ behaviors. Most participants were weakly associated with multiple personas. How exclusive each persona is should be carefully assessed when applying these personas for other OHC contexts. Such multiplicity of our personas agree with Zhao et al. [56]’s work on maintaining multiple faces on Facebook. Also, Goffman’s presentation of self [15] and Laurel’s virtual self [30] point to similar lines of argument that people exhibit varying self online. The unique contribution of our personas, however, is that we identified clusters of information seeking and online participation behaviors and began to illustrate patterns for how illness contexts, personal beliefs, and social context shape the personas.

7.4. Technical design implications for OHCs

We see three main areas in which our findings can inform future design of OHCs:

- (1) **Persona/participant type Detection:** Systems can profile each user's interests towards psychosocial and informational support over time. Hartzler et al. [18] used past posts of OHC users to profile their health interests. From these health-related profiles, we can further examine users' dominant persona at any given time and provide appropriate metrics to help them explore through OHC content. Future research should investigate how to predict a member's personas at a given time with minimal intrusion, for example by understanding the posting, viewing behaviors of members.
- (2) **Quality metrics development:** Our participants used cues (e.g., references, numbers, other peoples' confirmations) to assess the quality of posts. OHCs can index and present each post with enriched cues using metadata corresponding to these qualities. Systems can show the strengths of each poster's expertise by assessing their participation patterns, contents of posts, and reputation from other members. Users can freely create their own virtual "spheres" (e.g., money saving, vegan, pregnant, married, etc). Users can drag threads into these "spheres" that belong together. Recommendation systems can suggest posts to read and people to connect with, using the quality metrics for each individual depending on their predicted persona.
- (3) **Information scent and Recommendation.** For OHC search results, design features, such as glyph icons [51] can provide information scent around a dominant persona of the poster, quality metrics, and trails of what kinds of personas have visited the thread. These features can be used to effectively summarize the post content. Small glyphs can be useful for Opportunists and Adventurers who often skim through search results to explore 'something interesting'. To help Opportunists further navigate information, we can build on existing work on consumer based medical dictionaries [42] that connect medical entities and consumer centric keywords. Other users can tag threads and phrases with relevant keywords, using a human-machine collaborative approach as discussed in Opinion Marks [29].

8. LIMITATION

Our study finding is built on a relatively small number convenience sample of survey respondents (n=184). We cannot generalize our findings to those who are OHC users due to the response bias. These limitations were, however, unavoidable considering the transient nature of OHC users together with a low response rate in OHCs and our narrow inclusion criteria. We attempted to best ameliorate this limitation by diversifying the recruiting site and methods. Personas are highly qualitative constructs, which can be difficult to quantify. One of the consequences to this problem is not being able to generate mutually exclusive personas that do not overlap. Another limitation that stems from the complexity of OHC personas as a construct is that while most findings from interviews were confirmed from the survey, some interview findings still needed further work to fully confirm and understand the

underlying mechanism. One example is being able to see the evolutionary aspect of personas in OHC use. We collected time of diagnosis to understand the amount of experience in managing illnesses. However, many survey participants reported more than one illness as their interests, providing multiple diagnosis years. Our methods did not fully address fitting what is complex and fluid (e.g., illness experience) into a number (e.g., years of diagnosis) and calculating its relationship with personas. Given these caveats, we opened up an important conversation for the field to understand what diverging needs OHC users have in online health social networks, and how we can strategize to tailor for individuals' personalized needs.

9. CONCLUSION

In this paper, we identified four personas that help illustrate diverging user needs in OHCs. These personas helped us understand the complex and fluid nature of an illness context, which drives online community participation behavior. Our work contributes to: (1) identifying the diverging psychosocial and dynamic nature of personas in OHCs; (2) extending online community user and information behavior literature by adding how illness contexts dynamically shape information behavior; and (3) extracting requirements for helping users consume and contribute high quality content in OHCs in a personalized manner. Our participants presented their own ways of coping with challenges—through science, psychosocial support, adventure, or being opportunistic. We provide a steppingstone to supporting the diverging perspectives of patients for strong, personalized health support. Our study contributes to the field's understanding of using online health social networks as a sustainable place to provide support to patients.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Highlights

- We show Caretakers, Scientists, Adventurers, and Opportunists as personas in OHCs.
- We present social quality and quantity metrics practitioners can use to detect these personas.
- These personas help improve retention in online social health networks.

