

Join, Stay or Go? A Closer Look at Members' Life Cycles in Online Health Communities

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Online health communities (OHCs) have become important resources from which members can obtain social support. Since most benefits of OHCs are provided by its members, it is crucial that OHCs maintain a critical mass of active members. This paper examines temporal changes in members' participation in a cancer-oriented OHC, focusing on the changes in members' motivations and behavior as they transition from newcomers to other roles or when they ultimately leave the community. Our work used mixed methods, combining behavioral log analysis, automated content analysis, surveys and interviews. We found that shifts in members' motivations seemed to be driven by two sources: the internal dynamics common to becoming a member of most online communities and the external needs associated with their cancer journey. When members' disease-driven needs for support decreased, most members quit the site. The motivations of those who stayed shifted from receiving support to providing it to others in the community. As in many online communities, old-timers contributed the vast majority of content. However, they encountered challenges that threatened their commitment, including negative emotions related to other members' deaths, which led them to take leaves of absence from the community or to drop out permanently. Implications for the motivation changes of OHC members are discussed.

CCS Concepts: • **Human-centered computing** → **Human computer interaction (HCI)**; • **Empirical studies in HCI**;

Additional Key Words and Phrases: online health communities, cancer, peer support, social support

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1 INTRODUCTION

Face-to-face health support groups are places where people come together to exchange social support around health related issues [28]. With the emergence of the Internet, online health

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communities (OHCs) allow people to gather in a virtual environment without restrictions stemming from geographic distance or temporal availability, offering them a platform to share experiences, ask questions, and receive and provide social support [22, 24]. OHCs are thus different from face-to-face support groups, in which groups of people gather at a set time and place to discuss problems and get advice. In the latter, professional experts and lay volunteers often help moderate discussions, provide guidance, and evaluate medical content. In contrast, OHCs are typically larger, and rely upon asynchronous communication among geographically dispersed people and on members to provide peer support [7]. Since the benefits of OHCs are provided by members, it is crucial that OHCs maintain a critical mass of active members.

Retaining members is a key challenge faced by many types of online communities, including question and answer sites [30], peer production platforms like Wikipedia [5, 31], and OHCs [24]. In an attempt to develop general principles, much of the research on how to retain members in online communities, including Kraut and Resnick's review [17], has been agnostic to community type. It is not clear, however, the extent to which conclusions from this research can be directly applied to OHCs. One feature that might prevent such direct application lies in that, unlike many other types of online communities, including peer production ones, OHC members' participation is often heavily dependent on their users' own health status and is mostly driven by temporary and intermittent needs [10, 13, 21]. Thus, it is reasonable that many newcomers join OHCs mainly for self-centered motivations, in search of actionable information that is specific to current challenges they are facing in their personal lives [11, 21]. In contrast, although there are exceptions (e.g., [16]), most research on participation in online communities does not examine how it is driven by offline events.

Existing work focusing on health communities has investigated factors that influence members' behavior and tenure (e.g., [12, 42, 44]). For example, Wang et al. [42] found that those looking for and receiving informational support were less likely to stick around than those looking for and receiving emotional support. Although a small fraction of members become core contributors in many online communities [33], we know little about the reasons they become valued core members in OHCs.

In this paper, we seek to explore the following research question: **how do OHC members' motivations and behavior change as they transition from newcomers to other roles or when they ultimately leave the community?** We take into account two dynamic processes holistically: the general, internal processes common to participation in many online communities (e.g., the reader-to-leader framework, [5, 25, 33]), and processes specific to health communities based on members' illness trajectory (e.g., their cancer journey, [8, 12, 14]).

We examine members' life cycle in the context of the American Cancer Society Cancer Survivors Network® (CSN). The research used a mixed-methods approach, which combined interviews, behavioral log analysis, content analysis and surveys. The research found that (1) members joined OHCs for self-oriented goals driven by the uncertainty generated by their disease state, especially their need to get relevant information and conduct social comparisons; (2) when members' disease-specific needs for support decreased or were satisfied, most members quit the site; the motivation of those who stayed became more community-oriented and shifted from obtaining support to helping other members in the community; and (3) old-timers experienced challenges that seemed to undermine their long-term commitment to the community, including strong negative emotions brought on by other members' passing away and other signs of burnout.

2 RELATED WORK

In this work, we are interested in the process by which individuals become valued core members of OHCs, taking into account the general internal process of participation in many online communities

and social groups, and the unique characteristics of OHC participation. In the following section, we first draw on classic theories on online communities to examine how and why community members change their behavior over the course of their participation. We then delve into our context by introducing OHCs. We discuss why members' behavior in OHCs might differ from those in other online communities, and why improved understanding of OHC members' life cycles might be crucial for its organizers.

2.1 Members' Life Cycles in Online Communities

Social computing researchers have examined how members change their participation in online communities over time (see [17] for a review). Typical of this genre is the Preece and Shneiderman's reader-to-leader framework, which describes how members of online communities evolve from being a lurker or reader, to a contributor and collaborator, and eventually to a community leader [33]. Bryant et al. [5] uses ideas from legitimate peripheral participation and activity theory to understand participation in the Wikipedia community as an adaptable process that evolves over time.

The changes in participation in online communities described in prior work fit into Levine and Moreland's more general group socialization framework [25], which attempts to explain changes in motivations for participation in most types of social groups. The model differentiates five phases of group membership, three of which are particularly relevant to our present concerns – (1) investigation, in which prospective members decide whether to join a group and the group decides whether to receive them; (2) socialization, in which new members seek to influence the group to satisfy their needs and the group seeks to influence them to meet its goals; and (3) maintenance, in which full members play specialized roles designed to meet both their needs and the group's goals. In all of these phases, the individuals and the group evaluate the past, present, and potential future benefits of their relationships. To the extent that the individual views the group as rewarding, he or she will be motivated to join during the investigation phase and to remain during the socialization and maintenance phases.

Such research attempts to explain the general dynamics of sustained participation and dropout in online communities and thereby has the potential to help designers and managers of online communities identify ways to better meet members' needs [3, 12, 18]. However, these general principles may not be directly applicable to the context of OHCs due to their unique characteristics and the influence of members' illness trajectories on member participation, which we will review in the following section.

2.2 Online Health Communities

OHCs are internet-based platforms where people come together to exchange social support around health related issues [15, 28, 43]. A substantial body of prior research has examined benefits conferred by participation in OHCs. This work [7, 28] suggests that participants in OHCs enjoy convenient access to other people with similar experiences, including those with significant first-hand experience dealing with relevant health problems. Social support is an important resource as patients and caregivers cope with corresponding disease. Through participating in OHCs, members obtain useful information sometimes not available from medical experts [7], such as effective strategies for coping with disease, side effects or family relations [22]. Members also receive emotional support from each other when facing life-threatening crises, which help them deal with emotionally crippling events [39]. These benefits may be due, at least in part, to immediate availability (i.e., 24/7 access without restriction of geographic locations) and the anonymity of OHCs [24].

