Collaboration between Sami and non-Sami formal and family caregivers in rural municipalities
Abstract

The aim of this study was to explore how caregivers experience collaboration in rural municipalities in northern Norway. We conducted fieldwork with a dementia team in addition to seventeen qualitative in-depth interviews with formal and family caregivers. The caregivers had ethnic Sami and ethnic Norwegian affiliation. The theme ‘negotiating ethnic and ethno-political positions’ was identified through thematic analysis and developed using positioning theory. Ethnicity involves dynamic and situated personal affiliations, and participants negotiate each other’s ethnic positions in practice. Negotiations of ethnic positions hamper collaboration between formal and family caregivers, and ethno-political positions reinforce stereotyped ethnic positions. This study contributes to the understanding of and the debate over positions on ethno-cultural collaboration in health care. In practice, participants negotiate the health policy concept of ‘cultural facilitation’, which must be broadened to ensure equal health-care services.

Keywords

Ethnicity, cultural facilitation, collaboration, negotiation, positioning theory, Sami
Introduction

Relationship and collaboration can have a direct impact on the quality of the health services provided. To improve collaboration, formal caregivers should be aware of the different and dynamic positions of both formal and family caregivers in interaction (Helgesen, Larsson, and Athlin 2013). To our knowledge, this is the first study to explore formal and family caregivers’ experiences in multi-cultural collaboration in home-based care for Sami people with dementia disease (DD). The authors’ focus is positions that can serve as barriers to equality in home-based care, not the experience of DD itself.

The Sami have experienced abuse because of the Norwegian government’s assimilation policy (Eidheim 1969; Olsen 2010). Ascribed ethnic positions might affect collaboration and access to health services. Governmental reports identify the Sami’s need for and right to facilitated services and claim ‘cultural facilitation’ as a solution to challenges to equitable health services (Ministry of Health and Care Services 1999). The authorities do not define the term ‘cultural facilitation’, but they relate it to knowledge about Sami language and culture, good communication and mutual understanding. The actors must define the term in practice for use in each situation.

One problem with cultural facilitation is the difficulty of defining others’ ethnicity (cf. Pettersen and Brustad 2013). Sami ethnicity was once interpreted by others to be about kinship, traditional living arrangements and lifestyles, but today, it is understood to involve dynamic and situated personal affiliations (Kramvig 2005). Governmental documents indicate the need to identify the particular challenges facing the Sami people in their interactions with public healthcare providers. These challenges should be resolved through research in addition to
dialogue and interaction among the government, service providers and users at various levels (Ministry of Health and Care Services 2009).

**Governmental health policy concerning the Sami**

The Sami traditionally live in four countries, Norway, Sweden, Finland and Russia. The majority of the Sami (approximately 70,000 persons) live in Norway; northern Norway has 40,000 Sami out of a population of 500,000 (Hansen and Sørlie 2012). The interior municipalities are historically connected to reindeer herding, and within the coastal municipalities, the Sami have traditionally worked as farmers and fishermen (Hoëm 2007). The assimilation policy that was in place from the mid-1850s until World War II functioned to consolidate Norway’s borders with other countries during a time of strong nationalism (Eriksen and Niemi 1995). The policy had the greatest impact on coastal Sami (Eidheim 1969). Social Darwinism, the central ideology at the time, led to the creation in Norway of an ethnic ranking that considered ethnic Norwegians the most civilized people and the Sami the most primitive. The government interpreted loyalty and a sense of belonging to the state to involve speaking Norwegian, and the government considered it necessary for the Sami to abandon their culture and language (Ministry of Labour and Social Affairs 2001). Society in general experienced increasing political awareness in the post-war period, and the revitalization of the Sami language and culture through ‘the Sami movement’ made the Sami’s special position visible and debated, especially after ‘the Alta affair’ (Blix, Hamran, and Normann 2013). The first official document that planned for a Sami parliament appeared in 1984 (Ministry of Justice and Public Security). Norway was the first state to ratify the ILO 169 convention in 1990 and thus recognize the Sami as indigenous people with special rights (Magga 2014). The current Norwegian government recognizes the Sami’s suffering caused
by the assimilation policy and has designed the current health policy to ensure equal opportunities and equal access to health care to the Sami. The suggested measures relate to Sami language, user participation, and the Sami’s view of health and the family's strong position as helpers (Ministry of Health and Care Services 2013).

