

Mental Health on a Shoestring? Assessing Awareness and Acceptance of Digital Phenotyping in Dhaka's Korail Slum: A Qualitative Study

Nadia Alam, Domenico Giacco, Sheikh Rasel, Mohammad Bulbul Ashraf Siddiqi, Swaran P. Singh, Sagar Jilka

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Abstract

Background: Digital phenotyping (DP), the process of using data from digital devices, like smartphones and wearable technology to understand and monitor people's behaviour, health, and daily activities, has shown significant promise in mental health care within high-income countries (HICs). However, its application in lower and middle-income countries (LMICs) is limited, particularly among impoverished populations such as slum residents.

Objective: This study investigates the awareness, knowledge, acceptance, and implementation of DP, including willingness to share data, and concerns regarding privacy and data security, among residents of Dhaka's Korail slum, one of Bangladesh's largest and most densely populated informal settlements.

Methods: We conducted eight focus group discussions (FGDs) with 38 participants with individuals diagnosed with serious mental disorders (SMDs) and their caregivers. The FGDs also included a section explaining what DP is.

Results: There was a general lack of awareness about DP among the participants. Most had no prior knowledge of DP, but after receiving an explanation, they acknowledged its potential applications and benefits. Participants recognized the utility of DP for health monitoring, particularly in managing mental health conditions. They expressed their interest in sharing data, if the content of their activities was not accessed. Despite these perceived benefits, significant concerns about privacy and data security emerged. Participants expressed fears about the potential misuse of their personal information, with some feeling resigned to the idea of already being constantly monitored. This highlights a critical barrier to the adoption of DP tools: the need for robust data protection measures and transparent communication to build trust among users. Participants stressed the need for DP to reflect local customs and practices.

Conclusions: To implement DP effectively in LMICs, educational initiatives are necessary to raise awareness and understanding of the technology. Additionally, robust data protection measures must be in place, and clear communication about these measures can help alleviate fears and build trust. DP tools should be adapted to fit the cultural context of the target population, possibly involving modifications to the types of data collected or the way data is interpreted. In conclusion, while DP holds potential to improve mental health care in underserved communities, addressing barriers related to awareness, privacy, culture and usability is crucial. Focusing on educational initiatives, robust data protection, cultural adaptation, user-friendly design, and community engagement, DP can become a valuable tool in bridging the mental health care gap in LMICs.

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Keywords: digital phenotyping, mental health, slums

Background

Mental Health Burden in LMICs

Mental health disorders constitute a substantial global health challenge, with approximately 80% of individuals affected residing in LMICs¹. Factors such as rapid urbanization, poverty, and frequent exposure to traumatic events contribute to the high prevalence of mental health problems in these settings. For instance, in the *Korail* slum of Dhaka, Bangladesh, the combination of poor living conditions, high population density, and limited access to mental health services² exacerbates the prevalence and impact of serious mental disorders (SMDs) like schizophrenia and major depressive disorder^{3,4}.

The mental health care gap in LMICs is stark. In Bangladesh, for example, the mental health workforce is critically insufficient, with fewer than 0.5 psychiatrists per 100,000 people⁵. Consequently, many individuals with mental health conditions remain untreated, leading to significant personal and societal costs. This treatment gap is particularly pronounced in urban slums where healthcare infrastructure is weakest, and social determinants of health are most severe.

The Role and Potential of Digital Phenotyping

Digital mental health tools could provide a solution, and digital phenotyping (DP) could revolutionize mental health care in LMICs by providing low-cost, scalable methods for early detection, monitoring, and intervention of mental health disorders. The widespread use of smartphones even in impoverished areas offers a unique opportunity to collect valuable data on individuals' behaviours and environments. This data can be used to identify early warning signs of relapse in SMDs, track treatment progress, and personalize interventions⁶.

