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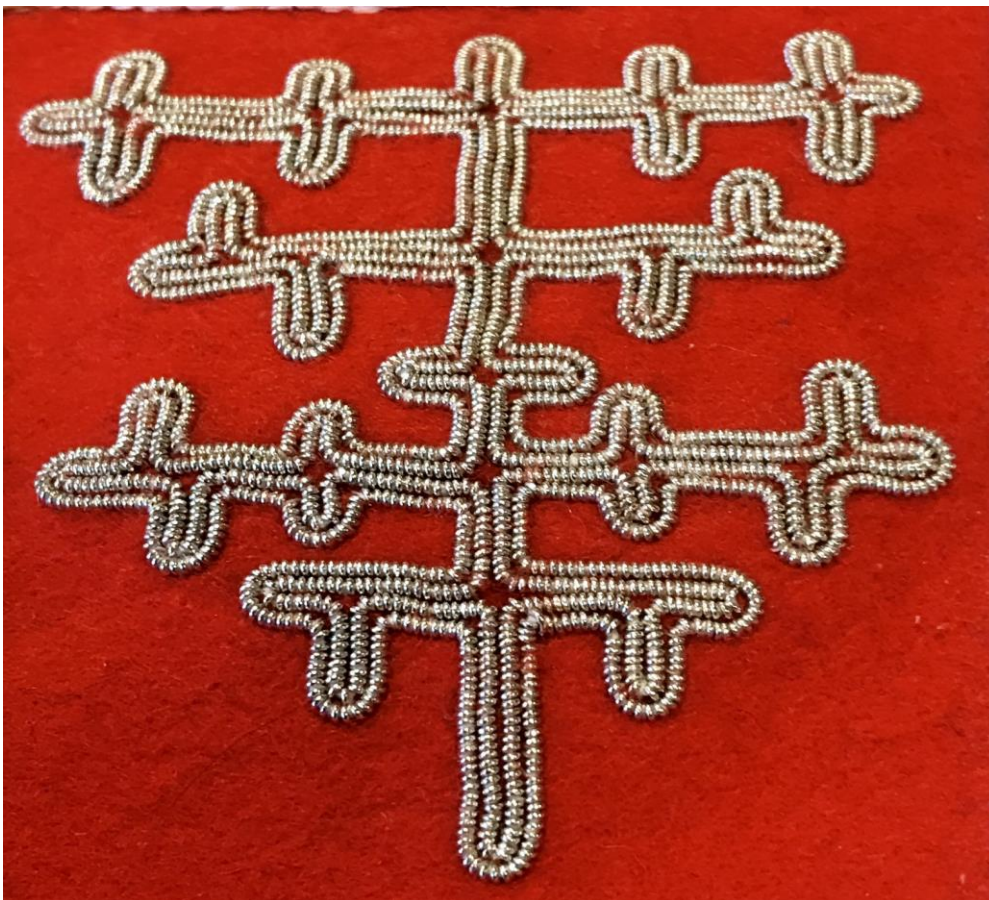
Faculty of Health Sciences – Department of Community Medicine

Mapping the experience and use of traditional healing in Northern Norway

Among conventional health care providers, users and traditional healers

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1 Preface

I grew up in a Lule Sami area in a family who sought help from traditional healers when someone became ill. To me this was normal and common. Being a nurse, I often wondered why something so normal and common could be so silent and difficult to talk about. It was difficult for the health personnel to discuss this with their patients, but it was also difficult to discuss this between themselves.

I hope my thesis can help create a platform for debate in the health services so that health personnel can talk openly with their patients about traditional healing without having to hide their faith and use. Furthermore, I hope that my thesis has provided a conceptual framework which makes it possible to talk about traditional healing in the health services, and that this will lead to a more holistic and culture sensitive health service in the North.

I would like to thank my employer Norway's National Research Center in Complementary and Alternative Medicine and The Research Council of Norway for having funded my PhD project.

I am grateful to all the participants for sharing their experience, knowledge, and stories about traditional healing and conventional medicine with me. I would also like to thank the language centers and community managers of the communities in which the data for my thesis was collected, for their support, help in finding informants, and for allowing me to interview the employees during work hours.

I would like to thank my supervisors in the first phase Nina Foss and Torunn Hamran. Thank you for believing in me and the project, and for helping me initiate this project.

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I would like to thank my main supervisor Trine Stub and co-supervisor Anita Salamonsen. I am most grateful to Trine who has pushed me and comforted me when things got tough, challenged me professionally, and who has believed in me all the way. I would like to thank Anita for important methodological and analytical input, and for maintaining belief in the richness of my culture. I would like to thank Agnete Kristoffersen for good discussions, professional input, and her comforting laughter. I would like to thank Jane Ekelund for proofreading. I would like to thank Solveig Wiesner and Tine Lillegård for technical assistance.

I would like to thank all of my colleagues at NAFKAM and the people at NIFAB who have made my workday more fun with their lovely sense of humor. I would like to thank my family, my grandmother, parents, siblings and friends, who have been my cheerleaders and supporters. Special thanks go to my three children Truls, Sivert and Carla, and last but not least, my husband Hans for their help and support.

2 Abstract

Background

Traditional healing is an ancient tradition in Northern Norway, and is still being used today. Traditional healing is practiced free of charge and in secrecy. Today the tradition combines religious prayers and Sami rituals. The use and experience of traditional healing are still conveyed orally through stories that are shared among families and social networks. The aim of this research project is to improve the knowledge of the people's (the Sami, Kven, and Norwegians) understanding of health, including the use of traditional healing. The project was conducted in two communities in the Sami language management area.

Aim

In this research project, we have investigated the social processes, the understanding and experience of traditional healing and conventional health care in three groups; The users, the traditional healers, and the health professionals. Furthermore, we have studied how traditional healing can be a coping strategy (resilience) for the users in cases of illness.

Method

A qualitative design was used in this project. We conducted 60 semi-structured interviews and 7 focus group interviews. The participants were health personnel, healers, and users of traditional healing. There were 38 female and 30 male participants in the project. The text data was transcribed verbatim and analyzed based on the criteria for content analysis. Some of the themes had been predefined, whereas others emerged during the analysis. NVivo 11 was used in the analysis process.

Results

Both the Sami and Norwegians often used traditional healing. The use of traditional healing was quite common and employed as a coping strategy in cases of illness. The users seldom reflected on the reasons for using healing as this was a natural part of their culture. In cases of illness, traditional healing was used in combination with conventional medical treatment. The users wanted the health personnel to have knowledge of the use of traditional healing to help facilitate

this use for the users when they were admitted in hospitals or nursing homes. Moreover, they would also welcome the presence of their social networks at the hospital and nursing homes when they became seriously ill.

The family network played an active role in handling illness. In cases of illness, the social network functioned as a collective working system and a safety net that provided practical help and support for the patients and their families. It was also the task of the social network to contact healers. Minor health complaints were handled by healers in the families, often through discussion, administration, and supervision from the elderly family members. In cases of serious illness, a larger social network was activated to contact local and regional healers so they could make joint efforts to heal the patient. It was quite common that many members of the network were present at a doctor's visit. They would grasp the patient's diagnosis so that the healers could use this in their healing rituals.

The healers in this research project explained their healing ability as a divine power that worked within them. The healers combine Christian prayers and Sami rituals with information from conventional medicine (diagnosis and medical test results) when conducting the healing rituals. Several of the healers had a history of healers in their families. The older healers trained the younger candidates. Some were trained already as children or young adults, when an older healer had discovered that they had the ability to heal (open-minded towards the spiritual). The healers had to be mentally strong, able to arouse trust, and trustworthy. It was believed that healers with warm hands or clairvoyant healers had extra healing power.

