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Patient Perceptions Of Machine Learning-Enabled Digital Mental Health

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ABSTRACT

Title: Patient Perceptions of Machine Learning-Enabled Digital Mental Health

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Objective: The mental health crisis is accelerating, with 55.8M American adults in treatment in 2022. Digital mental health is a growing field with implications for mental health care. The objective of this study was to understand patients' mental health treatment experience and the relationship with their perspectives of a novel digital health product geared toward improving care quality.

Methods: In December 2023, an IRB-exempt questionnaire was sent to undergraduate and graduate students at campuses across the North-East United States, as well as healthcare-focused Slack® groups.

Results: Of the 1,127 respondents, 28% were actively in treatment for their mental health, 25% were treated in the past, and 1% was on a waiting list. Of those with treatment exposure currently or in the past, 85% experienced challenges with communication during their clinical encounter. Among those, 69% experienced a negative emotional impact, began avoiding care, or even terminated care. Over half (57%) currently use or have used a digital health product. With an overview of the novel

digital health product, 71% were Very Likely to share data related to sleep and 62% were Very Likely to share activity data. There was a statistically significant association between treatment exposure and likelihood of data sharing (for Sleep: chi squared χ^2 ($df = 2$, $n = 1,124$) $= 14.03$, $p = 0.001$; for Activity: χ^2 ($df = 2$, $n = 1,121$) $= 22.13$, $p < 0.001$). Fewer respondents were Very Likely to share sleep and activity compared to expected frequencies if they had exposure to treatment with challenges. For mobile application retention, 351 respondents would fill out a 2–3-minute survey daily and 541 would consider it.

Conclusion: There exists a Data Gap between patients and clinicians, driven by communication challenges that impact the care experience for patients. There exists a clear role for a digital health product that addresses the Data Gap to improve care quality, assuming privacy concerns and patient retention incentives are addressed and implemented.

ACKNOWLEDGMENTS

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INTRODUCTION

In 2022, there were 59.3 million American adults with Any Mental Illness (AMI).[1] Around 55.8 million received past-year mental health treatment; among those that were treated, 30.0 million (M) had AMI and 25.9M had no mental illness per the National Survey on Drug Use and Health (NSDUH).[2]/2/24 4:17:00 PM Treatment settings varied, with 35.1M (63%) receiving outpatient treatment, 38.9M (70%) receiving a prescription medication, 31.0M (56%) receiving telehealth treatment, and 3.4M (6%) receiving inpatient or residential treatment.[1]

It comes as no surprise that the mental health crisis has accelerated since the Covid pandemic – both in terms of the number of American adults with AMI as well as the treated population. In 2019, 51.5M American adults had AMI.[2] This increased to 52.9M American adults in 2020, 58.5M in 2021, and, ultimately, 59.3M in 2022.[1,2] Overall, these numbers represent a 15% increase in the AMI population in 2022 compared to pre-Covid (2019).

The acceleration is even more stark among the treated population. In 2019, 40.2M Americans received past-year mental health treatment or services, jumping to 41.4M in 2020, 46.5 in 2021 (12% increase versus 2020), and 55.8M in 2022 (20% increase versus 2021).[1,2,3] Overall, these numbers represent a 39% increase in the treated population compared to 2019, with the starkest change being in the outpatient setting (35.1M in 2022 compared to 20.6M in 2019).[1,2,3]

These NSDUH statistics suggest that the rate of adults seeking and enrolling in mental health treatment is accelerating faster than the number of adults with mental illness. Unfortunately, there is a shortage of mental health clinicians.[4] There were only

38.4K active psychiatrists in 2021 per the Association of American Medical Colleges[5], representing a ratio of around 900:1 adults treated with a prescription medication to total number of active psychiatrists in 2021.[3,4]

Telehealth and virtual services have become increasingly accepted by patients and clinicians, since the Covid pandemic placed restrictions on in-person care.[6] In fact, the NSDUH only began asking about telehealth services starting in 2021.[3] Psychiatry is a field unlike some other medical specialties in which telehealth has continued to play a role in treatment.[6]

Telehealth, with increasing acceptance, is just one virtual service that has become increasingly popular. Digital mental health (mHealth) is an emerging field, with 10,000 new mental health related applications (apps) released in 2020.[7] Per the American Psychiatric Association, *"the goals of mHealth are to improve health outcomes through convenient, patient-driven access to mental health support and self-management tools".*[7] Digital health applications represent a variety of functions, including *"symptom tracking, habit formation or targeted behavior change, peer support, and more. Sometimes these apps are meant to be used as an adjunct to treatment in coordination with a mental health professional".*[8]

The mHealth landscape can be segmented many ways. One way is via regulatory implications. Depending on the function of the digital health app, the regulatory implications vary as determined by The Food and Drug Administration (FDA).[9,10] Some higher-risk mobile applications that are classified as a device require regulatory oversight, while other lower-risk applications do not.[9,10] Another way to segment is via the function of the application itself. For example, some mHealth applications provide

teletherapy or virtual care, while others are more user-driven and can include "Health and Wellness" (such as those that offer guided meditation or self-help).[11] Still others can be considered more medical or clinical, for example, focusing on the patient / clinician interaction.[7,11]

The advancements in technology, including wearable devices and sensors as well as machine learning (ML), are increasingly investigated as potential use cases for digital mental health, such as remote patient monitoring (RPM).[12,13] Wearable devices can provide insights into sleep, activity, and vital signs (such as heart rate, heart rate variability, respiratory rate, and oxygen blood saturation).[12] RPM can additionally include insights into social behavior based on how users interact with their phone.[13] Recent research has shown that social media, another growing trend, has become part of many people's daily lives, and the impact of social media can be both positive and negative on a user's mood, loneliness, body image, and more.[14]

The potential benefits of mHealth and RPM are vast. The data generated on each individual person can paint a picture of who they are in between clinician visits. However, there are emerging concerns around data privacy and daily engagement (patient retention).[15,16,17] Additionally, much of the conversation around mental health care concerns and innovation has revolved around access to care, as opposed to any challenges with the quality of care itself.[4,11,18]

This paper, therefore, seeks to understand the mental health care experience from a patient's perspective, while investigating a specific use case for mHealth that focuses on care quality rather than care access.

