

'The same care providers over time who make individual adjustments and have competence' Older South Sami People in Sweden's expectations of home nursing care

Tove M. Ness RN, PhD (Associate Professor)¹ , Siv Söderberg RNT, PhD (Professor)²  and Ove Hellzèn RN, PhD (Professor)³ 

¹Faculty of Nursing and Health Sciences, Nord University, Namsos, Norway, ²Department of Nursing, Mid-Sweden University, Östersund, Sweden and ³Department of Nursing, Mid-Sweden University, Sundsvall, Sweden

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This study is part of a larger research project designed to examine the view of home nursing care from the perspective of older South Sami people in Sweden. In the present study, we present findings from the point of view of their expectations of home nursing care. The Sami are an indigenous population living in northern Sweden, Norway, Finland and the Kola Peninsula, and consist of different Sami people, of which the South Sami population is one. This population consists of approximately 2000 persons living in the central regions of Sweden and Norway. Fifty-six older South Sami people participated in the study. Semi-structured interviews

were conducted over the telephone and were analysed using latent content analysis. The main findings show how older South Sami people's expectation for home nursing care contains the same care providers over time, individual adjustments and competent care providers and do not differ from the general Swedish population. Interpersonal interaction is a hallmark of nursing care and other healthcare disciplines. Ideally, interpersonal care is achieved when individual care providers have few care receivers, which promote continuity in care, individual adjustments based on the care receivers individual needs and care providers with professional and relational competence.

Keywords: South Sami people, expectations, home nursing care, qualitative content analysis.

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Introduction

This study is part of a larger research project designed to examine the view of home nursing care from the perspective of older South Sami people in Sweden. In this study, we present findings concerning their expectations of home nursing care.

The Sami are an indigenous population living in northern Sweden, Norway, Finland and the Kola Peninsula. The United Nations define indigenous people as having a historical continuity in areas later occupied or colonised by foreign nation states. Indigenous people look at themselves as different from existing populations in the same areas, striving to preserve, develop and transfer own traditionally areas and ethnic identity to future generations (1). The Sami people have their own culture, customs,

language and connection to their own land (Såpmi) through a natural economy of hunting, fishing, reindeer husbandry and farming. The size of the Sami population is approximately 80.000–100.000 people. In Sweden, there are approximately 36.000 Sami people (2), and about 2.500 support themselves completely or partly from reindeer husbandry (3). The reindeer husbandry is organised into economic associations called 'samebyar' (Sami villages).

International research shows that the Sami in the Nordic countries have a much better health situation compared to other indigenous people in the Arctic regions (4,5) and that they have a similar health status as the rest of the population (6), and the same life expectancy and mortality patterns (7). Research shows (e.g. (8)) that indigenous peoples tend to have a lack of confidence in health and care services. In Sweden, reindeer-herding Sami have lower confidence in primary health care and psychiatry services compared to the majority population (9), and Sami people also have lower confidence in

Correspondence to:

Tove M. Ness, Faculty of Nursing and Health Sciences, Nord University, Finn Christensens vei 1, 7801 Namsos, Norway.
E-mail: tove.m.ness@nord.no

municipal health and care services compared to the majority population in Norway and Sweden (9,10).

Being old and being Sami can imply challenges and concerns, because these people cannot participate in earlier activities because of impairments, for example, hunting, reindeer herding, fishing and berry picking. This can lead to less contact with their families (11), isolation and loneliness (12). Living as a minority in a majority population can influence health negatively, meaning the older Sami can be specifically vulnerable (13). For the Sami people, this has created a twofold issue. First, they have to fight against a general lack of knowledge about the Sami and Sami culture. Second, there are even minorities within the minority, such as being a South Sami (14) and the fact that the South Sami people are a minority within the minority means that their unique culture is hidden by the North Sami culture. According to Turi, Bals, Skre and Kvernmo (15), the South Sami people have lost their homogeneous cultural identity.