The health personnel understood traditional healing as a part of the patients' toolkit that they used when they got ill. The use of traditional healers helped the patients activate their own self-healing powers. In addition, they helped the patients maintain hope and faith in coping. The health personnel in our research project had no education in traditional healing. Nevertheless, many of them conducted traditional healing, including the use of familiar rituals upon the patients' request. The health personnel claimed that this provided the users with more culturally sensitive health care services, even though the use was never documented in the patients' medical records.

Conclusion

We understand the use of traditional healing as a mechanism of resilience or coping strategy on individual, social, and cultural levels. This tradition may be regarded as an expression of the culture in Northern Norway, that binds people to an environment which is linked to a culture with a spiritual dimension that has long-lasting traditions in the communities in which this research project was conducted. The use of traditional healing was an expression of the need for a spiritual dimension, that conventional health care providers do not meet.

The users in this research project employed parallel treatment methods from the Norwegian conventional health care system and traditional medicine. The use of traditional healing indicated active patients and their social networks. The health personnel and traditional healers helped them meet the patients' individual needs in cases of illness.

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6 List of abbreviations

| | |
|--------|--|
| CAM | Complementary and Alternative Medicine |
| NAFKAM | The National Research Center in Complementary and Alternative Medicine |
| WHO | The World Health Organization |

7 List of papers

Paper I

Larsen AL, Hamran T, Foss N, Mellom profesjonell og folkelig kunnskap: En kvalitativ studie av helsepersonell sin kunnskap om og håndtering av "læsing" i en norsk-samisk kommune. English: Between professional and popular knowledge: A qualitative study of health personnel's knowledge and handling of "*reading*" in a Norwegian-Sami municipality. *Vård i Norden*, 2014. 34 (4): p. 53-57.

Paper II

Langås-Larsen A, Salamonsen S, Kristoffersen AE, Hamran T, Evjen B, Stub T: "There are more things in heaven and earth!" How knowledge about traditional healing affects clinical practice: Interviews with conventional health personnel. *IJCH International Journal of Circumpolar Health*, 2017. Vol.76,1398010.

Paper III

Langås-Larsen A, Salamonsen S, Kristoffersen AE, Stub T: "The prayer circles in the air": A qualitative study about traditional healers from Northern Norway. *International Journal of Circumpolar Health*. Submitted in November, 2017.

Paper IV

Langås-Larsen A, Salamonsen S, Kristoffersen AE, Hamran T, Evjen B, Stub T: "We own the illness": A qualitative study of networks in two communities with mixed ethnicity in Northern Norway". *IJCH International Journal of Circumpolar Health*. Submitted in August, 2017.

8 Definitions of terminology used in the thesis

Complementary and Alternative Medicine (CAM) is understood as health-related interventions practiced outside the official health care system by unauthorized health personnel. Moreover, treatment practiced within the official health services or by authorized health personnel is also covered by the term alternative treatment if the methods are essentially used outside the established health services.

Culture is a set of guidelines (both explicit and implicit) that individual inherit as a member of a particular society, and tell them how to view the world, how to experience it emotionally, and how to behave in relation to other people, to supernatural forces or gods, and to the natural environment.

Curing is understood as a combination of Christian prayers and traditional Sami rituals, for instance, when the healer uses elements from nature, such as steel, water, moss, earth, and stones.

Healing is understood as "doing whole". Healing is something practiced by healers, that initiates a healing process so that the patients may obtain healing, e.g., when the pathogenic process is halted, the patient may begin healing - moving from a state of disease to a state of renewed health.

Healer or spiritual healer is a person who exercises above all the practice of the laying on of hands, prayers, and/or meditation while most importantly considering himself connected to a transcendent or spiritual power. A healer has his abilities based on natural abilities or attachments. They are not necessarily linked to religious beliefs. Traditional healing includes, among other things, the use of animal products, herbs and plant products, stopping blood, cupping, and massage.

Kven is a Norwegian concept of the Finnish settlers and their descendants, who live in Northern Norway.

Laestadianism is a Lutheran revival movement that started in Lapland in the middle of the 19th century. The movement got the name from a Swedish pastor and administrator of the Swedish Lutheran State Church, Lars Levi Laestadius (1800-1861).

Norwegianization or Assimilation is the period from approximately 1850 to 1980 when the Norwegian state had an official policy of assimilating the Sami and Kven into the Norwegian society.

Placebo is a harmless pill, medicine, or procedure prescribed more for the psychological benefit of the patient than for any physiological effect. The placebo effect refers to any improvement of the condition of an individual who has received a placebo treatment. It is assumed that if the placebo had not been given, no such improvement would have been observed. In contrast, placebo response refers to the change in an individual caused by a placebo manipulation.

Reading is a form of traditional medicine and describes the treatment provided by a healer when he or she reads a religious healing prayer for illness or health concern.

Resilience (coping, resistance, and survival mechanisms) is an analytical concept which emphasizes people's health promoting processes and how they cope when faced with suffering and stress.

Siida describes a network that consists of extended families and a working community. The term is often used in reindeer herding and describes families, relatives, and other people who work together in a reindeer herding area.

State Church is understood as the Lutheran Church of Norway.

The Sami is an ethnic minority group in Norway with the status of indigenous people with their own language and cultural history. The Sami are settled in the northern part of Norway, Sweden, Finland, and Russia. Norway has the largest Sami population in Scandinavia. The number of Sami people is usually estimated at 40,000-80,000. After World War II it was illegal to register ethnicity in public registers. Therefore, we do not know the exact number of the Sami population in Norway.

The Sami language management area consists of 11 communities in Norway, where Sami and Norwegian have equal language status. These communities receive financial support from the government and have a special responsibility to promote the Sami language. The population has a special right to be addressed in their own language when they contact the public health services, also outside the region.

The Sápmi is the term that the Sami themselves use when they refer to the Sami area. Sápmi is the area in the northernmost parts of the four countries in which the Sami originally lived before the state borders were formed in Norway, Sweden, Finland, and Russia.

Traditional healers in Northern Norway are often called healers, curers, helpers, readers, and in some places blowers.

Traditional Medicine/Folk Medicine (including traditional healing) may be understood as “the sum total of the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures used in the maintenance of health, whether they are explicable or not, used in the prevention, diagnosis, improvement, or treatment of physical and mental illness”.

Traditional network consists of an extended family (the close family, relatives, neighbors, and friends). The tradition of organizing large family networks is mostly known from the nomadic reindeer herders. They work together with several families in Sami homes (Siida).

9 Introduction

9.1 Historical background

The recently employed nursing care manager in Karasjok municipality in Finnmark, Ragnhild Nystad, stated in the professional journal *Sykepleien* in 1989 (1) that the health care services may have maltreated many Sami patients due to lack of knowledge of the Sami language and cultural expression. Offering language courses for health personnel was often not sufficient to prevent maltreatment of patients as the Sami culture differs very much from that of the Norwegian. The differences appear in the health care system and the family's importance in case of illness. According to Nystad, many Sami have two health care systems. They use the official health care system as well as the traditional system that consists of noaidis and hands-on healers. The traditional system is often used in secrecy. An important function of the traditional system is to provide additional competence when conventional medicine falls short (e.g., stop bleedings).

Another difference is the concept of family that includes more members compared to what is common in the Norwegian culture. An example of this is that third and fourth cousins are regarded as close relatives in the Sami culture. In case of severe disease and death process, it is therefore common that the entire family (including third and fourth cousins) are present.

Based on this, we wanted to develop qualitative knowledge of social processes and understanding of the use of traditional healing and conventional health care in two communities with large proportions of Sami people. We wanted to examine the understanding and experience in these three groups: People who seek help, employees in primary health care services, and traditional healers. The questions and methodological approach in the three groups will partly overlap (see table 9.4 aims of the research plan).

