The Future of Research on Online Health Communities: Discussing Membership, Structure, and Support

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ABSTRACT

Online health communities (OHCs) are spaces where people gather for informational and emotional support around specific medical conditions and concerns. Although OHCs are an active and exciting research area that continuously attracts a wide range of approaches and methodologies, the focus has been mostly on a limited selection of OHCs or medical conditions. At the same time, there are novel challenges that OHCs face, including changes to the medical system resulting from the COVID-19 crisis, increased medical misinformation propagating online, and additional focus on personalized medical advice that is less attainable in traditional medical systems. This workshop will bring together researchers to discuss and produce generalizable lessons about membership, structure, and support in OHCs in the context of these novel changes, generating research agendas for future exploration and design of OHCs.

CCS CONCEPTS

• **Human-centered computing** → **Collaborative and social computing**.

KEYWORDS

online health communities, sensemaking, self-management, healthcare providers, caregivers

1 INTRODUCTION

Online health communities (OHCs) are virtual spaces where people congregate to exchange support on shared medical concerns, share advice on communicating with healthcare providers, collectively interpret new medical literature, and offer each other emotional support [10]. OHCs can take many forms, from dedicated forums around a specific topic (e.g., cancer [14]), to groups formed on broader social networks (e.g., Facebook [39]), to groups constructed by researchers [20], to informal communities which pop up to connect existing care networks of friends and family with a shared medical concern [24]. OHC membership might be exclusive to peers [31], include other stakeholders such as caregivers and healthcare providers [16], or target a broader audience for health activism [13].

OHCs have long been the focus of researchers in the fields of Computer-Supported Cooperative Work (CSCW) and Human-Computer Interaction (HCI). Prior research has focused on diverse topics, such as the type of support requested and provided by members [1, 30], the different roles that members assume [2], how members come together to generate shared knowledge through collective sensemaking [21, 28], the relationship of patients, informal caregivers, and healthcare providers within and outside the OHCs [9, 15], the challenges in content moderation [8], why members leave [23], and the design challenges in building successful and engaging communities [11]. OHCs have been mostly found to have a positive impact on members' lives by creating feelings of empathy and empowerment [35], especially in the context of underdiagnosed, rare, or 'enigmatic' diseases where medical support can be more difficult to obtain [19, 28, 38]. Methodologies in studying these questions have ranged from qualitative observations [4], quantitative statistical analysis [32, 37], mixed-methods analyses [14], and approaches for designing health communities [5, 20]. OHCs that have been studied before support a wide range of health diagnoses, such as diabetes [25], fertility [3], migraines [27], substance use

disorders [31], antidepressant discontinuation [28], and chronic diseases [34]. The CSCW conference and subsequently the Proceedings of the ACM on Human-Computer Interaction have considerably and continuously contributed to this growing body of research on OHCs, e.g., [7, 17, 18, 36]. With their history of research in CSCW, the study and design of OHCs warrant further discussion to provide a global understanding of what we have learned so far.

At the same time, new challenges are arising and are challenging how healthcare, and as a consequence OHCs, operate. For example, there is a growing appreciation of individual differences in disease trajectories, with entire countries setting strategic plans for understanding and supporting individualized healthcare (e.g., NIH calls for understanding individual differences in response to nutrition [26]), thus placing new importance on capturing and understanding unique personal experiences of individuals. Medical misinformation propagated online is recognized as pervasive and with dire consequences [12] and requires a careful discussion of its relationship with OHCs. Finally, the global health crisis that was brought by the spread of the COVID-19 virus has resulted in major changes in health care: many non-urgent clinical interactions have transitioned to telemedicine [22], health care workers face increased mental health challenges in the form of stress, anxiety, depressive symptoms, and insomnia [33], and experts warn of long-term consequences on the physical and mental health of the general population [6, 29]. In this shifting landscape, it is imperative that researchers discuss the opportunities and challenges that OHCs now face and to carefully map future research agendas.