**Literature review**

Several Nordic studies support the authorities’ focus on measures specific to the Sami population and claim that there is a need for even greater efforts (Turi et al. 2009; Tervo and Nikkonen 2010; Daerga et al. 2012; Bongo 2012). A study on reindeer herders in Northern Sweden shows significantly lower confidence in primary health care, mental health and social services among the Sami compared to the non-Sami population (Daerga et al. 2012). Sami-speaking patients are also less satisfied than Norwegian-speaking patients with regard to the quality of mental health (Sorlie and Nergard 2005) and general practice (GP) services (Nystad, Melhus, & Lund, 2008). The Northern Research Institute (NORUT) outlined the following potential barriers to protect the Sami Acts:

- Low degree of institutionalization of the Sami Acts
- Lack of accountability by the ‘appropriate authority’
- Additional costs related to bilingualism
- Knowledge and attitudes among the population, politicians and the administration

The research is twofold, however, and statistics present no evidence of differences in status or in the prevalence of disease among the Sami, as mentioned in a literature review (Blix, Hamran,
and Normann 2012). Research also suggests that ethnic barriers do not prevent the use of general hospitals and health-care specialists (Gaski et al. 2011).

International studies note that people who belong to an ethnic minority may understand health and disease differently than the majority population. In combination with health-care providers’ lack of cultural knowledge, such differences can result in delayed treatment, with consequences such as exhausted family members when contact with the health care system is finally achieved (Mukadam et al. 2011; Gray et al. 2009; Griffin-Pierce et al. 2008). American studies suggest that cultural facilitation should focus on ethnicity, language, culture, and an understanding of historical ties and that it should include both sensitivity and longer meetings (Moore et al. 2013; Armstrong et al. 2013).

Factors in addition to a lack of cultural knowledge in multicultural municipalities present challenges in providing equal health services. Broderstad and Sorlie (2012) show that health-care services are difficult to maintain in small, multi-cultural, rural communities because of an aging population and depopulation. In small municipalities, multiplex relationships and limited health-care and social opportunities can create further barriers to the Sami’s use of health-care services (Silviken, Berntsen, and Dyregrov 2014).

**Methods**

**Design**

The project employed an exploratory qualitative research approach. Interactional perspectives inspired the methods. This perspective allows social and cultural patterns to appear by considering the actors’ positions and symbols, activities, actions and/or valuation of actions. This perspective also considers the researcher’s own contribution to the creation of meaning (Järvinen
and Mik-Meyer 2005). The authors used fieldwork with a dementia team and semi-structured interviews to explore and guide the interpretation of caregivers’ experiences. The interview guide included aspects of DD, the need for formal help, measures and collaboration during health-care service provision.

Participants and recruitments

We recruited participants from five rural municipalities in northern Norway. In these municipalities, the percentage of the Sami population ranged from twenty to more than ninety (Ministry of Labour and Social Affairs 2008). We sent invitations to eight health-care leaders in both interior and coastal municipalities. Four coastal municipalities and one interior municipality agreed to participate in data collection. Purposeful sampling (cf. Polit and Beck 2008, 355) from these municipalities resulted in sixteen women and one man. Ten of the participants were formal caregivers, and seven were family caregivers. Eight were ethnic Sami, four were of mixed ethnicity, and five were ethnic Norwegians.

Data collection

The participants received both written and oral information about the study’s purpose, voluntary participation, confidentiality, and the possibility of withdrawing before the data analysis process before they provided oral and written informed consent to participate in the study. The authors gave the participants who spoke Sami the opportunity to speak their native language with the interviewer using an interpreter, but none considered it necessary. All participants spoke Norwegian. Digital audio files, transcribed interviews and notes are archived at Norwegian Social Science Data Services (NSD nr. 32173) according to their guidelines (Norwegian Social
Science Data Services (NSD) 2012). The study needed no approval from the Regional Committees for Medical and Health Research Ethics (REK).

