Indigenous life stories; narratives of health and resistance

Title: Indigenous life stories – narratives of health and resistance. A dialogical narrative analysis

Blix, B.H., Hamran, T., & Normann, H.K.

Preprint version of manuscript published in CJNR 2012, Vol. 44, Issue 2, 64-85

Running title: Indigenous life stories; narratives of health and resistance

We certify that the submission is original work and is not under review at any other publication. There are no conflicts of interests or financial interests to report.

Abstract

The Sami people have historically been exposed to sevel assimilation processes. The objective of this study was to explore elderly Saint's experiences of health. Nineteen elderly Sami individuals in Norway were interviewed. This paper is a dialogical narrative analysis of the life stories of three Sami women. The life stories are perceived as narratives of health and resistance. Postcolonial theory provides a framework for understanding the impact of historical and socioeconomic factors in people's lives and health. Narratives of resistance demonstrate that people are not passive victims of the legacy of colonialism. Resistance is not a passive state but an active process, and so is health. The resistance is a resource that should be appreciated in health care services, both at a systemic level, e.g. through authentic pathership with indigenous elderly in planning and shaping of health care services, and in individual encounters between patients and health care providers.

Key words: Indigenous people, Sami, health, resistance, postcolonial theory, dialogical narrative analysis.

Introduction

While performing research in the field of indigenous people and health, one frequently encounters a distinct tendency in research literature and theorizing. This is the commonly held view that "cultural competence" is of great significance in the interactions between health care providers and "minority patients". This view is described as an emerging "mantra of contemporary nursing practice" (Dreher and MacNaughton 2002). Over the last decades matters of culture, health, and health care have been discussed extensively in the literature (cf. Vandenberg 2010). The focus on cultural competence is also reflected in various official government documents (e.g., US Department of Health and Human Services Office of Minority Health 2001; Romanov 2002; Joint Commission on Hospital Accreditation 2008) and in the education of health care providers (Office of Minority Health 2002; Ring, Nyquist and Mitchell 2008; Like 2011; Mancuso 2011). In our offician, the focus on cultural competence is too narrow, and it has several implications. Culture appears to be perceived as something relevant only to people differing from the majority. Furthermore, the focus on culture might divert attention away from the broader historical and social contexts that influence people's health and the experiences with health care services.

This paper is based on a qualitative study of elderly Sami individuals' experiences of aging, health, and illness. Through the presentation and discussion of three elderly Sami women's life stories, we illuminate how the history of colonization is present in the elderly women's lives and impacts their health experiences. We demonstrate how elderly women, while telling their stories, actively engage with the impact of history on their lives and health. We argue that an acknowledgment of health as an active engagement with history renders the focus on "cultural competence" in health care too narrow. The paper starts with a brief presentation of the Sami and an outline of some significant events in the history of the Sami in the Norwegian national state. This is followed by a short presentation of research regarding

the Sami and health issues. We next present some central key concepts, including life story, health, postcolonial theory, and narratives of resistance. This is followed by a description of the research method and methodological considerations. Subsequently, the life stories of three Sami women are presented and discussed. We argue that understanding health as a condition of subjectivity and as influenced by broader historical and social contexts is necessary to gain a richer understanding of indigenous people's health.

The Sami

The Sami are an indigenous people living in Norway, Sweden, Finland, and Russia. The Sami population is estimated to be between 50,000 and 80,000 (Sámi Institutat Nordic Sami Institute 2008). The vast majority of Sami live in Norway. Statistics Norway estimates the Sami population of Norway to be 40,000 individuals. Historically, the Sami were reindeer herders; and small-scale farmers, and fishermen. Today approximately 10% of the Sami in Norway are occupied in the traditional ways of tiving (Statistics Norway 2010). A report from the Sami Language council in 2000 estimates that there are approximately 25,000 Samispeaking persons in Norway (Ministry of Local Government and Regional Development 2001).

The national states have made strong efforts to assimilate the Sami into the majority population. In Norway, the process of assimilation, frequently referred to as "Norwegianization", lasted from 1850 to approximately 1980. According to the *Land Act* of 1902, preferty could only be transferred to Norwegian citizens (i.e., persons capable of speaking, reading and writing Norwegian), and proficiency in the Norwegian language continued to be a criterion for buying or leasing state land until the 1940s. The Sami language was prohibited in Norwegian schools from 1860 until 1959. The residential schools were important arenas for the Norwegianization of Sami children. The assimilation process was paralleled by individual experiences of stigmatization and discrimination (Minde 2003).

During the 1950s, a growing Sami movement initiated an ethnic and cultural revitalization process. The establishment of a general education based on the Sami language and culture was of great importance to the Sami movement (Eidheim 1997). During the 1970s and 1980s, an "aboriginalization of Sami ethnopolitics and self-understanding" occurred (Eidheim 1992; Thuen 1995). The Sami movement established contact with organizations representing indigenous people in other parts of the world. The general increase in living standards and improvements in the welfare and health care systems in Norway during the 1960s and 1970s contributed to the ethnic revitalization process.

The public assimilation policy culminated in 1980 with *the Alta affair*, in which the Norwegian state decided to dam the Alta-Kautokeino watercourse despite considerable protest from the Sami, who argued that the damming would threaten the grazing areas and calving places used by the reindeer-herding Sami. This dispute brought national and international attention to the rights of the Sami. In 1989, the Sami Act was enacted (Ministry of Government Administration Reform and Charch Affairs 1987) to enable the Sami people in Norway to safeguard and develop their language, culture, and way of life. The *Sami Parliament* was subsequently established in 1989. The Norwegian government ratified the International Labour Organisation (ILO) Convention No. 169 (International Labour Organisation 1989) (in 1990).

