Life Transitions and Online Health Communities: Reflecting on Adoption, Use, and Disengagement

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ABSTRACT

Online health communities are places where people can come together in order to exchange social support at a particular point in an individual's life. There are, however, relatively few accounts that look across multiple communities across the lifespan. In this paper, we reflect on four case studies of research on different online health communities in order to identify patterns in how individuals selectively adopt, use, and disengage from these communities throughout their lives. We argue that users leaving communities is not necessarily a failing of the site's design or purpose; rather, it is a logical reaction to changing life circumstances. In characterizing this pattern, we contribute a set of implications for design and management that bear consideration by online community designers, developers, moderators, and end users. Ultimately this may lead to a smoother transition from community to community and ensure that social support needs are being met more consistently in response to changing life circumstances.

Author Keywords
Online communities; social support; health; transitions; lifespan.

ACM Classification Keywords
H.5.3 (Computer-supported cooperative work).

INTRODUCTION

The growth of the internet has resulted in opportunities for organizations and individuals to create specialized websites that address specific concerns. One of the domains that has benefited most from this practice is that of online health-related communities, where users facing health or life conditions can find support. Whether communication in these communities is performed in email lists, forums, social networking sites, or some other technology, they provide a constantly available source of information and support throughout the lifespan as people and their conditions change.

In this paper, we "zoom out" from use of a single online community to look more broadly at how users joined, used, and left communities of different types and at different points in their lives. By adopting this more multi-community perspective, we speak to the shifting life circumstances that result in some communities being more helpful at certain times than others. Recasting online community use in this broader context allows us to notice more nuanced patterns of behavior that are not as evident, even in longitudinal studies of a single community.

To provide such a perspective, we reflect on case studies of research with four unique online communities addressing different health events from different parts of the lifespan: young adult sports concussion, pregnancy and birth choices, breast cancer, and finally bereavement. We first provide a background on social support and online health communities, noting that most work focuses on a single community or type of community, and that even longitudinal studies rarely look across different stages of life. We then describe our four case studies in more detail and summarize their major findings. Instead of providing rich details about each individual community, we foreground the interdisciplinary discussion that arose from comparing our methods, types of communities, and research aims. Our comparisons among the four communities highlighted issues of community adoption, use, and disengagement, which we illustrate with examples drawn from the cases. We contribute a set of considerations for community managers, developers, and designers.

BACKGROUND

Social Support

Social support has been conceptualized and measured in a variety of different ways. It is often used in a broad sense to refer to any means by which social relationships might promote health and well-being [7]. Cohen, Gottlieb and Underwood conceive of social support in terms of the functional provisions of relationships such as emotional, instrumental and informational resources, and the health

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benefits accrued from participation in one or more social groups [7]. In this sense, the term “social support” encompasses the social resources that are perceived to be available or are actually received from others and the influence that integration in a social group can have on cognition, emotion, behavior and biological responses that are beneficial to health and well-being. While the exact mechanisms by which social relationships affect health remains unclear, nearly 30 years of research has consistently demonstrated that they have a powerful effect on physical and mental health, and may extend survival [3].

Some researchers have suggested that online support communities offer a form of support that cannot be achieved face-to-face [6]. Frequently reported advantages include the anonymity of the medium and the resulting lack of stigmatization, followed by its availability, diversity of experience, similarity of experience and greater information and resources. Disadvantages include the inability to engage in cues that we normally rely upon in face-to-face settings, including a lack of non-verbal cues which can lead to misunderstandings, flaming or negative comments, deception and slower feedback [42]. Despite these disadvantages, shifting life circumstances can precipitate a turn to online communities for supplemental support.

Online Health Communities

Recent years have seen the launch of many health-specific social networks [31]. Such communities can serve to either support or suppress health-promoting behaviours [2, 9], though they have been noted as having largely positive effects [12]. This is possibly because they offer a means for people to learn more about the day-to-day aspects of living with a disease, managing a health condition or treatment side effects, and other lived experience aspects of health [9].

Within an online health community, people adopt many roles. Maloney-Krichmar & Preece [22] identified examples of classic group membership roles enacted within a longstanding online health community as a means of documenting the social processes and norms within the community. These included task roles (e.g. ‘information giver – provides data and facts,’ ‘opinion seeker – asks for opinions, values & feelings’), socio-emotional roles (e.g. ‘harmonizer – mediates conflicts among group members’), and individualistic roles (e.g. ‘recognition-seeker – self-aggrandizing’).

