Self-characterized Illness Phase and Information Needs of Participants in an Online Cancer Forum

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Abstract

A diagnosis of cancer is the first step on a long journey of treatment, follow-up, and maintenance or survivorship. As 5-year survivorship rates among cancer patients increase, more cancer survivors will participate in online discussion forums and support groups to assist current cancer patients through their illness. Online venues are both optimal for the exchange of patient expertise and a safe space for patients to "meet" others undergoing similar experiences. This paper presents the findings of content analysis in a general cancer forum hosted on reddit.com (r/cancer). We delineate the types of conversations found on the forum and their conceptual "shapes" (e.g., call and response of question and answer, sharing of stories), and describe connections between self-characterized cancer illness phase and stated information needs. We find that online participants posting immediately after diagnosis or during treatment tend to ask for advice; survivors are more likely to share information in the form of personal narratives; and terminal patients seek acknowledgement from the community and validation in their choices. These findings demonstrate that information systems design tailored to illness phase can expedite information finding and increase information relevance for cancer patients and survivors.

Introduction

A 30-something woman, Rebecca, is diagnosed with Hodgkin's lymphoma. A few minutes after the surgeon has delivered the diagnostic news and left, a nurse enters the examination room to give Rebecca helpful information about what comes next: pamphlets for support groups, phone numbers to call with questions, and the name of her new oncologist. The patient is trying to follow all of the instructions and information, but when the nurse starts to review a pamphlet about hair loss, Rebecca's thoughts start to wander. She leaves the examination room with an armful of paper, completely overwhelmed. Later that night,

though, she starts to think of questions. 'Will I need someone with me at chemotherapy appointments?' 'Will I definitely lose my hair?' Sitting alone at home, Rebecca opens the browser on her smartphone, and starts to search for answers, and – maybe – other patients who might be going through the same thing.

The above scenario is just one example of the information deluge and emotional side-effects that cancer patients face upon diagnosis. Especially for individuals who do not have a direct caregiver—such as young adults or individuals who live alone without immediate support—the patient must not only cope with treatment but also seeking, managing, and organizing information. This effect has been shown to be at least part-time "work" unto itself (Unruh & Pratt 2008), and emotional aspects of the cancer experience, such as fear, anxiety, and physical exhaustion, can lead to long-term information avoidance among cancer patients (Germeni and Schulz 2014; Lambert et al. 2009).

Existing research into the emotional and informational needs of cancer patients identifies differences in experience by factors such as age or gender, but largely neglects illness phase as an influencer of information needs, or designs research to study individuals in specific phases of illness, such as newly diagnosed or survivors in remission. Massimi et al. (2014) study participation in online health communities from a lifecycle viewpoint (e.g., adoption, use, and disengagement) —which provides useful context for sharing and/or participating in relation to illness phase. With the exception of Ziebland et al. (2004), who explicitly linked some phases of the cancer experience to information seeking on the Internet, there is little work on examining different information needs dictated by phase in the cancer illness journey. Our aim is to determine to what extent illness phase influences information needs among cancer patients and survivors.

For this paper, we analyze and describe cancer patients' and survivors' participation in an online forum (r/cancer—

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a community located on the news aggregation and discussion site reddit[1]). Specifically, we investigate information needs as a function of participants' self-characterized illness phase. We demonstrate that participants in the online forum both ask for and contribute information in specific ways, based on self-characterized illness phase. The themes we find in our analysis lead to a discussion of the potential for improving information systems and participatory communities to better meet patient needs in the future.

Literature review

In designing and executing this study, we were mindful not only of current work in the area of understanding how cancer patients and survivors use online forums in different phases of illness, but also best practices related to studying online health support groups. Although public, r/cancer is nonetheless comprised of individuals who many consider to be a vulnerable population. Thus, our related work covers two main areas of literature: (1) the ethics of studying vulnerable populations and online communities, and (2) current work in the space of online cancer forums, concentrating on qualitative explorations of cancer patient and survivor information needs.