In many communities, especially those outside the *Sami core areas*, the differences between the Sami and the Norwegians are not always obvious (Kramvig 2005; Olsen 2010). The coastal Sami population was strongly affected by assimilation and stigmatization. In these areas, fewer people speak the Sami language, and people might not possess or identify with symbolic expressions of a collective Sami cultural heritage. To some people in these areas, "Saminess" is considered to be part of the distant past and seemingly of little relevance in their present, everyday life (Gaski 2008; Olsen 2010). Today's elderly Sami have lived their

lives in this area of tension between assimilation, revitalization, and ambiguity. Considering the history of assimilation, stigmatization, and discrimination, it appears reasonable to assume that a Sami heritage contested throughout a lifespan might be of significance to health and well-being in old age. As noted by Minde (2003: 141), "'the Sami pain' ... may have been widespread among those who were in opposition, but probably even more deep-felt and traumatic among those who tried most eagerly to adapt to the assimilation pressure".

Previous research

Previous research on health issues among the Sami has primarily been quantitative, and results for the Sami are often compared with results for the majority population. The focus has been on health behaviour (e.g., Spein, Sexton and Kvernmo 2004 Spein 2008), risk for disease (e.g., Hassler 2005; Nystad, Utsi, Selmer, Brox, Melhus and Lund 2008) or causes of death (Hassler, Johansson, Sjölander, Grönberg and Danber 2005). Research suggests that the Sami do not face the same health-related challenges as other indigenous people in Canada, the United States, Russia, or Greenland (Symorand Wilson 2009). Many health problems faced by indigenous people in the circumpotar region, such as an increased risk of diabetes, cardiovascular diseases, infectious diseases, and lung cancer, are not prevalent among the Sami (Hassler, Kvernmo and Kozlov 2008). Life expectancies at birth are virtually the same for the Sami and the non-Sami, and the mortality rates for specific causes are quite similar (Hassler et al. 2005; Brustad, Pettersen, Melhus and Lund 2009). Some researchers (Gaski, Melhus Deraas and Førde 2011) have attributed the apparent absence of health differences between the Sami and the Norwegian population to the assimilation process, as though health equity was a positive side-effect of assimilation. We believe that the causal relations are more complex. In Norway, health services are largely public, which might facilitate higher levels of access to health services (Hassler et al. 2008), and the living standards are generally high in Norway.

Regardless of statistics showing no health differences between the Sami and the majority population, research has identified several health-related challenges. Sami-speaking patients are less satisfied with the services provided by municipal general practitioners (Nystad, Melhus and Lund 2008), and a study of mental health care revealed that the Sami patients were less satisfied with treatment, contact with staff, and treatment alliance than Norwegian patients (Sørlie and Nergaard 2005). Self-reported health is worse for the Sami than the Norwegian majority population. This difference is most significant in Sami women living outside the Sami core areas (Hansen, Melhus and Lund 2010). Sami individuals are more likely to experience discrimination and bullying than the general population in Norway (Hansen, Melhus, Høgmo and Lund 2008), and discrimination is strongly associated with elevated levels of psychological distress (Hansen and Sartie 2012). These findings suggest that merely looking at statistics regarding life expectancies, mortality rates, and disease incidences may be insufficient when grapping with issues regarding the Sami people, health, and health care.

With the exception of quantitative measures of self-reported health as "poor", "not very good", "good", and "very good" (Hansen et al. 2010), we did not identify any studies that explored the experiences of the health of the Sami people. In the present study, we explore the life stories of elderly Sami as sources of insight regarding their perceptions of health. Frank (2006: 434, italics original) states that "(p)eople understand themselves as seven through the stories they tell and the stories they feel part of. Stories about *health* are, sooner or later, stories about the contemporary shaping of that particular human aspiration, being a *healthy self*".

Life stories, health, postcolonial theory, and narratives of resistance

In the present study, life stories were defined as the stories people tell about their lives in the context of the qualitative research interview. The plural form, "stories", was used intentionally to emphasize both that an individual always has many life stories and that the stories they tell do not necessarily constitute one continuous and coherent *life history*. A dialogical perspective, such as the one pursued in the present study, enables the possibility of multiple truths about lives. Riessman (2008: 8) reminds us that "we revise and edit the remembered past to square with our identities in the present" and that "stories must always be considered in context, for storytelling occurs at a historical moment with its circulating discourses and power relations". This plurality of truths and stories is not considered a problem in the present study but rather an opportunity for further understanding.

According to the philosopher van Hooft, health on experience and a condition of subjectivity, which he defines as "the pre-intentional activity of constituting oneself as a self" (van Hooft 1997: 24). The material dimension of health refers to all of the processes of an organism that are necessary for biological life, such as respiration, circulation, and metabolism. The pragmatic dimension of health is about everyday practical concerns and the activities in which we engage. The conative dimension of health is about our "reaching out of subjectivity towards the world and others" (van Hooft 1997: 25) through care and desire.

Finally, the integrative dimension of health is about striving for meaning; the "need to give our lives a structure analogous to the narrative form of a history" (van Hooft 1997: 26). The nation of health espoused by van Hooft as a condition of subjectivity justifies an interest in life stories as sources of insight regarding perceptions of health. Life stories reflect all four of van Hooft's dimensions of health, the integrative being the most obvious. In addition to providing life structure, life stories are about something: everyday life, care, and desire.

Furthermore, life stories are embodied; they are about bodies, and they are told through

bodies. However, studies suggest that health inequities between "ethnic" or "cultural" groups are largely consequences of socioeconomic differences (Ahmed, Mohammed and Williams 2007). By exclusively focusing on health as a condition of subjectivity, we risk ignoring the impact of historical, social, political, and economic factors on people's health.