Given the critical role that social support plays in OHCs, prior research has examined the dynamics of social support and how receiving social support influences members' subsequent participation in OHCs. For example, Introne et al. [12] analyzed data of thirteen disease-specific

discussion forums hosted by the WebMD OHC and found that a small group of core senior members generate the majority of support for others. Ploderer et al. [32] found that more senior roles in OHCs are often occupied by those who have successfully managed their own health problems and have the knowledge and experience to support others. Wang et al. [42] found that those looking for and receiving social support stay longer than those looking for and receiving informational support.

Although we have some quantitative evidence that a small set of core and senior members in OHCs contribute the majority of content, we understand little about the reasons why these groups of people stick around and altruistically provide informational and emotional support to others. More importantly, we need a holistic understanding about how and why OHC members evolve from newcomers to old-timers. Unlike members in other online communities, OHC members' participation is often strongly impacted by members' personal healthcare events [8, 12, 14]). For example, Massimi et al. [24] proposes that the adoption and disengagement decisions are often triggered by their changing life circumstances. For cancer patients specifically, Jacobs et al. [14] proposes a cancer journey framework, where they suggest that HCI researchers should address cancer patients' journeys in a holistic manner: encompassing patients' cancer experiences from diagnosis through survivorship, considering numerous physical and emotional challenges, and balancing clinical tasks alongside the responsibilities of daily life. This also urges HCI researchers to examine to what extent members' online behavior would be affected by their offline cancer experiences, as such understandings could help organizers of OHCs make better informed decisions.

Furthermore, existing research on OHCs has largely focused on the benefits and support members receive from their participation, and few researchers have studied how people cope with the challenges associated with their illness trajectories, as well as the potential risks of participating in OHCs. Members of OHCs are usually individuals with existing health problems and thus especially psychologically vulnerable [20]. Viewing information related to health symptoms and others' problems can trigger negative emotional outcomes, including feeling overwhelmed and frightened [19]. Participation in OHCs may also remind members of their social identity as a cancer survivor and cause a fear of relapse. It is therefore crucial to understand how members in OHCs cope with physical and emotional challenges during their participation.

3 METHODOLOGY

3.1 Research Site

Our research site was the Cancer Survivors Network (CSN)¹, a collection of online peer support groups organized by the American Cancer Society. Launched in July 2000, CSN was designed to offer cancer patients and their families experienced-based knowledge and social support from other members [9]. According to a report published in 2018, CSN attracts over 3 million unique visitors per year and over 140,00 people register new CSN accounts per year. The majority of the members are cancer patients; other members include families and friends, who have been impacted by cancer [9].

3.2 Research Methods

This research used mixed methods incorporating both qualitative and quantitative analyses. We first interviewed 20 long-time CSN participants. The qualitative analysis of the interview transcripts was used to inform a series of targeted quantitative analyses, and the results of the quantitative analyses are presented alongside the qualitatively derived narratives. The quantitative analyses are based on surveys with over 5,000 CSN members and behavioral logs from over 130,000. Table 1

¹<https://csn.cancer.org>

summarizes the sample size of each data source and the time period each group of participants stayed on CSN, defined as the number of days between their registration date and the last time they logged into CSN. Our interview sample represents a small group of highly motivated old-timers on CSN. Our behavioral log analysis sample represents the entire population of CSN users, whereas the survey sample is based on a large but selected group of more motivated users.

3.2.1 Interviews. To explore how OHC members' participation change over time, we conducted semi-structured interviews with 20 CSN users. We first identified all users who had logged onto CSN at least once in the six months prior to recruitment, sent email interview invitations to 300 members who had registered over a year ago, of whom 19 responded and were interviewed (6.3%), and to 300 people who had registered for CSN in the past year, of whom only one (0.3%) responded and was interviewed. Our interviews took place remotely via Skype, Google Hangout or phone call. The average age of the interviewees was 56.3 (sd =10.63), with all but one more than 45 years old. Among the 20 participants, 17 were cancer survivors and three were caregivers to cancer patients. Although we sent out interview invitations to a random sample of recent users, those who responded had been active on the site far longer than average: all but one had registered more than a year before the interview date.

The interview typically lasted around an hour. During the interview, the participants were shown samples of their posts on the site and were asked to describe their experiences when they first joined the site, made their first post, and made their most recent post (e.g., Could you please navigate me to the very first thread that you started/the most recent thread you started? Can you tell me why you posted this message?). They also reflected on their motivations and challenges on CSN both when they first joined and during later stages (e.g., Now that you've been on CSN for X years, what are your current reasons for using CSN?). Finally, they discussed how their experiences of using CSN had changed over their tenure (e.g., How do you think your experience have changed over time?).

All 20 interviews were recorded and transcribed. We started inductive, open-ended qualitative coding by tagging topics in the transcripts. We then tried to build connections between the tags to identify emerging themes from the interview data. Finally, we grouped various themes into different stages of participation and drew key quotes to illustrate our findings. In addition to interviews, we also looked at interviewees' posts and comments to better understand their experiences on CSN. Note, as part of the consent processes, interviewees gave permission to view their posts and discuss their posts with them. Examining the interviewees' profiles and posting history allowed us to better understand the context of their CSN journey and to effectively facilitate the interviews. Some of the discussion posts were used as probes to elicit interviewees' reactions and thoughts at the time

	Sample size	CSN tenure
Interviews	20	All participants except 1 stayed more than a year.
Surveys	5,426, answered all or part of the survey questions	Median tenure = 10 days, 1,648 (30.4%) participants stayed more than a year.
Behavioral logs	136,323	Median tenure = 1 day, 9,920 (7.2%) participants stayed more than a year.

Table 1. Sample size and characteristics of each data collection method

of posting; this technique asks participants to recall an actual event, and the probe serves to make up for some of the drawbacks (e.g., inaccurate memories) associated with retrospection [37].

3.2.2 Log data analysis. The behavioral log data consists of the users' posts, comments, profiles and history of login session history on CSN between August 2008 and August 2018. Note all message traffic on CSN can be viewed by the public without registration. The behavioral log data was obtained through a collaboration with the American Cancer Society; the university's IRB and US federal regulations do not consider the analysis of publicly available data to be human-subjects research. All our data were anonymized before analyzing. The sample consisted of 136,323 users who had logged onto CSN during this period. In addition, we leveraged machine learning models to measure features of their posts and comments. The machine learning models were those developed by Yang et al. [44] based on social support definitions in [4], in which linguistic features of the posts predict the extent to which support-relevant constructs appear in them. Specifically, the models predicted **support-seeking actions**—how much thread-starting posts sought **informational support** and **emotional support**, as well as how much **positive and negative self-disclosure** they contained. We also examined **support-provision actions** in replies to posts, including how much informational and emotional support a reply contained. Full details regarding the machine learning models used are in [44] and summarized in Table 2. Human annotation agreement on a training dataset was high (mean ICC=.84), and the machine learning models were highly correlated with the average of the human judgments (mean Pearson correlation $r=.71$). We then applied these models to estimate six types of support-related actions in posts from our corpus.

