Digit 2024 Proceedings

Diffusion Interest Group In Information Technology

12-15-2024

Youth and Depression: Exploring Diffusion of Patient-Generated Health Data for Depression Care among Young Adults

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Research-in-Progress Paper

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Abstract

The use of patient-generated health data (PGHD) in the treatment of depression can provide valuable insights into patients' everyday lives and the success of the employed therapy. Young adults are an interesting target group for using PGHD, as they are tech-savvy and, therefore, particularly suited to the use of technologies such as PGHD. Although technological advances enable users to collect a multitude of different PGHD types, not all of them are relevant for depression. Similarly, there are types of PGHD that are associated with a great deal of effort when collecting them and are, therefore, not suitable for all users. Therefore, we identified different user types based on their data preferences and analyzed constructs from the UTAUT questionnaire to identify factors for the diffusion of PGHD in depression care among young adults. To achieve this, we analyzed data from 218 survey responses. *Using a subsequent cluster analysis, we identified four different user types: "Balanced Trackers," "Mental Trackers," "Minimalist Trackers," and "Proactive Trackers." Based on these clusters, we show different possibilities for which user group and which types of PGHD are best suited and which factors are important for the diffusion of PGHD. Our preliminary results indicate that behavioral intention varies between clusters. At the same time, factors such as effort expectancy, performance expectancy, and facilitating conditions are generally high in all groups, suggesting ease of use and perceived benefits of PGHD in depression treatment, while social influence seems to have only a limited impact on user acceptance.*

Keywords: Health information technology (HIT), Mental Health Care, Patient-Centered Care, mHealth Technologies

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Introduction

Depression is an illness that affects many young adults. During COVID-19, the prevalence of depression has risen sharply, especially in the younger population (Varma et al. 2021). At the same time, the number of therapy spots is limited. During COVID, many individuals also began to seek help through the use of mental health apps, as they are easily accessible through smartphones (Aziz et al. 2022), while the most common disease treated through these apps is depression (Larsen et al. 2016). These apps can help users through interventions or monitor the progression of mental illnesses. This mental health monitoring is performed primarily based on patient-generated health data (PGHD).

PGHD refers to patients' health-related information produced, documented, and gathered by patients. While these data types have long been used for selected diseases such as diabetes (e.g., blood glucose measurements) or hypertension (e.g., blood pressure measurements) (Shah and Garg 2015; Turner et al. 2021), patients can now collect many other types of data for more diseases, such as depression, through digital devices. This data includes active (e.g., questionnaires, mood barometers) or passive (e.g., steps, sleep) data (Shapiro et al. 2012). This new form of disease monitoring opens new possibilities for care as clinicians gain a deeper insight into patients' lives. These objective measurements provide insights into the success of the therapy and the course of the disease (Burgermaster et al. 2020).

Moreover, although young individuals are generally interested in digital mental health interventions, they seek new tools that better align with their intended uses (Sawrikar and Mote 2022). However, at this time, it is not clear how the diffusion of PGHD for depression care can be improved among young adults. Young adults could be particularly well suited for mHealth interventions, as they use smartphones more frequently and have adopted their technology more (Lal et al. 2015). That is why it is essential to research how PGHD can be used to treat depression better and to ensure that young adults are not overlooked when developing and introducing these technologies.

Therefore, we conducted a quantitative survey to identify the user types for using PGHD in depression care in young adults and the characteristics that drive the diffusion of these technologies. In this article, we aim to answer the following research questions:

RQ1: *What are the user types for using PGHD in depression care among young adults?*

RQ2: What are the factors for technology acceptance of PGHD in depression care among young adults?

Theoretical Background

To better understand how the use of PGHD for depression treatment in young adults can be advanced, we seek to identify user groups and their characteristics that drive the diffusion of these technologies. To this end, we focus on PGHD and technology acceptance in the theoretical background of this study.

Patient-Generated Health Data

PGHD refers to health-related data created, recorded, and collected by patients. Integrating this data into healthcare workflows can significantly improve diagnosis and treatment. (Shapiro et al. 2012). PGHD thus opens up new possibilities for the diagnosis and treatment of diseases (Burgermaster et al. 2020). Integrating PGHD into clinical workflows enables personalized treatment approaches for more conditions. (Cahn et al. 2018).