Postcolonial theory provides a framework for understanding how people's health is closely related to historical, social, political, and economic factors. Browne (2005: 69) some up postcolonial theory as "a body of critical perspectives that share a political and social concern about the legacy of colonialism, and how this legacy shapes relations at the individual, institutional, and societal levels". Critics of postcolonial theory have pointed to a tendency to focus on the presumed shared experiences of colonization among group members and a tendency to overlook the agency of "the oppressed" (cf. Browne, Smye and Varcoe 2005). In the present study, however, we particularly focus on the agency of "the oppressed" by studying the life stories of elderly Sami. Based on the material presented, we argue that there is no contradiction between perceiving the elderly Sami as active and engaged while simultaneously acknowledging the impact of a history of colonization on their lives. Several scholars (e.g., Stone-Mediatore 2003; Mishler 2005) have advocated considering "marginal experience narratives" that might function as narratives of resistance. Stone-Mediatore (2003: 9) argues that stories of marginalized people "precisely by virtue of their artful and engaged elements, can respond to the inchoate, contradictory, unpredictable aspects of historical experience and can thereby destabilize ossified truths and foster critical inquiry into the uncertainties and complexities of historical life". We assert that the stories presented in this paper can be regarded as narratives of resistance.

Methods

Participants and recruitment

The nineteen participants in the present study were between 68 and 96 years old, considered themselves to be Sami, and were experiencing various health problems. There were eleven women and eight men. One participant lived in a nursing home, three lived in assisted living facilities, and fifteen lived in their own homes with or without help from home-care services. The participants were living in two municipalities in the two northernmost counties of Norway. Both municipalities have ethnic composite populations. One municipality is part of the Sami *core area*, and the Sami constitute a considerable proportion of the population. The other municipality is not considered part of the Sami core area, and the Sami are a small minority in the community.

The participants were primarily recruited in two ways: through managers for local nursing homes and home care services or through tocal senior associations. Written information letters in both Sami and Norwegian languages were distributed, and people interested in learning about the study and possibly participating sent their written consent in postage-paid envelopes. After receiving the consent letters, we contacted the individuals to provide additional information regarding the study and to make appointments for interviews. Initially, 22 people agreed to participate in the study. Three people were excluded due to doubts regarding their ability to provide informed consent.

Interviews

Appenatic interview guide was used in the interviews. All of the interviews started with the interviewer inviting the interviewee to tell about her or his life in the manner of her or his choice. The interviewer was conscious not to interrupt the stories, but the interviewees varied in the manner in which they told their stories. Some subjects spoke continuously without solicitation; others needed assistance, including more or less specific probes to help them

continue with their stories. The interviews moved thematically back and forth between stories about the past, reflections on the present, and thoughts about the future. The interviews were conducted either in the homes of the interviewees or in the nursing home / assisted living facilities where they lived. The interviews lasted between 45 and 150 minutes and were digitally recorded.

Ethics

The study was approved by the Regional Committee for Medical Research Ethics. The interviewees were limited to persons capable of giving informed consent. The participants were informed about their right to withdraw from the study without stating a reason and were assured confidentiality.

All interviews were conducted in the Norwegian language. Sami was the first language for all interviewees from the Sami core area and for one interviewee from outside the Sami core area. Norwegian was the first language for nine of the interviewees from outside the Sami core area. Seven of the Sami speaking interviewees reported speaking Norwegian fluently and maintained that it was not problematic to be interviewed in Norwegian. However, three of the Sami-speaking interviewees did express concern about whether they would be able to express themselves satisfactorily in Norwegian. These concerns were expressed when the interviewer, upon receiving consent letters, made initial contact to make interview appointments. The interviewer then offered to use an interpreter, but the interviewees all chose to do the interviews in Norwegian. In retrospect, we realize that the interviewer should have offered to use an interpreter in *all* interviews with Sami-speaking interviewees. We have reflected on how interviews not conducted in the first language of the interviewees may have affected the material. This shortcoming may have influenced *how* the interviewees told their stories because the first language is usually richer in details and nuances than languages acquired later in life. It may also have influenced *what* was related in

the interviews. A Norwegian-speaking interviewer might be perceived as a representative for the majority society, which in turn might contribute to a distance between the interviewer and the interviewee. Before the interviews, we were concerned that this perception would keep the interviewee from addressing issues such as assimilation and minority experiences. While this problem may have occurred, interview material rich with descriptions and stories concerning these issues also suggests that it might not have had a significant impact. The interview material indicates a great willingness among the interviewees to share their life stories.

During or after the interviews, all of the interviewees expressed appreciation for being interviewed on this matter.

Dialogical narrative analysis

The digital sound files were transcribed verbatim. Field notes were recorded and used at several stages in the research process. Following transcription, the tapes were re-played, the transcribed texts were re-read to allow the researcher to become re-acquainted with the material, and summaries of every interview were written. Following this phase, we returned to the transcribed interviews and began carching the material for stories. The interviewer noticed some stories during the interviews, and some became evident during the transcription process. However, more subtle stories, some of them amounting to only a few sentences, were revealed through this purposeful reading. As noted by Riessman (2008), the stories in a text often do not have clear-cut borders, and the researcher participates in the creation of stories, rather that finding" them in the interviews, by deciding what to present as stories.

The stories in the present study were created in the context of the qualitative research interview, and the stories should be considered neither as direct representations of historical events nor as direct reflections of the identities of the participants. The stories are "acts of engagement with researchers" (Frank 2005: 968) and they are designed for particular

recipients (Riessman 2008). The stories developed from the dialogue between the interviewer and the interviewee. This dialogue continued into the further analysis.

Given the scope of the present study, exploring elderly Sami individuals' experiences of health through the stories they told about their lives, a dialogical narrative analysis, as suggested by Frank (2005; 2010, 2012), appeared to be a suitable approach. According to Frank (2010: 71), dialogical narrative analysis "studies the mirroring between what is told in the story – the story's content – and what happens as a result of telling that story – teseffects". A dialogical narrative analysis is not about locating themes as finalizing descriptions or statements about who the research participants are. Rather, it is about representing individual struggles in all of their ambivalence and unfinalizability (Frank 2005). A dialogical narrative analysis is about treating stories as actors. The analysis is narrative not because the stories are the data but because we study *how stories act*. Frank (2010) poses several questions that initiate the analysis by calling attention to *what the stories do*: What is at stake for whom? How does the story and the particular way it is told define or redefine those stakes, raising or lowering them? How does the story change people's sense of what is possible, what is permitted, and what is responsible or irresponsible? Keeping these questions in mind, we turn to the stories.

