

# “Can I Not Be Suicidal on a Sunday?”: Understanding Technology-Mediated Pathways to Mental Health Support

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## ABSTRACT

Individuals in distress adopt varied pathways in pursuit of care that aligns with their individual needs. Prior work has established that the first resource an individual leverages can influence later care and recovery, but less is understood about how the *design* of a point of care might interact with subsequent pathways to care. We investigate how the design of the Indian mental health helpline system interacts with complex sociocultural factors to marginalize caller needs. We draw on interviews with 18 helpline stakeholders, including individuals who have engaged with helplines in the past, shedding light on how they navigate both technological and structural barriers in pursuit of relief. Finally, we use a design justice framework rooted in Amartya Sen’s conceptualization of realization-focused justice to discuss implications and present recommendations towards the design of technology-mediated points of mental health support.

## CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**; *User studies*.

## KEYWORDS

Mental Health; India; Pathways to Care; Realization-Focused Justice; Social Justice; Technology-Mediated Mental Health Support

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## 1 INTRODUCTION

**[Content Warning]** “I didn’t even care to see what helpline it was—I just found the number and kept on dialing, kept on calling them. But they were not picking up, so I went back to read what was written in the description. It said it was Monday to Saturday. And I remember, it was Sunday. 9PM-ish. So I was like, what the fuck? Are you kidding me? Can I not be suicidal on a Sunday? And I didn’t know about this before—I thought all the helplines are 24/7.”—*Juhi*

In the wake of tragedy or crisis, telephone-based helplines aim to quickly connect people to information [33, 74] and care [42]. For those in immense and often unexpected distress, the accessibility [62, 119] and experience of using [96, 115] these technology-mediated crisis resources can make the difference between life and death [1]. With the intention of providing support to callers experiencing severe mental distress or suicidal ideation through volunteer-based telephone counseling [65], mental health helplines are a simple and pervasive [15, 17, 47, 107] form of technology-mediated mental health support (TMMHS) [87] system. The care that mental health helplines provide is not limited to crisis support however. Volunteers have observed that callers will also use helplines as a substitute for formal mental health care or to ask for information about mental health [65, 87]. Due to their ubiquitous nature, mental health helplines can also function as an initial point of access to care [11]. Through facilitating connections with broader mental health services, mental health helplines can potentially be the first step on a pathway to further psychiatric care [59, 77].

Our experience of mental health, including how we understand [52] and express [78] how we are feeling to others, is fundamentally tied to the societies that we belong to and the identities that we hold [86]. Social norms [57], laws [66], and our relation to institutions created to provide for or govern our well-being [73] all have an influence on what kinds of care we believe is accessible to us, and how we go about finding care. The utilization of “points of first care” [11] can thus be as diverse as helplines [18, 59], a referral by a general practitioner [21], or religious and traditional healers [14]. In these interactions, later engagements with care resources are influenced by the institutions that assess and validate distress, or what Goldberg and Huxley conceptualize as a “pathway to psychiatric care” [40]. The pathways available to individuals in

distress are influenced by societal factors, including marginalization, stigma, and oppression.

It is well understood that interactions with the “point of first contact” [11] with care can influence an individual’s later engagements with care, but little work has been done to understand how interactions with *technology-mediated* points of access to care influence an individual’s experiences with a broader pathway to care, particularly given the influence of societal factors at each point of care. Though past work has understood how helplines do satisfy caller needs [24, 36, 64], little research has been done to understand how helplines may *not* accommodate caller needs, and who is excluded from accessing care via helplines. The Mental Health Care Act of 2017 [31] affirms that every person [61] in India has the right to access (government-funded) mental healthcare—however, little work has been done to understand where existing resources, such as helplines, may not be doing justice to people’s care needs.

In this work, we ask: **how does the design of the Indian mental health helpline system interact with societal factors to marginalize callers’ individual, identity-based needs?** We focus our investigation around India given the diversity of forms of care practiced [8, 91], the immense resource constraints associated with delivering care [3, 28, 31, 50], and the role that helplines play in understanding and meeting care needs in this ecosystem [87, 109]. Past work in this space has focused on how helpline volunteers in India negotiate and meet the needs of callers [87, 108], but little work has been done to understand the experiences of callers, including their discovery and experiences with care both through and outside of the helpline system. Given the structural and individual nature of mental health [86], understanding these experiences is important when considering how existing resources might meet or marginalize the needs of people in distress, and towards facilitating more equitable and potentially technology-mediated points of access to care.

Through interviews with 18 helpline stakeholders, including individuals who have engaged with helplines in the past, we investigate how callers discover and use helplines, the barriers they face when using them, and the pathways they take to find care that works for them. We then use a design justice [23] approach to understand how callers’ needs are not met as a result of both the interface of the helpline system and overarching societal factors, such as stigma, class, and identity-based prejudices. We find that callers frequently call helplines in a state of immediate distress after trying other options for care, and are faced with an opaque system that often does not meet their individual needs at each step of their quest for care. Stemming from the stigma associated with mental health concerns, callers have little frame of reference for what the experience of calling a helpline might look like, and also little opportunity to safely hold helplines accountable when experiences are lacking or harmful.

This work makes multiple contributions. First, leveraging Costanza-Chock’s design justice framework [23], we highlight the lived experiences of marginalized individuals who have found their needs not met by institutions created to meet those needs. Second, engaging Sen’s delineation between transcendental institutional justice (*niti*) and experienced, realization-focused justice (*nyaya*) [102], we foreground the role of systemic factors that shape how people access and pursue their pathways to care. Finally, we leverage Sen’s

framework to provide recommendations for a more just helpline system, and discuss the implications of this work for the design and evaluation of TMMHS systems.

**Privacy and Ethics:** This study was approved by the the Georgia Institute of Technology and Microsoft Research ethics and institutional review boards. Further information on approaches taken by the researchers to protect participant privacy, safety, and accurately represent the lived experiences of participants without compromising anonymity can be found in Section 4.1. In discussing the experiences that helpline callers have in seeking and engaging with care, this paper presents graphic descriptions of self-harm, suicidal ideation, and sexual harassment. Following Pendse et al.’s [87] suggested use of content warnings, we add a bolded **CW** tag before any quotes that have graphic descriptions of suicide or self-harm.

## 2 RELATED WORK

Understanding whether care institutions successfully provide for the care to the most marginalized necessitates a deep exploration of the lived experiences of those who engage with care, as well as a deep consideration of the structural factors that influence access to care. In this work, we engage with a design justice [23] framework to understand how structural factors and the design of the helpline system interact to prevent realized, *experienced* justice [102] from being done to the needs of those in intense distress at each point of the process of accessing care through helplines.

### 2.1 Pathways to Care

The pathway to psychiatric care model was first proposed by Goldberg and Huxley [40] to map out the process by which people come to be defined as mentally ill and receive escalating forms of mental health care. In their original framework, Goldberg and Huxley theorized that one could escalate the level of care received based on progressive referrals from health professionals [45]. In Goldberg and Huxley’s conceptualization, this pathway began with community health professionals and ended with inpatient admission to a hospital. Power to determine the legitimacy and mode of care for distress, including whether care necessitated specialist care from a psychiatrist, was thus put in the hands of referring health professionals [34, 45]. This power differential can be problematic, as health professionals, often trained to identify Western symptoms of mental illness, can often miss culturally bound symptoms [78]. As a result, those with the same psychiatric illness may proceed along a pathway to care in drastically different ways [11]. As a consequence of the power differential between the institution providing care and the person in distress, the potential pathway of care that an individual may have access to is dependent on the level to which institutions on that pathway validate the identity of the individual and their understanding of their distress. Systemic and institutional biases against these identity-based factors may prevent justice from being done to the care needs of those in distress, and potentially even make mental health concerns worse, such as observed in the case of systemic racism against minorities [75].