Results for: atkins

1-10 of 201 results for *atkins*

Reply: type 2

over 2 years ag

first of all I am surprised at the dosage of metformin. Someone correct me but I thought the ther.....[Read more](#)

Posted by max9821

6 replies

Reply: New to type 2 less than 8 months have spent 2 months in hospital

over 2 years ag

So many of us here have gone through much in the search for understanding to control this disease.....[Read more](#)

Posted by betatoo

19 replies

Reply: Can I stop the meds?

over 2 years ag

Figure 1.

A screenshot of a prototypical OHC shown to participants as a probe on how they read and post in OHCs.

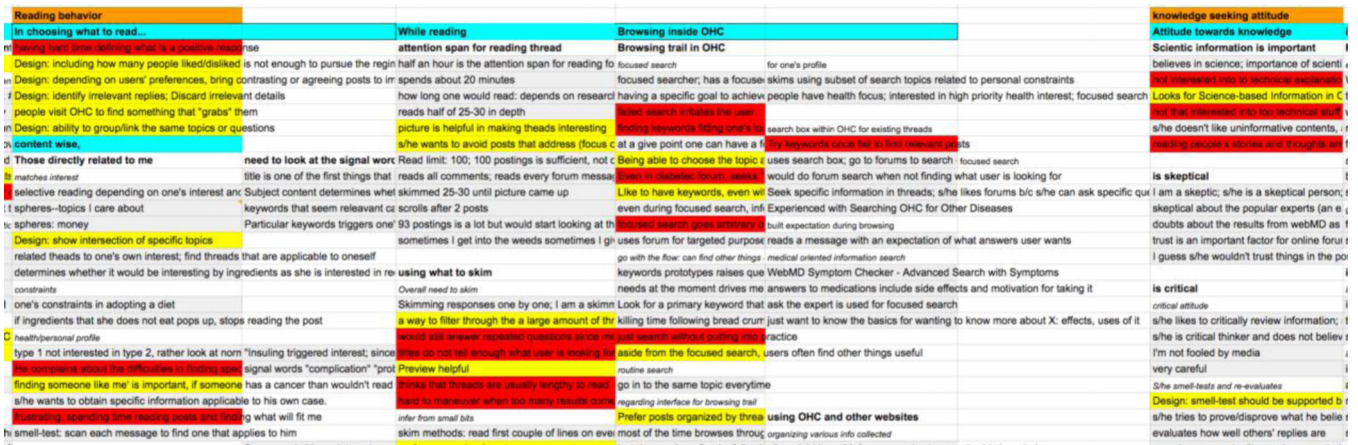


Figure 2. A screenshot of the affinity diagramming exercise [4] in eliciting emerging usage behavior, patterns and values that led to an initial set of personas. The full diagram is included in the Appendix.