9.1.1 The Sami – the indigenous people in Norway

The Sami are an indigenous people who live in Norway, Sweden, Finland, and Russia. The area traditionally inhabited by the Sami is known as Sápmi. There is no present internationally acknowledged definition of the concept indigenous. This is the definition of indigenous people according to The ILO's convention No. 169 on indigenous and tribal people in independent countries:

Peoples in independent countries who are regarded as indigenous on account of their descent from the populations which inhabited the country, or a geographical region to which the country belongs, at the time of conquest or colonisation or the establishment of present state boundaries and who, irrespective of their legal status, retain some or all of their own social, economic, cultural, and political institutions (C169 - Indigenous and Tribal Peoples Convention, 1989).

According to this definition, the Sami must be regarded as indigenous people. Article 108 of the Norwegian Constitution states that the Sami have the right to develop their own culture and language. According to Article 1-5 in the Sami Act, Sami and Norwegian have equal language status (2). Therefore, a Sami language management area was established (Nordland, Troms, and Finnmark). There is no official record of the Sami people. Therefore, there is no exact number of the Sami population in Norway. However, the number has been estimated between 50,000 and 65,000.

9.1.2 Official documents

The Sami generally have less academic education than the majority of the Norwegian population. This is especially true for the older generation. However, Sami and non-Sami people at the same level of education report few differences in sickness (3). Therefore, there is no indication that the Sami and the majority of the Norwegian population differ much regarding health condition,

prevalence of disease, and life expectancy (4). It seems like the difference in health between indigenous and non-indigenous people, that is quite common in other Western countries, is no problem in Norway (5). According to Kvernmo, this can be attributed to the present socio-economic conditions of the Sami in Norway. Nevertheless, more research is needed, and health services must be facilitated for the Sami population because the Sami have their own culture, language, and tradition, as well as their own understanding of disease (4, 5).

Report No. 48 to the Storting (2008-2009) The Coordination Reform (6) states that "the Sami people have long traditions of helping themselves using personal networks to prevent health problems and solve personal problems". A common challenge is to get the health care personnel to play along with these resources to complement each other. Health personnel are often skeptical of traditional medicine and spiritual assistance from the local environment.

9.2 Traditional medicine in Norway

The World Health Organization distinguishes between Complementary and Alternative Medicine (CAM) and traditional medicine (TM). However, traditional medicine is considered as CAM (7). CAM is defined as a treatment modality that is used alongside conventional treatments, but not considered standard medical treatment (8). CAM is commonly used in Norway (9, 10), and the most frequently used CAM modalities are massage therapy, acupuncture, naprapathy, reflexology, osteopathy, cupping, and healing (11).

9.2.1 Literature review (searches)

The following electronic databases were searched for articles: Pubmed, Web of Science, Scopus, and High North Research Documents. To find additional studies not found in electronic or manual searches, the reference lists of publications were also checked.

Search methods: Depending on the database, various combinations of MESH terms and keywords were used. These MESH terms were used: Traditional medicine, faith healing, spiritual healing, health personnel. These keywords were used: Traditional healing, Indigenous healing, Sami, Saami, Sapmi, Siida, Lappish, lapp, lappland.

9.2.2 Literature review (results)

9.2.2.1 Quantitative studies

Traditional medicine is understood as “the sum total of the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement, or treatment of physical and mental illness” .

People in Northern Norway have long traditions of using traditional medicine. This tradition includes knowledge of different diseases and how these can be cured (12-14). The Sami people have had this knowledge long before conventional medicine came to this part of the country (15). The healing tradition was important to survive at a time when there were few doctors in Northern Norway. The noaidi (Sami healer) Johan Kåven was for instance known for being able to heal people using words (14). Furthermore, in a letter from 1872 Kåven was described as a frequently consulted «doctor» who had a hospital in his home (16).

Reading is a form of traditional medicine and describes the treatment conducted by traditional healers when they read a healing prayer over the illness (12, 17, 18). The knowledge comes from natural gifts and teaching from older to younger people, mainly inside the family. Furthermore, a healer is understood as a person who, above all, exercises the practice of the laying on of hands, prayers, and/or meditation while most importantly considering himself connected to a transcendent or spiritual power (19, 20).

In 1975 Efskind & Johansen (21) conducted a survey among 150 participants from Alta about their relationship to folk medicine and supernatural healing (prayer, the laying on of hands, and blood-stemming). Forty-two percent of the participants reported that they had sought help from a traditional healer or people with supernatural powers. More than half (55%) stated that they believed in healing by prayers and the laying on of hands.

The following year, Bruusgaard and Efskind followed this up (22) by conducting a national survey on attitudes to and the use of folk medicine (herbs, homeopathy, spiritual and religious healing). In this study, 43% stated that they believed in spiritual healing and people who possessed special gifts, and 33% believed in religious healing. The researchers argued that folk medicine is not a typical phenomenon of Northern Norway, even though the study revealed a higher number of people who believed in people with special gifts and religious healing in

Northern Norway (63%) compared to the rest of the country (41%). There were more people in rural areas, where the health care services are less developed, who had faith in these phenomena.

In 1975, a Norwegian health survey found that 0.4% of the population had visited a CAM provider (chiropractor, homeopath, or other kinds of providers) during the last 14 days. Ten years later, this number had increased to 1.4% (13). The reason for this might be the increased number of treatment forms included in this survey (acupuncture, homeopathy, naturopathy, reflexology, and healing). The health survey from 1995 (23) reported that 16,000 people had sought help from a healer during the last 12 months (13). This study revealed that there were more women than men who sought help from CAM providers. The study did not differentiate between modern healing and traditional healing, and the concept of traditional healer was not specifically mentioned. Healers were defined as *natural healers*, *naturopaths*, and *other providers*.

Steinsbekk (24) found that most of the people who sought help in CAM modalities did so on the recommendation by friends and acquaintances.

In 1978, Gjerdal (25) conducted a study in Fredrikstad and found that 16 out of 100 patients who were hospitalized in the internal medicine ward at the city hospital of Fredrikstad, had sought help from paramedical personnel. One of the patients described the provider as a *woman with electric hands*. Gjerdal argued that seriously ill people may often be irrational, which is the reason why they use, and will continue to use traditional medicine.

A study (26) compared the use of CAM in Scandinavia. This revealed that one third of the Norwegian participants had used some form of CAM treatment during the past twelve months. The CAM treatments examined in this study were healing/spiritual healing, homeopathy, chiropractic, acupuncture, reflexology, and massage (26).

During the period 2000-2002, Sørliie and Nergård (27) studied the use of traditional healing among 68 psychiatric patients in the emergency ward at the University Hospital of North Norway (UNN). The results from this study showed that Sami patients used traditional healing to a larger extent compared to Norwegian patients. Sixty-five percent of the Sami patients used traditional healing, whereas 38% of the Norwegian patients used such healers. The health personnel at the ward were unaware of the extensive use of traditional healing among these patients.

Sexton and Sørliie (28) conducted a larger study on the use of traditional healing among 186 psychiatric patients in Finnmark and North Troms. In line with the findings of Sørliie and Nergård, these researchers found that Sami patients used more healing, including traditional healing compared to Norwegian patients. Furthermore, the Sami patients had greater faith in religion and spirituality compared to the Norwegian patients. Moreover, they were less content with the conventional treatment.

Sexton and Sørliie (29) also examined the patients' attitudes towards integrating traditional healing in their treatment. Eighty-one percent of the Sami patients were positive to such an integration compared to 37% of the Norwegian patients. Forty-eight percent of the Sami patients used traditional healing, whereas 31% of the Norwegian patients had used healing for their complaints. These studies revealed that psychiatric patients use healing, but under-communicate such use to the health personnel (27, 28).

