Nurture: Assisted Pediatrics for Indian Parents

Neha Kumar  
Georgia Institute of Technology, USA  
neha.kumar@gatech.edu

Rajesh Chandwani  
Indian Institute of Management Ahmedabad, India  
rajeshc@iima.ac.in

Julie Kientz  
University of Washington, USA  
jkientz@uw.edu

ABSTRACT

Early detection of developmental and growth deviations enables early intervention so that children and parents suffer minimal irreversible physical and financial damage. In India however, pediatricians operate within acute time constraints that keep them from performing comprehensive developmental assessments for their patients. Parents’ lack of awareness regarding growth and development milestones further hinders early detection. Our paper contributes the design and evaluation of a probe that seeks to understand the needs of variously resource-constrained middle-class parents in India for monitoring their children’s growth, development, and immunization milestones. Our findings highlight the potential of mobile information-based applications to engage, assist, and empower Indian parents. In addition, we describe the affordances of a design process that originated amidst a richly resourced hackerspace organized to address the needs of under-resourced settings, and discuss the consequences of this process on our design.

CCS CONCEPTS
• Human-centered computing → Empirical studies in HCI;

KEYWORDS
Parenting; Children’s Health; Design; Hackerspaces; HCI4D

ACM Reference format:

1 INTRODUCTION

In India, approximately 22 million children are affected by developmental delays [27] that often go undetected or are detected late, at extensive cost to parents and irreversible damage to the child. In addition, 30% children do not adhere to immunization schedules [45], 40% are malnourished [44], and an estimated 7% suffer from obesity [35]. Growth and developmental issues, along with incomplete immunization, are the most prevalent preventable issues that contribute to child morbidity and mortality. Early detection of growth and developmental delays is critical for early intervention and minimizing physical and financial costs [30], and it depends on careful and continuous monitoring by pediatricians and/or parents. However, due to acute time constraints, pediatricians are frequently unable to perform complete comprehensive developmental assessment in routine pediatric visits [6]. Parents’ lack of information on growth and development monitoring further hinders early detection. In this paper, we contribute to a burgeoning body of mobile health (mHealth) research as we highlight the potential of mobile information-based applications to engage, assist, and empower urban middle-class Indian parents in ensuring the well-being of their babies.

Nurture is a mobile health (mHealth) application that we designed to enable Indian parents to monitor growth, development, and immunization milestones of their children between the ages of 0 and 2. As mobile phones become increasingly ubiquitous and smartphones more accessible, Nurture’s technology is well-positioned to target a large cross-section of India’s growing middle-class population. With the design and evaluation of Nurture, we are the first—to the best of our knowledge—to study the role that technology might play to support parents in their need for monitoring their children’s growth, development, and immunization in the Indian context. Here, we draw on the research contributed by Kientz et al. [22] and their follow-on work situated in the United States [43]. Targeting this problem for a different populace, as we discuss, brings up new sociocultural, infrastructural, and technological challenges; health behaviors and information-seeking practices are culturally situated, pediatricians work on acutely constrained timelines, and mobile adoption and use also differ. As we present the lessons we learned from Nurture, we also discuss the opportunities and challenges that our design process highlighted, in that it originated in a richly resourced hacker environment that was created to address the needs of poorly resourced settings, aligning its goals with HCI for Development (HCI4D).

In this paper, we first present background on the problem we try to address, motivating the need for Nurture in the Indian context. We describe the body of work that we draw on and extend, including research on parent-children interaction, hacker environments, and global health in HCI. We then provide details on our methodological approach, elaborating on the role the hackerspace played in Nurture’s design. Next, we list the findings from our needs assessment exercise, our iterative design process, and the qualitative evaluation we conducted. Our study revealed that parents using Nurture found that the application left them successfully engaged, assisted, and empowered. Parents were likely to collect records more frequently and carefully, and reported higher involvement, awareness, and confidence in tracking milestones.

Our paper thus contributes (1) the design and evaluation of a probe that seeks to understand and address the needs of variously
2 BACKGROUND

Tests for comprehensive developmental assessment of children such as the Bayley Scale of Infant Development (BSID) and the Mullen Scales of Early Learning provide multidimensional information on a child’s developmental status, including gross and fine motor skills, communication, hand-eye coordination, problem solving, among others [48]. These tests are administered in a clinical setting where a qualified observer examines the child and offers normative scores for the specific dimension of development being assessed, based on the child’s ability to perform. The psychometric properties of these tests are shown to be highly satisfactory [2]. However, the normative data that form the basis of these comprehensive development assessment tools are typically limited to a particular country’s context where the specific test has been created. Translating and validating the tool with normative data for other contexts is tedious and time consuming [26]. For instance, items relating to the use of forks are not contextually relevant for most Indian infants. Similarly, items relating to mirrors have been shown to not be highly reliable or valid for the Indian context [19].

The Development Assessment Scale for Indian Infants (DASII), based on BSID, is a comprehensive development assessment tool that was developed specifically for the Indian context [31]. DASII provides normative Indian data to score the child on development status and is considered the gold standard for developmental assessment in India [33]. It can be used to assess development from 0 to 30 months and provides scores for motor and mental development quotients (DQ). The specific tests on motor and mental scales are grouped into five and ten clusters respectively, representing particular aspects of development. The five motor clusters are (1) neck control, (2) body control, (3) coordinated movements, (4) locomotion, and (5) manipulation. The mental clusters are (1) visual cognizance, (2) auditory cognizance, (3) reaching and exploring, (4) memory, (5) social interaction, (6) language-communication, (7) language- vocabulary, (8) understanding relationships, (9) differentiation by use, shapes and movements and (10) manual dexterity. DQ compares the developmental age of a child to his/her chronological age: if the DQ is 100, above 100, or below 100, the child’s performance is labeled at par, above par, or below par, respectively.

