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“All I expect is that they accept that I am a Sami” *an analysis of experiences of healthcare encounters and expectations for future care services among older South Sami in Norway*

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ABSTRACT

The aim of this study first aims to forward our empirical knowledge of how older Sami experience healthcare encounters in Norway and what they expect in terms of future care services, and second, to forward our understanding of how more culturally safe services could be offered to the Sami population, 30 years after they were officially recognised as an Indigenous People. A qualitative interpretative and constructivist research design was used. 12 older South Sami were interviewed about their experiences with healthcare encounters, and their expectations for future care services. The results showed that the participants sometimes felt deprioritised and misunderstood by healthcare professionals. Moreover, they sometimes experienced that healthcare professionals had little or no knowledge about Sami history, culture and cosmology. They worried that they would not be accepted for being Sami if one day they would have to move into a nursing home. To conclude, the participants of this study are situated in a colonising context characterised by personal and collective experiences of accumulated discrimination that have taken place over many generations. The concepts of health equity and accumulated discrimination provide useful insights in the further development of culturally safe services for Indigenous Peoples in Norway and beyond.

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Introduction

The Sami were recognised as an Indigenous people in Norway in 1990 through the ratification of ILO Convention 169 [1]. This official recognition entails that the Sami, in the same vein as all citizens in the country, have the right to equal access to healthcare services. Several studies, however, indicate that the Sami experience lower quality services than the majority population [2–6]. This is particularly due to healthcare professionals' lack of competence in Sami languages and cultures and an insufficient use of interpretation services (ibid). Moreover, when healthcare professionals fail to understand the experiences and symptoms of the Sami care receivers, this is sometimes interpreted by the care receivers as disrespectful or a failure to recognise their background and identity [5].

In a study from the South Sami context, care receivers reported that they sometimes felt powerless when meeting healthcare professionals, and that they only sought medical assistance if deemed strictly necessary [7]. South Sami care receivers in home based nursing, moreover, reported that they often felt of less value

than “the others”, e.g. the ethnic Norwegians [8]. Another study found that the nurses working in home based care in the South Sami area reported that they treated everyone the same, regardless of the care receivers' ethnic identity [9]. Regarding future home healthcare, research from the South Sami area in Sweden shows that older South Sami prefer healthcare professionals with a South Sami background who speak South Sami [10], even if this is not always considered to be the most important when receiving care [11].

Research from all over Saepmie (South Sami spelling of Sápmi) indicates that the Norwegian welfare system does not offer healthcare services adapted to Sami values and cosmology. Rather, the same standardised healthcare services developed for the majority population are offered to all [4,5,9,12,13]. However, according to international research, Indigenous care receivers often experience standardised services as lower quality services [14–17]. One reason is that the mere assumption that healthcare professionals are able to “treat everybody the same” in fact tends to “gloss over” or

even disguise the occurrence of various discrimination processes [42, p. 124]. This was confirmed in a study from Northern Norway indicating that Sami people experienced more discrimination than non-Sami [18]. The same study also found that Sami who had never learnt their mother tongue, as is often the case in the South Sami community, felt more vulnerable compared to those who spoke Sami language [18].

Theoretical perspectives and research questions

Culturally safe nursing was developed to better understand and address discrimination processes in healthcare provision [19]. The approach, originally developed among Maori in New Zealand, is based on the importance of cultural humility in the interaction between healthcare professionals and care receivers with Indigenous backgrounds. Using cultural humility in healthcare means to try to establish a caring environment “where there is no assault, challenge or denial of their identity, of who they (the care receivers) are and what they need. It is about shared respect, shared meaning, shared knowledge and experience, of learning together with dignity, and truly listening” [20, p. 213]. Cultural humility and respect are particularly important when healthcare professionals meet vulnerable care receivers [21,22]. This includes care receivers with LGBT-identity [23], persons with a migrant background [24], or persons with an Indigenous background [14,17,25]. [3] stress the need for focusing on culturally safe nursing and critical consciousness among healthcare professionals. This, according to [3], entails that healthcare professionals and healthcare systems should 1) scrutinise the “taken for granted” power structures and challenge their own cultural values, and 2) take responsibility for actual ethnic inequalities in healthcare service delivery. In these ways, the perspective of culturally safe nursing may shed light on power imbalances and discrimination processes at both the interpersonal and systemic levels.

