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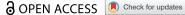
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A culturally sensitive approach to Indigenous older Sámi living with memory loss- disconnected from their environment and spirituality

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ABSTRACT

The aim of this article is to discuss attitudes to memory loss in old age among older Sámi people in the Arctic region of Norway. What preferences and lived experiences are expressed when older Sámi people need health and social care because of memory loss? According to the Sámi Act (§ 108), the Sámi Indigenous people in Norway have a legal right to receive equitable health and social services adapted to the Sámi language, traditional lifestyle and religious customs. However, standard services are offered that are adapted to the majority of clients in a homogenisation of needs and wishes, and older Sámi clients are treated in the same way regardless of their cultural background. Ethnographic interviews and participant observation illustrated as case studies. Older Sámis' long-term connectedness to nature and spirituality makes them sensitive to the changes in the environment. Healthcare personnel enable older Sámi to feel connected to their environment and spirituality in old age, by facilitating culturally sensitive care. This study explores a need of culturally sensitive approach to health care, aiming to increase the understanding of the preferences and lived experiences of Indigenous older people with cognitive impairment.

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KEYWORDS

Culturally-sensitive research; traditions; spirituality; health; Indigenous older Sámi; memory impairment

Introduction

Almost half a million people in the Nordic countries are living with dementia [1]. In Norway the number is estimated at over 100,000 people [2]. However, there is a lack of research on this topic with regard to Indigenous Sámi people and ethnic minorities. Minority ethnic groups often fail to access services and Indigenous people are less likely to use formal health care services [3]. In Norway, many Sámi lack trust in institutions [4]. Such assumptions may lead to exclusion and neglect as well as greater barriers to help and support [5].

The ethnic minority in this article is the Sámi Indigenous people in Northern Scandinavia and Northern Russia, a population estimated at between 60,000 and 110,000. Approximately 70% of the Sámi live in Norway and most of these live in the Arctic region and in the northernmost county of Finnmark, which also houses other ethnic groups, such as ethnic Norwegians, and the Kvens, a people of Finnish oriain.

Recent years have seen several key reforms in public health and care services in Norway, such as the "Coordination Reform" [6] and "Plan for People with Dementia 2025 [7]. One of the main goals is to give local authorities more responsibility to care for patients following severe illness. This means in practice that older patients are discharged from hospitals to their homes as soon as possible. Community care nurses now have a wider field of responsibility, because many homecare patients need more medical care [8]. In the national plan for people with dementia the main goal is a more dementia-friendly society which includes person-centred care (PCC). In principle, PCC is meant to enhance respect for patients' background and preferences. For Sámi people as Norwegian citizens living in a minority situation, there are problems with its implementation. There are particular challenges in the ways Norwegian health care personnel relate to and take care of Sámi people with dementia and their relatives [7].

Studies show that health care workers usually emphasise that they do not make any distinction between Sámi and non-Sámi clients. However, this is in fact a problem. Sámi clients are often made to feel invisible, which may prevent them from verbalising their unique health problems. By viewing older Sámi as older ethnic Norwegians, nurses neglect Sámi cultural identity and worldview [9].

The Sámi traditional lifestyle and belief system as preventative factors

The Sámi's long-term connectedness to nature and spirituality are well known among Sámi reseachers [10,11]. Bergland who has studied reindeer herding in Norway, has noticed the intimate relationship of the Sámi to nature: this relationship is a result of the fact that life and activity are strongly linked to the sea, mountains, forests and wilderness, which has affected the feelings and identities of the Sámi. In spite of major changes in reindeer herding, it seems that the contact with nature of previous forms of reindeer husbandry still strongly influences Sámi identity [12,13]. The idea that Indigenous people honour the land and all creatures who inhabit it and recognise this interconnectedis grounded in reality past ness contemporary [14].

History, local industry and cultural interaction across ethnic groups have meant that there are still remnants of the traditional collective culture and view of life, especially amongst older people [12,13]. Living in a Western society, the Sámi tend to define themselves as interdependent parts of a group. This seems to exist across ethnicity. Everyone belongs to a network of family, friends and neighbours, who provide assistance when needed. The ability to mobilise and provide assistance for each other is a cultural capital of knowledge, ideas and habits inherited from earlier generations and passed on to new ones.