These comprehensive development tests are designed to be administered by trained personnel, preferably professionals with clinical experience such as clinical psychologists or pediatricians. They require the child’s cooperation at the time that the test is administered in a formal clinical setting [19]. The test may take about 45 minutes on average if the child is cooperative. However, children may require multiple clinical sittings to adjust to the new environment. This can be time-consuming and cumbersome, causing pediatricians to rarely conduct these tests. There is a need for developing brief, effective, and easier-to-administer means of development assessment. Although briefer screening approaches exist [38], they are naturally not as comprehensive, and rely on secondary reports from caregivers. The reports are based on a set of questions posed to the caregiver. The reliability of responses is questionable, and the questions usually do not cover the multidimensional development process [29].

Growth is a crucial aspect that needs to be monitored, especially for young children. Poor growth in early childhood is associated with adverse functional implications such as poor cognition and scholastic performance, low productivity, lower adult wages, macro- and micro-nutritional deficiencies, higher prevalence of morbidities related to nutritional deficiencies, and if followed by excessive weight gain in later part of childhood, increased risk of chronic diseases [8]. Given that malnutrition is as high as 40% in India [44] and obesity rates are also rising [35], meticulous growth monitoring becomes especially important. The World Health Organization (WHO) and the Indian Academy of Pediatricians (IAP) suggest the child’s height, weight, and head circumference as the most relevant parameters for monitoring growth [4]. The Body Mass Index (BMI) can be computed from the first two and also needs to be monitored regularly for detecting childhood obesity, a problem of increasing relevance in India. IAP charts are the most widely accepted charts used for this purpose [41].

An important aspect of developmental screening is enabling parents and/or health workers to carry out the requisite assessment. Research shows that parents’ accounts of their child’s developmental status and concerns about developmental deviations once they are sufficiently aware of the normal developmental process, are significantly accurate and valid [24]. Parents can screen for growth and developmental variations using tools such as growth charts (e.g., WHO/IAP charts) and development charts (e.g., Trivandrum Development Screening Chart and Ages and Stages Questionnaire) [11, 47]. However, even when charts are available, studies show that parents in India do not use them to monitor growth and development of their children [39], relying on pediatricians to do most of the monitoring.

Missed immunizations are also a serious concern in India and the object of much study, even if there is some awareness across socioeconomic strata, and immunization is largely seen as desirable and important, thanks to dedicated drives organized by the state and agencies such as UNICEF through the decades. Statistics vary depending on sources, but there is consensus that—at the rural level—the problem is largely rooted in infrastructural inadequacies. Medical facilities and resources are not easily accessible in rural
India, and a number of problems contribute towards high infant mortality and morbidity [40]. On the parent end, also in rural but particularly in urban India, the most common reason for missed immunizations is simply forgetfulness and a lack of understanding and awareness of how the different doses are structured. This is a gap that needs addressing, and not by information delivery alone.

3 RELATED WORK

Mobile technologies are rapidly stepping in to assist users with their (and their babies’) health-related needs. At the same time, there are also mobile tools available that allow parents to more actively record and share their babies’ memories. Below we discuss these two bodies of work that we draw on and extend. We also engage with the body of work that constitutes HCI4D, aiming to expand the scope of this research. For the HCI4D context in particular, we summarize the attention that hackerspaces have received in the HCI community to subsequently build on the discussion of how these environments might shape design and innovation.

3.1 HCI and Children’s Health

The HCI community has seen a substantive body of work that focuses on helping parents to monitor children’s health and well-being. This includes the early contribution by Kientz et al. in 2009 [22] of a software application called Baby Steps to track babies’ development. @BabySteps was follow-on work [43] that enabled parents to record their children’s milestones through Twitter responses, and used hashtags to parse incoming data and provide customized feedback. ENSURE [34] allows parents to organize their children’s health data and share it with the relevant caregivers, and Fitbaby [15] enables parents of premature infants to track their children’s health and wellness. The focus of ENSURE and Fitbaby is on general health observation; they are not particularly intended for developmental screening. However, Estrellita, a mobile application for parents with premature babies, was designed by Hayes et al. to track the milestones of premature babies for early detection [16]. In addition, various pediatric informatics tools have been designed by Fiks et al., Johnson et al., and Slagle et al. [12, 18, 42]. There are also tools in the market that aim to do one or more of these tasks, such as Baby Connect1, Trixie Tracker2, and WhatToExpect.Com. We extend this growing body of work by studying how a problem as global in scope might be addressed in an environment that is geographically, technologically, infrastructurally, culturally, and medically distinct in its composition. Our tool entails the situated design of a comprehensive and interactive system for recording and analyzing data related to child growth, development and immunization, specifically within the Indian context. We use this tool primarily as a probe to learn more about the Indian parents who might be target users of such applications.

