

Designing for and Reflecting upon Resilience in Health and Wellbeing

Xinning Gui

College of Information Sciences and
Technology, Pennsylvania State
University
State College, PA, USA
xinninggui@psu.edu

Yuhan Luo

Department of Computer Science,
City University of Hong Kong
Hong Kong SAR, China
yuhanluo@cityu.edu.hk

Xianghua (Sharon) Ding

School of Computing Science,
University of Glasgow
Glasgow, UK
xianghua.ding@gmail.com

Saeed Abdullah

College of Information Sciences and
Technology, Pennsylvania State
University
State College, PA, USA
saeed@psu.edu

Emma Dixon

School of Computing, Clemson
University
Clemson, SC, USA
eschare@g.clemson.edu

Shaowen Bardzell

College of Information Sciences and
Technology, Pennsylvania State
University
State College, PA, USA
sbardzell@psu.edu

ABSTRACT

Resilience has been a long-standing theme in HCI research and design. However, prior work has different conceptualizations of resilience, tackles resilience at different scales, and focuses on resilience as the ability to adapt to adversity. This one-day workshop will bring together HCI researchers, interaction designers, health-care professionals, healthcare service users, and carepartners to critically reflect upon the epistemological stances on resilience and foreground the notion of resilience in health and wellbeing research. Our workshop themes include: 1) reflecting upon the diverse conceptualizations of resilience; 2) designing for resilience from a social justice perspective; 3) designing for multi-stakeholder resilience for individuals, families, communities, and society.

CCS CONCEPTS

- **Human-centered computing** → **HCI design and evaluation methods; Interaction design theory, concepts and paradigms;**
- **Applied computing** → **Health informatics.**

KEYWORDS

Resilience, Health and Wellbeing, Social Justice

ACM Reference Format:

Xinning Gui, Yuhan Luo, Xianghua (Sharon) Ding, Saeed Abdullah, Emma Dixon, and Shaowen Bardzell. 2023. Designing for and Reflecting upon Resilience in Health and Wellbeing. In *Designing Interactive Systems Conference (DIS Companion '23)*, July 10–14, 2023, Pittsburgh, PA, USA. ACM, New York, NY, USA, 3 pages. <https://doi.org/10.1145/3563703.3591456>

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than the author(s) must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from permissions@acm.org.

Designing Interactive Systems Conference 2023 (DIS '23), July 10–14, 2023, Pittsburgh, PA
© 2023 Copyright held by the owner/author(s). Publication rights licensed to ACM.
ACM ISBN 978-1-4503-9898-5/23/07...\$15.00
<https://doi.org/10.1145/3563703.3591456>

1 INTRODUCTION

Resilience, usually defined as the ability to adapt to adversity [8], is a critical component of health technology design [12]. Prior research has shown that patients with terminal illnesses can benefit from personal resilience to keep faith and improve quality of life [20]; carepartners with strengthened resilience are less likely to experience emotional distress while providing care [18]. In HCI, there has been a significant amount of work (e.g., [1, 2, 6, 7, 10, 13, 16, 19, 21, 22, 24]) on designing for resilience in health and wellbeing, although some of the work may not directly use the term “resilience”. This line of research primarily concerns individuals’ adaptive practices in the face of adversity and how technology design can support stressful situations such as chronic illness, carepartner burden, mental health struggles, health infrastructural breakdown, and public health crises such as the COVID-19 pandemic.

However, the approach towards resilience could go far beyond individual terms. For example, rather than merely focusing on individual adaptability, we may ask what creates adversity in the first place and how researchers can approach related issues. Different conceptualizations of resilience warrant a broader discussion and critical reflection on how we approach designing for resilience, considering that such differences in the conceptualizations could lead to the use of different methodologies [5].

To broaden and deepen our understanding of and design for resilience in health and wellbeing, this workshop will bring together researchers from diverse methodological, theoretical, and topical backgrounds to identify and characterize the research space situated at the intersection of human-computer interaction, health informatics, and design research, to form meaningful conversations across disciplinary contexts, and to collectively envision a resilient health and wellbeing research agenda.

2 MOTIVATION AND WORKSHOP THEMES

In this section, we outline our workshop themes and articulate the motivation for each theme.

