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## Review

# Online cancer communities as informatics intervention for social support: conceptualization, characterization, and impact

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## ABSTRACT

**Objectives:** The Internet and social media are revolutionizing how social support is exchanged and perceived, making online health communities (OHCs) one of the most exciting research areas in health informatics. This paper aims to provide a framework for organizing research of OHCs and help identify questions to explore for future informatics research. Based on the framework, we conceptualize OHCs from a social support standpoint and identify variables of interest in characterizing community members. For the sake of this tutorial, we focus our review on online cancer communities.

**Target audience:** The primary target audience is informaticists interested in understanding ways to characterize OHCs, their members, and the impact of participation, and in creating tools to facilitate outcome research of OHCs. OHC designers and moderators are also among the target audience for this tutorial.

**Scope:** The tutorial provides an informatics point of view of online cancer communities, with social support as their leading element. We conceptualize OHCs according to 3 major variables: type of support, source of support, and setting in which the support is exchanged. We summarize current research and synthesize the findings for 2 primary research questions on online cancer communities: (1) the impact of using online social support on an individual's health, and (2) the characteristics of the community, its members, and their interactions. We discuss ways in which future research in informatics in social support and OHCs can ultimately benefit patients.

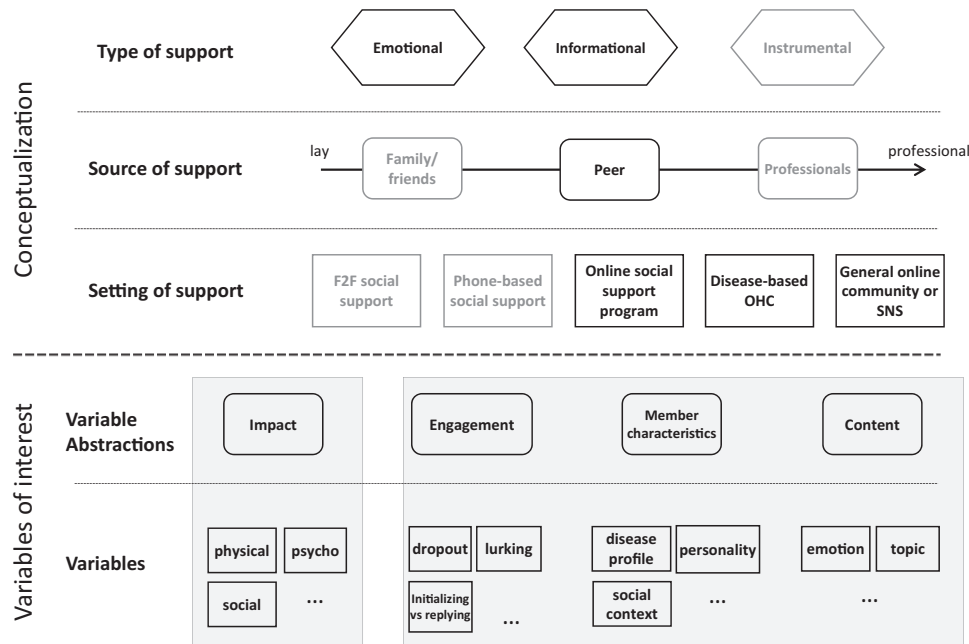
**Key words:** online health communities, social support, peer support, impact, characterization, conceptualization

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## INTRODUCTION

The Internet in recent years has changed the way patients seek health-related information. Traditionally, patients with chronic or life-threatening conditions received most of the information about their disease from their care providers. While providers tend to focus on the clinical impact of the disease and might ignore its impact on a patient's emotional well-being and daily life,<sup>1</sup> online health communities (OHCs), including online support groups and mailing lists,

act as a complementary source of support for patients.<sup>2</sup> For several illnesses, including life-threatening ones like cancer, patients increasingly rely on online forums, discussion boards, and social networks to exchange information, practical tips, and stories about their condition and get social support from their peers.<sup>3–7</sup> User-generated content shared in OHCs is becoming a valuable resource for researchers to understand patients' decision-making behaviors in the management of their health. Moreover, it can complement the more



**Figure 1.** A framework for studying online health communities. Two meta-layers, conceptualization and variables of interest, represent how OHCs fit in the landscape of social support and what variables of interest are studied by the research community, respectively.

typical clinical data collected from hospital information systems and electronic health records.