In line with this, [26], stresses that as members of different cultural groups, all humans tend to favour their own group. Healthcare professionals, therefore, need to increase their awareness of this unconscious bias by naming it, anticipating it, and creating systems to reduce it [27]. A central concept in this regard is “cumulative discrimination”, which captures discriminatory processes occurring over time and in different contexts [28]. Cumulative discrimination, according to [21], may foster objective barriers against participation in various arenas in society, and may also increase the subjective feeling of exclusion [e.g 44] or culturally

unsafe healthcare services. Another central concept in this study is “health equity” [29] also called “substantial equality” [22], which refers to equal access of services that are provided in a manner and according to standards that meet any unique needs and circumstances such as cultural, social, economic and historical disadvantage.

In this article, we study not only the participants’ stories about their encounters with *nurses* but also those with other healthcare professionals. Therefore, rather than using the term culturally safe nursing, we will use the more generic term culturally safe healthcare encounters. Healthcare encounters may be short-term or long-lasting, brief or recurring [30]. A good healthcare encounter is often described as meeting healthcare professionals who focus on the needs of the care receivers and who are willing to include the care receivers in the decision-making process [31]. On the other hand, a lack of time in healthcare encounters may lead to a narrow focus on the disease and disease-related information, at the expense of how the care receivers can cope with symptoms [32].

Thus, drawing on rich empirical data from in-depth interviews with 12 older South Sami, this article explores the following research question: How do older South Sami experience healthcare encounters, and what are their expectations for future long-term care? The aim of this study is therefore twofold: first, it aims to forward our empirical knowledge of how older Sami experience healthcare encounters in Norway and what they expect in terms of future care services; and second, it aims to forward our understanding of how more culturally safe services could be offered to the Sami population, 30 years after they were officially recognised as an Indigenous People.

The South Sami – a brief context

The Sami population lives in a vast geographical area and numbers approximately 50,000–65,000 in Norway, 20,000 in Sweden, 8000 in Finland, and 2000 in Russia [45, p. 53]. The Sami consist of several subgroups, including the South Sami population of approximately 2000 people living in Sweden and Norway [33,34]. Each Sami subgroup has their own language and customs [35], but due to the strong colonisation process that took place from especially 1850 onwards, many Sami today have lost their mother tongue [36–39]. This is particularly the case among Sami families who live in Norwegian speaking communities in the coastal and inland areas of the country, such as the South Sami population. It is assumed that today only approximately

500 persons can speak the South Sami language in Sweden and Norway [40,41].

After many generations of harsh assimilation policies, there has been a change in the official approach since the 1980s. The Sami Parliament was established in 1989, and in 1990, the Sami were officially recognised as an Indigenous people in Norway. Currently, a public reconciliation commission is underway [42,43], but it is not quite clear whether the commission will consider only ethnically based wrongdoings that took place in the past, or if it will also examine discrimination processes that continue to take place today, including in encounters between Indigenous care recipients and professionals in the healthcare sector.

Methods

Design and choice of methods

This article is based on data from a study on ageing and care in Indigenous communities financed by the Norwegian Research Council (grant number 287301). In this article we wanted to better understand how older South Sami experience healthcare services as well as their expectations for the future. A qualitative, interpretative and constructivist grounded theory research design was used [15].