An interview study with 10 older South Sami people receiving home nursing care revealed feelings of being less valued than the majority population. The same study revealed the ongoing subtle colonisation that the South Sami are still exposed to, and they are treated as other Norwegians and their cultural background is not considered (11). Another study by Ness, Hellzen and Enmarker (16) showed that nurses in home nursing care had trouble understanding the culture regarding the South Sami. Some nurses were challenged when older South Sami people had different views on time and knowledge about disease, which could involve complications in the patient–nurse relationship and could threaten patient safety. According to Hanssen (13), being old and Sami with dementia living in a nursing home highlight the necessity of a common language and cultural understanding in order to offer care in a dignified way for the patient, next of kin and care providers. Having cultural competence as care providers has a connection to greater well-being for the care receivers (17).

Among others, Muñoz and Luckman (18) and Leininger and McFarland (19) state that communication is fundamental in nursing care, and therefore, transcultural communication is important in caring for patients with a different cultural background. Problems based on cultural differences and challenges, communication difficulties and psychological ill health are common when meeting people with different cultural backgrounds. The fact that nurses' cultural perception affects the outcome of the nurse–patient meeting and can lead to problems in communication is a recurring concern (20). Nurses must be aware of cultural differences in their work that might affect the care they give, and they should talk with persons with different cultural backgrounds in order to provide good care. In the literature, it is shown that nurses feel insufficient in the meeting with patients and that

they wish to become more culture-competent (e.g. (21)). Such issues might thus arise in meeting between South Sami patients and nurses in home nursing care.

Logically, when older South Sami people contact health and care services that do not have knowledge about the Sami culture, there is a risk of not receiving individualised care based on the cultural competence of the care providers. This can result in impaired well-being and meaningfulness in daily life for older Sami. Increasing cultural knowledge among care providers also increases the understanding of other cultures. Care providers themselves must actively seek cultural knowledge in order to be better able to care for people with different cultural backgrounds as a way to increase person-centred care. Therefore, the aim of this study was to describe older South Sami people in Sweden's expectations of home nursing care.

Material and methods

A qualitative design was chosen for this study. When studying peoples' experiences, and lives, it is important to talk to them to try to understand the world from their point of view (22). The aim in this method is not to generalise, but to see the uniqueness in each situation, using an inductive style, where the participants' perspectives become the foundation of new knowledge (23).

Context

The Sami population consists of different Sami people, which the South Sami population is one. This population consists of approximately 2000 persons living in the central regions of Sweden and Norway. The South Sami people have a close connection over the national border due to the traditional reindeer migration, and because of this, there are close family relations between South Sami in Sweden and Norway (24).

Participants and procedure

Altogether, 189 persons with South Sami background were asked to participate (in three rounds) by written request. Fifty-six older Sami people agreed to participate in the study (25 men and 31 women) and in the age of 65 to 90 years (median = 74). All participants came from the South Sami area in Sweden, and all participants were registered on the electoral list with the Sami Parliament. Nonresponse was high, due among other things, to the fact that the data collection took place over the summer, and many possible participants might have been occupied with reindeer herding. All participants lived in their own homes. Several of the participants had expectations about home nursing care.

Interviews

Semi-structured interviews (c.f. (22)) were conducted over the telephone by an interviewer with South Sami background during the summer of 2016. The participants were asked to describe their expectations regarding home nursing care. All interviews were recorded and transcribed verbatim by the interviewer. All personal information was replaced with codes.

Analysis

The interviews were subjected to qualitative content analysis. Content analysis is a method that systematically analyses written or verbal communication (25) and can be defined as 'a process of identifying and categorizing the primary patterns in data' (22). Manifest content analysis, as used in this study, has the advantages of being close to the empirical data and therefore maintaining reliability (26).

The analysis was conducted in the following three steps. The interviews were read several times in order to get a sense of the whole. The text was then structurally analysed and read to identify meaning units, guided by the aim of the study and labelled with codes. The meaning units were then condensed. The

condensed and coded meaning units were analysed and compared with respect to differences and similarities and were subsequently abstracted into subcategories. Subcategories were then formulated for subsequent abstraction into categories. An example of the analysis process is given in Table 1. The authors also discussed possible differences in interpretations until consensus was reached (c.f. (22)).

Ethical considerations

Informed consent was obtained before participation, and information about the opportunity to withdraw from the study was given. The study was approved by the Regional Ethical Review Board at Umeå University (No 2016/33-31Ö) in Sweden was carried out and in accordance with the Declaration of Helsinki (27).