Disease-specific OHCs have been a subject of research for several years now. A wide range of studies have been carried out for purposes such as creating social support interventions,<sup>8–10</sup> understanding patient behaviors,<sup>11–13</sup> assisting community facilitators,<sup>14</sup> and mining critical disease- or medication-specific information.<sup>15,16</sup> Focusing on online cancer communities, a number of research studies have investigated social support outcomes of participation.<sup>17–26</sup> Most of these studies are based on social support groups created and maintained by health researchers, especially health psychologists, and they usually focus on examining clinical outcomes through experimental designs. As large-scale public social networks and asynchronous discussion boards attract more patients, and thus produce vast amounts of peer-to-peer interactions, there is unprecedented potential to leverage novel informatics methods to study OHC content at scale. This tutorial is targeted at assisting informatics researchers, equipped with informatics methods and tools, in formulating relevant research questions to advance the state of knowledge development in the field.

In this paper, we introduce current research theories and trends in OHCs, paying special attention to online cancer communities, by using a proposed framework to summarize the landscape. In particular, we identify key variables of OHCs from a social support standpoint, and summarize current research of OHCs with an emphasis on informatics approaches. We show how our framework can be used to identify and organize research questions, elucidate opportunities and challenges in informatics research, and propose future research directions.

## A FRAMEWORK FOR STUDYING ONLINE HEALTH COMMUNITIES

In this section, we describe how we organize the research on OHCs from a social support standpoint. We propose a framework, which

describes the landscape of social support and where OHC is situated and summarizes research questions investigated.

The framework has 2 meta-layers, illustrated in Figure 1, and is derived as follows. The upper meta-layer (Conceptualization) synthesizes existing social support theories<sup>27–29</sup> and identifies 3 major aspects of social support pertaining to the definition of OHCs.

The first sublayer within Conceptualization lists types of social support, which can be informational, emotional, or instrumental.<sup>28</sup> The second sublayer represents sources of social support, ranging from laypeople in one's social network to professional caregivers.<sup>27</sup> The third sublayer, setting of support, represents online or offline exchange of support and types of online venues.<sup>28,30,31</sup> It is noteworthy that the proposed framework is not able to cover every aspect of social support, and that the 3 dimensions could have complex interactions in real-world interventions.

Based on this framework, we identify where OHC fits in the landscape of social support, which we define as the *online* groups for patients exchanging *peer* support, primarily *informational* and *emotional* support. Irrelevant variables are grayed out from the framework to show our emphasis of discussion in this tutorial.

We use the lower meta-layer (Variables of Interest) in our framework to synthesize current OHC research. In general, research questions can be classified into 2 categories: impact of participation and characterization of OHCs. Characterization of communities can be further divided into several subquestions: member characteristics, contents, member engagements, and so on. Variables in this meta-layer were obtained through a review of the literature.

The literature search was carried out with the following query on PubMed, and focuses on communities with an emphasis on cancer: (“community” OR “communities” OR “network” OR “support” OR “peer-to-peer” OR “forum”) AND (“online” OR “internet” OR “on-line”) AND “cancer” (constraint: in title). There was no time constraint to the search. The search was executed in July 2015 and returned 140 publications. Out of the 140 publications, 24 were excluded as irrelevant to our focus of study with

**Table 1.** Number of studies in our publication pool for analysis, grouped by focus of the study with respect to variables in our framework

Variable abstraction	Variable of focus	Number of studies
Social support and OHC	Setting of support	13
	Type of support	6
Impact of OHC participation	Psychological impact	28
	Physical impact	4
	Behavioral impact	8
	RCT	10
	Others	5
Member characteristics	Demographics	24
	Disease profile	9
	Personality	7
	Motif of usage	5
	Social status	4
	Others	4
Content	Topic	27
	Emotion	17
	Others	6
Engagement	Lurking	5
	Activeness	3
	Dropout (attrition)	2
	Others	3
Others	Community creation	5
	Reviews	8

respect to online peer support. We further expanded the set of publications by including 44 more that either were not indexed in PubMed or were in the reference of our pool of publications that did not match our search query. The literature analysis to identify the variables of interest studied within the peer-support framework was thus carried out over a pool of  $116 + 44 = 160$  papers. Of particular note for this tutorial, although the framework was designed by analyzing the literature primarily from the psycho-oncology research community, we also present some studies outside of cancer that are closely relevant to specific variables of interest in the following sections, particularly those relying on informatics approaches.

