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EXPLORING THE POTENTIALS OF PATIENT-GENERATED HEALTH DATA FOR THE TREATMENT OF DEPRESSION

Research Paper

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Abstract

Patient-generated health data (PGHD) enables healthcare professionals to get deeper insights into patients with depression, thus offering the opportunity to improve their treatment. However, due to the variety and methods for collecting PGHD, not all types are relevant for healthcare professionals in depression care. To identify relevant types of PGHD for the treatment of depression, we conducted a qualitative focus group study with 13 healthcare professionals and follow-up interviews. The study's key findings include relevant identified PGHD concerning their collection effort. In addition, the results show a clear preference for PGHD that both have strong connections to depressive symptoms and use passive collection methods, such as sleep data and activity levels. With this article, we contribute to the usage of PGHD in clinical settings and thus create a better understanding of relevant types of PGHD for the treatment of depression.

Keywords: Health information technology (HIT), Mental Health Care, Patient-Centered Care, Mobile Applications, Information Overload

1 Introduction

Patient-generated health data (PGHD) is, by definition, health-related data created, recorded, and gathered by the patient, including health and treatment history, symptoms, lifestyle choices, and other information (Shapiro et al., 2012). This kind of data has already been used for several decades in the healthcare sector (Ziegler et al., 1989). Traditionally, this kind of data has been collected for selected illnesses with dedicated, often hardware-bound devices (Cahn et al., 2018). Such diseases include diabetes and hypertension (Shah and Garg, 2015, Turner et al., 2021).

With mobile sensors and smartphones, collecting personal health data has become less cumbersome for patients. Thus, further opportunities arose to improve the diagnosis and treatment of many diseases, including mental health disorders (Burgermaster et al., 2020, Danis, 2016, Hartmann et al., 2019). However, while the usage of PGHD for diseases such as diabetes and hypertension has been widely studied (Shah and Garg, 2015, Turner et al., 2021), the potential of PGHD for treating mental health disorders, such as depression, remains largely unexplored.

The topic of depression care is of the highest interest and importance (Gensichen et al., 2022). Depression is one of the most common mental illnesses (Jacobi et al., 2014). Moreover, the incidence of this condition worldwide has escalated to approximately 25% amongst the general population after the onset of the COVID-19 pandemic. (Bueno-Notivol et al., 2021). Therefore, the role of PGHD in diagnosing and treating depression is of the highest relevance.

To improve the usage of PGHD for the treatment of depression, we need to develop a clear understanding of the potential of PGHD in the context of mental health disorders. Firstly, we need to understand which types of PGHD are relevant, and secondly, we need to understand which of these relevant types of PGHD can be collected by patients with reasonable effort. Therefore, we postulate the following two research questions:

RQ1: What are the relevant types of PGHD to improve the treatment of depression?

RQ2: How can these types of PGHD be classified according to the dimensions of their relevance and effort of the collection?

To answer these questions, we conducted a focus group study with 13 healthcare professionals who specialized in the treatment of depression. This focus group study aimed to work with experts from the field of depression care to obtain their valuable opinions on using PGHD for their work, to stimulate the exchange of experts, and to generate outcomes that otherwise would not have been identified through individual interviews. The present article is structured as follows: Initially, we will give insights into the related literature. Subsequently, we present the methods used for the conducted focus group study. This section is followed by the results section, where we will present the outcomes of the focus group study. Finally, we discuss the results and postulate a future research agenda.

2 Theoretical background

This section aims to give insights into several aspects of research conducted on PGHD in depression care. To begin with, we provide a general overview of PGHD in healthcare and then summarize in which manner PGHD is currently used in depression care.

2.1 Patient-Generated Health Data in Healthcare

PGHD is data that reflects patients' everyday behaviors, including but not limited to physical activity, mood, diet, sleep, and (disease) symptoms (Choe et al., 2018). A general definition of PGHD has been given by Shapiro et al. (2012), describing the data as: "health-related data created, recorded, gathered by the patient, including health and treatment history, symptoms, lifestyle choices, and other information". According to this definition, PGHD differs in two ways from data collected in clinical settings and encounters with healthcare providers (Chung and Basch, 2015):

1. Patients record and capture the data themselves rather than the healthcare professionals.
2. The patient decides how and with whom the data is shared and distributed.

With these differentiations from data collected in clinical settings, PGHD can expand the conventional question-answer process during patient-clinician interactions by generating data outside of clinical settings and transferring this process to the patient's everyday life. (Lindroth et al., 2018). This enables healthcare providers to gain deeper insights into the lives of their patients and thus supports the diagnosis of diseases (Zhang et al., 2019). These improved insights into the patient's symptoms, life, and persona can help the clinician in several ways (Burgermaster et al., 2020). Treatment of diseases can be personalized (Cahn et al., 2018), and consultation and treatment planning can be improved by avoiding unnecessary consultations (Burns et al., 2019).