Studies in HICs have demonstrated the efficacy of DP in various mental health contexts (Liang, Zheng and Zeng, 2019). For instance, passive data from smartphones, such as GPS and call logs, have been used to predict relapse in schizophrenia⁷. These methodologies, however, need to be adapted for LMIC where cultural norms, technological access, and health infrastructure differ markedly. For instance, communication patterns, social interactions, and even the use of technology can differ widely between populations in HICs and those in LMICs³. There is often a lack of understanding and awareness about digital health technologies among the general population and healthcare providers in LMICs³. In the Korail slum, while smartphone usage is common, the concept of DP might be largely unknown. This gap in knowledge necessitates educational initiatives to inform communities about the benefits and implications of DP. These initiatives should aim to demystify the technology, explaining how it works and how it can be used to improve mental health outcomes.

Importance of Context-Specific Research

Understanding the level of awareness, knowledge, and acceptance of DP

among residents of LMICs is essential for the successful implementation of digital health interventions⁸. Awareness and acceptance are crucial as limited understanding can hinder adoption and effectiveness¹, with scepticism about sharing personal data posing a significant challenge⁹. Cultural attitudes towards mental health and technology also play a significant role, as stigmatization and cultural beliefs can impact perceptions of DP¹⁰. Addressing data privacy concerns is critical, as transparency and robust protection measures can enhance trust^{11,12}. Engaging the community in the design and implementation of DP tools through participatory approaches can improve usability and relevance, ensuring that interventions meet the specific needs and preferences of the population¹³, thereby increasing their sustainability.

While DP has shown promise in high-income countries, its adoption in LMICs remains limited, and no qualitative research exists¹⁴ to understand people's perceptions and acceptance of this technology in these settings. Understanding these perceptions is vital for developing culturally sensitive and effective DP that can improve mental health outcomes in these underserved populations. This study aims to explore the awareness, knowledge, and acceptance of DP among residents of the *Korail* slum in Dhaka, Bangladesh through focus group discussions (FGD).

Methods

Study Design

This study was approved by the University of Warwick Biomedical and Scientific Research Ethics Committee (BSREC 100/22-23). This study employs a qualitative research design to explore the awareness, knowledge, and acceptance of DP among residents of the *Korail* slum in Dhaka, Bangladesh. The qualitative approach was chosen to gather in-depth insights into the participants' perceptions and attitudes towards DP. The study is part of a mixed-methods project Transforming access to care for serious mental disorders in slums (the TRANSFORM Project)⁴.

Participants

Participants were recruited from the *Korail* slum, one of the largest and most densely populated slums in Dhaka. The inclusion criteria were: residents of the Korail slum, aged 18 years or older, and either diagnosed with a serious mental disorder (SMD) or caregivers of individuals diagnosed with SMD. Participants were identified through the TRANSFORM project where community engagement representatives well known and respected in the area supported recruitment.

Procedure

Focus Group Discussions

The FGDs were conducted in the field offices of the TRANSFORM Project⁴. The FGDs were structured to ensure a diverse representation of the community, including different genders, ages, and socioeconomic status. Each session was moderated by a trained facilitator, with the assistance of a note-taker. The

moderator guided the discussions using a semi-structured topic guide, which included questions about participants' understanding of DPs, their current use of digital devices, their willingness to share data, and their concerns regarding privacy and data security (see supplementary information for topic guide). Participants were asked about their understanding and views on DP, including its perceived usefulness, comfort levels with data sharing, potential community acceptance, and DP related concerns.

To ensure all participants had a similar baseline knowledge of the DP, prior to the start of the FGD, DP was explained in simple Bengali language as:

Digital phenotyping is a method through which data is collected from smartphones and other smart devices to understand individual's behaviour from their regular daily activities. Researchers can use this data to study social cohesion and interactions, behavioural patterns, speech, mobility etc., which are known as digital phenotypes.

Data from the phone includes phone usage, location, use of social media (such as Facebook, TikTok). An application is installed on participants' phones after explaining what sort of data will be collected from them, which will allow researchers to collect that data. The data will only be accessible to those involved in the study. The data generated by the app can be used to identify potential mental health problems which can be understood through phone usage patterns.

