Research Square

Preprints are preliminary reports that have not undergone peer review.
They should not be considered conclusive, used to inform clinical practice,
or referenced by the media as validated information.

Experiences of Patients with Severe Mental Illness Reading Their Open Notes: Qualitative Study on Effects of Online Record Access on the Therapeutic Relationship

Mareike Weibezahl
1. Department for Psychiatry and Psychotherapy, Center for Mental Health, Brandenburg Medical School, Immanuel Hospital Rüdersdorf

Eva Meier-Diedrich
1. Department for Psychiatry and Psychotherapy, Center for Mental Health, Brandenburg Medical School, Immanuel Hospital Rüdersdorf

Jonas Wördemann
1. Department for Psychiatry and Psychotherapy, Center for Mental Health, Brandenburg Medical School, Immanuel Hospital Rüdersdorf

Julian Schwarz
julian.schwarz@mhb-fontane.de

1. Department for Psychiatry and Psychotherapy, Center for Mental Health, Brandenburg Medical School, Immanuel Hospital Rüdersdorf

Research Article

Keywords: open notes, opennotes, clinical notes, electronic health record, health care professionals, online record access, patient participation, severe mental illness, doctor-patient relationship, therapeutic relationship

Posted Date: July 16th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-10116650/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License.
Read Full License

Additional Declarations: No competing interests reported.

Abstract

Aim

This study explores how outpatients with severe mental illness (SMI) experience reading their clinical notes via online record access (ORA). It examines effects on illness management and the therapeutic relationship. We identify which open notes features influence the therapeutic relationship from the patient's view.

Methods

13 active ORA users with SMI at three university outpatient clinics in Brandenburg, Germany were interviewed. Those with acute psychiatric conditions causing major cognitive or social issues, risk of self-harm or harm to others were excluded. Semistructured phone interviews were transcribed and analyzed with qualitative content analysis.

Results

Several patients with SMI reported positive effects on the relationship with their health care professional (HCP) from open notes use. Others found it difficult to articulate this, but the analysis suggests they likely experienced similar effects or already had a good relationship with their HCP. None reported negative effects of open notes use on the relationship with their HCP. The positive effects were attributed to greater transparency, improved HCP availability, opportunities to rebalance power dynamics, better access to shared decision making and strengthened trust. Patients felt more seen, influential and more involved with their illness and treatment. They reported higher self-efficacy especially around medication treatment. Benefits included having a second perspective to contrast self-perceptions, less irritation from lack of access to their HCP’s notes and better self-management.

Conclusion

Open notes' positive effects on the therapeutic relationship highlight their value for patients with SMI at risk from poor therapy adherence, limited illness insight and fluctuating treatment motivation. This group may benefit especially from open notes’ impact on trust and self-management.

Trial Registration:

German Clinical Trial Register DRKS00030188 (https://drks.de/search/en/trial/DRKS00030188). Registration date: 11.10.2022.

Background

More and more countries offer online record access (ORA) as part of electronic health records (EHRs) [1, 2]. Patient access to their health care professional's (HCP) clinical notes via ORA is referred to as "open notes" [1–4]. This practice has been extensively tested and implemented in healthcare systems like the United States, Canada and Australia [5], Sweden [6], the UK [7], Norway, Estonia (since 2005), Finland and several other European countries [8, 9].

Research conducted in general health settings indicates clear benefits of patient access to clinical notes, including improved treatment satisfaction, transparency, patient engagement, patient-clinician communication and health literacy [5, 10, 11]. Additionally, open notes enhance medication adherence and safety in patients [12], help patients to identify and correct treatment errors [13], increase a sense of control over the treatment and reduce anxieties regarding the treatment process [14]. HCPs generally view open notes as a valuable tool to promote patient engagement, even though it may be connected to an additional workload related to documentation and communication [15, 16].

Studies conducted in mental healthcare generally yield similar results to those in general health settings, but they also highlight distinct ethical and practical challenges [17–19]. For example, managing disagreements between patients and HCPs regarding the content of clinical notes, as well as discussing exceptions to or limitations of access for patient groups with specific diagnoses or acute conditions, such as severe mental illnesses (SMI) [20, 21]. SMI are commonly characterized by conditions including (1) nonorganic psychoses, bipolar disorders, personality disorders or severe chronic depression; (2) a prolonged psychiatric history involving multiple hospitalizations or outpatient treatments; or (3) moderate impairment in work and leisure activities alongside mild impairment in basic needs [18]. HCPs often hold reservations about offering access to open notes to patients with SMI [18]. Their concerns primarily relate to the possibility that reading the notes might contribute to self-harm or violent behavior, especially in patients with whom establishing a trusting relationship is challenging [21]. Patient surveys, however, have demonstrated that patients with SMI using open notes also exhibit an improved understanding of medication prescriptions, higher medication adherence and a greater sense of control over their medication [21, 22]. Nevertheless, the adoption of open notes among patients with SMI remains lower compared to those receiving treatment for somatic conditions [22, 23].

Despite promising preliminary evidence – such as patients with post-traumatic stress disorder, bipolar and psychotic disorders reporting strengthened trust and validation from insight into detailed, clinical notes [24] – little qualitative research exists on the experiences of patients with SMI using open notes [25, 26]. Evidence indicates that HCPs with psychotherapeutic training frequently anticipate a rupture in the therapeutic alliance [27, 28]. They worry that patients might be startled if they encounter sensitive information that had not been discussed before; psychodynamic therapists are especially cautious about documenting transference-related content [27, 28].

The therapeutic relationship holds particular importance for patients with SMI, who often require frequent engagement, face medication adherence challenges and benefit from trust-building, yet little is

known about open notes' direct effects on it [25, 26]. While preliminary evidence indicates use of open notes may enhance transparency and empowerment without widespread harm, understanding patient experiences remains critical, because poor implementation risks exacerbating stigma or conflict [20].

This underscores the need to further explore how patients with SMI experience reading their clinical notes within outpatient care and how this affects their self-understanding, illness management and the therapeutic relationship. The aim of this study is to explore the specific aspects of open notes that influence the therapeutic relationship from the perspective of patients affected by a severe mental health condition.

Methods

Study Design

This study is part of the PEPPPSY project (Piloting and Evaluation of a Participatory Patient-Accessible Electronic Health Record in Psychiatry and Somatics; 2021–2026) that focuses on piloting and evaluating a participatory patient record in psychiatry and somatic medicine [29, 30]. In the PEPPPSY project, patients are provided with access to their HCPs' clinical notes via a dedicated patient portal. The project aims to examine the development, implementation, processes and outcomes of the corresponding patient portal from the perspectives of patients and HCPs.