In the Arctic region, Læstadianism, a revival movement within the Lutheran church, mainly in northern Scandinavia, has had considerable influence on the philosophy of the Sámi and Kvens. In many Sámi districts, both believers and non-believers have attended Sunday services, which became a cultural enclave for Sámi values and norms [10]. In that respect, Sámi culture has been protected by its connection to the Læstadian community. The encounter between Sámi traditional religion and Christianity has influenced Sámi culture in various ways. The old Sámi religion (shamanism) went into inner exile, disguised as Laestadian Christianity [10]. In this way, it could escape part of the cultural oppression that the Norwegian state and the church exercised against the Sámi as an Indigenous people. Within the Laestadian environments and congregations, many of the Sámi traditions, such as their natural religious tradition, have been able to survive and be renewed [10,11].

The Læstadian doctrines have also taught the Sámi how to behave to become "a real Christian" [10]. Sometimes people, both Sámi and non-Sámi, with ties to the Læstadian movement can feel the lack of "real faith". The Sámi may be more inclined to think that they sin more than Norwegian Læstadians do. This seems to be a prolonged consequence of the prohibition by the Norwegian church of old Sámi religion. We can also find traces of this prohibition in Læstadian Christianity. Many Sámi experience the lack of "real" Christianity in their mind and heart so strongly that they feel ill [4]. However, many older people who have been socialised and educated in a secular culture are influenced by Læstadian values and norms [15]. When they grow old, the faith from their childhood is activated and becomes essential in their lives. Some talk about going home (to God). The lack of knowledge of Sámi traditions and religious customs among home care providers leads to an oppressive practice and results in participation barriers to older Sámi people and their families [16].

Nature, storytelling and memory impairment

Changes in traditional lifestyle change the people. Traditionally, family caregivers have taken care of those in need. To-day, when many young Sámi (families) have moved to towns and cities, this becomes a challenge. Hulko points out that bringing older people and children together can foster intergenerational communication, preserve historical and geographical knowledge, and also ensure that seniors maintain an active role in their communities and retain good health. Inter-generational communication of this kind is also a means of exchanging knowledge across generations, knowledge that has been protected or regenerated by the older people [14]. The fact that identity is linked to places indicates a potential in using nature and the cultural landscape in health and environmental care. In the book "Creating Culturally Appropriate Outside Spaces and Experiences for People with Dementia", the authors show how people can use nature as a resource in older years in general and in relation to dementia in particular [,17].

Integrity-enhancing environments are important for older people as preventative factors. Memory impairment is in this context associated with the first signs of memory loss. It is a normal cognitive ageing process, but can also be associated with forms of dementia-like symptoms associated with stressful life events such as sickness, grief, dependence on social services, or moving into a nursing home. Moving from home to a nursing home affects older people's identity. Previous studies among minority ethnic groups or Indigenous peoples have reported that factors contributing to low service use include rural locations [3] and

beliefs that dementia is part of the normal ageing process [18]. Research shows that being in nature has a positive influence on mental well-being, which also affects the brain [19]. Research from Indigenous areas shows that the place and the landscape are related to people's identity [20]. Being deprived of the land is a great loss, and getting back to the land that the Indigenous people have been robbed of is of great importance for mental health [21].

In one Sámi municipality, an attempt has been made to safeguard Sámi culture, language and way of life. At one nursing home, a Sámi garden has been created for cultural activities. The garden is an area with a "lavvo", a turf-covered tent placed among the short birch trees behind the nursing home; in line with tradition, it stands on a natural plot. Here, traditional Sámi food is eaten, the talk is in Sámi and occasionally someone will sing a "joik", a Sámi traditional form of singing. Experience from this Sámi garden shows that identity and affiliation are confirmed in association with other persons of Sámi background and lifestyle.

Norwegian studies reported that institutionalisation for older people has improved quality of life, but still there are nursings homes where the everyday life of the residents is spent in passivity, where sleeping and waiting is what happens for large parts of the day [22].