Data Collection

The FGDs were audio recorded to ensure accurate capture of the discussions. The recordings were then transcribed verbatim and translated into English. To maintain confidentiality, all personal identifiers were removed during transcription. The translated transcripts were reviewed by the research team to ensure accuracy and fidelity to the original conversations.

Data Analysis

The qualitative data from the FGDs were analysed using NVivo 14 software. A thematic analysis approach was employed to identify patterns and themes within the data. The analysis followed the five stages of data analysis described by Pope, Ziebland, and Mays (2000): familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation¹⁵.

Each transcript was read multiple times to enhance familiarity with the data. Initial thoughts, reflections, and preliminary codes were noted. The transcript was then read again, and preliminary themes were recorded. Preliminary themes were subsequently grouped into clusters based on common features and meanings. These themes were validated by cross-checking with the transcript to ensure they accurately represented the data. This process was repeated for each transcript to maintain consistency. The themes from all transcripts were then compared and combined into master themes to create a comprehensive portrayal of the participants' experiences. The master themes were checked and re-checked against the transcripts to ensure they were well-represented and grounded in the data. Commonalities among the preliminary themes were identified and represented as sub-themes, reflecting lower-order aspects of the master themes. The final coding framework was reviewed and refined by three researchers (NA, SR and SJ) to ensure reliability and validity.

Discrepancies were resolved through discussion and consensus.

Results

Demographic Information

Eight FGDs were held with homogenous groups of either people with lived experiences or their caregivers and each FGD included 4-6 participants. There was a total of 38 participants, with an average age of 37 years (\pm 13.7). Participants were predominantly women (79%) and educated to primary (26%) or secondary level (26%). Smartphone ownership was roughly split, with 45% owning smartphones but nearly (92%) had access to a smartphone via family members. See Table 1 for participant demographics.

Table 1. Participant demographic information (N=38)	
Age (mean ±SD)	37 (± 13.7)
Gender, female (N, %)	30 (79%)
Education level (N, %)	
No education	5 (13%)
Primary	11 (29%)
Middle School	16 (42%)
Highschool	4 (11%)
Undergraduate	2 (5%)
Marital Status (N, %)	
Married	29 (76%)
Unmarried	4 (11%)
Widowed	4 (11%)
Divorced	1 (2%)
Employed (N, %)	
Yes	12 (32%)
No	26 (68%)
Smartphone Ownership (N, %)	
Yes	17 (45%)
No	21 (55%)
Average Length of Smartphone	3.33±1.15 years.
Ownership (mean years ±SD)	
Smartphone Ownership in Family (N, %)	
Yes	35 (92%)
No	3 (8%)

Awareness and Understanding of Digital Phenotyping

The FGDs revealed a general lack of awareness about DP. Initially, most participants reported to have had no prior knowledge or understanding of the concept and many participants expressed surprise upon learning about the

tracking capabilities associated with DP, with responses like, "I didn't know someone could track my phone," (caregiver) indicating a widespread unfamiliarity with the concept. Participants initially understood DP as government or police surveillance. For instance, one participant expressed, "Good, you will be able to catch criminals" (caregiver), "It helps in tracking lost phones and finding people in emergencies," (patient) and "knowing the location can help in emergencies" (caregiver). After further discussion, participants began to grasp the notion of DP and its implications. Several participants acknowledged an increased understanding, with comments highlighting their comprehension of both pros and cons of DP, "Now that I understand, it has both pros and cons." (patient) and "I see now how it works; it has its advantages and disadvantages." (caregiver). This shift in understanding highlighted the importance of educational interventions to enhance awareness of DP and its potential applications.

