Challenges, Tensions, and Opportunities in Designing Ecosystems to Support the Management of Complex Health Needs

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ABSTRACT

The intertwined and sometimes contradictory work of managing complex health needs (e.g., discordant, enigmatic, and/or rare conditions) creates many challenges for patients, caregivers, and healthcare providers. While researchers have created interventions such as technologies and services to address particular health needs, interventions must be designed to better account for gaps in technologies and interdependencies across health needs. In this workshop we will adopt an ecosystems perspective to better understand the nature of complex needs and how to support the management of those needs through holistic and multi-faceted support. Using a hands-on design sprint technique, participants will (1) map out different complex care ecosystems, (2) generate ideas for technologies, services, and other multi-faceted interventions to address gaps in those ecosystems, and (3) choose the most promising ideas to further develop and refine. We will close by reflecting together on what we have created, our approaches to design, and the theories and concepts that shaped our approaches. Through this process, we will collectively generate an agenda for research and design to better support the management of complex health needs.

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CCS CONCEPTS

• **Human-centered computing** → *HCI theory, concepts and models*; *Human computer interaction (HCI)*; *Collaborative and social computing*; • **Applied computing** → **Consumer health**; **Health care information systems**; **Health informatics**.

KEYWORDS

complex care, multimorbidity, design, workshop

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1 BACKGROUND

Individuals with complex health needs and members of their care networks struggle to manage health and well-being because of limited resources and fragmented health care infrastructure. Complex health needs include multimorbidity, vulnerability, and frequent use of health services [20]. Complexity might be caused by health-related factors (e.g., discordant, enigmatic, and/or rare conditions) and by personal and psychosocial factors (e.g., disenfranchisement, stigma, culture, life transitions). People with complex needs face more quality of care problems, higher healthcare costs, and more self-care work [7]. These challenges also complicate the use of technologies designed to support their health management.

Researchers have identified numerous important considerations when designing to support health management for complex health needs. These include designing for different perspectives among formal and informal care networks [18, 33], balancing health priorities among patients, caregivers, and healthcare providers [5], navigating cultural values, sociocultural practices, community perceptions, and norms [4, 29], managing trade-offs between different risks and treatment options [11], building patient expertise [1], supporting infrastructuring work [22], and fostering a sense of control [2]. Given these many necessary considerations, these individuals and their care networks require more than siloed solutions; they need multifaceted and holistic support.

To begin to bring about solutions that enable this multifaceted support, we draw from recent conceptualizations of technology ecosystems [10, 16, 44], a useful lens for bringing more attention to the importance of understanding the lived experiences of people with complex care needs. To date, many solutions have been created with the intent to provide support for a particular condition (e.g., diabetes, cancer, or depression), but far fewer support individuals across multiple health-related and social needs [32]. Going beyond user-centered design that may be scoped to a particular technology or a health need, ecosystem thinking helps reframe the design space to account for interdependencies across different needs and technologies, and across formal and informal health care settings in the home and in the community. It also accounts for the role of social needs, culture, and zeitgeist.

To investigate how to provide multi-faceted and holistic support for complex health needs, this workshop will bring together interdisciplinary researchers through the lens of ecosystems. We will explore how to address needs within particular contexts (e.g., studying specific illnesses) while tracing how those fit within larger ecosystems. We will map existing technologies and services, examine our design processes, engage with theory, and explore how we can collaborate with interdisciplinary stakeholders (e.g., industry designers, hospital administrators, social workers). The specific questions we approach during the workshop will be influenced by participants' interests, and we include initial directions in the Workshop Goals section below. Based on the reflections and discussions from the workshop, we will identify major challenges, priorities, and opportunities for future research to design ecosystems that better address complex health needs.