Results

Expecting the same care providers over time

The category 'Expecting the same care providers over time' consists of the two subcategories of 'expecting care providers to know and recognize me' and 'not having to explain myself all the time'.

Table 1 Example of the analysis process

Meaning unit	Condensed meaning unit	Subcategory	Category
I don't want so many care providers. I want them to recognise me. //... maybe they can follow a schedule so it is the same person every second or third day? My sister in law had help, and she did not really make a connection with any of the care providers because there were so many. And if you are ill, you get even worse if you do not have a connection with any of the care providers.	Not many care providers. Being recognised. Maybe follow their own schedule. Sister-in-law did not make connection with care providers. Worse if too many and not have connection.	Expecting care providers to know and recognize me	Expecting the same care providers over time
If I need care in the future, I would appreciate if they consider my needs and my clinical picture.	Would appreciate if care providers see needs and see clinical picture	Seeing my needs	Expecting individual adjustments when receiving care
I don't care where they are from (the care providers), if they are Sami or not. //... Yes, they can be who they are, I simply don't care. //... The only thing that matters is that they are competent. They must know what they are doing.	Do not care whether care providers are Sami or not. Must not what they are doing. Being competent.	Professional competence	Expecting care providers to have competence
...I expect them to be interested and to have the knowledge they need so they know how to care for old persons.	Must be interested and have knowledge. Know-how to care for old persons.	Professional competence	Expecting care providers to have competence

Expecting care providers to know and recognise me

Most participants stressed that they expect the same care providers over time when receiving care in the future. Although most participants hoped, they would be able to manage without help from any care providers. A small number of care providers could represent continuity and was therefore an important issue for several participants. The number of care providers there can be while still ensuring continuity was mentioned. Is that correct?, and one said:

‘I think 5 or 6 care providers is enough - some who receive care have 10 to 20 care providers who comes and go from the house’.

A small number of care providers were of importance to several participants because they wanted to know the person providing the care, and vice versa. Additionally, some participants expressed sympathy for temporary care providers during vacation time. The need for being recognised was highlighted, and some told about experiences of receiving care from other family members and thus had expectations about their own care. One said:

‘I don’t want so many care providers. I want them to recognise me...//... maybe they can follow a schedule so it is the same person every second or third day? My sister in law had help, and she did not really make a connection with any of the care providers because there were so many. And if you are ill, you get even worse if you do not have a connection with any of the care providers’.

Living in rural areas was seen as beneficial by some participants because they know everybody, and therefore future care providers. One person pitied those living in urban areas because their care providers will probably be unknown to the care receivers. They expressed that a small number of care providers who know them can represent continuity.

Not having to explain myself all the time

Expecting a small number of care providers were expressed by the participants in relation to having to explain their needs to several different care providers. Having many care providers suggests that one will have to repeat information about one’s own needs. One person expressed a fear of stress for both care providers and themselves:

‘I believe that if it’s the same personnel, then I will not have to nag about my needs all the time... //...

having to nag means being stressed for me, and that is not good for the one helping me either’.

Another reason for wanting to know one’s care providers was that unknown care providers might represent anxiety about becoming exhausted. One person expressed it in this way:

‘Not having the same personnel means that I’ve to explain about my needs all the time...//... I think that is very exhausting...//... having to tell the same things all the time’.

Expecting individual adjustments when receiving care

The category ‘*Expecting individual adjustments when receiving care*’ consists of the two subcategories of ‘*seeing my needs*’ and ‘*being flexible*’.

Seeing my needs

Most participants stressed that if they find themselves in a situation needing care, they expect care providers who see their needs. This could involve everything from how to receive care and make food to what to get from the grocery store. In addition, some participants highlighted the need for care providers to consider their clinical picture. One person expressed the need for seeing their clinical picture in this way:

‘If I need care in the future, I would appreciate if they consider my needs and my clinical picture’.

Another issue that was relevant and important for several participants in seeing their needs was to consider their possible demands when receiving care. Several participants highlighted the hope of being treated well. This was also expressed by one person who in addition was concerned about being violated by care providers:

‘This is so they can care for them humanly and not violate them too much. They have to consider ones needs and one’s specific situation’.