Types of Data Residents are Willing to Share

Residents showed a willingness to share specific types of data, particularly they talked about communication and app usage. Participants frequently mentioned the use of their phones for making calls, with one stating, "It (phone calls), you can use that data. I use the phone mainly to make calls," (caregiver) and another noting, "I talk to my children and husband on the phone. So, it can be used maybe." (caregiver). Similarly, messaging apps like WhatsApp were commonly used, with comments such as, "We use messaging apps like WhatsApp, so you can get that data" (patient) indicating a prevalent reliance on these platforms for communication and their opinions regarding collection of those data. Participants directly agreed that they were willing to share communication data with comment such as, "You can see how much we talk"(patient), but did not want their communication content to be seen with one participant saying, "Knowing more than they need (referring to content of communication) to is bad"(caregiver). App usage also emerged as a significant area of data sharing, with participants highlighting their engagement with various apps for communication and entertainment. Examples included, "I use WhatsApp, Facebook, and Bkash," and "Apps like TikTok and YouTube are frequently used in our home" (caregiver). Participants revealed that DP can offer insights into personal preferences and behaviours, as one participant noted, "They can know who likes which drama, who listens to music, who likes music. Can understand people's tastes."(patient)

Additionally, location data was recognized for its utility, especially in emergencies, with statements like, "Tracking (location) can help us...", (patient). Participants highlighted various practical benefits of location tracking, such as its convenience for navigation and travel. One participant noted, "I keep location on my phone; it is convenient to go somewhere," (caregiver) emphasizing the everyday utility of this feature. Overall, participants recognized that location services could significantly aid in navigation and safety. When asked if it was okay for their location to be used for DP, participants were mostly in agreement with comment such as "I think it is good. Digital phenotyping is better in this case." (patient) When asked if it would be perceived dangerous to track people's location, participants disagreed with comments such as "No knowing this is not a problem. It's better for me" (patient) and "In some

circumstances it is good (referring to location tracking)" (caregiver).

Perceived Benefits and Risks

Participants identified several benefits of DP, particularly in health monitoring. Participants highlighted the potential of smartphones and apps to improve the management of mental health conditions. Participants made comment such as, "It will be very helpful for monitoring health conditions" (caregiver) and "Health monitoring through apps can provide immediate assistance" (caregiver). They highlighted the convenience and usefulness of receiving counselling and medical treatment through mobile phones, with one participant noting, "If you receive counselling, get treatment and diagnosis through mobile phones, it will be very helpful." (patient). The immediacy and accessibility of health monitoring through apps and opportunities were appreciated, with practical benefits in managing treatment schedules and medication reminders. Overall, the perceived benefits of DP among participants were substantial for improved health monitoring and management, highlighting the potential of digital tools to improve overall well-being.

Despite the general willingness to share data, participants expressed considerable concerns regarding privacy and data security. Many were apprehensive about the potential misuse of their personal information. One participant articulated this fear: "Someone will know your personal information; is that not a bad side of it?" (caregiver). This sentiment was widely shared, with participants expressing fears that their private conversations and activities could be monitored and exploited. A participant highlighted this anxiety, saying, "Fear, because if I go to tell any information to someone, they are recording these things behind me; if my secret is leaked, I may be in danger" (caregiver). added. "Some people can harm us with information"(patient), underscoring the potential risks associated with data breaches. There was also a sense of resignation among some participants regarding surveillance. One participant mentioned, "No problem, we are already being watched"(patient), reflecting a belief that privacy invasions are already a part of their reality. This feeling was further echoed by another participant, "We have no problem if you track. We have no problem if you hack", (caregiver) indicating a degree of desensitization to privacy concerns.

Participants also expressed nuanced views about the tracking and monitoring of data. While some acknowledged the necessity of such measures for security purposes, they were wary of their potential for misuse. For instance, one participant remarked, "If they want to track a criminal they can; I didn't do anything, why should they track mine", (patient) highlighting a concern that innocent individuals might be unjustly monitored. Another participant questioned the motives behind data collection, stating, "I don't know why. But they take it for their own interests" (caregiver), suggesting scepticism towards the intentions.

The concern extended to the practical usability and accessibility of digital tools, particularly among older family members. One participant pointed out, "It can be challenging to teach older family members how to use health apps" (caregiver), emphasizing the need for user-friendly interfaces and adequate support systems. Another participant noted, "It saves time and travel costs, but not everyone knows how to use the apps properly", indicating that

technological literacy remains a significant barrier.