Setting

While countries like the US and Sweden have implemented access to medical and psychiatric notes, Germany lags behind despite the German Civil Code granting patients health data inspection rights since 2013. ORA launched in 2021 via insurer-specific apps. The "German Act to Accelerate the Digitalization of the Healthcare System" mandates that all health insurance companies offer ORA for laboratory results and medication overviews since 2025 [31]. Yet, there is no timeline for implementing open notes as part of ORA in Germany.

This study was conducted at three psychiatric outpatient university clinics at Brandenburg Medical School Theodor Fontane (MHB), Immanuel Klinik Rüdersdorf. Located in the metropolitan region Berlin/Brandenburg, the clinics are responsible for providing mental healthcare services to approximately 255,000 inhabitants in the catchment area. These outpatient clinics offer specialized care for patients who require a comprehensive, multidisciplinary approach due to the nature, severity or duration of their conditions. The eligibility for receiving treatment in these psychiatric outpatient clinics is based on specific diagnoses, including SMI and other diagnoses, as determined by the insurance providers and the hospital association. These patients typically require comprehensive and multidisciplinary psychiatric treatment and often lack access to adequate care in other outpatient settings such as psychiatric or general medical practices due to the severity or chronicity of their psychiatric conditions.

PEPPPSY App

The patient portal pilot, PEPPPSY, was initiated as part of a research collaboration between the Norwegian University of Science and Technology and MHB. The portal was developed through an ongoing iterative and participatory process. In addition to accessing clinical notes, patients can respond to HCPs' entries with comments. HCPs are then notified of these comments and can respond to patients within the same thread.

Interview Guide

The interview guide was adapted from a tool previously developed, tested and used in earlier PEPPPSY project studies, tailored to address the current research question [32] (s. Appendix, Table 3). For this study, the guide was further refined based on a literature search focusing on the therapeutic relationship in the context of open notes using Google Scholar and PubMed [33]. It includes questions on participants' previous experiences with open notes, particularly how their use affected treatment and the relationship with their HCPs. The adapted guide was pre-tested in two sessions with psychiatric outpatients at MHB. Since no modifications were required, the first two interviews were included in the final analysis.

Participants and Sampling

From December 2023 to December 2024, eligible patients were approached and selected from the 3 study centers by MW consecutively. Participants had to be aged 18 years or older, diagnosed with SMI confirmed by an external report, currently receiving treatment in an outpatient psychiatric clinic and be active ORA users measured by login frequency. Exclusion criteria were acute psychiatric conditions or symptoms such as disorientation, severe delusions, hallucinations, katatonia, agitation that may be associated with significant impairment of cognitive and social functioning, acute self-harm or harm to others. Eligible patients were informed about the study and provided written informed consent.

Data collection

At enrollment, sociodemographic data were collected from all participants (N = 13). Afterwards, semistructured interviews were conducted via telephone by MW who was not the outpatient treatment provider of any of the participating patients. The mean duration of the interviews was 42 minutes. Since two participants were non-native German speakers, their interviews were conducted in English. Throughout the study, the research team kept field notes documenting observations and contextual information [34]. Information on the diagnoses of the study participants according to the International Classification of Diseases (ICD-10) was taken from the patients' medical records. Data collection continued until theoretical saturation was reached, defined as the point when no new categories emerged and the meanings of categories and subcategories were fully established [35].

Data analysis

The qualitative interviews were audio-recorded, pseudonymized, transcribed and analyzed by MW using MAXQDA 2024 software. Kuckartz' approach to qualitative content analysis (QCA) was used for analysis, because it allows for a deductive-inductive approach to data analysis [36]. Qualitative methods are appropriate for addressing the research question. They help reconstruct patients' perception of treatment effects and the therapeutic relationship by categorizing vague thematic expressions and shared patterns in patients' narratives, which are inaccessible by quantitative methods.

First, each transcript was read closely with the research question in mind. Key passages were marked, insights were recorded in memos and brief summaries of each case were created. Second, deductive main categories were created. These were derived from previous studies and open notes literature. The main categories provided a framework for sorting the material and developing inductive subcategories through iterative refinement until theoretical saturation was reached. A coding guide with definitions and examples was developed and finalized after two other researchers from our group coded selected parts of the material. Thus, interrater reliability was ensured. Using the finalized coding guide, two more rounds of coding were performed on the complete material. Finally, thematic summaries of each category in every case were written. These formed a summary framework which provided the basis for the results.

For quality assurance purposes, the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist was used (s. Appendix, Table 2).

Ethical considerations

This study was approved by the ethics committee of MHB (E-01-20210727) and registered with the German Clinical Trials Register (DRKS00030188). Participants were informed of the study content and procedures both verbally and in writing. Informed written consent was then obtained from all participants. All participants had the right to withdraw from the study at any time without any adverse consequences. All data were pseudonymized. Participants were offered a compensation of €30 for their participation.

Results

Sample

A total of 13 patients were interviewed. Their complete sociodemographic data are shown in Table 1. We used first names as pseudonyms for participants to integrate their statements into the text and convey a sense of authenticity, which was considered appropriate given the study's focus on the therapeutic relationship. Except for one person, all participants self-identified as White. The age of the patients

ranged from 20 to 62 years, with a mean of 40 years. A total of 61,54% (8/13) of the patients identified as male, and 38,46% (5/13) identified as female.

Table 1
Sociodemographic data of participants (n = 13)

Alias	Gender	Age	Ethnicity	Interview Language	Diagnosis (ICD-10)
1. Bertram	M	62	White	German	F32.2
2. Claudia	W	25	White	German	F60.31, F32.1
3. Donna	W	48	White	German	F60.31, F33.2, F45.41
4. Emil	M	50	White	German	F32.1
5. Fiona	W	21	White	German	F61, F33.1
6. Georg	M	20	White	German	F32.2
7. Hubert	M	59	White	German	F34.1, F51.0, F45.41
8. Ivo	M	25	White	German	F20.0, F12.2
9. Jan	M	53	White	German	F31.6, F41.0
10. Karl	M	43	White	German	F33.1, F90.0
11. Lars	M	35	White	English	F20.0
12. Mara	W	43	White	German	F31.0, Z73
13. Nora	W	36	N/A	English	F33.2

Qualitative Findings

The results are presented in three main categories divided into multiple subcategories (s. Figure 1). The first main category “Reading Experience” looks at the general experience of patients with SMI with open notes. The second main category “Coping with Illness” provides a perspective on the more practical aspects of open notes use on patients with SMI dealing with their illness. Finally, the third main category “Therapeutic Relationship” captures the effects of open notes use on the relationship between patients with SMI and their HCPs. First-name pseudonyms protect participants' privacy in interview quotes. All German quotes were translated into English.

Reading Experience

Comprehensibility

Almost all participants stated that they found their notes comprehensible (12/13, 92.3%). One participant noted that he had not paid much attention to the notes themselves but rather used open

notes to contact his HCP. Another participant mentioned that there had been one instance in which reading her notes had prompted her to look up a professional term (“euthymic”).

