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Barriers to Mental Health Service Utilization Among TB and Diabetes Patients in Karachi, Pakistan

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Abstract

Tuberculosis and diabetes have high comorbidity with depression and anxiety however service uptake for mental health is limited. This study explores perceptions about mental health and illness and the factors influencing the uptake of mental health services for TB and diabetes patients.

Between Oct-Nov 2017, semi-structured focus groups and in-depth interviews were conducted with 65 individuals, study participants included tuberculosis and diabetes patients, community members and healthcare practitioners.

Guided by the Andersen behavioral model of health service utilization, themes were categorized as enabling, predisposing and need factors. Major factors influencing uptake of mental health services included a lack of awareness regarding mental health issues and availability of services for mental health treatment. As well as sociocultural factors such as religious beliefs, reliance on faith/spiritual healers and social support.

This study identifies a major need for culturally sensitive awareness raising and community outreach programs to help eradicate this gap.

Introduction

Mental health disorders are becoming an increasing global concern. The World Health Organization [1] estimates that 4.4% of the global population suffers from depression, believing it to be the single largest contributor to global disability (7.5% of all years lived with disability in 2015). In Pakistan, prevalence estimates for depression and anxiety are 4.2% and 3.5 percent respectively. Given that the population of Pakistan is approximately 207.7 million [2], these numbers indicate that nearly 16 million people may have depression or anxiety.

While major depression seems to affect the general population at a high rate, the degree to which it affects individuals with medical illnesses, such as Tuberculosis (TB) and diabetes, is much higher [3,4,5].

Underlying mental health conditions can negatively impact health outcomes due to increased risk of relapse or non-adherence [6,7,4]. Given that TB and diabetes are major public health concerns within Pakistan, the WHO [8] estimated Pakistan to be the 5th highest TB burden country globally. With the national prevalence for diabetes in adults estimated at 13% [9], it is imperative to address mental health issues within these populations.

However, both demand and supply side factors have led to a substantial treatment gap for mental health. Treatment for mental health issues is allocated a minute proportion of resources. The total expenditure on health per person is USD 37; of which mental health expenditure per capita is USD 0.01 [10] In terms of qualified personnel, there is one psychologist or psychiatrist per 200,000 people [11].

The paucity of resources, however, is not the only factor contributing to the mental health treatment gap in low and middle-income countries like Pakistan [12]. Highlighted that even when there are mental health services available, 75% of those in need do not avail these services.

There are myriad reasons for the underutilization of mental health services, including stigma as well as other societal and cultural beliefs, and attitudes [13]. Perceptions, beliefs and attitudes towards mental health can vary greatly between cultures [14] and these factors directly influence the uptake of mental health services as well as the choice of treatment for mental health problems [15].

Considering the proportion of the populace impacted by TB and diabetes in Pakistan, it is important to understand the barriers from a population health systems point of view in order to develop better policies and structures that can reduce treatment default, non-adherence and death rates. We conducted a qualitative study to explore perceptions about mental health and mental illness, as well as the barriers to the uptake of mental health services faced by TB and diabetes patients, caregivers and healthcare providers.

Methods

Setting

This study was carried out at a large, free-of-cost, private tertiary care hospital in Karachi, Pakistan. The individuals seeking care at this hospital as well as the catchment population typically consist of low to lower middle income individuals from diverse ethnic backgrounds.

Population

Target population included individuals seeking care at the facility for TB and/or Diabetes, their caregivers and healthcare providers working with these populations.

Recruitment

Between October-November 2017, participants for the study were recruited using convenience-based sampling. Patients seeking care for TB and Diabetes at the hospital site were identified via hospital records. Healthcare providers were identified through the human resource rosters and community members were recruited from the waiting areas for caregivers in the hospital. Selected candidates from the patient and healthcare provider pool were first contacted via phone and were invited to participate in either a single Focus Group Discussion (FGD) or an In-Depth Interview (IDI). Community members were approached directly within the waiting areas of the hospital. The FGDs and IDIs took place at either hospital itself, or the project teams' office or another private space mutually decided upon. All sessions were audio recorded and were approximately 40-60 minutes long. The discussion questions focused on individual and community level knowledge, attitudes and practices regarding mental health and participants were advised not to disclose any personal mental health issues or experiences. All participants were also offered the option of availing free of cost mental health counselling in the event that the discussion caused any distress. All participants were ≥18 years of age and able to speak Urdu.