In addition, pathways to care can be non-linear and bidirectional [11, 39], and the forms of care that help people attain relief can be provided by a diverse set of institutions, including traditional healers, mental health helplines [87], community-based care [49] or

even digital mental health applications [48, 114]. In India in particular, work on pathways to care has focused around examinations of the amount of time associated with gaining psychiatric care given a more pervasive point of first contact with care, such as practitioners of Western medicine, religious healers, and specialized mental health professionals [32, 56]. Little work has been done to understand what alternative pathways to care might look like outside of a deterministic progression from informal to psychiatric care.

In this work, we build on past work to analyze the factors that influence how people in distress find care. We analyze how structural factors and the design of the helpline system have an influence on whose care needs are met and how those needs are met at each point of an individual's pathway to care. Given the influence of these structural factors, we call for a greater consideration of social justice at each point of care when using a "pathways to care" approach to understand individuals' care needs and design new approaches to aid.

## 2.2 Technology-Mediated Points of Access to Care

Bhui and Bhugra [11] call the starting point of a pathway to care the "point of first contact." These points of first contact can have an influence on people's engagements with mental health care. For example, several studies in the UK have shown that as a result of systemic racism among law enforcement [75], Black individuals are more likely than white individuals to come into contact with mental health services via police [70], and more likely to later be involuntarily and forcibly hospitalized [69]. As noted by Morgan et al. [71], it is theorized that constant and successive negative interactions with a systemically racist mental healthcare system are the reason for what Morgan et al. dub a "vicious cycle of negative experiences, coercion, disengagement, [and] relapse" [71, 98].

The first point of contact with information about mental health and potentially avenues to care can often be technologically mediated, such as through Internet searches [13]. While past work has explored the usability of mental health technologies through user reviews for mental health apps [82], various user evaluations of their interface [114], how they might integrate within clinical workflows [76], including their impact on the therapeutic alliance [41], little work has been done to understand how the affordances and interactions associated with the design of a particular TMMHS system have an influence on later engagements with mental health care.

Rather, the success of a TMMHS system has often been associated with measurements of immediate and short-term relief [44, 116] as opposed to looking more holistically at how experiences with the technology might influence later pathways to care. Looking specifically at crisis helplines in India, Pendse et al. [87] explored the different ways that mental health helpline volunteers come to understand their role on the helpline and carry out that role to help callers while maintaining self-care practices. We build upon this past work, elevating the lived experiences of callers as they interact with the helpline system that helpline volunteers support. In particular, we articulate and contextualize difficulties callers have experienced in connecting with helplines [67, 79].

## 2.3 Realization-Focused Justice in Providing Care

Questions around how sociotechnical systems can support or exacerbate individual needs have become a growing field of study in Human-Computer Interaction (HCI). In particular, recent work [23, 29] in HCI has emphasized the importance of a greater sensitivity to how sociotechnical systems might amplify the oppression of those who are most marginalized [22, 25], with this sensitivity embodied through orienting design practices towards the pursuit of social justice. In their work on social justice oriented design, Dombrowski et al. [29] acknowledge the existence of diverse and vibrant orientations of thinking about the practice of social justice. This conceptualization of social justice is rooted in a multidimensional [58] approach to Rawls's framework of distributive justice [94], an approach emphasizing "justice as fairness," embodied through "the assessment of a system based on the perspectives of those subject to its control." However, as Dombrowski et al. note [29], the term "social justice" simply functions as a mechanism for thinking about how power and privilege shape our interactions with each other, with institutions, and with technology. Other researchers in HCI have used different conceptualizations of justice as a mechanism to analyze privilege and power, including Young's emphasis on relational justice in the context of oppression [55, 118], indigenous frameworks around restorative justice [97, 120], and disability justice [9, 89]. Others have proposed a closer integration of conceptualizations of justice into design frameworks, including Asad's work describing methodological practices prefiguring a more equitable relationship between researchers and non-researchers [4] and the work of the Design Justice Network [23].

To analyze the different ways that societal factors interact with the design of the helpline systems to marginalize callers needs, we engage a design justice approach [23]. In their approach to evaluate technological systems, Costanza-Chock [23] notes the importance of "centering the voices of those who are directly impacted by the outcomes of the design process" in working to understand how the design and interface of the system might marginalize certain users' needs by design, or reproduce societal inequities. Rather than looking broadly at the existence of resources and systems, Costanza-Chock urges us to look directly at whether these resources and systems do justice to people's individual needs. Similarly, in the fields of clinical psychology and psychiatry, researchers have recently noted the critical need to include the voices of those with lived experience with mental health in the design of interventions [43], with a focus on those with the most marginalized identities [117]. However, Costanza-Chock does not tie the design justice paradigm to any specific historical conception of justice, noting more broadly the importance of centering stakeholder and community perspectives when determining whether a system might be doing justice to those it serves.

As noted in prior HCI research [29, 55] and beyond [99, 102], though Rawls advocates for justice to be done from the perspective of those most marginalized [94], Rawls's notions of distributive justice root themselves in an ideal form of justice as achieved via *institutions*, and overlook community [88] and relational [118] forms of oppression and justice. In his critique of Rawls's distributive justice framework, Sen [102] draws on study of pre-colonial Indian

jurisprudence to describe the concepts of *niti* and *nyaya*: the difference between institutional justice and realization-focused justice. In Sen’s conceptualization, while *niti* refers to the procedural and legal ways that justice may be enacted, *nyaya* refers to “the world that actually emerges, not just the institutions or rules we happen to have” [102] and the realization of the justice promoted by the institutions and laws created via *niti*. Sen makes it clear that this form of realization-focused justice requires a two-fold effort—both the creation of institutions that support the practice of an ideal justice, and specific attention and action around the removal of injustices from the perspective of those whose needs are not met. In prior HCI scholarship, Mudliar [72] has engaged Sen’s conceptualization of *niti* and *nyaya* to illustrate challenges around biometric scanning for food entitlements in India. Padmanabhan and Abraham [83] have also acknowledged the role of *niti* and *nyaya* in shaping fairer machine learning algorithms.

Our findings align well with Sen’s framework around justice. The Indian Mental Health Care Act of 2017 provides that every person in India has a right to access mental healthcare funded by the government [31]. Additionally, many mental health helpline numbers exist for individuals in distress in India [79, 87]. However, as we discuss below, our detailed interviews with those who have engaged with the helpline system find that these resources are often not accessible to callers. This occurs both as a result of the specific user experience associated with the helpline system as well as the structural factors that limit open discussion and access around mental health resources. While justice may be done with regards to *niti*-oriented institutional justice, many in distress do not find their needs met at different points on their pathway to care.

In this work, we leverage Sen’s definitions of justice when engaging with a design justice approach to understand how the design of the helplines interacts with societal factors to keep callers from experiencing *nyaya*-oriented realized justice towards their immediate care needs. As we suggest design implications for a more inclusive and usable helpline system, we pay special attention to the kind of world that callers emphasize would accommodate their mental health needs outside of simply their immediate interactions with the affordances of the helpline. Inspired by a *nyaya*-oriented framework, we orient our recommendations towards that world.

### 3 MENTAL HEALTHCARE IN INDIA

India has a long history of community-based care for mental health concerns [113], and helplines fit into the broader historical pattern of care being sought from diverse points of contact and mediums [54]. Prior to European colonization of the Indian subcontinent, care for mental health concerns in India was framed by community healers as being a part of overall health, with little separation between body and mind [54]. It is likely that the only institutional care that individuals would receive was tied to religious institutions or hospices devoted broadly to health [20, 53, 85]. However, colonization resulted in the creation of the first asylums in India [54] as well as the globalization of the asylum system in the 19th century [20]. Institutions formed under this colonial paradigm were primarily created for the use of British soldiers and settlers [53, 103],

and framed those experiencing mental illness as being fundamentally dangerous to society as a justification for segregation of those experiencing mental illness [104].