STATEMENT OF PURPOSE

The objective of this study was to understand patient perceptions of a specific digital health innovation aimed at improving the quality of mental health care. This specific innovation was founded by students at Yale School of Medicine and School of Management. The author aimed to understand experiences with mental health treatment and any relationship with privacy concerns and willingness to complete a daily check-in. No specific hypotheses were tested.

METHODS

Contributions: C.G. designed the study, created and deployed the survey, distributed it to respondents, analyzed the data, conducted the statistical analyses, and drafted the manuscript.

Human Subjects Research: Institutional Review Board (IRB) exemption was submitted to Yale Human Research Protection Program (IRB protocol ID: 2000036518, with Teresa Chahine as the Principal Investigator). Exemption Determination was received on November 27, 2023 under Exempt Category 2(ii).

Ethics Statement: This study was conducted in accordance with the ethical conducts in research. Participation was voluntary, consent was obtained from all participants, and all data were anonymized before analysis.

Conflict of Interest: The primary author, C.G., has a vested financial interest in a startup, Lucid.Care Labs. C.G. holds a 40% equity stake in the company, although has taken zero financial compensation at the time of this manuscript. However, it is important

to note that the specific digital health innovation evaluated in this manuscript is based on Lucid.Care Labs.

　　Study design: The survey was designed to understand respondents' 1) mental health treatment experience, 2) experience with digital health and perceptions toward a specific digital health innovation, and 3) demographic information. Survey questions are listed out in Table 1.

Table 1. Survey details

Section 1. Mental health treatment	
1.1: treatment	Have you ever received treatment for your mental health?
1.1b: treatment details	What treatment have you received or are receiving?
1.2: challenges	What challenges have you experienced during treatment?
1.2b: challenge frequency	How often did you experience these challenges?
1.2c: impact of challenges	How did experiencing these challenges affect you?
1.3: waitlist	How long have you been waiting to see someone for your mental health?
Section 2a. Digital health	
2.1: digital health	What digital health products do you currently use or have used in the past?
2.2: wearable	Do you own a wearable device?
2.2b: wearable details	What wearable device do you own?

Section 2b. Specific digital health product	
2.3: privacy	How likely are you to allow access to the following data with this digital health product? [Respondents were asked to select Very Likely, Somewhat Likely, and Not Likely for data sources of: sleep, activity, social media screentime, messaging screentime, social media content, location, and financial data]
2.3b: privacy motivation	What would make you feel more comfortable sharing data in general?
2.4: daily survey	Would you fill out a short (<2-3 minute) daily survey for 30 days? This survey would ask about your symptoms, health behaviors, and medication adherence. The objective is to provide useful feedback for your clinician and help our product learn more about you to give you better insights.
2.4b: survey motivation	What would motivate you to fill out a daily survey for 30 days? Please rank your top 3, with number 1 being the most important
Section 3. Demographic	
3.1: age	How old are you?
3.2: gender	How would you describe yourself?
3.3: ethnicity	Are you Hispanic / Latino?
3.4: race	How do you identify?

A) Section 1: 1.1b and 1.2 were shown to respondents who selected that they are currently or formerly in treatment. 1.2b and 1.2c were shown to respondents who noted experiencing a challenge in 1.2. 1.3 was shown to respondents who indicated that they are on a waiting list for treatment based on 1.1. **B) Section 2**: 2.2b was shown to respondents that selected "yes" to owning a wearable in 2.2. 2.3b was shown to respondents who selected "somewhat likely" or "not likely" in response to 2.3 (as opposed to "very likely"). 2.4b was shown to respondents who selected "maybe" or "no" in response to 2.4 (as opposed to "yes").

The specific digital health innovation was presented as follows in Section 2b:

We are introducing a new product that bridges the "gap" between you and your clinician. Our initial focus is mental health – those who are in treatment, were in treatment, considering treatment, or just want more control over their day-to-day life.

- *How? We ask for your permission to collect data (such as sleep and screentime) and combine it with a daily check-in.*

- *Why? We empower you with insights. Our goal is to make you feel more in control of your recovery and reduce uncertainty around your treatment journey.*

- *How does it affect my treatment? We create a personalized report for your clinician, enabling them to evaluate your treatment and progress more effectively.*

All survey responses were optional. Three respondents were randomly chosen to receive a $50 gift card to Amazon as incentive to complete the survey. These gift cards were distributed in February 2024 by the study author.

Survey distribution: The survey was built via Qualtrics[XM] and distributed via an anonymous Qualtrics[XM] link between December 7, 2023 to December 11, 2023. The survey was closed on December 18, 2023; at that time, all in progress responses were stopped, and no new responses were allowed.

The survey was distributed to the following schools via email or Slack®: Yale graduate schools of management, medicine, public health, law, nursing, and Yale College (undergraduate). Access to Yale was obtained via the author's affiliation and a resource maintained by the Yale Computer Society called MailYale, which "*helps easily generate email lists for the Yale community*".[19] The survey was also distributed to New York University (NYU) law school via a contact in their Google group. Finally, the survey was sent via Slack® to several channels that the author is in: Graduate Healthcare Club, MBA Entrepreneurs, Mental Health Startup Community, and Out Of Pocket.

Data access: Respondents' data was exported from Qualtrics[XM] to Microsoft Excel® and analyzed according to the statistical methods described below.

Statistical Methods A total of 1,304 responses were recorded on Qualtrics[XM]. Out of those, 1,127 surveys were completed based on the "Finished" status as determined by Qualtrics[XM]. This excluded respondents who had opened the survey and began the survey, but did not complete the survey in its entirety. A total $n = 1,127$ was used for analyses.

Survey manipulation: Certain responses were summarized and simplified into binary and categorical answers to inform descriptive and statistical analyses.