Researchers have previously focused on user loyalty to an online community, and reasons for leaving. Brandtzaeg and Heim identified 9 reasons people left communities, including a lack of interesting people, poor usability, and poor content [5]. Sandaunet reports that reasons for withdrawal from an online community for breast cancer patients might be due in part to the challenge of “fitting in” [30]. Examples include: a need to avoid painful details about cancer, not being “ill enough” to participate, the challenge of establishing a legitimate position in the group, the organization of everyday life, and illness phases that did not motivate participation. These concerns are mediated by a need to present an appropriate image to a given group (e.g., Facebook vs. a specific health community) [24].

In much of the work in online health communities, the focus has been on creating communities and keeping them active. Although some work has examined obtaining the right “fit” with an online community, it still remains an underexplored

Life event	*Study design*	*Number and type of communities*	*Sample size and method of collection data*	*Moderators*
Sports concussion [1]	1-Arm pre-post feasibility study of a Facebook group intervention	1 (Facebook group)	Questionnaire (n=11) (concussion symptoms)	Health professionals
Birth (pregnancy options) [39]	Cross-sectional content analysis of threads and survey of members in birth online communities	4 (existing websites, 2 very large with>20k members, 1 moderate with 5-10k members, and 1 small with <2k members)	Web-based questionnaire with closed- and open-ended questions (n=744), content analysis (n=60 threads)	Largely volunteers, (some paid staff at larger sites), not health professionals
Breast cancer [4]	Cross-sectional survey and in-depth qualitative interviews with breast cancer survivors who were members of a national support agency	Unrestricted and variable. From a list of 20 websites, users reported using a median of 4 (IQR 4.2)	In-person and web-based questionnaire (n=73), In-person and telephone interviews (n=12)	Largely volunteers (some paid staff at larger sites); one also offered forums moderated by health professionals
Bereavement [21]	Longitudinal prototype deployment study	1 (custom website, prototype)	Interviews, system logs, questionnaires (social support, grief) (n=19)	Trained volunteers from a local support group

Table 1. Characteristics of the communities and studies under consideration. More information about each study can be found in the references listed in the first column.

space [35]. What is even less understood is how life circumstances are affecting patterns of use and adoption, and especially how these change over time [27].

Research into online health communities has generally selected a particular website or type of community for in-depth examination, and reported on findings about usage of that website. For example, Maloney-Krichmar & Preece provide an in-depth analysis of a community for people with knee injuries [22]. Huh and Ackerman focus on a lifelong condition – diabetes – and how it is discussed in a particular online diabetes support community [14]. Newman et al. move closer towards our goals in their study of people's perceptions of Facebook as a place for sharing health information, especially as they highlight how and why people choose to use social networking sites for health concerns [24]. Though they did not study a health community, Lampe et al. move closer to the current study in their longitudinal investigation of a website called Everythings2.com where they found that initial reasons for using the website were different from the ones that kept them there, such as for entertainment or information-sharing purposes – echoing some of the findings of our work [18]. What we notice is that single communities are often studied in depth, and that when multiple communities are studied, it is around a single theme (e.g., diabetes).

CASE STUDIES

Because our research goal was to take a more longitudinal, lifespan-oriented perspective, we saw a need to put multiple, diverse online health communities in conversation with one another. In order to ground our discussion of how users could move from community to community throughout the lifespan, we present brief descriptions of four case studies that stem from our own research and different disciplinary perspectives. Each author of this paper studied a different community in detail, and the cases presented here are summaries of their work. It should be noted that each author was highly familiar with one of the communities; two of the authors designed and deployed the communities under consideration (sports concussion, bereavement). Table 1 provides more information about the topic and format of the case studies.

We do not suggest that a single user might use all four communities in their lives, but we believe that the communities in these case studies are a sufficiently diverse sampling of the types of available communities that people engage with when dealing with changing life circumstances. Comparing and contrasting among four different cases permits us some explanatory power, and as Yin points out, a case study method is appropriate for examining questions of *how* [43] – in this case, we are interested in how people adopt, use, and leave online communities at different stages of life. Adopting a case study approach further allows us to draw upon four rich, but diverse, data sets in our findings.

We begin with a system for young persons dealing with sports concussion. We then turn to early adulthood by examining an online community for pregnant women. Following this we examine a community primarily used by middle-aged women facing breast cancer, before concluding with a case study that examined people of all ages who were dealing with grief in an online bereavement support group.

Sports Concussion

Concussion in sport has been suggested as a major public health issue [39], and is the focus of much current attention in the mainstream media [10]. Although awareness and recognition of sports concussion is rising [34], inconsistencies in the knowledge and understanding of this condition are still being reported at a community level [38]. The use of social networking sites to facilitate the knowledge transfer process and for support have been suggested as a potential strategy to assist individuals recovering from a sports concussion [28], but to date few studies have appraised their use in this manner.