Thoughts and Feelings while Reading

Participants showed strong interest in reading their notes. Many felt pleasant anticipation. Individual experiences varied: The main positive was curiosity about the HCP’s view, as it could confirm or question their own experience. Some patients found it useful to compare the HCP’s description of them with their self-view (6/13, 46.2%):

(...) well, I only experience the session or treatment subjectively through my own perception, and it's actually quite interesting to see how someone from the outside, for example, perceived my behaviors or expressions. So you get a bit of a different perspective on yourself. So I found that rather beneficial, I would say. [Fiona, 21]

This kind of experience was often associated with feeling understood as well as with a sense of trust and reassurance in participants’ relationship with their HCP. It can also be understood as patients being curious about their HCPs.

A little less than half of the participants (6/13, 46.2%) reported no negative feelings during reading. Two felt distressed or sad at first, because the note content reminded them of their mental state or tough life events. Another two patients mentioned self-blame or guilt regarding their condition while reading the notes, in the sense that they felt they should have done more or done things differently, and that it was their fault. This faded with ongoing open notes use.

One patient had mixed feelings about reading about himself from a medical perspective and in medical jargon. It irritated him, as it made him feel less unique and worried his HCP might not treat him as an individual:

So, to put it a bit strongly, it made me doubt my individuality a bit. Not quite that drastic. Maybe it also made me realize that I’m just one of many patients (...) it also has a bit of a routine character, and it makes me worry a little – um – that it might be possible for my doctor to treat it very routinely and maybe overlook individual needs and wishes of mine. [Emil, 50]

At the same time, Emil seemed relieved to realize that he is one of many patients: “There's also something positive about it – the knowledge that I’m not alone with my situation, with my problems.” [Emil, 50]. Thus, there is ambiguity between his wish to be a unique case and the knowledge that if he is not this means his HCPs have experience and routine in treating others like him, which is a benefit.

Another participant suspected that his notes had been written specifically for him, and the HCP kept the real notes hidden. He appeared convinced of this idea because the notes were written in plain language, not medical jargon, and he could easily understand them.

Misunderstandings, Errors and Omissions

Most participants said that they felt accurately represented in their clinical notes (11/13, 84.6%). Two participants noted slightly misleading phrasing in sentences, but felt this was too minimal to mention to their HCP. No participant found an actual error. One participant assumed the HCP omitted stressful content on purpose, while all other participants saw their notes as complete. Most participants reported that they never withheld information due to concerns that it might be documented (11/13, 84.6%). In two cases, interviewed patients revealed that they had omitted information. In one case, this concerned a very specific piece of information the participant considered sensitive. In the other case, the participant was uncertain in general about whether her HCP was interested in the details of her experience. This uncertainty was independent of open notes. Consequently, she sometimes chose not to go into details: “It's difficult. Yeah, maybe because you don’t know how detailed you should be sometimes, or not, I’d say. That’s when I think, is he even interested?” [Donna, 48].

Coping with Illness

Treatment Motivation

Six of thirteen participants associated open notes use with higher treatment motivation (46.2%), while four of the remaining seven reported already high motivation (30.8%). The other three participants only stated that open notes use had not influenced their treatment motivation without elaborating on their motivation in general (23.1%). Increased treatment motivation was connected to at least one of three factors linked to open notes use: a chance to mentally prepare for appointments with HCPs, feeling more included in the treatment process and a greater interest in their own illness with the possibility of influencing it.

For example, Claudia was motivated by reading her notes, because it gave her a chance to mentally prepare for her appointment by organizing her thoughts and questions:

What has changed is that, because I could reread what was discussed in the last conversation, I was able to make a plan. Okay, this is the topic for today or this is what I want to bring up today. That also gives a little bit of motivation. [Claudia, 25]

Georg noted an increased treatment motivation due to open notes use and linked it to feeling more included as well as a better treatment experience: “It leads to me feeling understood by my doctor and also gives me more of a feeling that he is treating me well.” [Georg, 20].

Two other participants (15.4%) reported that the notes helped them gain insight into their illness or at least made them more interested in it, also because they felt they might be able to influence it more than before.

Self-Organization and Self-Management

More than half of the participants reported that open notes helped them create an inner structure for self-reflection (8/13, 61.5%). This often became relevant before or after the appointments, when they

would read their notes. For example, Jan called open notes his “digital diary” [Jan, 53], because they helped him remember past conversations when he was dealing with problems in the present. Karl found the inner structure for self-reflection provided by open notes especially helpful because he had trouble concentrating and remembering what was said during the conversations due to his “ADHD” [Karl, 43]. In Ivo’s case, creating an inner structure for self-reflection through open notes was connected to him noticing new things about himself and acting on them: In the beginning, he was irritated by his HCP writing down that he had trouble concentrating, but then this turned out to be a starting point for Ivo to talk to his parents about their perspective on him, which lead to a sense of acceptance and taking steps toward personal change.

A desire for personal change can also be identified in Emil’s case. Open notes helped him open a room for reflection in which he could set personal goals in dealing with his illness:

As I said before, you read through it and can set goals for yourself. I didn’t fall back, I moved forward again. It was kind of like that. You can say, this is where you were before and now you’ve come this far. Like a crab, two steps forward and one step back. Then when you calmly read through the documentation and think it over, you can see clearly. And then we just start again from the beginning, right? [Emil, 50]

Taking Initiative and Developing Agency

Nearly all participants (12/13, 92,3%) highlighted asynchronous communication with their HCP as beneficial. More than half of the participants (7/13, 53.8%) mentioned specific situations concerning their medication, in which they had found it very helpful to be able to contact their HCP and take action themselves.

There are several examples in which participants contacted their HCPs via the portal’s comment function to discuss medication issues and quickly reach solutions, as opposed to waiting for the next appointment. The following quote illustrates this:

Claudia: We kind of stopped one medication. Well, actually, it’s now only taken as needed, and something else was added in the morning. Uh, something that’s supposed to have a somewhat balancing effect. We first started with 50 milligrams. The doctor then immediately said, okay, let’s first see if that’s enough or if we need more. Uh, exactly, then I tried it out for a few days. I noticed that it wasn’t enough yet. I then asked about it, and then we agreed on 100 milligrams.

Interviewer: Yes, and did I understand correctly that you would say that if this comment function and this shared documentation hadn’t existed, you would probably have taken the 50 milligrams for longer? Or you would assume that it would have taken longer?

Claudia: Probably, yes. [Claudia, 25]

Here, the participant described a situation in which she began taking a new medication. After noticing that it was not working as well as it should, she used open notes' comment function to contact her HCP and request a dose adjustment. Without this option, she would have had to wait until her next appointment to bring this up. Moreover, the quote shows that HCPs may use open notes to engage with patients in an unbureaucratic way and take their wishes genuinely into account. Also, another participant explained that previously, in a crisis situation, she would have changed her medication herself without consulting her HCP, because she had no quick way of reaching them. This observation points to the relevance of open notes as a different form of access to HCPs.