2 WORKSHOP GOALS

This workshop seeks to bring together researchers with wide-ranging experiences who have studied or are interested in OHCs and who understand the unique opportunities for novel research. We aim to create generalizable lessons about what we already know about OHCs, while also mapping out research agendas for future research in the area to account for and respond to the ongoing changes in OHCs and healthcare in general.

Some of the questions we aim to answer include but are not limited to: (i) what have we learned about the reasons people join OHCs and the kind of support members seek and provide to each other?, (ii) what are the underlying processes and consequences of collective sensemaking?, (iii) what are the different ways that OHCs are organized and manage membership and what are the consequences of their structures?, (iv) what are points of friction between members and the established medical community?,(v) how is medical knowledge exchanged and generated within OHCs and what are the consequences of potential propagation of misinformation?, and (vi) how is the COVID-19 pandemic shaping OHCs and what will the long-term consequences be on their purpose, structure, function, and relationship to the medical community?

We also hope to cultivate a network among scholars and practitioners with different amounts and areas of experience, to foster collaboration, and to raise collective awareness of the questions and topics we are tackling. By bringing together organizers across academia and industry, with a diverse history of health conditions studied (e.g., mental health, diabetes, cancer, substance use disorder, rare diseases) and methods used (e.g., qualitative analysis of posts,

ethnographic work, quantitative analysis, building novel communities), we offer a wide range of past experience of OHC work and varied networks from which to recruit workshop attendees. As a final outcome, we will summarize the discussions and disseminate our findings to the broader community, e.g., through an ACM Interactions or longer survey of the field, and propose a future agenda for what remains as unanswered questions in the face of changing social media, web platforms, and health care.

To summarize, the workshop has the following broad goals:

- Facilitate networking among scholars deeply interested in understanding and designing OHCs.
- Define parameters of OHCs: different member groups, organizational structures, support goals, etc.
- Outcomes: community-cultivated reading list, aim for workshop report in a venue like ACM Interactions or a review article on the state of the field, future research agenda.

3 LOGISTICS AND FORMAT

We propose a four-hour synchronous workshop (1-day). In addition to the organizers, we intend to accept submissions from 10–15 participants. If supported by the conference, we would be open to allowing for up to 20 CSCW attendees to register for the workshop without presenting a workshop paper.

Workshop submissions should be no more than 3 pages (excluding references) in ACM's template. We expect that workshop submissions will describe preliminary empirical work or present a provocative research agenda in line with the questions described in the workshop goals. Each submission will be reviewed by two workshop organizers and be given some light feedback.

We will develop a website for the workshop with information about workshop goals, deadlines, and the agenda. Ahead of the workshop, workshop attendees will be sent the accepted workshop papers. We will also circulate a document to help cultivate a collective reading list on research papers relevant to OHCs, which we will maintain and post to the workshop website.

All participants will be given a form to fill in prior to their attendance, and we will share the results with all attendees prior to the workshop. The form will act as a template for each participant to briefly introduce themselves and their interests in relation to the workshop. For example, it will ask them about the specific OHCs they are interested in and might have studied in the past, the unique characteristic of these communities and how they generalize to OHC, and what they hope that the workshop will cover and assist them with in their future research. Paper authors will be invited to prepare a 3-minute video that will become available before the workshop to all attendees.

The workshop will start on the conference platform with a brief introduction from the organizers. Videos will be then streamed in real time and each presenter will be available for a short Q&A. The workshop will then transition to Gather.town which allows for customization of virtual spaces and to our experience for more organic socialization compared to video-conferencing platforms. We will provide some unstructured socialization time to allow participants and presenters to mingle, network, and ask follow-up questions from the presentation session. After a short break, the organizers will convene breakout discussions in two rounds of 30 minutes. In

each round, participants can join one of many separate rooms on Gather.town discussing questions i–vi listed in our research goals. We will divide topics and rooms based on the number of attendees to ensure a lively but focused conversation (e.g., 4-5 participants). Each room will have at least one organizer who will act as the notetaker/scribe for the discussion, putting notes in a shared slide deck. Workshop participants can explore different rooms, or elect to stick with their room to continue the discussion. In the report back session in the conference platform, one workshop participant will present the slide for each discussion. We will conclude with a broader conversation about existing lessons about OHCs and open questions, and will discuss a potential workshop report or review article.