To evaluate the potential for Facebook to assist the management of sports concussion, an interactive concussion management intervention was created using a multi-stage, needs-focused development process. This intervention was a Facebook group which was moderated by experienced healthcare professionals. To test the feasibility of this intervention, a preliminary small-scale pilot study was conducted and the success of this community was measured using a mixed methods approach. User satisfaction with the intervention was the primary outcome measure. Objective measurements of symptoms were also made before and after the trial, using elements of the Sports Concussion Assessment Tool 2, which is the widely-accepted best-practice method of assessing an injured athlete with a suspected concussion [15].

The research team actively recruited participants who had sustained a concussion playing sport at a recreational (non-elite) level, and were aged between 18 and 28 years old. People may have joined the community out of interest as it was a novel approach to healthcare, or because their concussion symptoms were not being adequately managed by existing means (i.e., by consultation with their doctor and by finding information independently either online or in written format). The posts in this community were broadly categorized into groups; "Asking a question" and "Commenting on a link" were the two most common uses of this community by participants, with "Sharing a story/link" and "Sharing updates on progress/recovery" being used to a lesser degree. Only one person left the group before the community ended, with that individual stating that they left the group as they were symptom-free and therefore felt that they did not need to be a part of the community.

The presence of users in this community was only ever intended to be for the duration of the 3-month trial or until their symptoms resolved (whichever came first). Although the community was created for a finite period it was hoped that the concussion education and management principles shared in the group would stay with the users long beyond this, and that it would be of assistance to them should they or anyone they know sustain a concussion in the future. It was expected that positive experiences of being in the group might also prompt users of this community to seek our similar communities in the future for other health-related needs.

Birth Choices

The Internet is a major source of information for pregnant women [17, 19]. In addition to seeking information, they also seek community with other parents and hopeful parents. Women who are pregnant, trying to become pregnant [21], or raising young children may seek out online communities as a substitute for, or supplement to, social interaction in their physical communities [8, 20].

This case study examined women's use of online pregnancy and parenting communities to explore the effects that participating in such communities might have on women's and their families' opinions and choices of birth place (e.g., home, hospital or birth center) and birth attendant (e.g., obstetrician, family physician, midwife, or unassisted birth.) A cross-sectional analysis approach was used to identify 480 relevant threads in four communities, 60 of which were randomly selected for in-depth, interdisciplinary qualitative analysis. Members of these online communities (n=744) were concurrently surveyed, recruiting respondents through postings in these communities and related sites.

Members of these communities were, for the most part, women who were, wanted to become, or had been pregnant. Community members who responded to the survey indicated that their purposes for participating in online pregnancy and parenting communities included getting information from others (97%), emotional support (87%), providing information to others (83%), friendship (65%) and entertainment (62%). The analysis of patterns across communities revealed that different communities espoused different values, and this affected the content and character of information and support provided. For example, some communities' members saw home birth as a valid, safe choice, at least under certain circumstances, whereas members from other communities saw it as a much riskier choice. Survey respondents who made choices more outside the norm (e.g., home birth, unassisted birth) more frequently reported that participating in the communities helped shape their opinions surrounding birth and parenting choices (Chi-squared (5) = 53.31, $p < .001$). Observations of community participation suggest that most members participate during periods of greatest need for information or support, typically during and immediately after their pregnancy, but others continue to engage with other community members to discuss parenting and other issues, splinter off into new communities, and may even form offline friendships with other members who may reside in the same geographical area. Those who leave may do so because of pregnancy loss, lack of fit with the group, or a lack of continued interest, especially after they have had their babies.

In the long term, most community members will associate these communities with the intensity of pregnancy and parenting. Their relationships with community members grow from shared experiences of that time. As their children grow and they exit their childbearing years, their interests and attention naturally shift to other topics.

Breast Cancer

Several studies have demonstrated that online communities provide breast cancer survivors with important benefits. These include: reassurance and hope for the future [31, 32, 37]; reduced feelings of isolation and uncertainty [29, 32, 36, 37]; and validation of concerns not dealt with by health professionals [31]. In addition, they enable breast cancer survivors to become better informed [13, 31, 37], better able to cope [29] and prepared for their interactions with health professionals [13, 36]. Little is known about the extent to which breast cancer survivors use online communities, or the conditions that influence use.