After collecting the publication pool, 2 investigators (S.Z. and N.E.) manually coded each publication by finding its primary variable of interest with regard to OHCs. Variables discovered in the annotation were then refined and synthesized by 3 investigators (S.Z., N.E., and S.B.). This process was carried out iteratively, refining both framework and publication annotations until the framework in Figure 1 was obtained.

Table 1 provides an overview of the 160 papers in the analysis pool and how many of them contribute to each aspect of our framework in the final coding. A complete list of all publications along with their associated annotations is given at <http://people.dbmi.columbia.edu/noemie/ohc/literature.html>. Some of the studies have more than 1 code according to our framework. For the sake of this tutorial, in the following sections we discuss each layer of the framework by providing representative examples based on the coding.

## DEFINING OHCS FROM THE STANDPOINT OF SOCIAL SUPPORT

In this section, we describe how the concept of OHCs emerges in the larger context of social support following the first meta-layer of our framework. As previously mentioned, one of the most important

**Table 2.** Examples of informational, emotional, and instrumental social support

Informational support	“I had a bilateral with radical on the right and prophylactic on the left. I think all you can do is gentle exercise to strengthen your back (yoga).”	Support providing
Emotional support	“Thank you for being supportive. It is hard for me to write here because other people here are so brave and strong and I am ashamed of being just tired and angry.”	Support reception
Instrumental support	“Can someone help file my insurance claim?”	Support requesting

purposes of participating in an OHC is to seek and exchange social support with others.<sup>21,32,33</sup> We describe the connection between social support and OHCs here as an additional guide for organizing the research.

### Type of support

Social support can be classified from different perspectives, eg, for overcoming life adversities or in pursuing opportunities.<sup>34</sup> In this tutorial we introduce the classification from one particular angle closely related to OHCs. The classification contains 3 specific types of social support: informational support, emotional support, and instrumental support. They are defined as exchange of information, nurturance, and tangible assistance, respectively.<sup>28</sup> Examples in Table 2 are snippets of posts from an OHC, the discussion boards of breastcancer.org, which showcase exchanges of the 3 types of support. The examples are also instances of support providing, support requesting, and support reception, which conceptualize type of support from another perspective.

In online settings, informational and emotional types of support are usually exchanged more frequently than instrumental assistance,<sup>35,36</sup> in textual or multimedia content posted in forums, bulletin boards, and social networks.

### Source of support

The second building block of social support is the source of support. According to a social classification given by Dennis,<sup>27</sup> social support obtained through one's social relationships can be from embedded social members like family and friends, as well as from professionally created networks like social support groups. Dennis mentioned that although family members and friends are crucial sources of support, in distressing times members of such social networks may not be able to fully appreciate the stressful experience of patients. Instead, peers who share similar problems can be a better choice when one needs emotional support such as empathy and encouragement from others. It was suggested that the spirit of pursuing peer support is to find “similar others,” and that the desire to communicate with people who share similar problems is the fundamental motivation of participating in an OHC.<sup>13,26,33,37</sup>

### Setting of support

Traditional face-to-face peer support groups have several limitations.<sup>38</sup> First, many patients are physically weak and not able to walk or drive to the site for group discussion; second, some patients have full-time jobs, hindering them from participating regularly;

**Table 3.** Experimental studies of online peer support groups. + indicates an identified impact and – means no outcome observed using the measurement. bc: breast cancer; pc: prostate cancer; cc: colorectal cancer; pre-post: pre-post study design with no control group; RCT: randomized controlled trial