3.2 Recording Babies’ Firsts

Parents across cultures like to record their children’s firsts—as memoirs for themselves or for sharing with friends and relatives [17]. Van Dijck [46] emphasized that the migration of mediated memories from tangible to digital formats like digital photos, video clips, and blogs meant that these memories could be shared remotely and were easily retrievable for retrospective assessment. There have also been efforts to enhance the experience of capturing a child’s memorable moments. Several years ago, Kientz and Abowd [21] explored the use of KidCam, a semi-continuous and semi-mobile technology design that enhances the recording of a child’s moment of interest. Khan et al. [20] designed and tested KidzFrame, a system that connected caretakers at daycare centers with working parents: the caretakers could upload photos and messages on the KidzFrame website that was accessible by parents. Scholars have investigated how mothers share photographs and memoirs of their children using social networking sites [32]. Kumar and Schoenebeck [25] suggested that mothers like to share the photographs that represent happy moments and significant achievements such as cute and funny photos and photos related to milestones, family, and friends. They posited that the purpose of sharing these memoirs may be to receive validation of good parenting. Ammari and Schoenebeck [3] further noted that not only mothers, but fathers too access social media to share their experiences of fatherhood, archive memories, and seek social support. While technology design for children’s health largely addresses technical medical aspects, this body of work relates to the emotional connect that parenthood entails. Our work aims to link both aspects—monitoring children’s growth and development and saving memories—as we design for the Indian context.

3.3 mHealth & HCI4D

Prior HCI research that examines the use of technology for health in low-resource regions has tried to leverage the rapidly increasing mobile penetration in the developing world to design technologies for various application areas, such as data collection, providing access to information, training, disease surveillance, and monitoring of health services [9]. Some of this work includes Ramachandran et al.’s study of the creation and use of mobile videos by Indian frontline health workers [36], De Renzi et al.’s e-IMCI mobile phone tool that guided Tanzanian health workers through the IMCI treatment algorithm [10], and Chaudhri et al.’s smartphone-based monitoring system in South African human milk banks [7]. Each of these works affirms that HCI4D research is characterized by an acute sensitivity to infrastructural conditions and constraints, in addition to addressing the needs of the needier sections of society. Nurture does not currently address the needs of the most vulnerable; instead, it addresses that cross-section of India’s population first that is mHealth-ready at present. However, its design is situated amidst resource-constrained infrastructures and brings us to question and possibly expand the scope of research typically viewed as HCI4D.

3.4 The Contribution of Hackerspaces

In recent years, HCI has shown a growing interest in hacker environments, considering but also critiquing their role as potential sites of technological innovation. In 2014, Lindtner et al. [28] extended this body of work to discuss ongoing efforts toward entrepreneurism and professionalization by presenting ethnographic research conducted with makers over several years. In 2015, Fox et al. [13] conducted a qualitative analysis of feminist hackerspaces and contended that these sites provide social platforms to step beyond the
We now describe the process that led to this paper, starting from the ideation in a hackerspace, a detailed needs assessment exercise to attain deeper understanding of the sociotechnical context, and the process of iterating on our design that included three rounds of evaluation that we detail below.

4 METHODOLOGY

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4.1 From Challenge to Hack

The idea of Nurture was born at a hackathon—one in a now periodic series of hacker events organized at research labs located across India (organizing actors are anonymized). The focus of this hackathon was on reproductive, maternal, newborn and child health (RMNCH) and it brought together approximately 300-400 participants and mentors from a wide variety of backgrounds, including frontline workers, doctors, researchers, practitioners, public health experts, technology and design experts, and business entrepreneurs. The first day of this four-day event included a visit to and conversations at rural and semi-urban primary healthcare centers (PHCs) near Bangalore. The second day included 10 hours of talks, panels, and discussions that listed and explained challenges being experienced in RMNCH from a range of perspectives. The third day began with team formation, when motivated individuals did a round of pitches before the participants all formed teams and worked with a group of mentors to proceed with the design process. The ‘hacking’ continued for 36 hours, after which teams presented their ideas before an audience of judges, each of whom had a unique experience and perspective to offer. Nurture won first prize at the event, competing among 40 teams. What appealed most to the judges was the design of the baby book on the front end to draw parents, juxtaposed with the notification system on the back end that sought to inform them.

4.2 From Hack to Prototype

During our needs assessment phase, we conducted a detailed, open-ended survey of 50 Indian parents (living in India). We asked the parents questions about their backgrounds, how they recorded memories of their children, which growth, development, or immunization milestones they remembered, the tools they used to record memories and/or milestones, and their pediatric visits. We also asked them to give us feedback on Nurture’s design goals. These parents fell into two categories—those who had a young child at home and those who had children of the age of 5 or above. We targeted the first set of individuals to better understand the concerns that were current in their minds as they navigated the hurdles that parenting brought forth. The second set of individuals gave us a better understanding of the milestones that were most memorable to them after some time had passed. These were Indian parents, but located in either US (25) or India (50), since the objective of our exercise was to understand and assess parent behavior and practices in these two countries, and understand how the surrounding health infrastructure contributed to distinct parenting practices. We also conducted interviews with five Indian pediatricians at this stage, asking them about their interactions with parents and children.

After our needs assessment exercise, we undertook an extensive process of iterative design for our product. We conducted a preliminary evaluation with a group of 15 domain experts. The goal of this exercise was to generate feedback on the content and design of our tool, both at first glance and after a few days of use. These individuals were spread across the world and included technology and design experts in the US and India. Our mobile health experts were individuals who were situated in the US and researching mHealth initiatives for resource-challenged environments. The pediatricians we spoke to were located in the cities of Bangalore (Karnataka), Ahmedabad (Gujarat), and Surat (Gujarat), and our public health experts had experience in working all over India. Collecting feedback across cities and continents was a challenge and took the better part of two months. This period coincided with yet another hackathon, like the one we had started our project with. We returned to the event, taking the opportunity to solicit rapidfire feedback from roughly 25 experts across domains.