The first author conducted interviews over a period of ten months using a digital recorder. The interviews lasted from 58 to 189 minutes, with an average time of 90 minutes. They took place in locations chosen by the participants. The 18 hours of fieldwork consisted of a dementia team in preparation and rework in conjunction with meetings with family caregivers. Notes from fieldwork and interviews served as frames for interpretation (cf. Coffey and Atkinson 1996, 140), but the quotes presented in the results are not from the interviews. The fieldwork included interactive observations (cf. Tjora 2012, 56) and supplemented the interviews on the relations and collaboration between formal caregivers in addition to the working conditions at institutions. It was useful, for example, to understand the mostly oral communication because of nearby offices and many informal contact points during the day. In two situations, the researcher observed discrepancies and unfriendly body language between formal caregivers of different ethnic affiliations and was able to ask about it in subsequent interviews.

**Data analysis and scientific adequacy**

As a structural tool for thematic analysis, the first author used the qualitative data-analysis computer software NVIVO 10 for Windows (QSR International Pty Ltd 1999-2014 2014). During the analysis, the author read and reread the transcript interviews and the notes and wrote memos and annotations to generate an initial interpretation of each interview. First, the author identified the parts of the material that related to ethnicity. Then, the author interpreted the meanings of these parts of the text into codes and further categorized and compared them across a matrix of positions, such as ethnic affiliation, caregiving position and gender. The further
development of themes emerged from these categories (cf. Tjora 2012, 175-95) and was inspired by positioning theory (cf. Van Langenhove and Harré 1999).

**Positioning theory**

Positioning theory provides a way of examining dynamic relationships by focusing on the actors’ positions relative to one another (Van Langenhove and Harré 1999). It relates to what people believe about their right or duty to perform and what they do in light of that belief (Harre and Slocum 2003, 105). Professional practice requires established professional and institutional frames and positions that participants are aware of, accept or negotiate (Måseide 2008, 370). Politicized demands, such as ‘cultural facilitation’, can change how formal and family caregivers understand their positions (cf. Juritzen, Engebretsen, and Heggen 2012). The participants in this study had formal roles as formal and family caregivers with certain professional and institutional rights and duties. Within these roles, they might hold many different positions, including ethnic positions, in social contexts. The structure of expectations for each position may vary across interactional situations and can be understood within storylines (Harre and Slocum 2003). As an analytical tool, positioning theory can help to examine whether positions relate to ethnicity and how positions may influence collaboration. The main theme interpreted in this study is ‘negotiating ethnic and ethno-political positions.’ The subthemes that emerged are the following: 1) ethnic position hampers collaboration, and 2) ethno-political positions reinforce stereotyped ethnic positions.
Limitations

One limitation of this study is sampling bias. Ethnic affiliation can relate to the area in which people live, and this study’s sample was mostly from coastal municipalities. Though the findings are consistent, including the data from participants living in the interior municipality, sampling from other rural municipalities could have produced different results.

With regard to the few men recruited, the members of the local dementia associations were mostly women, and few men work as formal caregivers. The interview with the man in this study did not stand out in any way.

We consider the largest bias to be the first author’s pre-understanding, position and positioning in the interview setting, especially related to ethnicity (cf. Järvinen and Mik-Meyer 2005, 34-5). The first author, who conducted the interviews, is non-Sami. Persons with both Sami and non-Sami affiliation stated prior to the study that Sami would not tell everything to non-Sami people. The interviewer had Sami friends and extended family, and she had contrasting personal experiences. However, we focused on collaboration rather than ethnicity in the interview guide, and the interviewer was aware of ethnic positioning in the interview. As the data collection continued and the participants told several stories about distrust between Sami and non-Sami, the interviewer felt it was necessary to ask the participants about her non-Sami affiliation and the possible consequences for the results. One participant laughed and said, ‘Well, that you have to figure out yourself. We (the Sami) will not tell you directly. You might understand it from what we tell you anyhow.’