Section 1 – mental health treatment experience: Respondents could select 5 different choices in response to their mental health treatment status: currently in treatment, formerly in treatment, on a waiting list, not in treatment but considering treatment, or not in treatment and never needed or wanted treatment. The treatment status was summarized into a binary yes/no to represent treatment exposure, with yes representing current and former treatment. Of those in treatment, respondents could select multiple treatment options including: Medications, Therapy, and Other (please specify). Treatment details were summarized into 3 categories of treatment type: Therapy only, Medications only, and Therapy and Medications. Respondents that selected "Other" in addition to Therapy and Medications were classified into the "Therapy and Medications" category. Respondents that selected "Other" only and manually typed "Counseling" as an explanation were classified into "Therapy only."

For "what challenges have you experienced during treatment?" and "how did experiencing these challenges affect you?", respondents could select multiple options. The two question responses were summarized as a binary yes/no for challenges experienced and impact on care. Respondents were also categorized via a combination of their treatment status and experience: No treatment, Treated with no challenges, and Treated with challenges. For the impact of the challenges on care, impact was split in 2 categories: 1) Emotional Impact (which included feeling hopeless, feeling worse, and having trouble treating treatment recommendations) and 2) Care Impact (which included changing clinicians, avoiding and stopping treatment, and stopping medications).

Section 2 – digital health: Respondent use of a digital health product in the past was summarized into a binary yes/no. When asked, "what would motivate you to fill out a daily survey for 30 days?", respondents ranked their top 3 choices. Each possible reason (answer choice) was classified into 3 groups: Top 3, Not top 3, and Would report for 30 days (to reflect the previous question if respondents selected they would fill out a daily survey for 30 days).

Descriptive findings: For each question, the distribution of responses per answer choice was analyzed and differences in frequency by treatment experience, challenges experienced during treatment, and impact of those challenges were noted. Additionally, the survey respondents' demographics was compared to NSDUH national data to evaluate how representative the sample was.[1]

Statistical tests: Chi-squared (χ^2) tests of independence were conducted using Microsoft Excel®. The author ensured that variables were mutually exclusive, counts per cell were at least 5, and categories made qualitative sense. An alpha of 0.05 was used to determine significance. Degrees of freedom (*df*) and sample size (*n*) are reported for every test. The following relationships were tested with a chi-squared: type of treatment and challenges with care, type of treatment and emotional / care impact of challenges, treatment exposure (binary yes/no) and likelihood of sharing certain types of data, and wearable ownership and likelihood of sharing certain types of data.

RESULTS

Demographics: Among the 1,127 respondents, 897 (80%) were classified as Gen Z (18-26 years old), 214 (19%) as Millennials (between 27-42 years of age), and the rest were 43 years old or older.[20] Most respondents (63%) identified as a cis woman and 348 (31%) identified as a cis man. The racial breakdown was 55% White, 35% Asian, 10% Mixed, and 8% Black or African American. Detailed demographic results are shown in Table 2.

Table 2. Demographics (*n*= 1,127)

Age	n	(%)
18 – 22 years old (y.o.)	635	(56%)
23 – 26 y.o.	262	(23%)
27 – 34 y.o.	184	(16%)
35 – 42 y.o.	30	(3%)
43+ y.o.	16	(1%)
Gender Identity	n	(%)
Cis woman	708	(63%)
Cis man	348	(31%)
Nonbinary	34	(3%)
Transgender	10	(1%)
Other	8	(1%)
Prefer not to answer	19	(2%)

Ethnicity	n	(%)
Hispanic / Latino	150	(13%)
Not Hispanic / Latino	977	(87%)

Race	n	(%)
White	616	(55%)
Asian	389	(35%)
Mixed Race	110	(10%)
Black or African American	91	(8%)
American Indian or Alaska Native	12	(1%)
Native Hawaiian or Other Pacific Islander	7	(1%)
Other	48	(4%)

A) Respondents could select multiple races, hence why percentages do not total 100%.

Treatment Experience: Among the 1,127 respondents, 314 (28%) were currently in treatment for their mental health, 287 (25%) were treated in the past, and the remaining 47% were not in active or past treatment (Table 3). For the remainder of this section, the term "treated population" encompasses the 601 respondents who noted active treatment or past treatment for mental health concerns.

Table 3. Mental health treatment status among respondents (*n* = 1127)

Treatment status	n	(%)
Currently in treatment	314	(28%)
Treated in the past but not currently	287	(25%)
On the waiting list for treatment	6	(1%)
Considered treatment	286	(25%)
Have never needed or wanted treatment	234	(21%)

Among those in current or past treatment (*n* = 601), 294 (49%) were in therapy only, 273 (45%) were treated with therapy and medications, and 34 (6%) received psychiatric medications only. The demographic breakdown of the treated sample is as follows: 404 (67%) identified as a cis woman, 142 (24%) identified as a cis man, 32 (5%) identified as nonbinary, 9 (<1%) identified as transgender, and 14 identified as "other" or "prefer not to answer." The racial breakdown among those in current or past treatment is as follows: 380 (63%) White, 172 (29%) Asian, 65 (11%) Mixed Race, 48 (8%) Black or African American, 5 (1%) American Indian or Alaska Native, 4 (1%) Native Hawaiian or Other Pacific Islander, and 28 (5%) Other.

The majority (85%) of treated respondents noted experiencing challenges with treatment: 311 (52%) withheld information from their clinician, 303 (50%) felt like there was not enough time to explain what was going on in their lives, 292 (49%) had trouble keeping track of what to talk about, 265 (44%) forgot to mention something important, and 107 (18%) had trouble answering their clinician's questions. Table 4 notes challenges, broken down by treatment type. Note that one respondent who was

categorized as Medications Only did not respond to this question, hence a total $n = 600$. Chi-squared (χ^2) analysis showed no statistically significant relationship between treatment type and whether challenges were experienced (χ^2 ($df = 2$, $n = 600$) = 4.62, $p = 0.10$).