Studying online communities and vulnerable populations

Liamputtong (2007) defines vulnerable populations as those that could be disadvantaged economically or socially by participating in research as a result of their perceived identity or circumstances through the information they share. Essentially, research conducted with cancer patients and survivors—or using latent traces of their participation in an online forum—must not be further disadvantaging to participants to achieve its end goals. Liamputtong's aspects of vulnerability cause us to refrain from using extended direct quotes or other potentially specific references to the dataset, so as to reduce the risk of causing exposure or embarrassment for members of the r/cancer community.

Qualitative methods and research design literature also examines the ethics and complications related to recruiting, observing, and interacting with vulnerable populations in online spaces (Bruckman 2012, 2014). Eysenbach and Till (2001) highlighted areas of particular issue in studying people with cancer online, noting that participants who feel as though their informed consent has not been obtained are thereby "taken advantage of" in their state of sickness and need.

It is also important we disclose that the first author is a member of the vulnerable population included in this research. Particular to research, "membership" here is de-

fined as interest in studying a population to which the researcher already belongs, and to which the researcher may have greater or more opportune access than a non-member (e.g., as a diagnosed cancer patient and participant in online cancer support forums; Adler & Adler 1987).

Cancer patients and survivors in online communities

Current research related to cancer patients' information behavior and needs are framed in several ways. One framing is descriptive, outlining patterns of behavior in online participation. In their study of cancer e-mail listservs, Meier et al. (2007) found that survivors were active in giving advice related to treatment and coping, and that the support was overwhelmingly informational, rather than emotional. Winefield (2006) defined and described "emotional support work" in online cancer communities, crediting high-volume participants to a cancer message board with bearing the brunt of emotional support in the community. Lobchuk et al. (2014) described an online lung cancer support group as an optimal space for not only informational support, but also "non-judgmental" emotional support.

Huh et al. (2012) and Ziebland et al. (2004) contextualize the patient participation in online activities as part of the needs of "the whole patient." Huh et al. (2012) identified shortcomings in the design of online support communities for people with chronic conditions, including cancer. Specifically, Huh and her coauthors noted disconnects between quantified patient experience (such as symptom logs) and narrative information – online support groups did not provide a way to link such data in order to facilitate insights for patients. Ziebland et al. (2004) found that Internet use was actually affecting cancer patients' experiences in the real world, and that patients used online information to investigate their care team's credentials ("do I have the best doctor?") and to double check information passed on by clinicians ("my doctor told me X, is this correct?").

Expertise – and particularly patient expertise – is also an important theme in the (largely) peer to peer information network of online communities. Hartzler and Pratt (2011) identified significant differences in the nature of expertise between patient-peers and clinicians; patient-peer information exchange was rooted in experience and personal narratives, while clinicians relied on evidence-based interventions and clinical training. Related to patient-peer expertise, Civan and Pratt (2007) described various types of informational support found in an online breast cancer group, and found that much of the advice exchanged took the form of suggested actions or knowledge from experience.

It is important to note, however, that engagement in online spaces is not routine for all patients: Helft et al.

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[1] www.reddit.com

(2005) found in their study of disadvantaged, rural patients, that online information use occurred at relatively low rates among cancer patients (10% reported seeking information for themselves). In addition, patients with low levels of education were more likely to be confused by the information they found online than helped by it. In selecting the r/cancer community for our study, we acknowledge that the majority of users whose behavior is described herein may already be savvy discussion board and/or computer users. Therefore, there may be less representation in the dataset for cancer patients with limited Internet access, low digital literacy, or other barriers to use. Although we do not mitigate this bias for this study, we intend to mitigate such bias in future studies by expanding the investigation of illness phase and information needs to offline experiences.

Methods

We scraped the top 1,000 posts of all time as of December 3, 2014, from the r/cancer subreddit. In this case, "top posts" are determined by a proprietary algorithm that takes into account total up- and down-votes over the lifetime of the post, including vote fuzzing utilized all over reddit to avoid vote gaming.[2] We chose top posts of all time as a method to operationalize the collection of posts deemed the most useful, informative, entertaining, or helpful according to the community as a whole. Although we do not claim that the top 1,000 posts will be a representative sample of overall r/cancer content, we chose this approach for two reasons. First, it honors the agency of participants as those who create and curate the community content. Second, top posts indicate "successful" interactions on the subreddit, which are a logical starting point for understanding what the community wants and on which to base design recom-

Figure 1: Breakdown of scraped dataset

mendations, as we have in the conclusion. The top posts were capped at 1,000 due to the nature of this study and the resources at our disposal.

