# UNIVERSITY OF TWENTE.

Faculty of behavioural, management and social sciences (BMS)

MSc thesis Health Psychology and Technology (25 ec)

Academic year: 2023-2024

# Enhancing Autonomy in Mental Health Treatment: Evaluating the Digital Patient Portal of Dimence Groep

November, 2023

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**Abstract**

**Background**

     Autonomy in mental health care has gained importance, and digital patient portals are seen as a potential tool to support this aspect of care. However, it is unclear how these portals align with patient needs and their effectiveness in promoting autonomy.

**Aim**

     This study aimed to investigate if and how patients experience autonomy in their treatment, the extent to which the digital patient portal meets the needs and expectations of different patient groups in specialized and generalized mental health care, and their role in promoting autonomy in the treatment.

**Methods**

     Semi-structured interviews were conducted with nine participants. Topics included the degree of autonomy during treatment, in what ways patients experienced autonomy, the addition of the digital patient portal and the patient needs regarding the portal. These interviews were transcribed and analyzed using a thematic analysis approach.

**Results**

     The findings revealed that patients reported experiencing a sense of autonomy in their mental health treatment, which could be categorized into three main themes; the therapeutic relationship, the sessions and the online tools. Within the therapeutic relationship the involvement and shared decision-making were reported to be beneficial for autonomy. The digital patient portal appeared to only be used by some, with many patients expressing reluctance to use it for reasons largely attributed to a disconnect between the portal's functionalities and the patients' actual needs. The portal should be made more easily accessible and findable, contain more interactive features such as a diary and have options for customization.

**Conclusion**

     This study highlights the need for patient autonomy in mental health treatments which can be found in various aspects such as the therapeutic relationship and online tools. It also shows a need for concrete improvements of the digital patient portal to enhance its contribution and help improve patient autonomy in treatment. Currently, the portal provided by Dimence Groep is not yet successfully implemented but has potential to enhance patient autonomy once the functionalities align more closely with patient needs. Future efforts should focus on making these portals more patient-centric to unlock their full potential in mental health care.

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**Introduction**

In the Netherlands, at least 1 in 3 people suffer from a mental disorder during their lifetime. In recent years, the Netherlands has witnessed a remarkable increase in the demand for mental health care services. Stress, anxiety, and depression are on the rise, particularly among the younger population. Moreover, the landscape of healthcare, including mental health care, is evolving rapidly with a growing call for technology integration all while emphasizing the crucial aspect of autonomy in the patient-clinician relationship (Kilbride & Joffe, 2018; Aboujaoude et al., 2020).

Concurrently, in the landscape of (mental) healthcare there has been an ongoing transformation in the patient-clinician relationship. This transformation marks a shift from traditional, paternalistic care towards a more patient-centred approach (Lee & Lin, 2010). Patient-centred care places the emphasis on looking beyond the illness, recognizing each individual as a whole entity with unique needs, experiences, and values (Smith & Williams, 2016). Central to this evolution is the concept of "autonomy" - the patient's right to make informed decisions about their healthcare based on their values, preferences, and understanding of their condition (Foureur & Galmiche, 2019). It involves the fundamental principle of respecting the patient's right to self-determination and actively involving them in decisions pertaining to their treatment. This is something the Dutch government has also increasingly voiced the wish for in (mental) health care (Ubbink et al., 2021). The degree to which patients experience autonomy in their treatment varies depending on the nature of their therapy and the context in which they engage with mental health services (Urheim et al., 2011).

While there is a substantial body of scientific research dedicated to the concepts of patient-centred care and autonomy and their beneficial addition to health care, there is a lack in research regarding the mental health sector and the practical application remains limited (Vermeer, 2015). Aside from the fact that including patients in the decision making process and taking their needs into regard is essential from an ethical perspective, improving patient autonomy in mental health care could also have many other benefits. For instance, a study from SH News (2012) which underlines the significance of patient autonomy for health care revealed a positive correlation between patients' mental health and autonomy supportive healthcare. A different study by Gluyas (2015) describes how patient-centred care has been shown to contribute to improved outcomes for patients, better use of resources, decreased costs and increased satisfaction with care.

These potential benefits considered, it is clear that as the demand for mental health care continues to rise, the significance of patient autonomy in shaping the future of mental health services becomes increasingly pronounced.

Simultaneously, digitalization and technological innovations have entered all aspects of life, including mental health care in the Netherlands. In the realm of Dutch mental health care (GGZ), technological advancements have found their way into treatment strategies and therapeutic interventions (Scheepers et al., 2018). Notably, a significant portion of mental health care professionals in the Netherlands (84%) as of 2018 incorporate digital technologies into their practice, ranging from videoconferencing to online therapy and electronic health records (EHRs) (Scheepers et al., 2018). The adoption of these digital technologies is not merely a consequence of their accessibility but is primarily driven by the needs of the patients. These digital tools foster improved communication and coordination among mental health care professionals, which may ultimately enhance patient autonomy as such communication can help patients feel more in control of their treatment, decisions and actions (Robinson et al., 2020; Scheepers et al., 2018).

In a bid to expand care access and reduce the strain on the mental health system, technology-based mental health services were initially introduced (Mohr et al., 2013). These services encompass various innovations, including mobile applications designed to support mental health and online therapy platforms equipped with virtual assistants and chatbots. A growing body of evidence attests to the effectiveness of mental health treatment delivered through these digital applications (Firth et al., 2017). Additionally, technological enhancements may help deepen understanding of mental illness recovery and improve the quality of care provided (Bauer & Moessner, 2012). These technological advances have the potential to improve patient autonomy and promote the application of patient-centred care in mental health.

Nonetheless, it has been argued that these technologies have not yet been fully integrated into the mental health system to realize their full potential impact (Lattie et al., 2020). Challenges arise, with many technology-based mental health implementations faltering due to a lack of understanding of the specific needs and requirements of both providers and users. Aref-Adib et al. (2019) acknowledge the difficulty in successfully implementing digital mental health interventions and services into real-world practice, despite their potential.

