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ORIGINAL RESEARCH ARTICLE

Experiences from using patient accessible electronic health records - a qualitative study within Sámi mental health patients in Norway

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ABSTRACT

Patient accessible electronic health records (PAEHR) has been implemented in the Norwegian public health care system since 2015. In Norway the indigenous minority is the Sámi people. Studies show that lingual and cultural competence of the health professionals can affect Sámi patients' user satisfaction with the health care system. A qualitative study was conducted to gather experience of PAEHR in mental health care for Sámi patients. Semi-structured interviews were conducted with five participants, who self-identified as Sámi, had experience as patients in mental health care, and had used the PAEHR service. The material was transcribed and coded and categorised using the framework method. Finally, the data was analysed using theoretic thematic analysis. The participants reported that the service was particularly helpful in identifying mis-understandings caused by different cultural perceptions between the patient and the therapist. Difficulties with Norwegian as written language in the journal were uncovered. The participants were ambiguous on whether cultural characteristics scold be recorded in the journal.

Introduction

Patient accessible electronic health records (PAEHR) has been implemented in three of four health regions in Norway since 2015. Research from other countries has shown that users' demographic and cultural background can affect the perceived utility of the service [1].

In this study we define culture as common values, traditions, moral, behaviour and habits acquired by a member of a community [2]. The only indigenous population in Norway are the Sámi, and there are cultural differences between them and the majority population. The Sámi population has the right to safeguard, preserve and develop their language, culture and way of life, as stated in the Norwegian constitution and the Sámi Act. They also have the right to be serviced by health care professionals who know their language and culture, and the health care service in Norway should be integrated and coordinated for Norwegian and Sámi population with sufficient consideration for the Sámi people and culture [3]. However, studies indicate that Sámi patients are unable to use their native language in treatments, and that health care professionals lack knowledge of Sámi culture. This may affect the Sámi populations' satisfaction with the Norwegian health care service [4]. Mental illness is regarded a stigma in many Sámi communities, and Sámi culture highly value autonomy and managing mental health issues without help from the public health care system [5, 6]. Furthermore, there are examples of Sámi-speaking patients feeling culturally unsafe in the Norwegian health care system for instance due to lack of Sami-speaking health care personnel [7]. Studies also show that Sámi users of the conventional public mental health care service may find that their belief of traditional healing is neither understood nor respected by the Norwegian health care system [8].

The introduction of PAEHR, particularly in mental health care, was preceded by debate. Health professionals raised concerns that access to their notes could exacerbate the condition of mentally ill patients [9], and that PAEHR was not suitable for the most severely sick patients in mental health care [10]. An emerging body of literature on the patients' experience paints a brighter picture of the service, showing that PAEHR has a positive impact on communication between a patient and health care staff [11, 12]. In the USA, a survey of military veterans with access to mental health care journal notes indicates improved self-efficacy, knowledge and patient-clinician relationships, regardless of the clinical or demographic characteristics of the patients [13]. Furthermore, a large patient survey across several

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locations and specialities in the US showed that patients are rarely troubled by reading their journal notes, the raised transparency increased patient engagement and non-white, less educated and non-English-speaking PAEHR users reported the highest benefit of PAEHR [1].

While previous research has investigated how Sámi cultural and lingual aspects can affect how health care is perceived, no previous research has explored how the PAEHR service is experienced among Sámi patients.

Aim of the study

The aim of the study was to investigate how a sample of Sámi mental health patients experienced using PAEHR and how their cultural background affected how they perceived the service.

Materials and methods

Ethics

All subjects provided their written informed consent to participate. The procedure for handling the data, including informed consent, contact information, audio files and verbatim transcripts, was approved by the Data Protection Officer of the University Hospital of North Norway. After considering the regulations, and preliminary consulting with the Regional Committees for Medical and Health Research Ethics (REK), the authors decided that in accordance with the Norwegian Act on Medical and Health Research §2 and §4, this study did not require approval from REK. After the start of this research project, the Norwegian Sámi Council introduced a mandatory collective consent form for Sámi health research [14]. While the project did not have the opportunity to formally receive collective consent from the ethics committee for Sámi research, the researchers were aware of the intentions of the collective consent: to acknowledge and preserve integrity of the Sámi participants and conducted the research accordingly.