Care Logistics

Overall, participants noted positive effects of open notes on organizational aspects of their care, particularly their appointments (9/13, 69.2%). Eight out of thirteen participants specified that they felt better prepared for their appointments, because they would read the notes beforehand (61.5%). Two participants felt less nervous about going to the appointments and perceived them as a more pleasant experience than before (15.4%). They connected this to having a clearer idea of what would be discussed during the appointment. One of them said that he had started attending his appointments more regularly because of this:

Ivo: Now I kind of like going to my appointments because of this documentation, and I show up more often than before. Because before, I always felt a bit like, well, what do I get out of this?

Interviewer: Okay, so you attend your appointments more regularly now, while before you would skip them occasionally?

Ivo: Exactly. Sometimes I just said to myself: Okay, I am going to sleep in today. [Ivo, 25]

Four participants (30.7%) explicitly stated that appointments were more efficient, because minor issues could be addressed faster and more easily via the comment function beforehand (e.g. making an appointment, getting a sick note, getting a prescription). This freed time for other concerns during the appointment. Moreover, a few participants felt that open notes also helped their HCPs to prepare better for the appointment, because they could be informed of patients' concerns beforehand (2/13, 15.4%). In one case, less appointments in person were needed because concerns were addressed via the comment function. A quote from Bertram's case helps to illustrate this aspect. He described the possibility of getting in touch with his HCP via the comment function as "It's kind of like a mini doctor's visit. If you have problems, you can write them down, discuss them with the doctor, and get a helpful response." [Bertram, 62].

Illness Understanding and Acceptance

A majority of participants reported that open notes gave them a better overview of their illness history (9/13, 69.2%). Two of them explicitly stated that the possibility of looking back on past periods of illness would help them recognize and deal with a new crisis in the future (15.4%).

A little more than half of the participants noted that their understanding of their illness, the symptoms with which it presented and its different stages had increased due to open notes use (7/13, 53.8%). Because of this, they felt capable not only of verifying what their HCP observed about them but also of informing their HCP of additional symptoms they noticed themselves. The following quote from Nora's case shows that access to a more objective perspective on one's illness can be helpful in challenging one's own experience and may encourage participants to take their illness situation more seriously:

(...) let's say if I was like, when I was, like, really, really sick, I actually did not know how bad it was until, like, maybe later on when I had to discuss again. So I would probably when I was really sick, I would, uh, (…) um, explain my situation or had a wrong impression of how serious my, my, my sickness is. Uh, but with the doctors' note, maybe it's actually more, um, more, you know, it's objective or, you know, clinically accurate. [Nora, 36]

The transcript of the interview with Nora suggests that she has experienced severe mental health crises before and has a tendency to minimize or even deny them. Reading her clinical notes and comparing them to her own experience seems to help her understand and accept her illness during these phases.

More than half of the participants said that open notes had helped them understand their illness better, specifically by helping them understand and accept their diagnosis (7/13, 53.8%). This can, for example, be observed in Fiona's case:

I'd say it maybe helped a bit with accepting the diagnosis. At first, the diagnosis was really new to me. It was the first time I was fully diagnosed, and it was really, really hard for me to accept at the beginning. But I think seeing it written out clearly, what the problem is, how it's being worked on, how it's talked about, I think that did help. (…) It made me more aware of my symptoms, and realizing that many behaviors or things I say come from those symptoms. Dealing with that, being aware of it, and accepting it is an important step in managing the illness. And I do think this helped with that. [Fiona, 21]

Considering that she had only recently been diagnosed and struggled to accept her new diagnosis, the clarity and objectivity of the HCP's assessment helped her understand her illness better and put her symptoms into perspective.

Therapeutic Relationship

Transparency

All participants reported that there was a higher level of transparency in their treatment process due to the use of open notes. They saw this as a positive aspect. In all thirteen cases, positive effects of increased transparency on the therapeutic relationship could be identified. Three participants were able to make this connection explicit, while others mentioned it more implicitly (23.1%). For example, Bertram said:

A better feeling … of well-being? Or how do you say it, feeling better overall? Not just feeling more understood but actually feeling healthier because of it. [Bertram, 62]

He seems to be looking for the right words, but the quote indicates that there has been a positive effect. As already shown in the other two main categories, about half of the participants said that they had been curious about their HCPs view on them before using open notes and therefore appreciated having access to their clinical notes (6/13, 46.2%). The third main category “Therapeutic Relationship” shows that participants associate this ability to “actually read what the doctor thinks about you” [Ivo, 25] with increased transparency. Moreover, a majority of participants associated increased transparency with greater trust in their HCP (7/13, 53.8%):

(…) I have developed greater trust in my doctor simply because the uncertainty about what his notes say about me has lessened. I have been able to better understand his thought process. [Georg, 20]

Georg also pointed out that the kind of transparency afforded by open notes is especially important in the context of mental health:

And if I compare that to a general practitioner, it’s easier to make an objective judgment for physical complaints. At least that’s my impression, that the doctor’s subjective perception matters less. But especially when it comes to mental health issues, it’s much harder to make that objective judgment. (…) And that’s where the added value is even greater. [Georg, 20]

He remarked that judgments about mental disorders are more subjective in comparison to somatic disorders and therefore the HCP’s subjective perspective is more relevant. Thus, he felt that for him as a patient it is even more important to have insight into the HCP’s subjective perspective and compare it with his own perspective.

Decision Making

Most participants reported that open notes had a positive influence on decision making in the treatment process (10/13, 76.9%). Mainly, they seemed to feel more involved in the process, as if they had more of a right to participate. Three of these ten participants said that even though they felt this way, they still preferred to let their doctor make the decisions (23.1%).

Georg’s case provides a good example of changed dynamics in decision making due to open notes use. The interview transcript suggests that he is rather informed about his illness.

Georg: My doctor initially rejected switching to a new medication because he thought it wasn’t suitable for me, but later that same evening he wrote again to say it might actually be possible.

(...)

Interviewer: Yes, that's an interesting interaction. So your doctor used the comment function to add a new aspect or to partially correct himself, could you say?

Georg: Yes, exactly. After he discussed it internally with his colleagues.

Interviewer: And how did you feel about that?

Georg: I was very surprised. Very positively surprised that there was such a quick response. And of course, that my suggestion was accepted and actually used.

Interviewer: Yes, it was a medication you had suggested before?

Georg: Yes, yes, something I had suggested once.