One notable example of a technological service aimed at enhancing patient autonomy is the digital patient portal. These online platforms empower patients by granting them access

to their personal health information and facilitating collaboration with care providers (Durocher et al., 2022). Patient portals offer functionalities such as appointment information, home access to medication records, visit summaries, and access to clinician's notes (What is a patient portal? | HealthIT.gov, n.d.). In mental healthcare settings, these portals are designed with specific objectives, all geared towards improving the delivery and experience of mental health services. They provide secure messaging tools, enabling ongoing communication and collaboration between patients and mental health providers (Ebert et al., 2019). A study by Van der Vaart et al. (2010) which focused on interactive health communication in patients with rheumatic disease identified three main aspects a digital patient portal should contain; information, communication and participation tools. Effective communication between patients and mental health providers is vital as it fosters a therapeutic relationship, a cornerstone of mental healthcare and may help increase autonomy. Patient portals empower patients to actively engage in their care by allowing access to their mental health records, treatment plans, and the ability to monitor their progress, enabling them to participate in decisions concerning their treatment (Wynia et al., 2010). Patient portals also contribute valuable data for research and quality improvement efforts in mental healthcare, aiding mental health professionals in assessing treatment effectiveness, identifying best practices, and enhancing overall care quality (Bashshur et al., 2017).

Despite the widespread adoption of online patient platforms in various healthcare settings, their integration into mental healthcare has lagged behind (Strudwick et al., 2018). In one study where the utilization of a patient portal was examined, distinct patient groups with varying mental health diagnoses were investigated. The findings showed that within seven out of eight groups, fewer than twenty percent of participants registered for the digital patient portal (Etingen et al., 2019). A different study focused on patient portal use in mental health reported 47% use which, though increased over time, was still concluded to be suboptimal adoption rates (Onyeaka et al., 2022). Studies specifically focused on the application of these portals indicate that when effectively implemented, they contribute to higher reports of patient autonomy (Kipping et al., 2016). Patients experiencing anxiety or depressive disorders are more inclined to use these portals, given their familiarity with online tools and the privacy they offer in accessing mental healthcare (Etingen et al., 2019). However, challenges remain, including understanding how patients conceptualize these portals and identifying their specific needs (Van den Bulck et al., 2018). It is therefore important to focus on those needs and expectations of the patients, in order to evaluate if a patient portal has been implemented successfully and will be adopted by the patients. Another

potential obstacle to portal adoption could be mental health professionals' reluctance to share sensitive information with patients (Strudwick et al., 2018; Turvey et al., 2022).

In light of this context, questions arise regarding whether patient portals contain the essential features and functionalities in order to provide the services they should be able to for the patients and whether this technology-based service adds value in practice. For this research specifically, one patient portal is studied to evaluate this. The research questions that emerge are: Does the patient portal meet the needs and expectations of patients, how is the patient portal being used by patients and lastly, to what extent does the digital patient portal promote autonomy? This research aims to explore the needs and expectations of different patient groups concerning autonomy in their mental health treatment, with a specific focus on the digital client portal.

**Research question**

To be able to describe which needs patients have in regard to patient portals and autonomy they experience during their treatment and how the portal fulfils these patient needs, the following research question was formulated:

*"How do the patients from Dimence Groep experience autonomy during their treatment and how can the use of (patient portal) technology influence this?"*

**Sub-questions**

Based on the literature, several sub-questions are posed in order to provide the research study with more depth of knowledge and added value. The sub-questions are as follows:

1. *How do the patients experience autonomy in their treatment?*

2. *How is the current digital patient portal being used by the different patient groups? (What are reasons for, and against, use of the portal?)*

3. *What are the needs of the patient regarding the content (functionalities) and lay-out of the patient portal and how does the current portal meet these requirements?*

4. *In what ways does the current digital patient portal improve autonomy and provide support to the patients?*

**Methods**

**Design**

The research was of a descriptive nature as the study aimed to define what the needs and wishes of patients are regarding the degree of autonomy in their therapy/treatment, as well as to analyse their experiences surrounding the digital client portal. The research instruments used were semi-structured in-depth interviews, making the research of a qualitative nature.

**Setting**

Dimence Groep created a patient portal in an attempt to improve patient autonomy and provide patients with information and tools, which is available to all the different divisions of the organisation. Dimence Groep is a Dutch organisation active in mainly the east of the Netherlands which specialises in mental health care throughout many different divisions, available at varying facilities and locations. Amongst others are, Transfore, Thubble and Anxiety & Mood. The client portal created by Dimence Groep (appendix A) functions as a treatment 'accessory' by allowing patients to view their personal treatment plan, therapy reports, ROM-questionnaires and upcoming appointments (Dimence, 2022).

**Participants and procedures**

The participants consisted of a heterogenous group of patients within different divisions of Dimence Groep. Because of the wide range of mental health care Dimence Groep offers, the research population included patients from multiple divisions, including (generalised) care in the form of online therapy, forensic psychiatry and specialised mental health care for anxiety disorders. There some exclusion criteria for the respondents, 1. Patients without access to the digital patient portal.  2. Low literate and illiterate patients and 3. Patients who have been assessed by their clinician as instable. The patients, by filling out an informed consent form, agreed to an interview which was audio recorded and transcribed, though the interviews were not able to be traced back to the patient and were made anonymous.

The research required the collection of original data as there is no previous study in this field or organisation that relates to the research topic at hand. The sampling method is purposive sampling. This form of non-probability sampling means that a select few patients

are chosen based on certain inclusion criteria from different patient groups to represent the different subsectors of mental health care that Dimence Groep offers.

Due to the nature of the study, various forms of approval from ethics and research committees were required before recruitment and data collection were possible. Firstly, the research proposal went through the METc for a non-CWO declaration (dossier code: 2023-16229). After this, the research proposal was sent to the ethics committee of the University of Twente and approved there (file code: 230021). Lastly, the entire research project including the written consent from all the participating divisions was sent to the internal CWO (research committee) of Dimence Groep (AB/160522).