Results

The three particular stories chosen for focused attention in this paper are not representative in the "statistical" sense of the word. They were chosen because of their particular clarity and distinctness with regard to the issues discussed in this paper: elderly people's experiences of health as expressed through their life stories and their active engagement with colonial history in the telling of their life stories. As noted by Frank (2012), the selection of stories in dialogical narrative analysis is based on what has been learned during the research process, even if a considerable part of this knowledge remains tacit to the researcher. In this

perspective, the interpretation and discussion of the three stories is informed by the knowledge developed through engagement with the stories of the other interviewees in the study.

Inga: Born in a turf hut

Inga is a woman from a reindeer-herding family from the core Sami areas. She says that she has been trying to live as decently as possible all her life to show that the Sami are not inferior. She says: "Perhaps people think that the Sami are not as good as other people. I think that this is because they don't know better." However, Inga does not think that all Norwegians perceive the Sami as inferior: "A lot of Sami girls marry Norwegian men. Perhaps the men that are marrying Sami girls don't see the Sami as bad."

Following this statement, Inga starts telling the story about her own birth. She was born in approximately 1920 in a turf hut of the type reindeer herders used intermittently while attending their herds. In addition to her mother, her father and her grandmother, several other people were in the hut at the time Inga was born. Inga's parents were sleeping on the floor when her mother went into labour. Inga relates:

"Then, my grandmother and, 'What is going on? The house is crowded!' Then, my father replied, 'We are trying to bring a new human being into the world.' There was a fireplace there and there was a fire in there. They had just cooked some meat. There were a lot of Sami people there. My father just threw away the meat broth and put water into the pot to heat it. Then, I was born. My father cut the umbilical cord. And my father washed me. It was my dad that washed me! Two waters: the first water he threw away and then another water. And my grandmother lay on the bed. They put my mother on the bed and me next to her. We stayed there for a couple of weeks before they drove away. It was just a hut of the kind the reindeer herders used. There I was born. There were no white clothes and... (*Laughs*). It was my father who delivered

me. And he almost washed me in meat broth... *Vuoi vuoi!* And I became human, too! Nowadays, the clothes are so white. Everything is so white and clean. But I was born there (*Laughs*). And I was healthy! I have never been sick. No nuisances. ... I am not sick, and I have had children myself. Lots of children. And they came so easily. That's how it is!"

Inga attended residential school as a child. She says: "We had to go there - the Sani kids. Luckily, I knew the language before I went to school." If the teachers heard the children speak Sami, they told the children not to. Inga tells a story about a teacher from the South that wanted to bring Inga with her to the South:

"There was this older teacher. She came all the way from the South. ... She had no children of her own, and she wasn't married either. She wanted to bring a Sami child to the South, to let the child go to school there. And she would pay for school for this child. I... if I would come with her, I would have my own room, and she would buy me clothes and everything. She promised. And I was so happy! I could go there and attend school! But, when I went home and told what the teacher said... 'She wants to take me there, so I can leave.' I can go to school there – there are lots of schools there.' At first my mother didn't say anything. Then, she said: 'You will learn to sew Sami boots (skallar and all Sami clothes. That's enough school for you!' She said that she would teach me to sew Sami clothes and that I would marry a Sami man, a reindeer hear. 'No, I don't want to get married. Never!', I said. I told the teacher 'You have to talk to my mother!' But my mother said no. 'Inga is not going anywhere! She will learn to sew Sami clothes, and she will marry a Sami man with reindeer.' And so it was. I was really angry with my mother. I cried and cried, but it didn't help. The teacher took another girl, from the orphanage. ... My mother said: 'You can live from

sewing Sami clothes. Not everybody can do that! But *you* can learn to do it.' (*Pause*)

And so it was."

There is an undertone of vulnerability in Inga's stories. In her own words, *all her life*, she has been conscious about her conduct, trying to prove wrong those who think Sami people are inferior. The vulnerability contained in her lifelong fight for equality emerges in a statement such as "I became human too". This is an individual expression of the history of assimilation. The story about the teacher, who wanted to "save" her by taking her away from her parents and give her the type of education, clothing, and housing that was valued in the majority society, is likewise an individual history of colonization.

Inga's stories are indeed individual expressions of the colonial history of assimilation of the Sami, but they are simultaneously narratives of resistance. Through her birth story, Inga resists the standards of the majority society "where ever thing is so white and clean". The majority society is represented by the missing "white clothes" and midwife, but none appear as missing at her birth. The birth story brings force and energy into Inga's lifelong project of proving the majority wrong. The turf flut, the delivery on the floor, and, perhaps most strikingly, the meat broth bring to mendous force to Inga's story. The statement, "It was my father who delivered me, and he almost washed me in meat broth," adds strength to Inga's story.

The story about the teacher from the South is also a narrative of resistance. In this story, it is inga's mother who represents the resistance. One aspect of this resistance is the mother forbidding Inga from going to the South with the teacher, but she also opposed the teacher. Given the historical and social circumstances, the power relations between a Sami woman and a teacher from the South, the mother's statement "Inga is not going anywhere!" is a strong expression of resistance. Inga is making her mother's resistance her own by telling about it in her life story. The tension between the majority society represented by the teacher

and Inga's mother's resistance is expressed through several binaries in the story. The teacher's tempting offer about school is opposed by the mother's "You should learn to sew Sami boots and all Sami clothes. That's enough school for you!". Furthermore, the teacher's enchanting promises about manufactured clothes is opposed by the mother's "Sami boots and Sami clothes". And in Inga's stories the prospect of having a room of her own is opposed to the crowded turf hut at her birth. Inga lets her mother have the final upper hand through the statement: "You can live from sewing Sami clothes. Not everybody can do that! But you can learn to do it." In this statement Inga, through the voice of her mother, expressed the privilege of being a Sami. Anyone could go to schools and wear manufactured clothes, but not everybody can learn to sew Sami clothes. Through the birth story inga's resistance against being inferior is expressed in the narration of her *healthy self*. The apparently frail elderly woman, nearly blind and barely able to walk, states: "Lam not sick, and I have had children myself. Lots of children. And they came so easily. That's how it is!"