Participants also expressed that they sympathise with care providers having their own routines when providing care, but still hoped that care providers will consider their needs.

Being flexible

Some participants highlight the need for care providers to be flexible when providing care. One person had worked as a care provider in the past and told about their own

experiences of being flexible as a care provider. The same person hoped that care providers would do the same as she did as a care provider:

'I think they should be flexible. I have worked as a care provider and I had to be flexible towards the person in need of care...//... You must see what the individual person needs...//... you must therefore be flexible. Yes, I think that'.

Being flexible could also contain other dimensions for the participants. One person underscored that being flexible means letting the person receiving care decide for themselves what care they need. The same person highlighted the need for deciding for herself as long as possible:

'I do want help with what I need help for, and I do want to decide for myself as long as I can'

Several participants highlighted that getting care when they need care as well as to the extent that they need care was something they expect from future care providers.

Expecting care providers to have competence

The category '*Expecting care providers too have competence*' consists of the two subcategories of '*professional competence*' and '*relational competence*'.

Professional competence

Several participants underscored that professional competence is one of the most essential characteristics a care provider is expected to possess. Therefore, participants' expressed that if they could choose the characteristics of future care providers, this characteristic would be appreciated. One person said:

'I don't care where they are from (the care providers), if they are Sami or not...//... Yes, they can be who they are, I simply don't care...//... The only thing that matters is that they are competent. They must know what they are doing'.

Professional competence also included knowledge according to the participants. Knowledge in this context is about their diseases and condition and then knowing how to care for them based on this knowledge. One person also highlighted the need for knowledge about how to care for old persons and:

'...I expect them to be interested and to have the knowledge they need so they know how to care for old persons'.

Professional competence also means providing the necessary time when visiting and providing care. In this context, using time wisely means that care providers use all the time needed to see the care receiver's entire and complex clinical picture.

Relational competence

Competence for the participants also meant relational competence, and several participants stressed that relational competence is a major issue when receiving care. Relational competence contains the dialog and that the dialog works was seen as essential for the participants:

'...when I need care in my home I hope I can communicate well with the care providers...//... yes, so I can talk to them, so I think there's something there...//... yes, that the dialog works'.

Another topic mentioned concerning relational competence was care providers' ability to be friendly and cheerful. This could be expressed by using humour:

'I hope they are helpful, nice, and can contribute to a good laugh'.

Another participant highlighted the importance for care providers to be polite when coming into and leaving their houses. Having relational competence also means using all the time needed when providing care for the participants. This could represent having time to sit down and talk to them as care receivers.

Discussion

Before discussing the implications of our findings, we acknowledge that our study has limitations. With regard to transferability, we accept that our study reflects the expectations of a small group of older indigenous people who constitute a national minority and who also constitute a minority within the group of Sami people. Our sample was also based on persons registered on the Sami Parliament electoral list in Sweden, which means that each individual must meet two self-reported criteria: (A) The person must consider himself or herself as being Sami and (B) any of the person's parents or grandparents must have spoken the Sami language in their home (28). We do not argue that the findings in this study are necessarily applicable to all older South Sami people's expectations of home nursing care or other cultural groups of Sami people because the Swedish Sami Parliament electoral list does not constitute a complete list of people with South Sami background. Another limitation is that the study only reflects expectations from older South Sami people living in Sweden, not in Norway.

The aim of this study was to describe older South Sami people in Sweden's expectations of home nursing care. In the interviews, they reflected their expectations of home nursing care. The expressions of their desires to home nursing care correspond well to the expressed needs of the general Swedish population (e.g. (29)). The main findings show how older South Sami people's expectations for home nursing care contain expectations of the same care providers over time, individual adjustments and competent care providers. Because we found no studies focusing on older South Sami people's expectations of home nursing care, we discuss our findings in the light of general studies of Sami people's and other indigenous populations' experiences of municipal health-care services in addition to the Swedish National Board of Health and recommendations.

The category '*Expecting the same care providers over time*' could be understood as the interpersonal level of continuity of care that concerns encounters between care providers and care receivers (30). This is in line with Worrall et al. (31) who state that continuity in care is beneficial and important when older people receive care and according to Russel et al. (32) who state that continuity in care is connected to improvement in care receivers' functional level and psychosocial well-being (33). The present study specifically highlighted expectations of the same care providers over time, meaning continuity regarding personnel and information from future care providers.