Because of privacy laws surrounding the patients, recruitment of participants was done by contacting clinicians from the participating divisions and providing them with a pamphlet and information regarding the research so that they could contact their patients and ask if they were open to participating. This also assured that the patients who were asked fit the inclusion criteria.

However, this proved to be a lot more challenging than expected and due to various reasons, clinicians often times were unsuccessful or unable to recruit patients. Some clinicians reported being too busy to take the time during their sessions, others reported a hesitancy from their clients or were not reachable via email, which led to a much smaller group of participants than was assumed in advance. The predetermined number of participants was 18, suggesting that each division would be able to acquire six participants. The actual uptake was nine participants.

The interviews were held face-to-face on the location at which the participant followed their therapy or online in the case of the online therapy-based participants. The participants signed the informed consent form before the interview started; in case of the online interviews, the participants had previously signed and sent the document beforehand. All the interviews were recorded with an audio recording device to be transcribed later on. The duration of the interviews varied slightly but stayed within 30-45 minutes as was predicted based on the interview scheme.

**Materials**

During the interview, the participants were asked questions which were predetermined from an interview scheme. This scheme (appendix B) focused on two main aspects, namely, autonomy and the patient portal. Starting out, the participants were given more information

about the nature and the reason of the research, about the procedure of the interview itself such as the fact that they would be looking at the portal online with the interviewer, and were reminded what would happen with their anonymized data. The first section of the interview had questions on the topic of autonomy. These questions focused on what they perceived to be autonomy, the ways in which they experience autonomy in their treatment, if they are able to make decisions about their treatment and if the clinician discusses any changes made in their treatment with them.

The second section of the interview focused on the patient portal. These questions consisted of asking if the participant was familiar with the portal, if they used it and if so, how often and how long. They were also asked about the current functionalities, whether they liked or disliked them, what they thought was missing or if anything should be removed from the portal. During these questions, the interviewer showed the version of the patient portal appropriate to the participant in question so they could see the functionalities when answering. During the interviews, more questions were asked if the patient wanted to elaborate on a topic or if the interviewer felt there was more to be asked about the response given.

**Data analyses**

The interviews were audiorecorded and transcribed verbatim. The data analysis started during the data collection phase, which means the data-analysis plan might have been subject to change once the analyses began. To ensure any changes were documented, a logbook was used. Here, the researcher documented any changes, ideas and thoughts which were relevant to the data analysis.

The data was analysed using Atlas.ti following a reflexive version of the thematic analysis approach as described by Braun & Clarke (2019). This process was predominantly deductive as it had a focus on the predetermined definition of autonomy, so there were some topics and core ideas to look for. The key steps that were followed included data familiarization, which was mostly done during transcriptions, code generation, constructing themes, reviewing and defining themes, and reporting findings for transparent research outcomes (Braun & Clarke, 2019) .The found codes were categorized in themes such as pattered responses or similar definitions in the data set, these were then reviewed and refined. For example, after coding data with the subcode "Shared decision-making" under the broader theme of "Therapeutic relationship," this theme was reviewed by checking if it adequately captures all mentions of decision making in the data and that there is no overlap with a different subcode in the theme.

Codes were also compared between themes, for example: Codes in the theme of "Sessions" such as "Motivation" and "Room for own ideas" were compared to codes from the "Therapeutic relationship" to ensure they are mutually exclusive and don't overlap with codes under this theme. During the coding process, the themes were also reviewed to assure accuracy and were changed if needed. The coding was partly (two interviews) done by two independent coders, who discussed their findings with the first researchers to achieve consensus and assure reliability. The codes were also regularly shown to a supervisor who reviewed the progress and helped refine the categories of the codes, which were eventually compounded into three main themes as is shown in table 2 of the results section.

## Results

### Characteristics of the participants

Of the nine participants in total, eight were women (table 1). Information regarding participants' ages and level of education was not collected as data due to considerations related to the gathering of personal data and the possible hesitance of participants herein. However, the group of participants consisted of patients from varying organisations which could be divided into two streams of mental health care, namely, online and offline based therapy. The majority of participants came from online-based mental health care, which was Thubble. The offline-based mental health care participants were either from Dimence Groep Anxiety and Mood Zutphen or from the forensic psychiatric facility Transfore (table 1).

Table 1

*Participants categorised by form mental health care delivery and gender*

|  | **Men** | **Women** | **Total** |
|---|---|---|---|
| **Offline mental health care** | 1 | 2 | 3 |
| **Online mental health care** | 0 | 6 | 6 |
| **Total** | **1** | **8** | **9** |

### Autonomy in treatment

*How do the patients experience autonomy in their current treatment?*

During the interviews, patients reported having a sense of autonomy which they ascribed to their connection with the clinician, shared decision-making during treatment and trust in the capabilities of their clinician. Ten categories were identified which either improved or undermined the sense of autonomy according to the participants. These ten categories could be subdivided into three main overarching themes of the treatment. Namely, the clinician relationship, the treatment sessions and lastly the online tools. Table 2 shows various treatment aspects reported by patients to positively or negatively affect their perceived autonomy.

Table 2

*Aspects of treatment increasing/decreasing autonomy according to patients (frequency mentioned)*

| Treatment aspect | Increases autonomy | Decreases autonomy |
| --- | --- | --- |
| **Therapeutic relationship** | Shared decision-making(7) | Patient feels too much responsibility (2) |
| | Clinician is involved and interested (4) | Clinician gives too little input (1) |
| **Sessions** | Room for own ideas and suggestions (6) | Sessions leave little room for depth (2) |
| | In accordance with patient's needs (3) | Sessions are confronting (1) |
| **Online tools** | Minddistrict homework (6) | Replaces human interactions (2) |

Despite the varying forms of mental health care and delivery of said care, there was a consensus regarding the importance of autonomy during treatment, with all participants agreeing there must always be a certain degree of autonomy, regardless of the context in which the treatment is being followed. This experience of autonomy was divided into three main themes. Firstly, the therapeutic relationship which included the feelings the patients had towards their clinician. Secondly the sessions, pertaining to the nature of the conversation, the duration and the ways in which the patient felt they had input. Lastly, the online tools, which relates to the patient portal and what it offers.