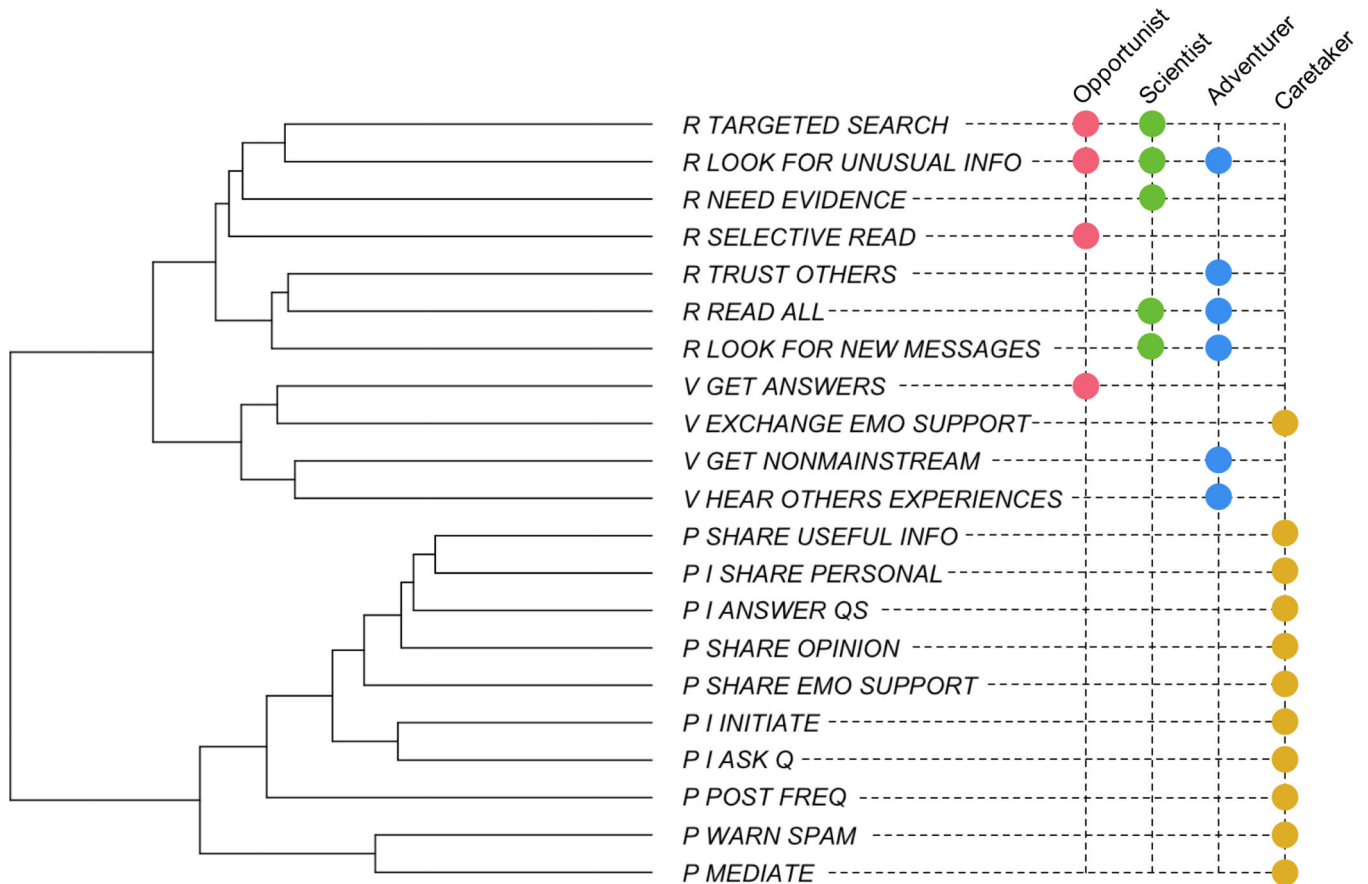


Figure 3. Cluster analysis results with the survey data. The colored circles and persona labels indicate their related questions on each persona’s value, reading, and posting behavior based on the affinity diagramming results (Shown in Figure 2). For instance, Opportunists indicated the group of personas who liked to conduct targeted search on search engines (R_TARGETED_SEARCH) and selectively read the topics they are interested in learning about (R_SELECTIVE_READ), and get answers to their focused questions (V_GET_ANSWERS). They also considered OHCs useful for getting unusual information they would not find elsewhere (R_LOOK_FOR_UNUSUAL_INFO).