In the HUNT study from North Trøndelag, which was conducted during the period 1997-2008, Steinsbekk (30) found that 9.4% of the adult population had sought a CAM provider over the past 12 months (1997). In this study, the *laying on of hands* was listed among the CAM providers. In 2008, the number of participants who had sought a CAM provider had risen to 12.6%. There were more patients with cancer diagnoses who sought CAM providers compared to patients with other diagnoses.

Based on the SAMINOR 1 survey, Bakken and her colleagues (10) examined the use of healers (both modern and traditional) and sleeping pills for insomnia among participants in areas with Norwegian and Sami settlements. They found that 16.7% (n=2 675) had sought help from a healer at one time or another. There was a greater use among participants with strong Sami affiliation. Thirty-two percent of the participants with this affiliation sought traditional healers in contrast to 21.8% of those with a weaker Sami affiliation. The non-Sami (11.8%) also used healing. Twice as many females as males used healing.

In 2012 (31) NAFKAM examined the use of CAM among the Norwegian population. The study involved 1,002 people older than 15 years, who were interviewed by phone. The study revealed that 45.5% had used CAM (including over the counter products), and 36.6% had visited a CAM

provider during the last 12 months. Of these, 3.7% reported to have seen a healer. There were 0.3% who received healing conducted by health personnel inside the health care services.

In 2016 (11), NAFKAM repeated the study, and found that the number of participants who had sought a healer for their medical conditions had decreased to 1.1%. Furthermore, the study revealed that one in four (24%) Norwegians had sought a CAM provider during the past twelve months. Healing was among the nine most commonly used CAM modalities. The healing concept included modern healing, the laying on of hands, as well as reading. Fifty-eight percent stated that the use of CAM had improved their health condition. Moreover, the study revealed that 5% of the adults with child support responsibilities sought help from CAM providers for their children. To date, no study has examined how the Norwegian population defines a CAM provider. However, we know that the most commonly used CAM providers are massage therapists, acupuncturists, reflexologists, spiritual healers, and homeopaths.

Kristoffersen et al. (32) analyzed data from 16,544 informants in the SAMINOR I survey. The study revealed that 13.8% had used traditional medicine at one time or another. Both the Norwegian and Sami participants used traditional medicine. The use was to a greater extent connected to membership in the Laestadian Lutheran Church (34.3%) followed by people living in Inner Finnmark (31.1%) as well as Sami ethnicity (25.7%). Kristoffersen found that 9.1% of the non-Sami participants sought help from traditional healers.

9.2.2.2 Qualitative studies

In 1999, Olsen and Eide (33) conducted a qualitative study in which they examined how Tysfjord municipality handled health and disease. The material included 20 participants. Half of them were Sami, and the other half were representatives from the health care service in the municipality. They found that both Norwegians and the Sami sought help from traditional healers. However, there were more Sami than Norwegians who used this form of treatment. Several Sami were Christian and had affiliation with the local Laestadian Lutheran Church. Furthermore, traditional healing was used as a supplement to the public health care service. Nevertheless, the researchers concluded that the patients seldom informed the health personnel about their use of traditional healing. The informants told the researchers of a Sami doctor who had worked in the municipality. The doctor knew of the healing culture and encouraged his patients to seek help from the healers as he was of the opinion that this form of treatment could

be a supplement to conventional treatment. According to these researchers, the use of traditional healing helped mobilize the social and religious resources among the inhabitants in the municipality (33).

The folklorist Mathisen (34) analyzed ancient literary sources and interviewed healers and people in North Trøndelag, Troms, and Finnmark. He examined the knowledge of traditional medicine that provided the basis for diagnosing a disease. He found that healing was generally understood as a miracle exercised by some kind of spiritual power or as an imbalance between supernatural forces. He was of the opinion that conventional medicine and traditional medicine were based on different values and principles. Conventional medicine understands and explains disease based on reasonable, scientific principles, whereas traditional medicine is understood as part of a cultural system, including irrationality and superstition. Mathisen referred to many great healers in Norway, such as Marcello Haugen in Southern Norway, famous healer families in Snaasa (Trønderlag), Bratteng from Fauske, and more healers from Northern Norway. Historically, the Sami and Kven healers have been known to possess extra strong healing powers. The most known healers in Northern Norway have been descendants of Sami and Kven people (34).

The anthropologist Nergård (35, 36) interviewed two Sami healers in Northern Norway, a female healer from a sea Sami Laestadian community, and a male healer from a reindeer herding community in Inner Finnmark. The female healer explained her abilities in a Christian Laestadian context, whereas the male noaidi explained his practice as an ancient Sami tradition, including spiritual assistance. The ancient Sami traditions were preserved and hidden in a new form in the Laestadianism. Therefore, the female healer could define her healing practice as a legitimate part of the Laestadianism.

Miller (37) examined how the knowledge of healing was passed on from the older to the younger healers. She followed a healer (mother) and her son over several years. She found that the knowledge was often passed on by means of four basic concepts and practices. 1. When a healer is to find his/her successor, he/she will often get spiritual assistance. 2. The healer continues to instruct the successor. 3. The ability to heal (gift of healing) is either passed on from a former healer during a period of practice or transferred to the successor in a dream. 4. The gift of healing is a special connection between the healer and an almighty God who can heal disease. Therefore, a healer has the ability to heal disease and to correct behavior «Bidjat». Miller and Nergård agree

that the healing tradition has its roots in Sami traditions from pre-Christian times. However, the present healing tradition is affected by Christianity, even though all healers have always supplied their own knowledge and understanding in their practice.

In 2015, Andersen et al. studied which coping strategies psychiatric patients in Finnmark used to maintain health (38). The participants in the study felt that talking to a healer and that other people prayed for them were effective health promotion measures. In the Laestadian community, many people had access to support networks and other health promotion resources. Many participants felt that health personnel lacked knowledge of people's everyday practical faith and how to handle disease. The researchers concluded that health personnel ought to increase their knowledge of local traditional coping strategies (such as contacting traditional healers) as well as encourage the patients to use these strategies in their handling of disease.

In a qualitative study, Sexton and Stabbursvik (39) interviewed 8 traditional healers. The participants lived in coastal and inland Sami areas and were of mixed ethnic background (Sami, Norwegian, and Kven). The interviews were conducted during 2003-2007. The healers came from healer families, and the knowledge had been passed on for several generations. The most commonly used methods were healing by prayer and the laying on of hands. Some healers also used moss and mushrooms in their healing. Others read a prayer over water which the patient was given to drink over several days. Some also used fire and earth rituals for healing. Several of the younger healers had a more modern approach. They combined traditional methods with elements of modern healing, such as chakra healing and the use of vitamins and minerals.

Hætta (17, 40) studied the transfer and management of the healing knowledge in Nordland. She interviewed 15 persons, and three of them were healers. The participants stated that the healing knowledge was secret, available to the healers only, and that it belonged to the local community. She found that the healers had different areas of expertise. Some were good at healing inflammation. Others could ease pain, and some could stop bleeding. The older healer decided on the criteria for teaching younger healers. Many were of the opinion that younger healers were more reluctant to use their healing knowledge as it was hard to combine such a practice with other types of work. That was why they did not want to take the role of the local healer. If the community knew of your ability to heal, the tradition was not to charge anything and not to turn anyone away.

In his field study from a Lule Sami area in Nordland, Myrvoll (41) found that the healing tradition was one of user control. It was the people's use of healing that has kept the tradition alive till today. In earlier times, when the doctor was far away, it was important that at least one member of the family or a person at the farm was able to stop bleeding as a vital first aid. Nevertheless, the tradition has adapted to new forms, such as the replacement of the old Sami gods with the Christian God (18, 41).