By the 1940s, spurred by Indian commissions surveying poor treatment at these institutions [51, 54], new policies, outpatient institutions, and journals devoted to the treatment and care of those with mental illness were created and iterated on over the course of the second half of the 20th century [20, 51, 80]. These new policies centered both medical *and* community forms of care, with one notable policy example being the National Mental Health Programme, instituted in 1982 [84]. Community-centered forms of care have been noted as being particularly important in India’s mental health policies given the necessity of a shared understanding of illness between care provider and those in distress for effective care [86, 91]. Identity-based factors, such as stigma [105] and caste [93], can have an influence on the kinds of care people find effective and can access. The latest of these policies, the Mental Health Care Act of 2017, affirms the Indian government’s commitment to providing mental healthcare to every person in India [31].

Past research [87, 108] has described how mental health helplines in India are also primarily community-led initiatives, funded by NGOs and other philanthropic organizations, and are often started by individuals who have experienced loss from suicide or have had lived experience with suicidal ideation [87]. Helplines broadly frame themselves as facilitating non-judgmental emotional support [108] and creating a safe space for people to express their feelings [87]. However, as a result of a resource-constrained mental healthcare system, helplines often function as conduits to the broader mental healthcare system, with volunteers providing recommendations and referrals to other points of care [87].

## 4 METHOD

### 4.1 Study Design and Recruitment

The goal of this study was to understand the perceptions and experiences that individuals in India have around mental health helplines. We conducted semi-structured interviews with 18 participants from diverse backgrounds and areas of India. Participants were recruited via a combination of purposive [60] and snowball sampling [101], online depression support groups on WhatsApp and Telegram, and Twitter. Due to commonly held beliefs that helplines in India “don’t get through” [67, 79], we broadened our selection criteria to include those we conceptualize as helpline stakeholders—individuals who expressed perceptions or opinions about the state of mental health helplines in India, explicitly chose to not call helplines in a state of distress, and wanted to speak to us given our research topic. Interviews were conducted until we had reached a point of saturation [12]. Interviews were done over WhatsApp and Telegram during The Coronavirus Disease 2019 (COVID-19) pandemic [81], all done over the course of June 2020.

Through these interviews, we aimed to elevate the lived experiences participants had interacting with the helpline system and the broader Indian mental health system while in a state of intense distress. Towards this goal of understanding specific participant needs and experiences, questions posed to participants were centered around their perceptions and experiences using helplines in India, with a particular focus around their understanding of gaps

**Table 1: This table includes the demographic information of all participants. All names used are pseudonyms.**

Name	Gender Identity (self-described)	Age	Location	Formal Mental Health Diagnoses (self-described)	Connected to a helpline?
Ashok	Male	31	Mumbai	Depression	No
Bhumika	Female	29	Delhi	Clinical Depression	No
Subhasini	Cisgender Female	23	Madurai	No specific diagnosis disclosed	Yes
Farah	Female	26	Not disclosed	No specific diagnosis disclosed	Yes
Vikram	Male	26	Bangalore	No specific diagnosis disclosed	Did not try
Diya	Female	26	Madurai	Anxiety Disorder	Yes
Suraj	Male	Undisclosed	Undisclosed	No specific diagnosis disclosed	No
Sandhya	Woman	27	Pune	Borderline Bipolar Disorder	Yes
Juhi	Female	25	Bangalore	Depression	No
Damini	Cisgender Woman	23	Mumbai	No specific diagnosis disclosed	No
Donna	Transwoman	29	Navi Mumbai, from West Bengal	No specific diagnosis disclosed	Did not try
Kiran	Female	21	Mumbai	Borderline Personality Disorder	Yes
Anu	Nonbinary	23	Mumbai	Depression	Did not try
Aashna	Cis Woman	21	Undisclosed	No specific diagnosis disclosed	Yes
Kashika	Female	22	Undisclosed	No specific diagnosis disclosed	Yes
Mitali	Female	22	Delhi	No specific diagnosis disclosed	No
Jayashri	Female	33	Bangalore	Psychosomatic Disorder	Yes
Priya	Female	24	Undisclosed	Depression and Anxiety	Did not try

and unmet needs in their experience and their strategies to fill those gaps. This often led to recommendations from participants for how to improve the service of helplines. Questions included “When did you last call a helpline?”, “How did you find information about helplines?”, and “In an ideal world, what would an experience with helplines look like?” When quoting participants, we use the exact language that they used to describe their relation to their suicidal ideation<sup>1</sup>.

Details about the diversity of our sample and the demographics of individual participants are in Table 1. Participants had a wide range with regards to gender identity and locality, and tended to be young, located in large urban areas, at a high level of formal education, and female. Though diverse, this sample was likely not representative of all helpline callers, and we discuss some of the limitations of this sample in our Discussion. As noted, 14 participants attempted to call mental health helplines at some point, and of those, 8 were able to get successfully connected with one. To accommodate anxiety that several participants had associated with phone calls, interviews were done via the medium participants felt most comfortable with. For 14 participants, this was over a phone call, and for 4 participants, this was over synchronous chat.

**Participant Safety and Risk Mitigation Measures:** This study was approved by the Georgia Institute of Technology and Microsoft Research ethics and institutional review boards (IRBs). To ensure participant safety, as a part of the consent process, participants were clearly told that they are free to end the interview at any time. Post-interview, participants were also debriefed on the content of their interview and sent the accepted draft version of the paper, and were told to let the interviewer know if there are parts of their disclosure that felt too sensitive or deanonymizing for publication. Several participants noted that they greatly appreciated this transparency in our research methods. Additionally, following Draucker et al. [30], after particularly overwhelming questions (such as those

on past suicidal ideation or self-harm), participants were briefly asked after answering if they felt okay and still wanted to continue the interview. To protect privacy, all names used for participants are culturally appropriate pseudonyms.

## 4.2 Analysis

To analyze the data, we used an inductive and iterative approach guided by our considerations of how helplines may not do justice to the care needs of participants and who may be excluded from making use of their services. We developed codes around caller perceptions and experiences, and then manually coded answers to interview questions to find themes. Through an “open coding” process, we organized specific language and concepts described by participants into broader themes using an interpretative qualitative analysis of interview transcripts [63]. Codes included “discomfort from friends after disclosing suicidal ideation,” “jokes about helpline not working,” “recommendation: helpline referral to therapists,” and “illness-centered framing of distress.” The broader themes that arose from this coding process focused around societal factors that influenced the participant’s mental health (such as their family or their income) or factors related to the helpline interface (such as connections between the helpline and other means of care). In our findings, we describe the role of these factors in how participants understood and used helplines.

**Positionality:** Our commitment to studying mental health helplines is part of a longer-term engagement of understanding how mental health support is made available to people from various backgrounds via technology-mediated means in India. All authors on this paper are of Indian origin, currently living in both India and the United States, and include authors with lived experience of mental illness.

## 5 FINDINGS

We now walk through the stages of helpline usage, and examine how both the experience of the helpline system and societal factors influence how and whether callers’ needs are met at each stage. We find that at every step of the pathway from feeling distress to finding

<sup>1</sup>In many cases, participants described their desire to “commit suicide.” This wording is widely not used to describe suicide in print as a result of the accompanying stigma associated with the word “commit” [7]. We still use it when quoting participants as part of our aim to represent participants’ lived experiences and understandings of their suicidal ideation as accurately as possible.

helpline-based care, the interface underlying the helpline system and complex societal factors together work to marginalize caller needs, with little potential for participants to hold helplines accountable or advocate for their specific needs. Though the helpline system is framed as an institution facilitating justice towards the needs of those in distress, as a result of its design and societal factors, the system was unable to offer experienced, *realized* justice or *nyaya* to the needs of callers at each step of care.

## 5.1 Finding Helplines

Participants reported being struck with intense distress or suicidal ideation, and looking for resources to relieve that distress. Finding other resources unavailable, such as friends or therapists, the mental health helpline was seen as the only available resource that might extinguish intense and short-lived distress.

**5.1.1** *“I need something. I need someone.”* Of the 14 participants who chose to call a helpline when in intense distress, only 8 were able to get connected with one. Participants described diverse avenues to helpline discovery, with varying levels of awareness of the existence and function of helplines before discovery. They reported learning about the helpline through information about mental health resources provided by their college, from friends who had more information on which helplines worked from lived experience, from seeing lists of suicide helplines in India in the past, and from searching means of suicide or for resources on Google.

