COMMUNICATION AND DAILY CARE

OF SAMI PATIENTS WITH DEMENTIA:

HEALTHCARE WORKERS` EXPERIENCES

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Preface

My journey through this study has been exciting, educational and challenging. It has been both exciting and challenging to be able to choose an interesting theme so 'close to home'. Through the process I have learned how to use research methods and learned how the different phases of research fit together as a whole. It has been new and educational for me to be able to create my own research.

Thanks to University of Bergen for giving me the opportunity to carry out this study and for all of the inspiring lectures throughout my studies.

I would like to thank all of my informants for all the insightful interviews. Without all the information I received I would not have been able to examine this phenomenon, which I had wanted to look in to more closely since the start of my studies.

A big thank you goes to my anonymous contact person in the nursing home who informed and found all of the participants for me to interview.

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Abstract

Purpose: The purpose of the study is to gather new knowledge on the experience of healthcare staff in their communication and daily care with Sami patients with dementia.

Method: Data was collected through five individual interviews. Interviewees were healthcare workers in a facility in Northern Norway who had daily care experience with Sami patients with dementia. The data from the interviews was analysed using descriptive and exploratory content analysis.

Results: Healthcare staff reported that language was essential to the quality of care. Other essential factors included their knowledge of the Sami culture as a means of supporting the patients' identities and activating their memories. Furthermore, awareness and focus were noted as supporting elements in care.

Conclusion: The data confirmed the assumption that healthcare staff had faced problematic situations when working with patients from native Sami populations. The interviews revealed how healthcare workers dealt with problematic situations; including the use of interpreters, taking language classes and the use of dictionaries. It seemed that all the problems noted by healthcare workers had solutions but that the overall issue of communication problems with Sami patients' needs more awareness.

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1 INTRODUCTION

As a registered nurse, I gained my work experience in a nursing home in Northern Norway, which had both emergency care and long-term care departments. At this nursing home, I took care of Sami patients in both of these departments and noticed the importance of my own expertise of Sami culture and language. For example, in emergency care, Sami patients often thanked me for translating words from Norwegian to Sami and for communicating medical terms in culturally relevant ways. Multimorbidity is often the reason for patients ending up in long-term care facilities and therefore, I was able to use my Sami knowledge to communicate and explain everyday situations to Sami patients in long-term care. For example, when patients with dementia were receiving medication, being fed and/or bathed, I was able to explain to them what was happening and assure them.

According to the World Health Organization (WHO) coding system, ICD-11, dementia is a progressive condition that affects a person's cognition including memory, orientation and communication skills and can lead to limited daily activity and behavioural and psychological symptoms (WHO, 2018). Losing the ability to take care of oneself without assistance from family or public healthcare services increases the need for long-term care. In Norway, 80 % of the people living in nursing homes have some type of dementia (Norwegian Ministry of healthcare services, Dementia plan 2020).

In patient care, communication can be regarded as an instrument used by practitioners in providing a feeling of safety to their patients. Communication is essential for ensuring that the patient and caregiver understand one another and that the patient is clearly informed of routines and treatment. Understanding requires communicating in the same language but also involves the use of body language (Schyve, 2007).

Most Sami people learn Norwegian at school as a second language whereas Sami is the mother tongue and is learned at home before commencing school. This is relevant with regards to dementia patients because memory loss can result in the forgetting of the most recently learned language (Rokstad, 1996). Therefore, in cases when Sami dementia patients interact with Norwegian healthcare workers at nursing homes, there is a heightened possibility for language and communication barriers between them.

1.1 Sami culture

The Sami tribe refers to a group of people located in Northern parts of Europe. The majority of the Sami population live in Norway with around 40 000 living mainly in the Northern county of Finnmark. In northern Finland, around 5700 Sami people live in Lapland, approximately 17000 Sami live in Northern Sweden and around 2000 Sami live in Russia, mainly located around the Kola peninsula. Sami people who live near the sea are called sea-Samer, the ones living near rivers are called river-Samer and the Sami who are reindeer herders live mainly in the mountains with the reindeer. Despite small geographical distances between the Sami and other population in Northern Europe, the passing of cultural heritage between Sami people is very different from others. Traditionally, Sami people have used nature to sustain themselves, through fishing, hunting, herding reindeer and using naturally occurring materials for building and making clothing and jewels. Despite the mainly traditional ways of living, a number of Sami's from recent generations have relocated to urban areas in search for opportunities, which are not available in the Northern parts.

There are several Sami tribes, which all have their own Sami language including North Sami, South Sami, Ume Sami, Pite Sami, Lule Sami, Inari Sami, Skolt Sami, Akkala Sami, Kildin Sami and Ter Sami. These languages have many similar features except for Skolt Sami, which has adopted some elements of Russian (Helander, 1992). In Norway, the dominant Sami languages are lulea samisk, southern Sami and sea Sami which are spoken by roughly 25 000 people. Given the estimated 40,000 Sami in Norway, this indicates the low proportion of the Sami population who speak their mother tongue (Arbeids- og inkluderingsdepartmentet, 2009).

If a person identifies him or herself through language, the near extinction of some of the Sami language means that the Sami identity may be impacted. In the Sami culture, the family, including distant relatives such as godparents, are considered to be in the 'inner circle' and hold great importance. In Sami families, it is usual for the family to take care of their elderly (Sosial- og Helsedepartement, 1995). In Sami culture it is also usual to communicate in a more indirect way (Dagsvold, 2010) and silence is considered to be a form of communication (Møllersen, 2019).

In the traditional Sami culture, it is not common for the elderly to be placed in care/nursing homes as non-institutional care is preferred. A study amongst healthcare workers in Northern Norway (Hansen Blix and Hamran, 2013) suggested that multiple

factors lie behind the Sami's reluctance to seek institutional healthcare services, including long distances, cultural norms and (Norwegian) language competence. There have been numerous clashes between Sami tribes and Norwegians living in the more southern parts of Norway. The conflicts between these two groups have predominantly been related to land rights regarding housing, mining, fishing and hunting, as well as the Sami's rights to their own cultural heritage and language. As a result of these conflicts, a Sami parliament was established which holds elections and meetings regarding internal and external matters pertaining to the rights of Samis (Helander, 1992).

The 'red thread' through all of Sami culture is the heavy reliance on nature. In the Sami life, food, clothing, hobbies, family and friends are all connected to nature in some way. The Sami language is also deeply ingrained in nature; although some of the vocabulary is not geographically bound, certain words are specific to the Sami population living in a particular region. For example, a hill and a section of a river or sea may have its own unique word.

The traditional national dress, the Sami Kofte, is a colorful garment which reflects where one comes from. Each Sami territory has its own Kofte with unique patterns and colors that represent the bloodlines, the national flag and nature. Nowadays, the traditional Kofte has seen some modern twists being added by younger generations, for example by using materials other than wool and more modern patterns and colors. Sami people are known for their colorful and creative handicrafts made from naturally occurring materials including bone, skin, silver, gold, stones and wool. Sami-owned land and Sami traditional professions have, over time, been adapted to suit more contemporary needs within the service sector, industry, travel and public sector. For example, Sami handicrafts are more often made with modern crafting tools. As a result of long distances to cities and business districts, there are a large number of independently owned, local Sami business in the Northern areas. Many of these businesses are currently inspired by a growing demand for tourist activities including fishing and hunting holidays, cabin holidays with ice fishing and snowmobile/husky/reindeer transport, hiking, aurora borealis hunting and slow living by the bonfire. People have showed great interest in the Sami traditional life, food making and culture in general. (Utdanningsdirektoratet, 2015).

As a result of cultural changes over time, elements of Sami culture and language were threatened in the past. In this regard the worst era was between1850-1980. During this

time, Sami children were not allowed to use Sami language at school, only Norwegian was permitted. This has resulted in generations of Sami people who have been cut off from their mother tongue/native language and have experienced shaming and "Norwegialization". These children have also adopted Norwegian traditions, language, values and religion in school and therefore ignored the Sami ways of life. However, the generation after 1980 have, to a large extent, recovered from this and brought back traditional knowledge and history through books, Sami news, poetry, as well as joining political parties (Minde, 2005).

As of 1989, in response to "Norwegialization", the Sami population have had their own parliament which works towards Sami democracy and rights in Sami land. The Sami parliament is called Sametinget and is located in Finnmark, Karasjok. The major concerns for this parliament include the laws affecting the Sami people and the laws of Finnmark regarding planning and building, culture, reindeer herding, training and place naming. Legislation around these areas are particularly relevant to the Northern culture and thus need to be regulated so as to work in-line with national laws and regulations. In this regard, legislation and rights pertaining to language and identity are particularly relevant with regards to the provision of healthcare services (Sametinget, 2019).

Norwegian legislation around Sami rights states that a country cannot claim aboriginal lands for its own purposes and that cultural heritage, including language, must be supported by national finances. Sami people only have the rights to use cultural products for sale purposes. The laws on Sami rights also stipulate that Sami people in Norway have the right to education and healthcare services which are delivered in their mother tongue/native language (ILO169, 1991). However, the law also states that the provision of services in native language/mother tongue is restricted to pre-arranged appointments (which allow for the booking of translation services); emergency services are not required to be delivered in the native Sami language.

The study presented in this thesis explores the experiences of Norwegian healthcare workers in their communication with and daily care of Sami dementia patients living with long term illnesses.

1.2 Dementia

Dementia is the term used to describe symptoms related to a decline in brain function. Some examples of diseases that cause dementia include Alzheimer`s disease, dementia with Lewy bodies, Huntington`s dementia or Parkinson`s disease, vascular dementia, Pick`s disease and frontotemporal dementia. Alzheimer`s disease is the most common form of dementia followed by vascular dementia. Alzheimer`s disease is also the second leading cause of death in the world, following heart disease (Johns, 2014).

Dementia as a generic term is used to describe a condition whereby the brain suffers from an organic failure. Dementia can be a sign of an acquired brain malfunction with symptoms such as lack of mental capacity and decline in psychological processes such as memory, language skills and thought processes. Therefore, a person suffering from dementia may show signs of reduced cognitive function in orientation, learning, logical thinking, communication and planning, as well as aphasia and agnosia. These symptoms of dementia affect an individual's ability to manage day-to-day activities (Tretteteig, 2016). Furthermore, a dementia diagnosis is chronic and the symptoms are incurable (Rokstad, 1996). As dementia develops, a person becomes more helpless and disabled. Behavioural and psychological symptoms such as irritation, apathy, depression, anxiety hallucination, delusions and confusion are also common in dementia and have negative implications on a person`s life (Ladecola, 2010).

An autopsy of a dementia patient will show parts of the brain which are clogged and structural changes in neurofibrillary tangles and amyloid plaques. Dementia is common in the elderly, but little is known about what differentiates natural aging from dementia (Johns, 2014).

As dementia develops, a patient will eventually require assisted living services or a nursing home to assist him/her with daily activities. As new environments can be challenging for dementia patients, it is important that any new environment is as 'home like' and familiar as possible to help the patient cope with the change. Furthermore, the design of the living facility must be arranged in a manner which encourages patients to complete daily tasks and activities. This is where recognisability and identity amongst with own culture needs to be supported. As dementia affects a person's self-perception negatively, it may cause apathy and isolation which can lead to loneliness and creates social barriers thereby impacting quality of life. For this reason, it is important that the social environment is adapted in such a way that the patient can maintain the level of

activity which aligns with their identity. Persons with dementia may also benefit from joining associations or clubs focused on physical activities or cultural services such as libraries, cinemas or concerts; all of which have activating effects on the individual (Norwegian ministry of healthcare services, dementia plan, 2020).

Technology can provide useful tools, which enable dementia patients to keep in contact with their family, organizations or healthcare services. Identity is the core of personality and can be described as a feeling, consciousness and evidence of the self. A person's identity is based on feedback from others as well as one's own opinions about oneself. Identity is a tool for seeing ourselves, seeing how others see us and it is used when we observe our surroundings. Feelings of identity can change if we feel different from others and it is related to our feelings about our life management. Feelings of defeat, cognitive impairment, perceptions of reality or memory changes in dementia can be negative and permanent. Therefore, going through these stages of dementia can be experienced as a life crisis for the patient (Norwegian ministry of healthcare services, dementia plan, 2020).