2.1 Reflecting on the Diverse Conceptualizations of Resilience in Health and Wellbeing

Reflecting on existing HCI work on understanding and designing for resilience in health and wellbeing, we have observed different conceptualizations of resilience. While some research treats resilience as a personal trait, others consider it a dynamic and ongoing process of adapting to conditions. For instance, Vigil-Hayes et al. [23] emphasized emotional resilience as an individual trait and sought to design a culturally centered, gamification-based behavioral health intervention for Native American and Alaska Native adolescents to support their emotional resilience development. Sin et al. [19] examined older adults' resilience as an individual capacity in response to COVID-19 pandemic. They documented how older adults adopted new technologies, improved their digital skills, and engaged in online activities to adapt to the pandemic. In contrast, Vyas and Dillahunt [24], in their study of low SES people's resilience practices, viewed resilience as "an ongoing, dynamic process" that reflects how people with low SES experience adversity in their daily lives and find ways to cope with it. Similarly, Karusala et al. [10] studied community health workers' resilient practices in dealing with missing and delayed payments. They also took "a process-oriented perspective" on resilience to examine how resilient efforts unfolded.

In addition, some researchers have adopted a wider ecological notion of resilience in broader person-environment (e.g., neighborhoods, policies) interactions [8]. For example, Tachtler et al. [21, 22] adopted the perspective of a social-ecological model of resilience when aiming to design technology to support unaccompanied migrant youth's mental health resilience. They underlined the value of "designing resilience promotion from an ecological rather than an individual approach" as a social-ecological model of resilience could help specify "different interactions, attributions, and interplays," and highlight relevant factors in unaccompanied migrant youth's mental health resilience at different levels (e.g., bio-, micro-, and macro-levels) which helps identify pathways for technical interventions to promote resilience.

The workshop is open to these epistemological stances and beyond. The ultimate goal is not to prioritize one over another, but to characterize, contextualize, and historicize them in their respective intellectual traditions, which paves the way for community building and collective identity formation.

2.2 Beyond Adaptation: Designing for Resilience From a Social Justice Perspective

Existing HCI research primarily considers *resilience* as adaptation to adversity. However, such a perspective may be limited as it does not include "any potential to alter aspects of the wider adversity context" [8]. From a social justice perspective, many adversities are caused by a wider adverse context in which inequality and social disadvantages are embedded. Responsibility lies with governments and policymakers who shape the wider socio-economic context [8]. Therefore, it may be more imperative to try to build people's capacity to adapt to adversity than to challenge the inequitable structure of society and accept health inequality [8]. For instance, health service failures could cause "forced engagement," where

patients and their carepartners have no choice but to exert their efforts to obtain adequate healthcare [6]. In this case, increasing people's resilience in navigating fragmented healthcare systems overlooks the political economy of the healthcare industry that is highly profitable but still fails to deliver satisfactory care[6].

Beyond understanding how individuals cope with adversity, there has been a call to challenge the structures that create adversity, and to push a new wave of resilience research incorporating social justice and activism [8]. We propose that HCI researchers and designers working on health resilience join this call and brainstorm how we could empower people, groups, and communities to challenge their adverse contexts. For example, how can we empower individuals to gain more control over the events that determine their health and wellbeing in the first place?

Pivoting from the adaption-oriented view of resilience, this workshop takes a structural and critical look at adversity. As such, adversity and resilience serve as a point of departure for a broader conversation on building a more just, equitable, and resilient society and designing sound computing technologies that harmonize with this goal.

2.3 From Individual Resilience to Multi-Stakeholder Resilience at Different Scales

The ultimate goal of the healthcare system is to preserve and restore good health, enabling people to live a high-quality life in society. In some circumstances, people can independently manage their health through self-monitoring, self-diagnosis, and self-care [14]; in other cases, the process of providing healthcare often involves multiple stakeholders, including family members, carepartners, clinicians, and medical institutions in addition to the health service users [7, 15]. In this light, the design of healthcare technologies can be centered around "resilient-selves" that focuses on supporting individuals' autonomy or "resilient care networks" that accounts for multiple stakeholders and their relationships.

Furthermore, resilience and associated interventions can occur at different scales, from individual and family, to community and broader societal levels [9]. Existing HCI research on resilience in health and illness has investigated various scales of resilience such as individual resilience (e.g., [1]), community resilience [11, 13], and family resilience [16]. The different scales of resilience are also related to how we perceive the magnitude and root causes of adversity. For instance, healthcare can fail at different scales, from self-care to socio-technical infrastructure. Correspondingly, design interventions should take place at every level.