The ethnic position might be a limitation, but the interviewer felt a rapport with all participants. One even offered to help the interviewer with a private task during the interview and said, ‘This is something I wouldn’t have done for everyone. I think we’ve got a good
relationship.’ The interviews are rich in data, and the participants emotionally shared their stories and thoughts. It is possible that the participants would tell other stories to another interviewer who shared their ethnic affiliation, but several of the Sami participants expressed thoughts similar to those of one Sami family caregiver: ‘It is different with you. I knew from the information letter what you wanted to talk about and could be prepared.’ The participants may have ascribed a spokesperson position to the interviewer and had agendas they wanted to broadcast anonymously. The reader should consider the results of this study not generalizable.

All the authors are non-Sami, which could have produced bias in the analysis. However, we had no specific assumptions about ethnicity related to collaboration in this field. Nonetheless, the results show some tendencies that are applicable to both Sami and non-Sami and, in a broader sense, to an understanding of the way that ascribed positions define individual actions.

Results – negotiating ethnic and ethno-political positions

Ethnic positions hamper collaboration

Ethnicity had the greatest impact on the categorization of the participants’ experiences of collaboration. A common phrase regardless of caregiving position or ethnic affiliation was similar to what one Sami family caregiver said: ‘As Sami, we do it like this.’ Ethnically ascribed positions had consequences for the way the participants viewed collaboration with each other and triggered different sets of rules for the interaction. Some caregivers related how they ‘coded’ the formal caregivers by ethnicity in the first meeting through verbal and nonverbal cues. The tension in the material shows that there are underlying conflicts concerning expected actions due to ethnic positions. The positioning is resolved through awareness, tolerating unpleasant
positions and negotiating positions. We present the interpreted ethnic positions and positioning of others in Table 1.

Four of the participants positioned themselves with mixed ethnic affiliation but still as Sami. They had a parent who was Sami and who spoke Sami as his or her mother tongue. These four participants had not learned the language themselves because of the assimilation policy. They stated their Sami position based on genetics. One participant said, ‘My mother thought that we did not need her language in a Norwegian society. She wanted us to be Norwegians. Today I think it is a pity. The Sami language could have been useful in many situations.’ The authors of the article categorized these participants as persons with weak Sami affiliation. Eight of the participants stated a strong Sami affiliation and spoke Sami themselves. One participant said, ‘I am a Sami, and my children and I speak Sami as a mother tongue.’ The authors categorized two persons as having weak non-Sami affiliation. The ethnic affiliation of others or their own ethnic affiliation was not something they considered. One of them said, ‘I do my job like I do in any home, no matter ethnic affiliation.’ Three participants expressed strong non-Sami affiliation as a response to prioritized resources to Sami users. One non-Sami said, ‘We are called racist if we are opposed to the VIP treatment to the Sami. This is impossible to say aloud, but nevertheless, I won’t do it anymore.’

**Carriers of distrust**

Participants in the study described the Sami as ‘skeptical, unsure, untrusting, and suspicious’ in collaboration with non-Sami. A non-Sami formal caregiver said, ‘Many (Sami) act like they have spikes on the outside. They think that we (non-Sami) do not like them.’ A Sami formal caregiver said, ‘A non-Sami is always interpreted as a stranger, even if she grew up and lived in the same
municipality.’ They cited their own experiences in interactions and generalized and transferred attitudes within their society. A Sami formal caregiver said,

It is very important not to reveal ourselves to strangers, especially Norwegians. Younger generations are reproducing their parents and grandparents’ wounds because of the assimilation policy, so the distrusting attitude toward the Norwegians is also detectable among the young Sami. We have become carriers of distrust.

They also indicated that the Sami did not use some public health-care offers because of a lack of trust. A Sami formal caregiver said,

Sami people do not use some services because it is not fair to mix them with the Norwegians. She (a Sami family caregiver) would not come because there were Norwegians there. She did not want them to think that someone from her family had the disease. Public services are not equal when the structure itself seems to exclude one group.

Several family caregivers said that they should have accepted help from the public health-care system at an earlier stage and claimed distrust of Norwegians as their primary reason for not seeking help. One Sami family caregiver said, ‘My advice to others must be not to be so afraid; they (the formal caregivers) are not that dangerous, and they do want what is best for us.’