***Therapeutic relationship***

Within the theme of the therapeutic relationship, the participants mentioned both positive and negative aspects with regard to their sense of autonomy with the general consensus landing on how involved their clinician was in their therapeutic relationship. One participant felt that by giving too little input, the clinician did not seem involved enough. They said the following on the matter:

> *"I know it is my decision to make, but sometimes I want to hear them say what they think is best for me. If I have to make the decision on my own, there is not really a point in doing this."*

However, the opposite was also reported by several participants, praising their clinician for being genuinely <u>involved and interested</u> in their treatment and progress allowing them to feel important and motivated. One participant said this:

> *"She will sometimes send me a little message or just a photo with an encouraging text and that is what I love about it, because I feel like it's more motivating this way."*

One participant reported losing some sense of autonomy when their clinician gave them <u>too much responsibility</u> early on in the treatment which made them feel like they were on their own.

### *Sessions*

Of the ways in which autonomy took form during sessions, answers varied depending on the context of the treatment the participants followed. One participant said the following:

> *"Every aspect of my treatment we discuss, nothing is done without my consent. That is something I wanted from the start and it has helped me be more involved in the process."*

Some participants noted more specifically that it was the <u>nature of the conversations</u> and the fact that they could give <u>suggestions</u> on what they wished to discuss or work on. One participant had the following to say on this:

> *"The sense of autonomy for me comes from our conversations. If I want to discuss something, that is always possible and if I want to work on one module instead of the other, we talk about it, that's never a problem."*

Other participants, however, reported that there <u>was not enough room</u> and or time during a session for them to allow meaningful conversations to occur, with one participant saying:

> *"It is usually more superficial talk than meaningful, deep conversations because there is not really enough time to go into details sometimes."*

Overall, the participants agreed upon feeling more autonomy during their treatment when their clinician left room for their own suggestions and the sessions were <u>in accordance with their needs.</u>

***Online tools***

On the topic of online tools, many of the participants had a positive view of the technological enhancements to their treatment which also led them to attribute these aspects to a heightened sense of autonomy. One participant said this on the subject of Minddistrict homework:

> *"I love being able to choose when to work on my homework and it really helps me in my progress. It doesn't take a long time and it's a flexibility I really appreciate."*

However, some of the participants viewed the addition of a digital enhancement tool not as an improvement but rather as taking away from the human aspect of therapy and decreasing their autonomy, with one participant saying the following:

> *"Anything I could look online for or do on there [patient portal], I would rather discuss face-to-face with my clinician."*

This topic showed more variance in answers depending on whether or not the participant in question followed traditional offline-based therapy or online-based therapy, with more critical notes and hesitancy shown towards the online tools by the former group.

**Current use of the patient portal**

*How is the current digital patient portal being used by the patients? What are reasons for, and against, using the portal?*

During the interviews, the participants were asked how often and for what reasons they used the portal. In the case they did not use it, they were asked for their reasons for not doing so. This was the case for two participants. There was a clear division regarding the online therapy aspect versus the offline, face-to-face therapy group pertaining to frequency of use (table 3).

Table 3

*Frequency of use of the patient portal in offline and online based therapy patients*

| | Monthly visit to portal (times) | | | | | Duration of visit (in minutes) | | | |
|---|---|---|---|---|---|---|---|---|---|
| | **0** | **1** | **2** | **3** | **4** | **0** | **1-2** | **2-5** | **5-10** |
| **Online therapy patients** | 0 | 0 | 2 | 1 | 3 | 0 | 1 | 2 | 3 |
| **Offline therapy patients** | 1 | 0 | 1 | 0 | 1 | 1 | 1 | 2 | 0 |

### *Frequency of use*

Participants reported a varying use of the patient portal with most users frequenting the website a total of once a week. One participant indicated they did not frequent the portal once on a monthly basis, whereas others estimated their frequency of use to be bi-monthly. The group of offline-based participants reported frequenting the platform fewer times than their online counterparts, with no consistency of frequency in their visits. The online-based therapy participants had a higher reported frequency of use, with most of these participants using the portal weekly and none of them reporting an absence of use.

### *Duration of use*

The duration of the visits were based on an estimation by the participants as no one could indicate for certain the amount of minutes they use the patient portal during a visit. Of all participants, three reported using the portal for five to ten minutes at a time, three estimated their visit duration to be around two to five minutes and two participants reported only needing one to two minutes for a visit. Only one participant stated they never used the portal thus totalling to zero minutes.

Once again the offline-based therapy participants reported an overall shorter duration of visits to the portal compared to their online counterparts. Notably, both groups stayed under ten minutes during their visits.

Explanations for visiting the portal for only a short duration of time was unanimous between both groups being that the portal did not have much to offer so it only took up to ten minutes to acquire the information sought out. One of the online group participants stated this was a good thing in regard to their already busy life:

*"I would only look at what she (clinician) had written about the session and
maybe a previous note too. But that's enough, I don't need any more online
activities, I'm busy enough as is."*

Subsequently, two participants from the offline-based therapy group also reported preferring a short visit to the portal due to time-management during their day-to-day lives, with one of the participants stating the portal should only be to check, not to add to their therapy.

Table 4 shows the reasons given during the interviews by patients for using or refraining from use of the portal.