Dementia can lower the ability to master feelings and emotions and therefore, things which have already been processed, might resurface in dementia patients. The loss of memory can have a significant effect on rational thinking and thus prevent a person from understanding a situation/context as a whole or in its entirety. For this reason, dementia can cause negative feelings such as anger and frustration when experiencing loss of identity, culture, language and control over one's own life (Rokstad, 111, 1996).

The staff in a nursing home have an important role in the daily life of patients; they are present in both the negative and positive patient experiences and are experts with regards to patient needs. Goal oriented and stabile routines are central to the work of nursing home staff, as their work requires patience, competence and capacity, as well as a professional approach. Nursing home staff who have well-functioning communication channels with teams of experts leads to motivated caregiving for patients. Structure and support to patients' daily activities is highlighted within dementia care and healthcare professionals are expected to provide this (Rokstad, 1996).

Daily activities include those actions, which take place from when a person wakes to when s/he goes to bed. Activities include personal hygiene (bathing, brushing teeth) and eating, which are referred to as *personal care activities*, but also includes other activities such as baking or hiking. Additional *instrumental activities* include those, which

require the use of tools, such as a telephone, washing machine or other technology. The field of dementia care benefits from this systematic way of grouping personal care activities because it makes it easier to report which activities the patient can carry out themselves, with guidance or with help. If there is need for help with daily activities, it suggests that the patient's motor skills are lowered along the path from sensing, perception, cognition, programming and motoric to reaction (Tretteteig, 2016).

Additional activities, which are used for rehabilitation, are called *environmental treatment*. Environmental treatment usually has two goals: increase activity levels and/or reduce symptoms. The most used environmental treatment amongst dementia patients is music. This type of rehabilitation requires that the patient is familiar with and enjoys the music being used. Listening, singing and moving activates not only cognitive functions but also the senses and can bring back memories from the past. Other environmental treatments can be anything from watching old movies to making traditional food (Tretteteig, 2016).

Although there are large numbers of dementia patients in institutional care, the healthcare services have not assumed the responsibility of these patients permanently. Condition, are evaluated every three months and reported to the municipality with suggestions. The length of the admittance depends on the development of symptoms, somatic changes and the suitability of the services offered to the patient by the institution (Rokstad, 1996).

Increasing the provision of healthcare services is essential because demographic forecasts indicate that the number of people with dementia will double by the year 2040. Healthcare provision can be increased for dementia patients by raising the competence and capacity of staff, improving the physical environments and increasing the involvement of voluntary workers and specialist healthcare services (Norwegian Ministry of Healthcare Services, Dementia plan 2020).

In 2014 there were 40 000 long-time care patient places available in Norway and 80% of these patients had dementia; this equates to approximately 32 000 places assumed by dementia patients (Folkehelseinstituttet, 2014).

The annual total cost of dementia care in the Norwegian health sector is estimated at 2.9 mil. Norwegian Kroner and long-term care is responsible for 60% of these costs (Vossius & Selbæk, 2015). Long-term care in an institution costs 75% of a person`s

yearly income up to 90 068 kr and 85 % of the income above. Although the costs per patient place varies between municipalities, these figures clearly show that dementia is a growing concern (Lovdata, 2011).

The culture of care, refers to the notion that the care provided is aligned with the surrounding environment and context. That is, the surrounding community provides the economic and political framework for the provision of care but when different care cultures interact, the less dominant (smaller) culture most often becomes embedded in the dominant culture of care. The three main elements of culture are organization, norms and beliefs (Kitwood, 2019).

1.2.1 Communication and linguistic problems

Ideally, communication should allow two people to understand each other. This understanding can also be achieved through non-verbal communication using movements, body positioning, facial expressions, eye contact, or using appropriate noises (which are not words). However, the use of physical contact and touching must feel safe and reassuring and therefore the use of non-verbal communication needs time, focus and devotion (Horn, 1993).

In intercultural contexts, communication is complex because language competency is not standardized amongst individuals and can therefore lead to misunderstandings in health institutions (Thornquist, 2006; Horntvedt, 2015).

Illness can result in situations where a person loses the ability to speak a learned language and remains only with native language skills. This is a common occurrence amongst people with dementia (Moe, 2004).

Communication is essential in our relations with other people and we verify each other as individuals through communication. A lack of communication may lead to reduced self-esteem and isolation. Communication includes verbal and non-verbal communication; from spoken words to body language including tone of voice, eye contact and clarity of the voice amongst others. Communication guidelines for work with dementia patients include speaking slowly and clearly, using help questions and giving them time to respond, assuring that you have understood what they are saying, putting things on simple terms, staying calm and listening as well as making eye contact (National healthcare service, 2017).

Communication consists of the following components: observing, feeling, needs and requests. In the observational phase, we look in to the situation and analyse what is happening and this is followed by the feeling phase where we decide whether we are experiencing judgement, joy, hurt, fear or amusement, for example. Thereafter a decision is made regarding what is needed and determine what can be done about the situation for ourselves or others (Rosenberg, 1943).

Communication plays a big part in our lives and it may also be affected by symptoms of dementia. The goal of communication is to be understood through using the resources available to us. As a tool, communication refers to the act of assigning words to feelings, thoughts and occurrences. The ability to express one's feelings and receive feedback are important elements of communication. Symptoms linked to dementia that may cause communication issues include aphasia (loss of words), memory loss and loss of understanding. Therefore, nonverbal communication may play a bigger role in communication as dementia develops. As a result of memory loss in dementia, the use of words may be affected and can result in insecurity and feelings of depression. For this reason, it is helpful to encourage dementia patients to use words. Furthermore, if an individual with dementia is made aware of their situation/issues and their resources, opportunities and goals, a plan can be activated to maintain or improve their current language use. Disease progression and the development of dementia symptoms can cause aphasia (loss of words) and eventually lead to silence. Dementia related symptoms have a destructive impact on all language apart from spontaneous voices (Horn, 1993).

For communication to be maintained and language skills retained, it is crucial to use words and vocabulary frequently, as well as in different contexts. For example, using words in both family and work-related contexts may contribute to a growing vocabulary. Indeed, language as socialization is dependent on these contexts and therefore by using it frequently allows one's vocabulary to grow and strengthen. The amount of language use required to improve vocabulary varies between individuals (Kayam, 2014).

In healthcare one of the practitioner`s main instruments in patient care is communication. This key instrument ensures that the patient and the practitioner have a common understanding with regards to routines and treatment, but also that the patient is informed of the situation and diagnoses. When communication fails because of language barriers, there is an increased risk of errors, bad quality of care and a risk to the pa-

tient's safety. Communication failures can be divided into three threat categories: communicational barrier, cultural differences and low health literacy (Schyve, 2007).

As most of the healthcare workers in the Sami regions are not Sami, they do not typically speak the language and have limited knowledge of the Sami culture. For this reason, it is not unusual that cultures collide in the nursing homes in these regions. Although most Sami people have learned the Norwegian language, dementia leads many patients to revert to exclusively using their native language/mother tongue. This means that when Sami patients with dementia meet Norwegian healthcare workers in facilities, language barriers are common and communication relies entirely on hand gestures, facial expressions and listening to the tones of voice. This in turn may lead to frustration, misunderstandings and poor healthcare.

2 THEORETICAL FRAMEWORK AND EARLIER RESEARCH

2.1 Person-centred care

The term *person-centred care* was first used by Tom Kitwood and Kathleen Bredin (Kitwood, 2019) and refers to putting the patient's needs and happiness first, no matter the illness they are faced with. Person-centred care sees the person and uses healthcare services to plan, develop and monitor in accordance with the individual patient's needs. In this approach the patient and their immediate family are centrally placed as the experts of their own needs and values. The aim of the approach is to focus on well-being and meet the patient's needs and consider them as a complete person with desires, values, social life, family situations and lifestyle choices. When using person-centred care, the patient's core/inner family circle are included as a resource in the care process. (Nasjonal Kompetansetjeneste, 2017).

Dementia care has improved remarkably in the past decade as standards and expectations have been met with positive planning which considers the needs and resources of the individual. Patient activities now play a bigger role in the care plan for dementia and there is a process of evaluation throughout followed throughout patient care. Pressure to provide higher quality care has risen as the pressure of ethical care has increased. Primary care is no longer simply about meeting the physical needs of patients but more about suiting the care plan to the patient's personal needs. In the current care culture, the main concerns are cost-effectiveness, structural inadequacies, limited professional capabilities of the staff and poor staffing levels (Kitwood, 4-5, 2019).

Training is a means of taking care of the healthcare workers by developing their skills. Education provides context to the concepts being used in a subject and implements them in to the practice. Training in person-centred care is dependent on personal knowledge of a patient, include their routines, culture and relationships. Sicknesses like dementia threaten the patient's identity and therefore requires   a lot of positive feedback, attention, encouragement and devotion from healthcare professionals. Equality, good communication and openness are also crucial when working with other vulnerabilities. In conclusion, professionals need to meet the psychosocial, social and physical needs of the patient in order to provide quality care (Kitwood, 137-139, 2019).

2.2   Philosophy of caring

Daily interaction and the provision of care to dementia patients requires both professional knowledge and self-awareness. For this thesis, I draw upon Kari Martinsen`s philosophy of caring as the theoretical framework for the concepts of caring and interaction. Caring is a practical act made possible by togetherness, solidarity and professionalism without expecting anything in return. Caring also means that the carer does not use the context/situation against the person being cared for. The goal of caring is to exercise highly moral practices with the aim of curing or relieving pain.

From Kari Martinsen`s perspective, the nurse's professional opinion is very important when seeking to understand a patient's ability to cope in specific situations. This is because nurses are in daily contact with patients and are familiar with the particular situations which cause distress and/or frustration to a patient. Due to their familiarity with patients, nurses are also able to interpret and understand patient reactions and behaviours which may be misleading and confusing to others. The nurse's in depth understanding of the patient is a result of long-term, daily interaction through the stages of dementia, combined with additional information from the immediate family of the patient. The extensive personal and medical information and experience that the nurse has with the patient may mean that s/he is a reliable spokesperson for the patient; however, this is not guaranteed. Understanding a patient's identity is a learned skill and by using these skills, healthcare professionals are able to support patients whose identity is threatened by their illness (Martinsen, 1989).

According to Kari Martinsen`s philosophy of caring, it is difficult to examine the nursing practice from a research perspective because nursing and practice can be considered as two interacting parts. The philosophy of caring describes the act of caring as rational, practical and high in morals. Furthermore, nursing and caring are not the same concept; nursing is not only caring and caring is not only nursing. Nursing requires the nurse to hold multiple roles and consider the patient in a context beyond simply a person who needs care. The act of caring is a relational and ethical process which requires an non-egocentric approach and the act of helping is considered as being human and acting like a human. However, in order to offer professional care, practical methods must be learned and the concepts of suffering and helping must be understood; it is more than being a 'good Samaritan'. Important knowledge lies in practical experience and this practical knowledge is often omitted within the nursing science perspective,

which is typically more method oriented and restricted. Nursing must include aspects of curiosity, questioning and wondering. However, the nursing science perspective can be problematic because the individual may exclude themselves from the context and may not consider their own role and impact on the environment being examined. Caring is fundamental to nursing and involves empathy, which is often seen as a female moral. According to Martinsen, caring is a situation-orientated, responsive, intuitive, holistic and context dependent phenomenon (Martinsen, 1989).

Martinsen (1989) assumes a feministic point of view and describes "professional care" as focused nursing resulting in better medical patient care. According to caring theory, the goal of good patient care starts from concrete actions and responsiveness whereby nurses must understand and recognize patient needs using their own knowledge and experience. This theory underlines the importance of professional knowledge within relief and help. Martinsen states that caring is the main tool for nursing. Nurses need to build relationships with patients by getting to know them and seeing them in their own contexts. This also requires them to follow the norms, regulations, activities and needs of society (Kirkevold, 2000).