Nymo (42) examined health and healing among the elderly in South Troms. She found that the participants combined the doctor's treatment with that of a traditional healer. They understood reading as a coping strategy (*birget*) for handling disease. Consequently, it was important to look after family members and neighbours as they worked as a safety net in cases of disease (42, 43).

Kiil's material is based on interviews with 12 patients at a psychiatric polyclinic in Northern Troms. She found that reading is a common way of seeking spiritual assistance, independent of ethnic and religious affiliation. Usually one of the family members would seek help from a healer or healers on behalf of the patient. These participants were reluctant to inform the health personnel about their use of healing, for fear of being perceived as sicker than they were or being misdiagnosed (44, 45).

Aspaas and Henriksen (46) made an information booklet about the healing traditions in Northern Norway which was published by The University of North Norway in 2002. The booklet has been translated into three languages: Norwegian, Sami, and English. The aim of the booklet was to provide health personnel with thorough information and knowledge about traditional healing. They claim that for many people in the North *reading* is an important cultural resource that can strengthen the patient's mental health and mobilize the patient's faith and inner resources in cases of stress and disease.

Henriksen (47) is a nurse. She has interviewed healers and users of the health care services in North Troms and West Finnmark. She found that the healing tradition was a loving and caring public health measure and practical help in the daily life. She found that *reading* was based on social care networks and an expression of the Christian faith and practice in Northern Norway. She describes how a 13 year old girl injured herself hitting a rock. She returned to the rock and

read *the stop bleeding formulas* that she had learned from her parents. In this way *the reading* worked as first aid.

In her Master thesis, Mehus (48) examined the significance of traditional healing for the users, health personnel, and scholars. The material included interviews with 6 persons (4 users, 2 health personnel, and 2 persons with college education). She found that *the reader* takes care of an important social responsibility, with which conventional medicine can not compete. The healer takes care of people's basic needs in cases of disease, independent of ethnicity. The nurses in her material had facilitated the contact with healers upon the patient's request. She found that the healers functioned as dormant preparedness when everything else had been tried.

9.3 Theory

9.3.1 Salutogenesis

The medical sociologist Aron Antonovsky (49, 50) has constructed a salutogenic model that focuses on health promoting factors. Salutogenesis is a term that describes an approach focusing on factors that support human health and well-being, rather than on factors that cause disease (pathogenesis). More specifically, the "salutogenic model" is concerned with the relationship between health, stress, and coping (50). When people are subjected to disease and stress, the health outcomes are unpredictable. Whether the outcome will be lethal, result in worsening, or improvement depends on how the health challenges are handled, among other things.

Instead of focusing on factors that cause disease (pathogenesis), Antonovsky is concerned with coping strategies and health promoting factors. That means the processes that lead to healthiness. According to Antonovsky, these three factors determine whether you are healthy, experience a sense of meaning, and/or coherence:

1. The person can understand and acknowledge events in his life (comprehensibility).
2. The person believes that he has the resources necessary to find a solution to the situation (manageability).
3. The person thinks it is worthwhile to find a positive solution to the situation (meaningfulness).

According to our participants, the first step in the process of contacting a traditional healer was that the patient or relatives understood and acknowledged the disease situation

(comprehensibility). The patient or relatives contacted a healer to get help handling the disease. It was comforting just to have someone to talk to about the problems (51). Many of our participants experienced that inviting other people (for example a healer or members of a network) into their disease situation helped them not feel alone handling the disease. This strategy provided peace and helped them maintain hope of an improved disease process (manageability).

The healers in our study assisted in regulating emotions, provided hope and faith in hopeless situations, based on a world view that was closely related to the patients' everyday faith and culture. Self-perception and coping are closely related. According to Antonovsky, people who are engaged and motivated are better able to understand, cope with, and get on in life, compared to people who are passive, discouraged, and unmotivated. All individuals long for existential control of their lives (52). Contacting traditional healers, provided the participants in our study with a sense of control of their situation. The participants used traditional healing as a coping strategy. This revealed an active attitude towards their own disease on many levels. In addition, it helped strengthen the patients on a general level (empowerment).

Myrvoll states that traditional healing is user controlled knowledge. It has existed and been preserved to the present due to demands and needs (41). Henriksen states that traditional healing is a kind of everyday faith that connects the patient and healer with an almighty divine power (47). In spite of the religious change to Christianity, traditional healing has survived and is still practiced, often in a Christian context (34, 41, 53). Therefore, traditional healing can be understood as a cultural coping strategy that unites the past, present, and future. In addition, the tradition can be understood as a link between the individual, the community, and a divine spiritual dimension. In other words, it is a coping strategy on several levels.

Related to Antonovsky's theory on meaning and coherence (49), there is the Sami term "birget", which means to manage or make it through life (54). Another Sami term is "birgehallat" which means coping as an individual as well as being able to interact with others (55). A third term is "Birgejupmi" that is understood as livelihood, survival capacity, and the way people (individuals and communities) maintain themselves in a certain area with its resources. Birgejupmi is a flexible process that demands resourcefulness and the use and development of local traditional knowledge in situ (56). The term birgejupmi is related to "árbediehtu". Árbe is understood as traditional, and diehtu is understood as knowledge, which is related to birget that also includes a

spiritual dimension of traditional knowledge (including the art of survival) (56). Nordin-Jonsson (57) integrates the terms *árbediehtu* and *birget* into the term resilience (see below).

9.3.2 Resilience

For a long time, the term resilience has been applied in psychology and behaviour research. The term may translate into "bouncing back" or "elasticity". This refers to people's capacity to recover in face of adversity (51). The term was firstly related to invulnerable children. These are children who grow up under adverse conditions. However, despite the tough conditions, they manage well in life.

Javo, who has examined Sami child-rearing, understands resilience as a protective factor. This protective factor may appear on several levels, such as individual, family, social context, and community level (58). Sami child-rearing is characterized by individual as well as collective values. On an individual level, children are supervised to manage on their own. Therefore, the Sami child-rearing is less characterized by rules and demands, such as regular eating and sleep schedules. Moreover, the child-rearing is based on collective values, such as living in harmony with nature and other people. Traditionally, large family groups have lived closely together. To avoid conflicts, the communication has been indirect and cooperative. Therefore, the child-rearing is based on indirect, cooperative communication.

The main aim of child-rearing is that the children should grow up to become independent individuals with the ability to cope on their own in the forest, at sea, and in the mountain. To achieve this, they need to learn how to reflect and make their own decisions (58). Problem solving is learned through listening to stories that illustrate possible solutions.

Most of the participants in our study had grown up listening to positive healing stories. It was quite common to contact healers when people got sick. Knowledge of the healing tradition was acquired through story telling and experiences in the family. Lena illustrated this by telling a story that had often been told in her family.

Lena: Yes, my mom often told about Kirsti who got burned, who got hot water on her back in the bathtub. She had to go to the hospital. And when Jakob Nilisa had read for her, the child didn't cry at all on the way to the hospital. I thought that was strange. This was a story we were told.

The healing stories have been essential in the Sami culture. Nergård is of the opinion that the story in itself has healing powers. Getting involved in the story telling also kept the network with its vivifying forces alive. Furthermore, he claimed that the stories can be understood as cultural maps for people to navigate through life's challenges (36). Based on this, these stories about traditional healing can be understood as resilience factors. They are cultural action maps and provide the users with a tool they can use to handle stress and disease.