Although our code called for the top 1,000 posts, we pulled down only 934 posts due to deletion of 66 posts over time, caused either by deletion of the thread itself, or erasure of the reddit account associated with the original post. We gathered the following information associated with the 934 posts: original poster handle; post score (or "karma," meaning net upvotes); post title and content; date of post; any hyperlinks shared in the post; as well as all commenter metadata and comments in reply to the original post.

To organize our data and identify a reasonable sample for qualitative coding, we first read through all the post titles and content to assemble an overview of the data into a schema. This simple, high-level categorization exercise specified two elements of each of the 934 posts: (1) role of the original poster—such as patient, caregiver/friend, or other, and (2) type of content—such as recognition or remembrance of a loved one with cancer or lost to cancer, phase of illness information seeking, or calls for help. These general categories gave us a sense of not only who used the forum, but how. Based on the initial data organization, as well as metadata pulled around posts, comments, and users, we present an overview of the dataset in the following section.

Description of dataset

At a high level, subreddit posts came in two forms: link posts and text (or self) posts. **Link posts** pointed to URLs that directed users to third-party sites or images hosted on third-party sites. These are not included in the coding sample due to inconsistencies with associated user information – often, it was not possible to determine the illness phase or exact role (e.g., patient or caregiver) of the original poster. **Text posts**, or self posts, consisted of text submitted directly to the original post in the thread, and ranged from two or three simple sentences to multi-page narratives. Only text posts were included in our coding sample, because we were better able to confirm that the original poster self-identified as a patient or survivor, and often self-characterized his or her illness phase.

Four categories of users posting to the subreddit were identified: caregiver/friend (42.6%), patient or survivor (38.8%), on behalf of community (17.5%), and other (1.1%). The greatest area of interest for this study was the text posts submitted by patients themselves. In these types of posts, the patient has an opportunity to self-identify illness phase and express information needs, if any. Thus, we concentrated on the 222 patient text posts identified in the original sample of 934 posts. A complete breakdown of the subreddit posts scraped is shown in Figure 1.
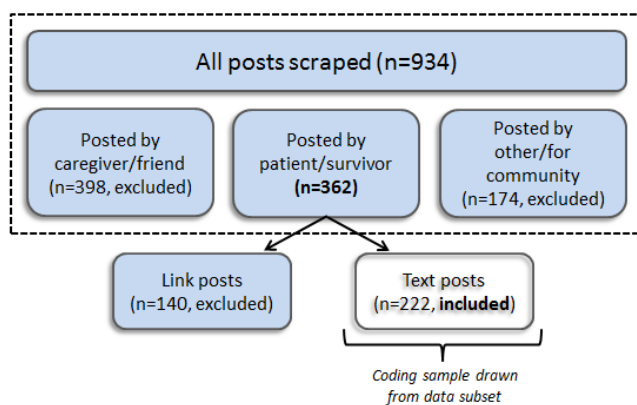
Post type: Illness phase	#Posts	%Posts	Average #Replies	Average Net Upvotes
Pre-Diagnosis	7	3.2%	19.4	13.4
Diagnosed	23	10.4%	23.2	14.5
Pre-treatment	10	4.5%	11.6	15.1
In Treatment	34	15.3%	14.9	18.5
Completing treatment	11	5.0%	13.7	28.5
Failing treatment	7	3.2%	15.7	18.6
Recurrence	16	7.2%	15.9	16.3
Survivor	68	30.6%	11.9	21.1
Terminal	25	11.3%	14.2	19.5
Undetermined	21	9.5%	14.0	21.1
Total	222	100.0%	14.7	19.3

Table 1: Further description of 222 text posts in dataset, classified by self-characterized illness phase

From there, we break down the 222 submissions in the dataset of interest further to give an overview of top posts submitted to the subreddit. Table 1 is intended to (1) give a breakdown of the data sampled in terms of self-characterized illness phases (i.e., phases the users generate through their statements and descriptions of current phase in illness journey) and (2) show the variation of number of replies elicited from the community in each type of post. The top three post types by volume in this data subset were those submitted by survivors, terminal patients, and those in treatment. Patients posting at the pre-diagnosis (e.g., "I have cancer but I don't know what type") and diagnosis ("I just found out I have stage III ovarian cancer") received the highest average number of comment responses.