Martinsen (1989) sets the basis for caring as a primary need in human relations. She reminds us that everyone may require care at some point and therefore, the act of providing care can involve self-reflection and improvement. Self-reflecting starts from one's relations with others. According to Martinsen, caring is a prerequisite for living as a human because our existence is heavily influenced by others. In a professional perspective however, the term caring must be free from expectations. Martinsen is inspired by philosophy of phenomenology and believes that caring is a result of patient experiences. In care situations, there are two active parties, the caregiver and the cared for. Caring is fundamental and natural (Martinsen, 1989).

Martinsen (2002) also focuses on power, and how power should be divided in a patient - caregiver relation. Nursing entails engaging and responsive caregiving with a positive aim and therefore, high moral standards should be used to prevent the misuse of power in nursing practice (Martinsen, 2002).

2.3   Research done earlier on the subject

A literature review from common databases, books and articles revealed different opinions and issues around the meanings, use of concepts and procedures with regards to the care of Sami dementia care. Pubmed, Cinahl, Oria and Google scholar were used to search for literature. The first searches on 'Sami patient with dementia' in PubMed and genetic searches in ALS in Oria and Cinahl provided no hits. The subsequent search on 'Sami dement' in Pubmed yielded five hits on screening, incidence and prevalence of Alzheimer`s type dementia. After checking my search in the MeSH-database, I used the search services, Sami health. The hits I got after this were mostly screenings, pilots and suggestions on how to improve healthcare systems, as well as five references that supported the importance of this study. The literature also revealed that Australia, Brasilia, Malaysia, United States, Russia, Sweden, Finland and Canada face a similar situation whereby more research is needed to support healthcare personnel working with a growing population of elderly Sami patients. Further key word searches on language barriers in healthcare yielded results from the United States, New Zealand, Australia, South-Africa, Ireland, Islamic countries, England and Canada, as well as results from the immigrant care field in multiple countries. The research focused on patients' and healthcare professionals' experience of language barriers in healthcare systems with multicultural staff teams. The most relevant studies for this thesis focused on the influence of language barriers on patient safety and the ways in which a multicultural operating team is experienced by colleagues. After the data collection (interviews) was completed, a search for 'Sami dementia health Norway' on PubMed and Google, provided interesting results on the influences of cultural background on intercultural dementia care and the use of joik in dementia care.

Based on the search results, I concluded that there are few studies relating to Sami in the north of Norway and therefore there is a need for more knowledge of Sami patients with dementia. This is especially true considering the predicted growing numbers elderly Sami patients. The perspectives of healthcare personnel in this field may provide a different point of view than the one provided by immediate family members of patients.

After completing the analysis of the data, I renewed my search using search terms including language barriers, healthcare, lack of cultural-related information healthcare Sami and need of integrated care Sami. My strategy to find the right search words

stemmed from my research questions for which I used the "three-legged question" technique (Bjørndal, Klovning & Flottorp, 2007). This strategy approaches a research problem in three different categories: the people you are researching, what type of intervention you are interested in and what aspect you are researching. In the current study the people are Sami patients with dementia, the intervention was to find out what tools help healthcare professionals in daily care and the aspect of interest was the communication between patients and healthcare professionals. The studies I chose to review were the ones related to my research questions, with a preference for the most recent studies.

2.4   Language barriers

The literature relating to language barriers reported that Sami patients with dementia live at home longer than the Norwegian elderly and receive home care support for as long as possible. This indicates that there is a certain comfort to stay at home even if support is less available (Mukadam, & Cooper, 2007; Hanssen, 2012; Hansen Blix & Hamran, 2017).The studies also identified a fear of language barriers amongst the Sami elderly. Language barriers in healthcare is a known issue (Larsen, Normann and Hamran, 2016) which needs more focus in order to find ways to deal with it. In the worst case scenario, language barriers may lead to poor patient care and cause risky situations with misunderstandings (Kale, 2010; Van Rosse, De Bruijne, and Suurmond, 2016). Language barriers between Sami elderly patients with dementia and Norwegian healthcare professionals have also been documented previously (Hansen Blix & Hamran, 2013).

The documented issues regarding unsatisfactory healthcare services amongst Sami generations are mostly based on language related issues. Therefore, in light of the previous research on the effects of language barriers in Sami healthcare provision in the general population, it is possible that these issues are multiplied in the provision of healthcare to Sami dementia patients (Nystad, Melhus and Lund, 2008; Turi, Bals, Skre and Kvernmo, 2009; Kvernmo, 2014). In addition to general language and cultural barriers, ethnic discrimination might also be one of the reasons (Hansen, 2015) why Sami youth report lower levels of health than the main population (Bombak & Bruce, 2012). The various language issues arising in the healthcare sector has resulted in the use of different tools and strategies including interpretation services and the provision of services in the pa-

tient's mother tongue (Kale, 2010; Dagsvold, Møllersen, and Stordahl, 2015) .Previous research has also highlighted the importance of cultural self-expression (Hanssen, 2011).

2.5   Lack of cultural-related knowledge

Cultural knowledge is also an important aspect raised within the field of multicultural healthcare provision. The increasing number of elderly patients is a growing issue, which also pertains to the Sami population. This means that the number of Sami patients in dementia care is also estimated to increase in the future, which in turn highlights the importance of understanding their culture-related needs as well as gaining more scientific dementia related data for the future (Catania & Panegyres, 2017). Within the modern standard of integrated care there is a demand for updated information about cultural changes because these matters are not often included in nursing education (Repo, Vahlberg and Salminen. 2017).

2.6   Need of integrated care

Previous studies have highlighted the importance of creating a 'home like' feeling through the use of familiar landscape and culture which cause feelings of belonging. The literature also states that integrated care as a principle, has become mainstream thinking amongst vulnerable patient groups such as the elderly. The is also a demand for further research to enable the provision of integrated care to extend to multicultural patient groups (Goodwin, 2010; Gaski, 2011; Lewis 2018).

3 PURPOSE AND RESEARCH QUESTIONS

3.1 Purpose

The purpose of this study is to explore and describe healthcare workers' experiences of caregiving to Sami patients with dementia in Norwegian nursing homes and what kind of support they have provided. In addition, this study will explore the language resources and native cultural knowledge amongst healthcare providers working with Sami patients in nursing homes.

3.2 Rerearch questions

What kind of experiences do the healthcare workers have in working with Sami patients with dementia in nursing homes?

4 METHOD

4.1 Methodology

In this chapter, I will describe the methodology used in this thesis with the aim of being transparent and provide insight in to the choices I have made. This will enable the reader to be critical of the work presented.

In this qualitative study, I have placed focus on the insight of the lived phenomena of Sami patient with dementia in the healthcare system. These lived phenomena are explained through the interviews with healthcare workers in Sami areas. This is because healthcare workers gain expertise through the provision of daily care to these patients. I want to shed light on the arising themes around this subject as well as find new and interesting meanings linked to it. My curiosity lies in the daily care and established routines that provide the best individual care for these patients. This research has the goal of examining the experiences of working with Sami patients with dementia from different perspectives and levels of expertise. The data for this research is based exclusively on the interviews with the informants (Kvale, 1996).

In this qualitative research, I have used semi-structured interviews to provide descriptive and specific data for analysis. The interview method provides direct access to the values, views and feelings around a topic of interest. This provides insight in to the daily routines within a phenomenon from an objective perspective (Kvale, 1996, 27-37).

All of the data was used and the responses from the interviews were used as citations and meaning units. All the interviews were transcribed directly in to Norwegian without translating. Parts of the transcripts were translated into English so that they could be used as examples in this thesis.

4.2 Recruiting

Registered nurses and licensed practicing nurses were recruited for the study based on their willingness to partake. This populations was selected because they interact and communicate directly with Sami dementia patients on a daily basis and were thus

thought to have the most to share. As a part of the planning process, I considered the location and selected two nursing homes in separate towns, with a large proportion of Sami inhabitants. This was to ensure that the nursing homes had the relevant patient group of Sami dementia patients. At one of the nursing homes, the head of the department provided contact details for the assistant head. The nursing homes were contacted in the planning phase to establish whether there was interest in taking part in the study; each contacted nursing home was provided with an information script about the study vie email (see attachment 2). Once approval was received from the Norwegian Centre for Research Data (attachment 3), the assistant head of the department shared the information script with the staff during the daily handover and interested staff were provided with my contact information. The eligibility criteria were as follows: staff have worked at the institution for at least six months, had experience with the relevant patient group and were willing to provide informed consent for participation – there was no age criteria for participation. The assistant head introduced me to the participating staff as a master student conducting research related to my master thesis.

I scheduled interviews based on times and dates that suited the staff and allowed them to take part in interviews lasting up to an hour.

4.3 Participants

The closest observers of Sami dementia patients living in a healthcare system are the healthcare personal working with them on a daily basis. In order to ensure that the facility I contacted for this study was appropriate for the study aims, I wanted to go to the very north of Norway and contact participants in predominantly Sami inhabited areas. This was hoped to provide access to institutions with Sami patients as well as Sami staff, which would allow for comparison with Norwegian staff and thus provide both outsider and insider perspectives of the tools used in care provision. I also wanted to include both registered nurses and licenced practicing nurses because they both have daily experience with Sami dementia patients in nursing homes. It was not possible to include both male and female perspectives as there were no males interested or available to partake.

The facility I contacted has 18 long-term places for patients, three facility places, one municipality somatic place and one emergency place. The facility is the local alterna-

tive to the nearest city hospital. The healthcare personnel I included were public nurses, doctors, doctor candidates, facility leader, registered nurses and licenced public nurses. The institution was suitable for my study as it offers mainly long-term care for patients with dementia.

To increase the validity of the study I conducted interviews with five healthcare staff members in one Northern town that had Sami's living in the nursing home where they worked. I deemed this number to be appropriate for capturing various points of view for the data. Collecting too little data may have given provided too little insight in to the matter, keeping in mind that qualitative research looks in depth at non-numeric data.

Both registered nurses and licenced practicing nurses are caregivers that work closely with the patient and take daily notes on the needs of the patient and any changes in physical and/or mental status. Through discussions with immediate family members, nurses gather information on the patients' background and personal needs. The facility where this research was carried out is predominantly a long-term care department serving 18 patients. The department is identified as a multi-residence housing facility with emergency care and long-term care in Northern Norway. Staff members with distant roles in patient care were excluded from the study.

All the included staff members had some skills with Sami language and worked at the same dementia department. Their responsibility was to provide care for the patients in terms of their daily activities and carry out procedures relating to medicine. All interviewees were females between the age of 30 and 60, with a large variety of cultural backgrounds (their nationalities are presented in table 6). The information on participants' nationalities was collected to ascertain where and when they had learned Sami, as well as their language level. One participant was Sami, one had learned from her Sami parents at home, one had had learned it at school, one had taken a language course and one was self-taught.

4.4 Data collection

The five interviews and observational notes were carried out in the week before Christmas in December 2018. Interviews took place over three days with an average of two interviews per day. Interviews were approximately 20-30 minutes in length and

were all recorded. Every interview followed a pre-determined theme of discussion and observational notes from the interviews were taken during the interview. Observational notes included data about tone of voice, facial expressions, reactions, body language and observed emotions. The notes were re-written to a clearer form after the interviews. The audio recordings of the interviews were transcribed using the word for word method.

An interview guide – a simple form of questions - was developed by me and my coaches and can be found in Attachment 1. The interview guide was written in Norwegian because the interviews with the nurses were in Norwegian. I found the guide helpful to keep the interview going and it helped me to remember my research goals during the interviews. It is easy to lose focus on what information one needs when engaging with the information provided by a respondent during the interview.