While improving the diagnosis and treatment of many diseases, PGHD enables another vital aspect of patient therapy: active patients' participation in the treatment process. The chronic care model (CCM) (Wagner et al., 1996) is a theoretical framework aimed at providing high-quality care to individuals with

chronic conditions, such as diabetes and heart diseases. The CCM highlights the advantage of involving patients in diagnosing and treating their diseases and thus supports patients' self-management. The CCM emphasizes a proactive, patient-centered approach to care delivered through a coordinated, integrated healthcare system. Although the model encompasses different critical elements, it underscores the significance of active patient participation in their treatment to enhance effectiveness. Educating patients to learn skills and tools to monitor their symptoms encourages self-monitoring. This prevents an excessive focus on the negative, which may contribute to patient's anxiety (Purtzer and Hermansen-Kobulnicky, 2016). Through the use of PGHD in therapy, patients get more involved in their treatment and can contribute to their health actively. With a PGHD-supported therapy, clinicians and patients create a value-co-creation environment to find the best therapy based on shared decision-making (Kim and Lee, 2017, Austin et al., 2020b). In addition, the collected data provides valuable insights into the patient's condition and treatment progress. An appropriate data perspective involves integrating relevant types of PGHD into the treatment workflow. However, mental health patients pose a particular challenge regarding active monitoring, mainly because they tend towards non-adherence and lack of collaboration (Porrás-Segovia et al., 2020). Therefore, it is crucial to integrate only relevant and easily collectible types of PGHD into depression care to alleviate the burden on patients.

The usage of PGHD in clinical settings can be roughly divided into three different stages: (1) the collection of PGHD, (2) the integration of PGHD into the clinical workflows, and (3) the usage of PGHD in patient-clinician interaction (Reindl-Spanner et al., 2022). As mentioned in the introduction, while PGHD offers many benefits for diagnosing and treating many diseases, many challenges must be faced in the above-described stages when introducing PGHD into clinical workflows (West et al., 2018).

While PGHD offers excellent potential for additional value in healthcare, several barriers may arise. On the one hand, the problem with (1) is that through smartphone usage, patients can collect all sorts of data about themselves. However, not all data the patient can collect is relevant for diagnosing or treating the patient's condition. As a result, the excessive data can overwhelm clinicians with information and lead to issues such as technostress (Ye, 2021) or information overload (Rodríguez et al., 2019). On the other hand, the collection of PGHD can sometimes be a burden (e.g., paper questionnaires about mental health) for the patients (Piras, 2019). Furthermore, these burdensome collection methods can cause patients to be more error-prone during data collection. However, less error-prone automated data collection methods often result in patients having privacy concerns (Ng et al., 2019).

2.2 Patient-Generated Health Data in Depression Care

After providing a general introduction to the opportunities of PGHD in healthcare, this section will provide an understanding of the state-of-the-art research regarding PGHD in depression care.

When working with mental health patients, the first challenges arise when collecting the data needed to improve the patient's treatment. The collection methods can be divided into two groups: active and passive. In contrast, active collection methods have been around longer; with the introduction of smartphones, smart sensors, and wearables (e.g., smart watches), a shift towards passive collection methods has occurred. Whereas data collection through active collection methods was initially rather time- and resource-consuming for patients (Piras, 2019), the mentioned modern technologies enable the collection of large amounts of data without requiring active patient involvement.

Active monitoring is challenging for mental health patients, given the psychiatric population's high rates of non-adherence and lack of collaboration (Porrás-Segovia et al., 2020). Furthermore, it is possible that active monitoring causes stress in already unstable patients, causing them to discontinue tracking (Porrás-Segovia et al., 2020, Wu et al., 2020). Nevertheless, active collection methods still have their *raison d'être* through mental health questionnaires (Nittas et al., 2019) or the active involvement of patients (Austin et al., 2020a). In passive monitoring, on the other hand, data is acquired from the devices' native sensors without requiring user engagement. Although current passive collection methods do not provide a direct view into psychological states like anxiety or mood, other parameters that seem relevant for physical and mental health can be tracked (Jayakody et al., 2014, Ng et al., 2019). These

include smartphone usage patterns, mobility, physical activity, sleep quality, and sleep habits (Borghouts et al., 2021). In addition to allowing the collection of nearly continuous patient information, it reduces recall bias and provides a more valid ecological setting (Porrás-Segovia et al., 2020).

PGHD offers significant opportunities to be introduced into depression care. However, currently, there is a lack of research on using PGHD in depression care. A first theory stream that the introduction of PGHD can extend is the "measurement-based care" trend. In this stream, reliable sources of data collection that support classic instruments, like questionnaires, are needed (Fortney et al., 2018). Therefore, PGHD offers ways to improve treatment decision-making based on systematically tracking symptoms and patients. However, other studies recommend that the patients collect PGHD, which are then discussed during counseling sessions. This procedure has improved therapeutic feedback (Meng et al., 2018). Further ideas for the usage of PGHD in depression care include the utilization of the obtained data as predictors for depression (Saeb et al., 2015, Hallgren et al., 2017). In this context, the collected data is used to produce comparative values based on established and validated questionnaires, which are then used to predict clinical risks. Furthermore, this prediction has the potential to identify patients who are not responding well to treatment or are disengaged, leading to timely clinical intervention if needed (Hallgren et al., 2017).