Kirmayer (59, 60) states that the term resilience is well suited when studying indigenous people. This is because the term must always be assessed in consideration of the peoples' culture, and different cultures generate resilience in different ways (61). The resilience perspective enables identifying hidden and socially marginalized coping strategies for health that would otherwise be invisible (62). In this perspective, it is not the traditional healing or the disease itself that are important, but the health promoting processes and mechanisms that are activated by the tradition (51). Examples of this are the relationship between generations, seeking practical and mental support in case of disease, as well as seeking help to maintain hope and ease anxiety. The Sami settlement has been characterized by small communities, in which they have been mutually dependent on each other's support to survive. Therefore, it has been essential to pass on the collective values (58).

9.3.2.1 Individual resilience

Bals et al. (63) found that learning about your culture might increase your own faith in coping abilities. Traditional healing can be understood as knowledge deeply rooted in the Sami, Kven, and North Norwegian culture (12, 36, 46). In our material, we found that when a patient contacts a healer to cure a disease, he/she used a coping strategy on an individual level.

9.3.2.2 Community resilience

Community resilience is understood as resources derived from the collective strengths that exist in the family, extended family networks, and communities. An example of this is people who get support and advice from the extended family, such as good parents, and advice across generations and kin networks. In addition to family support, access to cultural knowledge and sources like reindeer herding, handcrafts, traditional healing, and spirituality are important factors included in community resilience (60, 63, 64). In our material, the network took collective responsibility for the patient as well as for the relatives. They offered practical help, support, and took

responsibility for contacting and keeping in touch with the healer and the patient throughout the entire disease process.

Many communities are strengthening individual and collective agency through political activism, empowerment, and reconciliation (59). Both communities, in which this study was conducted, have been included in the Sami language management area, due to political activism, among other things. This has resulted in engagement and revitalization of the Sami culture and cultural expressions. Norwegian authorities have through domestic and international laws committed to facilitating the maintenance and development of the Sami language and culture (2, 15, 65).

9.3.2.3 Relational resilience

Resilience on a relational level is understood as people's ability to seek social support, connection, and reconnection with their own culture and spirituality (59, 60). One of the participants in the study explained:

Harald: As a matter of fact, traditional healing still matters quite a lot. Maybe it actually provides a deeper meaning, that you're part of a community, a society, part of a mindset.

The focus is on the strengthening processes derived from the relationships and networks surrounding the patient. Research shows that taking part in cultural knowledge and practice gives access to social support (63). Through collective story tellings, the participants in our study got access to alternative actions that they could apply in face of stress and disease.

9.3.2.4 Cultural resilience

Cultural resilience is defined as coping strategies that are found in nature, in the individual, and in the community, that allows a person to develop and cope with life difficulties. Cultural resilience may be important in healing and recovery. Cultural resilience factors may include factors in the individual (self-efficacy, intelligence and communication skills, Sami native language competence, traditional knowledge, traditional healing, spirituality, and traditional handcrafts). Cultural resilience is a collective term for individual and community resilience factors, that includes both culture and spirituality. In the case of indigenous peoples, some of these strategies of resilience draw from traditional knowledge, values, and practices, but they also reflect ongoing responses to the new challenges posed by evolving relationships with the

dominant society and emerging global networks of indigenous peoples pursuing common cause (59).

In our study, a nurse conducted a healing ritual on a patient with anxiety. This ritual is commonly used in cases of anxiety in the Sami culture (43). The nurse used a ritual that she knew the patient was accustomed to and that she strongly believed in. The ritual was familiar to her and helped ease the anxiety (66, 67).

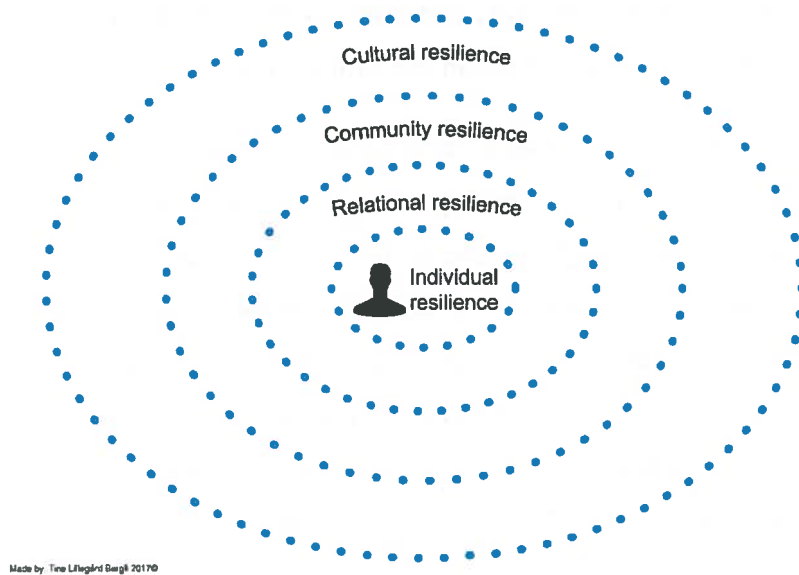


Figure 9-1 The figure shows the interaction and relation between different forms of resilience. Several dimensions interfere with each other and the transitions between them are floating.

9.3.3 Medical pluralism

The concept of medical pluralism implies that in any community, patients and their next of kin may resort to different kinds of therapies, even where these have mutually incompatible explanations for the illness (68). Medical pluralism exists in any arena where competing forms of systems of medical practices coexist (69).

In Norway, conventional medicine is the officially approved form of treatment (70, 71). However, anthropologists have found in their research that there is a vast diversity in medicine (69, 72). Even though the authorities have chosen conventional medicine as the official healthcare for the Norwegian population, they cannot control which treatment the patients choose or what they believe in (72). Therefore, in today's Norway traditional medicine exists along with

many other complementary and alternative forms of treatment outside the official health care services.

Psychiatric patients, for example, received conventional treatment whereas many people in addition contacted traditional healers. In a study of 186 psychiatric patients from North Troms and Finnmark, 67% (n=29) of the Sami patients and 45% (n=49) of the Norwegian patients had used traditional and complementary healing modalities (the laying on of hands, healing, distant healing, and “reading” or prayer) (28). In Northern Norway, such a practice is well known in Sami communities or in communities where the Laestadianism has strong traditions.

Patients are active and tailor their own holistic health care to meet medical, spiritual, as well as cultural needs (73). According to Henriksen, traditional healing is an expression of practical everyday faith (47). Similar to evening prayers or saying grace, traditional healers are contacted in cases of disease. Traditional medicine covers the need to be seen, seeking social and spiritual support, the need for group affiliation, as well as using treatment known to the culture (43, 48). Moreover, nothing should be left untried (Larsen, 2012). Conventional treatment meets other needs of the patient. Examples of this are making diagnosis, necessary health care, medical treatment, rehabilitation, as well as nursing and care (71).

Access to traditional healing and conventional health care helps the patient to have the best of two worlds: cultural validation, symptomatic cure (or relief), a greater sense of control of the disease process, as well as better understanding of its multi-dimensional causation, the benefit from two (or more) expert opinions from both physicians and healers (74).

A participant in our study knew she would have to go through painful surgery. Therefore, prior to the surgery she called a healer who read a healing prayer for her. In this way, she got the best of both worlds, that is medical help from the conventional health care system, in addition to help from a healer to cope with the pains following the surgery.