Literature	Subject (# sample)	Design	Outcome
Gustafson et al. (2001) <sup>39</sup>	bc (246)	RCT	+ social support
Lieberman et al. (2003) <sup>21</sup>	bc (67)	pre-post	+ reduced depression
Winzelberg et al. (2003) <sup>22</sup>	bc (72)	pre-post	+ reduced depression
Owen et al. (2005) <sup>8</sup>	bc (62)	RCT	– quality of life, psycho well-being, physical well-being
Lieberman and Goldstein (2005) <sup>48</sup>	bc (114)	pre-post	+ psycho well-being
Salzer et al. (2010) <sup>9</sup>	bc (78)	RCT	– psycho distress – quality of life
Hoybye et al. (2010) <sup>49</sup>	cancer (58)	RCT	– mood, adjustment, self-rated health
Ruland et al. (2013) <sup>19</sup>	bc and pc (325)	RCT	+ less symptom distress
Osei et al. (2013) <sup>50</sup>	pc (40)	RCT	– quality of life
Hwang et al. (2013) <sup>51</sup>	cc (306)	RCT	– colorectal cancer screening – fecal occult blood test
Stanton et al. (2013) <sup>20</sup>	bc (88)	RCT	+ less depressive symptoms
Borosund et al. (2014) <sup>18</sup>	bc (167)	RCT	+ reduced depression
Lepore et al. (2014) <sup>52</sup>	bc (184)	RCT	– mental health outcome

finally, patients living in less populated areas, especially those with rare diseases, may have difficulty finding others with the same condition.

The Internet has the potential to revolutionize the way patients exchange peer support, since they are much more likely to find similar others online than in a restricted geographical area, where traditional offline peer support happens. This gives rise to the third variable: the setting in which support is delivered, which is represented in the third sub-layer of the framework in Conceptualization. In the past decade we have seen a lot of investments by the psycho-oncology research community into designing Internet-based peer support groups.<sup>8,9,21,22,39</sup> Such studies have shown promise in improving the psychological well-being of patients and facilitating health management. Aside from online support groups, which are usually created and tightly controlled by researchers, OHCs are open to patients through registration, or full public availability is also becoming popular. This type of community includes those designed specifically for health purposes, such as the discussion boards of breastcancer.org,<sup>36,40,41</sup> the Cancer Survivors Network,<sup>15,42</sup> and PatientsLikeMe,<sup>43–45</sup> as well as general online communities and social networks such as Facebook,<sup>46</sup> where users also exchange health-related information and support.

## USING THE FRAMEWORK TO ORGANIZE RESEARCH QUESTIONS FOR ONLINE HEALTH COMMUNITIES

In the second meta-layer of our framework, we identified 2 main categories of research questions for OHCs, one regarding the impact of participation and the other regarding characterizing communities, members, and member behaviors. In the following sections, we present how research questions can be organized using our framework, and discuss how some of the research questions were investigated in previous studies. We suggest that most informatics research to date has focused on characterization of OHCs, leaving the potential for utilizing informatics techniques to study the impact of participation.

## Impact of participating in online peer support

The first research question that can be asked regarding OHCs is whether participation has a positive impact and, if so, what kind of benefit can be observed. A wide range of studies have aimed at answering this question by both experimental and observational approaches, but most of them are based on nonpublic online support groups created by health psychologists; meanwhile, no interventional studies with study control and prospective design have been carried out on public OHCs. Table 3 lists publications in our literature search with experimental study designs for online peer support groups for cancer specifically. A similar review with slightly different inclusion criteria can be found in the literature.<sup>47</sup> The Design column in the table lists the different types of study designs used. They are mostly randomized controlled trials, with a few pre-post studies.

