Information-Seeking, Finding Identity: Exploring the Role of Online Health Information in Illness Experience

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The identities we hold have a relationship with how we come to express and understand our experiences of illness. Language forms a means for us to express this understanding and experience to others, and receive information to clarify our own experiences. Having access to new information when undergoing an illness experience can be integral in supporting decision-making for one's health and well-being and change how we understand ourselves and our experience. Individuals are exposed to information about experiences of illness via search engines, social media, and other platforms online. This online health information may thus significantly influence the decision-making process. Research is needed to understand how the affordances of diverse online hubs for health information influence how people understand illness experiences and seek care. How people use the internet for information-seeking is often researched in individual health conditions. This workshop aims to explore the different methods researchers have used to understand online information-seeking journeys and to identify how the internet is, or can be, used to help users make sense of, and give meaning to, their experiences. Through convening a methodologically diverse set of researchers, we hope to generate a foundation and cohesive field of inquiry and community within HCI.

Additional Key Words and Phrases: sense-making, information-seeking, health informatics, algorithmically mediated resources, help-seeking, computer mediated communication, online communities, internet search behavior

1 INTRODUCTION

For individuals in distress, online information sources are becoming primary methods by which individuals understand their experience and make decisions regarding their health. The use of the Internet for public health information during

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the global Coronavirus Disease 2019 (COVID-19) pandemic [8] (hereafter called the COVID-19 pandemic) has only increased usage of online information for health.

Substantial work has been done to understand how individuals in distress seek information, including what source of information individuals choose to use, and how they validate and interpret that information they receive [4–6, 12]. However, information-seeking is not a unidirectional process—as individuals are exposed to new information about their health, their explanatory models of their experience change [3], and these shifts in understanding also influence what subsequent health information individuals search for. Identity and culture are core to these processes, both for how individuals understand their experience of illness [2, 3], and how they express it to others [7].

Understanding how interactions with technology-mediated tools and social platforms influence our own understandings of our identity is an emerging field within Human-Computer Interaction (HCI), including explorations of mental health resources and identity [11] and interactions with TikTok and queer identities [14]. Looking specifically to health, work centered around collective sense-making has analyzed how individuals tend to participate in online forums that are related to their understanding of their health condition [9]. The dynamics of these groups can also have an influence on individual sense-making and meaning-making activities [1], echoing literature from medical anthropology on how experiences of illness are socially constructed and individually experienced [3]. The information that individuals obtain online, and share with others, has an important influence on how individuals make decisions regarding their health, healthcare, and well-being in offline domains [13].

Looking to the digital health domain, diverse sets of stakeholders have an influence on online health information, including clinicians, interface designers, social media influencers, individuals with lived experiences with illness, and search engine algorithm designers, among others. Similarly, diverse sets of methods can be used to address this broader question, including analyses of online support groups or user comments, search engine audits, prototyping studies, and interviews. As diverse forms of studies address the core question of how people make sense of health information and integrate it into their broader sense of self, it is extremely important that researchers from different methodological and epistemological backgrounds stay in communication and collaboration with one another. It is through doing so that the field can ensure that different perspectives build off of each other, that the research we do remains ethical, and that the products of our research continue to benefit stakeholders, particularly individuals who are in distress and seeking care.

It is in service of this broader goal that we propose the following workshop, *Information-Seeking, Finding Identity: Exploring the Role of Online Health Information in Illness Experience*. In this workshop, we plan to convene a diverse mix of researchers, clinicians, practitioners, influencers, algorithm designers, and other stakeholders to together explore methods in better understanding online information-seeking journeys, the role they play in illness experience, and how we can together support more inclusive and equitable futures for individuals seeking support, solidarity, and care. We believe that it is very important to have this workshop at CSCW 2022, as it has been some time since the last workshop centered around health and information-seeking, and explored people's engagement and how health and illness influencers, massive online communities, and other new online spaces for individuals support people with information-seeking.

2 WORKSHOP THEMES AND GOALS

In this workshop, we will invite researchers from different disciplines (e.g., HCI, CSCW, clinical research) as well as groups not traditionally represented in this research, including clinicians, representatives from patient advocacy groups, influencers, public health educators, and other individuals who directly create content that influences how people think of their experiences of illness. In doing so, we aim to bridge research and practice by convening a diverse group of both

individuals who conduct research on explanatory models of illness online, as well as those individuals who leverage online platforms to participate in discourse around explanatory models of illness and identity.