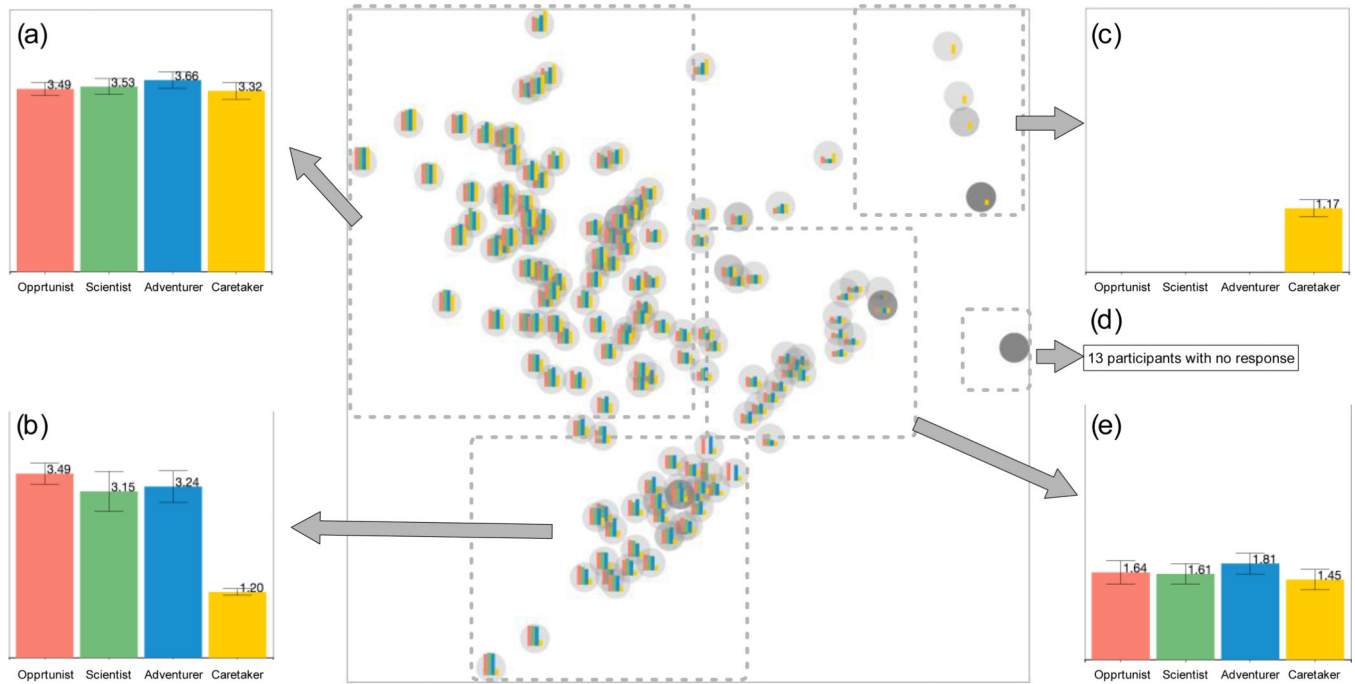


Figure 4. Clusters of survey participants based on the four persona scores, (a) participants with high scores in all personas; (b) participants with high scores in Opportunist and Scientist groups and low scores on Adventurer and Caretaker; (c) participants with low scores on Adventurer and Caretaker and no responses towards Opportunist and Scientist question groups; (d) participants with no response to any of the four persona questions; (e) participants with overall low scores to all four personas.

Table 1

Summary of representative characteristics of each persona with regards to reading and posting behavior and the values they seek from OHCs.

Personas	Reading behavior	Posting frequency	Values sought
<i>Opportunists</i>	Search targeted information, get the information they need and leave	Rarely	To get answers to their questions, hear others' experiences
<i>Scientists</i>	Need evidence, need to be updated with new information	Either actively post or lurk	To get updated with new, valid information
<i>Adventurers</i>	Browse information, steadily observe, look for information their health providers would not give	Indifferent	To get unusual information
<i>Caretakers</i>	Read everything, look for others who need psychosocial help	Frequently	To help others, build sense of community

Proportion of personas in each illness interest Illness interest is mutually inclusive per respondent.

Table 2

Personas	HIV % (raw response)	Cancer	Diabetes and Weight Loss	Heart Disease	Multiple Sclerosis	Parkinson	Fibromyalgia	Depression	Other
Opportunists	25% (4)	31% (5)	30% (21)	27% (4)	38% (3)	24% (8)	25% (3)	38% (6)	26% (13)
Scientists	25% (4)	31% (5)	24% (17)	27% (4)	25% (2)	29% (10)	25% (3)	19% (3)	30% (15)
Adventurers	25% (4)	25% (4)	27% (19)	33% (5)	25% (2)	32% (11)	42% (5)	38% (6)	32% (16)
Caretakers	25% (4)	12% (2)	19% (13)	13% (2)	12% (1)	15% (5)	8% (1)	6% (1)	12% (6)
Total	100% (16)	100% (16)	100% (70)	100% (15)	100% (8)	100% (34)	100% (12)	100% (16)	100% (50)