The highest average net upvotes was received by users posting that they had successfully completed treatment or a stage of treatment; these were often short, celebratory and encouraging posts for the community. Another category of threads, those typed as "undetermined," are those for which we were unable to determine the original poster's illness phase with certainty.

Finally we note that demographics of the r/cancer users cannot be determined from the method of latent data scraping we used in this research design. However, more general studies of reddit users indicate that its users tend to be male and young (Duggan & Smith 2013). We are able to see certain self-determined characteristics through subreddit flair: the r/cancer subreddit enables user-created descriptions, or flair, as an option in participating. **Flair** is highlighted text, displayed next to the handle of the user, and shown only in the r/cancer subreddit; i.e., the flair is not displayed if the user posts or comments in other subreddits. An example of such flair may be *M/27/Stomach cancer with mets diag 10/13* or *Alaska - Colon cancer - stIII* (note: both of these examples are fabricated). Although we used user flair on occasion to determine or verify the role of a participant (patient, survivor, etc.), because we are interested in contents of discussion threads, we do not describe flair use and content in detail for this paper.

Analysis

We ultimately coded approximately 20% of the 222 patient- or survivor-generated text posts described above, first pulling a random sample of 20% of the threads, then adding threads to ensure at least one thread from each category was identified (total coded threads n = 47). We began with a coding schema loosely adapted from Meier et al. (2007). The first author conducted open coding on 10 post threads, enlisting an independent coder to (1) test and validate the codebook and (2) add any other codes from themes identified. Once the codebook was finalized, the first author trained ZD to use the codebook. Intercoder reliability was then tested on 15% of the sample threads between authors JE and ZD, achieving simple agreement of 81% to demonstrate reliability of the coding scheme used. This level of agreement exceeds the 70% level suggested for exploratory work of this nature in Neuendorf (2002) and Joyce (2013). Subsequent to coding the entire sample, the authors assembled themes identified using the codes to yield the findings described below.

Findings

The content of original posts in the threads ranges from sharing personal narratives to posing questions about

treatment or survivorship. Often, as we found in our coding, the original poster (i.e., the thread starter) gave background information, such as illness prognosis or emotional state, before posing a question. Just as often, however, the original poster stated he or she didn't have questions, but needed to vent or sought other patients or survivors facing similar emotional states or treatment experiences.

We found that some participant behaviors transcended thread categories assigned by illness phase. For example, statements of acknowledging community members' feelings, and/or those encouraging perseverance, appeared in all discussion threads, regardless of illness phase. In addition, the act of exchanging narratives appeared to be a significant information sharing technique among participants, particularly among self-characterized survivors. Most importantly, we sought possible connections between self-characterized illness phase and thread contents and discussion replies. We found original posters tended to express different needs depending on illness phase, and the following sections detail our findings according to thread type.

Illness phases prior to treatment prompt questions
Threads begun by posters who had been recently diagnosed, or who were pre-treatment or just starting treatment, tended to seek advice, or contact with patients/survivors with similar diagnoses. These threads contained more call-and-response posts, where participants asked for clarification or further information from others. For example, in one thread, a patient feeling isolated after his or her very first treatment of chemotherapy uses the thread to volley responses and gather more helpful information. In this case, the original poster returns to the group to ask for more suggestions ("Any advice for [specific side effect]?"); in turn, responders ask about the original poster's cultural context ("Do you live in [country]?") when suggesting support groups.

Threads during treatment invited commiseration
Participants who started threads in the middle of treatment tended to receive replies that validated the normalcy of the treatment experience. For example, one original poster suffered from atypical peripheral neuropathy (numbness or pain in the extremities). The replies to this original poster contained stories of commiseration or recovery from neuropathy. Responders in this case also encouraged the original poster to contact his or her doctor for formal medical advice and help with the ongoing neuropathy. In this information exchange, replies referred to both the protocol of the chemotherapy (the particular drug regimen) and the side effects caused by different treatment protocols, indicating that information exchange does not depend on similar diagnoses or treatments to be helpful. Rather, an original poster may receive helpful information from a "patient like me" even if the two have little in common, such as cancer diagnosis, age, or gender.