3.2.3 Survey. The data also include responses from a survey sent out at the beginning of 2014, during which we emailed 83,589 CSN users who had logged in at least once between January 1, 2000 and October 30, 2013. The American Cancer Society sent out invitations to CSN members to participate in the survey so that the researchers would not have access to personally identifiable private information. Of the 83,589 emails sent out, at least 11,000 never received the survey based on undelivered and bounce back notifications. 5,426 people completed at least part of the survey (6.5%) and among them 55.81% finished. Because of missing data, there is some variability in the number of participants answering a particular question. Therefore we specify sample size for each analysis presented in later sections. In this paper, we mainly focused on participants' self-reported motivations for participating in CSN and their interpersonal attachment to other CSN members. Members' motivations to join online support groups were measured by four short, but highly reliable scales representing four common reasons why members join online support groups: to get informational support, to get emotional support, to conduct social comparisons, and to provide support to others. These four reasons were based on two in-depth, qualitative analyses of the reasons people participate in online groups in general, including health support groups, and in online cancer support groups [35, 36]. For each of the three statements, CSN members responded to the question "How valuable is participating in CSN for each of the following purposes?" using a 5-point Likert scale, where 1 = not at all and 5 = very much. Confirmatory factor analysis showed that the four factor solution is a good fit to the data (CFI=.971, TLI=.958, RMSEA=.087). In addition, the survey measured participants' attachment to other CSN members on a 5-item scale ($\alpha = .85$). Table 3 shows sample survey item for the motivation and attachment scales.

4 RESULTS

4.1 Initial motivation to participate in OHCs

According to the interviews, new members typically joined CSN shortly after being diagnosed or when they were in active treatment stages of their cancer (i.e., screening diagnosis, information

Support actions	Definition and examples	Corr.
Seeking informational support	Seek information, advice, referrals or knowledge in the thread starting post. <i>"I was wondering if anyone who has had whole brain radiation has had hair not grow, back on head?"</i>	0.73
Providing informational support	Provide informational support to the person starting the thread. <i>"It was explained to me that microcalcifications look like as if one were to throw rock salt on a blacktop driveway and they would 'cluster and fall' in many locations"</i>	0.79
Seeking emotional support	Seek understanding, encouragement, sympathy or caring in the thread starting post. <i>"So, much of the stuff I find on the web is 'doom and gloom'. Would love to hear from some long-term survivors!!!! Mainly cuz I'm scared, out of my wits about all this - any thoughts?"</i>	0.64
Providing emotional support	Provide emotional support <i>"I do understand the frustration and anger and sadness of having drugs fail you and then venturing forth on unknown territory yet again. This whole journey is fraught with crappy bumps and turns. wish you the best."</i>	0.75
Self-disclosing positively	Discuss positive thoughts or emotions, such as gratitude and love. <i>My family is so supportive and makes me feel like such a loved person."</i>	0.72
Self-disclosing negatively	Discuss negative thoughts or emotions, such as worry or anger. <i>"I am freaked out after reading my mammogram report"</i>	0.71

Table 2. Definitions, examples of six support-related actions, and our model accuracy as measured by the Pearson correlations between model predictions and human judgements.

Scale	Sample statement used in the survey	Alpha
Get informational support	To get information about the cancer I'm dealing with.	.86
Get emotional support	To be comforted by others in CSN who have been there.	.94
Conduct social comparison	To see how other CSN members like me are doing.	.87
Provide support to others	To help others solve their cancer-related problems.	.96
Interpersonal attachment	I feel very close to some of the people I've met on CSN.	.85

Table 3. Self-report scales, sample questions, and scale internal consistency (Cronbach's Alpha)

seeking, and acute care treatment) and thus were in need of informational support. The results, however, also indicate that new members are there for more than just information. Members' participation in CSN was aimed at reducing their uncertainty and anxiety about their disease. In addition, to find useful information, participants reported employing strategies such as conducting social comparisons with other members. Quantitative analysis supports the interview findings.

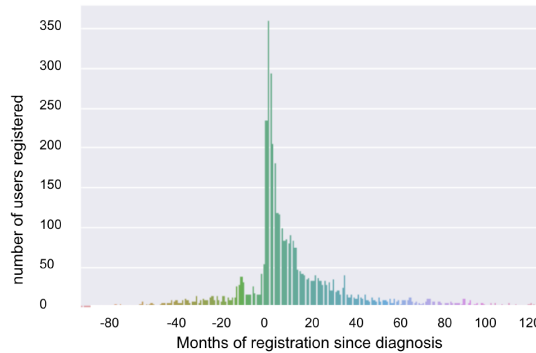


Fig. 1. Distribution of registration time since diagnosis

4.1.1 Members typically joined OHCs early in treatment when they were especially in need of help. All 20 interview participants reported joining CSN when they or their loved one were just diagnosed with cancer or were in active treatment of cancer. They described that they felt "shock[ed]," "horrified," "uncertain" or that they "did not know what to do" about their disease at the time. Eighteen of the 20 described a similar scenario about how they found out about the site: in order to know more about their disease, they chose to search online.

"Because I was there and I didn't know what I was going through. And I wanted answers that, the doctors couldn't... they couldn't tell me, they couldn't have real life experience." (P11)

"So I did ...well I started my research for [my partner's] cancer, I think the American Cancer Society site popped up. And so then I started searching, you know, for his particular type of cancer, I found the American Cancer Society to be actually very, very helpful..." (P5)

Our log data support the qualitative findings that most members joined OHCs in their early stages of treatment. Figure 1 shows the distribution of the time interval between CSN members' (or their loved one's) diagnosis time, derived from the survey ($N = 2928$), and their CSN registration date, derived from the log data. It shows that 44.8% of the users registered within three months of cancer diagnosis. This suggests that many newcomers join OHCs in search of actionable results that are specific to the challenges (i.e., cancer diagnosis in this case) they are facing in their offline life [3, 7].

Furthermore, the majority of users found CSN through informational search engines such as Google. For instance, according to Google Analytics data, a total of 6,305,602 unique users visited CSN via a search engine in 2017, probably searching for cancer information or support, but only 13,231 users created a new account during 2017. Although the data do not allow us to identify the pathways through which particular people joined CSN, this disparity between unique visitors versus registrations suggests that many users got to know about OHCs such as CSN when searching for relevant information on the Internet, and a minority decided that they wanted interaction with other survivors in addition to static information.

Self-reported data from our survey show also that informational needs stand out among other reasons for OHC participation. One-way ANOVA showed a statistically significant difference among the four types of motivations reported by survey participants ($F(3,11738)=134.99$, $p<0.0001$). Post-hoc Tukey tests indicate that members' needs for informational support were significantly

Motivations to use CSN	Mean	SD
Get informational support***	3.82 ^a	1.14
Conduct social comparison	3.33 ^b	1.23
Get emotional support	3.30 ^b	1.39
Provide support to others*	3.21 ^c	1.35

Table 4. Motivations to use CSN reported by survey participants.

