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Opportunities to improve digital adherence technologies and TB using human-centered design

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Dear Editor,

Digital adherence technologies (DATs) have emerged as a promising solution for supporting and supervising patients being treated for tuberculosis (TB). Despite considerable enthusiasm and wide-scale implementation (1), few clinical trials and programmatic data have demonstrated improvement in treatment outcomes and shown variable uptake and engagement by patients and providers (2–6).

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Human-centered design (HCD) is a well-established methodology for need finding and innovation that can be used to improve adoption and implementation challenges that have impeded the impact of DATs. HCD utilizes qualitative research methods to understand the values and motivations of users, and to systematically incorporates user input into the design or adaptation of products and interventions (7, 8). We applied the HCD methodology to characterize adherence challenges facing TB patients and identify opportunities to adapt 99DOTS – a low-cost DAT (9)– to better address these challenges.

We conducted a qualitative study utilizing the HCD methodology at 8 TB treatment units in Uganda. We purposefully sampled potential users of the 99DOTS platform (n=67), including TB patients (n=11), family members (n=5), health center staff (n=36), community health workers (n=7), and community leaders (n=8). Qualitative data were collected through semi-structured interviews involving open-ended questions about the experience of receiving and providing TB care and the challenges and enablers associated with TB medication adherence. Data analysis involves three steps: 1) Inductive identification of evolving thematic categories from review of interview transcripts; 2) Developing ‘insight statements’ based on an extrapolation of the themes; and 3) Translating each insight statement into an actionable ‘design opportunity’ (10, 11).

We identified 17 themes that supported seven main insights and associated design opportunities (Table 1) for the adaptation of 99DOTS.

Insight 1: Social stigma may be feared as much as the disease.

TB remains a highly stigmatized disease, with many patients going to great lengths to keep their diagnosis hidden. This occurs, in part, because the information about TB is often limited to its association with HIV, witchcraft, or the belief that TB portends death. As a result, TB patients described wanting to conceal any association with the disease. To address stigma, the design opportunity was summarized as: Make TB treatment discreet by avoiding non-conspicuous labels and visuals.

Insight 2: Packaging is used as an ad hoc and accidental reminder system.

Patients and health workers described using pill packaging as a reminder to return to clinic for refills or appointments. Missed doses in this context can results in patients waiting unnecessarily until the package is empty delaying refill appointments and engagement with health workers who are essential to monitor and encourage adherence. In addition, we observed patients removing pills from blister packs in random order – a serious potential problem with the 99DOTS system. To improve packaging, the design opportunity was summarized as: Guide sequential pill taking behavior and accurately track treatment milestones.

Insight 3: Health is defined by a return to normal strength and capability, which occurs before treatment completion.

Strength and productivity were highly valued by patients. The physical frailty resulting from TB prevents patients from contributing to their family and community. Many patients state their personal treatment goal is to be able to regain their strength to return to work

or care for their families. However, once patients regain their strength, their adherence to their medication lessens. To improve adherence, the design opportunity was summarized as: Reinforce the importance of treatment completion to sustain health at every point of contact.

Insight 4: Feeling a personal connection with healthcare workers is as important as receiving medical care.

TB patients trust and rely on health workers as partners in their treatment. TB patients are motivated to please their health care workers and greatly value their praise. Both health workers and TB patients are committed to maintaining and enhancing this human connection. To improve human connection, the design opportunity was summarized as: Leverage the relationship between patients and community health workers to personalize the treatment experience.

Insight 5: Local messages feel authentic; endorsements by famous figure heads are viewed with suspicion.

Patients were interested in, but not motivated by, health-related messages from celebrities such as politicians, sports figures, and religious leaders. Patients did not trust the messaging and believed it came from organizations that do not have their best interests in mind. Conversely, patients trusted their local health workers, who often conducted educational sessions where current TB patients could learn from cured TB patients from their community. To improve messaging, the design opportunity was summarized as: Incorporate authentic and personal adherence messages from the local community in the TB treatment program.

Insight 6: Patients are motivated by service to their community, but do not have enough knowledge to be maximally effective.

One reason patients seek treatment is to protect their community and family from contracting TB. Given the stigma around TB, patients lack sufficient information about treatment and how to prevent spread. Patients want and need more education on TB to share with their community. To improve knowledge, the design opportunity was summarized as: Empower individuals to be community stewards of infection control practices through language and literacy appropriate education.

Insight 7: Words and visuals can have multiple interpretations and an unintended negative impact on adherence behavior.