Table 4. Challenges with treatment among treated population ($n = 600$)

		By treatment type					
		Therapy only ($n = 294$)		Therapy + meds ($n = 272$)		Meds only ($n = 33$)	
Challenges experienced	n	n	(%)	n	(%)	n	(%)
I withheld information from my clinician	311	139	(47%)	159	(58%)	13	(38%)
I felt like there was not enough time to explain what was going on in my life	303	144	(49%)	146	(54%)	13	(38%)
I had trouble keeping track of what to talk about	292	151	(51%)	134	(49%)	7	(21%)
I forgot to mention something important	265	118	(40%)	139	(51%)	8	(24%)
I had trouble answering my clinician's questions	107	41	(14%)	63	(23%)	3	(9%)

I did not experience challenges with treatment	89	39	(13%)	41	(15%)	9	(26%)

A) Absolute counts (n) are shown in Table 4, with percentages (%) representing the percent of respondents who selected the associated challenge with treatment compared to the total in that specific treatment type (therapy only, therapy + meds, and meds only). Respondents could select multiple challenges with treatment, as long as they did not select "I did not experience challenges with treatment". **B)** One respondent who selected meds only did not answer the question about challenges, so an $n = 33$ was used to calculate percentages.

Respondents that experienced challenges ($n = 508$) were asked about the impact of challenges. One hundred fifty-six (31%) of respondents stated that challenges did not affect their care experience. Among the remaining 352 (69%), the most commonly experienced impact was "I felt worse" at 146 (29%), followed by "I stopped treatment altogether" (24%), and "I started avoiding treatment" (22%) (Table 5).

Table 5. Impact of challenges among those that were treated for mental health and experienced challenges with treatment ($n = 508$)

Impact of challenge	n	(%)
I felt worse	146	(29%)
I stopped treatment altogether	122	(24%)
I started avoiding treatment	110	(22%)

I changed clinicians	103	(20%)
I felt hopeless	92	(18%)
I had trouble trusting treatment recommendations	70	(14%)
I stopped taking my medications	51	(10%)
Other	36	(7%)

Impact was further evaluated via two dimensions: Emotional Impact (encompassing "I felt worse," "I felt hopeless," and "I had trouble trusting treatment recommendations") and Care Impact ("I stopped treatment altogether," "I started avoiding treatment," "I changed clinicians," and "I stopped taking my medications").

Two chi-squared analyses were conducted to evaluate the following null hypotheses: 1) There is no relationship between the type of treatment (medications only, therapy only, medications plus therapy) and the Emotional Impact of experiencing challenges with treatment, and 2) There is no relationship between the type of treatment and the Care Impact of experiencing challenges with treatment.

Both null hypotheses were rejected (for Emotional Impact: χ^2 (df = 2, n = 511) = 8.16, p = 0.02; for Care Impact: χ^2 (df = 2, n = 511) = 11.89, p = 0.003). When comparing the expected versus actual frequency values, there was a higher number of respondents that reported experiencing Emotional Impact among those that received combination therapy and medications (118 observed vs. 102 expected) and lower number of respondents that experienced Emotional Impact among those that received therapy only (97 observed versus 112 expected). There was no difference among those that received medications only. A similar pattern emerged among those that experienced Care Impact

(for those in therapy and medications, 129 were observed with Care Impact versus 110 expected; for those in therapy only, 102 with Care Impact were observed versus 121 expected; for those in medications only, no difference was noted in observed versus expected frequencies).

Digital health: Among the 1,127 survey respondents, 1,126 responded to questions around digital health experience and wearable ownership. The majority of respondents (57%) had used a digital health service before: 463 (41%) used a medication or sleep application (such as Calm or Headspace), 246 (22%) used a teletherapy service (such as Spring Health, Lyra, Better Help, or Ginger.io), 126 (11%) used a behavior change application (such as Noom or smoking cessation application), and 59 (5%) used a different type of service (such as mood logging applications, menstrual cycle tracking, fitness applications, calorie trackers, etc.).

Most respondents did not own a wearable device. Among the 507 (45%) that did, Apple watch was the most commonly owned wearable device at 367 (72%), followed by: Garmin at 72 (14%), Fitbit at 67 (13%), Whoop at 18 (4%), Oura ring at 15 (3%), other smart watches at 21 (4%) (which included Google, Samsung Galaxy, Withings, and others), and other wearable devices at 5 (1%). Some respondents owned multiple wearable devices.

Specific digital health application: Respondents were asked about the likelihood of sharing data sources with a specific application used to close the "gap" between them and their clinician. Respondents were most likely to allow access to activity data, followed by sleep and screentime (Table 6).

Table 6. Likelihood of allowing access to the following data types via a mobile application

		Likelihood of allowing access					
		Very likely		Somewhat likely		Not likely	
Data source	Total n	n	(%)	n	(%)	n	(%)
Activity	1,121	803	(71%)	232	(21%)	86	(8%)
Sleep	1,124	697	(62%)	301	(27%)	126	(11%)
Social media: screentime	1,123	497	(44%)	420	(37%)	206	(18%)
Messaging: screentime	1,123	416	(37%)	398	(35%)	309	(27%)
Location	1,124	175	(16%)	370	(33%)	579	(52%)
Social media: content	1,121	182	(16%)	306	(27%)	633	(56%)
Financial data	1,121	80	(7%)	204	(18%)	837	(74%)

A) Total n for each data source does not total 1,127 given that all questions were optional. **B)** Percentages are shown as a percentage of selecting "Very Likely," "Somewhat Likely," and "Not Likely" compared to the Total n for each data source.

Thirty respondents stated that they would be "very likely" to allow access to all data sources and 55 respondents selected "not likely" to all data sources.

Chi-squared analyses were conducted to investigate the following null hypothesis: There is no relationship between treatment exposure (in treatment – current or past vs. no treatment) and likelihood of sharing each specific data type (very likely, somewhat likely, and not likely). The author failed to reject the null for the following data types: Location (χ^2 ($df = 2$, $n = 1,124$) = 4.50, $p = 0.11$); Social Media Screentime (χ^2 ($df = 2$, $n = 1,123$) = 1.46, $p = 0.50$), Social Media Content (χ^2 ($df = 2$, $n = 1,121$) = 0.10, $p = 0.95$), Messaging Screentime (χ^2 ($df = 2$, $n = 1,123$) = 5.81, $p = 0.06$), and Financial Data (χ^2 ($df = 2$, $n = 1,121$) = 0.82, $p = 0.66$).