Table 4

*Reasons to use/not-use digital patient portal( and frequency mentioned)*

|  | Reasons to use portal | Reasons to not use portal |
| --- | --- | --- |
| **Online-based therapy** | Reading clinician's notes (4) | Minddistrict app has all the information needed (2) |
|  | Looking at ROM-results (2) | Lack of interest in what portal offers (1) |
| **Offline-based therapy** | Reading clinician's notes (3) | Lack of digital literacy (1) |
|  | Checking upcoming appointments (2) | Lack of interest in what portal offers (1) |
|  | Looking at ROM-results (1) | Lack of knowledge on portals functionalities (1) |

### Reasons to use the portal

Of all reported reasons for using the portal, to <u>read the clinician's notes</u> of their last session was the most frequently mentioned. One participant explained that the notes would help them view the sessions from a different perspective and said the following:

*"I would read it afterwards and that could be quite the pill to swallow. It is
not always pleasant, no. But, I always think it is useful and it gives me a*

*better sense of why I am in this treatment, it gives me a new perspective and*

*it can also help me decide how to engage in the next session."*

This was followed by the ability to <u>look at ROM-results</u> (routine outcome measures) after which the most mentioned reason in favor of using the portal was to check <u>upcoming appointments</u>. One participant said this:

*"The next appointment is something that easily slips my mind so I like to*

*check or double-check when my next session is, that is something I would*

*go to the portal to do."*

This reason was mentioned exclusively by offline-based therapy following participants, as the online based group also have other online tools to check any future appointments.

### *Reasons not to use the portal*

Several various reasons against the use of the portal were given by the participants, with the most often mentioned being <u>a lack of interest in what the portal offers</u>. This was followed by a reason that only pertains to the online-based therapy participants, which is the <u>access to Minddistrict</u>. Although there were more reported visits in the online-based group, there was also a reoccurring reason given by these participants not to visit the patient portal, namely, the Minddistrict App. This application is exclusive to the online-based therapy participants and includes some of the same information that the portal offers such as upcoming appointments or communication with their clinician, as well as their homework exercises and modules. One participant said the following:

*"I understand for other patients the portal may be very useful and relevant*

*to their therapy because that's all they have online. I just don't reach for it*

*when I think about therapy because of the Minddistrict app. Maybe they*

*should just be combined, then I'll use it."*

This was not the only mention of the Minddistrict application and the preference the patients showed towards using the App compared to the portal which is only available on desktop. Several participants acknowledged the fact that having an App made it more accessible and attractive to use. A different reason given by one participant was the fact that all her homework was on the App, so she had no reason to look at the portal, where one of the functionalities is the option for clinicians give homework exercises.

Conversely, the offline-based therapy participants who do not have the access to the Minddistrict application reported various different reasons for abstaining from the use of the

portal, such the fact that they were <u>uninterested in the content</u>, they were <u>uneducated on what the portal has to offer</u> or in one case a <u>lack of digital literacy</u>:

> *"I can't even find it with a google search. But therapy is a human-interaction, not digital so it shouldn't make a difference."*

While participants generally acknowledged the digital patient portal's usefulness and provided various reasons to use it, they also mentioned reasons against using the portal and an overall infrequency in visits to the platform.

**Needs of the patients and requirements regarding patient portal**

*What are the needs of the patients regarding the content (functionalities) and lay-out of the patient portal and how does the current portal meet these requirements?*

The various functionalities of the portal were described and shown to the participants during the interview whereafter they gave their opinion on them and explained whether or not they felt the functionality had any added value to the existing portal. The interviews revealed several common themes which were formed into three main categories of the digital patient portal. Table 5 shows these three main themes and sub-aspects of the portal which do not currently meet the requirements and needs reported by the participants. These do not include the functionalities the portal already contains, which were determined to be overall sufficient but not of significant value.

Table 5

*Overview of common themes in needs regarding patient portal*

| Categories | Themes | Quotes |
|---|---|---|
| Accessibility | 1. The portal should be easier to find from the website of the organization | *"There is not one mention of a link on the folder or even on the website. I had to call the helpdesk."* |
| | 2. Two-factor verification is important for subjective security | *"Because it's my personal dossier, I understand the two-factor login, it's all my personal details."* |
| | 3. Merging the portal with the application Thubble users have access to | *"No-one really likes websites, it would be practical if all this information was just in the app, which some of it already is."* |
| Lay-out | 4. The functionalities should be more clearly placed and less hidden | *"It's a bit like a maze, a lot of clicking on things and via-via finally getting where I need to be."* |
| | 5. Option of customising dashboard should be available | *"Nothing on this dashboard except maybe the upcoming appointments is important."* |
| | 6. The portal is unattractive to patients who use other online platforms | *"It is just not very nice to look at, if you compare it to other websites."* |
| Functionalities | 7. The portal should include a diary for the patient to share their thoughts and be accessible for the clinician | *"I would really like if I could just write down my thoughts here, I don't care if [clinician] can read. It's a lot safer than on paper or in my iPad notes."* |
| | 8. The clinician's notes and other communicatory messages should be able to be locked by patients | *"Those messages about my treatment, any little change shouldn't have to be open for me to see. I understand they need to document but it's not for me."* |
| | 9. Questionnaire results and outcomes should not be open to patients with raw data | *"For me this is gibberish, I can't interpret these scores, so I would rather not see them."* |

The general consensus among the participants was that most functions of the patient portal provided a certain degree of added value but only few, if any, being of significant importance. It was also noted that participants expressed a reluctance to remove any existing features from the portal, claiming they could be of importance to someone else other than themselves. Despite acknowledging the possible added value and showing hesitance about removing any functionalities, the participants expressed a lack of inclination towards actively using the digital patient portal in the future, so long as no improvements were made.

**The current patient portal**

*In what ways does the current digital patient portal improve autonomy and provide support to the patients?*

During the interviews, several patients reported that the digital patient portal missed an important aspect which prohibits the current portal to positively influence their sense of autonomy as they have no incentive for frequent use of the patient portal. For instance, one participant noted the portal lacks human connection which only their sessions contained. Two other participants mentioned that all decision making was done during sessions, in which they would be involved and therefore the portal was not of significant importance to the treatment and their progress.

However, the interviews did provide insight into properties of the portal that patients reported as being fruitful to their treatment and their sense of autonomy during their patient journey as are shown in table 6.