3 Method

The present study is embedded in a larger project (Gensichen et al., 2022) investigating the potential of technology-based support in treating depression, which is subject to the design science research (DSR) approach (Hevner et al., 2004). DSR involves constructing and assessing information system artifacts to create theoretical knowledge. DSR is driven by real-world requirements, seeking to address practical issues while adhering to rigorous theoretical principles (Hevner et al., 2004). With the present article, we aim to investigate the areas of application of PGHD in depression treatment; thus, we cover the relevance cycle of the DSR (Hevner, 2007). To explore the postulated research questions, we have chosen a focus group design for this study following the approach by Krueger (2014). As a first step, we conducted a focus group study (Krueger, 2014, Tremblay et al., 2010) with 13 healthcare professionals to identify the potential of PGHD in depression treatment. We chose a focus group study as the research method due to its flexibility, direct interaction with respondents, large amounts of rich data, and interactions within the group (Tremblay et al., 2010). As a second step, we conducted interviews with selected focus group participants to provide deeper insights and validate the focus group findings. This approach allowed us to stimulate the exchange of experts in the field and thus generate outcomes that could not have been identified through individual interviews. We conducted the focus groups study as a 3-hour workshop on the afternoon of March 23, 2022. The study was conducted in German language.

3.1 Study design

We will outline the steps of the focus group study in the following section.

Familiarization phase (45 min). To ensure that all participants shared a common understanding of PGHD, we started the focus group study by providing a short introduction to PGHD. After the introduction, we divided the focus group participants into four groups (2 to 4 persons, respectively). First, we asked the participants to identify all relevant types of PGHD for the treatment of depression, discuss them within their small group and write them down. The participants were allowed to use any source of information available to them. Subsequently, we asked the participants to cluster the identified PGHD based on common themes, resulting in a list of different categories of PGHD for each group. Finally, we concluded this phase with a short presentation of the results of all four focus groups.

Focus phase (45 min). In this step, we asked the participants to identify the PGHD types they deemed most important for treating depression. If they identified types of PGHD not considered in the previous step, they were free to add them to their list. At this stage, it was necessary that the participants freely

chose this ranking of PGHD's importance without limitations of workload, effort, data security, or feasibility. In the next step, we asked the participants to discuss the advantages and disadvantages of the identified PGHD regarding relevance and effort. The participants should rate/evaluate the types of PGHD based on the effort of collection, the frequency of collection, and the advantages and disadvantages of the different kinds of data. We provided the participants with a matrix template consisting of the dimensions "Effort to collect" and "Relevance for the treatment of depression". We asked them to place the identified PGHD within the matrix. This step resulted in a matrix for each group, providing an overview of types of PGHD which are rated based on relevance for depression care and effort to collect. Based on the matrix results, we asked the participants to identify the most essential/promising 3-5 types of PGHD.

Exchange phase (45 min). The last phase was dedicated to exchanging and validating the results in the group. We asked participants to present their matrix and highlight the most important types of PGHD for the treatment of depression. Participants discussed the importance of PGHD and elaborated on appropriate methods for collecting PGHD from the patient's perspective and integrating PGHD into the treatment process. This phase resulted in participants comparing their results and adjusting their findings based on the plenary discussion.

Interview phase. After completing the workshop, we appended an interview phase. The purpose of this phase was to validate the results obtained during the workshop with selected participants (n=7, please find these participants marked in Table 1). We selected participants based on diversity criteria to reduce confirmation, gender, and professional bias. In addition, as the study's overall goal is to identify potentially relevant types of PGHD in depression care, we selected participants whose profession includes daily patient contact with depressive patients. We conducted the interviews via online or face-to-face meetings about two weeks after the workshop. The interviews were carried out using a semi-structured approach and were captured in both video and audio formats. To conduct the interviews, we prepared four guiding questions, which were then used to develop the interviews. These four questions are as follows:

1. What is your perspective on the presented Relevance-Effort matrix for data collection?
2. In what manner should patients gather the data?
3. What approach would you employ to integrate this data into your treatment plan?
4. What steps should be taken to prepare the data for utilization?

3.2 Focus group study participants

The workshop included 13 experts (8 female, 5 male) working as healthcare professionals in different medical domains and specializing in treating depression. The healthcare domains of the participants are as follows: medical doctors, psychologists, pharmacists, and public health professionals. We collected consent from all attendees. Table 1 provides an overview of the participants' demographics.

3.3 Data analysis

We divided the data analysis into two steps. Firstly, we analyzed the data collected in the focus group study. For this purpose, we digitalized the content created by the participants. To do so, we photographed the respective documents and converted them into digital posters. After this step, we consolidated and clustered the results and inserted them into the matrix shown below (Figure 1). The resulting matrix represents our first finding for this paper.

Secondly, we performed several steps for the analysis of the interviews. To begin with, we transcribed the video and audio data of all interviews. Subsequently, we created a coding scheme to study the interviews following Mayring and Fenzl (2019). For this purpose, we created an initial coding scheme based on the scientific literature on the relevance of PGHD for depression care. In the next step, we refined the resulting codes with the findings from the focus group study to better align with our results from the focus group (Tremblay et al., 2010). We then moved on and used the coding scheme to code

the transcriptions. Finally, we used the coded transcriptions to analyze and validate our findings from the focus group study. With this step, we validated the results we present in figure 1. In addition, through the analysis of the interviews, two additional topics emerged, i.e., information overload through PGHD and presentation of PGHD, which we added to our results.

4 Results

In the following section, we present the results of the focus groups and the interviews. To begin with, we provide an overview of the classification of the essential types of PGHD for the treatment of depression based on a Relevance-Effort-to-collect Matrix. Subsequently, we will give additional insights into the interview results.