Laila: Does not want special treatment

Laila was born in the early 1930s. She grew up with seven brothers and sisters in a remote area on the coast. "It was a lonely spot. You had to go there by boat." She had a hard childhood, losing her father and a brother to the ocean when she was only seven years old. Laila has a congenital physical handicap, but she says: "When everything works up here (points to her head), it is okay."

"Year't complain about school. Lots of people do, but I can't complain. I liked school. I guess they had to be that strict... No, I can't complain." Laila did not speak Norwegian when she attended school. She relates: "Not knowing the language was the worst part. I didn't know when to say yes or no." She says that this was frightening, but it did not only concern herself:

Indigenous life stories; narratives of health and resistance

"We were, what I would say, equal. All the children attending school then at that school...

There were only a few who spoke Norwegian." The children were frankly not allowed to use the Sami language at school, but Laila relates:

"We did speak Sami. We did. We had a Norwegian teacher, but she... didn't care. She was old. She was a teacher for many years. She was the teacher for all my siblings – so you can imagine how old..."

After her confirmation, Laila "knew enough Norwegian" to go to the nearest town toenroll in cooking and sewing courses. Despite her physical handicap, Laila had several domestic posts, and she worked as a seamstress and a cook. She says: "Whenever something happened – a funeral, a christening, or a confirmation, I was in charge." She states:

"I wasn't the kind that laid down moping. I was active all the time. ... I went to school and everybody was equal. ... I wasn't the kind that shut myself away. Oh no! I wanted to stay out. I wanted to be in the midst. And the other kids in school – there was no bullying back then! Oh no! I was accepted everywhere, so it didn't bother me."

Laila has been active in interest groups for people with various handicaps for all of her adult life.

Laila's deceased husband "was a kind man". He subsisted on casual work. Laila relates:

"And he had a small... a *big* handicap. He was an illiterate. He didn't have any school... He had to struggle at home. ... And they had a teacher who didn't... who ignored those who didn't... know more."

Laila is clear about her Sami heritage; she immediately states that she is a Sami. However, she dislikes the focus on the Sami people in society: "I must say, I think it's almost too much about the Sami now. They say, 'We are Sami, we are Sami, I am Sami, I am Sami.' (*Raises her voice*) No, it is too much! ... I think so. They demand too much. That's the problem."

In addition to her congenital physical handicap, Laila has spent the last three years in a wheel chair. "It was my feet who couldn't... My feet refused." Despite all this, Laila says this about her health: "My health? I must say, my health is good. I am satisfied with my health of course, I have a few small nuisances, I do. But other than that... No."

Similar to Inga's story, the fight for equality is an undertone throughout Laila's story. Being treated as an equal is at stake throughout Laila's life story. Although she was born with a physical handicap, her life story, where "being in the midst" is a central theme, embodies her with a *healthy self*. To be healthy is to participate. The story Laila tells about her husband is somewhat quite different. She refers to his illiteracy as a *big* handicap". One can easily imagine how the husband's opportunities for participation and equality were restricted by his illiteracy. Laila's reflections on residential school life underline her emphasis on equality. She "can't complain" about school because, after all, almost all of the kids were in the same situation; few of them spoke any forwegian when attending school. The way she describes the aged Norwegian teacher gives her and the other Sami children the upper hand. Moreover, Laila eventually mastered Norwegian well enough to attend courses in town.

We perceive Laila's life story as a narrative of resistance. Like Inga, Laila expresses her resistance through the narration of her *healthy self*. She resists being different; she resists special treatment as a "handicapped" person. In this perspective, Laila's indignation with "Sami activism" becomes reasonable. Claiming special rights is exactly what she has been refraining from all her life. What she perceives as Sami people "demanding too much" raises the stakes of her equality.

Marit: Did not have to go to the gym to row

Marit was born early in the 1930s in a remote coastal community as one of six siblings. "We lived in a spot, I would almost say, not even birds would pay a visit." School was one of Marit's first encounters with society outside of home.

"Imagine that it's possible! I started school without understanding what the teacher talked about. I know I did read because I had learned to spell. So I did put the letters together, but I didn't know what I was reading! ... No, I didn't know what I was reading. *Now* I can read."

Marit and the other children were not allowed to speak Sami language in school:

"The teacher said 'You have to speak Norwegian.' Of course, we should speak Norwegian, but none of us understood... If it had been *today*, I would have told her.

But... but of course I did not say anything. Who should I tell?"

Marit relates about how the children were treated differently at school. She discusses the teacher's preferential treatment of two Norwegian brothers in her class. In addition, there were others who were not treated well.

"There were differences. None of us were wealthy, but I remember one boy who came from particularly poor conditions. I can't understand why they treated him like that...

He was put down. But when he did grow up, he attended schools, and he became a writer. Now he is dead."

Marit had severe asthma as a child. She spent a great deal of her childhood sick from asthma, and people used to say that she was a bashful child. She says:

"I never was bashful while among people speaking Sami, but I didn't speak

Norwegian back then. I didn't know enough Norwegian to participate in talking, I

didn't know... I didn't know Norwegian back then. Nowadays, some Norwegians say

'We remember, you used to be here – you spoke Norwegian well.' Yes, a little... I

guess I planned for hours the things I said. That is how it was. But they should discuss with me *now* – because *now* I can talk! I'm not bashful now!"

Marit resists that idea that the asthma robbed her of her youth:

"A lot of people have said to me 'You had no youth.' Youth? What do they mean by that? I had a youth like everybody else! While I was sick, the other youth visited. Back then, people visited! And when we went skiing, we all were together. If I was shorted breath, the others waited for me. Yes, they did."

Throughout her adult life, Marit has been sick from asthma.