Mean and SD are shown. Within columns, means with different superscripts were statistically different from each other. Get informational support is significantly higher than other three types of motivations (***: $p < 0.001$); to provide support to other members is significantly lower than other three types of motivations (*: $p < 0.05$).

higher than the other three types of motivations examined (mean = 3.82, versus all others, $p < 0.001$). Second most important was the use of CSN to make social comparisons (mean = 3.33) and to get emotional support (mean = 3.30). Participants also reported that they used CSN to provide support to others but the score is significantly lower than those of others (mean = 3.21, all $p < 0.05$). Table 4 contains the descriptive statistics for the four types of motivations reported by survey participants.

4.1.2 Members received support from OHCs that was otherwise unavailable via offline sources. Interview participants reported that obtaining disease-relevant information and conducting social comparisons with other users were two useful strategies to reduce their uncertainty. In particular, they described information from CSN as information "otherwise unavailable via offline sources" that sometimes facilitated their treatment decision-making.

"There were issues in my treatment that were pretty severe. And I didn't get information from doctors, but the other patients that had similar problems like I had, I read about them...like, when I was debating whether or not to have radiation after the chemo. And I went on CSN and I asked, Does anyone else have the same thing going? Well, I didn't get a whole lot of responses, [but as for] what I did get, that that's basically what I use for this." (P16)

Interviewees have stressed the helpfulness of assessing other members' situations, which could be more personalized than guidelines they received from doctors.

"The forum itself, I found very helpful... So it was just interesting to read other people, you know, going through the same thing, and, how they were dealing with it. Like, for instance, food was a big issue, you know, how are they eating? What were they eating? The pain was terrible, you know, how are they dealing with the pain?" (P12)

As for social comparisons, OHCs such as CSN allow patients and caregivers from all over the globe to participate and thus view a variety of cases. Specifically for new OHC members, upward social comparison (i.e., comparing one's situation with those who are better off) led to positive feelings about their situations.

"Doctors tell you, you know, come from a clinical side. CSN tells you, people who have lived it...So to hear from the people who have done it, it makes it okay. You know, when they say chemo is doable, it's, um, you know, it is doable, and yeah, let's do that." (P15)

While the majority of the interviewees reported that they joined CSN mainly to know more about their disease, interviewees also identified obtaining emotional support as an associated benefit brought by participating in CSN. Members got direct encouragement from fellow members regarding their situation, as P2 reflected:

"When I made my very first post, you know...I got responses immediately. Some are like, just a couple of words, saying that 'you could do it'. It does make me feel a whole lot better, seeing these responses."

Companionship with members in similar situations provides comfort and reduces feelings of isolation. Members expressed "not feeling alone."

"I think it was just comforting to be in a group of people that were going through the same thing. You know, I don't have my own personal friends [who] have this kind of stuff. I don't really know anybody who had this kind of cancer. Hmm. So I didn't have any personal resources." (P7)

Similar experiences also provide a common ground for better understanding each other, even compared with close family members and friends as P9 noted,

"Everybody said I looked fine. I didn't even look like I was sick... it made me mad because when you have this I guess there's a part of you that wants a lot of sympathy, empathy whatever you want to call it. [On CSN], you know you get something from these guys, as they are just like you. You know you could only expect hugs sent to others – it's still keystrokes, but was better than nothing. "

Our results are consistent with prior research that OHCs provide members with informational and associated emotional support that are otherwise unavailable to them [34, 40]. The results also echo prior work on cancer journey, which indicates patients tend to spend a lot of time seeking information to get their questions answered and thus informational support is of the most value to them [10].

These findings are consistent with prior work that treat participation in OHCs as primarily driven by the course of members' diseases: social support afforded by OHCs can help members navigate intense and difficult periods in their lives.

4.2 To leave or not to leave? A decision for continuous participation at OHCs

4.2.1 Most OHC members dropped out after their initial needs for joining the site were met, because continued participation brought few benefits. Participation in OHCs was primarily driven by the course of members' diseases: social support afforded by OHCs can help members navigate intense and difficult periods in their lives; over time, however, the amount of support they sought and received declined, as urgent questions got answered, and individuals developed additional mechanisms to cope with their diseases [7]. OHC members dropped out because they no longer found the group valuable. For example, cancer patients who have been declared in remission with "no evidence of disease" after receiving treatment often shifted the focus of their lives away from cancer. P7, who had not logged into CSN for three months before his interview, reported: *"As I stay longer, more that I give input and less that I need input. Probably just a year has gone by and in my life everything has become better."*

Our log data analysis results support the findings from the interview that the majority of users tend to quit quickly after initial use: 62.5% of registered members on CSN never logged in again after the first day of their participation. Among those who logged into CSN at least once after their registration date, the half life of their CSN participation was about 31 days. Together, these figures indicate that less than 20% of the users stayed on CSN for more than a month. Members who did stay sought less support over time. Figure 2 shows that the average amount of informational, emotional support seeking and negative self-disclosure per thread-starting post decreased and that positive self-disclosure increases over the first six months of members' participation. Those who never initiated a post sought less informational and emotional support over time. Specifically, the duration of CSN membership was negatively associated with the amount of informational and

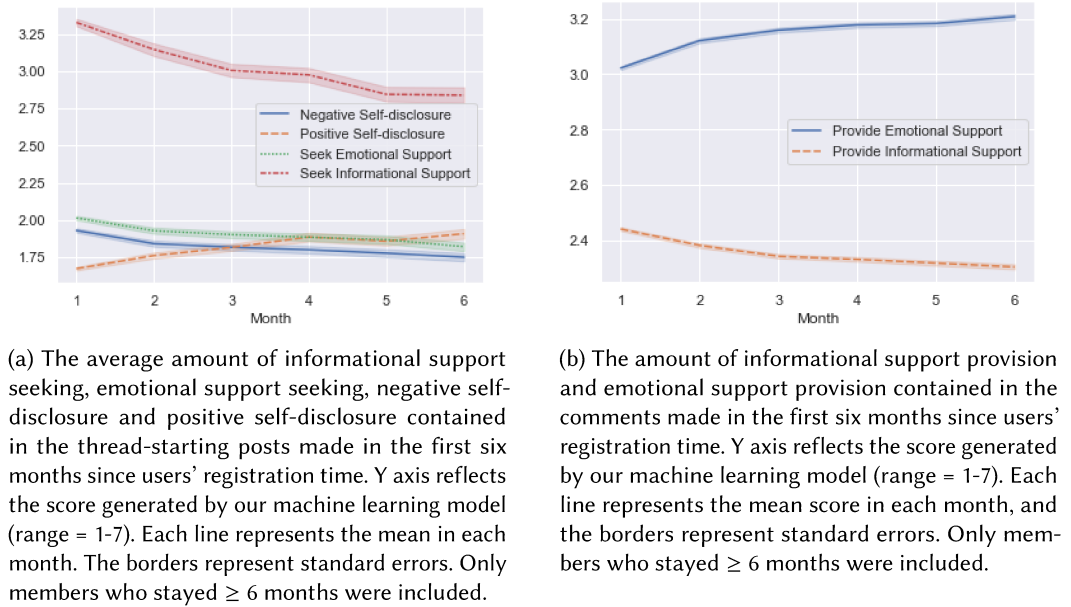


Fig. 2. How members' support seeking change within the first 6 months of their participation

emotional support the members sought in threads they started (coef = -0.0029, $p < 0.001$; coef = -0.0009, $p < 0.001$, respectively). Moreover, the longer members stayed on CSN, the more positive self-disclosure (coef = 0.0018, $p < 0.001$) and less negative self-disclosure (coef = -0.0009, $p < 0.001$) their posts contained. The decline in negative self-disclosure is consistent with the hypothesis that members are seeking less support over time because prior research has shown that negative self-disclosure is the major mechanism through which people seek support, especially emotional support, in online health support communities [42, 45].