[Georg, 20]

The quote demonstrates a more flexible process of decision making while using open notes and suggests that Georg feels empowered by this interaction. This indicates open notes' potential for offering patients a greater share in decision making and ultimately building trust between patients and HCPs.

Power Dynamics and Equality

Georg's case already shows that open notes can lead to a change in decision making and therefore also affects power dynamics between patients and HCPs, which was pointed out by almost half the participants (6/13, 46.2%). More specifically, several participants reported that being more involved in the decision-making process and increased transparency through open notes made them feel on more equal terms with their doctors (4/13, 30.8%). An example of this can be found in Fiona's case:

[...] so I had hoped and it did happen that I felt more on equal footing with my doctors. Like bringing a bit more openness and equality into the whole thing. And that definitely happened. [Fiona, 21]

She further elaborated: "(...) it's not about me sitting in a classroom with someone up front explaining things and telling me what to do. It's more like helping me help myself, so to speak." [Fiona, 21]. Her following statement underlined that she wanted to take an active part in her treatment process and saw open notes as a tool that helped her do that:

This is still primarily about me, my treatment, and my health, not about someone standing over me giving orders. And that's why I think it's really important. [Fiona, 21]

This demonstrates the potential of open notes to influence power dynamics in mental healthcare. One of the interviews highlights the relevance of this effect by showing that patients with SMI are likely to experience traditional power dynamics in psychiatry: Ivo has been involuntarily treated multiple times and refers to himself as "the guy without any rights" [Ivo, 25]. In his case, open notes allowed for an experience of different (less hierarchical) power dynamics.

Availability

Almost all participants reported that increased availability of their HCP had a positive influence on their treatment process (12/13, 92.3%). More than half of the participants said that this led to a more intensive interaction with their HCP (7/13, 53.8%). Increased availability was tied to the comment function which is part of the PEPPPSY portal. Except in one case, participants reported that their HCP had always replied to their comments at least within 48 hours.

A few participants said explicitly that the increased availability provided by open notes had had a positive influence on their relationship with their HCP (3/13, 23.1%). The following quote from Fiona's case shows this:

Because you end up having more contact in a different kind of way, I do believe it has improved the relationship in some way. You usually only see a psychiatrist, let's say, every eight weeks or so, and having more contact, whether written or in person, does something for the relationship and for how comfortable you feel. [Fiona, 21]

Nevertheless, not everyone felt comfortable with this opportunity to contact their HCP. Two participants voiced feelings of irritation or concern regarding this aspect of open notes (15.4%). Hubert reported being hesitant about using his access to open notes to contact his doctor: "I feel a bit guilty like I'm blocking the doctor from seeing other patients." [Hubert, 59]. And Mara was surprised that her doctor answered her questions within hours: "I was quite taken aback and thought: You usually never have time. And who's paying for that?" [Mara, 43].

Trust

When asked about the influence of open notes on the relationship with their HCP, more than half of the participants described that they felt better understood and validated (9/13, 69.2%). One patient described this as follows:

It makes me feel that, um, somehow it feels more cared for. Because I can understand. I can see that, okay, he understands my situation or, you know, he sees my situation clearly. So, I have more confidence in him. [Nora, 36]

Seven interviewed patients stated specifically that using open notes had increased trust in their relationship with their HCP (53.8%). For example, Bertram said "Yes, in the sense that it's changed because the level of trust has grown." [Bertram, 62]. Most of them expressed that using the notes made them feel more understood, because they had insight into their HCP's writings:

Because I can see that he really understood what I mean, what I share with him or write to him. And… I feel more understood. [Bertram, 62]

The other six participants reported that they could not really say whether open notes had influenced trust, usually because they felt that trust was good before or there were only small effects (46.2%). For

example, Mara stated that before using open notes, she already felt she could trust her HCP and was satisfied with the communication, but now she noticed that not knowing what her HCP wrote down about her had actually been irritating:

You're sitting there, right, just sitting there while the doctor is typing something. And yes, the communication was good, as I said, but what I meant with curiosity and humanity and so on … still, in that moment, I don't know what he's typing. And then finding out, like, ah, okay, that's what's written there, that gives a kind of sense of security, something in the direction of trust. Like a kind of checking: ah, okay, that's what he wrote, and now I know it. It gives that kind of security, that kind of… [Mara, 43]

The example again underlines the common experience of irritation when patients do not know what their HCPs write down about them. It also shows how this irritation can be resolved by using open notes which seems to help to strengthen trust.

Discussion

Principal Findings

Our results suggest that using open notes may improve therapeutic relationships among patients with SMI. Several factors appear to contribute to this effect: increased transparency, greater availability of HCPs, opportunities for changing power dynamics, easier access to shared decision making and strengthened trust. Patients described feeling more validated, having greater influence over decisions and a sense of equality in their treatment. Many noted more frequent contact with their HCP, greater self-efficacy (especially around medication management) and deeper engagement with their illness and treatment. Access to open notes facilitated quick discussions of treatment-related issues. It allowed patients to raise concerns rather than deciding alone or waiting for their next appointment in person, which could be crucial during crises. This effect may support increased medication adherence and a decreased risk of chronic progression in patients with SMI. Importantly, patients noted a shift in power dynamics. This is especially relevant in mental healthcare, not least because of the presence of involuntary treatment. Many patients also reflected on having been irritated in the past because they had no knowledge of their clinical notes' content. Open notes resolved this and thereby helped build trust.

Furthermore, our findings indicate that access to open notes in mental healthcare may help to improve self-management and reflection which could also be beneficial for patients with SMI. Notably, several participants pointed out the value of the second perspective open notes offered them. It challenged their own views on themselves and their illness. In critical conditions like psychosis or mania, difficulties in having a realistic self-perception are a core feature of the illness. Even though patients who experienced acute critical conditions were excluded from our study, some participants had experienced those kinds of conditions in their medical history. They stated that reading their clinical notes afterward helped reassure them about what had occurred. Many patients also gained clearer insight into their long illness histories. This aided their understanding and acceptance of chronic conditions. Decision making was

experienced as more flexible and interactive. HCPs were able to adjust doses and treatment plans more quickly in response to patient feedback.

These relational and self-management benefits underline open notes' potential for patients with SMI. For this group consistent therapy adherence (particularly to medication plans), limited insight into their illness and developing treatment motivation often represent serious challenges. Overall, these patterns underscore the potential of open notes for strengthening self-management and the therapeutic relationship in mental health care.

Our findings align with and expand on previous research on open notes in mental health care. Professionals assume that the use of open notes, and thus the structure and language of clinical notes, will affect the therapeutic relationship and specifically the power balance between patients and HCPs [17, 20, 24]. Interview data from patients with SMI shows that concerns about a negative effect of open notes on trust in the relationship with HCPs is a main reason for not using open notes [32]. Our findings provide further support that open notes can help improve trust for patients with SMI. Moreover, they strengthen previous research showing that HCPs anticipate open notes use in mental healthcare will increase trust [26]. They expect this to result from increased transparency and decreased power imbalances between patients and HCPs. Previous studies have also shown that trust can decrease when patients notice errors, omissions or a judgmental tone in their psychiatric clinical notes [24]. Yet, in our dataset, patients were mainly able to resolve misunderstandings without associating this with decreased trust.