The length of the interview was hard to estimate as they were about personal experiences. Interviewees were given an approximate duration of one hour before the start of the interview but on average they lasted between 20-30 minutes. The interviews were conducted one by one in a pre-selected, quiet room away from the department. The interview guide was used and all interviews were recorded.

The most suitable time for the participants was shortly before the afternoon shift change and therefore this time slot was scheduled for two days in the same week. One of the interviews was done later the same week because the participant had been sick on the planned date. Informants turned out to be multicultural, but it was still possible to conduct the interview in Norwegian as a common language.

The interview guide opened with an easy question about the phenomenon being investigated and was followed by relevant prompting questions which could add more personal insight and sensitivity to the initial response given. According to Jacobsen (2005), an interview guide should also include key words to help the researcher and have concluding interview questions, which tie the interview together and provide a red thread throughout. The interview guide helped me to obtain generic information from each interviewee about the phenomena being researched. In addition to the research questions I asked each participant how long they had worked in the field, their nationality, language background and age. This was done for analysis purposes to see what factors may influence the phenomenon being researched. Examples of questions in the interview guide are presented below and cover general questions about the topic, what

aspects are important to them, negative and the positive aspects, suggestions for resolving issues raised and free word and feedback.

"Can you tell me what your general experience has been with Sami patients in this facility?"

"How do you communicate with these patients?"

"What kind of experiences do you have with regards to what has been helpful in this communication?".

These questions were formulated openly to allow for the flow of the conversation and to see where the responses lead the conversation. Table 1 presents the data collected about the interviews and interview-guide can be found in Attachments 1.

The choice for using semi-structured interviews was based on the desire to discover new findings around this under researched phenomena, without restricting the interview to a certain direction or outcome. This ensured open conversation and allowed for unexpected findings whilst keeping the interview topics along the pre-determined themes established during the literature review.

In semi-structured interviews there is a general structure to the questions and a pre-decided topic that needs to be covered which serves as a guideline to the questions being asked. Therefore, the structure of the interview cannot be restrictive because it may prevent extra details from being covered during the interview. Therefore, the semi-structured interview provides the researcher with a large amount of freedom during the discussion. This means that the interview can cover more topics in broader subject areas and leaves room for the interviewee to say and express more during it. The semi-structured interview is useful for small studies or when the group being interviewed is big. The stages of doing an interview include finding a suitable method, planning a schedule, planning and preparing, interviewing, analysing results and finally reporting (Drever, 1995).

There are many ways on carrying out interviews but I found individual interviewing most fitting because it is more private and therefore allows for a trusting and open conversation about the person's own experiences and mastering techniques. The goal of the individual interview is to obtain relevant information regarding the research questions and to find out new information or verify previously collected information. It is im-

portant to keep in mind that an interview is not a debate, the object is the interviewed person and this person should be given the most room in the conversation. The interviewer`s role is to obtain answers and keep the conversation going. The structure of the interview should follow a pattern that creates a red thread throughout. The stages of the interview process include preparation, execution, post-work and analysis (Jacobsen, 2005).

4.5   Analysis

Qualitative content analysis (Graneheim & Lundman, 2003) was used to analyse the interview data. Qualitative content analysis focuses on the subject and context of the data and uses codes and categories to classify them. This method of analysis is used to present conflicting opinions and unresolved issues through the identification of key concepts and interpretation of their meanings. Qualitative content analysis can be used to both manifest and find hidden psychological meanings by including silence, sighs, laughter, posture and gestures in the analysis. In the study, I have used both *manifest* and *latent* analysis of the data because although most of the themes were identifiable by names and other features (manifest), others needed in-depth interpretation and analysis (latent) of the interview notes. In qualitative content analysis, the unit of analysis can be the object of the study or a theme that arises in interaction with the topic being explored. In the preparatory literature review for this study, a number of the articles suggested themes, which were relevant to my research question (Graneheim & Lundman, 2003).

Data analysis was started shortly after completion of the fieldwork. Transcription was started only when all the interviews had been completed in order to keep the themes generic and to avoid drawing conclusions based on single interviews. However, I rewrote my field notes directly after completing each interview because the notes taken during the interview were very chaotic and unclear. By rewriting my notes directly after the interview, the interview was 'fresh' in my mind and I was able to expand my notes – which resembled a mind map - to more complete and clear sentences. The field notes proved useful during the analysis process because they could bring me back to the interview context and envisage the respondent as I went over their responses and gained a deeper understanding of their meanings. The complete data set used for this

thesis consisted of interview recordings and transcripts, field notes and memos written during the analysis process.

Audio recordings of the interviews were transcribed in to a word document for analysis purposes. This required me to write word for word without any judgement or interpretation of the text. I used this approach because all the material followed a generic theme and the answers followed the same structure based on my interview guide. The observational notes from the interviews were used to fill in the details and gaps, which were not captured in the audio recordings. Through this, I was able to give meaning to the story and find the essence of the text without omitting important observations. The observational notes gave depth to the conversation by capturing, for example, the facial expressions, body language and tone of voice of the respondents (Kvale, 1996).

All the findings were included as valid material because I used all the responses as citations and meaning units. All of the interviews were transcribed in to Norwegian without translation to avoid losing detail in the translation process. In analysing the interview material, I used the three steps of qualitative content analysis.

In the first step, I used the transcribed material to identify manifest and latent contents and created a unit of analysis based on the text. This phase was relatively easy as I used the "word for word" transcripts and only some of the responses required deeper thought.

In the second step inserted all the responses in a table 1 as straight quotations and defined and allocated meaning units to them. During this step, I continuously condensed the meaning units into shorter sentences and continues to create even shorter codes for the sentences, whilst ensuring that their meaning was maintained. This is because the codes needed to be short enough to be used in the table 2 as categories for grouping similar interview data/responses.

By organising the data in this way, I was able to present all the interview responses according to the themes answering my research question.

To analyse the data further, I continued to read through the transcribed text multiple times to capture its essence. The next stage of the analysis involved reviewing the observational notes to identify instances, which mirrored the findings in the raw text and/or meaning units created. As the meaning units were condensed in the context of the interviews, a number of underlying meanings were found. At this stage of interpre-

tation, I was able to decide how many sub-themes were required as threads to link the meaning units and create a clearer storyline. This was a neat way to clean up chaotic text. For validation purposed, I marked the finalized sub-themes in the interview transcripts and asked my supervisors to review the transcripts and my observational notes to see if they agreed with the sub-themes. After this final reflection, I was happy with my analysis material because the themes matched the interviews, the sub themes and my transcripts.

After the meaning units were created, the sub-themes were considered against the literature reviewed. This allowed me to finalise the themes reflected by the meaning units and reject false interpretations of the interview text. After reading through the interview transcripts, topics were placed into categories. Codes and themes included anything from events to other phenomena and these were used to understand the context. I found this technique good for analysing interviews and illuminating lived experiences (Graneheim & Lundman, 2003).

Furthermore, the analysis process is illustrated with Tables (1, 2, 3, 4 and 5) in the appendixes.

4.6 Ethical aspects

This project required me to collect personal data from the informants and therefore ethical approval was required. I submitted a notification form to the Data Protection Official and this project was approved for study in accordance with the regulations of the Norwegian Centre of Research Data (511886).

To guarantee voluntary participation and to ensure the informants` right to withdraw at any time, all informants were presented with information sheets outlining their rights, as well as the details of the project and contact information for myself, my supervisor and the University. Every informant provided written consent for agreed voluntary participation.

Voluntary informed consent is an essential part of any research. It means that any data provided by a participant must be voluntary and participants must be informed about the purpose of the research and how the data will be used and stored (Research ethics committees, 2015).

According to Carter (Carter, 94, 2016) the process of informed consent should be ongoing through interactive dialogue between the researcher and informants. The process should include the provision of relevant information and full disclosure to participants who understand the details of the research. To ensure voluntary informed consent in this study, I developed a consent form, which contained detailed information on the project (see Attachments 2). Participants could also receive the consent form via email if this was preferred. To secure the participants' anonymity no names were used in the thesis. To further ensure anonymity, the audio recorder used for the study was stored in a locked safe and kept separately from the notebook and laptop. Upon completion of the project, the audio files will be deleted and the notebook destroyed.

The Norwegian Law of Healthcare Research (2009, §5) requires all healthcare research to be carried out with consideration and care. The law outlines that the research must respect the participants' rights and worthiness. Consideration of the participants' prosperity and integrity must be prioritized above the research society's goals. Ethical, medical, scientific and privacy considerations must be highly prioritized.

Interviews were recorded using an Olympus tape recorder vn-541pc with 4gb built in memory and the sound files were not transferred to any other device or storage space at any point. Interviews were listened to from the device and transcribed in to written form in a Word document that was not shared to any other workspace. The Word document containing the transcripts was stored on my personal laptop where it was used for analysis. The notebook of field notifications was kept on personal shelf at home and out of reach of others. Access to the study data was limited to myself and the two supervisors guiding my study.

Audi recordings and name lists will be kept responsibly without anyone having access to them. All information will be deleted when the research has ended and is published, by 31/12/2019.

5   FINDINGS

In this chapter, I will present the findings from the observational notes and semi-structured interviews with the five informants. The findings describe the experiences of these five healthcare workers in their care for Sami dementia patients. Three of the interviewees were registered nurses and two were licensed practical nurses, all of them were women and had worked at the institution for at least three years. One of the informants was Sami, one was Finnish, one was Russian and two were Norwegian. Participants were aged between 30 and 55 years.

The data analysis resulted in findings relating to the characteristics of the staff, content of the group, aspects thought to be important in the care of patients from native populations, as well as tools used in practical activities. In this section, I will shed a light on the findings in relation to the literature and theoretical framework presented in section three.

Table 6 Characteristics of the informants (n=5)

Profession	Background	Work experience	Sex
RN	Foreign with Sami status	30 years in total, 20 in Norway	Female
RN	Foreign	5 years in Norway	Female
RN	Norwegian, some self-taught Sami language skills	7 years	Female
LPN	Foreign, some Sami language skills due to course	18 years	Female
LPN	Norwegian, moderate Sami language skills from home	23 years	Female
RN=Registered practical nurse, LPN=Practical licenced nurse			

Direct translated quotations will be used as examples of the findings. The main findings from the data analysis were thematized.

The analysis contained four main themes:

- INDIVIDUALIZED CARE

- LANGUAGE AND CULTURE AS IDENTITY BASE

- INTERACTION REQUIRES A COMMON LANGUAGE

- SUPPORTING ELEMENTS

These themes are presented, as they were gathered, in tables 3, 4 and 5 and form the base of my findings. Other important matters brought up in the interviews included the importance of traditional activities in activating patients and the need for continuous communication with close relatives of the patient.

5.1 Individualized care

On a practical level, the informants perceived person-centred care of Sami patients with dementia means as care in which they are heard and seen as an individual. The concept of the individual included who they are as a person, in a community, what they worked with or had as hobby, whether they were religious, whether they had family or friends, and so on. Patients were activated with activities they were familiar with, could relate to and were linked to something from their past. For example, patients whom had earlier worked with reindeer interacted more with reindeer husbandry related news from the municipality. Patients also reacted to stimuli such as a picture of a grandchild or a familiar song. This kind of tailored activation of the patient required good background knowledge of the patient and local colleagues, as well as obtaining information from near relatives and friends. Close family and friends could inform the staff whether the patient was typically active, social or preferred a lot of alone time. This information was easy to access becaus they were situated in a small and tight-knit community where word travels easily. However, the sharing of information was done inside the facility in line with the healthcare workers' non- disclosure agreements. It was understood that patients with dementia needed a familiar person, thing or place to prevent restlessness. Patients did not always have the words to tell staff if they felt something was uncomfortable or pleasant and therefore the staff needed to obtain this information from other channels and/or by observing the patients over time.