Data analysis

Audio recordings were transcribed verbatim and translated into English. Both the transcriptions and translations were cross-verified for accuracy by the project team. The translated documents were de-identified and uploaded into the qualitative software Dedoose (Version 7.5.16; 2017). A preliminary codebook was constructed based on a review of the translations. Content analysis was performed and the transcripts were coded according to the identified thematic areas. Upon completion of the coding, all quotes corresponding to each of the codes were extracted into matrices and organized according to the major emergent themes.

The data analysis was guided by the Andersen Behavioral Model of Healthcare Utilization [16], a well-established conceptual model aimed at illuminating the factors that impact the utilization of healthcare services. Data extracted into the matrices was consolidated and inculcated into the adapted conceptual framework **(Figure 1)** with major themes categorized as "Enabling" "Predisposing" and "Need" factors.

Results

A total of 10 FGDs and 12 IDIs were conducted using a semi-structured guide **(Table 1)** with 65 individuals (26 males; 39 females). The participants consisted of patients seeking treatment for TB (n=22), Diabetes (DM) (n=19), and patients with both TB and DM (TBDM) (n=9), healthcare practitioners (n=6) as well as community members (n=9) **(Table 2)**. The qualitative results are presented by each of the Anderson Behavioral model themes (Figure 1): Predisposing, Enabling and Need factors and their commensurate subthemes, labeled by interview type (IDI or FGD); patient type (TB, DM, TBDM) or non-patient type (Community Member [CM] or Healthcare Practitioner [HCP]); and, age group and name (patients only). Supplemental quotes supporting these results can be found in **Table 3**.

Table 1: Representative Questions and Probes for Focus Group Discussions and In-Depth Interviews for patients, healthcare practitioners, and community members in Pakistan.

Thematic Domains	Questions and Probes
Perceptions about Mental Health	- What do you think is mental health?
	o What are the signs or characteristics of a healthy mind?
	o How can we tell that someone has mental illness?
Coping Mechanisms	- How can an individual cope with mental illness?
	- Do the mentally ill people take any steps to feel better?
Treatment Options	- If someone is mentally stressed or ill, whom do they go to for help?
	- Are there any services available in the community to help people affected by mental illness?
	o What kind of services can be provided to those who are mentally ill?
Challenges	- What impact does mental health have on a person's life?
Facilitators and Barriers	- What factors help to achieve mental health?
	- What are some obstacles in obtaining mental health?

Table 2: Demographic Characteristics of FGDs and IDIs Participants (Patients, Healthcare Practitioners and Community Members; N=65).

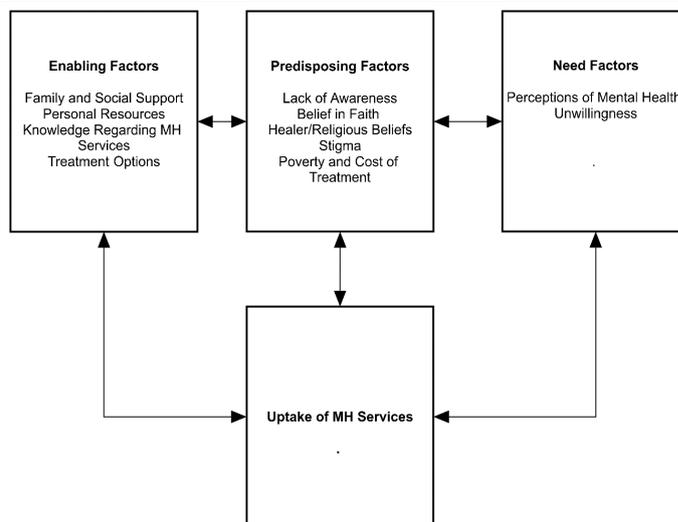|	No. of Participants		Mean Age	
	Male	Female	Male	Female
TB (Patients with TB)	10	12	39.6	28.7
DM (Patients with Diabetes Mellitus)	4	15	47.5	47.8
TBDM (Patients with TB and DM)	6	3	49.7	44.3
HCP (Healthcare Practitioners)	2	4	22.5	26.3
CM (Community Members)	4	5	32	27.4
Total	26	39	40.9	37.1

Figure 1: Conceptual Framework for Seeking Mental Health Services [16].