The available evidence suggests that open notes in mental healthcare can help patients reflect between appointments and strengthens engagement with the therapeutic process [37]. HCPs generally anticipate that open notes give patients a better overview of their treatment, but many also consider it unlikely that this will lead to greater engagement in the therapy process and are more concerned that patients might be offended by their notes [26, 27, 38]. Regarding this point, our findings suggest that the increased transparency open notes provide has a generally positive effect on the relationship between patients with SMI and their HCPs. Also, our results indicate a possibility for greater engagement with the treatment process, understanding of one's illness and self-efficacy in the context of open notes use for patients with SMI. In this context, it is important to take the treatment setting into account. Our study was conducted in an outpatient setting of a psychiatric hospital. In Germany these are set up specifically for patients with SMI to provide easily accessible multiprofessional treatment. This is very different from an outpatient psychotherapy setting, which has a clear focus on psychotherapeutic treatment. Consequently, the notes discussed by patients in our study mainly address medical issues and daily life management, rather than inner psychic conflicts. Therefore, our results are not necessarily generalizable to open notes in psychotherapeutic treatment, and we cannot draw conclusions from them about whether it is sensible to use open notes in that context.

The benefits of open notes for self-management in patients with SMI that this study identifies align with previous research on the effects of open notes in mental health care. This prior work highlights open

notes' potential for enabling patients to detect errors and take initiative in requesting corrections [5, 39–41]. Our study provides concrete examples of these benefits in the context of SMI, e.g. patients taking the initiative to solve medication issues.

Previous research has also shown that older patients with SMI gain a deeper understanding of their illness and treatment through open notes and benefit from improved access to HCPs, which leads to greater involvement in the treatment process [42, 43]. Our findings indicate that this might apply to younger patients with SMI as well.

Strengths and Limitations

The small sample size limits generalizability of the results. However, the sample is relatively heterogeneous, including persons from different age groups and non-native speakers, while focusing on more stable outpatients with SMI. Selection bias is a potential issue, as the study included only stable, self-selecting outpatients with SMI. This may result in overestimating the benefits of open notes by excluding more vulnerable patients and favoring those with higher motivation, better communication skills and greater understanding of their illness. Social desirability bias cannot be ruled out. Participants may have overemphasized positive aspects of open notes and been reluctant to criticize their HCPs. In the future, larger and possibly quantitative studies with a diverse selection of participants are desirable.

A strength of the study is its focus on a specific and understudied subgroup (patients with SMI) who often need life-long and intensive mental healthcare. By targeting this group, the study may contribute to improving the quality of their care. Additionally, the study addresses a complex and often subtle phenomenon, the therapeutic relationship, using qualitative interviews. This allows for a more in-depth exploration that quantitative methods cannot achieve.

Implications for Future Research and Practice

Future research should prioritize longitudinal and quantitative studies to validate qualitative insights on open notes' impact on adherence, self-efficacy and therapeutic relationships in diverse patient groups with SMI. Specific subgroups, like high-risk acute psychosis cases, should be studied using qualitative methods to assess whether the results of this study apply to them as well. Further evidence on the implementation and outcomes of patient access to clinical notes in German outpatient care is expected from the ongoing OpenNOTES study, the protocol of which has been published previously [44]. More broadly, changes in documentation, optimization opportunities through AI, technical, organizational and legal barriers to integration of open notes in mental health care in Germany need to be focused on [44, 45].

HCPs should observe and proactively discuss open notes' effect on the relationship with their patients. Routine debriefings with patients to clarify content, prevent misunderstandings or provide digital literacy as well as data security training should be considered. This may be especially relevant for patients with SMI and low-literacy users. Furthermore, HCPs should write patient-centered notes using plain,

nonjudgmental language to promote understanding and trust. This seems particularly important in a sensitive area such as mental healthcare, where misunderstandings can have significant effects on the therapeutic relationship. Tailored access, e.g. with temporary blocks, for acute or psychosis cases may be considered as well but warrants further research on this specific group.

Conclusions

This study demonstrates that use of open notes can positively impact therapeutic relationships between patients with SMI and HCPs. It illuminates the key contributing factors and their interactions. Our findings align with prior research on open notes' capacity to enhance patient engagement in treatment, recalibrate power dynamics and foster trust in HCPs. These relational effects are especially important for patients with SMI, who face heightened challenges with regard to therapy adherence, power imbalances and trust. Thus, the study underscores open notes' promise as a practical measure towards more patient-centered mental healthcare.

Abbreviations

COREQ
Consolidated Criteria for Reporting Qualitative Research
EHR
electronic health record
HCP
health care professional
ICD-10
International Classification of Diseases, 10th Revision
MHB
Brandenburg Medical School Theodor Fontane
ORA
online record access
PEPPPSY
Piloting and evaluation of a participatory patient-accessible electronic health record in Psychiatry and Somatics
SMI
severe mental illness

Declarations

Ethical approval and consent to participate

Informed written consent was obtained from all respondents to participate in the study. The ethics approval from the Ethics Committee of the Brandenburg Medical School (MHB) was obtained (E-01-

20210727), and the study was registered with the German Clinical Trial Register (DRKS00030188).

Consent for publication

Not applicable.

Competing interests

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Funding

Funded by the publication fund of Brandenburg Medical School (MHB), supported by the Springer DEAL agreement.

Author Contribution

M.W. wrote the first draft of the manuscript. J.S. modified successive drafts. J.S. designed the study. M.W. conducted the interviews. M.W. and J.S. conducted the data analysis. M.W. prepared all tables and figures. All authors contributed to planning, analysis, critical interpretation of findings, and approved the final manuscript.

Acknowledgements

Not applicable.

Data Availability

The qualitative data collected within the current study are not publicly available due to privacy restrictions but are available from the corresponding author on reasonable request.