4.3 From Prototype to Testing

We tested the next iteration of our prototype with 30 sets of parents (i.e. 60 individuals). After one month of use, we conducted detailed interviews to assess their initial response to Nurture. There were 30 (2x15) first-time parents and 30 (2x15) repeat parents. They were all from middle-class families—9 dual earner and 11 single earner. Working parents were mostly doctors, engineers, and researchers. Two weeks into this evaluation, we distributed a short open-ended survey to obtain their immediate feedback on the tool. We received 8 informative responses. At the end of 20 weeks, we interviewed all parents to gauge their experience over a relatively long duration. We tried to interview both parents together, but in 4 cases (3 mothers and 1 father) we could interview only one parent, since their spouse had not used the tool.

All data was collected by the first two authors, who are fluent English and Hindi speakers. Interviews were duly recorded and transcribed, before the data was put through a rigorous inductive analysis. We focused on the experience of our parent participants with using our tool, aiming to understand not just how they engaged with it for information, but also how they felt that Nurture assisted and/or empowered them in their parenting, to glean implications for the design of more such technologies. We present the results of our survey and interviews in the following section.

5 NEEDS ASSESSMENT

After the hackathon, we undertook a detailed needs assessment exercise, as described above, by distributing a survey to 50 Indian parents (located in India) and interviewing five Indian pediatricians. We now summarize our key survey and interview findings from this stage.
5.1 Parent Demographics

Parents were invited to fill out our survey via a combination of channels, including email, WhatsApp, Facebook, and SMS. There was a more or less even split between mothers (47%) and fathers (53%). Seventy-five percent of our respondents had an annual family income of over INR 25 lakhs (USD 38K), while 1% earned less than INR 5 lakhs (USD 7.5K). Remaining respondents were scattered in between.

5.2 Recording Memories

Given the socioeconomic distribution of our respondents, it is not surprising that almost all of them owned a smartphone. Eighty percent of parents shared that they took photos of their children every week, while 40% shared that they shot videos every week. Almost 90% stated that they used their smartphones for recording photos and videos. Although audio recordings were not as common, 40% of parents shared that they recorded the audio of their children at least once a month, and again, 90% used a smartphone for this purpose. We collected this data to validate our preliminary findings from the hackathon that emphasized the growing role of mobile phones in the recording of children’s memories.

5.3 Remembering Milestones

We asked questions regarding which milestones our respondents remembered from the growing years of their children. Overall, 67% of them said that they had recorded at least three major milestones using photo and video. Only a third of them recalled being concerned about their children’s milestones, although this number is likely to be influenced by self-reporting bias since parents may not recall the stresses they had suffered through once they had passed. Most (86%) of our respondents were only able to recall speech-related and gross motor milestones, confirming our suspicion that parents were mostly unaware of also-critical fine motor milestones.

5.4 Tools Used

To understand which platform would be an appropriate fit for our targeted users, we asked our survey respondents to list the array of tools (both hardware and software) that they used for recording memories and monitoring the health of their children. Two-thirds regularly shared photos and videos of their children on social networking sites. Only 7% used any kind of technology for monitoring their child’s growth and development, e.g., vimeo, wordpress, evernote, and babycenter. As for immunization tracking mechanisms, parents relied on paper charts that were given to them by their pediatrician at the time of the baby’s birth. As one of our parents added: “I see the immunization card often and remember the next.”

5.5 Doctors’ Visits

Another set of questions in our survey asked how often the parents saw their child’s pediatrician. Most parents did so once every six months or made “need-based” visits, when the focus of the visit would be on a particular ailment the child had. The goal of this set of questions was to ascertain the frequency and nature of doctors’ visits in the Indian context. We admit we were surprised to find that even among relatively affluent parents, doctors’ visits were few and far between, with little focus on growth and development aspects. Still, parents in both regions largely expressed considerable confidence in their pediatricians. On a scale from 1 (most confident) and 5 (least confident), only a sixth of all parents went over a 3.

5.6 What about Nurture?

In addition to the questions above, we asked our respondents to tell us whether they would appreciate having a tool like Nurture, fully recognizing that they may have been biased against giving negative responses (although the survey was anonymous). Even if they weren’t biased, their words may not accurately represent their behavior in the long term. Only 16% of our respondents stated that they would not like to use a mobile tool for monitoring their child’s development. As one parent shared: “Because every child has its own pace of development. I’d prefer a doctor tell me if my child is really late on a development milestone.” Almost a quarter claimed that they had no need for a mobile tool for tracking immunization (these were the parents who already had processes in place for this purpose, particularly due to their pediatricians). However, 83% claimed that they would like to use a mobile tool for tracking their baby’s firsts. Almost 70% were willing to pay for this tool, with one-fifth of our respondents enthusiastic enough to offer us USD 10 for it. According to one parent: “This seems a good initiative. As a parent, I may not be overly concerned about delays in certain developments in my child but yes, I would sure like to preserve moments of my child’s growth.” This is the insight that led to the design of our application as well, which we presently cover.

5.7 Interviews with Pediatricians

In our interviews with pediatricians, we asked how they assessed their patients’ growth, development, and immunization. All accepted that they did not assess all developmental aspects of a child’s growth because it would “take too long” and time was always short. They were enthusiastic about promoting an app like Nurture to their patients, and one of them confessed—“I feel guilty for not having time for monitoring my kids’ developmental needs. This gives me a way to redeem my guilt.” They liked the immunization reminders and were willing to respond briefly to patient concerns via the tool. Their only recommendation, which we took seriously, was that we take care to not cause premature and undue anxiety to parents.

6 NURTURE

Based on our needs assessment exercise, we developed Nurture (see Figure 1) as a mobile health (mHealth) technology for middle-class Indian parents who had easy access to smartphones but lacked adequate pediatric attention for the monitoring of growth, development, and immunization for their children. We emphasize that because this demographic has the technology and experiences the need, it is a fitting parent group to target first for an mHealth initiative in India, with tremendous scope for adoption.