Study design

To investigate how the Sámi cultural aspects could affect the use of PAEHR in mental health care, a qualitative study design was used. Based on user and professional input, a semi-structured interview guide was designed. Individuals with a Sámi cultural background and experience of reading their medical journal online were recruited via a variety of recruitment efforts. Interviews were conducted using either telephone or video conferencing, and recorded, then transcribed verbatim.

The basis of the interview guide

The basis of the interview guide was a synthesis of user input and input from mental health professionals in Sámi areas, compiled by an interdisciplinary research team with a background in PAEHR, mental health and Sámi health care services research. As a preparation to the interview guide, we wanted to identify important themes and receive input on how Sámi cultural aspects could affect the use of PAEHR in mental health. We invited PAEHR users, Sámi non-government organisations and individuals in the Tromsø and Karasjok areas, who were deemed to be knowledgeable about the topic, to participate in exploratory interviews. An exploratory interview with an individual user was conducted, in addition to exploratory interviews with a clinical social worker and a psychologist practising in a predominantly Northern-Sámi region. Based on input from these, the research team designed a semi-structured interview guide. The interview guide was used to guide the conversation towards topics that were of interest to the researcher, while allowing the participants to introduce additional topics. The interview was designed to take a maximum of one hour to complete.

Recruitment

The inclusion criteria for this study were: identifying as Sámi when meeting with health care services, having experience as patient in mental health care and having read the journal online. We reached out to the potential pool of participants through many different channels. In social media we paid for publicity on Facebook and reached over 33,546 inhabitants in Norway with our recruitment story. 2,202 persons clicked the link to read more about the project. The Instagram post reached 25,942 people and resulted in 257 clicks to read more about the project. We sent out a press release to 15 newspapers with a supposedly high level of Sámi-identifying readers, resulting in one printed story in a Sámi newspaper. We contacted 20 organisations of Sámi culture and language and asked them to communicate the recruitment need to their network. We also sent out posters to hang on information boards in primary care health centres in eight municipalities with a high Sámi population.

Semi-structured interviews

The participants were given the choice between conducting the interview over telephone or the secure video conferencing solution Whereby (Video Communication Services AS, Maaloy, Norway). One

participant opted for video conferencing, the rest for telephone. The interviews were recorded with an off-line digital recording device (Zoom H1n, Zoom corp., Tokyo, Japan) and transcribed verbatim.

Participants

The final study population comprised five persons, all of whom identified as Sámi. All lived in the northern parts of Norway. Two had either Northern Sámi or Lule Sámi as their native language, the rest had Norwegian. All had experience with mental health treatment in the Norwegian public health care system and had read their journal online. One had been hospitalised for mental health treatment previously, the rest had received outpatient treatment. Three women and two men participated. One of the participants was in the 30–40 age bracket and one was in the 50–60, while the other three were in the 40–50 bracket.

Analysis

The transcribed qualitative data material was analysed, using a variant of the framework method [15], by an interdisciplinary research team with backgrounds in psychology, economics and social anthropology. Firstly, a sample of two interviews was read by all members of the research team with the aim of identifying potential ideas for coding. The preliminary codes were then discussed in team meetings until a consensual set of codes was developed. Secondly, the team members read the manuscripts and applied the preliminary codes to passages of text. During this phase, the team had frequent meetings to revise codes by combining codes that yielded similar sematic content and introducing new codes for material that were relevant for the research questions but were not contained in the existing set of codes. Then, codes that were similar were grouped into categories and assigned a category label. Finally, when all meaningful passages of text were assigned a code and categorised, the material was theoretically thematically analysed [16]. While the analysis was theoretically driven by the research questions, the analysis also allowed for induction to accommodate for themes that were identified in the data that were relevant for the research questions, but not explicitly formulated beforehand.

Results

The categories, descriptions and summary findings from the framework analysis are presented in Table 1, followed by a presentation and analysis of the four themes that were identified in the thematic analysis.

Did the PAEHR provide utility for the participants?

Primarily, we wanted to gather the overall experiences of using PAEHR, including use patterns and in which contexts it was considered useful by the patients. To be able to further investigate utility in cultural context this was an important first mapping.