This case study examined the use of online communities by breast cancer survivors who are facilitators of face-to-face support groups (c.f., [25]). A cross-sectional survey was used to identify the extent of, and reasons for, online community use. Qualitative interviews with a purposive sample of the survey respondents were used to explore the conditions under which they used online communities. The sample for the survey was drawn from the 2008 and 2009 contact list of the attendees of a Canadian support group facilitator-training program. Participants recruited for the qualitative interview study were survey respondents who had used an online community and agreed to participate in a follow-up interview. In total, 73 of the 100 individuals surveyed returned a completed questionnaire, and 12 survey respondents participated in a follow-up interview.

In this study, respondents used online communities primarily for information and less so for emotional support. Of the 73 participants surveyed, 23 reported having used an online community (31.5%). The top reasons survey respondents reported for using online breast cancer communities were to find information about breast cancer and its treatment (91.3%) and to learn how to manage symptoms and side effects (69.6%). Less than 50% reported joining online communities to obtain emotional support (47.8%). Those who used online communities as a health resource did so intensely (e.g., on a daily basis) when their needs were greatest, which was predominantly during treatment for cancer (73.9%). According to interview participants, online communities played a distinct and supplemental role in comparison to traditional sources of supportive care. Many explained that were dissatisfied with the quality of information provided to them by their physicians, and considered face-to-face groups to be reserved for "emotional stuff". The main factors that motivated use of online communities post-treatment were the experience of a new or worsening symptom, the need for subsequent treatment, or to support other community members.

Most interview participants discovered online communities inadvertently while searching for information to address a particular unmet need. Some learned about online communities through an unsolicited recommendation from a family member, fellow breast cancer survivor, or support group member; only one person was referred to an online community by a health professional. Different online communities were not seen as being equivalent. Several interview participants described testing out a number of online communities before they found one that suited them. Not receiving a timely or supportive response caused some women to leave an online community in search of another. In addition, they appreciated the ability to "come and go" from online communities without incurring social consequences or feeling obligated to reciprocate support. Nearly all women described reaching a point at which they wanted to move beyond cancer and distance themselves from their online community.

As the effects of cancer and its treatment dissipate and individuals begin their transition to life beyond cancer, cancer survivors will have less need for online communities that focus on cancer. Some individuals may continue to participate in online cancer communities in order to support other cancer patients and survivors. Helping others has been reported by other researchers to be one of the primary reasons for staying involved in online cancer support groups [40].

Bereavement and Grief

Throughout their lives, people are inevitably faced with the loss of a loved one. Friends and family – those who have been around the longest – can be helpful in these circumstances. At the same time, the bereaved may not wish to burden these contacts with their own feelings of grief for fear of complicating or straining their relationships [26]. Turning to community-based support groups is one way of handling the situation, and provides the bereaved with an opportunity to talk to a set of compassionate peers.

This case study reports on findings from a 3-year long research project that investigated how the bereaved adopt and perceive sources of online support. The investigation included surveys, interviews, focus groups, and fieldwork with a community-based non-profit organization, ultimately producing a website that permits bereaved individuals to conduct online peer-support groups in a closed forum. The design of the website was based on the best practices established by the community organization, and was deployed in a 10-week exploratory study that collected feedback about design features through interviews and system logs.

Outcomes revealed that participants saw an online support group as a way to complement their existing forms of support. In other words, there were unmet support needs and an online group presented a low enough barrier to entry that participants felt it would be worthwhile to try. Surprisingly, not all participants joining the group did so because they needed support. Some participants reported joining the online support group in order to provide the benefit of their experience coping with their own grief, and sought to comfort others by making themselves available to those with fresher losses.

Once participants actually joined the group, their use was largely dependent on timing in two forms: how much time had passed since they endured the loss, and the timing of delivery of messages in the system. Individuals who had more recent losses tended to log in more frequently than those who had experienced a more distant loss. At the same time, some participants who had already dealt with their loss found that participation in the group could serve to dredge up unwanted emotions. This impacted the amount that people logged in and responded to messages in the support group, with up to an entire day passing between exchanges in the chat system. This lack of a rapid response resulted in situations where participants were sharing intimate and urgent thoughts without a timely acknowledgment of their feelings.

Ultimately participants left the group setting for these two reasons of timing. Those who were closer to their losses moved to more active groups and forms of support, and those who were further along simply stopped logging in as frequently because of the emotional burden it placed on them. A group of participants ultimately chose to take their conversation offline, and decided to hold an in-person weekly meeting instead. Participants often remarked on how helpful it would be in the future to have the option of an online support group available to them, but ideally with more activity.