Patient reminders are often coded to protect patient confidentiality and minimize stigma, but the unintentional downside can be literal interpretation of coded messages. Patients were particular about word choice and visuals and followed medical providers' instructions literally. For example, participants noted that if instructed to take medicines with food, some patients without food at home would not take their medications. To improve communication, the design opportunity was summarized as: Communicate clearly and accurately with simple graphics and culturally and linguistically appropriate text.

Using HCD – which places users at the forefront of design – we focused on how DATs can meet the needs and challenges TB patients face in adhering to TB treatment. Through

a process of in-context ethnographic interviews and observations, we synthesized a set of broadly applicable key insights that were then translated into design opportunities for adaptation of 99DOTS, with the ultimate goal of improving the patient experience of TB treatment. While changes to DATs alone will not address all of these insights, they help create a roadmap to the ways in which to facilitate a better treatment experience and process overall.

The insights outlined in this study illustrate a number of themes previously identified in the literature (7). We also identified additional emotional factors, such as mistrust of celebrity endorsements and motivation to please health workers, that can inform visuals and messaging incorporated into DATs in Uganda. Additionally, we found a number of structural barriers to adherence that can be ameliorated by incorporating design features that avoid common misinterpretation of dosing instructions.

In summary, HCD provides a structured process and set of tools that researchers and public health practitioners can use to adapt and tailor current and novel DATs to better address user-centered barriers. Ultimately, prioritizing the needs of users should lead to greater engagement with DATs and higher levels of adherence and treatment completion.

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REFERENCES

1. KNCV. Digital Adherence Technologies The Netherlands2020 [updated Jan 21, 2020. Available from: https://kncvtbc.atlassian.net/wiki/spaces/ADHERENCE/pages/222494774/Digital+Adherence+Technologies.
2. Subbaraman R, de Mondesert L, Musiimenta A, Pai M, Mayer KH, Thomas BE, et al. Digital adherence technologies for the management of tuberculosis therapy: mapping the landscape and research priorities. BMJ Glob Health. 2018;3(5):e001018.
3. Liu X, Lewis JJ, Zhang H, Lu W, Zhang S, Zheng G, et al. Effectiveness of Electronic Reminders to Improve Medication Adherence in Tuberculosis Patients: A Cluster-Randomised Trial. PLoS Med. 2015;12(9):e1001876.
4. Thakkar D, Piparva KG, Lakkad SG. A pilot project: 99DOTS information communication technology-based approach for tuberculosis treatment in Rajkot district. Lung India. 2019;36(2):108–11. [PubMed: 30829243]
5. Yoeli E, Rathauser J, Bhanot SP, Kimenye MK, Mailu E, Masini E, et al. Digital Health Support in Treatment for Tuberculosis. New England Journal of Medicine. 2019;381(10):986–7.
6. Thomas BE, Kumar JV, Chiranjeevi M, Shah D, Khandewale A, Thiruvengadam K, et al. Evaluation of the accuracy of 99DOTS, a novel cellphone-based strategy for monitoring adherence to tuberculosis medications: Comparison of digital adherence data with urine isoniazid testing. Clinical Infectious Diseases. 2020.
7. Brown T. Change by Design: Harper Business; 2019.
8. Bazzano AN, Martin J, Hicks E, Faughnan M, Murphy L. Human-centred design in global health: A scoping review of applications and contexts. PLOS ONE. 2017;12(11):e0186744.
9. Cross A, Gupta N, Liu B, Nair V, Kumar A, Kuttan R, et al. 99DOTS: a low-cost approach to monitoring and improving medication adherence. Proceedings of the Tenth International

Conference on Information and Communication Technologies and Development; Ahmedabad, India: Association for Computing Machinery; 2019. p. Article 15.

10. IDEO.org. The Field Guide to Human-Centered Design. Design Kit [Internet]. 2012; 37:[131 p.]. Available from: https://www.designkit.org/resources/1.
11. IDEO U. Why Generating Insights is an Important Skill: IDEO U; 2019 [Available from: https://www.ideou.com/blogs/inspiration/why-is-generating-insights-an-important-skill.

Table 1:

Insight Statements, Supporting Themes, and Design Opportunities

Insight 1: Social stigma may be feared as much as the disease.