Participants and procedure

Twelve older South Sami (five women and seven men) aged between 67 and 84 years ($md = 74$) living in scattered communities in rural parts of Mid- and Northern Norway agreed to participate in this study. All self-identified as South Sami. They spoke South Sami with varying levels of proficiency (from knowing basic terms to fluency). Some participants lived with their spouse; others lived alone. All participants had a background from reindeer-herding families but had been differently engaged in the husbandry themselves. While some of them had been full-time reindeer herders, others had engaged in reindeer husbandry in a more peripheral role (e.g. helping out in the high-season when the herd is to be moved over great distances, or during slaughtering), combined with other paid jobs, e.g. as health care providers or teachers. All participants had experiences with the healthcare system as a care receiver either in the municipality where they lived (primary care services, long-term care services), at the local hospital and/or at the district general hospital for more acute conditions or illnesses. Some participants had regular check-ups in the case of chronic conditions such as, e.g. cancer or heart disease.

To gain access to the field, the first author contacted two acquaintances in the South Sami community, who provided names and phone numbers of potential participants. In addition, snowballing was used, which means that the participants themselves suggested names and phone numbers of other persons they believed would have an interest in taking part in the study [44]. Six participants were recruited via the acquaintances, and a further six were recruited by use of snowballing. When the transcripts from these twelve participants had been analysed, the research team concluded that we had a sufficiently rich data material to answer our research questions. Further recruitment was therefore not pursued.

Interviews

Semi-structured qualitative in-depth interviews were conducted. The participants were invited to talk about themselves and their experiences of getting older, focusing on how they had been met by various healthcare professionals, both in municipal primary care or long-term care as well as in specialised healthcare services in local and central hospitals. Participants also shared expectations about future healthcare services. The interviews took place in the participant's own house, except for one participant who wanted to be interviewed in a café. During 3 of the interviews, the spouse was present. Whether the spouse was present or not did not seem to influence what was shared during the interviews that lasted from 47 minutes to 3 hours and 23 minutes ($md = 2.06$).

Data analysis

After transcriptions, a reflexive thematic approach was used to analyse the data [45,46]. In the following we will explain how the analysis was conducted to allow the readers to assess the trustworthiness and relevance of the findings [47]. First, the authors individually read the transcripts noting themes that attracted our attention. Second, the author team met on Teams to discuss the preliminary findings. A constant comparison of the data was done until we reached an agreement of the following themes: 1. Ambivalent healthcare encounters with the subthemes 1.1 "Sometimes we feel deprioritised", 1.2 "Sometimes we just don't understand each other" and 1.3 "They don't know anything about us"; and 2. Future expectations about healthcare services in the municipality with the following subtheme 2.1 "I hope they will accept me" as elaborated in the following. Our preliminary data analysis with themes was then presented and discussed with members of the South

Sami community by the first author. The community members found the data analysis interesting and recognised our preliminary findings. Thus, encouraged by the community members, we continued our analysis in the same vein.

Ethical considerations and roles in the research team

Informed written consent was obtained from all participants before they took part in this study. The participants were informed that they had the possibility to withdraw from the study at any given time. Moreover, they were guaranteed confidentiality. Thus, to secure the confidentiality of each participant, all healthcare professionals are referred to as he/him, while all participants are referred to as she/her. The study was approved by the Norwegian Centre for Research Data (project number 577949). While the first author collected the data and transcribed the interviews, the analysis, writing and revisions were done in close collaboration between both authors.

Findings

Ambivalent healthcare encounters

Sometimes we feel deprioritised

Let us start by emphasising that several of the participants shared positive stories about healthcare encounters. Some of them had met healthcare professionals who had sufficient time for them, who listened and were interested in them. These positive healthcare encounters took place both in the municipal healthcare services and/or at local or central hospitals. When the participants experienced that the healthcare professionals were nice and respectful, they felt safe and well taken care of. A particularly positive relationship with a general practitioner (GP) was described in the following way:

- P: I have a fantastic GP, and he is Norwegian!
 I: You must tell me about him and why he is fantastic.
 P: I can talk with him about everything, he has time to sit and listen to me. After I got my disease, he said I could just come to him and talk when I wanted. I do not think many GPs says that. (...) He gives me time when I need it.
 I: Does he know your background?
 P: Yes, he does, and I would say that is fantastic. He let me come when I want, it is like coming to my brother. We can talk about anything.