Most participants saw helplines as their last resort after other parts of their support network were found to be unavailable. Mitali described how she felt like she was violating a boundary if she called her therapist outside of their scheduled sessions. Bhumika described her experience of being forced to resort to helplines late at night, noting that she had already tried calling 5-10 friends prior to dialing helpline numbers and found that no one was available to answer her call. Similarly, Sandhya noted she started to believe that she was “disturbing people” when she called people while feeling suicidal or feeling an urge to self-harm, including her therapist.

Initiatives around suicide prevention and mental health in India have emphasized the importance of speaking openly to friends when suicidal [112]. However, in practice, speaking openly about feeling suicidal ended up being discouraging and exhausting for participants. Juhi described how her desire to talk to friends when suicidal often conflicted with her friends’ discomfort with open discussions around mental health, dissuading her from speaking openly to them. In her experience, friends would become “*defensive*” or “*alert*” when she mentioned that she was feeling suicidal to them, and she often found herself suddenly centering *their* needs, telling them “*don’t worry, I won’t die*” to alleviate their sudden panic. Similarly, Mitali described how her friends had actually asked her to stop talking to them about her mental health out of a sense of helplessness (CW):

“If I tell a friend that I feel like self-harming, he gets very uncomfortable with it. And so I respect his space and do not bring it up. Which means I cannot really talk about my mental health because both of those things happen very often. I am very often suicidal and very often, I feel like self-harming. [...] So I do

not really talk about my mental health with anyone.”—  
Mitali

Friends could also be hard to find for those experiencing continued severe mental distress. Mitali described how difficult it was to “*make new friends when you don’t have the energy to do even basic chores.*” Without friends sensitive to her mental health and willing to support her, helplines became one way that Mitali could potentially find a support network.

A majority of participants described calling during night, with several participants even noting that their feelings of distress were heightened at night. Additionally, night was noted by participants as a good time to call the helplines. Kiran explained how most live with an extended family that might not be open to conversations about mental health, and as a result, “*night is the only time when people can call up. When everybody else is asleep.*”

Participants who went to colleges that promoted the use of helpline numbers had a greater awareness of the existence of mental health helplines, and felt that helplines provided a different and less stigmatizing form of support than friends could provide. Farah described the process of asking friends for a helpline number (as opposed to direct support) when in a state of distress:

“I need an independent solution then and there, I don’t need sympathy. My friends give me sympathy and love and affection. (laughs) I need a tool. I need something. I need someone. I don’t want them to think of me like that. I’m okay being vulnerable with them, and my friends, especially my close friends, would know about my problems and my situation and all. But I want somebody who is far away. I don’t want to be identified by these experiences that I have every once in a while.”—Farah

Not all participants were aware of the existence of mental health helplines before calling, and were surprised to see Google recommend a mental health helpline number to them. Jayashri described her surprise (CW):

“So one night, it was really bad and I was crying for a very long time and I just wanted to kill myself and I actually—well, what I first Googled was “how to commit suicide.” [...] And then in the results, a lot of helpline numbers came. It was probably the first suggestion that came, open helplines *kar ke* [as displayed based on my query], you get these small prioritized results on Google. [...] Up until the moment I Googled for “how to commit suicide,” I had no idea that helplines even existed.”—Jayashri

In several different countries, including India, Google will recommend a helpline notice when an individual searches for a means of suicide or even simply, as Jayashri did, “how to commit suicide” [17]. Kiran drew a connection between Google’s recommendations and the helplines that people share with each other and on social media in her college, noting that Aasra, the helpline recommended at the time<sup>2</sup> was also most discussed by people in her circles.

<sup>2</sup>Over the course of fieldwork in June 2020, the helpline recommended by Google within its notice was actually changed from Aasra [2] to iCALL [46], potentially as a result of significant mention of a failure to get connected with Aasra by different news publications [67, 79]

Before calling, participants had little frame of reference for what their experience calling a helpline might be like, and called out of a sense of “*What do I have to lose?*” (Ashok) and wanting some form of relief in a state of imminent crisis. Subhasini similarly described her decision process as “[*not wanting*] to take this pain anymore” and thinking “*whatever advice they give, if I listen to it, then probably I will feel better.*” Mental health helplines in India do not frame themselves as being resources for solely those who are suicidal [87], but this is how they were still understood by participants, as highly sought emergency resources. Juhi described being conscientious of this fact when deciding whether to call or not, taking special care to make sure that her call did not displace other callers who may have more severe needs. Juhi viewed calling if she was not suicidal as “*wasting the time*” of volunteers.

As participants noted, dozens of helplines exist for the benefit of those in distress, but few central ways to find these numbers. While different organizations are doing their part by creating aggregated lists of numbers or by recommending numbers in search results, callers still have little understanding of what these helplines are for. Like Juhi, most assume they are only for those who are feeling suicidal, and proceed to not call even when they are feeling a lower level of distress that helplines institutionally aim to support.

**5.1.2 “The trust factor.”** For those who had some awareness of the existence of helplines before calling, trust factored strongly into which list of helplines participants decided to leverage when searching for help. Participants looked for websites and resources that showed that helplines were willing to accommodate and support their needs that were often identity-based. Diya described how counselors in her college encouraged students to call a recommended helpline if the counselors were unavailable, and as a result, that recommended helpline had what Diya dubbed “the trust factor.” Diya elaborated on this concept, noting that she would not have felt comfortable calling a random number without some sense of how her information would be stored or used by volunteers. Similarly, Damini described intentionally looking for resources that suited her identity-based needs:

“I looked at the Alt Story<sup>3</sup> website and there was sort of, like, it said that they care about your social location, they care about your caste, they care about—it sort of gave off the vibe. Plus, the person who started Alt Story before, we were friends.”—*Damini*

Damini also noted that helplines provided in Google results could often be from other countries (most commonly the United States), and thus irrelevant and non-usable for Indian callers. As a result, helpline aggregation websites from Indian organizations were most commonly used and trusted, particularly those endorsed by celebrities [35] or associated with initiatives around gender identity [110, 111] or community care [5].

Other participants did not feel too strongly about where the number was coming from, noting that in a state of distress, they

were not paying too much attention to information about the number and were looking for a source of relief. As Juhi noted about her decision process in finding a helpline:

“Because if you...if you are in that space, you don’t even want to know the name of that suicide helpline, it’s like just give me a fucking number and I’ll just call it. Give me something that will help.”—*Juhi*

**5.1.3 “And then they’ll call my parents.”** In these interactions, participants had little idea of where their data was stored or how it was used when they called the helplines. For some, trust that a helpline would not disclose identifying data from the calls is why they picked the helpline that they ended up calling. Others believed that helplines were a generally benevolent institution, and did not fear misuse of their data. Only Farah and Diya had considered where their information might be stored as well as what kind of data might be stored before they called a helpline. Similarly, as a result of yet unimplemented laws around confidentiality [31], some participants were nervous about the disclosure of information from calls or to mental health professionals, and were not aware of whether information about the confidentiality policy of helplines existed. Though helplines claim to be confidential, participants described breaches of privacy in other mental health resources in their lives. In one example, Kiran described a situation in which her school counselor disclosed information about her sessions to her college professors. Similarly, Kashika described calling a helpline out of a fear that her therapist would tell her mother she was feeling suicidal given past experiences.

Participants were particularly unsure of what happens when a person who calls expresses a tangible plan or high motivation to end their life. In particular, they expressed a lot of fear that the police or an ambulance would be called, which dissuaded them from calling. Juhi described feeling concerned that helpline volunteers might manipulate her given her vulnerable mental state to call her parents or some other person without her best interests in mind: “[*They may call*] ambulance, and police, and all of this. And then, and then they’ll call my parents and then fuck my life.”