Table I

Survey questions and descriptive results

Variable	Total Sample (n=184)
DEMOGRAPHICS	
AGE (%)	
< 18	4.9
18–29	7.1
30–49	33.7
50–64	37.5
>= 65	13.6
Not responded	3.3
GENDER (%)	
Female	64.7
Male	30.4
Not responded	4.9
EDUCATION (%)	
Some high school	19.0
Some college	40.2
Post graduate	33.2
Not responded	4.9
Other	2.7
RACE AND ETHNICITY (%)	
Black or African American	15.8
American Indian or Alaska Native	4.9
Asian or Asian American	2.2
Hispanic or Latino	7.1
Non-Hispanic White	62.0
Hawaiian or Other Pacific Islander	0.5
Not responded	7.6
MARITAL STATUS (%)	
Single	11.1
A member of an unmarried couple	5.9
Married	50.3
Divorced	20.3
Widowed	7.8
Not responded	4.6

Variable	Total Sample (n=184)
EMPLOYMENT (%)	
A homemaker	6.5
A student	8.7
Self-employed	9.2
Employed for wages	34.8
Out of work for less than 1 year	2.2
Out of work for more than 1 year	3.3
Retired	19.0
Unable to work	13.0
Not responded	3.3
PATIENT OR CAREGIVER (%)	
<i>Are you a patient or a caregiver of the health problem you identified above?</i>	
Patient	56.5
Caregiver	13.0
Neither	3.8
Not responded	26.6
ILLNESS OF INTEREST	
<i>Which illness, health, or wellness problems are you most interested in? Please specify one. (Open ended)</i>	
HIV positive	2.2
Cancer	8.2
Diabetes and weight management	17.9
Heart disease	3.8
Multiple Sclerosis	1.6
Parkinson's disease	7.1
Fibromyalgia	3.3
Depression	6.0
Etc.	17.9
Not responded	32.1
WHEN DIAGNOSED	
<i>How long were you or the patient diagnosed with the health problem identified above? (Open ended)</i>	
Less than a year	9
Between 1 year to 5 years or less	22
Between 5 years to 10 years or less	9
Between 10 years to 20 years or less	11
More than 20 years	9
Not responded	40

Variable	Total Sample (n=184)
READING BEHAVIOR	
<i>Please check how much you agree with the following statements. (% of Strongly Disagree (SD), Disagree (D) Neither agree or disagree (N), Agree (A), Strongly Agree (SA); NR=Non Response (n))</i>	
R_READ_ALL: [I read all messages in online health support groups as much as possible.]	SD: 12, D: 16, N:26, A: 18, SA: 9; NR=18
R_TRUST_OTHERS: [I trust what people post in the online health support groups I goto.]	SD: 8, D: 17, N: 36, A: 17, SA:2; NR=20
R_NEED_EVIDENCE: [I need scientific evidence for me to believe what people post in online health support groups.]	SD: 11, D: 14, N: 29, A: 20, SA: 9; NR=17
R_LOOK_FOR_UNUSUAL_INFO: [I look for unusual information otherwise difficult to find elsewhere.]	SD: 10, D: 14, N: 29, A: 21, SA: 7; NR=19
R_TARGETED_SEARCH: [I know what information I am looking for, and that is what I look for in the online health community.]	SD: 11, D: 16, N:29, A: 19, SA: 7; NR=18
R_SELECTIVE_READ: [I selectively read the messages.]	SD: 11, D: 13, N: 27, A: 20, SA: 8; NR=21
R_LOOK_FOR_NEW_MESSAGES: [I regularly visit the online health support groups to look for new messages posted that I haven't read yet.]	SD: 12, D: 15, N: 23, A: 20, SA: 11; NR=19
R_OTHER_READ: How do you select which message to read? (Open ended)	
• By_topic["I look for topics that interest or apply to me personally."]	24
• By_title_headline ["using the header to determine if the content is relevant to me"]	9
• All ["I usually try to read them all."]	6
• By_reliable_authors ["I pick the individuals I know are reliable and know what their talking about."]	5
• Scan_all ["I pretty much scan them all and if I think I have useful input, I input."]	4
• By_time ["I try to read the newest ones first sothat I can be current."]	3
• Reliable_source["If it appears to originate from an established, reliable source"]	2
• Catch_eye ["Whatever catches my eye"]	2
• Unanswered_questions ["I read the unanswered questionsto see if there is a topic I could support."]	1
• Length ["The longer detailed messages."]	1
POSTING BEHAVIOR	
a. P_POST_FREQ (%)	
<i>How often do you post messages in online health support groups?</i>	
Never	47
A few times a year	8
A few times a month	13
A few times a week	12
Everyday	6