References

1. Delbanco T, Walker J, Darer JD, Elmore JG, Feldman HJ, Leveille SG, et al. Open notes: doctors and patients signing on. Ann Intern Med. 2010;153:121–5.
2. Schwarz J, Esch T. OpenNotes in Mental Health? Pro. Nervenarzt. 2022;93:1163–4.
3. Website. https://doi.org/10.1007/s00115-022-01356-5

4. Hötger C, Heuser-Collier I. OpenNotes in Mental Health? Kontra. Nervenarzt. 2022;93:1165–6.
5. Walker J, Leveille S, Bell S, Chimowitz H, Dong Z, Elmore JG, et al. OpenNotes After 7 Years: Patient Experiences With Ongoing Access to Their Clinicians' Outpatient Visit Notes. J Med Internet Res. 2019;21:e13876.
6. Bärkås A, Scandurra I, Rexhepi H, Blease C, Cajander Å, Hägglund M. Patients' Access to Their Psychiatric Notes: Current Policies and Practices in Sweden. Int J Environ Res Public Health. 2021;18.
7. McMillan B, Davidge G, Blease C, Watson J. Implications of the changes to patient online records access in English primary care. Br J Gen Pract. 2022;72:558–9.
8. Essén A, Scandurra I, Gerrits R, Humphrey G, Johansen MA, Kierkegaard P, et al. Patient access to electronic health records: Differences across ten countries. Health Policy Technol. 2018;7:44–56.
9. Zanaboni P, Kummervold PE, Sørensen T, Johansen MA. Patient Use and Experience With Online Access to Electronic Health Records in Norway: Results From an Online Survey. J Med Internet Res. 2020;22:e16144.
10. Delbanco T, Walker J, Bell SK, Darer JD, Elmore JG, Farag N, et al. Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. Ann Intern Med. 2012;157:461–70.
11. Wolff JL, Darer JD, Berger A, Clarke D, Green JA, Stametz RA, et al. Inviting patients and care partners to read doctors' notes: OpenNotes and shared access to electronic medical records. J Am Med Inf Assoc. 2017;24:e166–72.
12. Bell SK, Mejilla R, Anselmo M, Darer JD, Elmore JG, Leveille S, et al. When doctors share visit notes with patients: a study of patient and doctor perceptions of documentation errors, safety opportunities and the patient-doctor relationship. BMJ Qual Saf. 2017;26:262–70.
13. Ammenwerth E, Neyer S, Hörbst A, Mueller G, Siebert U, Schnell-Inderst P. Adult patient access to electronic health records. Cochrane Database Syst Rev. 2021;2:CD012707.
14. Davis Giardina T, Menon S, Parrish DE, Sittig DF, Singh H. Patient access to medical records and healthcare outcomes: a systematic review. J Am Med Inf Assoc. 2014;21:737–41.
15. DesRoches CM, Leveille S, Bell SK, Dong ZJ, Elmore JG, Fernandez L, et al. The Views and Experiences of Clinicians Sharing Medical Record Notes With Patients. JAMA Netw Open. 2020;3:e201753.
16. Meier-Diedrich E, Blease C, Heinze M, Wördemann J, Schwarz J. Changes in Documentation After Implementing Open Notes in Mental Health Care: Pre-Post Mixed Methods Study. J Med Internet Res. 2025;27:e72667.
17. Dobscha SK, Denneson LM, Jacobson LE, Williams HB, Cromer R, Woods S. VA mental health clinician experiences and attitudes toward OpenNotes. Gen Hosp Psychiatry. 2016;38:89–93.
18. Petersson L, Erlingsdóttir G. Open Notes in Swedish Psychiatric Care (Part 1): Survey Among Psychiatric Care Professionals. JMIR Ment Health. 2018;5:e11.

19. Meier-Diedrich E, Lyckblad C, Davidge G, Hägglund M, Kharko A, McMillan B, et al. Impact of Patient Online Record Access on Documentation: Scoping Review. J Med Internet Res. 2025;27:e64762.
20. Denneson LM, Cromer R, Williams HB, Pisciotta M, Dobscha SK. A Qualitative Analysis of How Online Access to Mental Health Notes Is Changing Clinician Perceptions of Power and the Therapeutic Relationship. J Med Internet Res. 2017;19:e208.
21. Petersson L, Erlingsdóttir G. Open Notes in Swedish Psychiatric Care (Part 2): Survey Among Psychiatric Care Professionals. JMIR Ment Health. 2018;5:e10521.
22. Blease C, Dong Z, Torous J, Walker J, Hägglund M, DesRoches CM. Association of Patients Reading Clinical Notes With Perception of Medication Adherence Among Persons With Serious Mental Illness. JAMA Netw Open. 2021;4:e212823.
23. Etingen B, Hogan TP, Martinez RN, Shimada S, Stroupe K, Nazi K, et al. How Do Patients with Mental Health Diagnoses Use Online Patient Portals? An Observational Analysis from the Veterans Health Administration. Adm Policy Ment Health. 2019;46:596–608.
24. Cromer R, Denneson LM, Pisciotta M, Williams H, Woods S, Dobscha SK. Trust in Mental Health Clinicians Among Patients Who Access Clinical Notes Online. Psychiatr Serv. 2017;68:520–3.
25. Schwarz J, Bärkås A, Blease C, Collins L, Hägglund M, Markham S, et al. Sharing Clinical Notes and Electronic Health Records With People Affected by Mental Health Conditions: Scoping Review. JMIR Ment Health. 2021;8:e34170.
26. Schwarz J, Hoetger C, Pluschke L-S, Muehlensiepen F, Schneider M, Thoma S, et al. Psychiatrists' perceptions of conditions and consequences associated with the implementation of open notes: qualitative investigation. BMC Psychiatry. 2024;24:430.
27. Meier-Diedrich E, Neumann K, Heinze M, Schwarz J. [Attitudes and Expectations of Psychological and Medical Psychotherapists Towards Open Notes: Analysis of Qualitative Survey Responses]. Psychiatr Prax. 2024;51:376–84.
28. Chimowitz H, O'Neill S, Leveille S, Welch K, Walker J. Sharing Psychotherapy Notes with Patients: Therapists' Attitudes and Experiences. Soc Work. 2020;65:159–68.
29. Hochwarter S, Fehler G, Muente C, Eisenmann Y, Heinze M, Hibsch C, et al. Design of a Patient-Accessible Electronic Health Record System in Mental Health. Stud Health Technol Inf. 2022;294:583–4.
30. Gibson M, Halvorsen M, Joner MAA, Lehne M, Stautland ER, Svensson G et al. Pilot Testing and Evaluation of Participatory Patient Record in Psychiatric Care. SHI. 2022;:216–7.
31. Bundesrepublik Deutschland. Gesetz zur Beschleunigung der Digitalisierung des Gesundheitswesens (Digital-Gesetz - DigiG). 2024.
32. Schwarz J, Meier-Diedrich E, Neumann K, Heinze M, Eisenmann Y, Thoma S. Reasons for Acceptance or Rejection of Online Record Access Among Patients Affected by a Severe Mental Illness: Mixed Methods Study. JMIR Ment Health. 2024;11:e51126.
33. Kallio H, Pietilä A-M, Johnson M, Kangasniemi M. Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. J Adv Nurs. 2016;72:2954–65.