Table 6

*Supportive features of the digital portal*

| Feature | Function | Quotes |
| --- | --- | --- |
| Appointment Calendar | Shows the upcoming and previous appointments made | *"I like that I can check to see when my last session was or my next one takes place because I tend to forget."* *"If I had to choose the most useful feature, it's this."* |
| Clinician's notes | Any form of documentation made by the clinician about the sessions or other communication | *"It's good to have it all stored in one place, if I was unhappy about the therapy I could consult these notes."* *"They give me a good idea of how they thought about the session."* *"I like the transparency, nothing is kept secret and that makes me feel more trust."* |
| Treatment overview | A copy of the composed treatment plan made by the organisation with additional goals described | *"After a few months I was somewhat lost on what we were doing, but instead of asking, I looked on the portal."* |

The infrequent use of the portal, as reported by participants, poses a challenge when attempting to comprehensively evaluate the extent to which the portal can enhance the patients' sense of autonomy during their treatment. However, analyses of the interviews suggest that certain features of the portal as described in Table 6, do exhibit the potential to offer support to patients, which in turn may have a positive effect on their sense of autonomy. Mainly the increased sense of control over their treatment, being able to gain insights into what their clinician has written about them and having a clear overview of appointments and their treatment allows the patients to be more actively involved in their therapeutic journey.

**Discussion**

This study aimed to explore the degree to which patients of Dimence Groep experience autonomy, how they experience this in their treatment and what the role of the digital patient portal is in influencing the sense of autonomy. The main result was that patients of Dimence Groep experience an overall sense of autonomy in their treatment, which can be divided into three domains: the therapeutic relationship, sessions and online tools. These are influenced by factors like the involvement in the decision-making process, the involvement and interest of their clinician but also trust in their clinician. Although the importance of patient autonomy in treatment is apparent from the study results, the extent to which the digital patient portal contributes to the enhancement of patient autonomy remains uncertain due to deficiencies in the current portal, which may not sufficiently motivate frequent engagement for patients.

Results regarding how patients experience autonomy in their treatment showed that patients experience a sense of autonomy within their therapeutic contexts. However, it is essential to acknowledge that this sense of autonomy showed variation depending on the specific therapeutic background, with the patient from forensic psychiatry reporting only somewhat of sense of autonomy, whereas patients from online-based therapy reporting overall high levels of autonomy in all three of the main domains. These findings are in line with the study from Urheim et al. (2011). The participants reported gathering a sense of autonomy from the fact that they were able to make informed decisions and being actively involved in aspects regarding their treatment, as was also described by Foureur & Galmiche (2019). However, the autonomy was not attributed by participants to the use of the digital patient portal, whether it be due to lack of interest in use or lack of reported useful functionalities. This leaves previous findings of Kipling et al. (2016) and Scheepers et al. (2018) unconfirmed regarding an increased sense of autonomy due to effectively implemented portal use. This is due to the fact that the effectiveness of the implementation cannot be established based on this research. These findings suggest that more research focused on the effectiveness of the implementation of such a digital patient portal is needed in order to assess its effect on autonomy.

The variability in autonomy reported by participants underlines the subjective nature of the term 'autonomy' and the challenges associated with its measurement in research. It is important to recognize that the subjective perception of autonomy is influenced by individual factors, cultural background, and personal experiences, which may not have been fully captured by the defined topics. This limitation may influence the validity of the research

findings, as it is challenging to provide a comprehensive and objective assessment of patient autonomy.

Results regarding the current use of the digital patient portal showed that despite its availability and content appeared to be used less frequently and consistently by patients than was originally expected based on previous studies such as that of Etingen et al. (2019). One patient reported never using the portal and of all the participants that did use it, the majority frequented the portal no more than once a week for no more than ten minutes. Based on previous studies, it was expected that patients in this sector of health care would be more inclined to actively use such a patient portal. This somewhat in contrast to the findings of this study. In contrary to the research done by Durocher et al. (2022) the results from this study did not show an increased sense of empowerment from patients which could be attributed to the lack of use of the portal. Despite the portal including most functionalities described by Wynia et al. (2010) which would allow patients to empower them into more actively engaging in their treatment, this did not appear to be the case. It would also in part be explained by the challenges described by Van den Bulck et al. (2018) such as identifying the specific needs of the patients. These findings suggest that at this current point in time, the patient portal has not been successfully implemented and therefore is not being used to its potential. Subsequently, this is in line with the expectation provided by the study from Aref-Adib et al. (2019) who acknowledged the difficulty in successfully implementing digital mental health interventions and services into real-world practice, despite their potential.

The results regarding what the needs of the patients and the requirements are for the patient portal highlighted the lack of use of the current portal, which could in part be explained by the disconnect between the content and the needs of the patients. Of the three most important aspects (information, communication and participation tools) a portal should contain according to a study by Van der Vaart et al. (2010), the portal of Dimence Groep does not contain any communication functionality. And although the patient portal was identified to have several useful functionalities, there were multiple features reported to be lacking which patients thought were important, such as a form of communication within the portal. This confirms the previous findings in the the study by Van der Vaart et al. (2010) and these results are in line with the challenges of identifying patients' needs (Van den Bulck et al., 2018). This suggests that patient needs should be held in high regard when developing such a technological if wished to be effective.

Research question number four aimed to investigate the ways in which the current digital patient portal improves autonomy and provides support to different patient groups

according to the patients' perspectives. However, the findings of this study do not align with the earlier work conducted by Kipping et al. (2016), who suggested that digital patient portals have a positive impact on patient autonomy as in this study, participants did not report the portal to significantly enhance their autonomy because there was limited usage of the portal among the patient groups. A possible explanation for this incongruence could be the variations in patient characteristics which may affect how individuals perceive and use digital patient portals, as for example some patients may encounter barriers related to technology literacy. The limited usage of the portal observed in the study raises questions about its effectiveness in supporting patient autonomy. If patients are not actively engaging with the portal, it may fail to provide the intended benefits.

It can be concluded that the current version of the patient portal does not appear to improve autonomy. The limited usage of the portal and the absence of reported autonomy underscore the need for further research to understand the evolving role of digital patient portals in healthcare and to identify strategies for enhancing their effectiveness in supporting patient autonomy across patient groups.