*The Sami seem to understand us better*

]The participants in the study described as common knowledge the idea that instead of adhering to the hierarchical structure of the local health service, the Sami were more inclined to cooperate with other Sami regardless of formal position. A Sami formal caregiver said,

Sami health-care workers operate as a boundary between the Sami and public-service providers. The Sami know their position in the system when it comes to caring for each other. With me
working as an arbitrator between the Sami and the non-Sami and as a guide to public services, in a way, this is my position within Sami society.

The participants described narrow borders for acceptable behavior for non-Sami when cooperating with Sami people and related many examples of conflicts caused by language barriers and what they mentioned as a lack of cultural knowledge. The formal caregivers perceived the Sami health-care employees to have a better relationship with the patients because of their Sami affiliation, even if they could not speak Sami. One Sami nurse said,

In some homes, I cannot be a nurse. I must be a Sami. If my Norwegian colleagues copy me, the Sami user will consider them rude. The Norwegian nurses have to find their own way to build trust. I think we have to choose very different approaches to our work.

Because of the lack of Sami health-care workers, most Sami families had to collaborate with non-Sami health-care employees. Several formal caregivers called cultural facilitation ‘shortcuts to gain trust.’ They stated that non-Sami formal caregivers should always consider using an interpreter. They should also spend time, drink coffee and participate in small talk with the Sami family before they performed their assigned tasks. One procedure involved offering the Sami family the opportunity to collaborate with a Sami health-care provider regardless of needs that the person might have other than a common language. One Norwegian formal caregiver gave an example of a good start for interaction with a Sami family: ‘We invite a Sami colleague with us the first couple of visits to gain trust through the Sami co-worker.’ Highlighted points in the formal caregivers’ descriptions of cultural facilitation included the need for non-Sami to approach Sami families humbly. The family caregivers did not speak in terms of cultural facilitation, but they described ways to build a good relationship. One family caregiver said,
If they come and ask directly, as if they are investigating us - then we think, ‘Oh, they (the Norwegians) are here again and think they can do better than us.’ They do not know better. They should lay low and be humble, talk about things more in general first, like the weather and stuff like that.

Distrust breeds distrust

The non-Sami formal caregivers reported that despite their attempts to use what they had learned about cultural facilitation, the Sami families rejected them. A non-Sami formal caregiver said, ‘I tried as hard as I could! I am just not good enough as long as I am a Norwegian.’ A Sami nurse said, ‘It is difficult for Norwegian nurses to build a trusting relationship within a Sami family no matter what attempts they make at cultural facilitation.’ The distrust between Sami and non-Sami was mutual.

One Norwegian formal caregiver related how she prepared for a long visit with a Sami family and deprioritized other important tasks. Afterwards, she felt good about her work and the relationship she had built with this family. Later, a Sami colleague told her that the Sami family wanted a Sami nurse and thought she had acted ignorant and rude. She said, ‘I do not even know what I did wrong. They will not tell me. Now, I am even more cautious about what I can say or do.’ Other non-Sami formal caregivers felt that they had come under suspicion when they met some Sami families. They felt forced to an ethnic non-Sami position. The non-Sami caregivers understood this as something they needed to handle as professional health-care providers, but it made them feel uncomfortable. One non-Sami formal caregiver said,

It is demanding to thoroughly consider everything in the interaction and to wait for acceptance before further collaboration. Anyhow, this is how it is, and I have to do my job. Of course, it makes me wonder what they say about me when I have left.
**Ethnicity is no concern here**

Some non-Sami formal caregivers did not think ethnicity was a concern in their municipality. One non-Sami formal caregiver said that she had never thought about ethnic separating lines in the municipality before she began working in health-care and attended lectures in cultural facilitation. She said, ‘I became very unsure about the dos and don’ts. The Sami suddenly became strangers. I was afraid to do something wrong and thought about how many times I perhaps had done them wrong through the years.’ The lectures on Sami culture created unwanted boundaries of which she had not been aware and that she did not fully accept.

**Ethno-political positions reinforce stereotyped ethnic positions**

The participants supported the governmental goal of equitable services, but their interpretation of how this should be implemented in practical health care differed by ethnic affiliation. The colliding ethno-political perspectives differed in both the understanding of ethnic affiliation and the need for differentiation of the Sami group of people. The ethno-political positioning had negative consequences both for collaboration between colleagues and for collaboration between formal and family caregivers in home-based care.