The null was rejected for the following data sources: Sleep (χ^2 ($df = 2$, $n = 1,124$) = 14.03, $p = 0.001$) and Activity (χ^2 ($df = 2$, $n = 1,121$) = 22.13, $p < 0.001$). For sleep data, among those that were treated, a higher number of respondents selected "not likely" (87 observed versus 67 expected) and fewer selected "very likely" (357 observed versus 372 expected). Among those that were not treated, a higher number of respondents selected "very likely" at 340 observed versus expected of 325 and fewer selected "not likely" at 39 observed versus expected of 59. A similar pattern was seen for activity data. Among those that were treated, 63 selected "not likely" versus 46 expected, 138 selected "somewhat likely" versus 124 expected, and 397 selected "very likely" versus 428 expected. Among those that were not treated, 23 selected "not likely" versus 40 expected, 94 selected "somewhat likely" versus 108 expected, and 406 selected "very likely" versus 375 expected.

A chi-squared test was then conducted to analyze the null hypothesis that there is no relationship between challenges experienced during treatment (3 categories of no treatment, treatment with challenges experienced, treatment without challenges) and the

likelihood of sharing sleep data. The null was rejected (χ^2 ($df = 4$, $n = 1,124$) = 14.15, $p =$

0.01). Expected versus observed counts with a chi-squared was similar for those who

were treated but did not experience challenges. Among those that were treated with

challenges, 73 selected they would be "not likely" to share sleep data versus expected of

57, and 304 selected "very likely" versus expected of 316.

A similar chi-squared analysis was conducted to analyze the null hypothesis that

there is no relationship between challenges experienced (the same 3 categories of no

treatment, treatment with challenges experienced, treatment without challenges) and

likelihood of sharing activity data. The null was rejected (χ^2 ($df = 4$, $n = 1,121$) = 23.31, p

< 0.001). Among those that were treated and experienced challenges, 55 noted they

would be "not likely" to share activity data versus 39 expected, 114 selected "somewhat

likely" versus 105 expected, and 340 selected "very likely" versus 365 expected.

Additional chi-squared analyses were conducted to analyze the following null

hypotheses: There is no relationship between owning a wearable device (yes/no) and

likelihood of allowing access to the data sources of sleep, activity, location, screentime,

social media content, and financial data. The null was rejected for Sleep (χ^2 ($df = 2$, $n =$

1,123) = 13.19, $p = 0.001$), Activity (χ^2 ($df = 2$, $n = 1,120$) = 28.71, $p < 0.001$), and

Location (χ^2 ($df = 2$, $n = 1,123$) = 17.99, $p < 0.001$). For sleep, activity, and location data,

the observed frequency of respondents that selected "very likely" to allowing access was

higher than the expected frequency among wearable owners (compared to those that did

not own wearable devices). The author failed to reject the null for social media

screentime (χ^2 ($df = 2$, $n = 1,122$) = 1.01, $p = 0.60$), social media content (χ^2 ($df = 2$, $n =$

1,120) = 4.33, $p = 0.11$), messaging screentime (χ^2 ($df = 2$, $n = 1,122$) = 0.32, $p = 0.85$), and financial data (χ^2 ($df = 2$, $n = 1,120$) = 0.84, $p = 0.66$).

Among respondents that did not select "very likely" to allowing access to all data sources, 974 respondents answered the question of what would make them more likely to allow access to the following data sources (Table 7).

Table 7. Incentives for increasing likelihood of allowing access to data sources *(n = 974)*

Incentives	n	(%)
Transparency in how my data are being used and why	814	(84%)
Option to stop sharing my data at any point	799	(82%)
Strict enforcement of data privacy and security	798	(82%)
My clinician actually using my data reports	484	(50%)
My clinician's recommendation to use the app	407	(42%)
Other	35	(4%)
Nothing; I just don't want to share my data	80	(8%)

A) Respondents could select multiple incentives, hence why percentages do not equal 100%. **B)** Other includes ability to choose the data allowed, the option to view their own data, and specifics around data aggregation, storage, legal implications, and more.

A chi-squared was run to test the following null hypothesis: There is no relationship between treatment exposure (yes / no for received treatment currently or in the past) and selecting "My clinician's recommendation to use the app" as an incentive for sharing data. This null hypothesis was rejected (χ^2 ($df = 1$, $n = 1{,}127$) = 3.93, $p = 0.047$), with a higher-than-expected number of those who received treatment in the past choosing "clinician recommendation" as an incentive for data sharing (233 observed versus 217 expected) and fewer selecting "clinician recommendation" if they had no treatment exposure (174 observed versus 190 expected). A chi-squared was conducted to test the null hypothesis that there is no relationship between treatment exposure (yes / no) and selecting "my clinician actually using my data reports." The author failed to reject the null (χ^2 ($df = 1$, $n = 1{,}127$) = 0.06, $p = 0.80$).

Finally, respondents were asked about their willingness to complete a 2–3-minute survey every day for 30 days. Among the 1,127 respondents, 351 (31%) said "yes," 541 (48%) said "maybe", and 235 (21%) said "no." Among the 776 who selected maybe or no, respondents were asked, "What would motivate you to fill out a daily survey for 30 days?" and to rank their top 3 reasons. The following number of respondents completed the question: 728 ranked their top reason, 701 ranked their second reason, and 676 ranked their third reason. The most common top-3 reason was "financial reward" ($n = 533$) followed by "insight into my mental health" ($n = 517$). Fifty-one said that they would not self-report for 30 days. Details are listed in Table 8.

Table 8. Top-3 incentives for completing daily survey

Incentive	Number (n) that ranked in top 3	Rank #1 (n)	Rank #2 (n)	Rank #3 (n)
Financial reward for completing certain percentage of surveys	533	319	116	98
Insight into my mental health	517	224	190	103
A shorter survey (<1-2 minutes)	370	118	150	102
Better treatment experience	363	157	130	76
A fun app experience	270	71	94	105
My clinician's recommendation to complete surveys	265	76	105	84
Knowing that I can stop after 1 month	189	20	73	96
Virtual badges as a reward for completing surveys	138	8	41	89
Other	13	5	2	6
Nothing; I won't self-report for 30 days	51	24	6	21

A) Respondents were unlimited in how many reasons they could choose as their rank 1, rank 2, or rank 3. **B)** "Other" included personalization of questions, answering questions for personal reasons but not to share with others, app

reminders, multiple choice, privacy concerns, as part of evidence-based treatment

program, and for nonprofit (as opposed to for-profit) use.