Marit is clear and candid while speaking about her Sami heritage. She says: "We are Sami! I just think: I am a Sami. I am not at all a Norwegian. And everywhere I go I say: I am from here, and I am a Sami!" She associates being a Sami with being active. She says:

"I think it has been nice to be a Sami. While we were kids, we had to work outdoors with our parents. We didn't sit inside watching TV and then have to exercise at the gym. Nowadays, people have to exercise because they are only sitting. We had to row. Row! Nowadays, people row at the *gym*. They do! That's the difference, if I could say so, in being a Sami."

In Marit's story, her *healthy self* is at stake, but the stakes are lowered by the manner in which she tells her story. Health is associated with participation in Marit's story, like in Laila's story. To Marit, the Sami language is essential for her participation. She denies that she was a bashful child while among other Sami and able to participate by speaking her mother tongue. Furthermore, her severe asthma was not a problem in that it did not prevent her from being with the other kids. The other children made it possible for her to participate by visiting when she was sick and adjusting the speed of their skiing when she was short of breath. The stakes on her healthy self is lowered through the community with other Sami-speaking people.

As in the life stories of Inga and Laila, colonial history is also evident in Marit's story. This is most evident in her narrations about residential school life. Similar to the two other women, Marit is also presenting a narrative of resistance. She resists being sick and bashful, and it is her Sami heritage that is the key to a healthy, participating self. In Marit's story, her Sami heritage allowed her to engage in healthy activities, such as rowing. She obtains the upper hand by ridiculing how people today go to the gym to row, and she actually states that this is the difference between Sami and Norwegians.

Marit is proud to be a Sami; she states that she is "not at all a Norwegian". However, the history of assimilation is nevertheless present in the way Marit narrates her life.

Statements like "Now I can read", "If it had been today, I would have told her", and "they should discuss with me now – because now I can talk! I'm not bashful now!" suggest that the capacity to resist, at least partly, is contingent upon her mastery of the Norwegian language.

Discussion and implications

Life stories, such as the three stories presented in the present paper, are sources of insight into health experiences. The stories could be read through the lens of van Hooft's notion of health as an experience and a condition of subjectivity. Through such a reading, one could identify elements of all four dimensions of health: the material dimension expressed in Marit's shortness of breath and Laila's physical handicap; the pragmatic dimension expressed in rowing, sewing, and cooking; the conative dimension expressed in Laila's desire to be in the midst of the crowd; and the integrative dimension expressed in the structure and coherence of the stories. Van Hooft's notion of health is useful because it promotes a wide understanding of health that does not only focus on the absence of disease. If we exclusively focus on health as a condition of subjectivity, the key to quality care lies in the relationship between patients and health care providers, which is referred to as "the micro-ethics of 'humane care'" (Mishler 2004). From such a perspective, the call for cultural sensitivity and culturally

congruent care, understood as "culturally based care knowledge, acts, and decisions used in sensitive and knowledgeable ways to appropriately and meaningfully fit the cultural values, beliefs, and lifeways of clients" (Leininger and McFarland 2006: 15), in encounters with Sami and other minority patients appears reasonable. However, if people's experiences of health are perceived as also being influenced by historical and socioeconomic contexts, such a "micro" perspective is too narrow. We argue that the study of people's life stories allows for an examination of their health experiences as a condition of subjectivity and as influenced by historical and socioeconomic contexts. The stories are, of course, subjective accounts, but they simultaneously occur "at a historical moment with its circulating discourses and power relations" (Riessman 2008: 8), which are echoed and have an impact on what can and cannot be told in the individual stories. The collective history, such as the history of assimilation and colonization, has effects at the individual level (cf. Adelon 2005), and postcolonial theory provides a framework for understanding how present-day experiences are shaped by history (Browne et al. 2005).

The Sami heritage of the women described herein has a central place in all three stories and is closely connected to the women's experiences of health. This is not necessarily because being Sami implies that the women have certain cultural traits in common but rather because being a Sami in this particular historical period may have brought about experiences that persons from the majority group would not have. In this sense, the legacy of colonialism is inevitably present in the women's stories. This is evident in all of the women's stories regarding residential schools and being forbidden to speak their own language. The experience of belonging to a stigmatized minority group is evident in the way Inga, through being constantly conscious about her conduct, takes responsibility for how all Sami are perceived by the majority population. A person belonging to a non-stigmatized majority would not necessarily feel the same responsibility for the reputation of the whole group.

Herein perhaps lies a key to understanding Laila's indignation with Sami claiming special rights; the special rights of some representatives of the Sami brand the Sami as a group of people with special needs.

Health care providers encountering Sami and other minority patients who exclusively focus on them as minorities or cultural "others" risk ignoring the agency of their patients. From such a perspective, patients are considered "products" of their culture and even passive victims of the majority policy. Postcolonial theory calls attention to the impact of historical and socioeconomic factors on people's lives and forestalls attempts to represent them as issues of "cultural differences". Narratives of resistance, such as those presented in the current paper, illustrate that people are not necessarily passive victims of the legacy of colonialism. On the contrary, narratives of resistance are expressions of the agency of "the oppressed". Resistance is not a passive state but an active process, and so is health. The importance of considering indigenous people as active in response to their colonial situation, rather than simply as passive victims, is emphasized elsewhere (Adelson 2005). According to Frank (1995: 23, italics original), "(t)he truth of stories is not only what was experienced, but equally what becomes experience in the telling and its reception". Such stories are central means by which people can take control over their own representation (Stone-Mediatore 2003). Through their narratives of resistance, the women become the narrators of their own stories without completely becoming the authors of their lives (Ricoeur 1986: 131). They cannot change the historical and social settings of their life stories, but they certainly control what part these settings are allowed to play in their stories. As noted by Stone-Mediatore (2003), the narratives of resistance can destabilize ossified truths and thereby suggest that historical life might be more complex than it might appear at first glance. Marit's ridiculing of Norwegians that go to the gym to row is one example. Another example is the way Inga makes superfluous the whiteness and cleanliness of modern maternity care. Laila's

According to Ewick and Silbey (2003:1331), narratives of resistance reveal the tellers' consciousness of how opportunities and constraints are embedded in the normally taken for granted structures of social action. This is evident in the story about Inga's mother opposing the teacher from the South. While telling about her mother standing up to the teacher, Inga makes known her consciousness about the opportunities and constraints embedded in the social structures. The firm "Inga is not going anywhere" reverses the power relations between the Sami woman and the teacher from the South. Likewise, Marit's story about the tormented boy who grew up to be a writer demonstrates awareness about opportunities and constraints. The present study demonstrates that a narrative approach to issue regarding health and the Sami people unveil other "truths" than those described in statistics on mortality rates and disease incidence. Health is not a passive condition; it is an active process. The stories of these three women indicate that being a healthy tell can be an act of resistance.