Traditionally, continuity of care is considered to be a prerequisite for quality of care (34). The benefits of continuity in care providers are well-documented and are seen as a universal need for most people who receive nursing care, and not just as an issue for specific patient groups (35). The Swedish National Board of Health and Welfare emphasises the importance of continuity in care for older persons over 65 years of age (36). For example, they flag the essential fact that the average number of staff in home care over a 14-day period has increased from 12 to 15 from 2007 to 2017. This increase is a well-documented fact in home nursing care in other Western countries, for example in Norway (37) and in Canada (38). This is in line with the participants in our study who highlighted the need for the same care providers over time, and therefore continuity in care. They expressed expectations to be recognised and known by care providers and not to be forced to explain about themselves all the time when receiving care. The lack of continuity is also seen as a barrier to care, for example by indigenous peoples in Canada meeting different physicians in their municipality (39).

The category '*Individual adjustments when receiving care*' could be related to the Swedish National Board of Health and Welfare (40) where they emphasise the shift from older persons as a group, to focusing on the older

individual as unique, worthy and capable. This means moving the focus away from the disease or disability and towards the person's experiences related to disease and risk of disease, in other words, towards more person-centred care (41). In our study, the participants indicated an expectation for person-centred care and for meeting care providers who are able to see their needs as care receivers.

Individual adjustments when receiving care might facilitate care receiver's empowerment when the care providers show respect, listen and share decision-making with the individual person (42). To make individual assessments of a care receiver's needs is an important task that requires good knowledge and skills on the part of care providers and is according to Leplege et al. (43), a cornerstone of person-centred care. In our study, the participants highlighted the importance of care providers having sensitivity and flexibility when meeting with care receivers.

Individual adjustments when receiving care is a key issue in the care of older persons and, according to Taylor et al. (44), is a routine that helps care providers to determine the quality of their work. In order to achieve a good atmosphere in the meeting between care providers and care receivers, the older person's satisfaction with nursing care, participation and well-being must be taken into consideration. Logically, this means that care providers should take into account the care receiver's individual beliefs and values. Therefore, the care receiver's cultural background might be of importance. If this is true, it means that care providers should consider our study participants' South Sami background with its specific culture as important in order to adjust to individual needs and to provide person-centred care.

In a study where eight Sami men and women between 25 and 70 years of age were interviewed regarding their own or close relatives' experiences with local health and welfare services, Hedlund and Moe (45) found that care receivers had to adapt to care providers and that individual needs were not considered. This leads to the feelings of powerlessness and marginalisation among the care receivers. Melbøe (46) also found in her study about Sami persons with disabilities that individual adjustments were not made when next of kin only spoke Sami language, and information was only given in Norwegian. Participants in our study highlighted the need for individual adjustments when receiving care in home nursing care, and this might therefore imply, for example, speaking the Sami language if that is an individual adjustment that the care receiver expects.

The category '*Expecting care providers to have competence*' can be seen as an interpersonal dimension within nursing competence. Nursing competence has been defined as the capacity to integrate knowledge, skills, values and attitudes and to use these in the specific contextual

situation in practice (47). Patients have defined competent nursing skills as technical care and nursing knowledge (48) as well as providing individualised and patient-focused care, related to the person's needs and being able to create a caring relationship with involvement, commitment and concern (49).

Our study participants had some concurrent views of competence in nursing, and they expected care providers to have professional competence and described this, for example as having the knowledge needed about their specific situation when providing care. According to From et al. (50), being cared for by a competent and skilled care provider with sufficient time should be seen as a prerequisite for receiving good, safe and secure nursing care. For the individual older persons, the criterion of quality, including receiving practical professional care from competent personnel, is important (51). In addition to professional competence, our participants stressed the importance of relational competence and described this as having the ability to talk to care providers about everything, and having a laugh. These different views of competence in nursing show that competence in nursing is multifaceted and comprehensive.

Seeing care providers with relational competence as crucial is in accordance with, for example, Jacklin et al. (39) who found that care receivers with indigenous backgrounds in Canada perceive the care they receive from physicians in their municipality as better when the care provider has a relational-centred approach. This is in line with our participants who stress that seeing their needs when providing care is essential regarding individual adjustments for the individual care receiver.