DISCUSSION

Demographics: A total of 1,127 people were surveyed to understand their treatment experience and perceptions toward an ML-enabled digital health application. Overall, 314 (28%) were currently in treatment and 287 (25%) had been treated in the past. Among those in treatment, 67% identified as cis women. This is relatively consistent with NSDUH's 2022 data, which showed that 23% of American adults were in treatment for mental health, 63% of whom identified as female.[1]

The survey respondents overall skewed younger than the national average, with the vast majority reporting that they fall within the Gen Z or Millennial cohort, compared to NSDUH reporting 38% of treated patients being 50 or older.[1] Ethnically, 14% of our survey respondents were Hispanic / Latino compared to 11% nationally.[1] Survey respondents in treatment also had a slightly different racial makeup compared to NSDUH, with fewer reporting a race of White (63% vs. 73% nationally), and more respondents selecting Asian (29% versus 3.4% nationally) and Mixed Race (8% versus 3% nationally).[1]

The Data Gap: The Covid pandemic highlighted the physician shortage, demonstrating that access to mental healthcare is a clear barrier to care.[4] This survey suggests that the quality of mental health treatment is another barrier, specifically, that there exists a Data Gap between clinicians and patients, driven by communication challenges. This is informed by the 85% of respondents in past or current treatment who experienced challenges with treatment, including purposefully withholding information,

running out of time, having trouble keeping track of what to talk about, forgetting to mention something important, and having trouble answering their clinician's questions.

Among the 85% who experienced challenges, 70% of survey respondents indicated that these challenges impacted or were associated with their emotional status and care journey, with 225 respondents stating that they felt worse, felt hopeless, or had trouble trusting treatment recommendations (which was classified as Emotional Impact), and 242 stating that they stopped treatment, started avoiding treatment, changed clinicians, or stopped taking their medications (classified as Care Impact).

It has been shown that patients' withholding of information can negatively impact care.[21] As mental health care is often conversational between a patient and their clinician, it is unsurprising that communication challenges impact care. Diagnoses based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) have been criticized as subjective and biased, with symptom heterogeneity within a disorder and homogeneity across disorders contributing to false positives and misdiagnoses that can be exacerbated for specific disorders and populations.[22,23,24,25] In fact, mental health misdiagnosis rates in the primary care setting have been reported between 66% to 98% for major depressive disorder, bipolar disorder, panic disorder, generalized anxiety disorder, and social anxiety disorder.[26] Communication challenges, superimposed onto an already criticized DSM-5 could contribute to diagnostic issues, with implications for care efficacy.

In this study population, there was no relationship between the likelihood of experiencing challenges with the treatment categories of therapy only, combination therapy and medications, and medication only. However, there was a statistically significant relationship between the treatment category and likelihood of experiencing a

negative impact. Those in combination treatment (therapy and medications) were more likely to experience a negative Emotional Impact and Care Impact. There are several possible explanations. An important caveat is that only the binary experience of challenges was evaluated, not the severity, and the severity of challenges could differ by treatment category and explain the impact. Based on American Psychiatric Association practice guidelines for disorders such as Major Depressive Disorder, combination treatment could be a proxy for severity of mental health concerns.[27] Perhaps, the patients with more severe mental illnesses experience the challenges more deeply or the impact is felt more physically with possible medication side effects.[28] Assuming severity of mental illness is a possible explanation, it is unfortunate that those who are most in need of treatment are the same ones who are most negatively affected by the Data Gap.

Fewer respondents who received therapy only treatment indicated a negative Care or Emotional Impact. Previous studies have shown that multiple challenges arise with psychotherapy, including weak therapeutic alliance, inappropriate therapist behavior, and many more.[29] Future research could focus on understanding if patients who are in therapy are more tolerant of challenges and if the challenges themselves are felt less deeply (e.g., without medication side effects or given a possible lower severity course of their mental illness). Additionally, in future studies, it would be important to understand how the Data Gap and Emotional and Care Impact affect recovery and the quantifiable efficacy of medications and psychotherapy.

Digital Health: Digital mental health and mobile health (mHealth) and increasingly accepted as part of care.[8] In fact, 57% of the survey respondents had used a

digital health product before, including meditation / sleep applications, applications that provide virtual services / teletherapy, and behavior change applications. Fewer (45%) owned a wearable device, with the most common ones being Apple Watch at 72%, followed by wristbands at 31% (Garmin, Fitbit, Whoop).

In this survey, a short description of a specific digital health use case was shared, designed to close the Data Gap between a patient and their clinician by passively collecting user data and combining it with a daily check in. Users are offered insights into their mental health, control over their recovery, and more certainty around their treatment journey. Users can export a report for their clinician, using it to inform their care. Users' perception toward data sharing was analyzed as it relates to privacy concerns as well as willingness to engage in daily check ins within the context of this specific use case.

Privacy: Data privacy, especially in the time of machine learning and remote patient monitoring, has become a growing concern.[16] This survey therefore analyzed user willingness of allowing access to specific data types. Most users were "very likely" to share activity data (71%), followed by sleep data (62%), screentime for social media and messaging (44% and 37%, respectively), location (16%), social media content (16%), and, finally, financial data (7%).

A statistically significant association was found between treatment exposure and the likelihood of sharing sleep and activity data, with those who had experienced treatment currently or in the past being less likely to share those data. There was no relationship between treatment exposure and likelihood of sharing other types of data. When doing a deeper dive into sleep and activity data, a statistically significant relationship was found between likelihood of allowing access and treatment categories of

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no treatment, treatment with associated communication challenges, and treatment without associated communication challenges. Those who had experienced challenges with treatment were less likely to allow access to sleep and activity.