In the present article, we argued the necessity of combining micro- and macroperspectives while grappling with issues regarding indigenous people, health, and health care
services. The micro-perspective recuses on the face-to-face encounters between health care
providers and indigenous patients, while the macro-perspective demands a contextualization
of the interpersonal encounters. The narratives of resistance discussed in this paper illustrate
the importance of recognizing that the legacy of colonialism is present in the lives of Sami
elderly total without regarding them as passive victims. Such narratives of resistance
demonstrate that envisioning indigenous elderly solely as passive victims and not as active
agents would be not only insufficient but also offensive. The resistance is a resource that
should be appreciated by health care services both at a systemic level, e.g., through authentic
partnership with indigenous elderly in planning and shaping of health care services, and in
individual encounters between patients and health care providers.

Acknowledgements

This study was funded by The Research Council of Norway. The authors would like to thank the editorial board of Canadian Journal of Nursing Research and the two anonymous reviewers for constructive, inspiring, and clarifying comments on earlier drafts of this paper.

References

- Adelson, N. (2005). "The Embodyment of Inequity. Health Disparities in Aboriginal Canada." Canadian Journal of Public Health **96**(2): 45-61.
- Ahmed, A. T., S. A. Mohammed and D. R. Williams (2007). "Racial discrimination & health: pathways & evidence." <u>Indian Journal of Medical Research</u> 12(4): 318-327.
- Browne, A. (2005). "Discourses Influencing Nurses' Perceptions of First Nations Patients."

 <u>Canadian Journal of Nursing Research</u> 37(4): 62-87.
- Browne, A. J., V. L. Smye and C. Varcoe (2005). "The Relevance of Postcolonial Theoretical Perspectives to Research in Aboriginal Health." Canadian Journal of Nursing Research 37(4): 16-37.
- Brustad, M., T. Pettersen, M. Melhus and E. Lund (2009). "Mortality patterns in geographical areas with a high vs. low Sami population tensity in Arctic Norway." <u>Scandinavian</u> Journal of Public Health **37**(5): 475-4800
- Dreher, M. and N. MacNaughton (2002). "Cultural competence in nursing: Foundation or fallacy?" Nursing Outlook **50**(5)(181-186.
- Eidheim, H. (1992). Stages in the development of Sami selfhood. Oslo, Universitetet i Oslo.
- Eidheim, H. (1997). Ethno-political development among the Sami after World War II. <u>Sami Culture in a new era. The Norwegian Sami experience</u>. H. Gaski. Kárásjohka / Karasjok, Davvi Girji OS: 29-61.
- Ewick, P. and S. Silbey (2003). "Narrating Social Structure: Stories of Resistance to Legal Authority." American Journal of Sociology **108**(6): 1328-1372.
- Frank, A. W. (1995) The wounded storyteller. Body, illness and ethics. Chicago, The university of Chicago press.
- Frank, A. W. (2005). "What is dialogical research, and why should we do it?" <u>Qualitative</u> <u>Health Research</u> **15**(7): 964-974.
- Frank, A.W. (2006). "Health stories as connectors and subjectifiers." Health (London) 10(4): 1-440.
- Frank, A. W. (2010). <u>Letting stories breathe.</u> A socio-narratology. Chicago, University of Chicago press.
- Frank, A. W. (2012). Practicing Dialogical Narrative Analysis. <u>Varieties of Narrative Analysis</u>. J. A. Holstein and J. F. Gubrium. Thousand Oaks, California, SAGE Publications Inc.: 33-52.
- Gaski, L. (2008). Sami identity as a discursive formation: Essentialism and ambivalence.

 <u>Indigenous peoples: Self-determination, knowledge, indigeneity</u>. H. Minde. Delft, The Netherlands, Eburon Academic Publishers: 219 236.

- Gaski, M., M. Melhus, T. Deraas and O. H. Førde (2011). "Use of health care in the main area of Sami habitation in Norway catching up with national expenditure rates." <u>Rural and remote health</u> **11: 1655 Online**.
- Hansen, K. L., M. Melhus, A. Høgmo and E. Lund (2008). "Ethnic discrimination and bullying in the Sami and non-Sami populations in Norway: The Saminor Study." International Journal of Circumpolar Health **67**(1): 97-113.
- Hansen, K. L., M. Melhus and E. Lund (2010). "Ethnicity, self-reported health, discrimination and socio-economic status: a study of Sami and non-Sami Norwegian poulations."