1.1 Burgeoning Interest in Complex Care

People with complex health needs often have poor health outcomes and account for a high proportion of healthcare spending [20]. Additionally, this population is growing as the incidence of chronic conditions requiring long-term management increases worldwide [19]. As a result, there is interest in how to better support them, improve their health outcomes, and quality of life. A joint report from the National Center for Complex Health and Social Needs, the Center for Health Care Strategies, and the Institute for Healthcare Improvement provided a set of steps for improving the lives of people with complex needs, such as developing a shared identity across communities of practices, from grassroot movements to formal care providers [24]. Similarly, the National Academies of Sciences, Engineering, and Medicine [6, 14] highlighted the role of health information technology in supporting five activities that address complex needs by integrating health and social services: awareness (identifying people's social risks and assets), adjustment (transforming clinical care), assistance (connecting patients with social care resources), alignment (understanding and investing in community-based organizations), and advocacy (promoting policy that marshals necessary resources and boosts capacity to address social needs). There have also been efforts to streamline resource repositories to support people with complex health needs, including the Better Care Playbook (https://www.bettercareplaybook.org) and the Social Interventions Research and Evaluation Network (SIREN, https://sirenetwork.ucsf.edu).

The above initiatives focus mostly on the US healthcare context, but complex health needs are not unique to the US. Still, the definition and nature of complexity may differ across settings and regions [23, 35], particularly in the Global South. Multimorbidity is a priority for global health research [30], since the global incidence of chronic and noncommunicable diseases is rising. This trend is compounding with existing challenges in the Global South, including socioeconomic status, nutrition, and infectious disease [30].

These initiatives indicate a groundswell of interest and no shortage of resources, active research, and visions for the future of complex care. HCI researchers can play a key role in this emerging area, especially in designing technologies and technology-enabled services that improve multiple care trajectories. One core area of focus in this workshop will be to clarify how our strengths as HCI scholars complement those of scholars and practitioners in other disciplines. We believe that our focus on people's lived experiences can bring a lot more into view than is typically included in research focused on single conditions or standalone technologies. We also believe we can amplify our real-world impact by learning from scholars in health services and global health about how the products of our research can be implemented, deployed, and maintained in real-world settings.

We see this workshop as an opportunity to take stock of the state of the field of complex care and identify key avenues for HCI researchers to make critical contributions. In particular, we see an opportunity to bring together scholars working in disparate areas of complex care to adopt an ecosystems perspective and inform the design of technologies that improve the multiple trajectories of care for individuals and their care networks.

1.2 Joining Fragmented Complex Care Research in HCI With an Ecosystem Approach

An ecosystem approach is especially needed for people with complex health needs. Following definitions used by DeVito et al. [16] and Burgess et al. [10], we define a complex care ecosystem as the collection of technologies and services used to navigate complex health needs and coordinate healthcare amidst personal, structural, and environmental factors. Complex care ecosystems may include collections of technologies and services, such as paper journals to track symptoms [3], devices to collect biometric data [28], applications for messaging with formal and informal care providers [9, 17], and digital directories of community-based resources (e.g.,

https://www.findhelp.org). These ecosystems also include sociocultural factors that influence or shape individuals' care infrastructures in their home and community [27, 41, 42].

By adopting an ecosystems lens, we advocate for approaches to design that interlink services to address multi-faceted needs rather than developing standalone tools. Technologies and services that focus on single health conditions may fail to account for conflicting symptoms and the self-management associated with other health conditions (e.g., [37]), and a focus on health needs to the exclusion of social needs may similarly fail [39]. For instance, caregivers can suffer from emotional distress and financial risks when they provide intensive care to a loved one [13]. Siloed and narrowly-defined technologies also typically do not work well together. For example, it is uncommon for patient-generated health data to be integrated in electronic health records. Faced with fragmented technologies and services, people often have to assemble and maintain their own ecosystems. Gui and Chen [22] demonstrated these struggles in their examination of infrastructuring work by parents navigating breakdowns and misalignments across health technologies and services.

There are many examples of HCI research on complex care, including many from just the past few years. These include Guan et al. [21], who advocated designing for people with dementia and caregivers with their access to community care ecosystems in mind; Pendse et al. [34], who showed how helplines for mental health support can fail to account for people's marginalized identities and thwart their attempts to access care; Schurgin et al. [36], who identified coordination challenges for caregivers due to relationships, access to resources, and physical and mental barriers; and Chopra et al. [12], who illustrated how people with Polycystic Ovary Syndrome experienced stigma and uncertainty, shaping understanding of their condition and how they sought support.