When asked how the helplines would find out Juhi’s parents’ contact information, she described that they may take advantage of her distressed mental state and encourage her to call a friend or family member even if she would not have wanted to. The fear of family involvement was also mentioned by other participants. Sandhya described a situation in which she was planning on attempting suicide, and a friend contacted her family, which resulted in a clinician coming to her home. Sandhya felt uncomfortable with the power differential between her and the clinician sent to her home, and described her desire for an experience in which a peer “[*sat*] down and [*talked*] to [*her*] like an adult”. Institutional forms of care, such as escalation via an ambulance or a clinician, were seen as demeaning, potentially dangerous, or fearful by participants.

Media portrayals of people calling crisis lines when distressed had a strong influence on participant ideas around what happens when someone calls a mental health helpline, including perceptions about potential levels of police involvement. Juhi described seeing Western movies in which people called “911”<sup>4</sup> when feeling suicidal,

<sup>3</sup>The Alt Story is a website that does education and awareness work around mental health, and provides counseling services that are “affordable, intersectional feminist, trauma-informed, kink-aware, queer-affirmative and caste aware” in Bengaluru, Mumbai, and remotely [110].

<sup>4</sup>India’s emergency numbers are 100 and 112 [68].

and seeing a police and ambulance intervene: *“All these assumptions about what happens with police and ambulance came from that ‘911’ call only. Like whatever I see in movies, you know?”*

Participants expressed beliefs that even if the police were called, they would likely not be very helpful. Jayashri described how the experiences of a friend reporting their abuser to the police went nowhere, with police officers saying *“Ah, we also do that at home, it’s not a big deal”* and being unwilling to submit a First Information Report (FIR), and drew parallels to her friend’s experience to justify her doubt in the helpfulness of potential police involvement. Similarly, Damini expressed a strong belief that an involvement of the police in mental health crises would affect a caller’s mental health negatively, particularly given that suicide was only decriminalized in India in 2017 [31]. Rather than doing justice to caller needs, the involvement of the police was seen as a fearful possibility that could stigmatize callers.

Helpline policies tend to be very careful about the privacy of callers, and do not call any external party or authorities unless there is consent from the caller [87], even choosing to not intervene when a caller has begun the process of ending their life. However, participants made their decision to call as if these policies did not exist, as they were unaware of their existence. The individual agency that could be protected by these institutional policies was not realized by participants as a result of little available information on these policies or their implications for callers.

## 5.2 Using Helplines

Though participants expected to quickly receive support after calling a helpline, their real experiences were drastically different. Callers described a trial-and-error process of iterating through helpline numbers, a process that often forced callers to set their specific care needs aside and make do with whatever helpline they were able to connect to.

**5.2.1 “The phone just keeps ringing”.** Participants who found a list of numbers online dialed the first number they saw without looking at much information about the helpline. They shared their expectation that helplines would be available 24/7 and that they would be connected to a volunteer immediately based on representations of crisis helplines in media. Unfortunately, it was also often the case those helplines that claimed to be 24/7 actually did not end up being 24/7, including the helpline recommended by Google when participants searched means of suicide. As Kiran noted, though Aasra claimed to be a 24/7 helpline number, she was unable to connect with them, and at times, it would even say *“the number is not in use anymore”*. Ashok and Mitali described similar experiences with Aasra, noting that they had called as a result of it being recommended by Google’s helpline notice as a 24/7 helpline, but then being met with a busy tone (Mitali) or a process in which the line *“just kept on ringing”* (Ashok).

The constant and unending ringing associated with the helplines was cited by several participants as a particular source of additional anxiety, lending the expectation that someone might eventually pick up. As Farah described:

*“It just keeps ringing and it is so horrible because (laughs) it just makes you so ANXIOUS (laughs). Yeah, it just keeps ringing until it stops. You call and you*

*just keep praying, please pick up, PLEASE pick up. (laughs) Because every second is so long, right? It just feels like eternity. And you can’t just put your phone away and wait for it like a normal call. Or get back to them in 5 minutes. No, you need help right THEN and you start to literally count the number of times it rings. And then at the end it will say that all of the people are busy, get in touch with us in some time or something like that.”—Farah*

Three participants even cited the unending ringing as a source of comic relief, laughing at the fact that even the helplines would not pick up their call after they had exhausted their other resources. Bhumika joked, *“Well, if I need to feel suicidal, I’ll make sure to fit it during that time”* and Farah joked that the helpline not answering her call was *“the teatime joke of the day.”* While participants made light of the situation to cope, they also noted that this experience of their call for help not being answered made them feel *“worthless”* or *“hopeless,”* and frustrated with how helplines frame themselves.

For those who did make the decision to try to call, this process could be frustrating and tiring enough to dissuade someone from trying again. Suraj described how the exhaustion might dissuade a potential caller (CW): *“A person who isn’t in a good state isn’t going to try 10-20 phone numbers, it isn’t like he is looking for fixing an error in their code to keep digging. If they are in a such a bad state of mind, they won’t try much.”* For participants who chose to not use a helpline when in distress, the perception that no one would pick up was a main reason they were dissuaded. Anu noted that when someone is *“at the edge”* and is met with no response or the perpetual ring, it *“pushes you more towards the edge.”* This urgency combined with a lack of responsiveness also formed the main reason for why Anu had consciously chosen to not try a helpline when experiencing intense distress. Similarly, Vikram decided to not call helplines when in distress due to his preference for a more consistent method of getting support, such as through text messages with an office provided counseling service. However, some participants felt that calling a helpline might end up being valuable if they were connected, and still proceeded to attempt dialing.

There are dozens of different helplines in India [67, 79, 87], but callers are still unable to reach one when they most need help. Although institutional justice may be done through the existence of these helplines, justice is not realized by those who most need it.

**5.2.2 “Going through the motions”.** Given the possibility of an endless ring from any one individual number, to get connected, participants understood that their best chance at success when interfacing with the helpline system was to cast a wide net. Participants described a process of progressively trying each number they could find until the line was connected. Only two participants were connected with a helpline on the first try.

Farah described this process of urgently needing to call a helpline for her mother who was staying with her during the pandemic-related lockdown and was in distress:

*“So my boyfriend was also with me, and he was calling up helplines as well, and I was also calling up helplines as well, because we both had meetings to get back to at work and thought ‘well, this is a thing that needs to be taken care of.’ But [my mother] was unwell, and I*



could see it—so unwell, not eating, not drinking, and I felt so horrible. But yeah, so we called these helplines and my boyfriend finally got across to somebody and I said ‘Give me the phone.’”—*Farah*

After being connected, participants expected their interactions with the helplines to be a one-time interaction that happened with a volunteer. As a result, participants described being surprised when helplines called them back to check in, a common practice among Indian helplines that is done with caller consent [87]. Subhasini noted her strong appreciation for these follow-ups, noting that it was “refreshing” to have someone check in on her with some familiarity with “what [she was] going through and how [she was] doing” to ensure that Subhasini was doing well. Other participants noted the importance of making a deep connection with the human on the other side of the line, and wishing that they could consistently talk to the same volunteer to avoid the need to repeat their story with each call. This paralleled similar desires expressed by Indian helpline volunteers in Pendse et al.’s [87] study of volunteer motivations and experiences on Indian mental health helplines.

Several participants described storing the contacts of helplines that they knew that they were able to get connected to in their phones for future use. Kiran imagined she might need a helpline in the future, and thus proactively called each helpline she could find when she was feeling okay to figure out which helplines worked consistently and which ones did not, and saved the ones that did work. Even for those who were not connected, the existence of the helpline itself functioned as a safety net that almost all participants felt they could rely on if they did feel suicidal again, even if the helpline did not work. Participants felt like they had agency over their mental health through the existence of helplines as a resource they could potentially rely on when in distress. Subhasini noted that she felt particularly safe knowing that even after she ended the call, there was someone she could try to call and connect with in the future if she needed it. Damini noted that traditional metrics for measuring success (such as number of calls connected or helpline availability) might be inaccurate at measuring success.