Our guiding insight as we designed Nurture was that the progress pediatricians would like their patients to monitor can be tracked using an analogous set of milestones that parents record regularly, like babies’ firsts, through the use of a baby book, also highlighted
in [23]. Nurture integrates the two so that parents remain informed regarding essential milestones and their significance, but also sufficiently incentivized to input minimal but necessary information. While the parent is emotionally engaged in recording his/her child’s memories, Nurture non-intrusively monitors the child’s progress, gently nudging the parent to consult the doctor when the child falls behind. Our three main offerings, we reiterate, are (1) a multimedia tool that records memories in photos, video, audio, and note form—all in one place; (2) a growth, development, and immunization tracker that non-intrusively checks off milestones based on clinical best practices; and (3) a means for connecting directly with the child’s pediatrician.

7 FINDINGS

As we went through our iterative design process, we collected feedback from experts and target users in multiple rounds, as described above. These rounds of evaluation were not cleanly segre-gated. Rather, they were unavoidably and unpredictably organic. In Round 0, we received feedback and validation for our approach at the hackathon, which helped narrow in on the public health need we were looking to address. In Round 1, we collected feedback from a group of domain experts after they had used Nurture for 2-3 days, summarizing these below. In Round 2, we conducted a survey and interviews to obtain feedback from parents, after 20 weeks had passed since they were first given the application. The feedback we received was thoughtful, informative, and very valuable for our iterative design process. We describe next how our experts responded to the tool and how parents felt engaged, assisted, and empowered from their experience of using Nurture.

7.1 Responses from Experts

We received varied low and high level feedback at this stage, pointing us to minor fixes in our code, avenues to broaden our scope, and approaches to maximize adoption. Experts remarked on features that were less than obvious on first use, notifications that could sometimes be confusing to the user, and some inconsistencies with the interaction design. They also suggested ways in which Nurture could be adapted for use by frontline health workers in low-resource environments and incorporate potential partnerships with medical service provider start-ups in the urban domain. Pediatricians who had specialized in child development checked with us to ensure that early signs of developmental disorders such as autism would be visible with our tool. A public health expert advised us to “target obstetricians, not just pediatricians, since parents should start using it from birth. The recommendation must come from the [health care] provider, not from the Google Play store.” Nearly all of this feedback was factored in, informing our current and future plans.

7.2 Post-Use Survey Responses

Our survey responses indicated that most parents found our product “visually appealing” or “lucid and well presented”. Parents were in agreement that “the flow is good” and “the layout is intuitive,” calling our tool “simple, concise, and to the point.” One parent found the flow to be “satisfactory” but asked that the different actions that could be performed “be listed right on the center of the opening page.”

Parents were unanimous in their support of the “usefulness” of the features we provided. One parent said, “All features are useful. Measurements of height and weight was the most useful as I can show it to my pediatrician also.” Other parents also voiced their support, and some asked for additional features, such as the ability to edit and share photos and videos, as well as more detailed information on milestones, measurements, and vaccines. One parent suggested we make the tool more fun to use by including, for instance, records of Baby’s Favorites and Baby’s Dislikes.

In a quick survey, before parents had used the app for an extended period, we asked them to name their favorite feature. We received a range of responses, with roughly equal support for all four components—recording memories, checking milestones, storing measurement records, and keeping track of vaccination schedules. We also asked parents to tell us which feature was their least favorite. Here, they commented on the lack of photo-editing capability and missing instructions on how to measure head circumference. Most of their suggestions were feasible, though feedback on colors (e.g., wanting a pink background for baby girls and a blue one for baby boys) and other user interface details was less consistent.

7.3 Interview Responses

We now discuss the responses we received from our interview participants, having organized them into themes we distilled from analyzing our data. We chose these themes with the aim of providing an overview of the value the parents drew or hoped to draw from a tool like Nurture. We also note that, in contrast to the environment that Ammari and Schoenebeck [3] study, our primary respondents were fathers not mothers. Our assessment was that fathers were more active smartphone users. It is also true that they are typically the ones in charge of matters external to the home, pediatric visits being among them.

7.3.1 The Value of Record-Keeping. Traditional means of record-keeping have not been used actively or consistently, we found from pediatric charts of the older children of our study participants. One of our interview participants shared, “I lost the immunization chart given by pediatrician for my first child…now it is so good that it is online…I will have these records forever.” Another parent said he was glad to have “all the vaccines in one place.”

Being able to record memories in addition to immunization dates was also a welcome offering: “I have made a baby book for my first child who is three years old. Now [with Nurture] I can make it online—much more safe and permanent for my second child [2 months old]…I would like to make the same digital copy for my first child also…Does your tool allow that?” Overall, our assessment was that parents saw considerable value in being able to store and retrieve this information with relative ease, although this was new for them.

7.3.2 The Value of “Scientific Monitoring”. As our preliminary survey had indicated, Indian parents generally place considerable trust in the information they received from pediatricians. What they liked about our tool was that the information it provided had been validated by the IAP. Commenting on the list of milestones we had integrated, a parent shared:

Scientific verification of the information is a must for me…you told me that it is based on a test that
is performed by developmental pediatricians and it is being used widely…I also looked up the net after that…then I felt that this is good information that should be used.”

Parents drew comfort from their perception that their child was being monitored “scientifically” via Nurture, as Varun said:

“The information presented is in form of a scientific thing…it gives a perception that some scientific monitoring is being done. Even the doctor does some bit of it, but it is not detailed and there is no explanation. This is more detailed.”