In the citation the participant noted that her GP was Norwegian. He was very nice, because he was always available, and she was always welcome to talk about what was on her mind.

Moreover, some of the participants shared that they had experienced healthcare professionals who had called them by phone after a screening, surgery or treatment to provide important information, or just to check up on their patient. Thus, one participant said: "After I had finished the treatment in the hospital, the physician called me to ask how I was doing. I was told by someone that this physician used to call the patients he had treated". Getting personal phone calls from busy hospital physicians certainly created a feeling of being important and valued. A couple of the participants living with a severe disease even reported that they had direct access (a hotline) to the hospital.

However, while several of the participants had experienced positive healthcare encounters, some of them shared that they oftentimes felt deprioritised in healthcare

encounters. Feeling deprioritised occurred in various situations, for instance when healthcare professionals only had limited time to listen to them, or limited time to provide the information they would have needed to feel comfortable about their health situation. One of the participants said:

I get the impression that physicians today are so busy, they want to conduct as many consultations as possible, and they don't even have time to look up from the computer. They hardly look up. Who wants to talk to a physician who doesn't have the time to listen?

Another participant shared an uncomfortable experience when she had arrived a few minutes late to an appointment. She had even called the office from her cell phone to notify the secretary that her bus was delayed, but when she arrived, the GP met her with anger. She explained:

So there came this furious GP, making it clear to me that I was too late for the appointment. 'Well, I have phoned to notify', I said, but he wouldn't listen. When I got into his office, he did not let me talk or explain; 'He wanted silence when he worked' he said. (...) I was not allowed to speak to him, that was obvious. He made that clear!

The participant decided never to see that GP again.

Another theme that created a feeling of being deprioritised was when the hospital had forgotten to call them in for regular check-ups in the case of chronic conditions such as, e.g. cancer or heart disease. One participant explained:

I am supposed to be called in to the hospital for check-ups every 3 months. But on several occasions, I haven't heard anything from them after 3 months. So then, after another 2 months I call them and ask for the appointment myself. Yes, I have done that several times. And sometimes they seem a little bothered. Like: 'Are you supposed to be called in for a check-up now?' Yes, I say, that is for sure! I am waiting for the letter from you!

On one occasion the participant had been forced to ask her GP to request a check-up. When she finally received the screening, her condition had worsened. The participant commented: "That was a wakeup call for them, so now they have sharpened up. Now I always get my check-up appointments (from the hospital) in time".

Sometimes we just don't understand each other

Understanding the healthcare professionals was described as a challenge by some participants.

A participant said that there had been many GPs in their municipality over the years, and added: "I wouldn't say that is an issue for me, but there are some GPs you wish to see, and others you don't wish to see, if you know what I mean?" Several of the participants said the same: they wished to see a GP that they could understand and that understood them in return. In this study, unlike the situation in the northern part of Saepmie, e.g [5], interpreters were not mentioned as something they needed. However, it should be noted, as described above, that a lack of time or stress in healthcare encounters could prevent patients from being able to explain their symptoms or from understanding the explanations provided by the medical staff.

Moreover, and related to this, the participants explained that when they had met healthcare professionals that understood them and expressed care for them, they had sometimes chosen to travel quite far to see exactly this GP or specialist nurse, even if they were situated more than two hours' drive away. Thus, one participant said:

I do not have a GP in my municipality, because the GP I had was all over the place. One moment he was here, another moment he was taking shifts in the hospital, so I never knew when I could see him. (...) Then I met a GP who worked in another municipality, I asked him; 'Do you have the possibility to put me on your list?' He said yes. So now I have had the same GP for years (even if it is a long ride).

Others had chosen to keep their GP after their GP had moved to work in another municipality relatively far away. One participant said:

I have been with the same GP for years. Actually, when he moved to another municipality I asked if he could still be my GP because he knew me so well. And he agreed. You know, I couldn't bear (the idea) to tell my life story over and over again. I have kept this GP ever since.