One Norwegian nurse had a positive and effective experience of activating passive dementia patients using cultural activities on the Sami national day by making traditional Sami cuisine with patients. She described the situation:

" I was thinking about one Sami food making session we had on the shielded unit and we had this lady as a patient who was Sami and she got a reindeer head with an eye and she just started to carve like. Usually we had to feed her and there she just took the spoon and started and did it all herself and it was so good to see that they still can. Sometimes we hurry with situations and press them in the everyday routines, we should work on that. They should be allowed to try and do things by their own".

This situation was a great example of how something familiar can have a big impact on function and how patients with dementia need routines and engagement with familiar skills to be activated. These reminders seemed to yield good results in the example above.

I observed that rather than generating their answers, the interviewees often had specific examples of how a certain patient or situation had taught them something useful for the job. Knowing the patient as an individual was very important for the quality of care. The interviews also highlighted the importance of starting the care process from the moment patients are admitted, by gathering complete background information about the patient. This information was typically obtained from the patient's close relatives and other healthcare professionals that had worked with the patient. After this information was gathered, it was important to relay the information for further questions but also for it to be reported to other colleagues so as to better understand who the patient is or why they may act or react a certain way. This process of information gathering and sharing for each patient was seen as necessary for providing the best individual care but also to help the healthcare professionals in their work with the patient.

It was acknowledged that daily care became difficult if the patient had a bad day, felt unsafe or restless and therefor all efforts were made to prevent these circumstances. However, sometimes these efforts were not sufficient and caregivers had different methods such as switching the patient's caregiver between shifts, or taking a break and trying again after they had helped another patient. On some occasions a local caregiver was able to activate the patient because they could talk about people, places and happenings which were familiar to both parties and helped with the chemistry between them.

In an interview with a Norwegian nurse, she explained how she knew from a certain cultural behaviour what the patient was feeling. This is how she explained the situation:

" I have only the meetings with different personalities to compare to but for example one patient starts to yoik when she does not have it good and then she starts to sing and expresses it that way, with yoik that is".

The staff had, over time gained personal knowledge of the patient with aphasia by linking certain behaviors to specific reactions. The behaviors were used for expressing reactions after patient had lost his/her words.

The caregivers were proud of their professional knowledge and found it useful for linking together what they needed to know. Knowledge of illnesses as well as individual patients helped caregivers to differentiate between a symptom of illness and a normal reaction for the patient. Many were interested in specific courses and felt the need to link reasoning to create patterns.

Closeness, connection and communication were seen as key aspects for the job. Communication could have many forms and for patients with reduced communication skills, the most useful form was non-verbal communication. The staff used non-verbal communication interpreted from postures, facial expressions and bodily reactions to determine how the patient was feeling. Restlessness for example could be a sign of unease, the need for something and certain facial expression could signal irritation.

One caregiver explained about patient knowledge in daily care as follows:

" It is really individual how restless demented patient can express themselves somehow they calm down a bit, but they can`t really explain the problem there and then. Afterwards when the problem is solved you can see a small sign like holding they`re breast or expressing in some other small way that they are relieved. It is never a big sharing of a problem. Some caregivers see the signs very well and to others they don`t give a big meaning before they have gotten to know the patient".

5.2 Language and culture as identity base

According to the informants, being Sami meant different things to different people. Some people wanted to proudly display it with Sami songs that reminded them of past memories, places or people, whilst others found traditional cooking useful for freshen-

ing memories. To be acknowledged and identify themselves as a Sami seemed to be very important for the patients. This is because the culture and traditions were deeply rooted and defined them in many levels which helped them to remember who they were and how they used to be before the illness. As illness can pose a great threat to identity, it is important to support the patient in maintaining that identity. Language and culture can be used as daily tools to maintain identity and anchor patients in the present reality.

Using the patient's mother tongue/language seemed to be a big activating factor for many of the patients. To hear familiar and safe words being used in a facility environment made the settings more home like and the caregivers achieved deeper contact with the patients. This effect was experienced by several of the informants. It seemed like the Sami patients were more likely to rely on, communicate with and understand the healthcare workers who used Sami language in patient care. Using Sami language also seemed to enrich the vocabulary being used and prevented things being "lost in translation". Language was seen a big part of the patient's cultural identity.

The concept of Sami care was introduced with the use of key words such as multicultural, healthcare and the concept of good care. The ideal model of suitable Sami care is achieved when the patient's needs are identified and met. It is often enough to acknowledge and respect the (Sami) part of the patient, both as a matter of ethics and as a ground rule. In Sami municipalities, 'Saminess' is shown in several ways including patient identity, family or town traditions, choice of language , "a red day" (holiday), traditional food, hobbies or jobs. One informant who was interested in politics simplified the pattern as follows: law sets the ground ruling, there must be organizational support for the process and the town meet the requirements according to the financial plan they have made.

This is how one nurse explained the culture being displayed in the town through attitudes, city sights and many factors one does not usually thin about:

"This is a very Sami municipality we live in because it shows in anything starting from leaflets everywhere. The municipality is very good at showing the pride on being Sami and I have noticed that it has had an impact on my attitudes as well. I have started to cultivate the Sami in me more and I find it inspiring to hold the culture ".

In this example, it shows how the surrounding community can show their pride in a culture and support it. The respondent had become more interested in her own roots

with this support and developed a growing interested in learning the language. The department where the respondent worked was also very Sami based with 80% of the patients of Sami origin. In the place where she previously to lived, Sami culture was not something that anyone took any pride in or ascribed value to. In the history, the informant shared that her mother had lost interest in her own culture and now felt strange when wearing her national dress. Eventually her mother had also stopped speaking the language and adhered to the more common, Norwegian culture.

The municipality had realized that the Sami culture and language had been endangered in the past and therefore took political action to maintain/preserve it. One healthcare worker explained the situation as follows:

"They are working now towards strengthening the Sami part of the municipality here. Yes, but it is a little bit up to who is sitting in the chairman seats in the government, now I sit there myself. Now we have worked very hard to get the actions going in the municipal. The Sami part will just die out or get lost if no one works for it ".

Some families had deep roots in the Sami while others hid them or ignored their identity. People had different relations to their Sami history and heritage and it seemed that the importance given to cultural work changed according to political lines, who was in charge and how important it was to him/her. The current leadership in the municipality seemed to be along Sami lines and this was reflected in the focus on language and cultural matters which also benefited Sami patients at the time being.

Some caregivers noted that it was important to know if the patients had been traumatized by experiences of "norwegialization". This was because they could have reacted to such an experience by either hiding their own culture - as a result of residual shame - or feeling irritated by Norwegian patriotism. However, reactions of irritation could also be the result of other factors, including religion being pressed upon them. This situated is illustrated through the recounts of the "pagan" Sami from the north being pressured to assume the sophisticated ways, language and religion of the people from the Southern cities. Whereas as some adapted to this well, others took it as a threat to their own identity and felt like they had no space to exist.

One respondent explained how others can impact negatively on one's cultural identity and even cause one to hide it:

" My own mum she does not wear Kofte anymore because she got no acknowledgement for it and no one wanted to speak Sami or Finnish with her and when she came here she was just so upset of the whole thing. Then she became a true Norwegian, so if I was there where I used to live I do not think I would have been as interested in the culture I see it in my brothers as well they do not care about it so much it seems to be just me".

The municipality where the respondents worked was explained as being a very close, or even locked community, also in terms of Sami culture. It was possible to 'get in' to the municipality, but one did not necessarily 'fit in', as this required specific knowledge regarding the norms and habits of the community. One interviewee described this like as follows:

"Sami and Norwegian culture. In the Sami culture we do not speak about everything. Yea, it is a little locked, we do not reveal so much about ourselves maybe. You can`t just go to a Sami lady and tell what you did when you were young. You just don't. This kind of things you just take in to count and consider what you are saying. It is a privilege to work in a municipality where you were born. I know everyone and people from around here just need to see a house and they know all the history of it".

Certain parts of this may have been due to the "norwegialization" from the past. Some local healthcare workers had noticed that their own parents who had not previously spoken Sami language, had suddenly started to speak it (out of the blue) with their own children. This was explained as the result of a need for something familiar and easy but also the need to finally be recognized as a Sami person. Other interviewees considered similar situations as an early sign of old age.

5.3   Interaction requires a common language

In all the five interviews the importance of a common language in daily care situations was underlined. All of the respondents had had Sami patients with dementia who mainly or exclusively spoke Sami and as a result agreed that it was important to either learn Sami or work closely with someone who did. Perspectives on this issue differed amongst respondents from different nationalities. Non-Norwegian respondents found it particularly difficult to learn Sami language as they were already learning Norwegian as the common work language. Conversely, the two Norwegian respondents saw their

situation as an opportunity for self-improvement by learning the language and learning more about their own Sami roots. Finally, the Sami representative had a keen interest in sharing her knowledge of her culture and language, not least for the patient`s sake.

In many of the interviews respondents explained that they experienced more closeness with the patients after they had spoken the same language or talked about common contacts and histories. Below are some examples of their experiences:

"For example medicines. When I give them out it is so much easier to explain in their own language and it is easier for the patient to understand why they should use them. Then there is the mealtimes and basically everything from wash, food, medicines and really all the care situations".

The patients also experienced frustrations in care situations when lack of a common language reduced the connection between the caregiver and patient. These frustrations existed despite resources the healthcare workers had to draw on, including their knowledge of the patient, non-verbal cues and patients' body language, translation services and language cheat sheets. It seems that these tools were not always enough and some situations escalated when patient did not receive needed help.

"It is the most difficult situation when you just won`t understand. Then the patient might get irritated or even angry and you just don't get why. You just try to make a meaning and you do not know their background or know the patient and then it can really be a lot of frustration in the situation ".

However, some of the caregivers who did not share the culture or language had learned how to achieve the same closeness as who did. These quotes enlighten on the tools they used and saw on everyday basis:

"Many of the patients understand still both Norwegian and Sami and that is why I try first with the Norwegian. I do remember one time a patient was feeling very uneasy when I was about to give them a needle and she just would not co-operate or understand what was happening. I then picked up a Sami co-worker and she talked with the patient using the language and it went well after that. If she had not been there I do not know what I had done. It is helpful".

"It is very important that there are many Sami speaking nurses. There was another place I worked at in 2012 and there is many with Sami background so it was dif-

ficult not to speak it myself. When the emergency phone rang you could really face the problem. It is not in every shift you have that colleague who can translate for you and then it gets difficult. Where as in here quite many can I think".

"At this department there is this one woman as a patient who is very social and she has promised to teach us some Sami. I can just enter her room and learn a way and start with some buorre beaivvi and it is just easy".

These citations reflect many thoughts and the workers had many good ideas on how to deal with the issues faced and improve the tools they used for help. There were many other ideas about courses to take on ethics, language and culture. Some of the ideas related to where the courses should be taken or through what center, as well as every day tricks such as 'word a day' or 'idea tables'.

The municipality was previously dual cultured (Sami and Norwegian) but has become more multicultural in recent years. The caregivers noted that in their department alone, they had people from Russia, Finland, Thailand and Philippines. This seemed to work here and people were enlightened and curious about the new cultures. In their opinion, this was also enriching for the existing culture but considering the Sami patients in the department, could also result in additional cultural barriers because foreign staff had never heard the language. Foreign workers were also in a more difficult situation because they had had to first learn Norwegian and could only then prioritize learning Sami.

5.4 Supporting elements

In order to communicate with Sami patients, the interviewees used supporting resources and tools. These include colleagues, patients and visitors who speak Sami and translation pamphlets which translate commonly used words from Norwegian to Sami. In some situations, patients, colleagues or visitors had translated messages from Norwegian to Sami to unresponsive dementia patients and in other situations they translated from Sami patients to Norwegian caregivers. Some of the Sami patients and colleagues also offered to teach the staff about the Sami language and culture beyond the care context. Many of the respondents had learned the basics of the most commonly used terms and used them in their daily work to obtain response from the patients and develop a bond with them. It was also emphasized that although cultural knowledge

and language skills are linked, understanding of one does not guarantee understanding of the other. In the interview I had with a Sami caregiver she described her thoughts like this:

" Language is very important with the patients. When you are in a daily care situation with the patient you get a completely different contact when you speak Sami. You have something in common and it is not just the language but also the culture and understanding the culture. The experience of the living world with it gets different for the healthcare workers that speak Sami compared to those who do not. They have it easier and get deeper contact with the patients".