The lack of information shared by pediatricians was felt across the board, and Nurture was seen as filling that gap in a “scientific” way.

7.3.3 The Value of Greater Awareness. Parents expressed the desire to be more aware because they felt that this would make them better equipped to fill the gap left by their pediatricians, due to the constraints on time. As one parent shared:

“When I went to pediatrician, he asks some questions…does the child smile?…does he sit?…but he doesn’t explain all the things—why they are important and what is the sequence …we can’t ask him he is too busy…but we can come back home and look through this chart in leisure…and can test these things.”

Parents demonstrated an inclination to improve their knowledge and awareness, and to be able to exercise their choice with regards to selecting particular vaccines for their child. As in the case of Bipin, who claimed to have benefited from using Nurture:

“It definitely increased my knowledge and I should say I was able to see a lot of things…For example, I was given a vaccination schedule by my pediatrician which was different…he did not tell me about the pneumococcal vaccine…It is costly and also optional, so he might have assumed we will not take it…We normally rely on whatever he says and it was only after using this tool [Nurture] that I asked him about the pneumococcal vaccine…He said yes it is there but optional and it costs this much and I will give you if you want it…then we took it. I looked at the pediatrician’s chart after I used Nurture and then I found this discrepancy…he had written the optional vaccine at the end, but it had no mention of dates when to give and all that…maybe as it was not part of a regular schedule. I don’t know.”

In some cases, the use of Nurture also brought pediatricians to pay greater attention: “When I went to the pediatrician last, I told him to check the head circumference and then he said ‘everything is normal I can see that’…I told him we have to check it every month according to this IAP chart but he insisted that he can judge the growth and he thinks that it is normal…then when we were going he told the sister [nurse] to measure the head circumference…I felt good…as if something was missing…why did he deny the measurement earlier? I think his judgement was right but still…”

Being able to check off milestones on their own gave parents a feeling of satisfaction, that they were now better equipped to care for their child, particularly where their pediatricians would not have inspired enough trust. Parents were in consensus with the following views: “I felt so nice when I click that completed tab…I feel I have assessed an important aspect and it feels nice if your child has achieved the thing” and “It is so nice to know the developmental phase…It connects immediately.”

Parents also expressed greater confidence in their skills as caregivers. As Madhvi said: “I feel more confidence when the doctor says everything is okay after I have done the assessment myself. Earlier he used to say ‘everything is fine’—I thought he did not even see for 10 minutes. Did he see everything? Did he miss anything? Now I have more confidence on his statement that everything is fine…” This is because Madhvi was able to check for herself that what the doctor had said was accurate.

7.3.4 The Value of ‘More’ Information. We also received a list of requests for features and information to be added in our tool. For
example, one parent shared, “It would have been nice if you could have incorporated more information about these vaccines in detail, for example, what are the trade names that are available... you see there are so many brands—which ones should I buy... what are the side effects... what is the efficacy, etc.”

Parents also shared that first-timers would need much more information while second-time parents may not need the same level of detail, so the tool could be adapted appropriately for their use, assuming different levels of experience:

“First-time parents would like to know about sleeping patterns, feeding pattern, rashes, diaper rashes, etc. ... We can add lots of information about these things... even the experience shared by other parents about these problems. For example, if someone says that it is common... and parents also say that I had this problem with my child... nothing to worry... do this and that... that is so reassuring and informative.”

Parents certainly had a long list of questions that they claimed they would be interested in asking, many of which were around seeking solace and comfort from other parents who were in the same situation. We also witnessed a sense of unity across parents in terms of wanting to access—and be accessed—by other parents.

7.3.5 The Value of a Good User Experience. Though parents did appreciate being informed, they were also sometimes overwhelmed by too many reminders and gave us feedback to ensure that there was no point in time when too many milestones were due and being presented to the user:

“There is so much information at one place in this tool... if you see the list of milestones it says these are the milestones - about 80 or so I believe, can you just highlight the most important for us and not all of them... people don’t want to read too much at one place.”

As a result, we went through the comprehensive list of milestones and reduced the number in the top-level list so that some of the milestones could be clustered with others. This did not compromise the validity of our tool or remove any checks from the system, but did make it less of a visual burden.

Parents generally felt that we could go easy on the frequency of notifications. Daily notifications were sometimes overwhelming to them, and one parent suggested, “No, not daily! Once a week for example is fine... like—these milestones are waiting to be checked, you have not entered the monthly growth data, would you like to enter, etc.” while another said, “give 5-10 tasks to be completed in a week. For example, check these 5 things this week, that’s all. With a new baby, I don’t have much time to do more than that.”

Parents also commented on the nature of these notifications and suggested that there could be “more interesting ones also... such as—do you want to update the photograph of the baby, etc.” All parents saw value in the ‘baby book’ timeline that we offered, though some of them asked that we make it more engaging. “The design is I should say dull... it is not interesting. Looks too information-oriented rather than fun and interesting... maybe look at some other apps and take some cues.” More concrete suggestions were to “make it more visually appealing... like online shopping applications... they have so many photographs.” When we asked if including a collage of baby photos would work better, we were told, “Definitely. Yes. Better than a page where I need to put in data... like they have DPs [Display Pictures] on WhatsApp.” Visual design preferences vary across the world [37]. What we also noted, however, was that parents were very eager to give suggestions on how this tool could satisfy all their needs—how it might inform, engage, entertain, allow for sharing, and more. It is worth noting that since there is no other tool that provided them with this functionality, they were keen to have us improve and augment the features as per their utility and comfort.