Table 3: Supplementary quotes from Focus Group Discussion and In-Depth Interviews for patients, health care practitioners and community members.

Factors	Theme	Sub-Theme	Quote
Predisposing Factors	Lack of Awareness		Q: Tell me do you think there is something known as mental illness? X: I don't know. Q: You know how there is physical illness, is there also something as mental illness? X: Nature would know it best. I do not have much knowledge... Q: Can it exist, in your understanding? X: It might be possible..." - IDI-TB-Female-Above 50
	Belief in Faith Healers/Religious Beliefs		"They [individuals suffering from mental health problems] think that something has happened to them so they take them to faith healers. There are some who do not believe in doctors." - IDI-HCP-Female
	Stigma		"That happens because people feel that if we ask someone for help then they probably will not understand or they might ridicule." IDI-TB-Female-Below 50
Enabling Factors	Family and Social Support		"The environment at home.. Husband does not allow. [Why?] He just has his own mind."
			- IDI-DM-Female-Above 50
			"But if we sit near someone, talk to them, go out in open air, then our mind would change a bit, get better... I have brothers and sisters. My younger sister talks a lot and keeps teasing me even though I am sick but she still teases me... She asks me to talk and laugh. I like it when she teases me but I still don't talk and she asks me to talk."
			- FGD-TB-Females-Below 50
Need Factors	Personal Resources		"You will have to keep yourself fresh.. will have to distract your mind here and there... look at yourself.. will become fine."
			- IDI-DM-Female-Below 50
	Knowledge regarding Mental Health Services		"Not in my knowledge, there must be... if they are working on different ailments then definitely some work must be going on this [mental health] too."
			IDI-DM-Male-Below 50
	Treatment Options	Effectiveness of Treatment Options	"No. In my vicinity, I don't see any such centers. And secondly, even if you go to a doctor, he over-exaggerates your illness... ohhh you have this ohhh! You should treat the patient correctly. • IDI-CM-Male "Q: ...Do you think there should be any such thing [mental health services]? E: Yes, there should be but who will go to it? What use will it be of?" - IDI-TB-Male-Below 50

		Desired Treatment Options	"Q: ...if we have to improve mental health in your area, in your home, in your neighborhood what can we do? In your opinion what can we do? G: What you can do is, you can help us. Q: What kind of help? G: You can provide us good treatment. Q: Good treatment? G: In the way that if we have to talk, so we can share with you and tell you." - FGD-TBDM-Males
Perceptions of Mental Health		Signs of Healthy Mind	"That in which you can work without stress, be relaxed and able to manage things... which doesn't create problem in doing any work, like you work in a lot of stress and tension." - FGD-HCP
		Signs of Unhealthy Mind	"The mind starts thinking rubbish, gets angry all the time... getting angry over minor things...don't like anything." -FGD-TB-Females-Below 50

Major themes

Predisposing factors

Lack of awareness. Participants reported a lack of awareness regarding mental health issues whereas many did not identify mental health issues as something that they should seek help for.

Interviewer: "Hmmm...so what will be the cause of them [people experiencing mental health issues] not going?" Participant: "They tell themselves that there is nothing wrong with them and that they are fine."

-	IDI-TB-Female-Below 50

Interviewer: "There are also times when one doesn't want to help oneself? Why does it happen? What do people [experiencing mental health issues] think?"

Participant: "They just think that if life is going on like this then let it be."

-	IDI-TB-Female-Above 50

Belief in Faith Healers/Religious Beliefs. People's beliefs appeared to play a major role in determining their help-seeking behaviors. Due to religious inclinations, several participants mentioned that they would opt to seek help from faith healers instead of going to mental health professionals. *"In our society, patients reach the hospital when it is already too late. First, they are stuck with these faith healers and their talismans [who] say this will happen, that will happen; and by then it is too late."*

-	IDI-TBDM-Female

Participants also expressed their reliance on divine interventions in times of distress with the notion that a person's suffering is from God so the solution also comes from God.

"...sometimes friends come and we sit, so it seems like they are worried. When I ask, they tell me this way/that way there is a problem going on in their home. I say God willing, God will definitely work things out for the better. Worries come from God. Things will work out for the better."