There are also many useful examples of bringing whole health care ecosystems into view in the design process. Many scholars have used a social-ecological lens to highlight factors at different levels and how they interact. Jeong and Arriaga [25] used an ecological model to ground the design of mobile technologies for children with asthma in the context of their daily lives. Evans et al. [18] adopted an ecological perspective to examine how military culture influences the care needs of veterans with post-traumatic stress disorder. Tachtler et al. [38] applied Ungar's [40] social ecology of resilience to highlight factors in unaccompanied migrant youth's mental health resilience at bio-, micro-, chrono-, and macro-levels. Costa Figuerido and Chen [15] and Murnane et al. [31] adapted Bronfenbrenner's ecological systems theory [8] to identify factors at the micro-, meso, exo-, and macro-levels relevant to fertility data practices and serious mental illness, respectively.

However, more work is needed in order to make ecological models actionable for HCI research and design practice. How can HCI leverage theories and concepts from other disciplines to support more appropriate and transformative interactive systems? What new theoretical structures are needed in order to support ecosystem-informed design practice? What are the potential harms of greater connectivity and awareness in care coordination and management systems for health, and how can theory help us avoid those negative outcomes? These are just some of the questions we will dig into in this workshop.

2 ORGANIZERS

Each of the organizers has experience conducting research complex care settings across the globe. We bring diverse theoretical perspectives, methods, and backgrounds to these research settings, and we have strong representation from scholars at different points in their careers, including early-career researchers and established faculty. Additional information on each organizer is included below.

Tom Ongwere is an Assistant Professor in the Department of Computer Sciences at the University of Dayton. His research focuses on the study of techniques to help patients with discordant chronic comorbidities (DCCs) better prioritize their complex treatment plans. His current focus is on the tradeoffs impacting cost, decision making, patient care, use of doctors' time, and healthcare resources. Tom's research takes a systems approach, which he can apply to other problems also looking for a solution from the lens of all of the players.

Andrew Berry is an Assistant Professor in the Department of Medical Social Sciences at Northwestern University. He uses qualitative and participatory methods for research and design to engage and support people with multiple chronic conditions and social needs. He is currently exploring how to design information systems that combine patient-reported outcomes with patients' personal values to facilitate collaborative care planning with clinicians.

Clara Caldeira is a Computing Innovation Fellow in the Department of Informatics at Indiana University, Bloomington. She studies how technologies can support older adults and individuals with chronic conditions. She uses qualitative and quantitative methods to understand users' self-care practices, lived experiences, including psychological and cultural factors, and their collection and use of personal health data.

Rosa I. Arriaga is an Associate Professor of Interactive Computing at Georgia Tech. She uses psychological concepts and theories to design, build and deploy systems for improving the health and wellness of individuals with chronic illness. Bronfenbrenner's Ecological System Theory is a consistent source of inspiration and accountability for her research approach.

Amid Ayobi is a Research Associate in the Department of Computer Science at the University of Bristol. His work has included multidisciplinary projects aimed at supporting self-tracking in multiple sclerosis care, understanding the mental health needs of people from ethnic minority backgrounds, and co-designing machine learning systems with clinicians, data scientists, and people with diabetes.

Eleanor Burgess is a User Experience Researcher at Anthem Health Platforms. Her research investigates collaborative technologies for mental health support. She aims to map technology ecosystems (including social media, voice/video calls, online games, music, journals, among many other tools) and understand how people use them for health self-management.

Kay Connelly is a Provost Professor of Informatics at Indiana University. Her research focuses on pervasive and mobile computing technologies to empower both the ill and the healthy to manage and improve their own health and make healthy choices. Technologies of interest include smart homes, novel displays of everyday information, wearable devices and mobile applications.

Dr. Connelly has a particular interest in designing with low socioeconomic status populations and how to ensure technology meets their needs.

Patricia Franklin is a Professor in the Department of Medical Social Sciences at Northwestern University. Her research program has designed and implemented diverse methods to capture patient-reported health outcomes from national samples of patients and integrated these data with clinical and administrative data to generate real-world evidence. These integrated, longitudinal patient-centered data support quality improvement and research in learning health systems.

Andrew Miller is an Assistant Professor in the School of Informatics and Computing at IUPUI (Indiana University). He works with families of hospitalized children to design technologies that support resilient caregiver coordination, using qualitative methods to uncover challenges and opportunities as well as participant-involved design techniques to produce and evaluate exemplar prototypes.