The interviewees recognized that in later stages of dementia, some patients seem to lose their most recently learned language and those who had Sami as a mother language were more difficult to deal with when translation was not available. Non-verbal communication was highlighted as a solution used in these situations. Similar situations had also prompted three of the interviewees to sign up for a Sami language course. The municipality seemed to want to support these language courses for the staff, but registered nurses were not often able to attend these courses as there was a lack of qualified staff to replace them in their absence. This appeared to be rather complex supporting factor. One Norwegian interviewee described the situation in the department as follows:

"When you have those patients with dementia of a late phase it can get very difficult because I don't have the language and they only communicate with it. Then it can be very difficult if you do not have that colleague who speaks Sami but it works because we use body language and read in to situations. It is almost like a baby, you try to find out what is the problem and if you do not understand if it is the pain, need of a bathroom, hunger, thirst or restlessness then... I think this is the main reason why I seek for more language skills and have signed up for a language course".

6 DISCUSSION

I have chosen to discuss all the main themes in the light of existing theories and previous research. Presenting the themes in this way also sheds light on the themes and opens up the terminology around them.

6.1 Individualized care

During the interviews, many of the participants noted the importance of familiarity, understanding and closeness in everyday care for dementia patients. Closeness and familiarity often helped to create a sense of calm in the patients and emphasized the aspect of caring in the healthcare workers' job role. The curiosity of the nurses about the Sami culture also resulted in them learning aspects of the language, culture and background of the patients; as a result of their work, they became experts on their patients. Knowledge of the patient's background was seen as an important aspect of individualized care and amongst this specific patient group (Sami dementia patients), this required knowledge of the culture and language as well as knowledge around dementia, interaction skills and patient knowledge. All of the nurses took a great amount of pride in their work. Each participant highlighted the importance of good communication in achieving good individualized care and communication was repeatedly raised as a challenge in the nurses' daily work, either due to a lack of language knowledge or dementia-induced language barriers. Although language barriers were not expressly noted as a problem, the nurses were not able to overcome this barrier without developing new skills and methods. Individualized care, which involved recognizing, celebrating and taking interest in the patient's identity brought about positive results in patient activation.

Considering the patient as an individual was noted by all the participants as an element of good care. This seems to be in line with Tom Kitwood`s notion of person-centered care which aims to provide good individual care by taking the patient's personal details in to account and resulting in well-being (Kitwood, 2019).

By carefully regarding their patients, the nurses in this study were better able to understand them and therefore make their work more effective and enjoyable. This is in line with Kari Martinse`s description of a 'good nurse' as one which can interpret the pa-

tient and understand what causes them distress. The healthcare workers experienced positive results when they made adjustments to their language and cultural approach to suit their patient's needs. The nurses noted that it was very important to know the patient, their preferences and make personal notes of information provided by immediate family members (Martinsen, 1989).

6.2 Language and culture as identity base

The importance of acknowledging cultural and language factors in dementia care was highlighted in this study. This has implications for the education of healthcare workers practicing in the Northern regions. In the interviews, there were several mentions of the need to include Sami language and culture in the curriculum of healthcare studies in the Northern regions to ensure good cultural care. Many of the nurses noted that the role of language and culture in the provision of care should be introduced at an earlier stage of healthcare education. In an empirical study (Hanssen, 2012) of the role of cultural background in dementia a number of aspects were found to be important for the quality of care. These aspects included the use of a common language; understanding of the patient's spirituality; engaging in expressions of culture (for example joik); understanding of the patient`s cultural needs such as clothing, food or particular ways of life (such as being free-spirited and living close to nature).

This study used hermeneutic, thematic analysis and was a qualitative study that gathered data through interviews with nurses and family members. For ethical reasons, the study did not examine opinions on the current state of the care, but concluded that care can only be fulfilling if a patient is taken is considered as an individual with individual needs. However, individual and group needs may at times collide with objectives and resources (Hanssen 2012) and this was a common theme in the present study. Cultural knowledge and language were strong themes within patient care. Many of the themes resulting from the analysis were similar to the factors considered as important in the quality of cultural care. The informants also underlined the importance of taking cultural needs and individualization into consideration. Traditional clothing, singing (joik) and foods were used for patient activation purposes.

Aside from language, knowledge of the patient's traditional identity was seen as important for providing good individual care. The connection with the patient was often

stronger when nurses found a way to find the person behind the illness. The tradition nature of Sami culture provides many opportunities for integrating culture in to day-to-day care; for example through language, history, nature, food and handicrafts. The nurses in this study could activate the patients by looking at old photos or historic articles, as well as making handicrafts in the afternoons. Patients could also be included in the food making process or accompanied for a walk, which included discussions about the familiar surroundings. Such activities brought back memories for patients but also created a sense of routine. Some of the patients seemed highly sensitive towards the dominant or exclusive use of the Norwegian language because this was associated with memories of "norwegialization". These patients gave positive responses towards Sami speaking nurses.

6.3   Interaction requires a common language

The participants had many thoughts about how to overcome the barriers to functional communication and were willing to use various strategies in order to provide good care. In addition to the issues surrounding the Sami language, the multicultural work environment presented additional issues, including language problems. Some of the languages used in the nursing home, were similar but the workers from the other Scandinavian countries seemed to have more difficulties.

According to Kourkota & Papathanasiou (2014) good communication is an essential instrument for achieving good individualized care and includes understanding, courtesy and sincerity. To help takes time and confidentiality and requires the inclusion of the patient's close relations in to the care context. Good education and experience are the nurse`s tools for achieving this goal. Nursing aims to meet a person's human, biopsychosocial and spiritual needs in the areas of prevention, treatment, therapy, rehabilitation, education and health promotion. The professional knowledge of the patient gathered is very important to manage these tasks and is why communication on all levels is part of the nurse's work role. Communication can be defined briefly as an exchange of information, including feelings, thoughts and information. In light of the findings from the current study, taking individuality into account can be an essential for creating a trusting bond between a caregiver and the care recipient. It is a human way of making care more integrated and personal. In cases where illness posed a threat to the patient's identity, the caregivers considered it their job to support the patient to maintain it. Con-

sidering this, it is clear why the participants specified communication, education, professional knowledge and individualization as the predominant tools used in care.

The fact that healthcare workers were becoming increasingly multicultural seemed to be helpful in overcoming the language barriers they faced. Although the multicultural environment presented the possibility of language barriers, this was seen as more of a challenge than a threat. Similar challenges were captured in a study of perioperative nurses' experiences of communication in a multicultural operating theatre, which focused on the communication between multicultural staff (Clayton Judy, Neville Isaac Anton, 2016). In this study the staff described the experience as challenging but giving, stating that language barriers did exist. Another quantitative study examined the effect of language barriers on hospital care in the Netherlands. The study revealed patients' perspectives on current standards, communication tools used (e.g. using interpreters) and the level of satisfaction in the care received. These findings confirm the importance of using tools to support communication, as was found in the current study.

The majority of healthcare workers in the Sami regions of Norway are not Sami and do not know the language of culture. Therefore, cultural clashes are likely to continue. Most Sami people have learned Norwegian but with the onset of memory loss and dementia, patients are likely to revert to their mother tongue when communicating. This means that when Sami dementia patients interact with Norwegian healthcare workers at the facilities there will be language barriers which may lead to frustration, misunderstandings and poor healthcare. Communication is based on hand gestures, interpretation of facial expressions and tone of voice. Considering that dementia can cause confusion, frustration and misbehaviour in patients, the effects of the illness may also affect communication. Financial shortcomings in the Northern municipalities also seemed to pose a threat for the quality of Sami care with regards to staffing and education of healthcare workers. For example, even though Sami language courses for staff was suggested as a means to overcoming language barriers, this was simply not an option for the highly educated staff because there was a lack of qualified staff who could replace them whilst they attended courses. This was an issue that was repeatedly mentioned in the interviews.

6.4   Supporting elements

Sickness can result in a person losing his/her later learned language and cause them to speak exclusively in their mother tongue, as is often the case in dementia (Moe, 2004). Healthcare professionals have reported patients who have forgotten their later learned languages and switched over to their mother tongue after the onset of dementia (Sosial- og helsedepartementet, 1995). In light of this, it is clear why the informants linked language loss with dementia. The participants dealt with their patients' loss of words by using their mother tongue for communication wherever possible. The most frequently used methods/tools were the use of interpreters, language courses and phrasebooks that covered the most frequently used words for daily care in Sami. The findings in this study differ from the results of a previous survey study by Kale (2010) which examined healthcare workers' language support needs in cross-cultural communication settings. The survey concluded that although interpretation services were needed, it required initiative taking from the healthcare personnel and was rarely used (Kale, 2010). In my findings professional interpreters were hardly mentioned, but the role of interpreter was often assumed by the individuals who were present at the time.

6.5   Methodological considerations

The reliability of a study method can be regarded in terms of four connected aspects; credibility, reliability, validity and confirmability (Graneheim & Lundman, 2004; Polit & Beck, 2012).

The credibility of a study is often measured in terms of how well the study answers the research question (Polit & Beck, 2012). This study used five interviewees which I deemed to be sufficient, based on the level of repetition in the responses given by the interviewees. It would have been of interest to explore how nurses' experience of work with Sami patients with dementia differed in a different setting because people with the same background tend to think alike. However, the multicultural nature of my sample meant that it included a wide spread of cultural backgrounds and thus provided a 'colourful' range of results.

During the interviews, it was brought to my attention that healthcare workers in Northern Norway are very multicultural. For example in the department where the study was carried out, there were also staff from Thai and Swedish backgrounds.

It is assumed that the researcher is not working towards his/her own goals and conclusions, but is reflective and seeking knowledge to answer research questions. In order to prevent the researcher from leading the interview in a particular direction and violating the communication, it is necessary for them to be aware of the effect that they may have on the research. An example of a violation of communication may be when a researcher presents the research in such a way that it results in a desired meaning or perspective from the respondent. For example, gestures such as laughter or facial expressions may cause the respondent to omit certain information or views from an interview, or change his/her responses to be socially desirable/excepted. The researcher is a professional who sets the rules, starts and ends the interview, chooses the subject area, the study participants and analyses the data. This gives a lot of power and therefore responsibility to the researcher. Through learning about the dangers of social violence and staying within the guidelines of research methods one can avoid most of the negative effects of these power roles.

In order to obtain a representative study sample I searched for places in Northern Norway, which are mainly inhabited by Sami people and have institutions with high numbers of Sami patients and therefore the staff that are familiar working with them (Malterud, 2011, p. 56; Fangen, 2010, p.52).

The phenomena that I have studied is rare and therefore there are not many studies to compare and validate it against. However, this is positive as it can lead to new findings and the data can be used for further studies. A research field should not be limited to familiar subjects if the aim is to find new and up to date information that is temporally relevant.

Another possible approach for data collection could have been focus group interviews. As explained by Polit & Beck (2012), this method allows for discussions to flow in groups and can gather more information about a specific phenomenon as other participants can trigger memories and create conversation. It may have been necessary to change to focus groups if the informants were not open in the interview situation in this.

The method in this study used a semi-structured interview guide. If the interview approach had been unstructured (Polit &Beck, 2012) the informants would have spoken freely about how they had experienced the phenomenon (care of Sami dementia patients). This may have led to a free flow of sharing and more information about their

experiences. This would have required me to select the appropriate information for my questions and the ability understand the informants by using an interview guide it ensures that the conversation is guided in a certain direction. According to Polit & Beck (2012) and Graneheim & Lundman (2004), an interview guide is a good tool to increase credibility by sticking to a predetermined research theme.