Through creating this broader community, we hope to form a collaborative understanding of the different methods used to explore online information-seeking journeys and how the internet is used to support sense-making and meaning-making in users' health experiences. We also want to explore the impacts of identity (*e.g.*, gender, health, disability, etc) and how internet-mediated information journeys influence offline identity formation and pathways to care. Additionally, we hope that conversations between these communities can lead to fruitful collaborations that center the tangible impacts of our work (both current and future) on users in distress seeking care.

Through this workshop, we call for people to share experiences, theories, ideas, questions and opinions to form a stronger understanding of the following themes.

- *Approaches to Analyzing Information-Seeking Journeys and Identity* — We want to explore the different methods used and how they influence how people make sense of their information journeys, their illnesses and pathways to care, as well as how individual or group identities can affect these information journeys.
- *Algorithmic Biases* — What are the impacts of algorithmic biases and do these affect how people manage and understand their online information-seeking and ultimately the decisions they make about their healthcare?
- *The COVID-19 Pandemic* — How has the pandemic changed how people search for and validate information? Have the implications of misinformation that was spread during the pandemic affected people's trust in online information? We would also like to understand how the pandemic has changed people's perceptions of identity and norms with regards to their healthcare.
- *Illness and Identity Online in the Global South* — Discourse around searching for health information has often clustered around behaviors in Western countries. The privilege given to the West in these conversations echoes patterns from history, in which minority experiences of distress were marginalized [10]. We hope to have a vibrant discussion around the nuances to sense-making in non-Western contexts, asking the broader question of how interfaces for health information can be designed with structural, cultural, and local contexts in mind, to better support users from around the world.
- *Stigma & Sensitive Topics* — How do the implications of stigma and the impact of sensitivities affect how people search for and use information? We welcome contributions that explore whether online information helps or hinders access to information and healthcare services in the cases of stigmatised or sensitive topics, such as sexual and reproductive health.
- *Language* — Language is a powerful tool in communicating health information. Depending on one's culture, class, race, nationality, or religion, the tone, settings, and actors are understood/interpreted differently. We are interested in surfacing the cross-cultural concerns around online information-seeking (among non-native speakers).

We aim to build a long-standing collaborative group by providing a platform for people to come together, share ideas, and learn from one another. Activities before, during, and after will support continued engagement and further collaboration in this field of research. We will do this through the development of a website and social media accounts to aid the dissemination of relevant information for individuals engaged in this field of research. With the permission and consent of participants, we will share participant submissions to our workshop to the workshop attendees. We plan to compose a directory of engaged individuals that will support collaborations and support post-workshop mentorship

Time	Activity
9:00 - 9:10am EST	Introduce the workshop, including general structure and organizers
9:10 - 9.50am EST	Keynote Talk followed by Q&A
9.50 - 10.00am EST	Introduction of themes and breakout room plans
10.00 - 10:30am EST	First Round of Panels
10:30 - 11.00am EST	First breakout rooms to discuss experiences relevant to workshop themes
11:00 - 11:20am EST	Break
11:20 - 12:00pm EST	Second Round of Panels
12.00pm - 12:30pm EST	Breakout rooms to discuss future research collaborations and plans
12.30pm - 1.00pm EST	Closing remarks and reflections

Table 1. Workshop Schedule Overview

opportunities for early-career researchers. Our intention is that from this workshop we can then arrange future activities such as symposia that will support the continuation of collaborations.

3 WORKSHOP SCHEDULE

Given the virtual nature of the conference, we plan to begin workshop activities and disseminate information to promote engagement before the actual workshop and to continue after, to encourage asynchronous participation and enable participants in different time zones to contribute at their convenience.

From our previous work that has included collaborating with people in different time zones, specifically centering those in the Global South, we believe holding this workshop on Sunday from 9:00am - 1:00pm EST would encourage wide participation across time zones, with a particular amenability towards those in Asia.

For this workshop, we plan to begin with a keynote speaker. We will plan 2 rounds of panel discussions centered around different themes and break-out sessions where each panelist can host a more in-depth discussion on their theme. We will divide the themes between these two panel discussions based on their synergies. We will also schedule breaks for the well-being of all attendees.