“It’s not always like, the correct sort of metric to think that, if someone who has called a helpline and has not gone through suicide, it doesn’t necessarily mean that the helpline worked. Because when you are in a mental state where you’ve decided to call the helpline, you’ve already crossed a hurdle, because you’ve already gained some amount of control over your emotions at that point. So I think just going through the motions of trying to call a helpline calmed me down to an extent.”—*Damini*

Damini described that if there was a centralized helpline number, some kind of AI-powered Interactive Voice Response (IVR) system that guided callers through grounded exercises while they waited to be connected “*might just calm you down in that moment when you are feeling utterly helpless*” by interrupting thought spirals. Juhi also noted that those who store the numbers or install mental health related apps may never call and simply look at the resources as a moment of pause as they process their thoughts and ponder their next steps. Participants described a broad gap between the intended

justice as provided for by helpline organizations, and how justice was realized by participants.

5.2.3 “*I just wanted some temporary relief*”. Participants had differing expectations and experiences with regards to the care needs the helplines framed themselves as being able to accommodate, and the care needs helplines were actually able to accommodate. Participants expressed that what made the helplines unique was having a space to be able to vent out their feelings and cry freely, to be able to participate in “*moderated grounding*” (Farah) that helped extinguish panic attacks, exercises to help a caller realize that they may be in the midst of a “*thought spiral*” (Damini, Kiran). For participants, success was framed as any guided exercise or provided space that extinguished urges to end one’s life or self-harm. When asked what a successful interaction looked like, Sandhya responded (CW):

“I did not hurt myself. I mean, that was the whole goal of the call. And that was accomplished for that particular day. I won’t say that that one call completely healed me and I never hurt myself again. That was not the case, but that was also not even the intention of the call.”—*Sandhya*

Similarly, Diya noted a clear division in support from therapy versus support from helplines:

“I knew that this probably wouldn’t be—this wouldn’t be therapy. She’s not going to help me through all the issues that led to this moment of my life. But I just wanted some temporary relief, and I got that.”—*Diya*

Participants cited the goal of a helpline interaction not necessarily being to return to a “a happy state,” but for the helpline volunteer to guide them to “clarity and a sense of normal” (Farah) in which they had some level of agency over their state of crisis. However, several participants noted that they had little recourse for when helpline experiences especially did not help to meet these goals, and indicated that they wanted a mechanism to provide feedback on the experience that they had. Ashok described an experience where after a poor experience, he tried to call the helpline back to provide feedback, and being unable to be connected, he messaged the helpline’s Facebook page:

“So they have a Facebook page, and from what I remember, they were quite regular about posting about how you can reach out to us and all of that stuff. And I wrote them a message on Facebook—initially a politer one. [...] But yeah, I did send a second message after trying again on the phone. And I said ‘All right guys, thankfully, I managed to make a call to a friend so I am ok. But now I have tried you a number of times and I even messaged you on Facebook, you never replied. So this is not a way to run a hotline. So just take down your goddamn number.’”—*Ashok*

The helpline’s page responded with an adversarial response, noting that he had “*no business telling us what to do*” and apologizing that he was unable to be connected. Ashok never called a helpline again, but noted that a simpler way to provide feedback to helpline volunteers would be useful. In this situation, the caller was forced to use his personal Facebook profile to provide feedback.

This method of providing feedback was particularly dangerous, as it often required the participants to deanonymize themselves when attempting to hold institutions accountable. Jayashri described her experience trying to provide feedback after an experience in which she was feeling especially suicidal and was met with volunteers harassing her through making “*lewd jokes*” and asking her about her “*family life*”:

“I just wanted someone to answer the call, and actually tell them that I had this experience with your helpline and I really want to give bad feedback for this person. [...] After that, my friends told me, why do you want to take it there, especially if they escalate it to some level. Your anonymity will be compromised if you try to do this. Especially, that’s the thing—they say all this stuff about anonymity, but they have the number that I am calling from. It can be quite damaging, let it go, you’ve already had quite a bit to deal with.”—*Jayashri*

Given the non-linear nature of mental health recovery, participants also recognized that immediate post-call feedback may not reflect their overall perspectives on the support that the helpline offered. Participants recommended that feedback happen in some automated way after some time had passed since the interaction with helpline volunteers. Participants cited times of 12 hours to several days, noting that time to reflect on the experience of having called and processing their experience on the helpline gave them a better idea of how the experience could have been improved. Text messages were cited as one relatively welcome way for participants to provide feedback.

Given that participant needs in a moment of crisis were different based on the level and type of distress they were feeling, participants were reluctant to give feedback on the volunteer’s strategies themselves, preferring instead to provide feedback on the interface itself or on how the interaction made them feel. As Diya noted:

“The one thing that I would be okay sharing is whether I’d want to call again or not, but I don’t think I will be able to tell them ‘here, you didn’t do well’ or ‘here, you could do this better.’ Because, I don’t know, maybe another person in the same situation if they’d been answered that way [by the volunteer], maybe they would have gotten most of what they wanted.”—*Diya*

A good metric for feedback suggested by several participants was summarized well by Ashok—a simple question asking the caller whether the helpline made them feel “*safe*.”

Helpline policies are influenced both by the parent organization [100], as well as the individual centers that administer care [87]. These policies (*niti*, or institutional justice) are designed towards helping callers, but in the implementation of these policies (*nyaya*, or realized justice), there are many potential points of failure or risks of harm on the callers’ end. Callers also have no means of recourse to address these failures. This happens due to a combination of the stigma associated with speaking openly about calling a helpline, and an inability to reach the helplines, let alone to offer feedback. This can be particularly harmful given that helplines serve some of the most marginalized.

### 5.3 Pathways to Future Care

When helplines were unavailable, participants found it difficult to find other resources that could help them in their time of need. These resource constraints were often societal, influenced by perspectives on the identities the participant held (such as their sexual orientation), the kind of community-based and caste-aware care they needed, or stigma against mental illness in general. These systemic injustices kept participants from both being able to find support for their needs from helplines, and from being able to find sufficient alternative care elsewhere.

**5.3.1 “Depression as a rich person’s problem”.** Helplines were seen by participants as a stopgap measure in moments of severe crisis, and several participants noted that they had used other mental health care resources before, during, and after calling helplines. Of the 18 participants that we interviewed, 14 had seen a therapist at some point, 3 were not able to, and 1 did not disclose. However, most had only seen a therapist in the past for a small number of sessions, and were not consistently seeing a therapist at the time of interview. Additionally, 3 had exclusively seen the counselor at their college, and not sought outside resources for their mental health.

For those whose first experience with mental health resources were helplines, their experience with helplines had a strong impact on their later willingness to engage with mental health resources, both including calling the helpline again as well as exploring more formal care. Damini described how after a bad experience with a helpline, her friend was unwilling to try any other mental health resource until Damini herself booked an appointment for her friend.

“So there’s one friend who refused to go for therapy after having a bad experience [with helplines]—this is someone with whom I’ve had to engage for about a year to get her to just, let her know that all mental health help is not the same. [...] So yeah eventually I had to tell her, ‘you know, let me book a session for you.’ So it’s like, that’s the level of pursuing you have to do when someone is put off by one bad experience with a helpline. [...] So if I call a helpline one time, and I’m feeling suicidal, and it doesn’t work? In the future, calling the helplines? I might skip that step.”—*Damini*

Similarly, after a poor experience calling a helpline, Jayashri was never motivated to seek professional help for mental health concerns ever again, even when recommended to do so by a doctor. She later found support and relief from a rekindled relationship with her mother.