In summary, while there is a willingness among residents to share data for the benefits it might bring, significant concerns about privacy invasion and data misuse persist. These concerns are coupled with practical challenges related to the usability of digital tools, particularly for older and less tech-savvy individuals.

Adaptation of Digital Phenotyping Tools

The discussions underscored the necessity for DP tools to be culturally sensitive and user-friendly to ensure broad acceptance. Participants emphasized that these tools should reflect local customs and practices, as well as provide valuable information relevant to their daily lives. For instance, one participant mentioned, "Health apps could offer valuable information and support," (caregiver) highlighting the potential benefits of culturally tailored digital health solutions and information.

Additionally, adapting data collection methods to local behaviours and technological habits is essential. Given the high use of communication apps like WhatsApp and social media platforms such as Facebook and TikTok, DP tools could focus on analysing data from these sources to identify behavioural patterns relevant to mental health. As a participant noted, "We use WhatsApp, Facebook, and YouTube a lot; you can see our activities there" (caregiver).

Furthermore, addressing privacy concerns through robust data protection measures and transparent communication can build trust among users. One participant expressed, "If we know our data is safe and not misused, we will feel more comfortable sharing it"(patient). Incorporating local community feedback into the design of these tools can ensure they meet the specific needs and concerns of the population. Another participant highlighted, "If you involve us in the process, we can tell you what works best for us"(caregiver).

Discussion

Principal Results

By understanding the local context and involving the community in the research process, this study aims to create sustainable and impactful approach into DP research. The findings from this study highlight both the potential and the challenges associated with implementing DP in LMICs, particularly in underserved communities like the *Korail* slum in Dhaka, Bangladesh. The results indicate a general lack of awareness and understanding of DP among residents, though there is significant interest and perceived benefit.

The initial unfamiliarity with DP shows the need for targeted educational interventions. Despite the widespread use of smartphones in the community, most participants had not previously encountered the term or understood the concept. This lack of awareness could hinder the adoption of DP tools, as individuals are unlikely to engage with technologies they do not understand. Educational initiatives should therefore focus on explaining how DP works and its potential benefits in health¹.

Once informed about DP, participants recognized several significant benefits, particularly in the realm of health monitoring. The convenience and utility of location tracking in emergencies were noted as important advantages.

Participants saw potential in using smartphones and apps to manage mental health conditions. This reflects a broader trend in digital health where mobile health applications are increasingly recognized for their ability to provide immediate assistance, manage treatment schedules, and offer valuable health-related information⁶.

Comparison with Available Literature and Implications

Despite the perceived benefits, concerns about privacy and data security were prominent. Participants expressed fears that their personal information could be misused, with some feeling resigned to the idea that they are already being watched. This highlights a critical barrier to the adoption of DP tools: the need to ensure robust data protection measures and communicate these effectively to users. Participants in HICs have similar concerns to those in LMICs regarding data sharing, particularly in terms of privacy, data security, and ethical considerations. In HICs, participants express significant concerns about privacy and the potential misuse of their personal data^{16,17}. These concerns include the inadequacy of current regulations to protect sensitive personal information and the potential for data to be sold or analysed outside the healthcare system¹⁶.

Transparency, consent, accountability, and fairness are also critical issues. There is a strong emphasis on ensuring that DP tools are developed with robust data protection measures and clear communication about these measures to build trust ¹⁷¹⁶. In both HICs and LMICs, the willingness to share data is often contingent upon understanding how the data will be used and ensuring that robust measures are in place to protect privacy. Addressing these concerns through transparent practices and community engagement is crucial for the acceptance and effectiveness of DP technologies. While privacy is a universal issue, the extent and nature of these concerns can vary significantly. Participants from HICs generally have greater awareness and more robust expectations of privacy protection mechanisms, often influenced by stringent data protection regulations and a higher level of digital literacy¹⁸. In contrast, residents of Korail, despite recognizing the importance of privacy, might exhibit a certain resignation towards surveillance, possibly due to their frequent exposure to informal and less regulated data environments. Building trust through transparent data practices and addressing privacy concerns directly will be essential to foster acceptance^{11,19}.