THEMES AND DISCUSSION

Having described the research and sites in which our discussion is based, we now turn to some of the patterns of adoption, use, and disengagement that were borne out of comparison between these case studies. We arrived at these trends through iterative discussion, secondary review and comparative analysis of our data sets and collaborative writing among the researchers specializing in each of the four case studies, and refer back to these to provide specific examples of the trends we observe. Regular discussions occurred approximately once per month over the course of 8 months; meetings occurred in person, via teleconference, and as part of a panel at a health conference. These discussions were guided by a set of common questions jointly developed and individually answered in written form by each of the authors, and consolidated in an online collaborative document for comparative analysis. Discussion questions included:

- What are the characteristics of the group?
- What are their motivations to use online communities?
- How does this group use online communities?
- What were the effects of participation?
- Who is recognized as an authoritative source of information?
- What is the group's perspective on the nature of the technology?
- What is the group's perspective on what constitutes a successful online community?

Themes emerged from the collaborative writing, and were critiqued in light of the discussion and questions originating from the panel discussion at the health conference.

As the case studies illustrate, each community employed a different set of data collection and analysis procedures – some studies were more quantitative, others more qualitative (Table 1). Some focused on social support, while others were more on providing health information. These differences make direct comparisons difficult, but our goal in this section is to report back on an ongoing interdisciplinary discussion among the authors that draws out themes from our range of experiences.

Our goal in identifying these trends is not to provide an exhaustive list of behaviors, but rather to argue that contextualizing user behavior in a larger trajectory of use can identify overlooked considerations for developers, designers, and community managers. Further we would note that the four sites are drawn from a constellation of potential communities that could be drawn into this argument. Our aim is thus not to generalize behavior across communities, but rather illustrate how changing circumstances are brought to bear on the ways we seek out support online.

Adoption

Across our research studies, there were a number of trends concerning how, and why, users adopted particular communities. Adoption is of particular concern in a health context because participation in a community may create significant benefits for the individual and the health system, and health authorities may create online communities to provide support for their patients.

Self-selection

Observational studies concerning the efficacy of online support networks for health conditions suggest that they may have a beneficial effect [3]. As a result, professionals and policymakers may be eager to commission, encourage, and even “prescribe” these communities to patients. However, some communities may feel too formal or informal, reflect values the patient does not share, or provide information of differing degrees of applicability to a specific subset of the life condition (e.g., finding others who experienced a similar loss or medical information that may or may not apply to one’s individual condition). These findings have implications for the design of effectiveness studies, as study participants may have to self-select online communities in order to obtain benefit. Efforts that seek to use health communities as a way to provide care must offer multiple formats and options for the presentation of information. Correspondingly, there is an emerging need for systems that help users find a community that is the best fit for them. More research is also needed on the potential benefits and harms of online communities that promote controversial views on health (e.g., those that encourage eating disorders).

Unmet needs and professional authority

In all four cases, online communities were places where unmet needs could be satisfied, such as obtaining support not available from health care professionals, sharing and validating experiences, and finding practical answers and actionable results. However, the ways in which the communities fit into an authoritative idea of care differed. In the case of the sports concussion community, family doctors and physical therapists working with sports teams referred their clients to participate in the study, and thus, the community was integrated into care. On the other hand, some participants in the breast cancer community felt that their health care professionals did not regard online communities favorably, perhaps because information shared on these sites did not come from a medical authority. Even further along the spectrum, members of some birth communities were actively opposed to professional authorities in the domain of maternity care. Indeed, some of these communities specifically supported choices outside the statistical norm such as midwife-attended home birth or unassisted birth. Online communities are only one source of information and support among many pre-existing professional and personal sources, and depending on how well or poorly the sources align, this can cause tensions in how communities are adopted.

Reasons other than emotional support

When conceptualizing online communities we often imagine a user that is in search of actionable results that are specific to a condition or challenge that the individual is facing. It is well-established that users turn to these sites in order to share their experiences, and to learn more about how to reconcile their condition with their individual circumstances. By looking beyond in-community usage, we see reasons for adoption that are not motivated by the desire for support.

One common reason for joining was for the opportunity to “give back” to an organization or group of individuals as described in the breast cancer and bereavement case study. For example, some participants in the bereavement support group reported joining not because they needed help dealing with their grief, but because they had benefited from support groups in the past and saw it as fitting to repay their debt by listening and offering support. This often fits into larger goals concerning charity and awareness (e.g., contributing to the breast cancer patient community, helping other pregnant women to avoid a negative birth experience). The point in time when an individual joins a community is therefore an opportunity for an ongoing relationship with peers and broader social goals, such as advocacy or fundraising.