None of the participants could recall being informed about the PAEHR service by their health professionals. They had stumbled upon the service in an advertisement or media coverage. The participants had used the service routinely after being in contact with mental health care services. Another participant primarily read the journal as a parent on behalf of a child.

Reading the journal content made our participants more informed of the ongoing treatment and conclusions. One participant pointed out that reading the journal provided a welcomed perceived distance to his mental health condition:

> In a way, I get some distance to the mental health condition when I can read about myself. It is like I am no longer a subject, but an object observed by the clinician. I think it is alright to read about myself as the patient.

The PAEHR also functioned as a checkpoint of the relationship between the patient and the therapist and whether the content of the conversation was mutually understood. The ability to read stored information and give feedback on incorrect entries, including factually wrong information or patient statements that the patient did not recognise, were pointed out as a positive aspect of PAHER by the participants. The participants that had given feedback to the health professionals reported that the feedback was mostly welcomed. One of the participants had read the journal online and identified a fundamental lack of comprehension between himself and the health care professional, leading to a process that resulted in him changing therapist. He thought the language barrier was the reason for the misunderstanding.

One participant noted that when he became aware of the service, it was demanding to read a long history of clinical notes that concerned previous treatment. He described it as frightening to read journal notes that were tied to historical consultations, because of an overwhelming amount of information, and the fact that some of the content brought up memories that he perceived to belong to the past. Another participant said that when the therapist was open about the

Table 1. Categories identified from the framework analysis.

Category	Description	Findings
Utility	What the participants gained from reading journal notes electronically, including psychoeducative and information correction aspects, and how their feedback to health professionals was incorporated.	• Reading journal notes helped the participants become more informed about the treatment process.The participants could point out factual errors in the journal and have them corrected
Journal content	The participants' view of the journal content itself, and match / mismatch between the journal content and the understanding of the consultation in question	• Cultural information missing in the journal.One participant held back cultural information as (s)he preferred it not to be written in the journal
Journal language	The participants' reflections on the written language in the journal, reflections on journal content written in their non-native language, difference between written language and consultations language	• Some aspects of the journal notes went missing in the translation processSome participants would prefer the journal in their native language; however, they saw the difficulty of having a journal in a language that is not understandable for all therapists
Cultural knowledge in health services	The participants' thoughts about how cultural context indirectly affects the journal content, and how the health professionals' cultural knowledge affect the patients' perception of the clinical contact.	• The health professionals' cultural knowledge affected the patient-provider relationship.The health professionals' cultural knowledge affected the journal content
Awareness and extent of use	How the participants became aware of the PAEHR service, and their routines for using it.	• None of the participants were guided towards the PAEHR service by health professionalsThe participants used the service routinely after contact with the health services.

journal notes, and informed the patient throughout the whole process, it muted the potentially frightening feeling of the written journal and created openness in the relationship between therapist and patient.

> As long as they write what the patient said, it should be unproblematic for the patient to read it. I must admit, I would be more sceptical if I was *not* allowed to read it. It was a little scary knowing that something was written about me, but the Sámi clinician I visited explained what he wrote, and why he wrote it. It was comforting to see that the content of the journal matched what happened during the consultation.

Did health care professionals' knowledge of Sámi culture impact the patient-provider relation?

To contextualise the experience of the PAEHR service, we needed to understand the participants' impressions of mental health professionals' knowledge about Sámi culture.

The participants had different experiences and impressions of health professionals' knowledge and understanding of Sámi culture. The health professionals' knowledge of Sámi culture would impact how the participants perceived the patient-provider relation, and this impression would also impact what the patients anticipated when reading journal notes, and how they interpreted the journal content.

Descriptions of important Sámi culture factors were reflections about being a minority, mother language, family constellations, belonging to a reindeer family, and the Sámi way of communicating about health. One participant said that previous encounters with health care services without cultural knowledge had

made him specifically initiate contact with a health care service that was assumed to have knowledge about Sámi culture for further treatment.

> With the people from SANKS [Sámi Norwegian National Advisory Unit on Mental health and substance abuse], it is not necessarily where they come from that is the most important, but the fact that they possess knowledge about the culture. It's possibly a matter of trust … when I don't have to explain everything, but they intuitively recognise what I'm talking about.