7.3.6 The Value of Reflection. We had thought first-time parents would derive greater value from using our tool since they lacked experience but found that they were far more overwhelmed as well in their first few months of parenthood and developmental concerns fell low on their priority list. A first-time parent shared:

“I was so busy in these last three months, I used to forget to do so many things. How can I remember to use the tool? It has no in-built notifications like the shopping apps have - about new sales, new products, etc. When we get these notifications we might get tempted to see the app... You should build more notifications. Whenever I open the mobile some popup tries to attract me.”

Varun, whose baby was only 1.5 months old when he started using our tool, shared:

“I did not use the app too much. This is our first baby and it is so overwhelming. Last month she had diarrhoea and vomiting... we were busy going to hospitals all the time. And there is no support - me and my wife are the only ones to take care and you know - she keeps awake the whole night... it is too tiring.”

Second-time parents acknowledged, by contrast, that this tool brought them features that could have been useful earlier. Madhvi—a mother of a 6 year old and 14 month old, shared:

“My first child had LMA [lactic metabolic acidosis]... he started losing weight after three months... he became so weak. Whenever I told my pediatrician, they said you don’t feed him properly and he kept losing weight— it was so stressful... then he was started on top feed [formula] still lost weight. By 6 months he was 3.5 kg and we had so much trouble... then we started the bicarb treatment and he recovered... In my second child I started tracking the weight myself... again he showed a flat curve and began losing weight... the picture was appearing to be the same... I could sense it much before it became like previous... it was visible on the graph. He was also started on treatment for LMA after investigations and he recovered... I know these charts are so important!”

Another mother shared about her first child who had a developmental disorder:
We now reflect on the design process and decisions we took along with minimum intrusion, fully respecting existing relations between parents and pediatricians. The imbalance, with the goal to keep parents aware and informed but if there was a role that technology might play in addressing this, immunization discrepancies are not detected in time. We asked that can end up affecting the child if growth, development, and matters, existing methods of monitoring growth, development, and also overestimating the parents' awareness levels. Parents, however, are steeped in the tradition of placing considerable trust on the pediatrician and rely on his/her judgment in a big way. To worsen matters, existing methods of monitoring growth, development, and immunization are not very parent-friendly, and paper charts given to parents are frequently and easily misplaced, leading to loss of records and insufficient monitoring. All this creates an imbalance that can end up affecting the child if growth, development, and immunization discrepancies are not detected in time. We asked if there was a role that technology might play in addressing this imbalance, with the goal to keep parents aware and informed but with minimum intrusion, fully respecting existing relations between parents and pediatricians.

For our user study, we targeted a parent group that had experienced the gap we discussed above. This was our ‘niche audience’ consisting of smartphone users from the urban Indian middle class that has seen remarkable smartphone penetration in recent years. Recognizing the trust these parents placed in their pediatricians, our aim was to both honor this trust, but also supplement it where there were gaps (for instance, in the case of the parent asking that his baby’s head circumference be measured). Recognizing that authenticity of information was key, since parents were understandably very concerned about their babies’ wellness. We made it clear to our parents that our tool relied on ‘scientific’ information that came from the IAP; this was important to them. In this study, we were careful to convey that our proposed approach was to use Nurture not as the ‘end product’ but as a probe to determine the values of our parent group that we needed to address. Our major takeaway was that although our goal had been to assist and engage parents, there was a strong sense of them feeling empowered through the use of this tool. As we mentioned, parents felt that they had an alternative source of authentic information that they could use to respond to a doctor with. In healthcare, as compared to ‘compliance’-based approaches where the patient is a recipient of information, care, and treatment, the ‘empowerment’-based approach emphasizes enhancement of patient capabilities, so that they can play an active role in making their own choices and decisions [1]. This lens allows us, in our research, to view parents as having aspirations and perceptions that may diverge from those of healthcare providers. This has traditionally been missing in Indian healthcare settings, as Chandwani and Kulkarni also found [5]. As digital information systems rapidly bridge information gaps, particularly in resource-constrained environments, between patients who are keen and willing to learn and doctors who are overstrained for time, this deep value ascribed to patient empowerment can help inform the design of future systems.

8.1 Nurture: To Engage, Assist, and Empower

Our research illustrated the processes of pediatric care delivery in an urban Indian, middle class context and the constraints operating on them. Across socioeconomic strata, Indian pediatricians must cater to large populations and have limited time and attention to grant each patient (i.e. children and parents). This leads them to take ‘shortcuts’ at their own discretion (such as deciding that a parent will not opt for the pneumococcal vaccine), occasionally also overestimating the parents’ awareness levels. Parents, however, are steeped in the tradition of placing considerable technical context on the pediatrician and rely on his/her judgment in a big way. To worsen matters, existing methods of monitoring growth, development, and immunization are not very parent-friendly, and paper charts given to parents are frequently and easily misplaced, leading to loss of records and insufficient monitoring. All this creates an imbalance that can end up affecting the child if growth, development, and immunization discrepancies are not detected in time. We asked if there was a role that technology might play in addressing this imbalance, with the goal to keep parents aware and informed but with minimum intrusion, fully respecting existing relations between parents and pediatricians.