**Strengths and limitations of the study**

As for the research method used, semi-structured interviews offer the ability to dive deeply into participants' experiences and perspectives on autonomy in treatment. This approach allowed participants to express themselves in their own words, providing a nuanced understanding of their thoughts and emotions. The flexible nature, featuring an interview guide of questions, allowed for unexpected themes to come up in the conversation which was later found during the data analysis. This allowed participants to share their experiences authentically. Moreover, this method is particularly well-suited for qualitative research, enabling the capture of the depth and complexity of participants' narratives making it a strength with the context of this research.

However, there are weaknesses in this approach. Semi-structured interviews rely heavily on participants' self-reporting, making the data vulnerable to potential social desirability bias or participants providing responses they believe align with the researcher's expectations. To prevent this as much as possible, the researcher informed the participant that they were interested in exclusively the opinion of the participant and their individual experience. They assured them that no answers were wrong and that they hoped to gain as many insights for their research, making everything the participant wanted to share, relevant.

Furthermore, the small sample size used in this study, with only nine participants instead of the planned twenty, raises concerns about the reliability of the findings. It may not adequately represent the diversity of experiences and perspectives within the broader population. The recruitment challenges encountered in relying on clinicians for participant recruitment show the vulnerability of this research approach and the impact it may have on data collection. The reduced sample size due to recruitment difficulties may affect the study's overall validity and reliability. Perhaps an even more important limitation of the sample group is the selectivity. As the participants were only patients who were interested and willing to talk to an interviewer, this may fail to capture the full spectrum of experiences, potentially leading to a skewed perspective. Moreover, it may hinder the ability to identify significant patterns or themes in the data.

For future research, to broaden the research perspective, researchers might consider alternative research methods or even a mixed method study. Surveys, for instance, could have reached a larger sample more easily, with a lower threshold for participation while focus groups might have encouraged participants to engage in discussions that could give further insights. Both of these methods may also increase reliability of the study.
Further limitations of the study were the exclusion of certain data which could have been very insightful such as age, level of education and even information regarding the patient records could have provided objective data on treatment plans and patient interactions, though this might complicate the recruitment even further as patients are often wary of sharing such personal information and this could lead to hesitancy to participate.

Lastly, the reflective thematic analysis approach used to code the interviews by Clarke and Braun (2019) has since been reviewed and updated to better explain this approach as the first and most cited version left several aspects incompletely defined and open to interpretation. It is important to note that this could also be the case for this research as it did not make use of any newer versions of their publications.

**Recommendations**

Mental health care organisations such as Dimence Groep have the opportunity to use patient portals to enhance patient engagement and empowerment throughout their treatment journeys. The use of patient portals can improve the quality of care and the patient experience. However, this needs to be done correctly and with repeated evaluation of the way the portal is being used and received. The needs of the patients need to be held at a high

priority when making changes to the portal. This comes with its own set of challenges and ethical considerations.

Firstly, patient portals can facilitate enhanced communication between patients and their care teams. This would mean that patients can schedule appointments and ask questions through secure and timely communication. This fosters a sense of involvement in their care and encourages patient engagement. Aside from this, patients should have access to their health records, treatment plans, and educational resources via the portal. Providing this level of transparency empowers patients to make informed decisions about their treatment and actively engage in their mental health journey.

Furthermore, integrating self-management tools, such as a journaling feature or a way to document their mood within the patient portal enables patients to monitor their progress, set achievable goals, and actively participate in their treatment plans.

However, there are challenges to be aware of such as security of patient data. This is a primary concern and organisations must use adequate security measures, for instance through two-factor authentication and by obeying by the national laws set in place like 'General Data Protection Regulation' (GDPR) in the EU.
Another important factor is the limited digital health literacy of some patients. Organisations should offer some form of training and support to help them navigate and effectively use the portal. There should also be clear communication about the portal and its possibilities through the clinicians, as well as easy access via the main website of the organisation.

To overcome these challenges, organizations can adopt several strategies. These include comprehensive education and training for both patients and healthcare providers to ensure effective portal use, adhering to user-centred design principles to create a more user-friendly portal, and establishing an ethics committee or review board to oversee ethical considerations related to privacy and patient engagement. By carefully considering these practical implications, addressing potential challenges, and upholding ethical standards, mental health care such as Dimence Groep can use patient portals to enhance patient engagement, autonomy, and overall treatment outcomes. This benefits patients and contributes to the advancement of mental health care services.

**Conclusion**

In conclusion, patients from Dimence Groep experience a sense of autonomy in their treatment, driven by factors such as collaborative decision-making and trust in their clinicians. The patient portal, while having valuable supportive features, does not currently reveal a significant improvement on autonomy in patients. Although it has some supportive features that most participants found useful, it could enhance patient autonomy if certain improvements and considerations are implemented. By optimizing the portal's accessibility, user-friendliness, and customization options the portal would better encompass the needs of patients which could lead to increased engagement and in turn to a more positive influence on patients' autonomy in their treatment journey., it has the potential to play a more significant role in supporting patient autonomy during their therapeutic process.

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**Appendix A** Visuals portal