4.1 Relevance-Effort-to-collect Matrix of PGHD for the treatment of depression

The following section presents the findings based on a Relevance-Effort-to-collect Matrix (Figure 1). The matrix provides an overview of different types of PGHD. It categorizes them as follows: high relevance |low effort to collect (Quadrant 1), high relevance |high effort to collect (Quadrant 2), low relevance| low effort to collect (Quadrant 3), and low relevance |high effort to collect (Quadrant 4). Below we present each quadrant.

Quadrant 1 (High Relevance| low effort to collect): Sleep, Activity Levels, Cardiac Parameter, Vital Parameter, Online Behavior

Quadrant 1 represents the essential types of PGHD for treating depression, as these data types are highly relevant and can be easily collected by the patients.

Sleep. All groups identified sleep as a critical factor for depression. For this reason, sleep was rated as the most relevant item within the matrix. The correlation between sleep and depression has been shown before and is used as a diagnostic feature for depression (Tsunno et al., 2005). The sleep cluster contains different types of sleep data. This includes sleep quality, duration, number of sleep interruptions, time until the patient falls asleep, sleep regularity, and time of going to bed. Sleep data can be easily collected via smartphone apps or directly through other smart devices such as smartwatches (Ng et al., 2019). The data collected in this manner is also processed in most apps and visualized for the users.

	<i>Profession</i>	<i>Gender</i>	<i>Age</i>	<i>Interview</i>
Group1	<i>Psychologist</i>	<i>Female</i>	<i>28</i>	<i>Yes</i>
	<i>Psychologist</i>	<i>Female</i>	<i>29</i>	<i>No</i>
	<i>Psychologist</i>	<i>Female</i>	<i>27</i>	<i>Yes</i>
	<i>Doctor</i>	<i>Female</i>	<i>27</i>	<i>Yes</i>
Group2	<i>Psychiatrist</i>	<i>Female</i>	<i>Prefer not to say</i>	<i>Yes</i>
	<i>Psychologist</i>	<i>Female</i>	<i>27</i>	<i>No</i>
	<i>Pharmacist</i>	<i>Female</i>	<i>27</i>	<i>No</i>
	<i>Doctor</i>	<i>Male</i>	<i>27</i>	<i>Yes</i>
Group3	<i>Doctor</i>	<i>Male</i>	<i>43</i>	<i>Yes</i>
	<i>Doctor</i>	<i>Male</i>	<i>33</i>	<i>No</i>
	<i>Public Health Specialist</i>	<i>Female</i>	<i>27</i>	<i>No</i>
Group4	<i>Doctor</i>	<i>Male</i>	<i>36</i>	<i>Yes</i>
	<i>Doctor</i>	<i>Male</i>	<i>31</i>	<i>No</i>

Table 1: Study Participants' Demographics

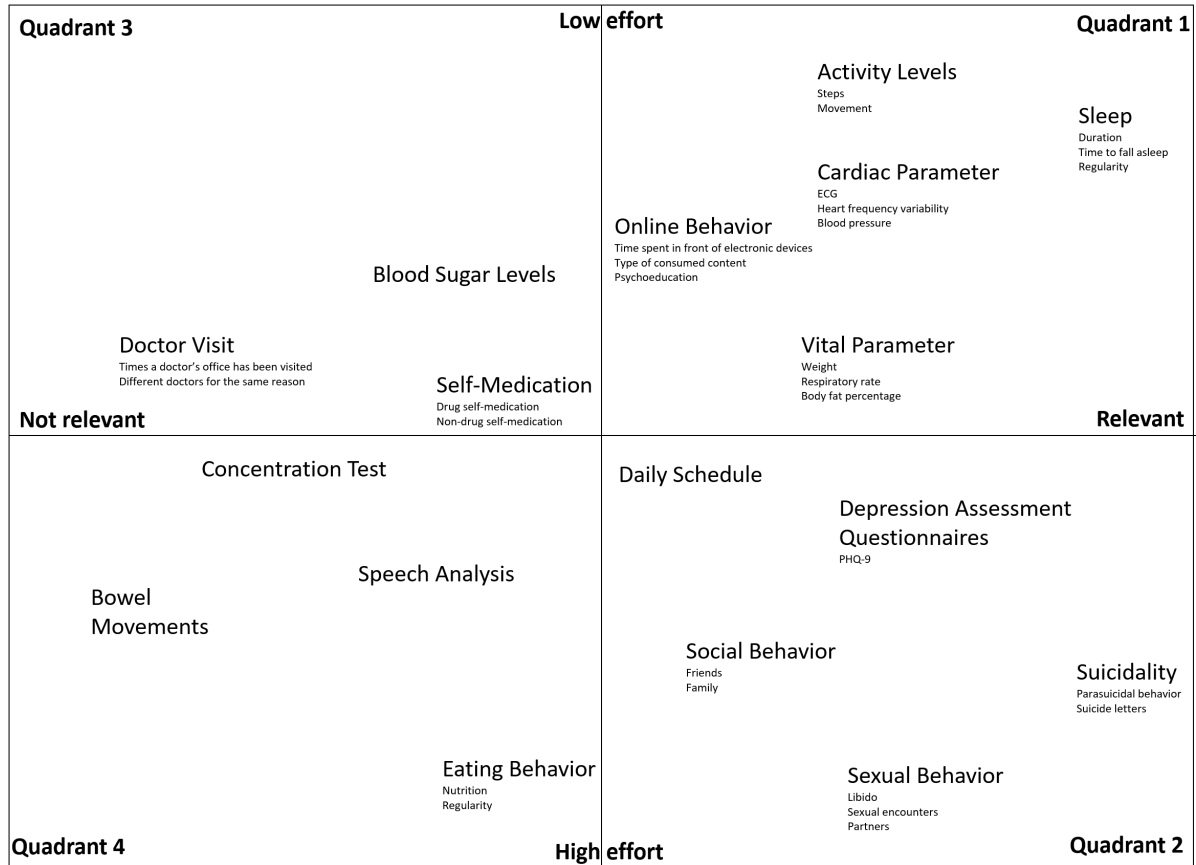


Figure 1: Relevance – Effort-to-collect Matrix of PGHD for the treatment of depression