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8.2 Hacking for Good

Hackathons such as the ones we attended helped to bring access to stakeholders and their diverse perspectives. However, that is not where life happens. Hackathons cannot replicate the sociotechnical context that one must have an understanding of if one is to design for it. Our experience illustrated this. Our time at the hackathon led us to articulate a certain set of design objectives in a prototype that resonated with participants and judges at the event. Most participants, however, were from middle-class or more affluent backgrounds and spoke from their perspectives. They were also not colocated, and represented a medley of experiences. The prototype we designed, then, was a tool that addressed social needs as these participants perceived them, from their disparate experiences. Our

“My daughter has been diagnosed with autism. It is a mild one…she goes to a normal school. Initially when I went to pediatrician and said she is not talking, he checked her overall and said does she walk, does she smile, does she understand? She could do all those but was not talking…only after I kept on complaining repeatedly he sent her for a detailed assessment when she was diagnosed. In my case I know that these things are so important…the communication aspect…and I am more conscious about them, but while using this tool I felt that it is good that all these aspects of development like communication are included. I know that if there is any problem in my second child I will be more confident to ask questions to the pediatrician…maybe an early detection might have helped my daughter.”

This value would certainly be challenging to address, since reflection only takes place over time. We note, however, that this was an important aspect of our participants’ interaction with Nurture—that it brought them to think back on experiences they had had with their older children, and do better the second time round.

8 DISCUSSION

We now reflect on the design process and decisions we took along the way, some more challenging than others, and the lessons we learned worth sharing with the HCI4D community. First, we summarize the understanding we gleaned of the sociotechnical context for our study, using Nurture as a probe, not just a prototype [14]. Next, we discuss the benefits and challenges of hackerspaces in the context of design processes, their effectiveness, and their sustainability. Finally, we engage with the ongoing debate in the HCI4D context that one must have an understanding of if one is to design for stakeholders and their diverse perspectives. However, that is not where life happens. Hackathons cannot replicate the sociotechnical context that one must have an understanding of if one is to design for it. Our experience illustrated this. Our time at the hackathon led us to articulate a certain set of design objectives in a prototype that resonated with participants and judges at the event. Most participants, however, were from middle-class or more affluent backgrounds and spoke from their perspectives. They were also not colocated, and represented a medley of experiences. The prototype we designed, then, was a tool that addressed social needs as these participants perceived them, from their disparate experiences. Our
design process also came to be limited by the perspectives we could obtain access to.

Despite the above challenges, we found the hackathon weekend fulfilling (and admittedly exhilarating) for many reasons. For those conducting cross-disciplinary research in India as with other countries in the Global South, access to research contacts, sites, and audiences is routinely, unduly challenging. Having a diverse group of stakeholders, with their richly diverse perspectives, present in one location for an extended weekend was a powerful means to identifying a real-world problem—articulated via real-world experiences of different stakeholders—and (hacking our way to) addressing it. The mentors present during the weekend helped to ensure that participants deliberated over the practicality, feasibility, and potential sustainability of proposed solutions, in addition to ensuring that our focus was on devising novel ways of using technology for improving lives of those in need.

8.3 Expanding the Scope of HCI4D

When we started our project, we were keen to address marginalized populations with limited access to growth, development, and immunization information for their newborns. This is the section of the population that HCI4D undertakings typically address—under-represented, under-resourced, and under-served. Middle class populations are generally overlooked in HCI4D, and certainly understandably so, since they are considered to be overall better equipped with resources to improve their lives in ways that they desire. Although we did our best to distribute our preliminary survey as widely as possible, across demographics, we were able to reach mostly middle class parents. Our limited access to lower income groups became apparent when we received our survey responses, but what also became apparent was that even more affluent Indian parents were inadequately informed and had poor access to resources that could aid them in monitoring growth and development of their children. They too experienced an acute need for the information we were intending to deliver via Nurture.

We learned that it can be imprudent to demand, as reviewers frequently do, that HCI4D must address the needs of only financially constrained users, and even among them—the most constrained ones. We argue for extending HCI4D’s scope to acknowledge poverty and constraint to be in monetary terms but also in terms of infrastructures (in this case medical/public health) and of access to information, among other scarce resources. Relaxing this scope might create space for more innovations that might offer insights for targeting further constrained populations. Also, HCI4D resources could be better utilized if needs expressly recognized were addressed before automatically targeting acutely impoverished sections of society. Our initial goals were aligned directly with more traditional HCI4D goals to focus on more underserved users, but through our process of iterative design and feedback, we recognized that it was more feasible to start with the needs of those who were constrained, lacked access to necessary information, and were—importantly—in a position to receive and act on this information (e.g., on account of being equipped with Android smartphones). This is in comparison to others who may be focused on more immediate newborn health and survival needs, and be hard-pressed to afford the ‘luxury’ of worrying about monitoring growth and development of their children.

9 CONCLUSION

Nurture is a mobile health (mHealth) technology that we iteratively designed to enable Indian parents to monitor growth, development, and immunization milestones of their child between the ages of 0 and 2. As mobile phones become increasingly ubiquitous and smartphones more accessible, Nurture is well-positioned to target a large cross-section of India’s growing middle-class population. With the design and evaluation of Nurture, we are the first to study the role that technology could play to support parents in their need for monitoring their children’s growth, development, and immunization in an Indian context.

In this paper, we discussed the results of our needs assessment exercise, our iterative design process, and the qualitative evaluation we conducted. Our study highlighted that Nurture was able to engage, assist, and empower Indian parents, suggesting that parents using Nurture were likely to collect records more frequently and carefully, also reporting higher involvement, awareness, and confidence in tracking milestones. We also reflected on our design process to (1) unpack and summarize our understanding of the parents’ need for ‘empowerment’ that we studied through Nurture as a design probe, (2) analyze the contributions of hacker environments to supporting innovation processes, as revealed by our participant observation, and (3) raise questions for the HCI4D community regarding where its boundaries lie, and whether they might be expanded for greater overall impact.

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