Poor experiences influenced whether people felt comfortable calling the helpline again. For example, Diya noted that she had thought about calling helplines again, but that “*the feeling of not having gotten enough out of it remained with [her]*” and she preferred to talk to a friend or a therapist when in intense distress. For many others, when helplines did not work, therapy was found desirable but not affordable. Ashok noted that, as a result of the ₹1500-2000<sup>5</sup> per session cost of therapy, most in India see “*depression as a rich person’s problem*,” with therapy being something that the average

<sup>5</sup>This is approximately \$20-30 (USD). As of 2019, average annual income per capita is estimated by the Indian government to be ₹96,563 [90], or approximately \$1,274 (USD).

person “*simply cannot afford.*” Juhi illustrated her search for affordable care and its inaccessibility given her financial situation and locality, noting that she would enthusiastically make use of “*scholarship for mental health.*”

“If somebody could like, give me a scholarship for mental health, I would totally take it. Like, please I need it, it’s so bad. Problem was that my parents didn’t know about it, so that’s why it was a financial issue for me. Mostly, I knew that I can afford one or two sessions. I was not sure who I can go to in [hometown] because I tried, but I was not comfortable about privacy.”—*Juhi*

As Juhi noted, due to the inaccessibility of other forms of care, online resources were a temporary and inconsistent measure that she attempted to make use of. However, online resources were rarely cited as being enough when a participant was in need. Anu noted that they had tried YourDost and 7Cups and found them lacking, determining that they were not “*at the stage such that non-professional help would have helped.*”

Even after participants were able to find a therapist, it could be the case that the therapist was not sensitive to their needs. Priya described how she attempted to see several different therapists, but when she started to describe her experience of being queer, the (male) therapists doubted her, asking her uncomfortable questions such as whether she was sure she was queer or if she had ever had sex with a man. She did not try therapy after those poor experiences, instead relying on friends when in times of distress. Similarly, Kiran described how after a therapist had breached her privacy, Kiran’s mother traveled to her town and made appointments with 5–6 psychologists per day until Kiran had found a psychologist who was a good fit. Kiran acknowledged that the privilege of having parents who validated her mental health and were wealthy enough to spend money on it was what made it possible for her to keep trying therapists until she was able to find one who worked.

Participants who had one-off experiences with therapists described not necessarily feeling significantly better after 1–2 sessions, and recommended that helplines be able to make recommendations for effective therapists in the area of the caller. Suraj suggested that “*suggesting therapists near [the caller’s] area*” and “*taking feedback from [the caller]*” to make better recommendations for therapists might be a way for helplines to more effectively help people. Anu even noted that they had found their excellent and well-matched therapist through an online list of therapists recommended and aggregated by a mental health helpline. For several participants, helplines functioned as a complement to therapy, which they could call when their therapists were not available. Participants described later processing their experiences calling the helplines with therapists, teasing out the deeper causes of why they may have been in such intense distress when they called, and work towards healing.

5.3.2 “*So there has to be a fundamental structural change.*” Identity played a substantial role with regards to the kind of care participants desired from helplines. In several cases, these identity-based needs around mental health formed the reason why participants were not likely to use the helpline when in distress. All participants who were not cisgender men or male-identified expressed a gender preference with regards to the person giving care. These

preferences were rooted in the forms of care that they wanted to get, shared experiences, and avoiding potential harassment (Kiran, Jayashri) or “*slut-shaming*” from volunteers (Damini): “*Yeah, I would prefer talking to a woman definitely. Because talking to a man, we don’t always have good experiences with guys. That could be really triggering again.*”

Participants who were members of the LGBTQ community were also outspoken about the need for queer affirmative volunteers on the helpline calls, as well as information online indicating that the helpline was a safe place for callers who were queer. Damini noted the constant fear that queer people have of feeling judged when accessing resources, and noted that information online might encourage someone “*who is really worried about being judged.*” to call.

Participants were mixed on whether they thought there should be separate helplines for LGBTQ people in India as in other countries [88]. Several strongly believed that a separate helpline would help them feel safer with regards to the specific LGBTQ-related issues that they might want to discuss. Aashna noted that she would have felt “*a hundred times more scared about calling a helpline if [she] wanted to talk to [helplines] about my queerness.*” Other participants stressed that a separate helpline for members of the LGBTQ community might cause more of a reason for members of Indian society to see the LGBTQ population as a separate, stigmatized group. Anu noted that a different helpline felt like a “*[separation] on the basis of identity*” and that it would not “*normalize us from having these identities, or we exist, or these things happen.*” They noted that so long as the volunteer was able to actively listen without being judgmental or giving unsolicited advice, it could give those who are in distress “*a big space between yourself and the edge.*”

Participants advocated for more queer affirmative volunteers to staff the existing helplines, as well as devoting energy to making the helplines accessible past a ring of no return, before devoting energy to a queer-affirmative helpline. Anu (who identified as nonbinary and queer) called it a “*breather*” when a mental health professional was queer, and noted:

“And a lot of people from the community should be given opportunities to volunteer and work on these helplines. [...] Because a lot of times, the fear of judgment harms us and keeps us away. It is shrouded in shame and guilt. So it stops us from reaching out. [...] So when a psychiatrist, or therapist, or helpline is queer affirmative or from the community, that helps a lot. Like okay, people start to have hope. That there ARE people like me out there, people who have life figured out. That it’s not completely hopeless.”—*Anu*

Anu went on to note that societal changes were necessary to make the helplines more queer affirmative, past simply making a separate line or having more volunteers on the helpline who were queer: “*We should not be thrown in the shadows again. If people are sensitized about it and the stigma around it is reduced, that would help so much.*” Both Anu and Priya described how they relied on a community of often queer or LGBT-identified friends around them when they were feeling especially distressed. Priya characterized formal mental health care as administered by a stigmatizing and “*conservative*” society.

Donna, a member of an organization supporting Bahujan<sup>6</sup> mental health also described how the helpline system does not work for people from adivasi<sup>7</sup> backgrounds by enforcing a “medicalization” of distress rooted in “upper caste savarna”<sup>8</sup> notions of normality and ways of understanding mental health, as opposed to indigenous ones.

“So there has to be a fundamental structural change, that’s what I am talking about. We need to recognize the wisdom that is existing in the [indigenous] communities, how they look at mental health. Because even if we have a helpline specifically for tribals, but the mental health professionals are all savarna, again the diagnosis will still be the same, the level of understanding will still be the same.”—Donna

Donna urged for a greater consideration of the different ways caste and identity might impact the way a caller might want to be cared for, particularly those who might be multiply marginalized [19, 22, 25], such as someone who is Bahujan and queer. To accommodate these specific needs, Donna stressed the importance of having separate but “interwoven” resources for mental health. Donna also emphasized the importance of including modes of providing and receiving care not formally recognized as mental health care, citing the example of how their mother would talk about her life and family with other “sisters” in the neighborhood as a form of “therapeutic” relief from domestic violence.

5.3.3 “We can’t take anybody with a disorder”. Several participants had a sense of shame about calling helplines in a time of need. When Farah disclosed to the interviewer that she had called several helplines and the interviewer responded positively, she exclaimed “Oh, huh, I didn’t [tell you I had called several helplines] because I thought you’d freak out. Like ‘I didn’t want a freak for this, I wanted somebody with a one-time experience.’” Similarly, Subhasini felt embarrassed that she felt the need to call the helplines, given that she was a mental health professional.

Participants described this stigma having an influence on when and how they accessed helplines, such as making sure to call during night so their family members did not know they had called. Sandhya noted that her parents were “scared” of mental illness, seeing it as “something abnormal,” as she believed her parents “[didn’t belong] to a generation where these things don’t happen a lot.”

In some cases, this stigma also had a direct impact on the kinds of resources participants were able to access in a time of need. Kiran described how she had been denied help from an online chat resource on a helpline’s website as a result of her borderline personality disorder (BPD) diagnosis. When she asked for resources and therapists specific to those with BPD, she was met with the answer of “we can’t take anybody with a disorder” and “you’ll need to see a specialist.” Even with this stigma, participants still found

diagnoses validating and useful in explaining and normalizing their feelings. Kiran noted that she “loved” her BPD diagnosis.

Of the participants interviewed, 9 mentioned that they had been formally diagnosed with some form of mental health issue. Given a lack of access to institutions that could formally validate their lived experiences, participants also doubted the validity of what they were feeling, noting that even though they felt like what they were experiencing were “panic attacks,” they had never been formally diagnosed. In describing their distress during interviews, participants would describe a symptom, but make sure to add a caveat afterwards expressing their lack of confidence in using clinical terminology for what they were experiencing, having never seen a psychiatrist. Self-doubt in whether expressions of clinical distress could be considered valid were heard from both participants who had not been formally diagnosed with a mental health issue and those who had been formally diagnosed with a mental health issue.