Primarily, this data can be collected passively, and the only hurdle for patients is wearing a smartwatch/smart sensor or turning on the recording app. In addition, a wide variety of applications is available to smartphone users in the various app stores to collect sleep data. Therefore, these types of data are considered easy to collect. The participants mentioned the high relevance of sleep data during the focus groups and confirmed in the subsequent participant interviews to confirm the results.

Activity Levels. Multiple groups have identified activity levels as a cluster of PGHD in different forms. A person's activity levels are interesting, as research has established links between physical activity and mental health (Paluska and Schwenk, 2000). These connections indicate that people with depression generally have lower activity levels than their healthy counterparts. The only effort users have to make to collect activity-level data is to always keep their smartphone or smartwatch with them. This simple handling means that users are hardly restricted in their everyday lives. By using activity data, patients can also be actively involved in their therapy in line with the chronic care model (Wagner et al., 1996). Workshop participants also mentioned gamification in the field of PGHD during the familiarization and focus phase. Patients who collect activity data about themselves could be incentivized to increase physical activity levels and reach daily activity goals through gamification solutions. This achievement of daily exercise milestones is vital for the patient's therapy and can improve the patient's overall (mental) health state (Kim et al., 2017).

Cardiac Parameter. For the presentation of our results, we distinguished the cluster of "Cardiac Parameters" from that of "Vital Parameters" because, concerning depression, heart diseases represent frequent comorbidities (Carney and Freedland, 2017). All groups recognized Cardiac Parameters as highly relevant. Cardiac Parameters include ECG values, blood pressure values, and, for example, heart rate variability. Cardiac Parameters are a type of PGHD that may be collected actively and passively and are among the types of PGHD that have been collected for many years. PGHD types in the cluster that can be gathered passively include heart rate variability, ECG data (Jim et al., 2020), and pulse

(although the latter can also be actively collected). On the other hand, blood pressure data, in particular, must be actively collected with a dedicated device and either written down on paper, entered into an app, or transferred directly to the smartphone (Nittas et al., 2019). In the case of passive data collection, smartwatches and smart sensors are primarily used in conjunction with a smartphone.

Vital Parameter. As described before, we have distinguished the vital and cardiac parameters. Accordingly, this category includes all values that can be collected from the patients concerning the body but not the heart itself. Examples from our workshop include respiratory rate, patient weight (BMI), and body fat percentage. These parameters are essential for the somatic diagnosis of depression and cardiac parameters. In particular, values such as BMI have already been linked to depression. They are, therefore, of great relevance to doctors, as the prevalence of depression is higher in highly obese or underweight patients (Scott et al., 2008, Onyike et al., 2003). On the other hand, a major criticism of these values is that they are not very easy for patients to collect on their own as they need active participation. Furthermore, this data helps doctors with the diagnosis and provides comparative values for improvements or deteriorations during therapy.

Online Behavior. Within the online behavior cluster, we describe all measurable values that deal with individuals spending time in front of a screen (smartphone, computer, etc.). These types of data have been associated with depression and anxiety disorders, especially regarding younger generations (Maras et al., 2015, Boers et al., 2019). These data types include app usage times, frequency of opening apps, which apps are used, and the time spent in front of screens. There are different levels of difficulty in collecting these values. Collecting the data is easy if the data collector utilizes only one device. However, as soon as several other independent devices are used, this data must be compiled and connected (in part also across platforms) (Rooksby et al., 2016). Collecting online behavior data can help uncover the excessive use of electronic devices. In this domain, correlations between excessive use of social media and depression have already been identified (Keles et al., 2020). Similarly, correlations between decreased sleep due to excessive use of electronic devices have been found in adolescents (Maras et al., 2015, Boers et al., 2019). Although these factors do not directly trigger depression, they do promote the development of depression. Visualizations of online behavior can then be used to teach patients to improve their use of electronic devices through psychoeducation. This can create better conditions for treating depression in the long term. In addition, the participants mentioned that collecting data on patients' psychoeducation use can provide interesting conclusions about patients' therapy success.

Quadrant 2 (High Relevance| high effort to collect): Suicidality, Sexual Behavior, Depression Assessment Questionnaires, Social Behavior, Daily Schedule

Quadrant 2 represents types of PGHD that are considered relevant for therapeutic use by healthcare professionals but are associated with a high effort to collect by the patients. Therefore, we consider these kinds of PGHD important for depression care but less important than the types of PGHD described in quadrant 1.