 International Journal of Circumpolar Health **69**(2).
- Hansen, K. L. and T. Sørlie (2012). "Ethnic discrimination and psychological distress: A study of Sami and non-Sami populations in Norway." <u>Transcultural Psychiatry</u> 49(1). 26-50.
- Hassler, S. (2005). The health conditions in the Sami population of Sweeden, 1961 2002:

 <u>Causes of death and incidencies of cancer and cardiovascular diseases.</u> PhD, Umea University, Sweeden.
- Hassler, S., R. Johansson, P. Sjölander, H. Grönberg and L. Damber (2005) Causes of death in the Sami population of Sweden, 1961–2000." <u>International Journal of Epidemiology</u> **34**(3): 623-629.
- Hassler, S., S. Kvernmo and A. Kozlov (2008). Sami. <u>Health transitions in Arctic populations</u>. T. K. Young and P. Bjerregaard. Toronto, Buffalo, Lordon, University of Toronto Press: 148 170.
- International Labour Organisation (1989). C169 Indigenous and Tribal Peoples Convention Convention concerning Indigenous and Tribal Peoples in Independent Countries. Geneva.
- Joint Commission on Hospital Accreditation (2008). The Joint Commission 2008 requirements related to the provision of contrally and linguistically appropriate health care. http://www.jointcommission.org/wccessed 2012-03-19).
- Kramvig, B. (2005). "The silent language of ethnicity." <u>European Journal of Cultural Studies</u> **8**(1): 45-64.
- Leininger, M. M. and M. R. McFarland (2006). <u>Culture care diversity and universality: A worldwide nursing theory</u>, Sudbury, Mass., Jones and Bartlett.
- Like, R. C. (2011). "Educating charicians about cultural competence and disparities in health and health care." <u>Journal of Continuing Education in the Health Professions</u> **31**(3): 196-206.
- Mancuso, L. (2011). "A oustomized, integrated approach to cultural competence education." Journal for Nurses in Staff Development 27(4): 170-180.
- Minde, H. (2003) Assimilation of the Sami Implementation and Consequences." <u>Acta Borealia</u> **20**(2): 121 146.
- Ministry of Covernment Administration Reform and Church Affairs (1987). Lov om Sametinget og andre samiske forhold (Act of 12 June 1987 No. 56 concerning the semeting (the Sami parliament) and other Sami legal matters (the Sami Act) as subsequently amended, most recently by Act of 11 April 2003 No. 22.) Text in English: http://www.ub.uio.no/ujur/ulovdata/lov-19870612-056-eng.pdf (accessed 2012-03-19).
- Ministry of Local Government and Regional Development (2001). St. meld. nr. 55 (2000) Om samepolitikken (Report no. 55 (2000) to the Storting. On Sami politics). Oslo.
- Mishler, E. G. (2004). "The unjust world problem: Towards an ethics of advocacy for healthcare providers and researchers." <u>Communication & Medicine</u> **1**(1): 97-104.
- Mishler, E. G. (2005). "Patient stories, narratives of resistance and the ethics of humane care: a la recherche du temps perdu." Health (London) 9(4): 431-451.

- Nystad, T., M. Melhus and E. Lund (2008). "Sami speakers are less satisfied with general practitioners' services." <u>International Journal of Circumpolar Health</u> **67**(1): 114-121.
- Nystad, T., E. Utsi, R. Selmer, J. Brox, M. Melhus and E. Lund (2008). "Distribution of apoB/apoA-I ratio and bood lipids in Sami, Kven and Norwegian populations: The Saminor Study." <u>International Journal of Circumpolar Health</u> **67**(1): 69-83.
- Office of Minority Health (2002). Teaching cultural competence in health care: A review of concepts, policies and practices. United States Department of Health and Human Services. Washington, DC.
- Olsen, K. O. K. (2010). <u>Identities, ethnicities and borderzones: examples from Finnmark, Northern Norway</u>. Stamsund, Orkana Akademisk.
- Ricoeur, P. (1986). Life: A story in search of a narrator. <u>Facts and values. Philosophical reflections from western and non-western perspectives.</u> M. C. Doeser and J. Narraay. Dordrecht / Boston / Lancaster, Martinus Nijhoff Publishers.
- Riessman, C. K. (2008). <u>Narrative methods for the human sciences</u>. Los Angeles, Sage Publications.
- Ring, J. M., J. G. Nyquist and S. Mitchell (2008). <u>Curriculum for culturally esponsive health</u> <u>care: The step-by-step guide for cultural competence training.</u> Oxford, England / New York, NY, Radcliffe.
- Romanov, R. (2002). Commission on the Future of Health Care in Canada. Building on Values: The Future of Health Care in Canada, Commission on the Future of Health Care in Canada. Saskatoon, Canada.
- Sámi Instituhtta Nordic Sami Institute. (2008). "Hvor mange samer er det egentlig...? (How many Sami are there really...?)." from http://www.sami-statistics.info/default.asp?nc=6809&id=110/decessed 2011-04-30).
- Spein, A. R. (2008). "Substance use among young indigenous Sami a summary of findings from the North Norwegian Youth Study International Journal of Circumpolar Health 67(1): 122-134.
- Spein, A. R., H. Sexton and S. Kvernmo (2004). "Predictors of smoking behaviour among indigenous sami adolescents and non-indigenous peers in north Norway." Scandinavian Journal of Public Health 32(2): 118-129.
- Statistics Norway (2010). Samisk statistikk 2010 Sámi statistihkka 2010 (Sami Statistics 2010). Oslo Kongsvinger, Statistisk sentralbyrå.
- Stone-Mediatore, S. (2003). <u>Reading across borders: storytelling and knowledges of resistance</u>. New York, Palgrave Macmillan.
- Symon, C. and S. J. Wilson (2009). <u>AMAP assessment 2009: Human health in the Arctic.</u> Oslo, Arctic Monitoring and Assessment Programme.
- Sørlie, T. and J.-T. Nergaard (2005). "Treatment Satisfaction and Recovery in Saami and Norvegian Patients Following Psychiatric Hospital Treatment: A Comparative Study." Transcultural Psychiatry **42**(2): 295-316.
- Thuen (1995). Quest for equity: Norway and the Saami challenge. St. John's, Institute of Social and Economic Research, Memorial University of Newfoundland.
- US Department of Health and Human Services Office of Minority Health (2001). National Standards for Culturally and Linguistically Appropriate Services in Health Care. Executive summary. Washington, D.C.
- van Hooft, S. (1997). "Health and subjectivity." Health (London) 1(1): 23-36.
- Vandenberg, H. E. R. (2010). "Culture theorizing past and present: trends and challenges." Nursing Philosophy 11(4): 238-249.