

# Designing Towards Healing

## Leveraging Lived Experience in Technology-Mediated Care

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“feeling butterflies in my stomach”

“Ah, a lot of work, pretty stressed, you know how it goes”

“Tired”

“Heartbroken”

“What does it feel like to not feel good?”

“Feeling blue”

“My chest feels tight”

“I am having a lot of tension”

“I just read R2’s review...”

“I just can’t do anything anymore, I’m so depressed”

Our identities influence how we understand how we are feeling, how we express how we are feeling, as well as the kind of care that we need and are able to receive.

Hearing people’s lived experiences and narratives around distress is paramount in understanding needs and designing with care (compared to a top-down approach).

### How can we leverage lived experience to design with care

### How can we design towards pathways to healing?

#### Cross-Cultural Differences on Online Mental Health Forums

- Defined a “moment of change” as an instance in which an individual who is seeking support later expresses that they are feeling better
- When dividing based on national identity, the prediction task failed, confirming past work on idioms of distress from medical anthropology
- People from minority groups mentioned their countries more (even when anonymous), used lower levels of clinical language, and were more likely to be supported by/support people from the same country (16x - 65x).
- Consistent on other mental health forums (7Cups)
- Greater cultural homophily in threads that had a moment of change

*Pruksachatkun, Yada, Sachin R. Pendse, and Amit Sharma. "Moments of change: Analyzing peer-based cognitive support in online mental health forums." In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems, pp. 1-13. 2019.*

*Pendse, Sachin R., Kate Niederhoffer, and Amit Sharma. "Cross-Cultural Differences in the Use of Online Mental Health Support Forums." Proceedings of the ACM on Human-Computer Interaction 3, no. CSCW (2019): 1-29.*

#### “Like Shock Absorbers”

- Language defines access – mismatches are common due to strategy
- People often use helplines as a form of mental health care due to lack of accessible and affordable healthcare – (elderly) volunteers study and sometimes lightly break the rules to help.
- Volunteers have to negotiate the needs of callers, which are often not what the helpline explicitly is supposed to offer (e.g. public television and farmers)
- In India (unlike other contexts), volunteers noted their love of repeat callers, as volunteers can form a relationship with callers akin to a therapeutic alliance (Horvath et al. 1993) and know that the person has not died.

*Pendse, Sachin R., Faisal M. Lalani, Munmun De Choudhury, Amit Sharma, and Neha Kumar. "Like Shock Absorbers": Understanding the Human Infrastructures of Technology-Mediated Mental Health Support. In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems, pp. 1-14. 2020.*

#### “Can I Not Be Suicidal on a Sunday?”

- Participants didn't know what to expect before calling (often finding out about helplines via Google’s recommended number or via friends), and were concerned about active (non-consensual) rescue
- Most helplines did not work for participants --- trial-and-error process
- Participants who had poor experiences couldn't leave any feedback, concerned about confidentiality being violated with bad feedback
- Class, caste, gender identity, and sexuality influenced how people understood and used (or explicitly decided not to use) the helplines

*Pendse, Sachin R., Amit Sharma, Aditya Vashistha, Munmun De Choudhury, and Neha Kumar. "Can I Not Be Suicidal on a Sunday?": Understanding Technology-Mediated Pathways to Mental Health Support. In Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems, pp. 1-16. 2021.*