**They do not want what is best for us**

The Sami participants expressed a firm belief that the government had to strengthen Sami rights and argued that a health-care system without special services for the Sami was not equal. Some Sami interpreted the municipalities’ lack of special measures for Sami people as retaliation. One said, ‘They can if they want to, but they do not even answer our written demands.’ Several Sami
participants expressed anger toward the non-Sami who did not take Sami-language courses. A Sami family caregiver commented on the Sami contractual rights to speak their mother tongue:

> It is our right! It is strange and it makes me wonder what they (the Norwegians) think of us (the Sami) when they do not want to learn about our language and us. They do live in a bilingual municipality in a bilingual state.

**The position as a Sami victim is outdated**

All non-Sami said that the Sami would potentially need cultural facilitation. They considered the differentiation for Sami groups fair if the Sami spoke Sami, worked as reindeer herders or had personal experience as victims of the assimilation policy. Some non-Sami protested when they considered the argument for differentiation irrelevant. One said, ‘They (the Sami) are no different than us (non-Sami). We all have grown up here in the same conditions. I cannot understand why they need something more than us.’ The Sami needed to fulfill criteria other than Sami affiliation to be truly in need of cultural facilitation. The extra criteria included the following list constructed by the authors using statements from the participants:

> The Sami mother tongue, working with reindeer herding or personal experience as a victim of the assimilation policy (grew up in an institution, denied the chance to speak their own language in school or in interaction with other public institutions).

Because of the perceived temporary nature of the conflicts, non-Sami formal caregivers did not prioritize lectures in Sami. One said, ‘I cannot say that I am motivated to take Sami classes. The Sami society is minor compared to us (the Norwegian society). Right now, we do not have any Sami patients in home-based care.’
Some of the non-Sami wanted to eliminate the divide caused by ethnicity, and they regarded cultural facilitation for the Sami as a temporary measure. A non-Sami formal caregiver said,

I do not want to apologize for something my ancestors once might have done a long time ago. I wish that we at some point could say that enough is enough. We do not need to poke the wounds repeatedly. It was enough a long time ago. It is demanding to collaborate if we have to cross these boundaries all the time.

The participants summarized the ethno-political issues as filled with tension. A non-Sami formal caregiver said, ‘The question of who has the right to call themselves Sami and claim extra resources is something that we cannot discuss here.’

**Discussion**

Eidheim’s fieldwork (1969) demonstrated that the Sami identity was a private matter, but locals could separate the Sami from the Norwegians. This study shows the locals’ problem in distinguishing between people’s ethnic affiliation. As a result of today’s more hybrid and dynamic ethnic belonging, the Sami identity may be more fragile (Olsen 2010). Some participants were barely aware of any ethnic differences related to the Sami in their municipality. Most participants coded each other in ethnic positions, and some positions created tension, conflicts and negotiations in some situations. There may be different answers for why ethnic and ethno-political positioning seems to be important in interaction, as shown in the results. Following Harré and Slocum (2003, 100), we present three hypotheses about how an understanding of possible positions in various settings could be exploited for conflict resolution: 1) routinized stereotypes, 2) necessary for collaboration, and 3) a way to negotiate the
preservation of Sami culture and language. We interpret the latter hypothesis to be the main conflict. The conflict related to the political discourse of preserving Sami culture and language contrasted with the egalitarian ideal (cf. Gullestad 2002) (Table 2).