Occasionally, patients in treatment employed a "venting" narrative, bringing out replies from the community that mirrored difficulties in narrowing down a diagnosis, frustrating interactions with friends or relatives in the real world, or other hardships. This commiseration-type reply chain gave the original poster a chance to exchange information and acknowledge similar difficulties with other respondents. Participants also employed metaphors in expressing their feelings about treatment. Anxiety was described as "sharing a room with death," or "waiting for the other shoe to drop"; the discomfort and pain of headaches during chemo was likened, in one instance, to "a pickaxe" in the patient's head.

Community participants often explicitly recognized the value of having a community to share experiences and be understood by online peers. In contrast, in the "real world," it was difficult for peers to listen to or empathize with troubles that patients and survivors faced. Online participants shared stories to vent frustrations about communication and interactions with friends, family, and acquaintances. A common complaint was receiving shallow encouragement from friends or family that "everything will be alright" or "at least you got the good cancer" for diagnoses such as thyroid cancer, which requires surgery and lifelong medication, but has a relatively high 5-year survival rate. As part of these interactions, participants often encouraged others to share updates online, where they could unburden themselves of negative information (such as recurrence, scan results with a poor prognosis, etc.) and not be faced with the "awkwardness" of face-to-face interaction.

Finally, for the posts by current patients about doubting their ability to continue with chemotherapy (a common complaint and topic of discussion), replies promoted the "one day at a time" model to avoid emotional, mental, or physical exhaustion. Fellow patients and survivors provided advised the patient in treatment to take time to enjoy simple moments in the current illness phase, and particularly to indulge in favorite foods so as to maintain strength during treatment.

Completing treatment is a time for celebration
Threads begun by those completing treatment were extremely popular, showing consistent value in the community, as judged by net upvotes from the community and number of replies. Responses tended to be short, offering congratulations (acknowledgement) and encouragement for the future. Occasionally, a participant would reply to express hope that he or she would also be able to achieve remission from the same type of cancer. In these instances – where those still in the treatment phase sought optimism for survivorship and hope for positive prognosis – similar diagnosis and treatment was important in the value of information exchanged. In this way, threads celebrating the completion of treatment were unique versus other illness

phase discussions, and underline the variations in information needs and exchange at different illness phases.

Cancer recurrence resembles diagnosis phase

Similar to pre-diagnosis and diagnosis threads, when original posters started a thread about cancer recurrence, they posted inquiries for more information, such as on treatments and what to expect. For this reason, these threads resembled posts from community participants who had just been diagnosed for the first time (i.e., in Figure 2, recurrence phase threads most closely resembled those associated with the diagnosis phase). This observation suggests that cancer recurrence lends a feeling of "starting over" to the cancer journey, where uncertainty is perhaps nearly as great as that of the first experience in treatment and recovery.