We will hold the actual workshop over Zoom Video Conferencing as this will enable the presentation of panel discussions and the creation of break-out rooms, which we will utilise through the workshop. We will also utilise collaborative online sharing platforms such as Padlet, to share key themes and questions and Miro, for participants to share ideas in the moment and support interaction throughout the workshop. We will have allocated people to ensure insights from these sharing tools are then fed back and shared during the workshop to encourage discussion.

A detailed workshop schedule can be seen in Table 1.

4 CALL FOR APPLICATIONS

Our workshop aims to bring together a diverse set of stakeholder participants to discuss lessons from research on online information-seeking for individual health conditions and how lessons and experiences can be shared.

To begin, co-organisers will share the call for participation with their diverse networks and research collaborators who are engaged in adjacent fields of research. We intend to use snowballing techniques for the call to be disseminated

beyond our initial networks. We plan to utilise email, mailing lists, and various social media avenues to connect with academics, industry specialists, and clinical health workers.

We will engage prospective participants in novel ways. We will request that they share their expressions of interest by submitting a 1-page document, an online poster, or a 90-second video sharing their insights, experiences, or interests in themes of the workshop and their motivation for participation followed by what they wish to get out of the workshop. We hope to attract diverse participants through the options of novel and interactive submission types. These will then be shared on the workshop website for others to engage with, with participant consent.

Workshop participants will be selected on the basis of prioritising diverse and cross-disciplinary interactions. We plan to host approximately 60 participants.

5 ORGANIZER BACKGROUNDS

Dilisha Patel is Post-doctoral Researcher in Human-Computer Interaction and Digital Health at UCL Interaction Centre. Her research uses qualitative methods to understand how users make sense of and find meaning in online information for their health and well-being. She has a particular interest in exploring how to make digital health information resources accessible and equitable for all. Her PhD thesis focused on the online information-seeking behaviours of men who experience fertility difficulties.

Sachin Pendse is a PhD student in Human-Centered Computing at Georgia Tech. His work is centered around the role of technology in how people come to understand, express, and seek care for their mental health. In particular, he focuses on how current methods in technology-mediated care might propagate patterns of oppression from offline spaces, and exclude people with marginalized identities from finding effective care.

Munmun De Choudhury is an Associate Professor in the School of Interactive Computing at the Georgia Institute of Technology. She works at the intersection of computer science and social science, with a particular focus on computational methods and artifacts to make sense of human behavior and psychological state. Her work broadly contributes to understanding how advances in machine learning and grounding in human-centered approaches can help us answer fundamental questions relating to our social lives.

Sarah Dsane is a lecturer at the Computer Science Department at Koforidua Technical University, Ghana. She is pursuing a PhD in Human-Computer Interaction at the University of Cape Town. Her research interest is understanding the information-seeking behaviour of bandwidth-constrained parents in South Africa and Ghana during the first thousand days of their child's life.

Kaylee Kruzan is a Research Assistant Professor in the Center for Behavioral Intervention Technologies at Northwestern University's Feinberg School of Medicine. Dr. Kruzan's research focuses on the design and evaluation of scalable digital mental health interventions for adolescents and young adults who are not engaged in formal treatment. She has a particular interest in using human-centered design methodologies to develop digital tools that fit within, and can facilitate, the help-seeking process. She earned her doctorate in Communication from Cornell University, an MSW from The Ohio State University, and an MA from University of Illinois at Chicago.

Neha Kumar is an Associate Professor at the Georgia Institute of Technology. She is jointly appointed at the Sam Nunn School of International Affairs and the School of Interactive Computing. She works at the intersection of human-centered computing and global development, engaging participatory, assets-based approaches towards technology design for/with communities that have historically been underserved.

Aneesha Singh is an Associate Professor of Human Computer Interaction at the UCL Interaction Centre, UK. She is interested in the design, adoption and use of personal health and wellbeing technologies in everyday contexts. Her

research focuses on digital health, ubiquitous computing, multisensory feedback and wearable technology, especially in sensitive and stigmatized populations.

Mark Warner is a Lecturer (Assistant Professor) of Computer Science at UCL, UK. He is a social computing researcher with interests in online privacy and disclosure, as well as online information-seeking and sense-making. Mark has been involved in research on various different health conditions, including HIV, infertility, and polycystic ovary syndrome (PCOS). He has a particular interest in understanding how people utilise online resources to help them make sense of life changes (including health diagnoses), and how people navigate issues of privacy and trust through sense-making processes.

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