1) Ethnic positions as routinized stereotypes. Combining the personalization of moral order and habituation can cause stereotyped perceptions to become completely privatized such that the person is no longer aware that he or she uses them to make assessments (Harré and Langenhove 1999). The well-known positions of Sami and Norwegian involve routinized behavior inherited through stories told within the social order. The primary focus of the ‘Sami movement’ was preservation and development of the group’s culture and language by developing ‘a collective Saami self-understanding’ (Olsen 2010, 96-114). It was about expressing the Sami as different from Norwegian culture. Sami language, clothing and reindeer herding differed most, but few, if any, of these expressions were present in contemporary coastal Sami society (Olsen 2010). These symbolic expressions fit non-Sami’s descriptions of a Sami who could rightfully claim special measures. Olsen (2003) argues that touristic and clear-cut boundary representations of the Sami can be problematic because non-Sami might think that a Sami who does not fit the stereotype is not entitled to receive special measures. One explanation for conflicts in collaboration may be that caregivers act out of a stereotypical perspective of a Sami and fail to acknowledge the Sami with other ethnic expressions. The stereotyped Norwegian may also play a part in a problem similar to that of minority groups. Formal caregivers might attempt to perform cultural facilitation, but the recipients negotiate what is appropriate in each individual situation. Training in cultural facilitation, contrary to its intentions, might reinforce group identity, thus creating and reproducing stereotyped positions characterized by precautions in interaction. Inclusive
processes that can help build coalitions instead of separations and confrontations can be crucial if ethnic stereotypes are to be eventually transformed (Canales 2000).

2) *Ethnic positioning as necessary for collaboration.* One particular challenge for the Sami in the use of health-care services was distrust because of ethnicity. Several studies have shown distrust in minority groups (Nystad, Melhus, and Lund 2008; Daerga et al. 2012; Armstrong et al. 2013; Moore et al. 2013). This study also shows mutual distrust in majority groups.

The results show distrust understood as what Grimen (2009, 101) termed ‘impersonal institutionalized distrust.’ This is an impersonal distrust ascribed to ethnicity. The historical and family stories of conflict caused by ethnic positions served as strong arguments for a set of rules or precautions for interaction between Sami and non-Sami. The precautions, exemplified as cultural facilitation measures, can be part of the chains of control necessary to make collaboration possible. When non-Sami tolerate the unpleasant ethnic positioning of themselves and act as expected by the other, we understand them as acknowledging the other’s position as a victim of the former assimilation policy. Positioning and unreflective interactions are part of all social interactions and can even be required to enable collaboration (Måseide 2008). For some Sami, non-Sami’s acknowledgement of possible cultural differences might be necessary to attempt to collaborate. The findings show that some Sami families explained delayed contact with health-care personnel with distrust. This increased the necessity for formal caregivers to act with respect for possible differences because of ethnic positions, particularly in coastal municipalities where the stereotype of the Sami seldom fits.

3) *Ethnic positions as a way to negotiate the preservation of Sami culture and language.* The Sami movement created belonging and confidence within Sami society but also marked boundaries with others (Olsen 2010). In situations that relate to the distribution of resources
based on ethnic categories, the differences are important. The storylines told by Sami who lived in both interior and coastal municipalities related to preserving Sami culture and language. Non-Sami said that some Sami were in need of specific measures but rejected the arguments for differentiations for all Sami. They explained this rejection based on an egalitarian ideal. Thus, this study supports research on the egalitarian ideal that permeates the Norwegian health-care system as disruptive to the protection of the Sami Acts (Ryymin and Andresen 2009). The participants may use the ethnic positions within the storylines to strengthen or decrease the resources available to preserve Sami culture and language. The rejection of these positions leads to extreme positions as ‘discriminators.’ This study supports previous research that has identified political discourse that reinforces clear-cut ethnic boundaries in areas with both Sami and non-Sami populations (Olsen 2003). Ethnic affiliation might be a private matter, but only until resources are at stake. However, the participants wanted to tell stories about ethnic conflicts despite the tension and emotions they revealed and despite the fact that they did not receive direct questions about ethnicity. We interpret this as meaning that these stories are necessary and productive forces for political discourse in the municipalities.

**Summary**

The participants described hampered collaboration because of ethnicity, distrust and a lack of cultural competence. These barriers have been outlined previously (Angell et al. 2012). This study expands these barriers by showing how the participants negotiate the necessity of the institutionalization of the Sami Acts. Official documents and previous research described cultural facilitation as a solution for cultural challenges (Moore et al. 2013; Armstrong et al. 2013; Bongo 2012; Turi et al. 2009). Participants in this study described rejection and conflicts despite
attempts at cultural facilitation. The findings show that the interpretation of cultural facilitation is within a social moral order that differs between the Sami and the non-Sami. Based on this study, we agree that a redefinition of the concept of cultural facilitation may be necessary, as Blix (2013) proposes. Measures to bridge cultural challenges seem to fail as a result of problems with knowledge of each other’s ethnic affiliation. Ethnicity is difficult to discuss because of the incongruity of discourses and the complexity of local society (Olsen 2010, 205). A governmental policy of cultural facilitation may limit the positions from which Sami persons can choose (Blix, Hamran, and Normann 2013). The participants negotiate in practice the position of Sami in need of cultural facilitation.