Aehong Min is a Ph.D. candidate in Health Informatics at Indiana University Bloomington. Her research focuses on technologies for the well-being and health of informal caregivers and their care recipients. Currently, she studies people with epilepsy and their caregivers and how to involve other stakeholders as caregivers, using mixed methods to identify challenges and design opportunities to support them.

Nervo Verdezoto is a Lecturer at the School of Computer Science and Informatics at Cardiff University. His work has investigated invisible care work in the home, hospital, and community health. His recent work explores how care infrastructures and sociotechnical and cultural practices influence maternal and child health in the Global South with particular focus on pregnancy complications and the double burden of malnutrition in children.

3 PRE-WORKSHOP PLANS

3.1 Key Dates

Our website and call for papers will be available December 16, 2021. Submissions to participate in the workshop are due February 24, 2022, with notification of acceptance in mid-March. The workshop date will be Saturday April 30 or Sunday May 1, 2022, and is yet to be determined.

3.2 Inviting Participants

We will distribute the call for participation on HCI email lists, social networks (e.g., CHI Meta) and in the SIGCHI Discord server. Organizers will also share the call outside HCI, including digital and public health communities, through social media and our professional networks. Our website (https://complexhealthchi.wordpress.com) contains contact information, information about the workshop, and details about how to participate.

4 WORKSHOP STRUCTURE

4.1 Synchronous, hybrid format with asynchronous participation

We will support in-person participation, remote participation via Zoom, and asynchronous participation. We will poll participants to understand attendance needs and adjust our approach to be inclusive and supportive. We plan to host a synchronous discussion among in-person and remote participants, and we invite asynchronous participation via Slack. Dedicated facilitators will support asynchronous and remote participants. This will include curated material for optimal user experience. In terms of technical capacities, we will seek live transcription support; use Zoom on organizers' laptops to enable remote participation; and support asynchronous engagement before, during, and after the workshop via collaboration software such as Slack, Miro, and Google Docs and Sheets. In particular, (1) before the workshop, we will post position papers and encourage participants to introduce themselves via brief profile; we will invite asynchronous, text-based discussion in Slack; and we will post all materials describing the design sprints and other workshop activities in advance; (2) during the workshop, organizers will post text-based notes from each design sprint and invite asynchronous, text-based discussion on Slack; and (3) after the workshop, organizers will post additional text summarizing the outcomes of the design sprints and reflective conversations and invite asynchronous, text-based discussion via Slack.

4.2 Workshop Goals

Our goal in this workshop is to explore questions such as the ones listed below.

Definitions: How are complex health needs defined, and under what circumstances does the definition shift? How do different cultures, value systems, and social conditions influence the definition? Who plays a role in defining complex health care needs? How do different approaches to financing health care influence the nature of complex care ecosystems (e.g., nationalized health care, value-based care, not-for-profit care)? How do these definitions change across different health conditions?

Data: What is the role of data in complex care ecosystems? How can we build technologies that leverage data across levels of an ecosystem (e.g., individual, family, community, society)? What becomes possible if data practices within complex care ecosystems are better connected, integrated, and coordinated? Who should own and/or finance data management systems for complex care? What ethical risks around data collection, privacy, security, and autonomy might arise in complex care ecosystems that are more tightly integrated?

Theory: What theories, models, and perspectives help researchers and designers grapple with complex care ecosystems? For example, HCI scholars have used Bronfenbrenner's [8] ecology of human development, Ungar's [40] social ecology of resilience, a care infrastructures perspective [27, 41, 42], and assets- and strengths-based perspectives [26, 43]. What aspects of these ecosystems should we consider (e.g., stakeholders, layers, technologies, data), and how can we account for tensions across them?

Design: How can we identify stakeholders in complex care, including roles with emerging significance (e.g., community health workers or healthcare policymakers)? How to design an ecosystem with multiple technologies in mind? How to account for dependencies and overlaps across different health needs and technologies? How to support people in navigating different technology options