Suicidality. By its very nature, suicidality is immensely important in depression. For this reason, participants considered measuring a person's suicidality as a relevant data source. It is essential to highlight that measuring suicidality is exceptionally challenging, and current suicidality screening questionnaires have only slightly better accuracy than random chance (Franklin et al., 2017). Therefore, participants suggested methods such as measuring parasuicidal behavior to indicate suicidality. Parasuicidal behavior is understood as any intentional, acute self-injurious behavior with or without suicidal intent, including both suicide attempts and self-mutilative behaviors (Panos et al., 2014). Some examples are driving too fast, excessive consumption of alcohol or drugs, or writing and sending suicide threats or suicide notes. Understandably, these metrics are also somewhat challenging to capture and require the patient's active involvement.

Sexual Behavior. The sexual behavior of patients may contain further indications for depression (Williams and Reynolds, 2006). The participants pointed out that the libido of the individuals may be significantly reduced. Unfortunately, collecting this data is very difficult, as these topics often cause shame among patients or are considered taboo in various cultural circles.

Depression Assessment Questionnaires. According to the current state of science, these questionnaires are mainly used to diagnose depression, determine its severity, and monitor therapeutic success (Kroenke et al., 2009). Usually, the therapists fill out these questionnaires during the treatment sessions. In a mobile setting, these questionnaires can be completed easily via an app and are conveniently collectible under normal circumstances. However, the situation is different for patients with depression, who are often lethargic and consider even the simplest activities difficult to handle (Fehnel et al., 2016). Especially patients with more severe forms of depression who have difficulties performing everyday activities such as eating, showering, or keeping their home clean, cannot be expected to complete a questionnaire via an app. These questionnaires include the PHQ-9 (Kroenke et al., 2001) questionnaire.

Social Behavior. The participants perceived patients' social behavior as relevant information for the treatment. The term "social behavior" in this context encompasses a broader context rather than just interactions with others. It mainly relates to the patient's involvement in social activities, including the frequency and the people they engage with. However, obtaining this type of PGHD was difficult due to its sensitive and private nature.

Daily Schedule. A documented daily routine of the patients provides clinicians with valuable insights into the daily lives of their patients. This renders the patients' narratives verifiable. In addition, the data allows clinicians to determine whether the values of other measurement points (e.g., activity levels) are realistic or whether the patients are falsifying the results. Furthermore, these data help clinicians determine if the patient's lifestyle supports their recovery and can assist in establishing healthy daily routines.

Quadrant 3 (Low Relevance| low effort to collect): Self-Medication, Blood Sugar Levels, Doctor Visit

Quadrant 3 represents types of PGHD that are of somewhat low relevance for healthcare professionals but are effortlessly collectible by the patients. Low relevance in this context means the data may not be relevant for depression care in general but valuable in specific cases.

Self-Medication. In many cases of developing depression, patients try various home remedies to counteract possible symptoms. Patients also often try to help the healing process with self-medication and the actual treatment (Markou et al., 1998). Detailed documentation of this self-medication can help the treating clinician to detect possible interactions and to control the therapy in the best possible way.

Blood Sugar Levels. Blood sugar levels are one of the types of PGHD that have been collected for several decades. As diabetes is a common comorbidity of depression, this type of PGHD is a relevant component for participants, primarily those who have diabetes, in the treatment of depression (Holt et al., 2014, Sartorius, 2022). However, the participants mentioned that tests with non-diabetic patients with depression might be conducted to exclude diabetes as a comorbidity.

Doctor Visit. Frequent doctor visits may indicate that a patient is seeking help but not receiving it or that their depression is not being recognized. Likewise, a possible prescription drug dependency may remain undetected due to many visits to several doctor's offices to obtain multiple prescriptions for different conditions (El-Aneed et al., 2009). Here, insight into the number and frequency of doctor visits can help the treating clinician (Guo et al., 2017).

Quadrant 4 (Low Relevance| high effort to collect): Eating Behavior, Speech Analysis, Concentration Test, Bowel Movements

For completeness, we would also like to list four types of PGHD mentioned in quadrant 4 and thus may be classified as irrelevant to the treatment of depression.

Eating Behavior. Eating behaviors reveal daily routines and nutrient intake; over/under-eating may indicate a depressive episode. (Zung et al., 1974, Frost et al., 1982).

Speech Analysis. Speech analysis informs doctors about changes in a patient's speech behavior during treatment but is limited to laboratory settings.

Concentration Test. Concentration tests provide insight into a patient's cognitive abilities.

Bowel Movements. According to the participants, bowel movements are not necessarily relevant for treating depression but were nevertheless included in the matrix due to completeness reasons.

4.2 Interview Phase

In the following paragraphs, we present the results of the conducted interviews. These interviews aimed to verify and validate the results of the presented matrix in one-on-one interviews. Firstly, the matrix we presented in the previous section was displayed to the interviewees, and they were asked for their respective opinions. All participants validated the classification of the PGHD clusters within the matrix and provided insights into their preferences regarding collection methods and ways to include the obtained data in their clinicians' workflows.

All participants showed a clear preference for passive PGHD collection methods. Two reasons primarily supported this preference: on the one hand, the interviewees justified using passive methods of collecting PGHD as being less invasive and thus less restrictive for the patients in their daily activities. On the other hand, the interviewees justified passive collection methods by arguing that, in their view, the collectors are significantly less likely to alter or falsify the data collected using passive methods. While passive collection methods are most relevant in depression care, it is still essential to collect PGHD actively in some cases. This can be the case if the collected data is highly relevant for the treatment (e.g., blood pressure data) because it can still offer valuable insights. Another situation that requires active data collection, according to the participants, is when patients should be activated to develop routines through specific daily activities. Thus, writing a diary of daily activities can provide insights to the treating psychiatrist and help the patients develop good routines for treating their illnesses.