They don't know anything about us

The most ambivalent aspect related to healthcare encounters described by some participants, however, was not related to feeling deprioritised or misunderstood. Rather, the most acute challenge was related to the awkward situation created by healthcare professionals knowing little or nothing about Sami culture and history. One participant illustrated this by saying:

I talked South Sami to my son when he was hospitalised. One healthcare professional overheard the conversation and asked what language I was talking. I replied that I was talking Sami. 'Oh, where in Finnmark (northernmost part of Norway) are you from?' he asked. I explained that we came from not far away. And he was Norwegian! Like, he was a clever and efficient healthcare professional, but he didn't even know that the South Sami population lives around here (in the local area).

Thus, although the participants highlighted that they did not expect that healthcare professionals to have in-depth knowledge about the Sami people and their history, some of them argued that the government should make sure that all citizens in Norway receive basic insights about Sami culture and the colonisation process that took place from 1850s onwards, to enable future healthcare professionals to become a little more knowledgeable. The need for increased insights about Sami history is illustrated in the following quote:

I went to a psychiatrist because I was a little depressed. My physician sent me. It had been a hard winter for me. My physician meant it would be nice for me to sort things a little bit out. When I came to the psychiatrist, he wanted me to talk about my childhood, because he thought that was where the dog was buried. So, I told him about my childhood and that I had grown up in a gamme. 'That was interesting', he said.

The participant explained that the next time she came to see the psychiatrist, he wanted to hear more about her childhood, and details about everyday life in the gamme, which is a traditional Sami hut made of turf, as well as about her experiences with being sent to the boarding school. She felt a bit uneasy about his interest in her childhood but continued to answer his questions. The third time she came to see him, however, she was really eager to go forward, but the psychiatrist persisted in asking questions about the gamme and the boarding

school. The participant then became upset and asked the psychiatrist: “How much do you know about the Sami people? How much did you have about this during your education?” Not much, he admitted. The participant exclaimed that clearly, he had learnt nothing at all about the Sami during his education, and added to the researcher, that the psychiatrist was not going to do research on her! And with those words, the therapeutic relationship was ended.

Future expectations about healthcare services in the municipality

I hope they will accept me

Regarding future healthcare services, participants shared that they were a bit worried about whether they would receive home based care services according to their needs. In particular, several shared that if they one day would need to move to a nursing home, they feared that they would not be accepted for being Sami. For example, would they receive the food they were accustomed to eating? In case of dementia, would they lose their ability to speak the majority language (Norwegian)? And if they did: Would anyone among the staff in the nursing home be able to talk with them in their mother tongue? Would the healthcare professionals ensure they could listen to Sami news or Sami TV? And would they have the Sami flag placed on their table on the Sami national day? Several of these concerns are illustrated in the following citation by one of the participants, who said:

If I have to be hospitalised due to a bone fracture or a heart attack, I have trust in the healthcare system. But if I end up in a nursing home, sitting there helpless, would the healthcare professionals understand my needs or would they treat me as anyone else? Like, would they help me so that I could hear Oddasat (Sami Radio and TV) or remind me of the 6th of February (Sami national day)? Would they make an effort on that day for me? Would they let me have some Sami literature? And what if I lose my language (Norwegian)?

As we can see from this citation, the participant had no worries if she would need acute assistance in the hospital. That was the same for the other participants in this study. Their worries were related to municipal long-term care, where the relational and cultural competence is of particular significance. Moreover, what the participants hoped for was to meet healthcare professionals that had time for them, both to listen and explain what needed to be explained. Being treated “as a normal person” was also mentioned by participants, as illustrated in the following citation:

- I: What do you want from the healthcare professionals if you would have to move to a nursing home sometime in the future?
- P: I don't want to move to a nursing home ... // ... Or, maybe they are better now, and a little more updated. Well, then, I hope that they will treat me as a normal person.