In this workshop, we welcome discussion related to any of the following topics: Designing for individual resilience (e.g., psychological resilience, physical resilience, resilience for special groups such as children, older adults, people with disabilities); Designing for resilient care support systems (e.g., self-tracking and other systems/tools for self-care); Designing for multi-stakeholder resilient networks (e.g., the network of carepartners/family, clinicians, social workers, patients themselves); Designing for healthcare infrastructure resilience (e.g., local and national healthcare infrastructure). In sum, the workshop takes a multi-stakeholder, multi-scale view

of resilience. We seek both to explicate the problem space and to envision possible (un)design approaches.

3 WORKSHOP GOALS AND OUTCOMES

Although there have been relevant workshops in HCI venues, including a CSCW 2021 workshop [3] on socially expressive technology design for personal enhancement of mental health resilience, a CHI 2019 workshop [4] on patients and carepartners' infrastructuring work, and a CHI 2022 workshop [17] on designing ecosystems to support the management of complex health needs (e.g., rare diseases), they differ from ours in scope and themes. Our workshop has several unique goals and anticipated outcomes:

- Setting a research and design agenda that envisions the future directions in supporting resilience in health and wellbeing with social justice and activism;
- Articulating stakeholder groups in the enactment or confinement of resilience in health and wellbeing;
- Identifying existing constraints, challenges, and design opportunities for resilience at different scales;
- Forming a community of researchers who share similar interests in understanding and designing for resilience in health and wellbeing.

4 CALL FOR PARTICIPATION

We invite researchers, interaction designers, health service users, carepartners, and healthcare practitioners to join our workshop to discuss, reflect upon, and brainstorm ways to design for resilience in health and wellbeing at various scales. Through unpacking the current practices and challenges people face when navigating the increasingly complex healthcare systems, reflecting on current conceptualizations and design efforts around resilience in health and wellbeing, and envisioning how to design for resilience from a social justice perspective, this workshop will set a research agenda that reimagines future directions for supporting resilience in health with social justice and activism.

We welcome submissions of abstracts (300-500 words) or short papers (2-4 pages, plus references) that are related to resilience in health and wellbeing. Topics include but are not limited to individual, family, group, and community resilience in coping with health conditions and health service breakdowns; technology design for resilience building and activism in health and wellbeing; theoretical perspectives on resilience in health and wellbeing. We recommend reviewing the Workshop Themes section for reference. Submissions may be work-in-progress or past research projects, autoethnography, position statements, literature reviews, and case studies.