**Figure 1**

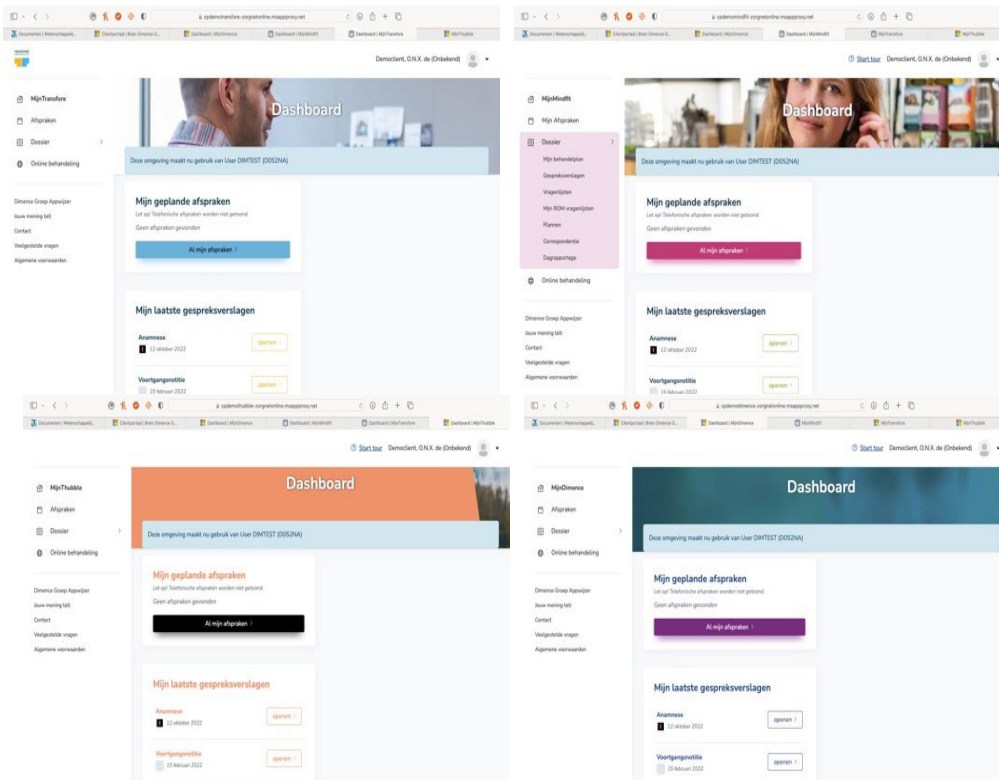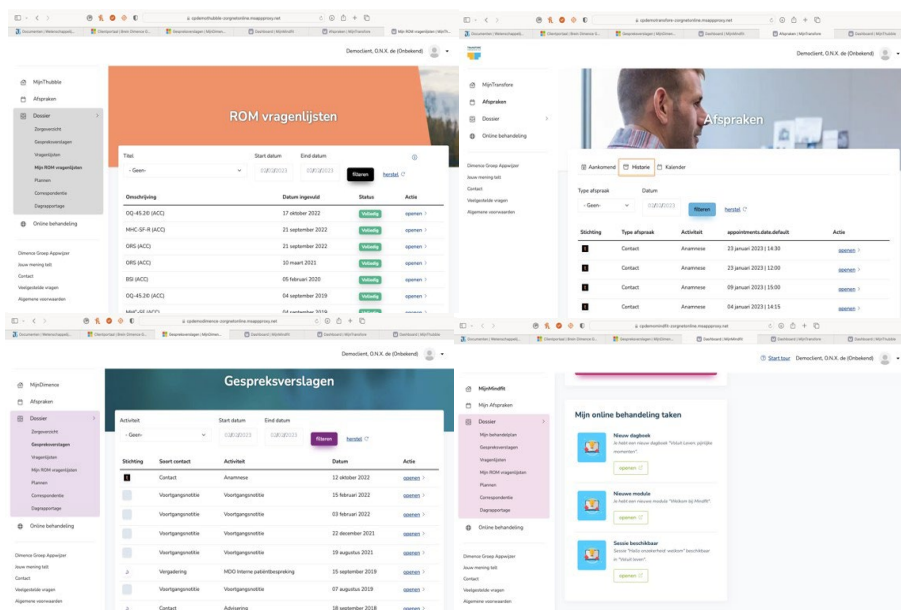*Screenshots of different patient portal dashboards*



**Figure 2**

*Screenshots of functionalities of the patient portal*

**Appendix B** Interview scheme

Introduction:

- The interviewer gives a brief introduction regarding their name, their research study and for what reasons they are doing the study, sign informed consent form
- The reason for the interview, the topic of the research and a small introduction of the themes of the interview such as autonomy and the digital patient portal
- Aim of the interview: gaining insight into the wants and needs of the patient regarding their sense of autonomy, their wish for control over their treatment, their thoughts on patient autonomy and how they view the patient portal
- Time: max. 45 minutes
- Structure: The interview starts off with an informed consent form which has to be filled in. Then the patient is asked if they have any questions before the interview starts. Move to interview questions according to the order described below, then move to topics the patient may further want to divulge in or elaborate on. The researcher will show the digital patient portal through the use of talking cards and screenshots and ask the patient their opinion on certain aspects of the platform. The interview ends with the researcher asking if there are any more questions

**Interview:**

Main themes: Patient autonomy, the treatment plan, digital patient portal

*Questions may be further complemented later based on patient and expert feedback.*
*Interview questions will be translated for respondents*

**Autonomy:**

1. Do you feel like you are able to make your own decisions in relation to your treatment and other aspects thereof?

2. Are you familiar with the term 'autonomy'? If so, do you feel like you have autonomy in your treatment and therapy?

3. How do you wish to experience autonomy in the context of the treatment? (elaborate)

4. Do you feel like you are involved in making decisions regarding your treatment plan or changes otherwise?

5. How important do you feel autonomy is for patients like you, in mental health care?

6. How would you rate your experience regarding patient autonomy right now? What would you want it to be?

7. Is autonomy something you have spoken about with your clinician? In the past or present

8. Would you like to be (more) involved in making decisions about these topics?

9. Does your clinician consult you when they want to change any aspect of the therapy or treatment?

**In case of forensic psychiatric patients**

10. Do you think you and other patients in the same area should have more autonomy over their treatment? Why or why not?

**Digital patient portal**
1. Are you familiar with the digital patient portal you have access to, provided by the division of mental health care you are in?

2. What do you know about this patient portal?

3. Have you used the portal? How often do you use it?

4. Have you spoken with your clinician about this portal and if so, have they voiced their opinion on it?

5. When would you like to use the patient portal? Time of day/week day
6. How long do you usually make use of the portal during a visit?

7. How important do you think it is for patients in mental health care to have access to a digital platform such as the patient portal? (elaborate)
8. What do you think is important for the patient portal to include for you as a patient?
9. What do you like/dislike about the patient portal?

10. Is there any aspect or element of the patient portal you feel is missing or could be removed?