Several participants also believed that health professionals' knowledge of Sámi culture impacted the clinical contact. A pre-understanding of cultural aspects from health professionals was highly appreciated, because the lack of such knowledge required the patient to give an introduction to relevant aspects [i.e. emphasis on kinship) of Sámi culture. One participant described how lack of knowledge of Sámi culture taxed their patience.

> In my experience, I almost always have to explain what Sámi is, and I'm not okay with that anymore, so I say: 'you need to go and read some books, if you don't know anything about it [Sámi culture].' I get a little upset with them.

Others had problems explaining and receiving understanding from the therapist.

> I feel I tried to explain, but it felt like talking to a brick wall and that they really did not understand anything of what I was trying to say.

Some culturally significant information about reality perception was omitted in consultations on purpose by the patients because they were unsure how it

would be perceived by the health professionals. The Sámi participants suspected that cultural understanding, tradition, and perception could be misunderstood or perhaps interpreted as a symptom of a psychiatric condition.

> I think about those that are no longer with us [ancestors]. It is almost like I ask the ancestors to show me the way from time to time. I haven't told any of my clinicians about this previously, not before I met the one I see now. She is very open. I have been afraid they would find me to be totally nuts if I told them things like that

Should the journal content mirror the patients' cultural self-image?

The participants had different expectations to the content of the journal after a consultation. Some reported that cultural characteristics about themselves were not described in the journal, despite it being a topic in the consultations. Topics of conversation that were perceived as important by the participant, but not mentioned in the journal entry, could affect how the patient perceived the relationship between patient and therapist.

> Yes, there were things that were important to me, but I could not find them in the journal. I especially remember being in one institution, where we talked about my large family and many relatives. This was not mentioned in the journal

However, not all participants felt that their cultural identity should be described in the journal. One participant meant that the importance of cultural aspects may differ depending on the context of the meeting. The cultural identity would not help treatments in all contexts, and therefore, whether it should be written in the journal should be context dependent.

> If I broke a leg, why would it be relevant to record in the journal whether I am Sámi or not, if it had no consequences for how they were to communicate with me? If it was the case that I didn't understand Norwegian, then it would have been relevant. There is no need to 'Sámify' every aspect of one's existence. It is not all about being Sámi. It is first and foremost about being a person, with all the individual needs that a person may have.

How did the journal language affect the patient's recognition of the journal content?

We found that the written language of the journal could affect the patient's recognition of the journal notes. When the patient's perception of the consultation and the journal content differed due to language differences, this could create mistrust or dissatisfaction for the patient. None of our participants had read journal notes in Sámi. Some had consultations in the Sámi language, but the record was written in Norwegian.

One participant said that while she ideally would like to have the journal notes in Sámi language, she understood the practicalities of keeping them in Norwegian, given that the journal must be comprehensible to other non-Sámi-speaking health professionals. Other participants pointed out that they feared not having sufficient language competence to understand medical terms in Sámi.

When the consultations were conducted in the Sámi language and translated into Norwegian in the journal, some of the participants had experienced that elements were lost in translation.

> Sometimes I wonder: "Why is it written like that – it is not what I said." The next time I was there, I mention it for the therapist, and it turns out there has been a misunderstanding when I have spoken in Sámi, and they have translated it to Norwegian.

One participant would prefer to have the journal written in his Sámi language, as he believed that would better reflect his emotional descriptions. He felt that the Sámi language contained figurative expressions that could be difficult to translate into Norwegian. Several participants described the Sámi language as a pictorial language with unpronounced meanings, which could complicate the translation process.

Discussion

The main finding in this study is that PAEHR enables patients to check the therapists' understanding and perception of what has been shared and said in the consultations. This is particularly related to identify misunderstandings caused by differing cultural perceptions between patient and therapist.