This can be interpreted in multiple ways. Experiencing challenges with treatment is associated with noticeable Emotional and Care Impacts in this study population. Experiencing challenges is likely to affect the therapeutic alliance, which is positively associated with mental health treatment success and adherence.[30,31,32] A lower therapeutic alliance has implications for patient confidence in their clinician and in their own care journey[31]. This can then lower a patient's willingness to share data with their clinician, especially if they have a lack of trust and confidence.

Notably, only sleep and activity were affected by this relationship between willingness to share data and treatment category. This is likely because sleep and activity are two common symptoms that are asked about in mental health care, with implications across psychiatric diagnoses including major depressive disorder, bipolar disorder, generalized anxiety disorder, and more.[33] The other data types of screentime, location, social media content, and financial data are less commonly discussed in clinical encounters, suggesting that patient familiarity of specific data sources as they relate to the care journey is likely to play a role in patient willingness to share.

Additionally, the relationship between wearable ownership and likelihood of allowing access to each data source was analyzed. There is a statistically significant relationship between wearable ownership and likelihood of allowing access to sleep, activity, and location data, with a higher likelihood of allowing access among wearable owners. No relationship was found between wearable ownership and likelihood of

allowing access to screentime, social media content, or financial data. This once again

suggests that patient familiarity plays a role in likelihood of data sharing, this time

positively, without a possible confounding factor of the therapeutic alliance.

Respondents were asked what would make them more willing to share data. The

number one reason was transparency in data use, followed by the option to stop sharing

data and strict enforcement of data privacy and security. A statistically significant

relationship was found between treatment exposure (current or past) and selecting

"clinician recommendation to use the app" as a reason to share their data. There was no

statistically significant relationship between treatment exposure and "my clinician

actually using my data reports" as a reason.

Retention: Patient engagement and retention with mobile health has become an

emerging issue with mobile health adoption.[17] In this specific use case, respondents were

asked if they would complete a survey that takes 2-3 minutes every day for 30 days. Out

of the 1,127 respondents, 351 (31%) said yes; the remainder said maybe (541) and no

(235). The most common incentives for completing the daily survey were financial

rewards, mental health insights, a shorter survey of 1-2 minutes, and better treatment

experience. Only 51 said that they would not be willing to self-report for 30 days. This

suggests that patient engagement can be improved via the design of the product itself,

taking into account user preferences and motivations, although a one-size-fits-all solution

for increasing engagement is unlikely to work.

Future Studies: In future studies, it would be important to understand how

communication challenges during treatment and impact of those challenges vary by

specific disorders. The impact on diagnostic and treatment decisions would be interesting

to quantify. Additionally, future studies should evaluate why certain challenges occur, such as withholding information, and explore the efficacy of possible solutions to closing the Data Gap. It would be interesting, with further innovation and advancements in mHealth and machine learning, to understand how patient perceptions toward privacy and daily app engagement change over time.

CHALLENGES AND LIMITATIONS

This survey was distributed to specific segments of the population, which included college campuses, higher education, and those with access to specific Slack® groups. Although the treated population was representative of the NSDUH 2022 in certain aspects (such as overall percentage in current treatment and gender breakdown), the population was skewed in other regards (such as age and racial breakdowns).[1] This skewed representation could affect the generalizability of this survey to the U.S. population as a whole.

Additionally, only one specific use case of a digital health application was offered and only two aspects of that application – privacy and patient retention (via daily check-in willingness) – were analyzed. Survey respondents were not shown any application specifics, including the types of insights that they could receive and the data that would be shown to their clinician. Users could change their mind around privacy concerns and engagement incentives after seeing specifics. Privacy and retention metrics and motivators are also likely to change depending on the specific use case and the benefits that users and clinicians would receive in turn.

DISSEMINATION

Plans for dissemination include presenting these findings at a possible conference. Peer-reviewed publications will be considered. Additionally, dissemination would include working with Lucid.Care Labs (as the author holds an equity stake). This dissemination could include a white paper published on the business' website. Ultimately, the objective is to inform clinical care and product development to improve care quality across the digital health spectrum.

CONCLUSION

In conclusion, this study showed that there exists a Data Gap between patients and clinicians in mental health care, defined as experiencing challenges with communication that are associated with negative emotional impact on patients and avoidance or termination of care. A specific use case was analyzed of a digital health application designed to close the Data Gap to understand patient's perception toward data privacy and motivators that would drive engagement and retention. Although patients would be most willing to allow access to activity and sleep data via a mobile app, experiencing communication challenges with mental health treatment (the Data Gap) is associated with being less willing to allow access. Daily patient engagement could be facilitated best by financial rewards and mental health insights. Overall, there exists a role for digital mental health to address not just access to mental health care, but also the quality of the care itself by closing the Data Gap.

REFERENCES

1. Substance Abuse and Mental Health Services Administration. 2022 NSDUH Detailed Tables | CBHSQ Data. Accessed January 15, 2024. https://www.samhsa.gov/data/report/2022-nsduh-detailed-tables

2. Substance Abuse and Mental Health Services Administration. 2020 NSDUH Detailed Tables | CBHSQ Data. Accessed January 15, 2024. https://www.samhsa.gov/data/report/2020-nsduh-detailed-tables

3. Substance Abuse and Mental Health Services Administration. 2021 NSDUH Detailed Tables | CBHSQ Data. Accessed January 15, 2024. https://www.samhsa.gov/data/report/2021-nsduh-detailed-tables

4. Satiani A, Niedermier J, Satiani B, Svendsen DP. Projected Workforce of Psychiatrists in the United States: A Population Analysis. *Psychiatr Serv*. 2018;69(6):710-713. doi:10.1176/appi.ps.201700344

5. Number of People per Active Physician by Specialty, 2021. AAMC. Accessed January 15, 2024. https://www.aamc.org/data-reports/workforce/data/number-people-active-physician-specialty-2021

6. Lo J, Rae M, Amin K, Cox C, Panchal N, Published BFM. Telehealth Has Played an Outsized Role Meeting Mental Health Needs During the COVID-19 Pandemic. KFF. Published March 15, 2022. Accessed January 15, 2024. https://www.kff.org/mental-health/issue-brief/telehealth-has-played-an-outsized-role-meeting-mental-health-needs-during-the-covid-19-pandemic/

7. American Psychiatric Association. Digital Mental Health. Accessed January 20, 2024. https://www.psychiatry.org:443/psychiatrists/practice/digital-mental-health

8. King D, Emerson M, Chan S, et al. *Resource Document on Digital Mental Health*. American Psychiatric Association; 2023.