As for the provision of support, log data analysis results show that the longer members stayed on CSN, the more emotional support (coef = 0.0010, $p < 0.001$), but the less informational support (coef = -0.0008, $p < 0.001$) they offered in their replies to other members' threads. Figure 2b illustrates that the amount of emotional support provision increased, whereas the amount of informational support provision decreased over the first six months of participation.

4.2.2 Members continue to participate in OHCs because of the obligations of reciprocity and the ties they formed with other community members. Notably, all but one interviewee showed "no evidence of disease" at the time of their interview, suggesting that they no longer needed or were actively seeking informational or emotional support. Although the remaining interviewee (P8) reported that her tumor was "spreading," she "has not been seeking for help recently," for she has gained "more than enough knowledge for her own disease". This is consistent with the cancer journey perspective [13], which predicts that the amount and way that members engage in OHCs depends on their disease state. Although the cancer journey perspective predicts that support-seeking will decline, it does not convincingly provide a rationale for why these members continued to participate even after remission.

Interviewees revealed a variety of reasons to stay and help other members on CSN. Some described a general reciprocity process, in which they wanted to return the favor to a community where they've been offered similar types of support when they were newcomers. P17 shared her experience of being helped when she was a newcomer to CSN and identified reciprocity as her reason of staying:

"When I was new to the site, I had everybody there who is undergoing chemo. You know, there was one lady who had undergone an IP chemo and she was able to tell me, you know, this is gonna hurt. She didn't lie: this is gonna hurt. You know what, since it is your best chance, here's what's you're gonna feel and she's able to describe it. That helped to take the fear of the unknown away. And because of this type of thing, this type of support I've got, I wanted to give back."

Interviewees also mentioned empathy as another reason for staying; based on their own experiences, participants could relate to other members' anxiety and uncertainty, and therefore wanted to provide support.

"...at the end of the day, you're by yourself and you know, your mind is going crazy. And that feeling of [being] all by yourself versus having people around you, especially with an unknown aggressive cancer, you know, never would have guessed it in a million years that you would have that. So if people can find their way to CSN, yeah, I remain. I can be there in a minute. I can remember exactly how I felt. I can remember exactly the things I was thinking." (P15)

In addition to altruism, OHC members' tenure on the site could also be influenced by their connection with other members. Interviewees indicated that they had developed some level of friendship, or at least had become acquainted with other members in the forum. Some expressed the desire to "check up on [their CSN acquaintance]" when on the site. Although five out of the 20 interviewees mentioned they've exchanged contact information with other members outside CSN (e.g., Facebook, email, or in-person meeting), most interviewees indicated that they just knew other members "on the cancer level." P1 described his friendship on CSN as follows:

"I don't know them very personally but I know them on the cancer level. And I know where they go and what they do and what they like just through the forum and stuff. You know if I have time and I'm sitting around, I'll log in and just see who is online and then ask how's Ann, or how's Ted or how's Matt². We just kind of talk about just stuff. You know, their cat's name, how much wood the guy split intermingled with ... how are you with your disease. "

Besides their online experiences on CSN, interviewees also quoted individual differences or their personality traits as the reason why they continued participating on the site. For example, some mentioned that they tend to do charity and volunteering work even offline.

"I wanted to help. I've been volunteering for a lot of stuff my entire life. I was a volunteer emergency services model in college [...] I volunteer now with a bunch of charities including this one in Florida." (P18)

Our log data analysis results provide additional insights about how people who choose to stay might be inherently different from those who drop out early - that is, their behavior differs even in initial days of their participation. Based on our analysis, members who stayed in the community for a long time were substantially more active even from the beginning of their CSN participation compared to those who dropped out within a year. Specifically, we compare three groups of CSN members: those who stayed on CSN for different lengths of time: *"early-dropouts"* who stayed up to

²Names have been pseudonymised.

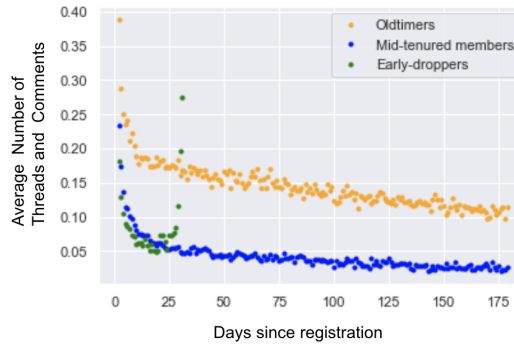


Fig. 3. The average number of posts and comments users made over the first 6 months of their participation. Early-dropouts stayed up to a month; mid-tenured stayed for a month to a year; old-timers stayed more than a year.

a month, "*mid-tenured members*" who stayed on CSN for 31 to 365 days, and "*old-timers*" who stayed longer than a year). In this analysis, we only consider those who logged into CSN at least once after registration ($N = 51,097$). We delineate early-dropouts and mid-tenured members at the thirty-day mark because the median minorlength of time these 51,097 users stayed on CSN was 31 days. We chose one year as the threshold for defining old-timers because cancer patients typically view the one-year mark as a milestone in their cancer treatment and call it their "canniversary." Figure 3 shows the average number of thread-starting posts and responding comments members made over the first six months of their participation for the three tenure groups. One way analysis of variance (ANOVA) analysis showed that old-timers started significantly more threads and commented more even during the first month of their participation ($F(2,87) = 6.82, p < 0.01$; 0.23 posts per person per day) than did mid-tenured members (0.11 posts per day) and early-dropouts (0.10 posts per person per day).

In addition to the *quantity* of members' posts, we also examined how the *content* of their posts during their first month of CSN participation varied as a function of how long they ultimately stayed on CSN. We found old-timers sought significantly less support (both emotional and informational), disclosed less negative content, but more positive content as compared with the two other groups in the earliest stage of their membership. We leveraged machine learning models to measure the amount of members' support seeking behavior and negative and positive self-disclosure contained in their thread-starting post. We then used one-way ANOVA to test the differences between these acts among early-dropouts, mid-tenured members and old-timers. Table 5 shows the mean score and the standard deviations for the amount of each of these support-related acts performed for the three tenure groups. The tenure groups differed in terms of emotional support seeking ($F(2, 32837) = 73.26, p < 0.001$). Post-hoc Tukey tests indicated that old-timers sought less emotional support than the other two groups of members (both $p < 0.001$) who did not differ from each other. The tenure groups also differed in terms of informational support seeking ($F(2, 32837) = 15.90, p < 0.001$), with the post-hoc Tukey tests revealing that old-timers sought significantly less informational support than the other two groups of members (both $p < 0.001$), who did not differ from each other.