The tentative agenda we plan to follow can be found below. All times are in PST. All of the organizers are located in North America, but we have attempted to pick a continuous block of time that will allow researchers throughout the globe to participate. We recognize the unfortunate reality of virtual conferences where participants in certain time zones might be negatively affected, and will work with submitters and attendees to modify our timing or support asynchronous participation as needed.

- 8:00am–8:05am Welcome and organizer introduction on conference platform
- 8:05am–9:15am Video presentations and Q&A on conference platform
- 9:15am–9:45am Unstructured Gather.town socialization time
- 9:45am–10:00am Break
- 10:00am-10:30am Gather.town breakout discussion round 1
- 10:00am–10:30am Gather.town breakout discussion round 2
- 11:00am–11:30am Report back
- 11:30am–12:00pm Discussion of next steps

We will advertise the workshop broadly in ACM SIGCHI-affiliated groups on social media and messaging platforms, such as the CSCW- and CHI-meta Facebook groups and the SIGCHI Discord channel, as well as our own social networks (e.g., Twitter feeds). We will additionally utilize the existing contacts of the organizers to directly reach out to other researchers conducting work on OHCs.

4 BACKGROUND OF THE ORGANIZERS

4.1 Alexandra Papoutsaki

Alexandra Papoutsaki is an Assistant Professor of Computer Science at Pomona College. Her work on OHCs focuses on how patients organize to provide peer support and discuss psychiatric care in the context of mental health concerns. She is particularly interested in the consequences of offering advice outside the medical system and in collaborative solutions between OHCs and healthcare providers.

4.2 Jina Huh-Yoo

Jina Huh-Yoo is an Assistant Professor at Drexel University in the College of Computing and Informatics. She has been a PI of NSF and NIH funded projects in improving information quality of OHCs and designing and evaluating smart health systems for family health. She serves on the Steering Committee of ACM CSCW (2019-), on the

Committee on Human Research at American Psychological Association (2020-2022), and on the Program Committees for ACM CHI, AMIA, IEEE/ACM CHASE, and EAI Pervasive Health conferences.

4.3 Haley MacLeod

Haley MacLeod is a Research Manager in the Communities Product Group at Facebook. Her research focuses on understanding how people express rich and multi-faceted identities online, including navigating tensions between privacy and expression in OHCs. Dr. MacLeod has studied support seeking needs and practices of different chronic illness populations, including rare and genetic conditions, skeleton-muscular conditions, cancer, and mental health.

4.4 Lena Mamykina

Lena Mamykina, PhD, is an Associate Professor in the Department of Biomedical Informatics at Columbia University. Dr. Mamykina's research interests include an individual's sensemaking and problem-solving in context of health management, collective sensemaking within online health support communities, clinical reasoning and decision-making, communication and coordination of work in clinical teams, and ways to integrate informatics interventions.

4.5 Andrew D. Miller

Andrew Miller is an Assistant Professor in the Human-Centered Computing Department at Indiana University-Purdue University Indianapolis (IUPUI). He studies how social computing technologies can empower people to help each other with their health and wellness. Dr. Miller has studied peer support for physical activity, OHCs for sensitive conditions, and online creative collaboration technologies. His current research focuses on family-based caregiving collaboration technologies in the children's hospital.

4.6 Svetlana Yarosh

Svetlana "Lana" Yarosh is an Associate Professor in the Computer Science & Engineering Department at University of Minnesota. Her research on OHCs has focused on understanding and enhancing the role of technology in facilitating social support. She has worked with OHCs focused on topics as diverse as cancer, substance use disorders, and early childhood parenting.

4.7 Daniel A. Epstein

Daniel Epstein is an Assistant Professor in the Department of Informatics at the University of California, Irvine. His work examines the role of patient-generated health data in OHCs, particularly around mental health and healthy eating. In addition to understanding use of data in existing communities, he also designs communities and sharing mechanisms to support conversations around data.

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