Furthermore, the interviews showed that different professional groups within the focus group participants preferred different presentations of the PGHD. The interviewed physicians stated they would like an overview of the collected data. This presentation should then highlight all values that do not correspond to the norm to allow them to recognize all values that do not correspond to the standard at a glance. The interviewed psychiatrists said they wanted to see the data displayed as progress curves. Both representatives stated they would like to have possibilities in the overview to display the data in detail.

In addition, all participants mentioned that they often face a deluge of data when incorporating PGHD into their clinical workflows. In this regard, the participants stated that in some cases, they receive data from patients during their consultations but cannot include them in their diagnosis or treatment due to their abundance. The participants expressed that they often feel overwhelmed by the amount of data presented to them by the patients. This data usually includes types of PGHD that are only of minor relevance to the acute clinical picture. Therefore, all participants advocated that the patients should collect only a few kinds of PGHD but that these should be relevant to their specific condition. The participants extended the scope of this statement beyond the particular case of depression illnesses through generalization.

Regarding the inclusion of collected data into the physicians' workflow, we could identify two different approaches: Firstly, the participants indicated that they would only have the data collected if they deemed it relevant for their treatment. Secondly, the participants stated that the data should primarily be used to understand the patients' narratives based on data points and to check the success of the therapy, for example, in relation to sleep quality and duration. On the other hand, the participants stated that the patients should collect the data to treat the symptoms connected to the values outside the normal range.

5 Discussion

This paper is one of the first to investigate the significance of PGHD for depression treatment and its collection efforts. The following paragraphs will critically review the presented results.

5.1 Key findings

The most essential identified PGHD for the treatment of depression are Sleep, Activity Levels, Cardiac Parameters, Vital Parameters, and Online Behavior. The collection of this data takes place passively. Sleep and activity levels can be collected so that patients only need to carry the devices used for collection, for example, smartphones, smartwatches, or fitness trackers (Ng et al., 2019). Nowadays, almost all cardiac parameters can also be tracked by a smartwatch. The only type of PGHD within the cardiac parameter cluster that requires patient activity is blood pressure data (Bourke et al., 2020). Patients collect this data with a blood pressure monitor, enter it into a smartphone independently, or transfer it via a dedicated app. Some vital signs we described can be collected passively (e.g., respiratory rate through smart sensors). However, the patient must use a weight or body fat percentage scale. Finally, the data in the "online behavior" cluster may be collected passively (e.g., screen time and used applications) (Rooksby et al., 2016).

Passive data collection is particularly suitable for disburdening patients but does not actively involve them in their treatment. An essential aspect of PGHD often found in scientific literature is that patients are encouraged to participate in their therapy (Danis, 2016, Wagner et al., 1996). PGHD usage in healthcare aims to improve care through comprehensive insights for healthcare professionals and to involve further patients in their treatment (Kim and Lee, 2017). PGHD that can be collected passively may be convenient for the patient, but they only partially address the advantage of actively involving the patient in the therapy. As depression patients might have issues with active data collection, we recommend a low entry threshold for collecting data due to the lethargy/chronic fatigue symptoms, that may persist even after healing or after the essentially successful therapy (Fava et al., 2014) associated with the disease. As a result, it may be considered more important, especially in the acute stage of the disease, that the data can be easily collected from the patients rather than having them actively collect it themselves. Therefore, we recommend that it be at the physician's discretion also to request active collection of PGHD from the patients if the medical condition permits to benefit from the patient's active involvement in their treatment.

PGHD has great potential to improve the treatment of depression but must not result in physician work overload. Many sources of current scientific literature already discuss whether introducing PGHD into clinical workflows can lead to healthcare professionals' overload (Choe et al., 2018, Cronin et al., 2018, Reading and Merrill, 2018, West et al., 2018). The five types of PGHD identified in this workshop that is both vastly relevant to the treatment of depression and deemed easy to collect for patients (Quadrant 1) may help reduce this burden on healthcare professionals. By reducing the number of types of PGHD provided to the treating healthcare professional, an overburdening of the physician, caused by too many types of PGHD that are either only slightly relevant or not relevant at all, can be counteracted. Following the "less is more" principle, reducing the collected data can alleviate the patient burden. Additionally, healthcare professionals can obtain the specific data they require for treatment more efficiently.

5.2 Theoretical contribution

With the present article, we contribute to several research areas. Firstly, with this paper, we extend research on the usage of PGHD (Austin et al., 2020a). We are among the first researchers to introduce types of PGHD that are specifically relevant to be collected for usage in depression therapy. This is particularly important because healthcare providers often encounter irrelevant PGHD (West et al., 2018). By reducing the number of types of PGHD collected and provided to healthcare professionals, the accessibility (usability of the PGHD integrated platform) of the data for the treating healthcare professionals can be ensured. We thus contribute to a better understanding of relevant types of PGHD in the treatment of mental health disorders and provide a foundation for the further investigation of the usage of PGHD for mental health disorders.