The Swedish National Board of Health and Welfare (36) underlines the importance that care providers should have competence regarding language and culture concerning national minorities. This can be seen as progress because Melbøe (46), for example, stresses that the welfare system today offers standardised services that are adapted to the majority population and that this leads to inequitable services because services are not adapted to Sami thinking, values, attitudes or philosophy of life. Participants in our study requested relational and professional competence from future care providers, but they did not express a specific need for care providers to hold knowledge regarding cultural competence when asked to narrate about own expectations about home nursing care. Even if our participants did not express it specifically, such needs might be implicit when expecting competent care providers who see individual needs when expecting individual adjustments when receiving care.

The aspects of care indicated above are all associated with an interpersonal dimension of care (38), but we know little about what older indigenous care receivers expect from future care. The expressions of our participants' desires for home nursing care correspond well to

the expressed needs of the general older Swedish population. The categories in our study address areas of dissatisfaction that have reported in Nordic and international research, including lack of continuity (51,52), poor adjustment (53) and lack of competence (52). Despite needs for improvement, several studies report a high level of general satisfaction with received care from older persons' perspectives (51,54).

The interpersonal dimension of care is a core element of health care (30), and this dimension of care implies the involvement of interpersonal interaction or relationships between care providers and the individual care receiver. Knowing each other generates commitment from the staff towards the patient and generates trust in the patient with respect to the staff (30,55). Establishing a trusting relationship upholds stability and presumably enhances the continuity of care (56). The staff-patient relationship is highlighted as a prerequisite for understanding patients' needs and overall situations which in turn is a prerequisite for individual adjustments when receiving care (57). Competence, professional, relational and cultural can thus be seen as a key component in care.

Our results show, to some extent, that the interpersonal dimension in care is requested in our study population. Even if, for example, discontinuity is unavoidable in health care, our findings show that there is considerable potential for improvement of home nursing care and that there are no differences between our participants with South Sami background in Sweden and the general Swedish population.

Methodological considerations

This study focuses on describing older south Sami people in Sweden's expectations of home nursing care. One of the strengths of qualitative research can be seen as its insight into complex phenomena, but it is often limited by small samples and might therefore not be generalisable. When reading this paper, it is important to remember that the findings presented are based on our participants' personal expectations and are discussed strictly from their perspective. The intention of this paper is not to generalise the findings, but only to illustrate the complexity of the expectations of older South Sami people in Sweden.

Telephone interviews were chosen as 56 informants participated in this study. This can be seen as disadvantageous in relation to face-to-face interviews, due to the loss of nonverbal and contextual data (58). Despite these challenges, Novick (58) questions the assumption that loss or distortion of data is detrimental to the interaction the conclusions. Telephone interviews might, in fact, be preferable when interviewing hard to reach informants (23) and when covering sensitive topics (e.g. (59)). Having an interviewer with a South Sami background was seen as preferable due to their knowledge about the

South Sami language and culture. Because South Sami people tend to live in sparsely inhabited places and because over 100 people should be reached, telephone interviews were chosen for the data collection.

Conclusion

In this study, our intention was to give an overall picture of older South Sami recipients' expectations about home nursing care. The findings show that older South Sami people's expectations for home nursing do not differ from the general Swedish population. Interpersonal interaction is a hallmark of nursing care and other healthcare disciplines. Ideally, interpersonal care is achieved when individual care providers have few care receivers, which promotes continuity in care, individual adjustments based on the care receivers' individual needs, and care providers with professional and relational competence. The question of cultural competence is briefly discussed in this study, but will be more closely reported in our next study.

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Conflict of interest

None.

Author contributions

The work presented was carried out in the collaboration between Ove Hellzen, Siv Söderberg and Tove Mentsen Ness. Tove Mentsen Ness carried out the initial analysis; however, all three authors have reflected on and continuously and critically worked with the assessments until a consensus was reached. All three authors have also contributed to the writing of the manuscript.

Ethical approval

The study was approved by the Regional Ethical Review Board at Umeå University (No 2016/33-31Ö) in Sweden and was carried out and in accordance with the Declaration of Helsinki (27).

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