The strictly organised everyday routines in the nursing home break with the traditional Sámi way of living and the rhythm of life internalised by older Sámi who have worked in traditional primary industries. Each season is linked to the yearly cycle and has its special activities. The cyclical nature of the traditional Sámi way of life is not consistent with the linear time of Western societies. Cyclical time is part of a circle where objects are linked to the seasons [23]. Within the framework of the public care service, many of the older Sámis' way of life markers are not understood, but defined as a deviation and in some contexts as the first signs of memory impairment. Old age and lack of knowledge about Sámi traditions and way of life can therefore lead to old Sámi people being easily perceived as having incipient dementia (memory impairment) long before they really have. This then affects how health professionals interpret and understand the older person's behaviour [24].

Methodology and material

The production of data for this article is based upon material collected during my PhD. Data were collected through ethnographic interviews and participant observation over a period during two years. In the first part of the period my data were collected through observation and in-dept interviews of ten older people living at home. They were recruited by a local Sámi woman and later on by snowball samling. When I later visited the village again, I found some of my informants in a nursing home, where I spent part of my fieldwork during these two years.

The informants I visited at home were from 60 to 90 years old. They defined themselves as Sámi. They were bilingual with Sámi as their mother tongue. They spoke both Sámi and Norwegian in conversation with me. Field notes were written down after each encounters. During the fieldwork two of the informants developed memory impairment; Berget and Olai. In order to guarantee confidentiality, I have used pseudonyms to keep the informants anonymous.

The overall aim of the research was to explore how older Sámi experience old age and how they express their health and lives in a context of a hundred years of colonisation and the slightly shorter period of decolonisation and the transformative practices initiated by the Sámi people themselves.

The researcher's background

The preliminary data consist of my experiences and points of view as a family member observing older people including my parents, and my experiences and interactions with staff from home care services and nursing homes. I have also grown up on a smallholding on the outskirts of a Sámi village. These experiences have helped to shape my academic points of view. During the fieldwork, I shared my contextual experiences with the informants, and was a "knower", as Nakata [25] says Indigenous people often are and have to be. I was an active participant in a movement to revitalise Sámi culture and language in the 1970s and 1980s, the period following the difficult colonisation period. Aspects of these movements sought to improve the professional health care system for Sámi patients by promoting understanding of Sámi culture and language with public health care workers providing services to Sámi patients [4]. These activities have contributed to the shaping of my academic points of view as a Sámi researcher.

Analysis

The conversations and observations were recorded after they took place. I revealed the information I discovered in the first conversations in the next meetings with the informants. Over time, the older people began to trust me more, and gave me more detailed descriptions of life as they actually experienced it. In ethnographic projects, interviewers must be able to



develop a sense of trust with people, become involved with them, get under the surface of what is said and observed and follow the relationship between the people and the data, and collaborate with the participants to understand their sensory and emotional experiences [26].

The process of writing developed from a dialogue between the interviewer, the interviewees and their relatives. As noted by Pink [27], I carefully used the words of the participants as much as possible, repeated what I heard to show my interest in learning from them, and participated in their activities. In this mode, researchers use their experience in relation to the studied population as part of the data. As I observed the participants, I also took careful note of their appearance and behaviour as well as their environment.

The analysis of the data is inspired by Kvale and Brinkmann [28] and their description of contextual content analysis. This analysis includes three phases: selfunderstanding, general understanding and theoretical interpretation. Through my openness and the "swirl of events", basic theoretical elements emerged and were arranged to be in harmony and reflect a broader concept of knowledge [4]. This process is how I have brought forth what Van Manen calls the "lived experience" [29].

Ethical implications

To gain access to the Sámi population, there were two factors I had to take into consideration. Firstly, the harsh assimilation process the Sámi people had been exposed to, being denied their own language, culture and livelihood, and secondly [9], the previous experiences of Sámi informants with non-Sámi researchers [30]. Telling about my own experience of not being allowed to speak Sámi at school was the key to getting under the surface of their experiences. I tried to ensure that my research did not have a stigmatising and disempowering effect on the participants [26].