Design Opportunity 1: *Make TB treatment discreet by avoiding non-conspicuous labels and visuals.*

Theme 1a: TB is a highly stigmatized disease.
Quote: "Now TB is a disease that brings stigma…Once they are diagnosed then they must use separate cups, they must not interact with community members, until after a period of time. So people fear… They will be isolated from the rest." – HCW

Theme 1b: Patients hide their diagnosis and any TB-related artifacts from their communities.
Quote: "I haven't told anyone, not even my husband…I decided to stay silent…. I decided not to say anything because for him he thinks that anyone who has TB has HIV as well. I fear if I told him he would stop supporting my family." –Patient

Theme 1c: Being associated with TB is a barrier to treatment.
Quote: "…they don't want to be seen [with TB medicines] so they put it somewhere else." –Patient

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Insight 2: Packaging is used as an ad hoc and accidental reminder system.

Design Opportunity 2: *Guide sequential pill taking behavior and accurately track treatment milestones.*

Theme 2a: Empty pill packages are used as prompts to return to clinic.
Quote: "I don't keep appointments at all…my last appointment was in July, but I still have drugs, so I didn't go" –Patient

Theme 2b: Patients have no formal reminder system for tracking daily treatment.
Quote: "The children are always encouraging me to take the pills and…if they don't remind me, I forget to take them"– Patient

Theme 2c: Patients may not systematically take their medication in order.
Quote: "Ugandans take pills wherever their finger falls." [Health worker moves finger all over the blister pack] –HCW

Insight 3: Health is defined by a return to normal strength and capability, which occurs before treatment completion.

Design Opportunity 3: *Reinforce the importance of treatment completion to sustain health at every point of contact.*

Theme 3a: Ugandan patients prioritize strength, productivity and the ability to work.
Quote: "After I finish my treatment, I was hoping…to continue to pursue my career by then…" –Patient

Theme 3b: Treatment adherence declines when patients feel better.
Quote: "At the beginning I used to take it well but when I started feeling better…I started giving myself some breaks." –Patient

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Insight 4: Feeling a personal connection with healthcare workers is as important as receiving medical care.

Design Opportunity 4: *Leverage the relationship between patients and community health workers to personalize the treatment experience.*

Theme 4a: Patients trust and rely on healthcare workers.
Quote: "My health worker's voice is the best… I want to listen from the health worker is asking me how [I] am feeling." –Patient

Theme 4b: Patients want to please and be praised by their health workers.
Quote: "He is most happy if the health worker says he is healthy and better." –Patient

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Insight 5: Local messages feel authentic; endorsements by famous figure heads are viewed with suspicion.

Design Opportunity 5: *Incorporate authentic and personal adherence messages from the local community in the TB treatment program.*

Theme 5a: TB-related messages from celebrities and politicians are not trusted.
Quote: "If a TB patient showed another patient all they got was a picture [of a celebrity] they might say 'this is all I got!'…they have had problems with people getting conned so you must make sure people don't think it is a con." –Community Leader

Theme 5b: Patients are motivated by messages from health workers and community members who have been cured of TB.
Quote: "[Audio messages should come from] The health worker - a message about recovering, around getting cured." –Patient

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Insight 6: Patients are motivated by service to their community, but do not have enough knowledge to be maximally effective.

Design Opportunity 6: *Empower individuals to be community stewards of infection control practices through language and literacy appropriate education.*

Theme 6a: Patients want to protect their family and community from TB.
Quote: "…I don't know how I can protect him as my friend, how I can protect the next kin to me, how I can protect the next sister to me…" –Patient

Theme 6b: Patients want to be knowledgeable about TB.
Quotes: "They always ask about infection control, in particular – sharing plates and cups...Even patient co infected are wondering about all the

drugs, won't they affect me? Or about the side effects, can I stay together with my spouse/children, about the household, the other big question is will I be cured?" –HCW

Insight 7: Words and visuals can have multiple interpretations and an unintended negative impact on adherence behavior.

Design Opportunity 7: *Communicate clearly and accurately with simple graphics and culturally and linguistically appropriate text.*

Theme 7a: Patients interpret instructions literally.
Quote: "Someone who had nothing to eat so they stopped [taking med] because they couldn't take on an empty stomach." –HCW

Theme 7b: Patients lack accurate and sufficient information to around TB.
Quote: "One must have enough food to take the treatment. Someone will say please I don't have food to take this treatment. Next time they missed the treatment so they say it is b/c I didn't have anything to eat." –HCW

Theme 7c: Unfamiliar or outdated words or visuals were confusing to patients.
Quote: "We don't say medication, we say tablet." –HCW

Abbreviations: TB, tuberculosis; VHT, village health team; HCW, health care worker