## 6 DISCUSSION

Through investigating the lived experiences of callers, we found a key gap between how care was intended by those who support helplines, and how that same care was experienced in practice by those who needed it most. In particular, the institutional promise of a quickly accessible active listener was rarely successfully realized for participants, an injustice highlighting the gap between *niti* and *nyaya* in how helplines were understood and experienced by participants. Participants who needed help immediately were met with endless ringing, a lack of quickly accessible information about the helplines’ operating protocols or volunteers, and uncertainty over the ability of the helplines to provide non-judgmental care to those with marginalized identities. At each turn of a participant’s attempted pathway to care, the system intended to facilitate their care interacted with societal factors in making the specific needs of participants invisible. Individual factors (such as gender identity, sexual orientation, or level of distress) influenced the kinds of care that participants felt were accessible to them, and thus influenced where and how they looked for resources when in need. When attempting to access what they understood to be accessible care via the helpline system, barriers rooted in the design of the helpline system limited their ability to engage with the resource, and further influenced their future interactions with other forms of care. These intersections between individual needs, societal factors, and the design of the system make clear the need for researchers to deeply consider how structural factors create hurdles along an individual’s pathway to care.

We found that participant needs were not met even though the institutions to meet those needs existed, such as legal promises of accessible healthcare [31] and a diversity of resources. This suggests that the Rawlsian notion of solely approaching justice based on the existence of resources or institutions [94] is not enough. We thus follow Sen’s [102] two-fold approach of both centering the realized, experienced injustices by callers, and being conscientious of what a greater justice for those with mental health concerns might look like. We use Costanza-Chock’s design justice framework [23] to articulate the harms perpetuated by the intersections of helpline design and societal marginalization. We view each harm as an injustice, and make recommendations for what a more just helpline

<sup>6</sup>A label used by the participant and their organization to describe those who are part of historically lower caste and indigenous communities in India, including Dalits, Adivasis, OBCs, Pasmandas, Nomadic Tribes [26].

<sup>7</sup>Indigenous Indian

<sup>8</sup>*Savarna* literally means “part of the caste system” in Sanskrit, and is used to describe those who were historically placed within a caste as a part of the caste system, as opposed to being seen as invisible and existing below the institution of caste itself [37]. This term is often used to describe those with the privilege of being of a higher caste [92].

might look like from the callers' perspectives, drawing inspiration from Sen's recommendation of *removing injustices* [102].

- (1) **Signaling Wait Time:** While multiple helplines numbers are available and able to dialed by anyone with a phone, this availability does not translate to accessibility. Participants are often met with a perpetual ringing, a busy tone, or a notice that a line has been disconnected, and expressed a desire to better understand how long it might take before their needs are met. Low-cost systems that estimate and report the wait-time associated with matching a caller to an agent poised to answer their call have been used in other domains [38], and would be a welcome addition to the mental health helpline system. Additionally, if wait-times are particularly high, call-backs could be leveraged [10, 106] with caller consent. Automated follow-ups could text the caller asking how they are doing and recommend resources based on their response until the line is free for the caller.
- (2) **Intelligent Call Routing:** While several helplines framed themselves as accessible at any time, participants found that these lines were not accessible when they needed them most (such as at night). Participants operated assuming that some of these helplines would fail to work, and would begin a process of iteratively trying helplines till one worked. This process could easily be quickly automated and parallelized to save callers time and energy, and interactive IVR-based systems could potentially be used to walk participants through grounding exercises with their consent. Predictive modeling of caller behavior used to efficiently route callers to the most free center in other domains [6, 27] could also be leveraged here.
- (3) **Supporting Pathways to Care:** Though there are legal provisions for accessible mental health care in India [31], participants described the process of trying to find care outside of helplines quite difficult and expensive. Several participants recommended that there be linkages with other forms of care for those who want more consistent care than what helplines could provide. These linkages might look like a separate menu for callers that provides location-specific recommendations for affordable therapists endorsed by the helpline, or specific referrals to other helplines or resources, such as a helpline specific to gender identity or sexual orientation (with caller consent).
- (4) **Mechanisms for Feedback:** In cases when helplines did not help participants, participants had little means of being able to hold the institutions accountable. Potential feedback mechanisms based on participant recommendations might include a separate number in which callers can anonymously leave open-ended feedback, automated text messages that ask the participant to report how they feel after some period of time, or a simple post-call question of whether the call made the caller feel "safe."

As Costanza-Chock notes, simple improvements to make the design of a system more usable do not necessarily mean that the system is more accessible [23]. Sen notes that realization-focused justice means that justice must be experienced from the perspective of individuals in need [102]. For helplines to do justice to the needs

of those they serve, they must both be accessible and also *understood* as accessible, so callers can pursue the care that suits their needs rather than what care happens to be available. Drawing from disability justice [89], as part of a design justice approach, Costanza-Chock stresses the importance of analyzing how interlocking and intersecting societal systems influence who can and cannot access care that meets their needs. We thus make recommendations for helpline organizers and journalists to act towards destigmatizing the practice of calling helplines and making them more accessible to those most marginalized.

- (1) **Information about Calling Experience:** The policy of helplines is to actively listen to anyone who calls in distress. As a result of stigma around open expression of mental distress and care, there were few open narratives about the experience of calling a helpline, and participants had little idea of what to expect before they called. Participants believed that they could only call when exceptionally distressed, and decided not to call even when it might have benefited them. News articles about suicide often end with a mental health helpline number at the end in case information is triggering [16], and helpline numbers are often copied and shared across social media after crisis [95]. However, there is little information attached about what happens *after* one calls the helpline. Adding a short description of what kinds of distress are supported by helplines and what happens when someone calls would enable callers to make better decisions about what resource to reach out to when distressed.
- (2) **Communicating Safety and Agency:** Helplines frame their services as being accessible to all, regardless of background [87]. Participants still felt wary of calling the helplines through fears of the helplines calling the police without their consent or fears of being judged by helpline volunteers due to their sexual orientation. More information about the forms of care practiced on a helpline, including queer affirmative policies and the fact that Indian helplines do not involve the police in care [87], would help callers feel safer when calling and feel more open to discussing their unfiltered thoughts and emotions.
- (3) **Volunteer Backgrounds and Diversity:** Participants expressed how mental health professionals in their lives had discounted their sexual orientation or their modes of experiencing care, and noted that this was an institutional resulting from a lack of awareness or diversity by those who decide what care looks like, and for who it is practiced. Participants urged a greater diversity of volunteers on the helpline, both from queer and Bahujan backgrounds, and the creation of separate but *interwoven* resources for those who are marginalized. Helpline administrators could intentionally target recruitment to members of these communities, and incorporate their experiences when designing policies on how helpline counseling is conducted.

It is important to note that though discussions of identity-based marginalization did arise in our study, our sample of participants was predominantly urban, young, and at a high level of formal education. Sen characterizes the practice of justice as being one that combines work done towards the pursuit of an ideal world

(*niti*), and immediate work to correct injustice based on the lived experiences of those most impacted (*nyaya*). The individual and structural recommendations we make here might make care slightly more accessible, but are incremental steps towards social justice and care for those experiencing mental health concerns. Further work is needed to understand how individuals from other communities not sampled might be marginalized by the design of the helpline, societal factors, or at other points on their pathway to care.

## 7 CONCLUSION

In this work, through interviews with 18 callers and stakeholders, we explore how the interface associated with mental health helplines in India interacted with complex societal factors to marginalize individual caller needs. We investigate the different ways that helplines are perceived and used, and find significant technical and societal barriers to successful care. Through engaging with a design justice [23] approach to understand how caller needs are not met by the design of the helpline, rooting our analysis in Amartya Sen's ideas around realization-focused justice [102], we explore what a more just pathway to care that utilizes the helpline system might look like for callers.

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