A valid critique of this study is that the author was familiar with the phenomenon and had lived and worked in the context being studied. This meant that it was difficult for the researcher to distance herself and her opinions from the study. One of the informants was also a former colleague of the researcher (one year ago). This does not imply that the researcher had an impact on this informant directly, but her knowledge of the researcher's opinions may have affected her answers in some way.

Another risk may lie in the fact that the nurses have adjusted to their situation to the extent that they did not think to bring up certain issues without being prompted about them.

The possible issues that may arise in a study are categorized as physical, psychological, social and economic. I dealt with these issues by selecting a research location which did not require large costs, entering researching in a familiar context and by taking the time to conduct the data collection myself (Carter, 2016, 104).

Vailidity is an important consideration for research and consists of internal and external validity. To achieve internal validity in the study I maintained a critical perspective towards the sources and literature I used to develop my research questions. In order to add external validity, I focused on contextualizing the outcomes of the study by considering how they could be implemented (Malterud, 2001, p.483-484).

The validity of a study entails internal and external validity. Internal validity refers to how the results of the study relate to the phenomena one is researching. External validity on the other hand, measures how the outcomes can be applied to other groups and contexts. Measuring these two factors is crucial in every step on the study process (Kvale, 2017). The reliability of a study is dependent on the ability to replicate its results (Graneheim & Lundman, 2004). According to Polit & Beck (2012) this can also be achieved by providing enough detail on the study to allow the reader to repeat it in a different context. The methodology for this study is described in detail and allows the reader to understand the research process as a whole.

The findings of this study gathered from a context, which is similar to many communities in the North of Norway. However it is not possible to claim that all municipalities in the north are similar to the one used in this study. It is also difficult to know whether all the communities in the North are equally multicultural despite having similar surroundings and happenings. This is a small, qualitative study, with a small sample being used to explore a larger community. With a quantitative approach, it may be possible to obtain percentages to make claims about common opinions.

Conducting the interviews in a quiet room outside of the department created peace and quiet for the participants to think through their answers and gave them time to formulate their answers as needed. Interruption may have created misunderstandings and hasty thoughts. In addition, the interviews were recorded which allowed the interviews to flow without having to stop to note things down.

According to Polit &Beck (2012), the confirmability of the study requires the results being in line with what the informants have described. In the research process, the author must be aware of how their personal and professional experiences can influence the study. The author also needs to be aware of their own opinions, thoughts and reflections so as not to affect the study process and/or results. In the beginning of the study, the author must clearly present their opinions in the study background.

It may be considered a weakness if the informants do not read through the transcribed interviews and analyse how well the transcripts capture their meanings. This method is considered the best way to prove the confirmability of the study (Wallengren & Henricson, 2012). For this reason, I followed the analysis method very carefully and presented all the findings in a table after the word for word translation.

According to Bordieu (2016), the deeper meaning of understanding requires looking in to communication as an interaction that arises from practical and theoretical means when an interview takes place. Interview trends have varied from empirical forms, sociology forms and ethnography forms with closed questions or open-ended ones. In all its forms, the goal of research has been to use science to explore the object of study and reproduce the findings for understanding and publication purposes. As any relationship, research also creates a relationship and this is a form of a social relationship as any. An aim of the study was of course to limit random interpretation by using a field notes that enable registration of bodily reading in addition to the "word to word" information. The

conclusion is that the research process is rather tricky in terms of interpreting the deeper meanings and gathering the important data required for drawing conclusions.

Productive communication in the research process should lead to the gathered data being free of subjective reasoning. The correct data should be included and/or excluded and the data should be analysed with an awareness of subjectively experience. Such as one's tone of voice and the emphasis placed on words. An interview is always pre-planned and follows the guidelines although it never strictly can be followed. Understanding cannot exist without seeing the other person's perspective and showing empathy and for this reason it is impossible to truly erase oneself from the situation. However, empathy does not results in understanding and one should always seek for the higher meaning and truth behind everything. Information is intelligible, reassuring and inviting. This aspect of empathy can on some level, verify that researchers have a chance of being truly objective (Bordieu, 2006).

Dementia care amongst Sami groups has been a great interest of mine for a long time. The recruitment of respondents for this study was easy for me because of my existing knowledge as a member of Sami community. I was aware of the problems in this field before I started my Masters studies. During the study, I focused on keeping an open mindset to avoid jumping to conclusions regarding other people's opinions. This is also part of the reason why I used the "word for word" method for transcribing.

A definite advantage of this study being 'close to home', was that I was able to contact reliable participants and therefore trustworthy answers to my questions.

6.6 Conclusion and further recommendations

Further studies in this field should use quantitative methods to examine how dementia effects language skills. More qualitative research is also needed regarding the daily activation of Sami patients and support to their self-identity. In addition to this, research could investigate ways in which to spread knowledge around the language and culture of Sami populations and the specific features required in terms of patient care.

This study examined the assumption that healthcare staff in the North, faced problematic situations with patients with dementia from native populations. The questions posed in the study were used to illuminate whether there was truth behind this assumption and to gain knowledge about the tools and methods that are used to overcome problematic situations. Interviewees shed light on how they dealt with problematic situations, which included the use of interpreters, language courses and the use of dictionaries. It seemed that there was a solution to every problem but that the problems themselves need more awareness. Awareness leads to an understanding of the issues and appropriate procedures to deal with them.

As a positive conclusion, a lot remains to be done to promote Sami healthcare but we seem to be on the right path. It is assuring to note that the issue of Sami healthcare is under consideration on many levels and action is being taken. As the Sami culture is a minority, which exists within a governmental area, it needs support as well as national finances and suitable knowledge included in education to sustain its existence. It also seems that the modern quality of care approach considers individuality to a greater extent, and therefore includes care culture and ethnicity, in accordance with the person-centred care theme.

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Appendixes

Table 1 Graphic illustration of meaning units

Meaning units	Condensed meaning units	Code
*Er det noe som spesielt du har notert i forhold til de som er norsk eller finsk? **«Jeg er sjølv veldig opptatt med språk fordi jeg har opplevet og ser at det er veldig viktig. Språket er veldig viktig når du er med pasienter. Når du er i den situasjonen at du steller pasienten så du for helt annerledes kontakt med pasienten når du snakker samisk. Det er noe som er felles og det er ikke bare språk men det er samtidig kultur og den her kulturforståelse og den hele verden blir helt annerledes en med de som snakker samisk en med de pleierne som ikke snakker samisk. Som snakker norsk. Og du kommer mye lengre frem. Det blir mye dypere og bedre kontakt med pasienten».**	Felles kultur og språk gir dypere pasientkontakt. Kulturen er en del av forståelsen av livsverden.	Felles kultur og språk konkluderer til dypere pasientkontakt.
*Ja. Så om kommunikasjon med disse pasienter da. Du nevnte de med stell. Er det noe annet du kan tenke med som situasjoner som konkrete eksempler hva som fungerte bra? **«Ja for eksempel mediciner. Når jeg deler ut mediciner det er lettere og forklare og det er lettere for pasienten og forstå hva slags mediciner og hvorfor de skal bruke de. Også er det matsituasjon. Det er viktig også. Som alt egentlig fra stell, til mat og mediciner og behandling. Ja og være sammen med de og gjøre ting i lag».**	Lettere og forklare til pasienten hva skjer under behandlingen med felles språk.	Lettere og forklare til pasienten hva skjer under behandlingen med felles språk.
*Så de som har kommet litt lengre med sykdom? **«Ja. Så hvis du for ikke den kontakten med dem så blir det nesten umulig og for eksempel stell eller. Fordi de er redd. De vet ikke hva som skjer. De forstår ikke norsk eller annet. Unntatt morsmålet sitt. Som da er samisk».**	Ofte de veldig demente har kommet seg tilbake med språk og mistet de nylige lærte. De da vil kreve morsmål (sami) til kommunikasjon.	Ofte de veldig demente har kommet seg tilbake med språk og mistet de nylige lærte.

Table 2 Graphic illustration of themes

Tema	Bedre språkkunnskap fører til bedre samhandling med samiske pasienter			
Kategori	Kommunikasjon, samhandling	Støttende faktorer	Manglende resurs, problem	Ideer
Sub kategori	Kurs, skole, multikulturalitet	Kolleger, pasienter, bruk I hverdagen	Finanse, tid	
Koder	Språk forståelse- bedre samhandlig,	Bruk av «frasebok», Bruk av kollegaer,	Brudd i kontakt,	
	Felles kultur og språk konkluderer til dypere pasientkontakt.	Lettere og forklare til pasienten hva skjer under behandlingen med felles språk.	Ofte de veldig demente har kommet seg tilbake med språk og mistet de nylige lærte.	Språk senter i kommune kunne ha gidt mere til pleiefelte men er ikke brukt så mye som man burde. Kurs eller pleieordbok hadde vært nyttig.

Table 2 Graphic illustration of themes

Table 3 Graphic illustration of person-centred care analysis table

	Personsentrert omsorg			
	Grunnlag for pasientkunnskap	**Relasjonelle forhold**	**Nonverbal kommunikasjon**	**Fagkunnskap**
	Grundig kartlegging	grunnlag for å hjelpe dem i hverdagen.	Nyttig og lese kroppspråk hvist man ikke har noen å tolke.	Hadde vært nyttig å lære om etikk, sykdomslære og kommunikasjon med samiske pasienter. Bokmaterialet finnes.
	Kartlegge pasienten livshistorie	de demente blir roligere.	Ved uro hjelper det med nærhet	Savner mere kunnskap.
	Kjent pleier	vet hva de liker og ikke liker eller om de har opplevd fornorsknings-prosessen negativt for eksempel.	Lærer seg pasienter personlige utrykker er en del av kommunikasjon.	
	tettere oppfølging			
	Pleierne blir kjent med pasienter	god relasjon med pasienten		
	Info fra pårørende	vite om pasienten hverdagslige behov.	Å være, rolig, gi nærhet og vise oppmerksomhet, er spesielt viktig med samisk pasienter.	
	blir kjent med dem som individer	Individuell tilrettelegging		
	Når man har jobbet over flere år på en arbeidsplass så har man tettere oppfølging med pasientene.	Mulighet til å tilrettelegge for religiøse behov	Pasientene ser på pleierne om de førstår dem. Vanskelig om man ikke gjør det.	
	dele informasjonen med kolleger.	Forteller pleierne hva om de skal presse på med sosial tilbud eller kveldsaktiviteter.		
	Finnes ikke noe fasit om hvordan man håndterer pasientene, man prøver seg fram og ser hva som fungerer	Snakke om felles kjente kan hjelper på kjemien.		
	Å ikke forstå eller kjenne til bakgrunnen kan føre til at pasienten blir irritert, sint og frustrert.			

Table 4 Graphic illustration of language and culture as identity base analysis table

Tabell 2				
Tema	**Språk og kultur som grunnlag for identitet**			
Kategori	**Språk og identitet**		**Kultur og identitet**	
Sub kategori	*Redusert språkforståelse*	*Språkelig mening*	*Kultur-felleskap*	*Kommunale tiltak*
	Samisk språk kommer mer til bruk ved aldern til de som har det som morsmål. Mange snakker norsk i tillegg til samisk. For lite fokus på samisk språk i huset.	Viktig at pasienten blir forstått på sitt morsmål. Erfart at foreldre har prioritert å snakke morsmålet sitt i alderdommen.	Fordel å kjenne til lokal kultur. Man vet hva som er akseptabert og snakke om og hva som er ikke. Samisk kultur er litt lukket. god harmoni mellom de norske og samer i kommunen Mange pasienter ønsker å dele sin kultur og fortelle historier med bilder. Fordel å bo i kommunen når man kjenner til historien til hver enkelt og vet hva de er interessert i og hva de ønsker å høre om. Lokal kjennskap gir felles samtaleemner, og fører til at pasientene lytter og roer seg. Skulle hatt mer aktivitet. Noen er flinkere og holde mere aktivitet til de gamle en andre. Finnes idee plakater i avdeling.	*Styrker* Kommunen er veldig stolt over den samiske kulturen, men har beholdt begge kulturene. Åpenbart samisk kommune. Kulturen er veldig tydelig rundt. Kommunen støtter de samiske mye i forhold til andre kommuner. Pasientgrunnlaget variere Man kan jobbe mere ordentlig med færre pasientgrunnlag. Folk i den samiske kommunen er villige til å hjelpe. 80% av pasienter i avdelingen er samisk talende. Mange i kommunestyre jobber for å prioritere samisk mere i kommunen.