In one thread started by a patient experiencing recurrence, the tone of the original post was of disbelief and fatigue; responses ranged from personal narratives of recurrence (to acknowledge and mirror the experiences of the original poster) to encouragement that the patient "did it before, and can do it again." In fact, the primary difference between threads about recurrence was the emotionality of the post (such as anger, frustration), whereas in first-diagnosis threads, original posters were more likely to express shock or fear.
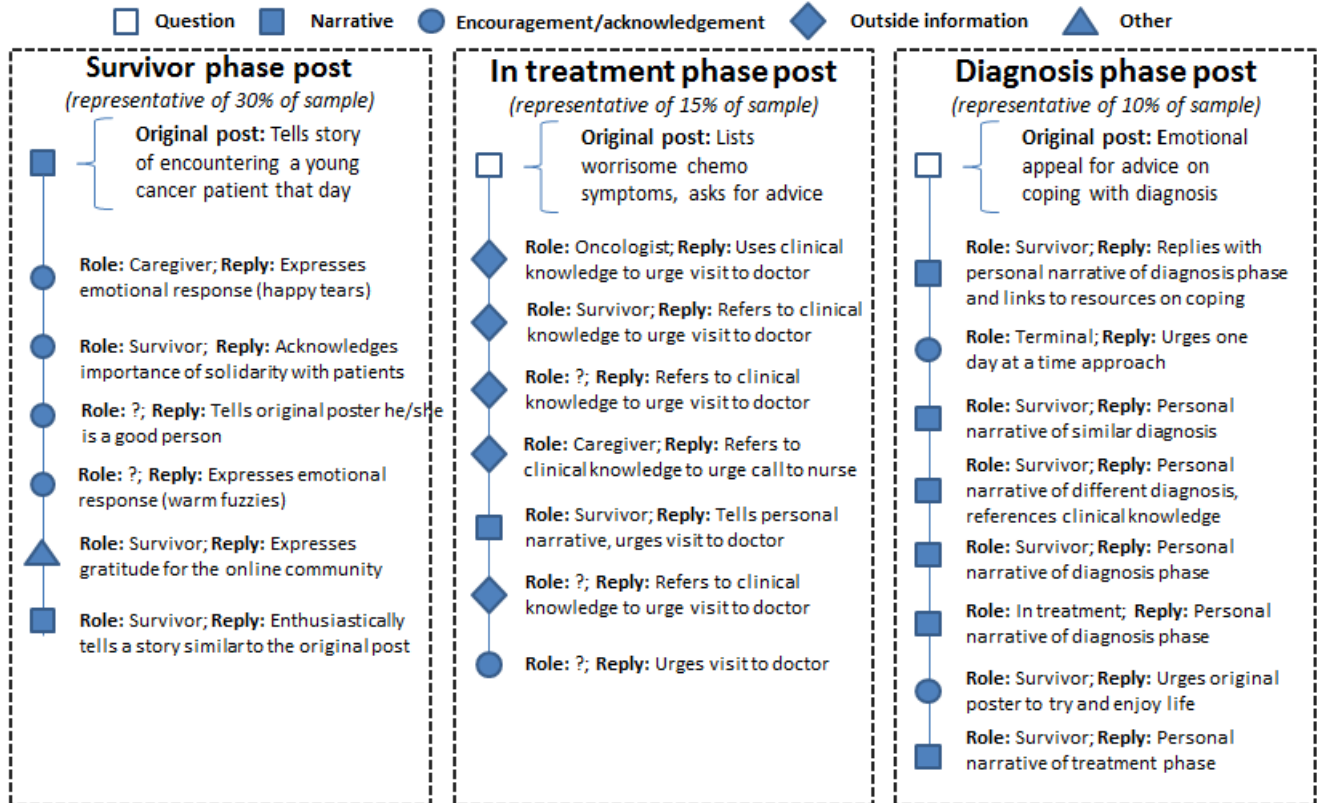
Survivors are the lifeblood of the community

Survivors start most threads in our sample and in the patient text posts we collected, usually sharing their illness stories with the community. In survivor threads, the most frequent responder actions were that of (1) acknowledging the original poster's experiences by (2) reciprocating with the replier's own cancer narrative. Furthermore, replies often mirrored the original post's tone; that is, if the original post took a humorous tone, replies tended to mimic that tone. Survivors often shared advice for those who were embarking on the survival phase of the journey, and survivors' thread responses incorporated advice about managing expectations related to survivor's guilt and ongoing side effects from treatment.

Survivors further seemed to generate goodwill in the community by using the tactics of acknowledgement and encouragement, both in original posts and in replies to other participants' threads. Acknowledgement responses observed tended to employ empathetic language (e.g., "I understand what that must be like") and often used personal narrative to support the acknowledgement. Examples of replies using acknowledgement would be "I know this is hard" or "It's a good feeling, isn't it?" Encouragement

Figure 2: Conceptual "shapes" of forum conversation correlated to illness phase of original poster

Survivor phase post
(representative of 30% of sample)

Original post: Tells story of encountering a young cancer patient that day

Role: Caregiver; **Reply:** Expresses emotional response (happy tears)

Role: Survivor; **Reply:** Acknowledges importance of solidarity with patients

Role: ?; **Reply:** Tells original poster he/she is a good person

Role: ?; **Reply:** Expresses emotional response (warm fuzzies)