34. Emerson RM, Fretz RI, Shaw LL. Writing Ethnographic Fieldnotes, Second Edition. University of Chicago Press; 2011.
35. Clarke V, Braun V, Hayfield N. Thematic analysis. In: Smith JA, editor. Qualitative Psychology: A Practical Guide to Research Methods. London: SAGE; 2015. pp. 222–48.
36. Kuckartz U, Rädiker S. Qualitative Content Analysis: Methods, Practice and Software. SAGE; 2023.
37. O'Neill S, Chimowitz H, Leveille S, Walker J. Embracing the new age of transparency: mental health patients reading their psychotherapy notes online. J Ment Health. 2019;28:527–35.
38. Schwarz J, Neumann K, Meier-Diedrich E, Mühlensiepen F, Hochwarter S, Blease C. Psychotherapists' views on open notes: An online survey from Germany. DIGITAL HEALTH. 2024. https://doi.org/10.1177/20552076241271813
39. Leveille SG, Fitzgerald P, Harcourt K, Dong Z, Bell S, O'Neill S, et al. Patients Evaluate Visit Notes Written by Their Clinicians: a Mixed Methods Investigation. J Gen Intern Med. 2020;35:3510–6.
40. Kharko A, Buergler S, Bärkås A, Hägglund M, Gaab J, Fagerlund AJ, et al. Open notes in psychotherapy: An exploratory mixed methods survey of psychotherapy students in Switzerland. Digit Health. 2024;10:20552076241242772.
41. Monaci M, Javaher S, Barello S. Open Notes in Mental Health: A Scoping Review of Stakeholder Experiences and Implications for Clinical Practice. Healthc (Basel). 2025;13.
42. Meier-Diedrich E, Dahling V, Esch T, Hägglund M, Heinze M, Hochwarter S, et al. Pilotierung und Evaluation einer partizipativen, digitalen Akte für gerontopsychiatrische Patienten und ihre Care-Partner. Nervenheilkunde. 2024;43:681–7.
43. Meier-Diedrich E, Esch T, Hägglund M, Heinze M, Hochwarter S, Speck J, et al. Experiences of Older Mental Health Patients and Their Care Partners Using a Proxy Account to Access Open Notes: Qualitative Interview Study. JMIR Aging. 2025;8:e66690.
44. Wurster F, Meier-Diedrich E, Demirer I, DesRoches C, Goldberg N, Hägglund M, et al. Online-Zugang zu klinischen Behandlungsnotizen für ambulant versorgte Patienten (Studienprotokoll zur OpenNOTES-Studie). Nervenheilkunde. 2024;43:714–9.
45. Ozkara Menekseoglu P, Weibezahl M, Ellingsen M, Sterkenburg J, Kharko A, Hochwarter S, et al. Errors in generative AI-based patient-centered mental health documentation: Psychiatrists' qualitative pre-post comparison (preprint). JMIR Ment Health. 2025. https://doi.org/10.2196/78351.

Figures

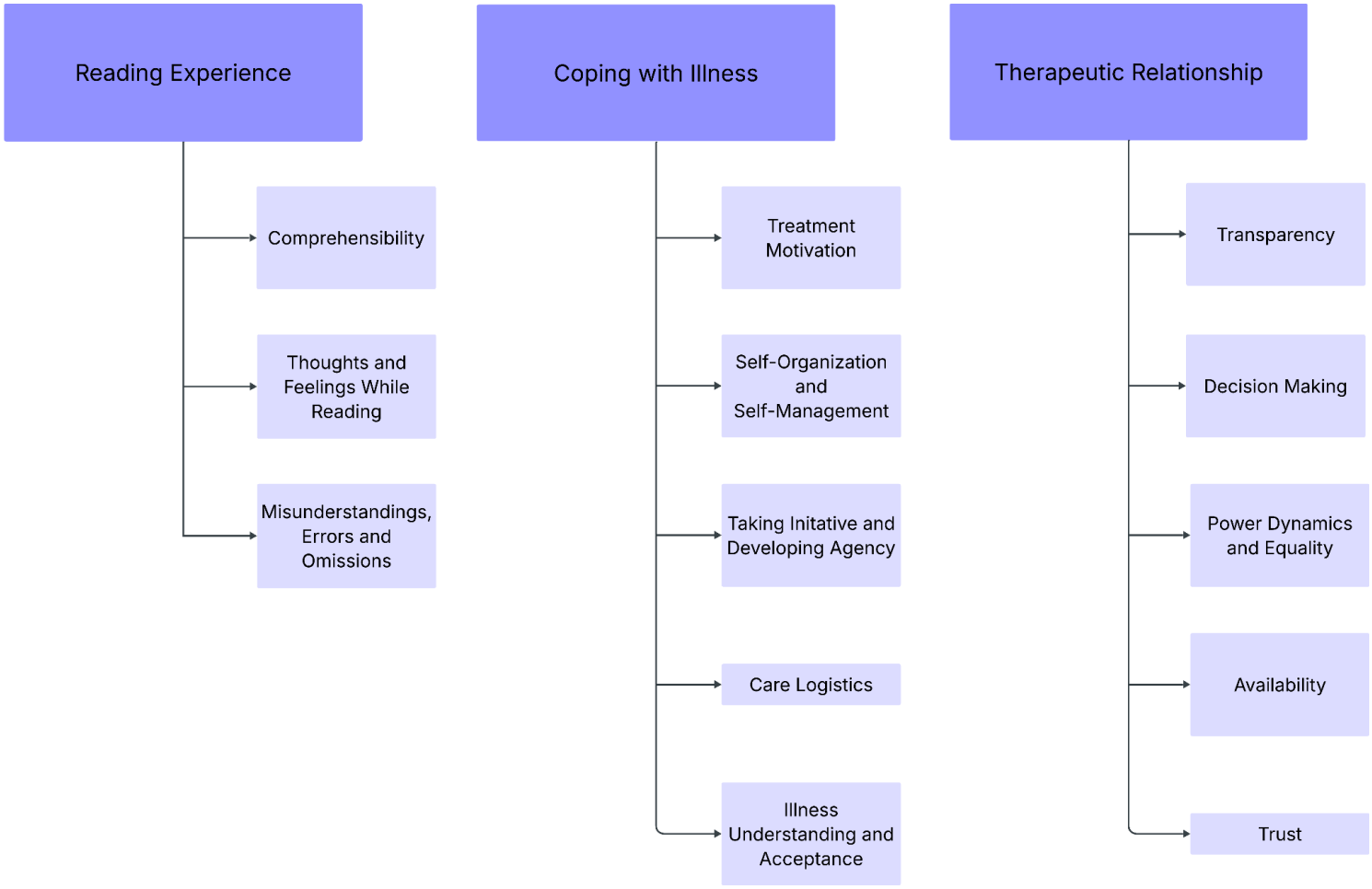


Figure 1

Overview of main and subcategories

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Appendix.docx