9.4 Aims of the research plan

Table 9-1 The aims, research questions and methodology applied in this research plan

| Aims | Research questions | Methodology | Publication |
|--|---|--|---|
| <ul style="list-style-type: none"> To describe health care providers' understanding of the practice of traditional healing, and how health care professionals handle it. | <ul style="list-style-type: none"> What are the health personnel's knowledge, understanding, and experience of traditional healing? How do health personnel's ethnic background influence the understanding and handling of patients who also seek help from "readers"? | <ul style="list-style-type: none"> 13 individual semi-structured interviews. 2 focus group interviews. | <p>1. The data in this publication is also included in paper two – below.</p> |
| <ul style="list-style-type: none"> To examine whether health personnel's knowledge, attitudes, and experiences of traditional healing affect their clinical practice. | <ul style="list-style-type: none"> Can traditional healing be understood as coping strategies for patients faced with stress and illness? | <ul style="list-style-type: none"> 32 individual semi-structured interviews. 2 focus group interviews. | <p>1</p> |
| <ul style="list-style-type: none"> Traditional healers' understanding of traditional healing, the healing process, and their own practice, as well as what characteristics healers should have. | <ul style="list-style-type: none"> What is traditional healing? The healers' perspective on the healing process Which abilities are required for traditional healers? | <ul style="list-style-type: none"> 15 individual semi-structured interviews. 1 focus group interviews. | <p>1</p> |
| <ul style="list-style-type: none"> To examine the extended family networks' function and responsibility in cases of illness in the family. | <ul style="list-style-type: none"> What are the tasks and functions of the extended network in cases of disease? What are the inner dynamics of the network? What does the network want the health personnel to know about how they handle disease? What kind of responsibility does the network take in case of disease in the family? | <ul style="list-style-type: none"> 13 individual semi-structured interviews. 4 focus group interviews. | <p>1</p> |

10 Methods and results for this research plan

In this section each individual study will be presented separately, including the following paragraphs.

1. Specific aims of the study.
2. Specific methodology applied in the study. (The methodology will be presented under study I, as all four studies applied the same methodology.)
3. Abstract of the publication.

10.1 General methodology applied in this research plan

Qualitative research can generate hypotheses for quantitative research and test the theoretical framework for a quantitative method (75). This approach can help the researcher to gain access to the views of the participants and address how an intervention is used in practice (76). The focus is on content, nature, and meaning (77, 78). In this research project, qualitative design was used to examine primary health care providers' knowledge and traditional healing in a Sami-Norwegian community in Northern Norway, and how they relate to patients who seek traditional healing in addition to conventional health care. The design was also applied to delineate the healers' perspective on the healing process, and moreover, investigate what the networks want the health personnel to know about how they handle disease.

10.2 Paper I: Between professional and popular knowledge. A qualitative study of health professionals' knowledge and handling of traditional spiritual healing in a Norwegian - Sami Municipality

10.2.1 Aims

The specific aims were:

1. What are the health personnel's knowledge, understanding and experience of traditional healing?
2. How do health personnel's ethnic background influence their understanding and handling of patients who also seek help from "readers."

10.2.2 Method

10.2.2.1 *Individual semi-structured interviews*

Semi-structured interviews are used when trying to understand daily life based on the participants' own lifeworld and perspective. The design makes it possible to acquire new knowledge about specific issues through allowing questions to be created during the interview, in addition to pre-defined themes and questions from the interview guide (79).

10.2.2.2 *Focus group interviews*

Focus group interviews generate different types of information compared to individual interviews, as the group dynamics may reveal reflections and issues of experience and individual practice, that may not be disclosed in individual interviews (80). The design is beneficial when the aim is to understand what different health care providers experience as important in their own practice (76, 81).

10.2.3 Abstract paper I

Abstract

Background: In Northern Norway spiritual healing traditions are still practiced, especially among people related to Sami background and culture. Studies indicate that the general public believes that health care professionals are skeptical when it comes to the traditional spiritual healing practice known as "reading" or læsing in Norwegian.

The purpose of this article is to describe health care providers' understanding of the practice of traditional healing, and how health care professionals handle it.

Methods: A qualitative study based on semi-structured interviews and two focus group interviews with 13 primary health care professionals, two physicians, seven nurses, and four welfare workers, was conducted in a rural Sami area in Northern Norway.

Findings: The study shows that health care professionals have great knowledge of and respect for *reading*. The knowledge is based on the health care personnel's relationships with the community. Health care professionals distinguish between how they relate to *reading* as private persons and as health care professionals.

Conclusion: The analysis provides an understanding of how traditional knowledge and professional biomedical knowledge play together in health care providers' work in primary health care. It can provide input into the development of a culturally sensitive public health care service.

10.3 Paper II: "There are more things in heaven and earth!" How knowledge about traditional healing affect clinical practice: Interviews with conventional health personnel

10.3.1 Aims

The global aim of this study was to examine whether health personnel's knowledge, attitudes, and experiences of traditional healing affect their clinical practice. In addition, we wanted to:

1. Investigate if traditional healing can be understood as coping strategies for patients faced with stress and illness.

10.3.2 Abstract paper II

Abstract

People with Sami and Norwegian background are frequent users of traditional medicine (TM). Traditional healing, such as religious prayers of healing (reading) and the laying on of hands, are examples of commonly used modalities. The global aim of this study is to examine whether health personnel's knowledge, attitudes, and experiences of traditional healing affect their clinical practice. Semi-structured individual interviews (n=32) and focus group interviews (n=2) were conducted among health personnel in two communities in Northern Norway. The text data was transcribed verbatim and analysed based on the criteria for content analysis. Six themes were identified. The participants had acquired their knowledge of traditional healing through their childhood, adolescence, and experience as health personnel in the communities. They all expressed that they were positive to the patients' use of traditional healing. They justified their attitudes, stating that "there are more things in heaven and earth" and they had faith in the placebo effects of traditional healing. The health personnel respected their patients' faith, and many facilitated the use of traditional healing. In some cases, they also applied traditional healing tools if the patients asked them to do so. The health personnel were positive and open-minded towards traditional healing. They considered reading as a tool that could help the patients to handle illness in a good way. Health personnel were willing to perform traditional healing and include traditional tools in their professional toolkit, even though these tools were not

documented as evidence-based treatment. In this way, they could offer their patients integrated health services which were tailored to the patients' treatment philosophy.

10.4 Paper III: "The prayer circles in the air": A qualitative study about traditional healers from Northern Norway

10.4.1 Aims

The specific aims were:

1. What is traditional healing and how is it practiced in two Sami Norwegian coastal communities today?
2. We wanted to examine the healers' perspective on the healing process and investigate which abilities are required for traditional healer.

10.4.2 Abstract paper III

Abstract

Background: In Northern Norway, traditional healing has been preserved by passing down the knowledge through generations. This knowledge is passed on to a few chosen successors and is not shared openly, but kept secret. In this study, religious prayers of healing (reading) and Sami rituals (curing) are examples of methods that are used. We have examined traditional healers' understanding of traditional healing, the healing process, their own practice, as well as what characteristics healers should have.

Method: Semi-structured individual interviews and focus group interviews were conducted among 15 traditional healers in two coastal Sami communities in Norway. A verbatim transcription of the text data was performed and coded in NVivo11.

Results: The traditional healers understood traditional healing as the initiation of the patient's self-healing power. This power was initiated through healing rituals and explained as the power of God and placebo effect. The traditional healers experienced themselves as channels for the power of God. During the healing ritual, the doctor's medical diagnoses, the patient's personalia, and a prayer in the name of The Father, The Son and The Holy Spirit were used in combination with steel and elements from the nature. The traditional healers stated that they had to be

trustworthy, calm, and mentally strong. Healers who claimed that they had supernatural abilities (clairvoyance or warm hands) were regarded as extra powerful.

Conclusion: The study shows that traditional healing is a religious practice that combines Christian prayers with traditional Sami rituals. The healers in our study used information from conventional medicine and knowledge about traditional medicine when conducting healing rituals.