Various types of PGHD are suitable for treating depression and support both the treating physician during therapy and the patient in monitoring their condition. However, not all types of PGHD are relevant for the diagnosis or treatment of depression (Reindl-Spanner et al. 2023). Moreover, collecting PGHD can be burdensome for patients (Piras 2019). Active collection methods can increase the proneness of errors, while passive methods, although less prone to errors, often raise concerns about data protection (Ng et al. 2019). Therefore, it is essential to precisely coordinate the data collected with the treated patient and adapt it to the patient's needs.

While PGHD shows potential in depression treatment, research in this area is still limited. One area that can be improved with the introduction of PGHD is data-based care, in which reliable data sources support established instruments such as questionnaires (Fortney et al. 2018). PGHD can improve treatment decisions by systematically tracking patient symptoms and progress. Some studies suggest that self-collected PGHD can improve therapeutic feedback during counseling sessions (Meng et al. 2018).

Technology Acceptance

In contrast to other theories of innovation diffusion, the theory of technology acceptance focuses on the individual factors of technology acceptance, with particular emphasis on factors influencing behavioral intention (Davis 1985). As digitalization permeates more areas of healthcare, it is crucial to identify the factors that lead patients to accept or reject new technologies. The "Unified Theory of Acceptance and Use of Technology" (UTAUT) model (Venkatesh et al. 2003) seeks to explore and explain these factors by identifying critical determinants of technology adoption.

In the UTAUT model, five factors are crucial for the diffusion of technologies. We, therefore, contextualize the use of PGHD in depression care as follows. **Performance Expectancy** refers to the extent to which a person believes a new technology will improve work performance. In this study, performance expectancy reflects subjective perceptions of the usefulness of PGHD for treating depression. **Effort Expectancy** refers to a person's subjective perception of the difficulty of using a technology. In this study, ease of use refers to how easy or difficult it is for people to use PGHD or to acquire knowledge about how to use PGHD. **Social Influence** is the extent to which an individual perceives that others believe they should use the new system. In our study, social influence refers to the influence of others' perceptions on the willingness to use PGHD to treat depression. In our study, **Facilitation Conditions** are defined as the extent to which individuals perceive that the existing PGHD infrastructure can support PGHD use. Finally, **Behavioral Intention** refers to a patient's motivation or willingness to actively collect, share, and use their health-related data to support their care.

Research Design

We decided to survey young adults in this study to identify possible user types for using PGHD in depression care based on their PGHD preferences and thereby gain insights into how using PGHD can be further disseminated in this population group. We, therefore, asked young adults to rate the relevance of certain PGHD types for treating depression and their attitudes towards using PGHD in mental health apps. We worked closely with psychologists and psychiatrists to develop the questionnaire and ensure the structure and questions were ethically sound.

Study Design

In the survey, we selected various types of PGHD relevant to depression care (Reindl-Spanner et al. 2023) and asked participants to rate them on a 7-point Likert scale from "not at all relevant" to "very relevant". In addition to collecting the relevance of data types, we asked the participants questions from the UTAUT questionnaire (Venkatesh et al. 2003), which we adapted to the context of PGHD in depression care.

Data Collection

For this study, we defined the target group as young adults between the ages of 18 and 30. We did not set any further inclusion or exclusion criteria to ensure a broad representation of this population. Table 1 provides an overview of the sample. We collected data from June to August 2024. A total of 250 people completed the survey. Recruitment was done via the authors' university network. The data were then thoroughly cleaned by excluding incomplete or incorrectly completed surveys (e.g., answering too quickly or answering patterns). This reduced the number of valid questionnaires to 218.

Data Analysis

We conducted a cluster analysis for the first part of the data analysis. We used the "factoextra" library in R to perform a clustering algorithm based on the participants' PGHD preferences. We followed the approach of Prommegger et al. (2024), who applied a similar algorithm in a different context. First, we normalized the survey results to eliminate redundant data and ensure that high-quality clusters were formed (Virmani et al. 2015). We calculated the optimal number of clusters using the total within-sum-of-squares method (elbow method). We found that the sum of the distances within the clusters decreased only slowly after four clusters, indicating the existence of four clusters. After deciding on four clusters, we conducted ANOVA analyses to identify significant differences in their characteristics.