In line with government regulations, journal content in Norwegian public health care is mainly written in Norwegian. This was also the case for the journals of all participants in this study. Consequently, for patients native in a Sámi language, there will at least be a one-stage translation from what occurred in the consultation to what appears in the journal. The participants in our study report that one of the benefits of PAEHR was to check if the journal reflected the communication between themselves and the health professional. [17], reveal that Sámi-speaking patients, regardless of their proficiency in Sámi language, have a better experience,

if the health professional speaks Sámi. If possible, a bilingual patient will often prefer to use both languages during consultations [17]. According to the Norwegian law on Patient Rights §3-5 (Lovdata), patients have the right to have an interpreter present at the consultation, if the health staff do not speak the Sámi language. It is the health professional's responsibility to make sure that the patient understands correctly the information provided to them. The information should be adjusted according to the patient's characteristics for example: age, experience, cultural and lingual background. Our study indicates that, while the translation is challenging even with an interpreter present, the PAEHR service may alleviate some of the problems, by providing the patient with means to read the assessments and conclusions in the journal.

In addition to lingual barriers, the cultural competence of the health staff may be of vital importance for providing adequate health care to Sámi patients. In various degrees our participants had found that therapists lacked knowledge of Sámi culture and cultural communication methods. They also experienced misinterpretation of the nonverbal and underlying meaning of the communication. The cultural context is likely to affect how patients communicate and understand symptoms of illness [18]. Previous research has pointed out that Sámi patients tend to describe illness with an emphasis on the functional consequence for the affected body part, rather than the location and intensity of the pain [19]. If the therapist is not aware of this way of communicating, the interpretation of what the patient says, and possibly not says, will be wrong. Consequently, the patients will not recognise the content of the journal. The easy access to the journal notes provided by PAEHR can help patients discover this kind of misinterpretation and lack of cultural competence on the part of the therapist. This is supported by a previous study that found the consistency between what occurs in consultations and what appears in the journal may increase patient trust and avoid negative consequences of PAEHR [20].

Cultural competence at both the institutional and individual levels are essential to the wellbeing of Sámi people [7]. Our results suggests that some Sámi patients under-communicate their beliefs in traditional healing and a spirit world where you can speak with your ancestors, for fear of wrong interpretation or stigma from their therapist. This result is in line with previous research [21, 22]. To mitigate the under-communication of cultural aspects, it has been suggested that the use of standardised formulas to address cultural aspects, such as a culturally adapted survey, can help patients talk about their beliefs in a spirit world, without being afraid of being diagnosed with a more severe mental health disorder [8]. Indeed, international research has pointed out that there is a growing recognition for the need of cultural competence training in health care personnel [23]. While it is reasonable to hypothesise that under-communication in mental health can affect the quality of treatment and ultimately health outcomes, the evidence on how interventions to improve culture competence in the health services affect treatment is sparse. A systematic review from 2015 on evaluations of interventions to improve culture competency in health care in several countries with an indigenous population identified 11 evaluations in the USA and 5 in Australia. The authors concluded that there was lack of methodologically rigorous evaluations, especially on how such interventions affect the health of indigenous peoples [24]. While the status is somewhat dated, we find it likely that that the conclusion is still relevant.

Our findings are divided on whether the patients want their information about social and cultural context recorded in the journal. The cultural information was important to them, and they could see the advantages of having the cultural aspects written in the journal, rather than having to explain their whole Sámi identity over again in case of change of therapist. However, some did not always see the need for their Sámi identity to be stated in the journal. While our results were ambiguous on this point, others outside the Norwegian context have suggested that the lack of cultural identifiers in the medical health record can make it harder to offer treatment that is tailored to the needs of the patient. For instance, an Australian study reported that many indigenous patients are not correctly registered as indigenous in the national cancer registries, making it harder to route the patients to indigenous-specific health care services [25]. Transferring this argument to the Sámi context in Norway, it is likely that some Sámi patients that might have preferred treatment in an indigenous-specific health care service like SANKS, is not presented with this option. On the other hand, our results suggest that the relationship between having a Sámi identity, and the relevance of the Sámi identity when being in the patient-role is not clear. A recent scoping-review [26] argues that incorporating cultural identifiers into the electronic health record seems feasible, but careful considerations should be taken when registering sensitive non-health data. Article 9 in the Norwegian Personal Data Act prohibits the processing of information on ethnic, racial, religious, and philosophic convictions (among others)

that can be linked to specific individuals. Systematic registration of cultural aspects of patients that can be triangulated to the categories in Article 9 is therefore possibly in conflict with legal regulations. As a middle ground, one possibility is to make information about indigenous-specific health care service easily available, as well as training health care professionals to identify cultural aspects in patients, so that they are able to present patients with the appropriate services, and route the patient there if the patient prefer so.