9. Food and Drug Administration. *Policy for Device Software Functions and Mobile Medical Applications: Guidance for Industry and Food and Drug Administration Staff*. Food and Drug Administration; 2022.

10. International Medical Device Regulators Forum. *Software as a Medical Device (SaMD): Key Definitions*.; 2013.

11. King DR, Emerson MR, Tartaglia J, Nanda G, Tatro NA. Methods for Navigating the Mobile Mental Health App Landscape for Clinical Use. *Curr Treat Options Psychiatry*. Published online May 24, 2023:1-15. doi:10.1007/s40501-023-00288-4

12. Gomes N, Pato M, Lourenço AR, Datia N. A Survey on Wearable Sensors for Mental Health Monitoring. *Sensors*. 2023;23(3):1330. doi:10.3390/s23031330

13. Hilty DM, Armstrong CM, Luxton DD, Gentry MT, Krupinski EA. A Scoping Review of Sensors, Wearables, and Remote Monitoring For Behavioral Health: Uses, Outcomes, Clinical Competencies, and Research Directions. *J Technol Behav Sci*. 2021;6(2):278-313. doi:10.1007/s41347-021-00199-2

14. Zsila Á, Reyes MES. Pros & cons: impacts of social media on mental health. *BMC Psychol*. 2023;11(1):201. doi:10.1186/s40359-023-01243-x

15. Arora S, Yttri J, Nilsen W. Privacy and Security in Mobile Health (mHealth) Research. *Alcohol Res Curr Rev*. 2014;36(1):143-152.

16. Schroeder T, Haug M, Gewald H. Data Privacy Concerns Using mHealth Apps and Smart Speakers: Comparative Interview Study Among Mature Adults. *JMIR Form Res*. 2022;6(6):e28025. doi:10.2196/28025

17. Amagai S, Pila S, Kaat AJ, Nowinski CJ, Gershon RC. Challenges in Participant Engagement and Retention Using Mobile Health Apps: Literature Review. *J Med Internet Res*. 2022;24(4):e35120. doi:10.2196/35120

18. Coombs NC, Meriwether WE, Caringi J, Newcomer SR. Barriers to healthcare access among U.S. adults with mental health challenges: A population-based study. *SSM - Popul Health*. 2021;15:100847. doi:10.1016/j.ssmph.2021.100847

19. Boesen E. MailYale. Accessed January 21, 2024. https://mailyale.com/

20. Dimock M. Defining generations: Where Millennials end and Generation Z begins. Pew Research Center. Accessed February 2, 2024. https://www.pewresearch.org/short-reads/2019/01/17/where-millennials-end-and-generation-z-begins/

21. Yang X, Parton J, Lewis D, Yang N, Hudnall M. Effect of Patient-Physician Relationship on Withholding Information Behavior: Analysis of Health Information National Trends Survey (2011-2018) Data. *J Med Internet Res*. 2020;22(1):e16713. doi:10.2196/16713

22. Wakefield JC. Diagnostic Issues and Controversies in DSM-5: Return of the False Positives Problem. *Annu Rev Clin Psychol*. 2016;12(1):105-132. doi:10.1146/annurev-clinpsy-032814-112800

23. Kuriakose S. DSM 5: Controversial Acceptance and Ongoing Challenges. *Am J Biomed Sci Res*. 2020;7(4):332.

24. Wakefield JC. DSM-5, psychiatric epidemiology and the false positives problem. *Epidemiol Psychiatr Sci*. 2015;24(3):188-196. doi:10.1017/S2045796015000116

25. Newson JJ, Pastukh V, Thiagarajan TC. Poor Separation of Clinical Symptom Profiles by DSM-5 Disorder Criteria. *Front Psychiatry*. 2021;12. Accessed January 20, 2024. https://www.frontiersin.org/articles/10.3389/fpsyt.2021.775762

26. Vermani M, Marcus M, Katzman MA. Rates of Detection of Mood and Anxiety Disorders in Primary Care: A Descriptive, Cross-Sectional Study. *Prim Care Companion CNS Disord*. 2011;13(2):PCC.10m01013. doi:10.4088/PCC.10m01013

27. Gelenberg AJ, Freeman MP, Markowitz JC, et al. WORK GROUP ON MAJOR DEPRESSIVE DISORDER. Published online 2010.

28. Mental Health Medications - National Institute of Mental Health (NIMH). Accessed January 21, 2024. https://www.nimh.nih.gov/health/topics/mental-health-medications

29. Vybíral Z, Ogles BM, Řiháček T, Urbancová B, Gocieková V. Negative experiences in psychotherapy from clients' perspective: A qualitative meta-analysis. *Psychother Res*. 2023;0(0):1-14. doi:10.1080/10503307.2023.2226813

30. Stubbe DE. The Therapeutic Alliance: The Fundamental Element of Psychotherapy. *Focus J Life Long Learn Psychiatry*. 2018;16(4):402-403. doi:10.1176/appi.focus.20180022

31. Flückiger C, Del Re AC, Wampold BE, Symonds D, Horvath AO. How central is the alliance in psychotherapy? A multilevel longitudinal meta-analysis. *J Couns Psychol*. 2012;59(1):10-17. doi:10.1037/a0025749

32. Thompson L, McCabe R. The effect of clinician-patient alliance and communication on treatment adherence in mental health care: a systematic review | BMC Psychiatry | Full Text. *BMC Psychiatry*. 2012;12(87). doi:10.1186/1471-244X-12-87

33. American Psychiatric Association, American Psychiatric Association, eds. *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*. 5th ed. American Psychiatric Association; 2013.