-	IDI-CM-Female

-	*"...the best is to talk to God. He can do everything... and He doesn't reveal anyone's secrets, nor does He ask for anything in return...[the] best approach is to ask from God and approach God."*

-	FGD-TB-Males-Below 50

Stigma. Another barrier identified was stigma. Many did not want to verbalize the problems they were facing citing fear of ridicule from family, friends or the community at large as the reason. Moreover, for many, the concept of experiencing mental health issues was linked to the fear of being labeled "insane".

"...even if I have a mental issue then I'd avoid sharing it because people will start considering me crazy and nobody likes to be called crazy. There is also a bit of a fear in people that I may go to such an institute...that people might call me crazy, might call me psycho.

This is very common here that someone does a minor thing and they say, "Go away psycho!"

-	IDI-CM-Male

"That happens because people feel that if we ask someone for help then they probably will not understand or they might ridicule."

-	IDI-TB-Female-Below 50

Poverty and cost of treatment. A dearth of financial resources was also mentioned as an impediment to seeking mental health treatment.

Interviewer: "Do you think there are any centers in our society that help such people?"

Participant: "Yes, there are a lot of centers that help but I cannot go there."

Interviewer: "Why?"

Participant: "Because they ask for money and that I do not have."

-IDI-DM-Female-Above 50

"When you are born in a poor family then where can you find mental peace? Someone is worried about the food, someone is worried about the rent, someone is worried about their job... actually God has given mental peace to those who have money. Where would we find mental peace?"

-	FGD-TB-Males-Above 50

Enabling factors

Family and social support. Participants identified sharing their problems and seeking help from family members, friends,

and people they are close to as one way to manage their mental distress and problems.

"... If you share, you can find a solution... Thinking maybe my mind was not working properly but the other person's mind may work and I might find a better solution..."

- IDI-TB-Male-Below 50

However, some participants reported the opposite. According to them, those who are willing to seek help are held back by family or friends due to a lack of understanding or awareness. *"I kept on saying take her to some psychiatric doctor. There should be something to fix this, but everyone thought that I was joking, or scaring them."*

- IDI-TBDM-Female

Personal resources. Whereas reliance on others was identified as one of the coping mechanisms, some participants also indicated self-help as a way of dealing with their mental distress instead of seeking external means of coping.

"Self-help is when a person would make his mind peaceful and won't let anything negative enter in his mind and he will feel happy... if he doesn't have friends then he can go and sit in the park, somewhere cool, and shouldn't think about worries... this will help get rid of the worries."

- FGD-TB-Males-Above 50

Knowledge regarding mental health services. Lack of knowledge regarding mental health services was recognized as another barrier in the uptake of mental health services. Many participants seemed to be unaware regarding the availability of mental health services.

"Yes, there are such people near our place who help get married... neighbors come over... we talk to them then it gives a temporary relief. But no one is there for mental health."

- FGD-DM-Females-Above 50

Question: "So you talked about the therapist, do you think that there are enough services in our society and in our community that can help people who have some sort of mental illness?" Participant: "Are you talking about professional therapists? Ummm... No!"

- IDI-HCP-Female

Effectiveness of treatment options. While identifying the available mental health services, participants expressed ambivalent opinions regarding the effectiveness of these services. *"These doctor people...they have links with people who sell medicine. They don't consider a patient as a patient but a customer. Now when a patient becomes a customer then you can yourself imagine how their treatment will be... Not all doctors are like this but you must have heard that one bad fish can spoil the whole pond. So, not all doctors are like this... after seeing the patient, they start his treatment and I have also seen people getting healthy."*

- -IDI-CM-Male

Interviewer: "Is this [mental health] service helpful?" Participant: "In my opinion, yes." Interviewer: "And how does it benefit you?"

Participant: "The person feels at peace, they tell their issues to someone else... The problems they cannot share with anyone, they tell you [mental health personnel] that so it was very beneficial for me, right, what I could not share with anyone else, I shared with you, this is beneficial."

- IDI-TBDM-Female

Desired treatment options. Participants suggested different ways through which mental health services can be provided. Having someone to listen to one's problems and helping to deal with them was identified as one of the most desired treatment options.

"...someone we can go talk to, share our problems with. Tell them our problems and whatever we tell them remains secret."

-FGD-TBDM-Females

"...for people who want to avail this service, there should be an office or clinic where there are people who you can share your things with, who cannot talk to anyone, can go there and discuss their issues, troubles and problems."