Another participant said that if she had to move to a nursing home, her hope was “to be treated respectfully and that I meet gentle and nice people, and not only that, but that they are professional”. A third participant expressed a similar hope in the following way:

- I: We have talked a little bit about the future, but I wonder if you could say something about your dreams for the future if you should need healthcare services?
- P: I hope I can get peace in the healthcare services, and that I meet professionals that know how to perform their profession and not base the services on myths and rumours.
- I: That they have knowledge about being a Sami?
- P: That is too much to ask for, but that they accept me.

Discussion

This article examines how older South Sami experience healthcare encounters and their expectations for long-term care. We found that despite the ratification of the ILO convention by Norway in 1990, healthcare encounters are still experienced as culturally ambivalent by South Sami care receivers. The participants shared that they sometimes felt deprioritised or misunderstood in healthcare encounters. The concrete challenges described were that healthcare professionals often did not have enough time for them, or that the hospital sometimes forgot to call them in for the check-ups required for chronic health conditions. Further, some participants reported that it was sometimes difficult for them to understand healthcare professionals. Therefore, when the participants met a “nice” GP or nice specialist nurse, they would make considerable effort to see exactly this healthcare professional even if located geographically far away. It should be noted that the lack of time during healthcare encounters has also been reported by patients of majority background [48], as well as by North Sami care receivers [5]. A study from Sweden, moreover, found that care receivers were often dissatisfied with the communication by healthcare professionals in primary healthcare centres as well as in hospitals, especially when they were met with a lack of empathy [30].

However, the participants, in addition to these general challenges, also experienced challenges that were more directly related to them being Sami; some shared that they felt that healthcare professionals did not know anything about the Sami culture or about the colonial history, and that as a consequence, they were sometimes met with ignorance or prejudice. The lack of knowledge of Sami history, culture and lifestyle among healthcare professionals has also been identified in other studies [49,50]. Meeting healthcare professionals with little or no knowledge about Sami culture and history may incite a feeling of inferiority amongst Sami people compared to ethnic majority Norwegian patients. This finding can be understood with the reference to the concept of cumulative discrimination [28], which reminds us that when a person, her family or community, has experienced various forms of exclusion or marginalisation over generations, previous experiences may frame the understanding of emerging events. A lack of awareness of Sami history may be experienced by the Indigenous person as sign of continued marginalisation. Thus, to achieve health equity, healthcare professionals need to be aware of how healthcare encounters are shaped by the care receivers' previous and prevailing experiences of subordination in the wider society. It is also important to note that idea of "standardised services" may contribute to masking discriminatory practices for patients with unique needs. These findings support previous research indicating that standardised healthcare services adapted to the majority population are often experienced as lower quality services among Indigenous patients [4,5,9,12–14,16,17].

Regarding the participants' hopes for the future, their main message was that they wished that they would be "accepted" and "respected" as a Sami, e.g. be served the food they were accustomed to eating, be able to celebrate important Sami events, and be allowed to listen to Sami news on the radio.

Conclusion and implications for the practice field

In line with [3], we argue that to achieve culturally safe healthcare encounters and health equity for all, healthcare professionals should challenge their own cultural values and beliefs. Increased awareness about our taken-for-grantedness increases the ability to tune into and be empathetic to the care receiver, which helps us realise that the ideal of treating everyone the same may cause blindness towards the discrimination processes that occur.

It is important to confront historical wrongdoings and to contribute to positive change. As a means in this regard, a framework aiming to promote culturally safe healthcare

services for Sami people in Norway is currently being introduced in the curriculum of 16 bachelor's and master's programmes such as medicine, nursing, and social work (e.g. Regulations on common framework for health and social care educations, 2017; Regulations on national guidelines for medicine education, 2020; Regulations on national guidelines for nursing education, 2019). We hope that this framework will constitute an important step forward towards more culturally safe healthcare encounters and increasing health equity, where Sami care receivers feel recognised and fully accepted for who they are.

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Authors' contribution

The work presented was carried out in the collaboration between Tove Mentsen Ness and Mai Camilla Munkejord. The first author has done the interviews and transcribed the interviews, but the analysis has been done in close collaborations between the two authors. Both authors have also contributed to the writing of the manuscript. The work has not been published and is not being considered for publication elsewhere.

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