REFERENCES

- [1] Sam Addison Ankenbauer and Alex Jiahong Lu. 2021. Navigating the "Glimmer of Hope": Challenges and Resilience among U.S. Older Adults in Seeking COVID-19 Vaccination. *CSCW '21: Companion Publication of the 2021 Conference on Computer Supported Cooperative Work and Social Computing*, 10–13. <https://doi.org/10.1145/3462204.3481768>
- [2] Laima Augustaitis, Leland A Merrill, Kristi E Gamarel, and Oliver L Haimson. 2021. Online transgender health information seeking: facilitators, barriers, and future directions. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–14.
- [3] Antje Budde, Mark Chignell, and Jamy Li. 2021. artech: Performance and Embodiment in Technology for Resilience and Mental Health. In *Companion Publication of the 2021 Conference on Computer Supported Cooperative Work and Social Computing*. 310–314.
- [4] Yunan Chen, Nervo Verdezoto, Xinning Gui, Xiaojuan Ma, Claus Bossen, Naveen Bagalkot, Valeria Herskovic, and Bernd Ploderer. 2019. Unpacking the infrastructuring work of patients and caregivers around the world. In *Extended abstracts of the 2019 CHI conference on human factors in computing systems*. 1–8.
- [5] Rachel Dias, Raquel Luiza Santos, Maria Fernanda Barroso de Sousa, Marcela Moreira Lima Nogueira, Bianca Torres, Tatiana Belfort, and Marcia Cristina Nascimento Dourado. 2015. Resilience of caregivers of people with dementia: a systematic review of biological and psychosocial determinants. *Trends in psychiatry and psychotherapy* 37 (2015), 12–19.
- [6] Xinning Gui and Yunan Chen. 2019. Making healthcare infrastructure work: Unpacking the infrastructuring work of individuals. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. 1–14.
- [7] Xinning Gui, Yunan Chen, and Kathleen H Pine. 2018. Navigating the Healthcare Service "Black Box" Individual Competence and Fragmented System. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW (2018), 1–26.
- [8] Angie Hart, Emily Gagnon, Suna Eryigit-Madzwamuse, Josh Cameron, Kay Aranda, Anne Rathbone, and Becky Heaver. 2016. Uniting resilience research and practice with an inequalities approach. *Sage Open* 6, 4 (2016), 2158244016682477.
- [9] Gail Hornor. 2017. Resilience. *Journal of pediatric health care* 31, 3 (2017), 384–390.
- [10] Naveena Karusala, Isaac Holeman, and Richard Anderson. 2019. Engaging identity, assets, and constraints in designing for resilience. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (2019), 1–23.
- [11] Elizabeth Kazunas, Michael S Klinkman, and Mark S Ackerman. 2019. Precarious interventions: Designing for ecologies of care. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (2019), 1–27.
- [12] Geun Myun Kim, Ji Young Lim, Eun Joo Kim, and Seung-Min Park. 2019. Resilience of patients with chronic diseases: A systematic review. *Health & social care in the community* 27, 4 (2019), 797–807.
- [13] Tiffany Knearem, Jeongwon Jo, Chun-Hua Tsai, and John M Carroll. 2022. Making community beliefs and capacities visible through care-mongering during covid-19. *Proceedings of the ACM on Human-Computer Interaction* 6, GROUP (2022), 1–19.
- [14] Yuhuan Luo. 2021. Designing Multimodal Self-Tracking Technologies to Promote Data Capture and Self-Reflection. In *Companion Publication of the 2021 ACM Designing Interactive Systems Conference*. 11–15.
- [15] Yuhuan Luo, Peiyi Liu, and Eun Kyoung Choe. 2019. Co-Designing food trackers with dietitians: Identifying design opportunities for food tracker customization. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. 1–13.
- [16] Sarah Nikkhah, Akash Uday Rode, Neha Kulkarni, Priyanjali Mittal, Emily Mueller, and Andrew Miller. 2022. Designing for Families as Adaptive Systems: Collaborative Emotional Support and Resilience in the Children's Hospital. In *CHI Conference on Human Factors in Computing Systems Extended Abstracts*. 1–8.
- [17] Tom Ongwere, Andrew BL Berry, Clara Caldeira, Rosa I Arriaga, Amid Ayobi, Eleanor R Burgess, Kay Connelly, Patricia Franklin, Andrew D Miller, Aehong Min, et al. 2022. Challenges, Tensions, and Opportunities in Designing Ecosystems to Support the Management of Complex Health Needs. In *CHI Conference on Human Factors in Computing Systems Extended Abstracts*. 1–7.
- [18] Carolina Palacio G, Alicia Krikorian, María José Gómez-Romero, and Joaquín T Limonero. 2020. Resilience in caregivers: A systematic review. *American Journal of Hospice and Palliative Medicine* 37, 8 (2020), 648–658.
- [19] Frances Sin, Sophie Berger, Ig-Jae Kim, and Dongwook Yoon. 2021. Digital social interaction in older adults during the COVID-19 pandemic. *Proceedings of the ACM on Human-Computer Interaction* 5, CSCW2 (2021), 1–20.
- [20] Joao Paulo Consentino Solano, Amanda Gomes da Silva, Ivan Agurtov Soares, Hazem Adel Ashmawi, and Joaquim Edson Vieira. 2016. Resilience and hope during advanced disease: a pilot study with metastatic colorectal cancer patients. *BMC palliative care* 15, 1 (2016), 1–8.
- [21] Franziska Tachtler, Toni Michel, Petr Slovák, and Geraldine Fitzpatrick. 2020. Supporting the Supporters of Unaccompanied Migrant Youth: Designing for Social-ecological Resilience. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–14.
- [22] Franziska Tachtler, Reem Talhouk, Toni Michel, Petr Slovak, and Geraldine Fitzpatrick. 2021. Unaccompanied migrant youth and mental health technologies: A social-ecological approach to understanding and designing. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. 1–19.
- [23] Morgan Vigil-Hayes, Ann Futterman Collier, Giovanni Castillo, Davona Blackhorse, Nikole Awbery, and John-Paul Abraham. 2019. Designing a mobile game that develops emotional resiliency in indian country. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems*. 1–6.
- [24] Dhaval Vyas and Tawanna Dillahunt. 2017. Everyday resilience: Supporting resilient strategies among low socioeconomic status communities. *Proceedings of the ACM on Human-Computer Interaction* 1, CSCW (2017), 1–21.