The stories of Berget and Olai are fragments of lived life as they conveyed them to me as a Sámi researcher. It is important for the development of history and progress to know who the "Other" is and what kind of relationship is revealed to the recipient. The person who receives the story must be aware of the role he or she plays in the process [31], even as a Sámi researcher. As a Sámi woman and researcher, my position and research activity gave Berget and Olai the opportunity to see their experiences and especially themselves in a new light. At the same time, I was careful not to force them to accept a new interpretation of their situation. Berget's son has read through the story about his mother, Olai had no close family left. The study was reported to the Norwegian Centre for Research Data (49,844).

The case studies

In this section, I will use two cases to illustrate two older Sami with memory loss, Berget (F) and Olai (M). Berget and Olai are representative for many older Sámi receiving care from son(s) and extended family living in a rural district [32]. When moving from their home and surroundings to more adapted housing in central areas of the municipality, they meet health professionals in nursing home who primarily speak Norwegian language. In some areas the health professionals have minimal knowledge of Sami culture and traditions [4]. The concept of care is here defined as a relational phenomenon that changes over time between the different people caring for the older person. Here, care is provided by sons and daughters in interaction with rural homecare. Neighbours are also part of the care offered through their concern and social support.

Berget

Berget was an 86-year-old Sámi widow when I first met her. She has one daughter, two sons and two grandchildren living in the same municipality. Berget lives at home and manages her daily activities with home-based care from her sons and homecare from health care providers. Berget lost her mother when she was a child, and grew up in foster care. Her foster mother had a stroke when she was 50 years old. Berget cared for her for almost 13 years until she died. It was a hard time for me with a lot of work, said Berget. Berget was a little reserved in the beginning, before I got to know her. She is a nice woman, kind and gentle. We got to know each other well. Her stories now were about her childhood and upbringing. In her childhood she joined the Læstadian congregations every Sunday with her mother. Berget also told about her sister who had died the previous summer. She had found her way back to her childhood faith in old age, and found peace in her soul and she was ready to die, she told me. Before her sister died, she also said something she thought was very important for Berget's restlessness and anxiety, namely "to move home to God". This was important for her sister to tell to Berget.

The first signs of memory impairment

During my stay in this Sámi village, Berget began to lose her memory. When Berget was sitting alone in her

own thoughts, it could be difficult to get contact with her. She looked at you, but it was as if she looked through you. Suddenly she smiled. I was wondering what she saw and heard. At this moment, her two grandchildren visited her, but she did not recognise them. It took a while for her to realise who they were. Sometimes she would forget to turn off the cooker when she made coffee or food, and sometimes her family or neighbours found her on her way to the shop at six o'clock in the morning.

Olai

Olai is an 85-year-old bachelor living alone. He had previously lived with a brother who was now dead. He was in a nursing home on a temporary basis when I met him for the second time. Every time I spoke to him, he mentioned that he would soon be home. Olai's life had been the life of a hunter. "You must live as long as you live. One goal I have had - the struggle to exist, the struggle for food, the struggle for existence". Life in the mountains had influenced Olai's attitude to many things. Olai was witty and had many good stories to tell. He often peered out of the window, and did not let himself sit down. Like many of his neighbours, he had grown up with fishing, farming and hunting. When I asked what he had lived off, he said he had been a hunter. "It's a hunter I am and it's hunting I've lived off. And I was a skilled hunter", he said.

The first signs of memory impairment

Olai was beginning to show signs of "inadequate ability to take care of himself". His brother's death had turned his life upside down. Home care had sent him to the nursing home to get him back into his daily rhythm. The stay in a nursing home was to get Olai back into his usual rhythm of everyday life. Olai was often restless and would wander back and forth, notably in late summer and autumn - in the hunting season. At that time, the staff had to keep an eye on him to prevent him from disappearing. They told me he had been brought back several times while on his way home. The staff at the nursing home had to keep his door locked.

Result and discussion

Experiencing memory impairment in late life, Berget and Olai's preferences from their cultural background are activated in their everyday life. Experience as spiritual beings living close to nature, animals and birds and the creator, and with an image based on the shamanistic world and the world of Christianity, their preferences and lived experiences are expressed as embodied knowledge in the community and in the encounter with the health care services. In life we perceive through the senses, and we gain experiences through being physically present. We experience a form of embodied knowledge, but in such a way that thought, body and feeling become integral parts of the whole [33]. This is in contrast to mind/body dualism, as noted by Kontos in her study of Alzheimer's patients [34].