Among the 10 randomized controlled trials, 4 rejected the null hypotheses. However, in 2 of the RCT studies with positive outcome,<sup>39,18</sup> the intervention packages included multipurpose web-based health management tools rather than purely peer support. As such, results from these studies cannot be interpreted directly as evidence that peer support led to the benefits. In addition, biases were reported in these studies that may also affect their validity, such as suboptimal strategy in randomization,<sup>49</sup> sample size too small to account for the larger-than-expected variation,<sup>19</sup> and reliance on self-reported data.<sup>52</sup>

Observational studies have also contributed to understanding the impact of group participation. Effects of participation have been identified as enhancing patient-provider understanding<sup>32</sup> and member self-empowerment,<sup>10,53</sup> and producing better outcomes in terms of stress, depression, and coping.<sup>54</sup>

There may have also been disadvantages associated with OHC participation. Owen et al.<sup>55</sup> found that compared to face-to-face groups, it is harder within online groups to build commitment and cohesion. Furthermore, it is more difficult for members to interpret others' tone and emotion in the absence of physical and nonverbal cues, which could lead to conflicts that quickly escalate.<sup>56</sup>

To date, although online peer support groups are getting increasingly popular, sound evidence to support the effectiveness of such groups is still in development. One of the primary reasons is that in most of the previous experimental studies, the sample size was not

sufficiently large, leading to the possibility that confounding factors moderated the outcome more than the independent variable of interest did (community usage). Factors like health status, offline support reception,<sup>57</sup> users' self-efficacy,<sup>58</sup> language use in communication,<sup>59</sup> and coping ability and style<sup>60</sup> were identified as moderators or predictors of effectiveness, which cannot be completely controlled in an experimental study with only hundreds of participants. Thus, identification of these underpinning variables is an important challenge for future informatics research. We will cover some of the issues in detail in the next section.

Another increasingly popular source of online peer support, large, asynchronous OHCs such as breast cancer forums and Facebook groups overcome the issue of sample scarcity by attracting large populations of targeted patients. More recently, informatics approaches, particularly automatic content analysis based on computational or statistical methods, have been proposed to study outcomes in these types of communities.<sup>36,41,42</sup> These studies of online communities may involve larger samples from patient populations, overcoming sparsity, but have limitations in the validity of automated methods and an inability to build a causal relationship between usage and outcome, because their study designs are retrospective and observational.

The impact of OHCs has traditionally been investigated primarily by health researchers, especially health psychologists. Informaticists have an opportunity to advance OHC outcome research by developing smart, scalable, and robust tools that analyze OHC content at scale and identify multidimensional descriptions of confounding variables.

### Characterizing online health communities and their members

Given the difficulties of studying the social support impact of online groups and the complexity of online communities, researchers are increasingly interested in characterizing OHCs and their members, which is where most informatics research lies. There are a lot of variables to consider regarding OHCs, such as their facilitators/moderators, users, and interactions. Not all variables are included in our framework. For example, the purpose of the group when it was originally created,<sup>46</sup> creators' participation in the group,<sup>61</sup> and type of support group<sup>37</sup> may also be vital to the community's development. We synthesize 3 abstractions of variables that have been investigated in previous research and are fundamental building blocks of OHCs. They are also critical sources of research questions for future work.

#### Member characteristics

Member characteristics include personal profiles, containing demographic information, health status, and personality traits. In reality, member characteristics can be far more complex than those in the proposed framework. For example, gender plays a significant role in online interaction,<sup>62-65</sup> which leads to different themes of interaction in communities dominated by men and women. Age is another demographic variable that makes a significant difference.<sup>41,66-68</sup> Informatics techniques can be particularly helpful in identifying some of the member characteristics that are hidden, such as users' personalities.<sup>69</sup>

#### Disease

The first major member characteristic to consider when studying OHCs is the targeted disease. OHC research has been focused on communities for different diseases with different emphases, such as

diabetes,<sup>70</sup> weight loss control,<sup>71</sup> depression,<sup>72,73</sup> smoking,<sup>74</sup> and so on. Davidson et al. compared social support groups for 20 categories of diseases, from life-threatening ones like cancer and AIDS to chronic ones like diabetes. They found that support seeking was highest for diseases viewed as stigmatizing, such as AIDS and breast cancer, and lowest for less embarrassing but equally devastating conditions such as heart disease.<sup>2</sup> Within the scope of cancer, differences were identified between breast cancer communities and prostate cancer communities.<sup>75</sup> Besides the effect of gender, the fact that breast cancer patients have higher survival rates and more treatment options also shapes how and what users discuss: breast cancer communities, in general, share more emotional support and less informational support than prostate cancer communities. Moreover, results from analyzing data from the National Health Interview Survey provide evidence that cancer survivors made greater use of community-based support groups than healthy participants or those with other chronic health conditions.<sup>76</sup>