Role: Survivor; **Reply:** Expresses gratitude for the online community

Role: Survivor; **Reply:** Enthusiastically tells a story similar to the original post

In treatment phase post
(representative of 15% of sample)

Original post: Lists worrisome chemo symptoms, asks for advice

Role: Oncologist; **Reply:** Uses clinical knowledge to urge visit to doctor

Role: Survivor; **Reply:** Refers to clinical knowledge to urge visit to doctor

Role: ?; **Reply:** Refers to clinical knowledge to urge visit to doctor

Role: Caregiver; **Reply:** Refers to clinical knowledge to urge call to nurse

Role: Survivor; **Reply:** Tells personal narrative, urges visit to doctor

Role: ?; **Reply:** Refers to clinical knowledge to urge visit to doctor

Role: ?; **Reply:** Urges visit to doctor

Diagnosis phase post
(representative of 10% of sample)

Original post: Emotional appeal for advice on coping with diagnosis

Role: Survivor; **Reply:** Replies with personal narrative of diagnosis phase and links to resources on coping

Role: Terminal; **Reply:** Urges one day at a time approach

Role: Survivor; **Reply:** Personal narrative of similar diagnosis

Role: Survivor; **Reply:** Personal narrative of different diagnosis, references clinical knowledge

Role: Survivor; **Reply:** Personal narrative of diagnosis phase

Role: In treatment; **Reply:** Personal narrative of diagnosis phase

Role: Survivor; **Reply:** Urges original poster to try and enjoy life

Role: Survivor; **Reply:** Personal narrative of treatment phase

ranged from best wishes for the future to prompting other participants to take a specific action ("I really think you should talk to your oncologist. Remember you have to take extra good care of yourself when you're neutropenic!"). The consistency with which survivor replies to other community members used empathetic recognition of other participants' emotional states was remarkable in all types of illness phase threads. All the threads sampled (47) contained some type of acknowledging or encouraging response to the original poster's emotional state or illness phase experience.

Discussion

Our content analysis demonstrates that patient and survivor participants in the community exhibit different information and emotional needs depending on their illness phase. For example, newly diagnosed patients, and those just undertaking treatment or in treatment, express more amplified feelings of uncertainty and seek out experience-based information from fellow patients and survivors. In some cases, the new patient (or patient experiencing recurrence, since those participants sought information in a similar manner to newly diagnosed patients) asked specifically for information from patients with the same diagnosis or using the same treatment protocol. However, in seeking advice related to side effects, emotional impact, or validation of feelings and experiences, the "closeness" of experience from responders in the community proved less important.

After identifying the self-characterized illness phase of the thread's original poster, we examined code occurrence between the thread starter and the string of replies, giving us a general "shape" of discussions within each illness phase type (see Figure 2). This figure provides insight as to community participants' information and/or emotional needs – and the help the community provides according to those needs – as they relate to illness phase.

Importantly, advising and supporting other patients and survivors was not performed in a vacuum; participants recognized that the specific online space of r/cancer was just one mode of seeking understanding or information. Community participants often pointed to other online resources – as indicated in Figure 2 – such as peer-reviewed medical articles, Wikipedia, or organizations such as the American Cancer Society or online support groups specific to certain types of cancer (e.g., colon or testicular cancer). Narratives are also an essential part of exchanging experience-based information, which echoes the findings of Civan and Pratt (2007) and Hartzler and Pratt (2011).

In describing the discussions that take place in this virtual space cancer patients and survivors use during and after their illness journey, we find that different self-characterized illness phases arrange the priority of information needs and affect the response of the online community (see Table 2). Patients new to the cancer experience (those newly diagnosed or starting treatment) require more reassurance, advice from personal experience, and greater attention from the community in attending to clarifying questions from the patient starting the discussion thread. Patients in treatment largely take to the discussion board to commiserate with peers.