Another reason for joining was to develop a better understanding of the condition more generally, without necessarily seeking emotional support. Participants in all four types of communities reported that they were interested in obtaining scientific (and non-scientific) information about their condition, and worked to develop an expertise on the topic through both study and personal experience. Even if the kinds of information were not applicable to their specific condition, the goal of joining was to develop expertise around a more general phenomenon. For these users, the goal was not to seek support, but to observe how supportive behavior was carried out in an online setting and to make personal assessments about its viability as a format for conversation. For these kinds of users, articles and more formal resources concerning the phenomenon in question may be helpful additions to conversation. Indeed, in the case of both the bereavement and sports concussion groups, the people who strove to attain an expert understanding had multiple encounters with their conditions (i.e., multiple concussions or multiple losses). This was also the case in birth communities, where women's previous experiences with pregnancy and birth influenced decision making in subsequent pregnancies.

Use

There are several ways one might use an online health community: to answer a question, to converse, or simply as a way to socialize or pass time. In our work at different stages of the life course, what we have observed is that use of online communities is marked by transience.

We often think of a successful community as one where members are continually participating. This kind of success makes sense for many types of online communities (e.g,, a fantasy football league or an online gaming site). However, this same kind of focus on growing and consistent engagement finds itself out of place in certain health contexts. In the same way that one does not wish to spend one's entire life in a hospital, one does not necessarily want to be part of an online health community forever. In our case studies, health communities were characterized by temporary and intermittent use driven by changing life events. This is especially pronounced in communities for people dealing with "long-term" conditions, such as breast cancer and grief.

Surprise of sticking around

When participants talked about their health event, they often spoke of their perception that the event and its repercussions would be temporary. They imagined that they would eventually move on and find a new normal. Years later, a small number of participants expressed surprise that they were actually still participating in online communities related to their health event. Several participants who signed up for the bereavement support group had experienced their loss over 5 years ago, and one woman in the breast cancer community noted:

> *"Well actually I'm kind of in a place right now that I didn't anticipate after only five years. I'm realizing how my concerns, my focus is turning and I'm finding that I'm starting to pull away. I'm not quite ready yet to leave the [mailing] list because of the information... but um I didn't anticipate being here at this five year junction. But I'm finding that maybe it's a natural progression for most people."*

Motivations for sticking around vary. It may be because sharing expertise is important, or because friendships spring up between users. Whatever the reason, online health communities include people whose use is not in response to a current event, but one that occurred in the more distant past.

At the same time, even the most seasoned participants felt that eventually they would leave, but at an ill-defined point in the future. If people are using online support communities years beyond the incident that brought them there, this raises important issues concerning community management and system design. Specifically, systems should be designed to allow users to grow over time and fill shifting roles – from "newbie" to expert. Moreover as people settle into a community, social functions unrelated to the health event (e.g., so-called "off-topic" discussions) may become more important to the vitality of the community.

This also raises questions concerning the health of individuals who participate in a community for a lengthy period of time. While these websites can be helpful for coping with the health event, they may encourage dependence. Relying on a community for too long may signal an inability to adjust, but it may be difficult to say when discontinuing participation is warranted. This concern warrants further research.

Recurrence

For those that do stop using a community, the constant availability of online health communities makes it easy for them to rejoin. Participants reported becoming active again and seeking support each time they lost a loved one, became pregnant, or their cancer diagnosis changed or a new symptom emerged. Each time a user returns to a community, their circumstances differ. For example, a woman who is having her second child may be seeking answers to a different set of questions than when she had her first. In the case of breast cancer, participants would return to the community upon receiving new information about their treatment or diagnosis; for example, if the disease had progressed further.

Returning to a community following time away is a different experience from joining a community for the first time. Participants who had a negative condition they sought to bounce back from may be hesitant and view their return as a step backwards in terms of recovery. They may expect to find familiar people and conversations, but these kinds of supports may no longer exist, or exist in an altered form. Reintegration may be difficult; their motivations may set them apart from others who are at different points in their lives.

Disengagement

Support found in a community can help people through intense and/or difficult periods in their lives. Over time, the amount of perceived support may decline as questions are answered, and individuals develop their own mechanisms for adjusting to their new circumstances. Moving on from a community should not be seen as a failure of the community; on the contrary, leaving a community can be the result of the community's ability to help them adjust, or events entirely external to their engagement with the community. For example, in the sports concussion study, participants whose symptoms had resolved found little use in continued interaction with the health professionals on the site. Similarly, after giving birth, users of pregnancy-focused communities sometimes tapered off their usage because pregnancy and birth options were simply no longer the foremost issue. In addition to moving on due to the development of adaptive coping strategies, we note several mechanisms that participants used to facilitate this process, and discuss what happens offline when people discontinue their use of these communities.