#### Personality and psychological well-being

The relationship between psychological factors and physical health has been investigated scientifically for many years.<sup>77</sup> Health psychologists have found that a health event like a heart attack is more likely to develop in persons who are chronically irritated or hostile, and they have established models of linkage between personality and health.<sup>28</sup> It is also reported that optimistic patients are more likely to positively react to cancer-related experiences and ultimately see benefits of the experience.<sup>78</sup> Batenburg and Das<sup>60</sup> mentioned that in an online peer-to-peer support group, the benefit of participation critically depended on users' coping styles; actively dealing with emotions and thoughts was related to a positive outcome. Other psychological factors, such as self-efficacy,<sup>58</sup> emotional well-being,<sup>77,79</sup> and communication competence,<sup>80</sup> also play important roles.

#### Content

In most current OHCs, members communicate via posts that are mostly textual but also contain a rich set of images and links to external resources. The messages deliver information and sentiment, influencing users' perceptions of social support from the group, and even their intention to sustain participation.<sup>81</sup> For example, people adjusted their behavior in response to whether the messages they received were informational or emotional,<sup>36,82</sup> and such differences in message content can affect members' perceived empathy.<sup>83</sup> Conversely, message content can also influence whether informational or emotional support is elicited.<sup>11</sup> Content analysis also reveals how individuals in communities make sense of community environments collectively.<sup>12</sup> Recently, natural language processing techniques have been used to analyze OHC content,<sup>41,82,84</sup> with the caveat that these techniques are still facing various open research questions.<sup>85</sup> Two major dimensions of content are identified as they appear as frequent topics of previous works: topics and emotions.<sup>15</sup>

#### Topics

When the Internet first became an option for peer-to-peer communication, Sharf observed that in an online breast cancer group, topics regarding basic classifications or definitions of tumors and diagnosis were most prevalent,<sup>32</sup> indicating that Internet support was primarily a complementary source of information in the early years. A variety of themes, such as relationship/family issues, became popular in online peer discussions later on,<sup>59,75</sup> but disease-specific topics like



treatment, diagnosis, and interpretation of lab test results are most prevalent.<sup>86–88</sup> Specific topics of discussion were identified as well. For example, based on content analysis, Meier et al.<sup>87</sup> found that the most common topics in 10 cancer mailing lists were about treatment information and how to communicate with health care providers. Owen et al.<sup>75</sup> proposed a topic schema that includes 7 categories to code messages in online interactions. Based on the schema, the prevalence of different topics can be quantified.

### Emotions

Members of communities express different emotions depending on the context. Type and amount of expression of emotion and perception can be crucial to attaining optimal benefits for cancer patients.<sup>89</sup> Based on an Internet support group, Owen et al.<sup>90</sup> built a relationship between linguistic indicators of emotions and self-report of emotional suppression, observing a significant interaction between emotional suppression and use of cognitive words on mood disturbance. Liess et al.<sup>91</sup> manually coded content from face-to-face and online cancer support groups according to a categorization of emotion, including positive, primary negative, defensive/hostile, constraint, and neutral affect.

Researchers have realized that human annotation can be costly and inefficient in content analysis. To solve this problem, Pennebaker et al.<sup>92</sup> created the resource Linguistic Inquiry and Word Count (LIWC), grouping words into psychologically meaningful categories. The dictionaries for emotion words in LIWC have been widely used by researchers in automating emotion analysis of text.<sup>91,93</sup> Sentiment analysis, also referred to as opinion mining, is a type of technique to determine the overall contextual polarity of content to some topic. Sentiment analysis is sometimes regarded as a simplification of emotion analysis that only considers the general polarity of mood.<sup>94</sup> Equipped with such linguistic resources, automatic sentiment classification methods based on machine learning<sup>94</sup> have been exploited to investigate sentiment in forum posts published by patient users. For instance, studies found that thread originators change their sentiment in a positive direction after reviewing others' replies and self-replying,<sup>42</sup> and such changes are largely a result of postings from influential users.<sup>84</sup> It was also found that sustained participation in peer support communities would make users express more positive sentiments in their posts.<sup>41</sup>