In contrast, survivors and terminal patients seek acknowledgement and a safe space to express emotions or validate life decisions or changed viewpoints. Those facing recurrence may regress to a space where information is again an urgent and very emotional need, as with patients newly diagnosed or starting treatment (and, in case of recurrence, these patients are often facing treatment for a second or third time). Finally, in all phases of information seeking and sharing during the cancer journey, the exchange of personal narratives proves to be an effective and engaging way to convey acknowledgement of experience and emotion, advice, and/or encouragement. Although telling stories may be therapeutic for the writer, participants' approval of such posts (in the form of upvotes or acknowledging responses) indicates that narratives are also im-

Table 2. Illness phase and aspects of information needs and sharing

	Pre-diagnosis; Diagnosed; recurrence	In treatment	Completing treatment	Survivor	Terminal
Greatest emotional need	Reassurance	Commiseration	Acknowledgement	Validation of identity	Validation of decisions, identity
Greatest information need	Specific information about treatment, prognosis	Specific information about side effects, emotional toll	Transition to survivorship	Sharing like experiences	N/A
Community response	Personal narratives, encouragement	Personal narratives	Acknowledgement, encouragement	Personal narratives	Acknowledgement

portant vehicles for information regardless of illness phase.

We propose that these findings are helpful for the design and maintenance of online cancer support communities in two important ways. First, community guides, FAQs, or thread groups could be organized and presented according to illness phase. This would help newly diagnosed patients to browse information that could quickly reassure them in their "new normal." This design consideration would also facilitate interaction among patients in similar phases and with like informational and emotional needs, decreasing the burden on the user to seek out relevant information. In a more general sense, this design suggestion underlines the important features of online communities that facilitate new user intake and phase change in information needs. Features such as FAQs or community guides on fora should be informed by user experiences unique to the community, to facilitate meeting information needs and increasing the relevancy of information encountered.

Second, in communities where matching with survivor peers is important, the matching algorithm or administration may be able to disregard details such as exact cancer diagnosis or protocol of treatment in favor of quickly finding a survivor peer for a newly diagnosed patient. Since our analysis shows that emotional reassurance is paramount in the newly-diagnosed phase, the peer could not only deliver reassurance, but assist in finding information. This design recommendation could ostensibly be applied to other communities where emotional and informational needs are closely aligned (e.g., other fora for illness support, bereavement groups, addiction support). In effect, both of these design implications would utilize illness phase to amplify the value of informational and emotional support work accomplished in an online cancer support community.

Limitations

This study is limited in its generalizability due to its qualitative nature and the relatively specific case of this forum (r/cancer). It is possible that another venue—such as a forum targeted to patients with a certain type of cancer, or moderated by medical professionals rather than lay volunteers—would yield a different dynamic among participants, even if the same coding schema were used. For example, the acts of acknowledgement and encouragement for which we coded may be unique to this community, rather than the online cancer forum world in general. However, this inquiry is intended to explore illness phase and information needs among cancer patients and survivors, setting the groundwork for more in-depth investigation of this subject. We construct a rich set of themes about participants' stated needs in the course of their forum participation. We also highlight the agency that patients demonstrate in their own illness journeys, a point of view we

hope gives patients seeking and sharing information online a voice; however, we cannot claim to make generalizable findings to the entire population of cancer patients and survivors.

Conclusion

A cancer diagnosis opens up a patient's future to uncertainty and fear; the information needs of cancer patients have been traditionally studied in terms of formal and informal settings—such as clinician/patient communication versus peer to peer support and information exchange. The adjustment from one illness phase to another is bound to impact the information a patient or survivor seeks and shares; thus, we sought a connection between self-characterized illness phase and stated information needs. Our content analysis of one online cancer group shows that informational and emotional support needs vary based on illness phase. At different points in the cancer journey, patients and survivors may seek information and comfort (diagnosis; in treatment; recurrence); companionship (in treatment; survivorship); validation (terminal or maintenance patients). In addition, survivors act as an important part of assisting patients at all illness phases, offering encouragement and companionship through sharing their stories. At all phases, patients and survivors work to demonstrate a keen understanding of the ups and downs of the illness journey implicitly—through community standards of acknowledgement and encouragement—or explicitly, through sharing narratives of similar experiences. These shifting informational and emotional needs can and should be explored as an aspect of future information systems design, (1) to expedite the process of finding information for new cancer patients, and those undergoing recurrence, as well as (2) to better match patients or survivors with individuals in a similar illness phase, rather than individuals with identical diagnosis or treatment experiences.

Acknowledgments

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