Access to journal notes for patients with mental illness improves self-efficacy, knowledge and patient-clinician relationships, regardless of the clinical or demographic characteristics of the patients [13]. However, it has been shown that minorities, and non-native speakers, perceive the PAEHR service as especially useful, due to increased understanding of, and trust in health care staff [1]. Some aspects of Sámi culture may leave Sámi patients more vulnerable in their encounter with the health care system. As indicated by the present study, the PAEHR can add transparency to mental health treatment, and help uncover potential misinterpretations due to lack of cultural understanding.

Strengths and limitations of the study

Despite an elaborate recruitment strategy, five participants were recruited to the study. In the original recruitment strategy, the researchers planned to be physically present at Sámi venues, like musical festivals and patient organisation meetings in Sámi areas. This was planned to build visibility for the project and providing possible candidates with the opportunity to informally enquire about their eligibility with the inclusion criteria for the project. Adversity, the high mark of pandemic restrictions coincided with the recruitment period, making physical presence out of the picture. This left remote recruitment through newspaper ads, social media and posters the only alternative. This may have affected both the number of participants, as well as introduce a recruitment bias. In particular, the inclusion criteria requiring participants to "identify as Sámi in your meeting with health care services" might appear dichotomous rather than multi-dimensional and continuous when presented in written material without the opportunity to informally enquire about the meaning. We suspect that this may have introduced an unintended high threshold for participating, making only individuals that felt sufficiently Sámi sign up. The volume of the data material did not reach saturation, giving a high probability that there are perspectives and experiences that are not captured in this study. The results from this study should be regarded as exploratory, and not suitable for drawing conclusions about the larger population. However, the qualitative analysis identified themes that could be useful when designing studies to further investigate the topic.

Semi-structured interview guide

(REC START)

Note for interviewer

No disease specific information!
No identifiable information!
Is it first-hand or second-hand experiences?

Background

Age (age group: under 20, 20-30, 30-40, 40-50, 50-60, 60-70,> 70)
Location (Where are you from? Resident area?)
Background\identity\upbringing\culture (North Sámi, South Sámi, Lule Sámi)
Language (mother tongue): Do you understand Sami? Did you have the opportunity to receive Sami language training when you went to school?

PAEHR (use)

("All patients now you the opportunity to log in to helse-norge.no, have you ever logged in".)
Experience with and the perception of the PAEHR service:

- Do you use the journal access service? How much/often?
- Where did you hear about the journal access service?
- When do you use it? (after each contact with the health service?)
- How do you experience reading your medical records from psychiatry online?

Mental health

Experience from mental health care: Admission or consultations? How many years?

Relationship to health care

- Sami health personnel vs Norwegian health personnel. Have you experienced any differences in being treated by Sami/Norwegian personnel? (language)

- Would you have preferred that the medical conversation had taken place in Sami, and that the medical record had been written in Sami?
- Would you like your language and cultural background to be noted in the journal?
- How did your cultural background play into your relationship with healthcare professionals?
- How did you reading your journal online affect your overall relationship with the healthcare services?
- How did reading the journal affect your perception of the treatment process? (inside)

Contents of the journal

- Have you experienced that topics you have talked about in connection with your culture are omitted from the journal? (eg alternative medicine, family relationships, outlook on life)
- How did you feel that it was included/not included?
- Have you experienced that you have failed to tell something to your therapist because you do not want it to be written in the medical record?
- If yes: What topics have you not told your therapist about?
- Have you yourself asked the therapist not to include topics that are discussed during the treatment in the medical record? (Issues around relatives, private zone, view of life)
- What kind of topics?
- Why did you not want it recorded in the journal?
- Have you reading the medical record and got the impression that your therapist has not understood what you have said?
- What did you do with it?
- (Does the content of the journal note reflect the conversation you had with the therapist?)
- Have you experienced generalization/biases from clinicians involving your Sami identity ? If yes, is it expressed in the journal notes?

Snowballing – do you know anybody that could be relevant for this study?

Acknowledgments

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