### Engagement

Here we refer to the study of behaviors of community participants, such as posting activity (initializing discussion vs replying to others' posts), lurking, and dropping out of the community, as well as behaviors of creators and moderators of the community.<sup>95,96</sup> For instance, the distinctions between support reception through initializing discussions and support providing through replying and giving feedback are widely studied.<sup>41,89,97,98</sup> Here we discuss 2 important behaviors of users influencing community activity, lurking and dropping out.

### Lurking

Lurking refers to observing but not participating in Internet culture. The rule of 1% indicates that in online communities or social networks, more than 90% of users lurk and only 10% contribute content, the vast majority of which is by the 1% super-users. Van Mierlo<sup>99</sup> suggested that the 1% rule also holds true for OHCs, finding more than half of users lurking.

Researchers show great interest in identifying who lurks and why they lurk. In surveys lurkers indicate that the primary reasons for lurking include “reading is enough,” “have nothing to offer,” “topic not relevant to myself,” “want to talk to similar others,” etc.<sup>37,100</sup> Lurkers tend to be older,<sup>53</sup> have a shorter history of illness<sup>101</sup> and are less depressed.<sup>89</sup> Specific to cancer, patients with lower-stage cancer are more likely to lurk.<sup>102</sup> In terms of how lurking affects the benefits of participation, most of the studies suggest that lurkers receive less benefit, with some exceptions such as having a higher level of perceived functional well-being<sup>103</sup> and the same level of self-empowerment.<sup>102</sup>

### Dropping out

Dropping out, also referred to as attrition, is withdrawing from participation in the group. In a broader scope, dropping out means discontinuing participation in eHealth applications and the related phenomenon of dropping out of eHealth trials. Eysenbach proposed the “law of attrition” to describe the phenomenon that the majority of participants, sometimes over 90%, quit Internet-based trials or applications.<sup>104</sup> Researchers have found that active or influential members are critical in keeping a community active,<sup>84,105–107</sup> and active members' dropping out can drastically reduce the community's activity and cohesion. Studying dropout in peer-to-peer support groups, especially public communities, can be difficult for researchers. Unlike lurkers, users who drop out of a community do not come back to read the content, which makes it impossible to collect any feedback from them. The only way so far to study these members is to use retrospective data. For example, Wang et al.<sup>36</sup> did a survival analysis on a breast cancer forum, showing that users who received emotional support were more likely to keep participating, while users who received informational support were more likely to drop out.

## CONCLUSIONS

In this tutorial, we introduced research on online health communities and social support for informatics. We identified 3 major building blocks of social support: type of support, source of support, and setting in which the support is received. We also defined OHCs as the online platforms for peer patients to exchange informational and emotional support. Literature review suggested that studying the impact of community participation can be complex and is beyond the capability of most current informatics techniques, unless a proper experimental setup is available. To form a better characterization of online peer support, we synthesized related research into 3 major categories: member characteristics, content, and member engagement.

Traditionally, social support for patients has been in the realm of health psychology research. Existing interventions through OHCs have been carried out in tight experimental setups with full control of the research setting and access to necessary subjects' information to answer research questions and identify outcomes. More recently, informatics techniques, both qualitative and quantitative, have been sought in OHC research, but with little control over the underlying design choices of the community, in contrast to the other types of interventions. This tutorial represents one of our efforts to bridge the gap between health researchers' need for informatics solutions and informaticists' perception of OHC research. We show how informatics research of OHCs can be organized by our framework, and what research questions can be asked following the conceptualization. We

believe that this is an exciting and unprecedented time for OHC research: informaticists and health and behavioral researchers can join forces and study the role of online social support and patient health through meaningful collaborations.

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## CONTRIBUTORS

S.Z. did the literature review and wrote the manuscript. S.Z., S.B., and N.E. did the manual coding of literature. E.B., J.O., S.B., and N.E. participated in creating the framework and wrote the manuscript.

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## COMPETING INTEREST

None.

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