Table 5 Graphic illustration of interaction requires common language analysis table

Samhandling forutsetter felles språk						
Manglende språkkunnskap			Støtte faktorer			
Manglende samiske språkferdigheter	*Tap av språk/ Demens*	*Multikulturelle språk barrierer*	*Kollega*	*Pasient*	*Pårørende*	*Hjelpe-midler/ kommunal støtte*
Språk forståelse bedrer samhandling Lettere og forklare til pasienten hva skjer under behandlingen med felles språk. Fortelle ting på samisk gir en annen veldig spesielle meningen i motsetning til andre språker. Hjelper og kan språket og kan bruke det til hverdag. Å ikke forstå hva som sies kan føre til	vanskelig å få kontakt med langkomme nt demente pasienter. vanskelig å bli forstått med langtidsdem ente samiske pasienter. Pasienter med langt kommet demens har mistet språket de	Når man bare prøver seg med språk og gjentar mye så er det en fin måte og lære på. Utenlandske prioriterer først å lære seg norsk og da er det viktig at det er noen samisk talende på vakt hele tiden. Man blir fort vant til og bruke de andre til å fortolke og lærer ikke språket selv.	Bruk av kollegaer, Overlappe hverendre eller trekke seg litt ut i vanskelig pleiesituasjon hjelper. Mulig å hente en samisk talende kollega til å tolke hvis de er på jobb. henter kollega for å tolke. Samisk talende kolleger kunne bli tatt mere til bruk og lære	De fleste husker norsk og snakker det. Mange pasienter forstår norsk så man prøver med det først. Opplever en pasient i avdeling som språk ressurs.	ringe pårørende til å fortolke. Viktig å bli kjent med pårørende. Viktig å kjenne og holde kontakten med pårørende til pasientene. ha større fokus på kontakt med pårørende. Pårørende mister sine kjente når de ikke kjenner dem igjen og	*Frasebok* Bruk av «frasebok», Positivt og ha med seg oversettelse av samiske setninger. Positivt i andre kommuner og ha med seg til daglig pleie en liten frasebok hefte. Mulig å bruke en liten pleieordbok med de vanlige frasene. Mange kolleger har lært seg sjølv med språket. Pleieordbok hadde vært nyttig. *Kurs* Samisk høyskole i Kautokeino er en annen mulig resurs til og tilby språkkurs.

Attachment 1 Interview guide

INTERVIEW QUIDE

General info

Følgende spøsrmåler skal skape sentralt mening til phenomena og hva vil intervju person si. Personal data skal være I koder og skal ikke vise I papirene.

Hoved spørsmåler

1. Hvordan opplevelser har du med Samiske pasienter I helsesektoret?

2. Hvordan kommuniserer du med disse pasientene? Har du fått noe hjelpemidler til og bruke?

Hjelpe spørsmåler

1. Gi eksempel om et situasjon som fungerte bra?

2. Gi eksempel om et situasjon som fungerte dårlig?

3. Kjenner du til disse pasientene?

4. Har dere kontakt med pårørende?

Attachment 2 Informasjonsbrev

Vil du delta i forskningsprosjektet?

"Samhandling med samiske pasienter med demens på sykehjem"

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å undersøke helsepersonells erfaring i arbeid med urbefolkning som har demens og bor på sykehjem.

I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål
Målet med studien er å beskrive helsepersonells erfaring med samhandling med pasienter med demens på sykehjem I en samisk befolkning. Studien vil vektlegge språk og kulturelle perspektiver i samhandling med sykehjemspasienter i en samisk befolkning i Norge.

Forskningsspørsmål:
Hvilke erfaringer har helsepersonell med samhandling som samiske pasienter med demens på sykehjem? Hva er positive erfaringer og hva er negative/vanskelig situasjoner?
Studien er en del av masterstudiet i helsefag studieretning sykepleie ved Institutt for Global Helse og samfunnsmedisin, Universitet i Bergen

Ansvarlig for forskningsprosjektet
Instituttleder Guri Rørtveit
Veiledere: Eva Gjengedal og Frøydis Bruvik
Master student Tanja Lukkari

Hvorfor får du spørsmål om å delta?
Vi ønsker å rekruttere sykepleiere og helsefagarbeidere som arbeider på et sykehjem i Nord-Norge i et område med urbefolkning.

Rekruttering: Leder informerer og deler ut informasjonsskriv til personale ved den aktuelle avdelingen. Personalet som ønsker å delta respondere selv til masterstudenten ved E-Mail eller SMS.

Vi ønsker å rekruttere ansatte som har seks måneds arbeidserfaring med denne pasientgruppen, variert alder og begge kjønn om mulig. Vi vil også inkludere både Samisk og norsktalende.

Hva innebærer det for deg å delta?
Det vil bli gjennomført et individuelt intervju om dine erfaringer i samhandling med samiske personer med demens. Intervjuet vil varer inntil en time og gjennomføres på sykehjemmet. Kun intervjueren og den som blir intervjuet vil være tilsted.

Utover spørsmål om navn, alder, utdanninga og relevant yrkeserfaring, vil det ikke innhentes personidentifiserende data.

Det er frivillig å delta
Det er frivillig og delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du senere velger å trekke deg.

Ditt personvern –hvordan vi oppbevarer og bruker dine opplysninger
Data som innhentes vil kun brukes til formålene vi har beskrevet i dette brevet. Alle opplysninger vil behandles konfidensielt og i samsvar med personvernregelverket.

Tilgang til data har kun jeg og veilederne min. Navn og kontaktopplysningene vil erstattes med en kode som lagres på egen navneliste adskilt fra lydfiler og transkripsjoner. Data lagres på kryptert på passord beskyttet PC.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?
Alle data vil slettes ved prosjektslutt, senest 31.12. 2019.

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

innsyn i hvilke personopplysninger som er registrert om deg,

å få rettet personopplysninger om deg,

få slettet personopplysninger om deg,

få utlevert en kopi av dine personopplysninger (dataportabilitet), og

å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra *Universitet i Bergen* har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

Instituttleder Guri Rørtveit E-Mail: Guri.Rortveit@uib.no

Hovedveileder Frøydis Bruvik E-Mail: froydis.bruvik@uib.no
Masterstudent: E-Mail; tanjalukkari@gmail.com

Vårt personvernombud Janecke Veim E-Mail: Janecke.Veim@uib.no

NSD – Norsk senter for forskningsdata AS (personverntjenester@nsd.no) /telefon: 55 58 21 17.

Med vennlig hilsen

Prosjektansvarlig(Forsker/veileder)   Master student

Frøydis Bruvik   Tanja Lukkari
Tlf 48248234   Tlf 45833107
                                                       (*tanjalukkari@gmail.com*)

Field Code Changed

Attachment 3   NSD vurdering

NSD sin vurdering

Prosjekttittel

Indigenous dement patient and healthcare

 Referansenummer

511886

 Registrert

09.10.2018 av Tanja Annika Lukkari - Tanja.Lukkari@student.uib.no

 Behandlingsansvarlig institusjon

Universitetet i Bergen / Det medisinske fakultet / Institutt for global helse og samfunnsmedisin

 Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Frøydis Brudvik , froydis.brudvik@uib.no, tlf: 4748248234

  Type prosjekt

Studentprosjekt, masterstudium

 Kontaktinformasjon, student

Tanja, tanjalukkari@gmail.com, tlf: 45833107

 Prosjektperiode

09.10.2018 - 31.12.2019

 Status

03.12.2018 - Vurdert

 Vurdering (1)

03.12.2018 - Vurdert

Det er vår vurdering at behandlingen vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet med vedlegg den 03.12.18, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte. MELD ENDRINGER Dersom behandlingen av personopplysninger endrer seg, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før endringen gjennomføres. TYPE OPPLYSNINGER OG VARIGHET Prosjektet vil behandle særlige kategorier av personopplysninger om etnisk opprinnelse og alminnelige personopplysninger frem til 31.12.19 LOVLIG GRUNNLAG Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake. Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 a), jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2). PERSONVERNPRINSIPPER NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen: - om lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen - formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål - dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet - lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet DE REGISTRERTES RETTIGHETER Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20). NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13. Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned. FØLG DIN INSTITUSJONS RETNINGSLINJER NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32). For å forsikre dere om at kravene oppfylles, må prosjektansvarlig følge interne retningslinjer/rådføre seg med behandlingsansvarlig institusjon. OPPFØLGING AV PROSJEKTET NSD vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet. Lykke til med prosjektet! Kontaktperson hos NSD: Silje Fjelberg Opsvik Tlf. Personverntjenester: 55 58 21 17 (tast 1)
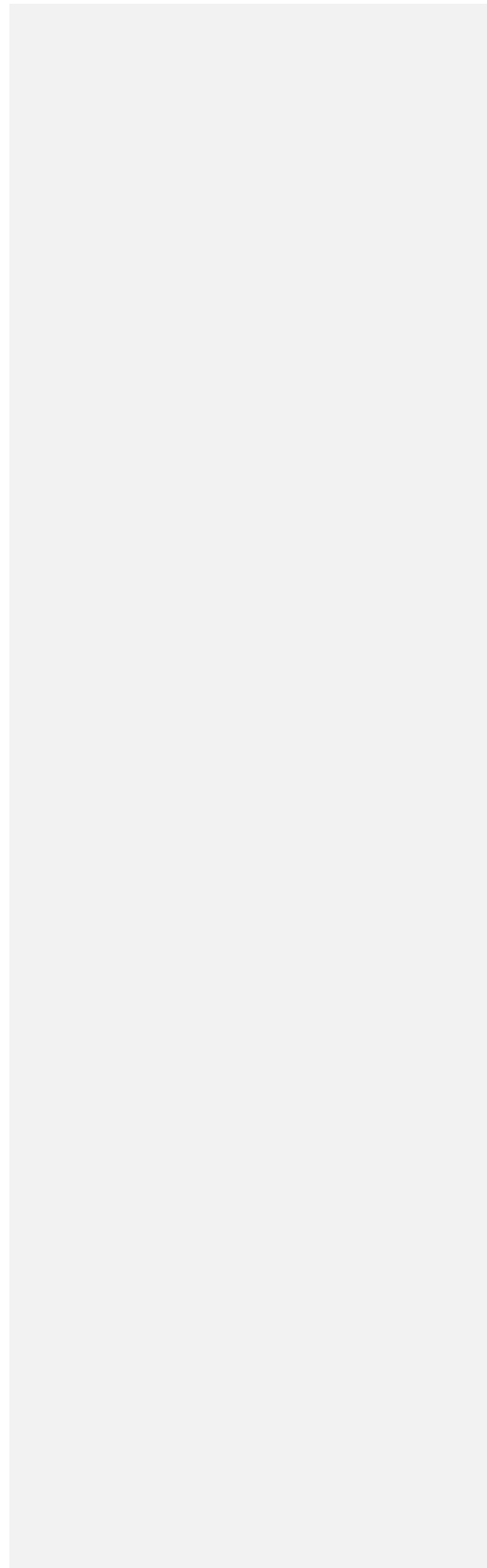
Attachment 4 Samtykkeskjema

Samtykkeerklæring til deltagelse i forskningsprosjektet?

"Samhandling med samiske pasienter med demens

på sykehjem"

Jeg har mottatt og forstått informasjon om prosjektet *"Samhandling med samiske pasienter med demens på sykehjem)*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

Å delta i *intervju*

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. *(31.12.2019)*

(Signert av prosjektdeltaker, dato)