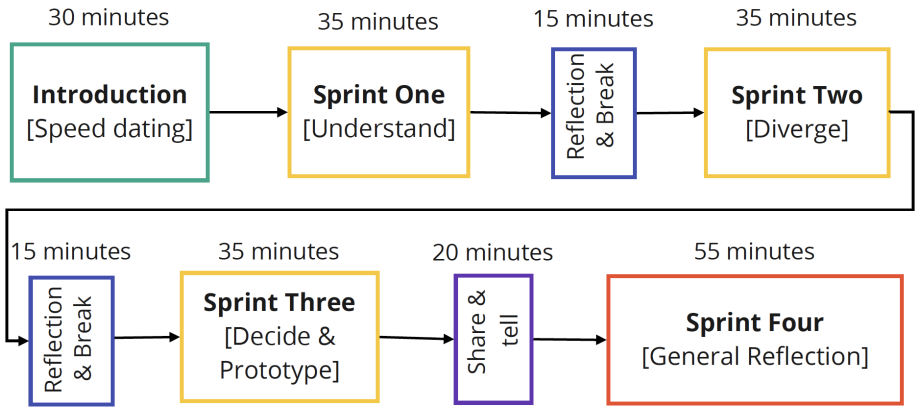

Figure 1: Workshop flow

to meet their personalized needs? What aspects of complex care ecosystems can most benefit from contributions from HCI scholars?

4.3 Workshop Design

We will engage participants through hands-on Design Thinking activities. Organizers have experience in teaching Design Thinking methods and running workshops with heterogeneous groups. See (**Figure: 1**) for the flow of activities. We will complete three short design sprints in groups of 5 to 8 people. One workshop organizer will join each group to facilitate and take notes. Before the workshop we will review submitted position papers and abstracts and identify themes (e.g., common theory, methods, application domains).

We will begin by introducing participants to the organizers and each other through a "speed dating" activity. Then we will commence with the three design sprints. Below we discuss the activities and goals for each sprint. Between sprints, participants will share and reflect as a group.

In the first sprint (understand), participants will review themes from position papers and share their own experiences with complex care needs. They will use Miro or similar tools to collect themes and document the discussion. An example product of this phase could be a journey map showing how the patient, providers, and healthcare system interact. Participants will identify central issues that arose in their discussion.

The second sprint (diverge) will start with reflection on the ideas generated in the first sprint to ensure common understanding of the themes. Then participants will brainstorm conceptual designs, tools, and ecosystems to address issues and challenges identified in the first sprint. Participants will evaluate these ideas based on how well they will meet the complex needs they identified.

In the third sprint (decide and prototype), they will expand and refine ideas from the second sprint. They will throw out some design ideas and combine others together to form an ecosystem. During the share and tell session, the participants will discuss how this ecosystem will address the complex care needs they identified.

We will conclude with reflection and discussion of key questions, themes and recommendations for future work. The workshop organizers will facilitate each design sprint, lasting 40 minutes. After the workshop, we will use thematic analysis to analyze the data generated through workshop activities. Results will inform post-workshop activities.

5 POST-WORKSHOP PLANS

We will invite participants to write an Interactions paper discussing an agenda for HCI Research on complex health needs. The paper will be based on the workshop, including the discussions among participants in groups and themes that arise during the sprints. We also will ask participants about their interest in additional activities, such as a shared platform for continued discussion, new collaborations, and grant proposals. We also have interest and buy-in from the journal Interacting with Computers to compile a special issue on this topic.

6 CALL FOR PARTICIPATION

The goal of this workshop is to explore how an ecosystems perspective can reveal opportunities to support the management of complex health needs. During the workshop we will share our experiences and perspectives on complex care through an ecosystems lens, engage in a series of hands-on activities to imagine better support for complex needs, and collectively generate an agenda for future research in this area. We invite submissions of short papers (2-4 pages, plus references) or abstracts (300 words). Submissions are due February 24, 2022. Format submissions according to the single column ACM template (https://www.acm.org/publications/taps/word-template-workflow) and email them to complexhealth.chi@gmail.com. Submissions should focus on complex health needs, technology ecosystems, and related topics. We recommend reviewing the questions in the Workshop Goals section for guidance. Submissions may discuss ongoing research projects or past research experiences, or may include literature reviews, theoretical perspectives, or position statements. Submissions will be juried by the organizers. Accepted submissions will be posted on our website (https://complexhealthchi.wordpress.com). At least one author of each accepted submission must attend the workshop, and workshop participants must register for the workshop and at least one day of the conference. We plan to support hybrid participation

from remote and in-person attendees. If you have questions about submission, please contact complexhealth.chi@gmail.com.

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