The necessity for DP tools to be culturally sensitive and user-friendly was also emphasized. Participants stressed that these tools should reflect local customs and practices and be accessible to all, including older and less techsavvy individuals. This points to the importance of designing digital health tools that are not only technologically effective but also culturally relevant and easy to use. Engaging the community in the design and implementation process can enhance the relevance and acceptance of these tools²⁰.

The findings suggest several practical implications for the implementation of DP in LMICs. There is a need for comprehensive educational initiatives to raise awareness and understanding of DP. These programs should use local languages and culturally relevant metaphors to explain the technology and its benefits⁹. Robust measures must be in place to protect users' data, and clear communication about these measures can help alleviate fears and build trust

among users¹². DP tools should be adapted to fit the cultural context of the target population, possibly involving modifications to the types of data collected or the way data is interpreted to ensure it is relevant and acceptable²¹. The usability of digital tools is crucial, particularly for older and less technologically literate individuals. Tools should be designed with these users in mind, providing simple interfaces and adequate support systems²². Involving the community in the design, testing, and deployment of DP tools can improve their acceptability and effectiveness. Participatory approaches ensure that interventions are tailored to meet the specific needs and preferences of the community²³.

Strengths and Limitations

Despite the valuable insights gained from this study, several limitations should be acknowledged. Firstly, the sample size of 38 participants, although sufficient for qualitative analysis, may not fully capture the diverse experiences and perspectives of all residents within the Korail slum. This limitation in sample diversity could affect the generalizability of the findings to other slum communities or urban poor populations in different LMIC settings²⁴. Secondly, the reliance on FGDs as the primary data collection method may have influenced participants' responses due to social desirability bias. Participants might have felt pressured to conform to perceived group norms or expectations, potentially limiting the expression of dissenting views or concerns about DP²⁵. Another limitation is the potential for translation. DP is an emerging technology ²³and it might be difficult to understand in general, and in the FGD the meaning of DP was explained in Bengali from an English explanation. This process might have introduced nuances or misinterpretations among participants²⁶. Ensuring accurate and culturally sensitive translation is critical, but even with meticulous efforts, some meaning can be lost or altered. Moreover, the study's design captures a snapshot of participants' perceptions and attitudes at a single point time. Longitudinal research could provide a more comprehensive understanding of how awareness, acceptance, and concerns about DP evolve over time, particularly as participants become more familiar with the technology²⁷. Technological limitations also played a role. Although smartphone usage is relatively common, the varying degrees of technological literacy among participants could influence their understanding and engagement with DP tools. Future studies should consider incorporating training sessions to ensure all participants have a baseline understanding of the technology being discussed²⁸. Lastly, while this study focused on a specific slum in Dhaka, the findings might not be directly applicable to other urban or rural settings in Bangladesh or other LMICs without considering local cultural, social, and economic contexts. Comparative studies across different settings are necessary to validate and expand upon these findings²⁹.

Finally, integrating DP tools into existing health systems can be challenging. Health systems in LMICs are often under-resourced and fragmented, which can complicate the implementation of new technologies¹. Successful integration requires collaboration with local health authorities and stakeholders to align DP initiatives with national health priorities and infrastructure. Training healthcare providers to use and interpret DP data is also crucial to ensure that the technology can be effectively utilized in clinical practice³⁰.

Conclusions

This study shows the potential of use of DP to improve mental health care in underserved communities like the *Korail* slum. However, for these tools to be effective, it is crucial to address the existing barriers related to awareness, privacy, cultural sensitivity, and usability. By focusing on educational initiatives, robust data protection, cultural adaptation, user-friendly design, and community engagement, DP can become a significant tool in bridging the mental health care gap in LMICs. Further research is needed to develop and implement these solutions in a way that is both effective and sustainable.

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Abbreviations:

FGD: Focus Group Discussion HIC: High-Income Country

LMIC: Low- and Middle-Income Country

SMD: Serious Mental Disorder

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