Secondly, we contribute to research on Information Systems (IS) in healthcare. With this paper, we contribute to the challenge to the scholarly IS field by Chiasson and Davidson (2004) to incorporate

health IS research in core IS research. By doing this, we contribute to several streams within IS research in healthcare. We explore the usage of smart wearable devices, including smartwatches and smart sensors. These devices are the subject of the Internet of Things research domain. With this article, we also contribute to a further understanding of how to use these devices in healthcare contexts and make data collection less demanding on the patients (Al-Fuqaha et al., 2015). In this area, our article contributes to using and understanding passively collected data through these devices (Ng et al., 2019). In addition, we contribute to a further understanding within the IS community of data collection and use in healthcare environments. Due to the multidisciplinary nature of IS in healthcare, it is of the highest importance that research is conducted from different perspectives with participation from all involved parties (Fichman et al., 2011).

5.3 Practical contribution

In addition to the theoretical contributions, our study also provides practical contributions. We identified the most relevant PGHD for the treatment of depression. We thus provided new opportunities for healthcare professionals to integrate PGHD into treating their patients suffering from depression. This article's most important practical contribution is the types of PGHD within quadrant 1 of the presented matrix (Figure 1), which are considered relevant for healthcare professionals and easy to collect for patients. By using these types of PGHD within an application to support the treatment of depression, different professional groups can use the same IT solution. This has the effect that the complexity of its architectures can be reduced by reducing the heterogeneity of the used applications.

Furthermore, our findings help clinicians treat depression in different ways. Firstly, our results can be used to gain a broader understanding of the usage of PGHD in clinical contexts, particularly in the treatment of depression. Secondly, by showing a clear preference for the passive collection of PGHD, our findings may be used as orientation in decision-making regarding selecting PGHD collection methods for therapy. Ultimately, by reducing collected types of PGHD, our findings may help reduce the burden on clinicians.

5.4 Limitations

Our study, like all other studies, is subject to limitations. The limitations of this study are primarily attributed to the selection of participants. First, the number of study participants ($n=13$) was limited. We acknowledge that this small number of experts may have impacted the study results, as they reflect the opinions of the included experts. Recruiting more participants proved challenging due to the limited availability of clinicians and psychiatrists, resulting in fewer participants. The difficulty was compounded by the busy schedules and time constraints of the potential participants, which made it challenging to schedule the workshop on a suitable date for everyone. However, this small, controlled environment allowed us to offer the participants a safe environment to be creative and collect their ideas. In addition, through this small number of participants, we could work more closely with the participants during the workshop and thus better capture the results and dynamics of the groups. Future research should verify our results through a more extensive survey of clinicians and affected patients.

Similarly, we acknowledge that the focus group participants were relatively young and, as a result, might be more tech-savvy than other older clinicians. We recognize that this characteristic may have had an impact on the results of the study. To develop a solution that less tech-savvy people can use, it is also necessary to interview people who represent a diverse age structure.

Lastly, we would like to mention that our study focused on the opinions of healthcare professionals. This group might have different beliefs and needs concerning PGHD than affected patients. As the participants' insights on the usage of PGHD play an important role, we recommend conducting further research that includes patients' perspectives on collecting PGHD for their illnesses.

5.5 Future Research

The results are a first step towards optimizing IT support for healthcare professionals dealing with depressed patients. Based on the results of this article, further research efforts are conceivable. Initially, the workshop participants expressed a strong interest in PGHD types that they deemed essential for their work, despite requiring significant patient effort to collect. These PGHD types hold significant potential to enhance depression treatment, with mental health assessment questionnaires being particularly interesting for improvement. However, actively collecting this type of PGHD is challenging as few options are available, and patients must take the initiative themselves.

Furthermore, it's possible to extend and validate the findings of this study through additional efforts. For instance, organizing further expert workshops could broaden the results through additional qualitative research. For example, workshops could be held with experts from individual disciplines (general practitioners, psychiatrists, psychologists, etc.) to precisely ascertain these groups' requirements. On the other hand, it is desirable to validate the results of this article with quantitative studies.

Another critical aspect of future research is the patient perspective. In this workshop, only the professional perspective of treatment optimization of depressive disorders was covered. Despite their experience with depression and treating mental health issues, the participants' ability to empathize with their patients is limited. Therefore, we acknowledge that a survey capturing the patient's actual perspective cannot be replaced. It is important to note that while a PGHD type may seem easy for patients to collect, it may not be as straightforward in practice. Patients may face difficulties collecting it, and there may be low acceptance or none among patients to collect such PGHD.

Lastly, efforts to implement the collected types of PGHD within quadrant 1 in an application are helpful. Several applications already implement the relevant and easy-to-collect types of PGHD. Still, there is no available application that collects these types of PGHD (sleep, activity level, heart parameters, vital signs, and online behavior) in one application and provides them to the treating healthcare specialist.

6 Conclusion

In this article, we presented the results of a focus group study and interviews with healthcare specialists from different disciplines to explore the relevance of different types of PGHD for diagnosing and treating patients with depression. The results represent a collection of the kinds of PGHD, which were ranked in a matrix according to their relevance for clinicians' work and ease of collection for patients. In the matrix, sleep, and activity levels, cardiac and vital parameters, and online patient behavior stood out as types of PGHD that are highly relevant for the treatment of depression as well as not associated with great effort for the patients to collect. Based on these results, we have established a clear preference for passive collection methods to relieve patients. Our research findings enhance the comprehension of PGHD in healthcare contexts and aid in preventing information overload for healthcare professionals resulting from excessive data. By examining the significance and collection efforts required for specific types of PGHD, we also strive to enhance depression care through the utilization of PGHD.

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