Variable	Total Sample (n=184)
No response	13
Other (Just started)	1
<i>Please answer how often you post in the online health support group with the following intentions.</i>	
<i>(% of Never (1), Rarely (2) Sometimes (3) Often (4) Very Often (5); NR=Non Response)</i>	
b. P_I_ASK_Q: [I ask questions.]	1: 33,2: 16, 3:23, 4: 10, 5: 2; NR=17
c. P_I_INITIATE: [I initiate discussions.]	1: 39,2: 10,3:21, 4: 8, 5: 3; NR=19
d. P_I_ANSWER_QS: [I answer others' questions.]	1: 35,2: 10,3: 17, 4: 15, 5: 4; NR=17
e. P_I_SHARE_PERSONAL: [I share my personal experiences]	1: 35,2: 10, 3: 19, 4: 14, 5: 5; NR=17
f. P_SHARE_OPINION: [I share my opinions]	1: 33,2: 14,3: 18, 4: 14, 5: 5; NR=16
g. P_SHARE_USEFUL_INFO: [I share useful information]	1: 32,2: 10,3: 18, 4: 17, 5: 4; NR=19
h. P_SHARE_EMO_SUPPORT: [I share emotional support with other members.]	1: 34,2: 10,3: 17, 4: 14, 5: 8; NR=17
i. P_WARN_SPAM: [I warn about spams and advertisements.]	1: 43,2: 16, 3: 12, 4:6, 5: 4; NR=18
j. P_MEDIATE: [I mediate members to help conversations stay on track]	1: 47,2: 14, 3: 14, 4: 5, 5: 1; NR=19
k. P_OTHER_INTENTIONS_POSTING: If there are any, please share any other intentions you have in posting messages in the online health support groups. (Open ended)	
• To_share_useful_info["I feel the need to share things I learn from my own research."]	13
• To_share_emotional_support ["To those who need additional inspiration related to belief, confidence, support and prayer."]	9
• To_share_personal_experiences ["It helps to have someone to share experiences with. We may have the same disease, but it is unique to each of us, but at the same time there are many commonalities."]	4
• To_get_provide_advocacy ["support others in being their own advocates for health care."]	4
• To_ask_questions ["To learn and stay abreast of new developments"]	1
• To_share_opinions ["Something is seriously "broken" in Medicare and needs attention and amendment."]	1
• To_share_everydaylife ["You typically post what is going on in your life."]	1

VALUES SOUGHT

The reason for visiting the online health support group is: (% of Not true at all (1), Not True, I don't know, True, Very True (5); NR=Non Response)

a. V_EXCHANGE_EMO_SUPPORT: [To exchange emotional support]	1: 14,2: 10,3:21, 4:23, 5: 15; NR=18
b. V_HEAR_OTHERS_EXPERIENCES: [To hear about personal experiences from other patients]	1: 7,2: 7, 3: 18,4: 33, 5: 16; NR=20
c. V_GET_N ON MAIN STREAM: [Togain non-mainstream information]	1: 9, 2: 0, 3:24,4: 26, 5: 13; NR=20

Variable	Total Sample (n=184)
d. V_GET_ANSWERS: [To answer [my] questions about the illness]	1: 13, 2: 9, 3: 20, 4: 27, 5: 10; NR=21
e. V_OTHER_VALUE: If there are other reasons why you participate in the online health support group, please explain. (Open ended)	
• Get_share_information ["I want a community that shares/understands the surrounding issues"]	16
• Make_personal_connections ["I really want more personal connections with people on the site"]	6
• Get_share_emotional_support ["I feel less isolated"]	6
• Get_share_experience ["to provide peer support to others based on my experience of parkinson's"]	3
• Share_simple_information ["It's simply information that the medical community and health workers (like my doula) prefer not to share or don't really know."]	1
• Get_idea_for_the_general_life["to get other ideas to improve general lifestyle, activities"]	1

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