The tenure groups also differed in terms of negative self-disclosure ($F(2, 32837) = 78.94, p < 0.001$), with the post-hoc Tukey tests revealing that old-timers disclosed significantly less negative content than the other two groups of members (both $p < 0.001$); members who stayed beyond a month also disclosed less negative content than members who dropped out within a month ($p = 0.009$). Finally,

	seek emo support		seek info support		negative self-disclosure		positive self-disclosure	
	mean	sd	mean	sd	mean	sd	mean	sd
Early-dropouts	2.14 ^a	1.03	3.41 ^a	1.60	2.07 ^a	1.00	1.56 ^a	0.65
Mid-tenured members	2.12 ^a	0.98	3.41 ^a	1.58	2.30 ^b	0.96	1.62 ^b	0.70
Oldtimers	2.00 ^b	0.91	3.31 ^b	1.56	1.91 ^c	0.88	1.69 ^c	0.74

Table 5. Four types of support acts performed by early-dropouts, mid-tenured members and oldtimers in threads started within the first 30 days of their participation. Within columns, means with different superscripts were statistically different from each other.

the tenure groups differed in terms of positive self-disclosure ($F(2, 32837) = 94.89, p < 0.001$). Unlike the other support-relevant actions, the post-hoc Tukey tests indicated that old-timers disclosed significantly *more* positive content than the other two groups (both $p < 0.001$); members who stayed beyond a month also disclosed more positive content than those who left within a month ($p < 0.001$).

4.2.3 The small group of old-timers in OHCs contributed to the community in multiple ways. Interviewees reported that old-timers on CSN make important contributions to the community by providing both direct and indirect support. Seven out of 20 interviewees recalled that they were directly supported by other members when they first joined the community, with support coming from those with similar cancer experiences to be especially helpful. For example, P20 said: *"And immediately [after registration] I got a personal message from a person. Her husband was a survivor but 15 years younger than my husband, but identical cancer, identical circumstances. And so that was like a lifeline to me."*

Interviewees also reported that having experienced cancer treatment themselves enabled them to better help others. P2 described a scenario where she used her own experience to support other members: *"I'll post on the discussion group because somebody will say, 'I'm waiting for my results and I'm not sure how I feel about this or I'm freaking out.' And I'll say well this is what happened to me. Yes it's really tough to wait for results but you just have to do one day at a time and leave ... a little blurb on it."*

Besides offering others knowledge relevant to their disease, experienced members had also learned strategies for how to best respond to others. P6 noted a specific strategy she thought might be useful when trying to help others: *"...You can't throw out all the negative stuff all at once, which would made them even more worried. Rather you need to go bit by bit..."* P10, on the other hand, was sensitive to the type of information members of the community should be providing: *"I don't say specific things as you should do this, do that, for I know I'm no doctor."*

In addition to directly responding to other members to provide support, interviewees indicated that old-timers were also able to help in an indirect manner. First, by contributing the majority of the content on CSN, old-timers effectively made CSN an active group, which in turn attracted prospective members. P2 observed that she joined CSN after deciding it had a critical mass of activity [23]:

"I found the online forum. So then I clicked on there, and I was pleasantly surprised, maybe pleasant not the right word for cancer, but it was just really nice, because I went in there, and there was like, all the different cancers. And so I found the head and neck cancer and I went in there, and it seemed like, that was actually a pretty active forum. And, you know, people ask lots of questions."

Comments made by:	Reply to threads started by early-dropouts	Reply to threads started by mid-tenured members	Reply to threads started by oldtimers
Early-dropouts	17,942 (24.3%)	7,846 (10.6%)	11,643 (2.0%)
Mid-tenured members	6,030 (4.4%)	40,339 (29.7%)	36,108 (5.9%)
Oldtimers	48,037 (65.0%)	89,611 (65.9%)	562,408 (92.2%)

Table 6. Interactions between early-dropouts, mid-tenured members and oldtimers.

Second, responses old-timers left for a particular thread benefited other members and even unregistered lurkers who browsed the conversations on CSN, as P8 noted:

"I think there's an awful lot of people, newcomers like me back then, [who] just go on there and spend hours on there just reading other people's posts, seeing what their issues were, and reading how other cancer patients got through treatment."

In addition, as previously discussed, newcomers to OHCs often sought upward social comparisons with other members who have shown "no evidence of disease" after treatment to gain optimism and inspiration during their own treatment. Old-timers who have undergone treatment and improved their health conditions served as natural "role models" for this type of comparison. Interview participants also reported feeling hopeful after reading old-timers' positive updates after their treatment was over, as P14 remembers:

"I read about these, you know, 'don't feel bad. I felt the same way you did, but there is light at the end of the tunnel.' You know, people who are battling don't give up, and life does get better after treatments were over."

Our quantitative analyses provide further evidence of old-timers' contributions to the community. Not only do they generate the majority of the content, but they also disproportionately provide emotional support to others. As is well known from prior research on many types of online groups [30, 31] including OHCs [12], a small group of core contributors on CSN were the heavy contributors. Although only 7.2% of CSN members stayed longer than a year on CSN, they contributed the vast majority of the content on CSN by initializing 66,604 threads (61.6% of the total) and creating 742,396 replies to others (85.1% of the total). Table 6 illustrates the pattern of interactions among early-dropouts, mid-tenured members and old-timers, operationalized as the number of comments each group made to thread-starting posts initiated by each group. The overwhelming majority of interactions that old-timers had were with fellow old-timers (i.e., 92% of the comments written by old-timers were replies to threads started by other old-timers). This finding strongly suggests that interpersonal ties and repeated interaction with fellow old-timers were major reasons for their continued participation on the site. However, old-timers were so active on the site, they also provided the most comments regardless of who initiated the thread. For example, they provided 65% of the replies to threads started by both early-dropouts and mid-tenured members. Thus, in a very concrete sense, old-timers were the fuel that kept this OHC running. In addition to posting more content, old-timers' comments contained more emotional support compared to the comments of those who dropped out earlier. Using Welch's t-test, we compared comments posted by those who stay less than a year and old-timers in terms of their average amounts of informational support and emotional support, as illustrated in 4a. Old-timers' comments contained significantly more emotional support ($t(161747) = 66.33, p < 0.001$) but less informational support ($t(159364) = -63.96, p < 0.001$). This latter finding can potentially be explained, in part, by the fact that

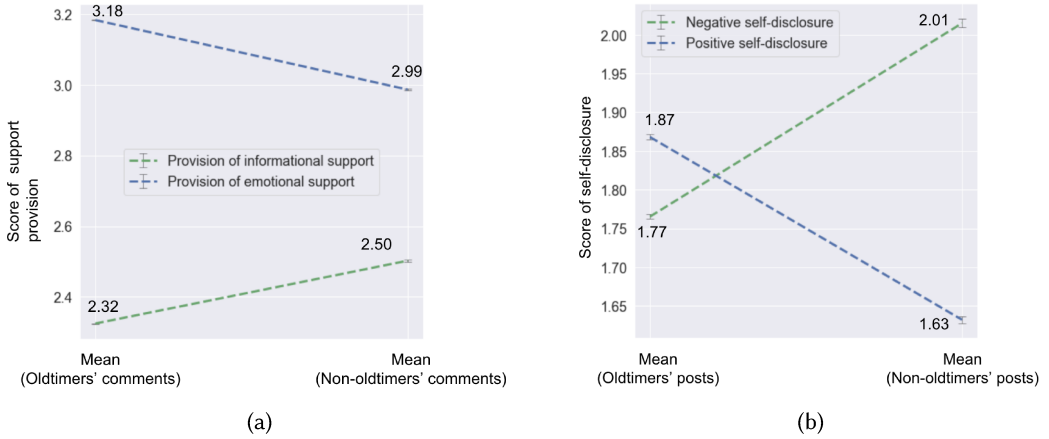


Fig. 4. The comparison of old-timer and non-old-timers' support provision (a) and self-disclosure (b) based on Welch's t-test.

old-timers primarily communicate with other old-timers, who no longer need or seek informational support.