Preliminary Results

User Types

Our analysis allowed us to identify four clusters for tracking PGHD in mental health apps. The first cluster (n=74) is characterized by finding data relevant in a very balanced way, with a slight bias towards physical data. The second cluster (N=38) is characterized by a high relevance of PGHD associated with psychological values. The third cluster (N=17) is characterized by a general aversion to the relevance of PGHD, and the fourth cluster (N=89) consists of individuals who generally find PGHD very relevant. We found significant differences between the clusters concerning whether they had already been diagnosed with depression (p = .027 *) and their behavioral intention (p = .034 *) to use PGHD. The details for the clusters can be found in Table 1 (the two highest means compared to the other clusters are marked fat). In the following, we present the clusters in detail, followed by the UTAUT constructs' results.

The first cluster – **Balanced Trackers** – is defined by individuals who consistently score many types of PGHDs for mental and physical health (e.g., suicidality, stress, sleep) at above-average levels. This cluster focuses on mental and physical health data without focusing on either area to an extreme degree. When comparing the values for diagnosed depression, the rate in this cluster is comparably low, which justifies the fact that several PGHD for mental health were not rated as highly in this cluster. Nevertheless, the behavioral intention to collect PGHD for mental health apps is relatively high in this cluster, which indicates a high level of commitment among people in this cluster to improving their mental health. In summary, cluster 1 comprises people motivated to collect PGHD from physical and mental areas.

The second cluster – **Mental Trackers** – is characterized above all by a strong focus on mental health issues. It is striking that the focus of this cluster is primarily on PGHDs that are related to mental health problems. For this cluster, these include suicidal tendencies, mood tracking, tracking depression questionnaires, hygiene, or alcohol consumption. In contrast, the individuals in this cluster found physical PGHDs less relevant. This can be explained by the fact that the rates of depression diagnoses were highest in this cluster. Furthermore, we found the lowest behavioral intention score in this cluster. This indicates that while people in this cluster recognize the relevance of PGHD for treating depression based on the diagnoses, they are less motivated to collect the data. As a result, this cluster is primarily made up of people who, based on their own experience, consider certain types of PGHD to be essential for the treatment of depression but who show significantly less motivation to collect this data.

The third cluster – **Minimalist Trackers** – has below-average scores in all types of PGHD. Of the data types, essential types such as sleep, stress, or symptom tracking fare best in this cluster. In terms of depression, this cluster has an average score, which confirms the presence of depression diagnoses in this cluster, but they are not as prevalent as in the second cluster. In contrast to the below-average assessment of the relevance of the data, this cluster has an average behavioral intention for tracking PGHD. Cluster three thus represents a group interested in tracking data but does not necessarily link it to treating mental health problems and considers it relevant.

The fourth cluster – **Proactive Trackers** – considers almost all data types, including physical, mental, and environmental data, essential for treating depression. In addition, this cluster has an equally high number of diagnoses of depression. In addition to the high relevance of the data, this cluster has the highest behavioral intention score, showing a high motivation to collect PGHD for the treatment of depression.

Despite the relatively high rate of depression, their high behavioral intention suggests that these individuals are proactive about managing their health, leveraging comprehensive data to support their behaviors.

Although there are no significant differences between the clusters in the UTAUT constructs apart from Behavioral Intention, the results of the constructs are still interesting. The value for Effort Expectation is rated highest by users, indicating that PGHD technologies are considered easy to use. Similarly, the value for Performance Expectancy is consistently high, suggesting that PGHD can help treat depression. Similarly, the values for Facilitating Conditions are relatively high, implying that the available infrastructures are suitable for using PGHD. The results for Behavioral Intention vary between the clusters, indicating different degrees of users' intention to continue using the system. Finally, all clusters rate Social Influence very low, indicating that social factors play a minor role in using PGHD.