-IDI-TBDM-Female

Need factors

Perceptions of mental health. Perceptions regarding mental health centered on the concept of either a healthy mind or an unhealthy mind and symptoms of mental health problems.

Signs of a healthy mind. Participants defined being mentally healthy as equivalent to a life that is peaceful and stable. According to them, if a person was free from tension and stress and able to function in his daily life effectively then s/he is regarded as a mentally healthy individual.

"There is peace, everything is good, a person is fine... there is no tension so a person is fine... no illnesses."

IDI-DM-Female

Signs of an unhealthy mind. Many spoke about their perception of mental health in the context of experiencing mental health issues such as disruptions in routine, an inability to focus and function effectively, mood swings and withdrawal from friends and family.

"My mind doesn't work... I keep forgetting things... I don't even realize what I am saying, then my daughter reminds me what I had to say... my mind doesn't work... my mind is completely ruined."

-IDI-TB-Female

"When [the patient] becomes depressed, his eating, etc., everything will change; his timings will change, his sleeping timings will change. The way he used to talk to people previously, now won't do that, etc."

-IDI-HCP-Female

"...I become quiet...I do not talk to anyone...I stand here or sometimes I go stand there. I try to involve myself in something else. I never used to get angry at anything but now I feel angry also."

- IDI-TBDM-Female

Unwillingness. Unwillingness to seek mental health services also appeared to be an influencing factor for the uptake of mental health services. Participants expressed doubts with regards

to the usefulness of such treatment options.

Interviewer: "Do you think there should be any such thing [mental health services]?"

Participant: "Yes, there should be but who will go to it? What use will it be of?"

Interviewer: "Yes, right..."
Participant: "Yes, who will agree, who has that much time?

-IDI-Male-TB-Below 50

Discussion

Guided by Andersen Behavioral model of health service utilization [16], our study results suggest a significant knowledge gap within disease populations (TB and DM) and healthcare providers regarding mental health and mental health services in Pakistan. Many people do not identify mental health issues as something that requires professional treatment. Moreover, certain sociocultural factors negatively impact help-seeking behavior.

In our study, understanding of mental health was dichotomously expressed: it was described as either having a 'healthy' mind that denoted stability and functionality or having an 'unhealthy' mind; a state described in terms of symptomatology, indicating a lack of understanding mental health on a continuum [17]. Moreover, compared to the research done in East Africa whereby individuals misjudged the common signs and symptoms of mental illnesses as those of physical illnesses [18] we found that while most people were accurately able to describe the common signs and symptoms associated with mental illness, many failed to reconcile these symptoms with having a condition that required seeking professional help. The lack of awareness and understanding of mental health can thus act as a predisposing factor and can lead to identification and treatment gaps.

Furthermore, our results indicated that while some desired professional mental health services, they seemed to be unaware regarding the availability of these services within their vicinity or even the existence of such services at all. This was not only the case for patients and community members but also for some healthcare practitioners. The knowledge gap on the part of healthcare practitioners is concerning as general physicians and primary care centers frequently become the first point of contact when a need for professional aid is identified. A sensitization and awareness campaign targeted at healthcare practitioners can thus be an important step in strengthening the overall mental health care system in the country.

 [19] Also found that while patients knew about the availability of medicines for mental illnesses, they were not aware of the other treatment options, hence seeking help for MH issues is usually directed towards medical sector professionals whereby first-line access is medication [20]. Since several of our participants expressed the desire for such services, bridging this knowledge gap may enable the utilization of mental health services.

Moreover, in lieu of professional help, many individuals attempt to use personal resources to cope, or opt for family and social support as a treatment option instead of seeking professional help. Similar to when it comes to medical health issues, it may be that people consider commonly prevalent mental health issues as treatable at home with social support and would only seek professional help if the symptoms are perceived as severe. This was also deduced by [21] who found that study participants recommended family care as a preferred treatment option for mental illnesses.

Family and social support can be both an enabling factor and an impediment towards seeking mental health care. This can potentially be amplified in communities with collectivist cultures such as Pakistan where family members frequently have a significant involvement in all aspects of an individual's life. According to [20] this constitutes a cognitive barrier whereby the mere act of seeking MH services is based on culturally informed conceptions shared by a group of individuals. A supportive family can propel an individual towards seeking care, however, research suggests often, family members either fail to identify or understand the signs of mental distress and thus tend to ignore them or try to keep the signs and symptoms hidden due to the fear of stigmatization [22].