We also conducted a set of six ANOVA analyses to examine whether old-timers' support provision varied based on the recipient of the support. We looked at replies to threads started by early-dropouts, mid-tenured members and old-timers separately, and investigated how old-timers' support provision differed from the other two groups of members. Figure 5 shows the mean amount of informational and emotional support provided in comments by early-dropouts, mid-tenured members and old-timers to the threads started by these three groups. We could see that, despite providing less informational support overall, old-timers were the most likely to provide informational support to early dropouts (mean = 2.90) and a reasonable amount to mid-tenured members (mean = 2.69). They provided little informational support to fellow old-timers. As for emotional support, old-timers provided more compared with early-dropouts and mid-tenured members regardless of the recipient.

4.3 Challenges of long-term participation in OHCs

Old-timers faced some unique challenges brought about by their own health problems and prior experience participating in an OHC. Reflecting theories about non-use of HCI systems [38] and the disease journey perspective [24], disengagement with OHCs is not necessarily a failure of the site's design, but may represent a logical reaction to one's changing life circumstances (e.g., remission or ending of treatment). However, as we have seen, a minority of members stay in the community to offer help to others even though their initial needs and life circumstances have changed. Although these old-timers indicated that they were eager to stay and support others, they also pointed to challenges and risks of continuing their participation, which could lead some of them to drop out of the community in the future.

It is reasonable to draw similarities between the behaviors of old-timers on CSN and the reasons offline volunteers stop their volunteerism, such as a need to return to other commitments in their lives and undesirable interaction with the beneficiaries, which may lead to a decrease in the value they place on their volunteer work and their satisfaction with it [2]. In addition, old-timers in OHCs may be plagued with the stresses similar to the burnout experienced by offline volunteers [6, 26]

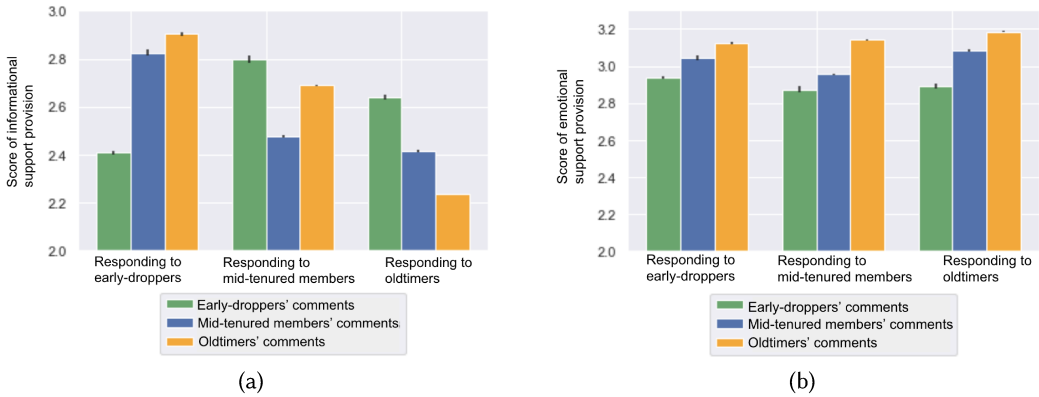


Fig. 5. The average amount of informational support (a) and emotional support (b) per thread-starting post provided in comments by early-dropouts, mid-tenured members and oldtimers to the threads started by these groups.

Old-timers on CSN did express similar complaints. For instance, P9 explained how "wanting to get over with cancer" could lead to (tentative) dropout:

"Sometimes I finally want to be done with the whole experience you know, I just don't want...Like my wife, she can't watch an ad for the Cancer Centers of America, she can't watch a movie that has cancer in it because she just can't handle it. She doesn't want anything to do with it. Sometimes I think about that too. People step away from this – they're done they don't want to do this anymore. "

Interviewees also reported unpleasant interactions with other members on CSN, as P13 reflected interacting with "a couple of whiners":

"For example this one woman, she respond to all of these posts repeating her own experience, yeah, over and over and over and over. But she never answered any of these questions."

Nevertheless, interviewees insisted that, despite "feeling uncomfortable" with these experiences sometimes, these were not what drove them away. They felt capable of "handling it or just ignoring it." However, the old-timers on CSN expressed an additional challenge that seems specific to cancer-oriented OHCs: distress related to hearing of fellow members' deaths. Eleven of the 20 interviews expressed feeling "shocked" or "saddened" when reading about other members' deaths.

"I know them through the message board, not personally. But yeah, there's been a lot of members that I become feathered by them passing. It was very difficult I would cry. I would be you know... I would feel very hurt I would just...you do become very sad." (P11)

"But it's got to be depressing after a while reading about people that lost their battle with cancer. I could connect with them, though I never actually met them face to face, we had a bond because of a website. And you end up losing those people to something that you almost died from. So it's got to be depressing." (P13)

While similar scenarios have been described in prior work [1, 34], we found that discovering peers' deaths may have been especially heartbreaking for experienced CSN members because they often felt very connected to fellow OHC members, as P10 expressed:

"I think probably a couple different things [for me to take a break]. Among them, when one or two of the women have died. It really affects you because you feel like you know some of these women via the posts on there...You know a lot of what they've done through so it's really hard to think that way."

Moreover, reading about other members growing sicker or dying may lead to downward social comparison, that is, comparing one's situation with those who are in a less desirable position. Unlike those who are earlier in the treatment, the direction of members' social comparison may change as a result of these losses. Earlier in their participation, members were able to perform upward social comparison with patients who are better off than they were and to seek for both information and optimism when relatively new to the site. However, as some stayed longer, they started to make downward social comparisons, comparing themselves to fellow users who are in worse off situations than they are. P3 illustrated this point by saying:

"Seeing them dying...or being very very sick, I feel like I can do very little regarding this. The only thing I could do is to send prayers, which I think seems really weak."

P6 brought up that he can't help "reflecting that same situation to myself. What about it was me who suffered from that recurrence?" Legg et al. [20] suggested that downward comparisons could be threatening when they invoke concerns about another member's possible negative future cancer events, which could increase anxiety about one's own situation.