Cultural facilitation may fail because of a lack of reflection and dialogue about possible stereotyped ethnic positions. It may also fail due to formal caregivers’ lack of awareness of the necessity of ethnic positions in some situations. Mostly, the measures fail because the actors position themselves and the other within a conflicting ethno-political discourse. Health-care professionals need to be aware of and discuss the consequences for collaboration related to their and others’ possible positions. By identifying how conscious and unconscious positions in everyday life affect understanding of the self and the other, it is possible to change positions (Van Langenhove and Harré 1999; Goffman 1992). We propose this article as a starting point for a dialogue to target possible problematic positions. The authors also recommend further research that focuses on ethno-political positions with an attempt to reduce precautions in interactions.

**Conclusion**

To our knowledge, this is the first study to explore the experiences of both formal and family caregivers in home-based care in an ethno-cultural landscape. The findings present mutual ethnic
positioning that might serve as routinized stereotypes, as a necessary factor for collaboration, or as a way to negotiate the preservation of Sami language and culture. Either way, ethnic positions, especially ethno-political positions, hamper collaboration between formal and family caregivers. The conflicts between Sami and non-Sami are subtle, but the tension is high. It is difficult for non-Sami formal caregivers to reach the Sami population with public-health services, and in several cases, despite special measures, cultural estrangement delays and complicates collaboration. To achieve good collaboration, both the majority and minority groups must take responsibility for the debate about appropriate ethnic and ethno-political positions. This study can contribute to the understanding and debate regarding positions in ethno-cultural interactions.

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Helgesen, Anne Karin, Maria Larsson, and Elsy Athlin. 2013. "How Do Relatives of Persons with Dementia Experience Their Role in the Patient Participation Process in Special Care Units?" *Journal of Clinical Nursing* 22 (11-12): 1672-1681.


<table>
<thead>
<tr>
<th>Interpreted positions of the participants</th>
<th>The storylines about the Sami</th>
<th>The storylines about the non-Sami formal caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weak Sami affiliation (One formal and three family caregivers)</td>
<td>Sami understand us better</td>
<td>There is nothing wrong with them; they just are not Sami</td>
</tr>
<tr>
<td>Strong Sami affiliation (four formal and four family caregivers)</td>
<td>Carriers of distrust in need of specific measures</td>
<td>They do not want what is best for us</td>
</tr>
<tr>
<td>Weak non-Sami affiliation (two formal caregivers)</td>
<td>Ethnicity is no concern here/Distrust breeds distrust</td>
<td>Ethnicity is no concern here/ Distrust breeds distrust</td>
</tr>
<tr>
<td>Strong non-Sami affiliation (three formal caregivers)</td>
<td>The position as a Sami victim is outdated</td>
<td>We are exposed to racism</td>
</tr>
</tbody>
</table>
### Table 2 – Typology of possible conflicting storylines that might hamper collaboration

<table>
<thead>
<tr>
<th></th>
<th>Sami</th>
<th>Non-Sami</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Preserving Sami culture and langue</strong></td>
<td>- Sami understand us better (weak and strong positions)</td>
<td>- Some Sami are carriers of distrust in need of specific measures (weak and strong positions)</td>
</tr>
<tr>
<td></td>
<td>- Carriers of distrust in need of specific measures (strong positions)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- They (the Norwegians) do not want what is best for us (strong positions)</td>
<td></td>
</tr>
<tr>
<td><strong>Egalitarian ideal, without special needs for some groups</strong></td>
<td></td>
<td>- Ethnicity is no concern here/Distrust breeds distrust (weak position)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- We are exposed to racism (strong position)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- The position as a Sami victim is outdated (strong position)</td>
</tr>
</tbody>
</table>