When Berget talked to me about her sister's choice before she died, Berget reflected on her own conscience regarding her faith: Was she a true Christian? Had she failed her parents' faith? The quote about her sister coming home to God seemed to support the idea that Berget had become disconnected from her spirituality. Going to the Læstadian service every Sunday with her mother, Berget's anxiety and memory loss were a factor that worried her family members and the home nurses. They attributed Berget's increasing anxiety to her memory loss. Health professionals are told that memory loss in old age often leads to emotional symptoms such as anxiety and restlessness [35,36]. That is true, but Berget also has preferences and culture-specific knowledge from another lifestyle: the Læstadian church life.

Not being able to attend the Læstadian chuch life anymore, Berget feel anxiety how to become a good Christian in order to move home to God. Not being able for health personal to understand Berget's co-existing needs (memory loss and spiritual disconnection), Berget is not able to reconcile with her doubts and actions while she is still alive.

Berget had been a smallholder, and her rhythm of life is connected to the eight seasons of planting, crop growth and harvest. She has also worked with animals, such as herding, milking, calving or lambing, which dominated her everyday life. With memory loss, it is common for time and space to merge [37,38]. Observing her on the road to the shop at six in the morning did not surprise her sons. It was quite common to go to the shop before milking the cows. For Berget, it is a logical action based on the rhythm of life Berget has internalised. The neighbours, however, were of another opinion. They experienced the first sign of memory impairment, and expressed concern about Berget's situation to the home care services.

For Olai, the spiritual dimension of life has a broader meaning; it is linked to nature and his lived life as a hunter. Sámi cultural landscapes are not just physical traces of settlement and activity, but also place names, local traditions and storytelling related to the places.

Lifestyle-based socialisation has not only affected older Sámi in their thinking, but also in their feelings and identity. This is expressed in a form of restlessness especially in the late summer and autumn, as clearly seen in Olai. Old Sámi men have through their whole life been exposed to outdoor activities and contact with nature. The alienation Olai experienced in the nursing home made him unsure and insecure.

Moving from home to a nursing home is a difficult transition for most older people [22], not just a challenge for Olai, particularly among male residents who are still able to move. As a narrator of Sámi names of cultural monuments during the trip outdoors, Olai represents a way of life that marks a distance from other lifestyles. For Olai, it is more than just getting out; the essential point is that he "goes along" with a Sámi companion and is seen as an independent "self" [38]. After an hour or so, he said, "Now we can go back". The rest of the day Olai was relaxed and seemed satisfied.

Facilitating outdoor experiences is a service that forms part of a new concept of nursing homes in Norway, called joy of life homes [39]. Outdoor experiences once in a week are one of nine criteria in this care home concept. For Sámi residents it is important to have activities which remains them about elements from their Sámi way of living.

Conclusion

A culturally sensitive approach in health care is a relatively new concept. A diversity of opinion as to what the approach consists of and how it should be implemented can lead to a better understanding and the development of theory [40]. This article try to challenge the negative and deterministic view of the standard paradigm of dementia care as Contos describe in her work [34]. For Berget and Olai, life has been linked to work and duty, which are affected by their traditions, rhythm of life and health when they grow older. By bringing in the perspective of the embodied knowledge, Berget's and Olai's long-term connectedness to nature and spirituality seems to make them sensitive to the changes in the environment. The the sociocultural sources of bodily practices are seen in their actions, gestures, faces and attitude.

Society's attitude to memory impairment in old age influences Berget's and Olai's situations in different ways. A culturally sensitive approach is needed in order to maintain the cognitive reserve, and prevent older Sámi being easily perceived as having incipient dementia (memory impairment) when they act in a manner due to their preferences and lived experiences. Cultural differences affect how health professionals interpret and understand older people's behaviour, particularly those with memory impairment. The case studies applies to older people in other Indigenous and minorities cultures [2], because loss of second language (here Norwegian) can be an early indicator of the development of memory loss [41].

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