			Cluster 1	Cluster 2	Cluster 3	Cluster 4
	Datatype	Mean Overall	**Balanced Trackers**	**Mental Trackers**	**Minimalist Trackers**	**Proactive Trackers**
	N	218	74	38	17	89
1	Suicidality	6.34	6.28	**6.55**	4.29	**6.70**
2	Stress	6.28	**6.31**	5.87	4.65	**6.75**
3	Sleep	6.26	**6.23**	5.79	5.35	**6.65**
4	Medication	6.24	**6.30**	5.87	4.65	**6.65**
5	Mood	6.18	5.97	**6.08**	4.47	**6.73**
6	Alcohol	6.11	6.08	**6.24**	3.47	**6.58**
7	Symptoms	6.01	**6.15**	5.29	5.18	**6.38**
8	Depression Questionnaire	5.94	5.73	**6.08**	4.29	**6.37**
9	Weight	5.94	**5.97**	5.26	4.41	**6.48**
10	Nutrition	5.84	**5.66**	5.37	4.41	**6.47**
11	Sport	5.71	**5.92**	4.45	4.82	**6.25**
12	Social Interactions	5.70	**5.58**	5.29	3.18	**6.45**
13	Daily Routine	5.58	**5.38**	5.13	3.59	**6.31**
14	Hygiene	5.39	5.01	**5.24**	3.35	**6.15**
15	Pulse	5.33	**5.65**	3.97	4.94	**5.72**
16	Steps	5.28	**5.27**	4.08	5.12	**5.84**
17	Blood Pressure	5.21	**5.61**	3.76	4.82	**5.56**
18	Screentime	4.87	**4.64**	3.89	3.29	**5.78**
19	Oxygen Saturation	4.78	**5.03**	3.32	4.29	**5.30**
20	Weather	4.19	3.72	3.42	**3.59**	**5.03**
21	Communication	4.07	**3.57**	3.00	3.12	**5.13**
UTAUT Constructs						
	Behavioral Intention	4.27	**4.24**	3.76	4.02	**4.58**
	Performance Expectancy	4.44	4.37	4.20	**4.43**	**4.63**
	Effort Expectation	5.27	**5.18**	**5.18**	5.03	**5.42**
	Social Influence	1.83	**1.80**	1.68	1.55	**1.95**
	Facilitating Conditions	4.96	4.90	**4.93**	4.57	**5.10**

Table 1: Cluster breakdown of the sample

Preliminary Discussion

With our preliminary results, we open two areas for further investigation: First, we identified multiple user types and their characteristics for personalizing PGHD for depression care among young adults. This shows that these user groups have different requirements for using PGHD. Therefore, it is essential to address these requirements so that the diffusion of PGHD for depression care within the clusters can be further advanced. **Cluster 1** has a balanced understanding of the relevance of PGHD in depression care. Users from this cluster rate many types of PGHD as relevant, both physical and mental. In addition, they have an above-average behavioral intention to use this data. Due to the many high ratings for physical data, it is conceivable to use passive methods to collect PGHD for this cluster, as these can be tracked using wearables. This can significantly reduce the effort required to collect data while adapting the collection method to the preferred types of PGHD. **Cluster 2** considers the types of PGHD that also have a psychological background to be particularly relevant. The motivation for collecting PGHD in this cluster could be increased by communicating the benefits of the data for the treatment of depression and by collecting precisely the types of data that they consider relevant. This meets the needs of the cluster and creates tangible value. To counteract the high expectations in terms of effort, this cluster needs to use less complex technologies and thus reduce cognitive and emotional hurdles. **Cluster 3** consists of people who consider PGHD, in general, to be less relevant for the treatment of depression than the other clusters. This group focuses on monitoring a few basic metrics. Therefore, it is important to show how PGHD technology can improve their ability to monitor these specific metrics, such as sleep, symptoms, or steps. To account for the comparatively low behavioral intention, it is essential to precisely use the data types rated as relevant within the cluster. **Cluster 4** rates almost all types of PGHD as the most relevant among the clusters and has by far the highest behavioral intention to use this data. This suggests that the individuals in this cluster are already collecting PGHD. Given their proactive nature, they are motivated to try new health technologies and are likely to experiment with and advocate for PGHD technologies. For people in this cluster, many different types of data can be used, which, together with the treating healthcare professional, can be tailored precisely to the needs of the treatment. For this cluster, it can be crucial that the technology offers advanced insights and thus creates a holistic approach to health based on PGHD.