This collectivist culture can also contribute to the fear of stigmatization [23], which in itself can be a major predisposing factor that acts as a barrier. During the interviews, many people expressed fear and hesitancy attached towards seeking mental health care due to the negative attitudes and reactions they might face from people in their surroundings.

Religious inclinations also seem to heavily influence help seeking behavior. Our analysis showed that many people believed that the way to cope with mental health issues is to ask God for help. Some people mentioned that these issues themselves are from God, therefore, He [God] is the only one who can provide relief, thus they rely on prayers as a coping mechanism. Religious leanings can also lead people to seeking help from faith healers as opposed to medical professionals [24].

Such beliefs hinder seeking professional help as these may encourage waiting for the problems to get resolved themselves through the power of prayer and divine intervention. These barriers and cultural beliefs will have to be taken into consideration when designing awareness programs to help overcome these barriers. Moreover, the buy-in of faith healers and integrated modes of care may prove to be a worthwhile strategy.

Perceived effectiveness of mental health services also plays a part in its utilization. There were some who expressed positive opinions regarding the effectiveness of mental health interventions. Citing the benefits, they expressed that it mainly helps with the unburdening of their problems. The positive perceptions regarding the effectiveness of treatment can be translated into a greater willingness to seek treatment making it an enabling factor. The importance of the role of caregivers and healthcare practitioners in fostering positive perceptions regarding treatment initiation and adherence has been highlighted in multiple studies [25, 26]. However, some expressed doubts regarding effectiveness as well as about doctors and medical practitioners in general. A few participants displayed a certain apathy and indifference towards mental health and mental health treatment. According to them, seeking help from a professional is a stress in itself as they usually tend to exaggerate the symptoms whereas some also appeared to underestimate the symptoms of mental health issues and thus did not think it significant enough to seek a professional's help. The negative perceptions, especially in caregivers and TB patients, may further perpetuate the tendency to go to faith healers despite the uncertainty of treatment success.

The paucity of financial resources can also pose a barrier to seeking mental health treatment. Poverty is a commonly shared risk factor for individuals affected by clinical depression [1] diabetes [27] as well as TB [28]. Hence, separately or together, all three conditions [TB, diabetes and depression], can worsen poverty by causing functional impairments to seeking employment with composite treatment costs [29,30]. It was described as a mental stressor and the lack of resources combined with other factors such as the knowledge gap and inclination towards self-contained coping strategies, seeking help for mental health issues becomes relegated as low priority. It is worth noting that in terms of frequency the cost of treatment was not cited as a barrier as often as expected, however, this can be because many people are unaware of this as a treatment option to begin with.

Implications for policy and practice

Our study identifies major barriers to mental health service uptake for TB and diabetes patients. Strategies tackling these barriers should be considered as an integral part of programs design for these populations.

Conclusion

It is apparent from our findings that a comprehensive awareness campaign is required which, alongside educating people about mental health, should give particular attention to helping people identify the points at which help is sought. Moreover, it should disseminate information pertaining to availability of the low-cost mental health services in different areas. Program design should also be culturally sensitive and should take into account factors such as family influence and religious leanings in order to be effective.

Identifying and building collaborative relationships with community leaders, healthcare practitioners, and faith healers should also be considered as a key community engagement strategy, as these groups can play a crucial part in mobilizing people to seek appropriate help which can increase uptake and help change community attitudes.

Limitations

Nearly all the participants excluding some healthcare practitioners were residents of one locality in Karachi, which is one of the six districts in Karachi and belonged to a low or lower middle income socioeconomic background. A sample consisting of participants from all six districts of Karachi and with greater socioeconomic diversity should be considered for future studies to provide a more comprehensive picture. Furthermore, the number of participants per group was also unequal due to the high dropout rate mostly found in disease populations (TB and Diabetes) and their caregivers.

Lastly, most participants belonged to a clinical population hence, the findings cannot be generalized to the non-clinical population.

Ethical statement

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. Ethical approval for the research was obtained from the Institutional Review Boards of Harvard Faculty of Medicine (IRB16-1334) and Interactive Research and Development (IRD_IRB_2016_05_002).

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