Changing types and levels of need

Among the more obvious reasons for leaving a community was because an individual found the information they were seeking. Patients seeking specific answers to their health questions were often able to obtain the information they needed. A participant in the breast cancer study explained:

"I was bragging to my doctor about that website…I was telling him 'you have no idea the support systems that women have' ... any question I had was answered, any fear I had was reassured, and I didn't have to seek out as much help."

In contrast, meeting the needs of those seeking emotional support could take more time as interpersonal relationships are established, developed, and ultimately used as a resource for coping. In any case, these types of transactions – interpersonal or emotional – satisfied a need.

This provides a neat endpoint for an articulation of the community's role in providing support to an individual, but a person's needs continue to evolve independently of the community. Patient support needs do not come in the form of individual transactions at a single point in time, but rather needs emerge unevenly and across long periods of time. Mundane forces independent of the health condition, such as attending a social function, can cause new issues to emerge or old issues to dissipate suddenly. For example, a bereaved mother who lost one of her children recounted how she felt she had finally learned to cope until she was at a party where a stranger asked "How many children do you have?" This triggered a return to a support group and brought with it a new set of questions that needed new answers. Correspondingly, in the sports concussion study, the disappearance of symptoms prompted users to quit the community suddenly. This characterization of needs as shifting and unpredictable may help designers and managers to shape interaction flows and organize resources in the community.

Transitioning to face-to-face

Online support communities often act as match-making services that allow people to find others in a similar situation. At the same time, individuals may find an affinity for other users based on their personalities, location, or other factors. In these cases, users may choose to move their interactions to other modalities. In the bereavement study, members of the bereaved parents group set up a time for them to meet at one of the participants' homes and get to know one another in real life. Some members of pregnancy communities similarly moved their conversations to face-to-face.

In the breast cancer case study, all of the individuals surveyed chose to lead a face-to-face support group post-treatment, while only 39% of users of online communities chose to provide support to the members of their online community. In other words, moderating a face-to-face support group was more attractive to participants than moderating an online group. Similarly, in the bereavement support community, moderators reported that moderating online was less fulfilling than experiences leading face-to-face groups. This would suggest that perhaps the rewards of moderating are better felt or appreciated when face-to-face (e.g., being able to see that you've helped someone). The higher quality exchanges made available in face-to-face contact may be a contributor to individuals leaving the online community.

Overexposure

Online support communities necessarily contain a great deal of personal, emotionally-laden material. Engaging with this material on a regular basis can be difficult in a number of ways. For new members, reading through all of this information can be overwhelming. A tension exists: on the one hand, a user is more likely to find what they are looking for in a large community, but at the same time, the plethora of information can suggest that their problem is endlessly complex, unknowable, and capable of overwhelming them.

Beyond the sheer amount of information available, the emotional content of others' stories can be difficult to break away from. As one reads, one inextricably relates to the suffering, confusion, excitement or despair of others in the community. Over time these emotions comingle with one's own emotions, sharpening the intensity of the emotions that one experiences, as a member of the young adults bereavement group described:

"It was very hard for me emotionally and way harder than I thought it would be after hearing everyone's story. I felt like... pretty upset about it truthfully. It was hard for me to come back...hearing all the sad stories again was really hard for me to take because I'm in a different place now... people using it seem to be getting a lot out of it but for me I'm just a bit heartbroken."

What is less well understood, and contributes to disengagement with health communities, is how exposure to negative experiences and information affects adaptive coping processes. This is especially concerning given the pervasiveness of mobile technology that permits people to connect to these communities anytime, and anyplace. The burden of managing exposure is shifted onto the individual, who may not always be able to monitor their own responses.

Communities that comingle participants who are at different stages in reaction to their health event also face a tension. On one hand, more experienced members can offer their expertise and support to people who are closer to the event. On the other, the stories that these community "veterans" share can sometimes lead participants to ask themselves if they will also be "stuck" dealing with the event years from now. In the breast cancer study, reading stories of women who were worse off influenced some participants to withdraw from the online community to avoid anxiety provoking details of cancer.

IMPLICATIONS FOR DESIGN AND MANAGEMENT

In raising these issues in our discussion, we have drawn together some of the commonalities present across our four case studies. We now distill these discussion points into a set of implications for community designers and managers.

Communities grow and shrink – and that's okay.