Second, in addition to the clusters, our preliminary results on the UTAUT constructs also provide insights into ways to promote further the diffusion of PGHD for depression care among young adults. First, the data shows different ratings between the clusters for **Behavioral Intention**. While some clusters show a solid intention to use PGHD for depression care, others show lower values. These differences reflect the complex interplay between the individual perception of performance expectation, effort expectation, and the supporting conditions. According to UTAUT, behavioral intention is an essential predictor of actual system use (Venkatesh et al. 2003). Therefore, it could be crucial to consider the factors that reduce behavioral intention in specific clusters. **Effort Expectancy** is a significant factor, with consistently high scores across all clusters, indicating that users perceive the system as easy to use. This is crucial for acceptance, as ease of use in UTAUT is a decisive factor for the acceptance of technology (Venkatesh et al. 2003). It suggests that reducing complexity increases the potential for adoption. Moreover, the results for **Performance Expectancy** are also high. Despite some differences between the clusters, this still indicates that users see the use of PGHD as improving depression care in general. In technology acceptance, the perceived usefulness of technology is an essential factor (Venkatesh et al. 2003). Accordingly, if specific performance concerns are addressed in underperforming clusters, this could increase acceptance. The results for the **Facilitating Conditions** are relatively high in all clusters, indicating that users generally feel well-supported by the infrastructure and resources required to use the system. In technology acceptance, this value is a crucial direct influence on the actual use of a system (Venkatesh et al. 2003). In the context of PGHD for depression care, users should be provided with extensive education before data collection and sufficient onboarding when using the technology. Furthermore, the compatibility of devices for collecting PGHD with existing technologies should be improved, and data should be accessible across different platforms. By improving these conditions, barriers to acceptance can be minimized, making it easier for users to integrate the system into their daily routines. Finally, the low values for **Social Influence** suggest that social factors in this context have only minimal influence on users' decisions. This contrasts with traditional acceptance models, in which social influences are essential (Venkatesh et al. 2003). However, for PGHD use, individual expectations and ease of use appear to be more critical for acceptance than the influence of the social environment, suggesting that diffusion strategies should focus on users' internal motivators rather than social validation.

Conclusion and Further Theoretical Development

Our preliminary results contribute to a broader understanding of the use of PGHD in depression care for young adults. We were able to identify different user types of PGHD in depression care and gain a further understanding of its diffusion among young adults. We intend to develop our study in several ways based on these preliminary results.

First, to improve the generalizability of our results and to refine the calculations, we plan to collect further data in different contexts (healthy and depressed individuals) using the questionnaire we have developed. In addition, we recognize that including further technological aspects is essential to a thorough understanding of the contribution of factors influencing the diffusion of mental health apps that use PGHD. Therefore, we aim to include factors such as privacy concerns and technology affinity, and an assessment of each type of PGHD will be considered in our model according to their privacy concerns. These further psychological and environmental factors may thus provide further insights into understanding user groups.

By collecting further data, we plan to increase the sizes of the clusters in such a way that, based on UTAUT, we can not only consider the constructs individually but also have a sufficiently large sample size for each cluster to estimate the influences of the constructs in a structural equation model for each cluster. As a result, we expect to be able to show different significant and strong influences in the UTAUT model between the clusters. Our preliminary results indicate that especially the constructs in which there are more considerable differences in the ratings between the clusters will show differences in the influences in a structural equation model. In this way, we aim to contribute to a broader understanding of health technology acceptance among young adults.

In addition to the individual level, which we aim to map by embedding it in the literature on technology acceptance, we also aim to consider the population level by using the diffusion of innovation theory. (Rogers et al. 2003). In this context, it is essential for us to consider how the individual stages of the diffusion of the innovation process are used in the context of PGHD for depression care and to identify the key driving factors. Based on the clusters we have identified, we aim to highlight the differences between the clusters and thus be able to address the needs of each user group in the future. In addition, we want to subdivide the user groups we have identified into adopter groups (e.g., innovators, early majority, etc.) for innovations in healthcare. In doing so, we aim to contribute to a broader understanding of which factors need to be considered when implementing innovative technologies in depression care.

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