5 DISCUSSION

This research investigated how members of OHCs evolve as they stay longer on the site. We employed a mixed-methods approach combining interviews, surveys, behavioral log analysis and automated content analysis. The research was informed by both a disease-journey perspective, which argues that changes in motivation and participation in OHCs are primarily driven by the members' disease states, and a more general online communities perspective, which argues that the changes are more generic, reflecting internal dynamics common to many types of online communities. Consistent with the disease-journey perspective, results indicate that members seemed to join the OHC because of health crises shortly after they were initially diagnosed or while undergoing active treatment. They were seeking informational support, often to inform disease-relevant decisions, and social comparison, to better cope with the uncertainty associated with their disease. However, most quickly left as their initial informational needs were met. Among the minority who continued to participate over an extended period, motivations for participation often shifted from receiving support to providing it to others. As in many other online communities [31], a small group of old-timers were responsible for the majority of the interactions in the OHCs. They were both capable and willing to provide support to other members. As in other online communities, the heavy contributors behaved differently from those who dropped out quickly after joining the community. But our research also presents several strands of evidence suggesting that the shift from self-centered to other-centered motivations was associated with their greater feelings of connection to and repeated interactions with other long-term members of the community.

The core members left for many of the reasons people might leave any community. However, one of the major contributions of our research was identifying reasons for leaving that are unique to OHCs – the emotional toll of participation, especially from reading about the poor health and even death of fellow members. Old-timers want to help others, but doing so had negative consequences that made continuing participation difficult and seemed to lead them to take a break or indefinitely quit using the site.

A strength of our work is the comprehensiveness of our findings, which were derived from a combination of behavioral logs, surveys and interviews; with all these data available, this paper

provides a relatively holistic view of members' experiences in OHCs. Most of the prior work that studied members' journeys in OHCs relied either on quantitative methods, analyzing log data (e.g., [12]), or qualitative ones relying on interviews and surveys (e.g., [24]), and thus were often only able to focus on either changes in OHC members' observable behavior or changes in their self-reported motivations. Our work leverages both self-reported data including surveys and interviews, and behavioral data, which allows us to examine changes in OHC members' motivation (i.e., what they thought) and behavior (i.e., what they did) as they stayed longer in the community. These analyses used retrospective interviews in which participants reflected on their experiences at different times, and one-time surveys to compare old-timers with shorter-tenured members and longitudinal data, including behavioral logs to examine how individual members' motivation and behavior changed over time.

6 DESIGN IMPLICATIONS

Our work confirms previous research showing that a small subset of a community provides most of the contributions and that in OHCs, their participation pattern shifts from seeking support to providing it. Despite the importance of these core old-timers in keeping the community alive, most features of OHCs are aimed at the process of providing disease support. We echo prior research such as [41], as we urge for more targeted designs for members in different stages of their OHC journey, specifically to support the unique needs of the old-timers.

Designers of OHCs could highlight thread-starting posts that are seeking support in their areas of expertise, thus making it easier for them to help others needing their experience. They could also consider implementing a badge system, which could visualize the expertise and status of an old-timer. Not only would such a badge system serve to better match support seekers with support providers, but it is also likely to encourage providers to offer more support, either to fulfill explicit roles or to gain reputation in the community.

In addition, we suggest providing some degree of training to old-timers to help them be more effective support providers, to forewarn them about potential risks of participation and to provide them with strategies to better cope with the stress and anxiety brought about through participation. As discussed previously, old-timers behave differently than people who will drop out, even in the first month of participation. Thus, it should be possible to identify these potential backbone members shortly after they join the community. This early identification would allow community managers to take steps to retain and develop them. Practices in other types of online communities (e.g., [27, 30]) have demonstrated benefits of doing so. 7Cups.com [29], a community for the exchange of mental health support, offers training to volunteers but does no filtering to identify candidates who are likely to be heavy contributors to the community. Similar training programs have been implemented in offline settings. For example, Legg et al. [20] designed a 2-day training course that covered psychological aspects of the cancer journey, role requirements of a support volunteer, and effective interpersonal skills to utilize in the peer support setting. Training modules like these could potentially benefit old-timers in online support groups such as CSN.

Finally, our research identified a dilemma faced by the core old-timers of CSN, who are both capable and willing to help, but faced emotional challenges that led some to drop out of further participation. One way to encourage participation from old-timers who have taken a hiatus is to remind community members who registered earlier to briefly come back and engage lightly with the community. While such encouragement could certainly be implemented via a formal email invitation, designers of OHCs could also consider making banners or initiating threads that list the advantages of old-timers checking-in, so that members are aware of the benefits afforded by their actions. An intervention like this would enhance a practice we noticed in the community, in which people provide anniversary updates about their health. These announcements, usually one

year or five years from a patient's treatment time, are a way to inform fellow members of one's health status as well as a way to offer hope to other members of the community. For example, P16, who had not logged into CSN for the three months before his interview said that that he would probably make a post on his one-year anniversary day: "... So, I thought that I would be make a post, you know, in another month or so, my one year anniversary and say, I'm cured and, I'm back to normal. And, you know, if I can go through with it, you can do that type of thing." Members reported feeling "hopeful" after seeing examples of old-timers being cured and thus were able to make upward social comparisons. Sharing celebratory updates is a relatively low-effort contribution from the old-timers that does not involve too much exposure to emotionally-laden content such as reading and responding to other members' posts. Nor does it require a lot of commitment and time. Nevertheless, this type of check-in action could greatly benefit other members and the broader community, and may encourage old-timers to reengage with the community.

7 LIMITATIONS

Our work has several limitations. First, we only focus on one specific online community focused on cancer, so we cannot necessarily generalize findings to other OHCs without further investigation. In particular, cancer is a deadly disease with severe life-threatening consequences. We expect members in other types of OHCs, such as those for mental illness, weight-loss or parenting, to face slightly different challenges. Second, our interview and survey methods introduced a selection bias. As shown in Table 1, both interviewees and survey respondents participated in CSN longer than a modal CSN user and thus are likely to be more motivated. Moreover, since 95% of our interviewees were old-timers, the interviews were only able to investigate members' experiences as newcomers in a retrospective way. This data provides no first-hand, contemporaneous accounts from newcomers or those who dropped out earlier from OHCs. However, we believe the sampling bias is mitigated in our study. In particular, our analysis using the behavioral log data, which covers all CSN members, confirmed many of the conclusions drawn from the survey and interview data. The behavioral log data provided a view of the comprehensive landscape of the community before jumping to a more motivated sub-population.

8 CONCLUSION

Our work investigated how members of the CSN, an OHC dedicated to cancer patients and caregivers, evolve as they stay longer on the site. Combining data from interviews, surveys, behavioral log analysis and automated content analysis, we provide a relatively holistic view of members' OHC journeys, with both their online community journey and cancer journey considered. Our results indicated that members joined OHCs primarily from self interest and quickly left as their needs were met. As in many other online communities, a small group of old-timers continued to participate over an extended period with their motivation shifting from receiving support to providing it to others. This minority group of members is responsible for the majority of the interactions in OHCs, but face significant challenges including reading about the deaths of fellow members during their extended participation period.

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