The case studies and discussion have outlined the ways that people adopt and disengage from a given online health community. In presenting how and why people join and leave, we wish to show that turnover and/or reduction in community membership is always happening due to users' changing life circumstances. Overexposure, for example, is the result of too much use and may result in worse outcomes. We raise this issue to add some nuance to ongoing discussions of how to encourage contribution to online health communities, which often suggest that metrics like popularity and community size are the most important factors for perceived utility (e.g., [16]).

For community managers, this has several implications. First, because communities often rely on a critical mass of individuals in order for users to find meaningful support exchanges, it is important to find ways to keep the community active. This is a well-established concern, however. The second, less obvious implication is that users' departure should be expected and perhaps even facilitated. There are opportunities to make an individual's transition away from the community more graceful and supportive by supporting "ramp down" behavior and by facilitating engagement with a different online community if needed (e.g., transitioning from curative to palliative treatment in the case of breast cancer survivors, or transitioning from pregnancy to parenting). Better support of transitions into and away from the community may lead to better health outcomes in the long-term, and as a byproduct, yield insight into existing users.

Technically speaking, these transitions could take many forms. For example, rather than labeling users who have benefited from the community in the past as "inactive," it might be more useful to denote them as role models or "survivors" depending on the health condition. Alternatively, if users change to a different board, being able to set up a "forwarding address" could be useful. Other systems might allow users to participate in multiple communities simultaneously; for example, a system that aggregates content across communities (similar to an RSS reader) could be useful for helping individuals synthesize and selectively interact with supportive content tailored to their situation.

Help people find the right community more easily.

With the proliferation and diversification of online communities comes a problem of scale. While some users may seek out the oldest, largest, or most well-known community, most people have needs that may be best met through lesser-known communities, or through a combination of multiple communities. Developing more sophisticated means for matching users with the set of communities that could meet their needs at a given point in time is a challenge that remains to be solved, and one that requires attention to presentation of self and the anticipated benefit of participation [24, 35]. Expertise in recommendation systems could be leveraged to help users identify the communities that meet their needs, but could prove challenging because users may have trouble articulating their needs, and because aggregating all communities – who may consider each other as competitors – into a maintainable database would be difficult.

Support reintegration.

Community designers and managers should take note of the needs of individuals who are returning to a community after a period of time away. As we saw in the case studies, people who returned to a community were facing a different set of circumstances from those that they initially arrived at the community with. Helping people to reintegrate could be accomplished technically. For example, providing services to summarize and draw attention to important conversations that occurred would be a helpful tool for returning users. Returning users might also be flagged as returning in the user interface for moderators (e.g., highlighting their username) to pay special attention to their requests for support.

A community's success can be measured in many ways.

The success of a community can be measured in terms of the number of users, how often they log in, the number of discussion topics available or active, and so on. A community's success may also be measured by how well the information or services offered meet the needs of users, and if their expectations regarding the availability and quality of support are met. Did they get a suitable answer to their question? Did they learn a new coping strategy? Measures of how users learn and develop adaptive mechanisms that replace the need for support from an online community are needed.

At the same time, our work suggests that leaving isn't always a failing of the community or its design, but rather a natural part of the community's lifecycle. There are less obvious measures of success related to how well communities support transitions. For example, measures of how well a site supports more experienced users in assisting those seeking information may indicate the richness of the expertise in a community. Designers might consider how to ease this transition from support recipient into support provider (e.g., incorporating ways to train users to become better moderators).

Another measure related to transitions is how well a community connects people in relationships outside the community. Are email lists established? Do people connect on Facebook as well? Do they meet face-to-face? An online community's success may be measured by considering how well it leads to richer, more stable, and more intimate relationships among members. It remains a challenge to both system designers and community managers how to operationalize these measurements, but collecting and tracking this data could demonstrate that an outwardly small, inactive community may still be providing benefit to those who find it.

CONCLUSION

In this paper we have drawn on our experiences with four case studies of online health communities that address different periods in an individual's life. Based on discussion among the authors, we have found thematic elements that cut across cases and identify issues dealing with community adoption, use, and disengagement. As we have shown, online health communities are places that patients strategically and purposefully use to meet their needs in a shifting, ongoing trajectory of health. We suggest that designers and community managers should take note of this by paying better attention to how people transition from community to community. Growth and active participation are not the only measures of success; indeed, the greatest successes of a community, such as the development of coping mechanisms and stronger off-band support channels, may actually result in a reduction in usage. Providing more support for finding, returning to, and transitioning among multiple communities may meet patient needs more fully.

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