10.5 Paper IV: "We own the illness": A qualitative study of networks in two communities with mixed ethnicity in Northern Norway

10.5.1 Aims

The main research question was:

1. What are the tasks and functions of extended networks in Northern Norway in cases of disease? We wanted to particularly examine the networks' inner dynamics and investigate what the networks want the health personnel to know about how they handle disease.
2. Further, we wanted to investigate the responsibility the networks take in case of disease in the family. This is so far underexplored and possibly important aspect of understanding the Sami, Kven, and Norwegian inhabitants' health practices in Northern Norway.

10.5.2 Abstract paper IV

Abstract

Background: When people in Northern Norway get ill, they often use traditional medicine, such as religious prayers for healing (reading) and the laying on of hands. The global aim of this study was to examine the extended family networks' function and responsibility in cases of illness in the family, in two Northern Norwegian communities with populations of mixed ethnicity. Further, we wanted to investigate what the networks wanted the conventional health care personnel to know about how they handle illness and disease.

Methods: Semi-structured individual interviews with 13 participants and four focus group interviews with a total of 11 participants were conducted. The text data was transcribed verbatim and analyzed based on the criteria for content analysis. Three main themes and several sub-themes were identified.

Results: The participants grew up in areas where it was common to seek help from traditional healers. The communities were organized in large traditional networks (Siidas), which consisted of family, relatives, and neighbors. These networks shared responsibility for the patient, and they provided practical help and support for the family. Determined by the severity of the disease, the network was responsible for contacting one or several healers. According to the network, health care personnel should make room for the entire network to visit the patient in severe and life-threatening situations.

Conclusion: Traditional networks are an extra resource for people in these communities. The networks were activated when people experienced stress and illness. It seems to be essential in handling and disseminating hope and manageability on an individual, as well as a collective level. Health personnel working in communities with mixed ethnicity should have thorough knowledge of the mixed culture, including the importance of traditional network to the patients.

11 Discussion

We understand the use of traditional healing as a mechanism of resilience or coping strategy on individual, social, and cultural levels. This tradition may be regarded as an expression of the culture in Northern Norway that binds people to a community which is linked to a culture with a spiritual dimension that has long-lasting traditions in the communities in which this research project was conducted. The use of traditional healing was an expression of the need for a spiritual dimension that conventional health care providers do not meet.

The users in this research project employed parallel treatment methods from the Norwegian conventional health care system and traditional medicine. The use of traditional healing indicated active patients and their social networks. The health personnel and traditional healers helped them meet the patients' individual needs in cases of illness. In our opinion, the results from this study may help us recognize traditional strategies for managing illness. Shedding light on this tradition may enable health personnel to facilitate for culture specific traditions and make the health services more open-minded towards the use of traditional medicine in cases of illness. The results from this study may provide health personnel with increased knowledge and understanding of the use of traditional healing, which can be beneficial to ethnic minorities.

The research team was especially aware of the Sami's bad experiences with previous research and the bad reputation of research in the Sami culture (see section 11.2). Therefore, we thoroughly informed the participants of the purpose of the study, which was to focus on the particular and health promoting aspects of using traditional healing. Furthermore, we consulted local resource persons and culture bearers in the community. In addition, the relationship with the participants were nurtured. This made the participants feel safe. Moreover, it made them want to participate in the study. However, conducting research among indigenous populations with previous bad experience, requires special attention to research ethics and user involvement. This will therefore be the focus in the discussion.

11.1 Research ethics

The term ethics is derived from the Greek word "ethos" which means habit and character. Ethics is the teaching of morals, and in research, this involves conforming to ethical guidelines and commitments to good research practice (82). Violations of these guidelines may lead to legal sanctions. Several of the ethical guidelines are embodied in various documents such as The Declaration of Helsinki (83) and The Nuremberg Code (84).

During World War II cruel medical experiments were conducted on the prisoners. To prevent recurrence of similar abuse, it was decided that international ethical guidelines for medical research involving humans had to be developed. The present ethical guidelines are based on these, which are embodied in The Nuremberg Code of 1947 (85). Researchers must conform to these ethical standards which state that all research is to be voluntary and that the participants are to be informed of the duration, purpose, benefits, and risks of participating in the study. Despite The Nuremberg Code, people have been abused in medical or health science research. Research has been conducted with human participants without their consent, or the consent has been given based on unclear terms (86). Examples of this are the conduct of research on war children who were born by Norwegian mothers and German fathers during World War II (87), mentally ill people, persons in jail and in institutions, as well as ethnic groups such as the Sami (The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH) (2002).

Based on this, The World Medical Association developed new ethical guidelines that were embodied in The Declaration of Helsinki in 1964 and that have been amended several times, most recently in 2013. In 1985, Norway adopted The Declaration of Helsinki, and several

countries have followed Norway's example (86). According to these guidelines, an independent ethics committee must assess all research projects in health care.

Prior to our study, we applied for ethical approval from The Norwegian Centre for Research Data (NSD) (project number: 38334). The main objective of The NSD is to assure that the privacy and rights of the participants are protected according to ethical principles. In our application to The NSD, we had to state how anonymity was to be protected (the participants were given fictitious names) and how the data was to be stored (in a locked cabinet at the researcher's office, and storing the key elsewhere), as well as the date for deleting the research data (in 2022).

The guidelines in The Declaration of Helsinki include requirements of voluntary informed consent. Nevertheless, the welfare of the research subjects is always the responsibility of the researcher, even when the participants have given their written consent (85). To obtain collective consent, as opposed to individual consent, the researcher must contact an indigenous organization, authority, or community leaders. If research is to be conducted on the Sami, for example, you could apply for consent from the Sami Parliament, which is the elected body and the voice of the Sami. There is no obligation on the researcher to obtain collective consent according to the present guidelines. However, guidelines for Sami health research involving human biological material are being developed, that will require collective consent to be obtained from the Sami Parliament or another institution appointed by the Sami Parliament (88). Obtaining collective consent is often a time consuming process, which is a disadvantage in research projects of short duration (89).

The main focus of our research was not to study the Sami as a group. We chose to concentrate on the phenomenon of traditional healing among three different groups (health care personnel, users of traditional healing, and traditional healers) in Northern Norway. We collected a relatively large amount of qualitative data from interviews with many Sami participants. Therefore, we obtained individual consent from the participants as well as collective consent from the political managers of the communities in which the study was conducted.

The Declaration of Helsinki states that vulnerable populations must be given special protection. Vulnerable populations are defined as people who cannot give consent themselves. Examples of such groups might be children, mentally ill people, prisoners, and ethnic minorities (82).

Ethnic origin is considered sensitive information. It is illegal to record data on ethnicity in Norwegian public health databases (90). According to Kvernmo et al. (88), ethnicity data should be used as information in health research only to improve the knowledge of health science and not to stigmatize ethnic groups. In this research project, we divided the participants into three groups according to their ethnicity, Sami, Kven and Norwegian. We used the following two criteria (91):

- the participants' own definition (subjective aim)
- the ethnicity and home language of the parents and grandparents, based on the participants' information (objective aim)

The Declaration of Helsinki comprises research and protection of patients but does not include the same kind of protection of health personnel (75). Malterud claims that the responsibility for exercising sufficient discretion regarding ethical and proper research on health personnel lies with each individual researcher.

11.2 The history of research on minorities in Norway

Lappology is an outdated term for the science of the Sami language, history, religion, and culture (92). The discipline of lappology had its heyday from the middle of the 19th century till after World War II (93). Much of the lappology research was used to classify and emphasize ethnic hierarchy. Norwegians were regarded as superior to the Sami and Kven. This legitimized the abuse of power and supremacy over this population.

The lappology was based on the social Darwinism (1850-1950). The basic idea was "the survival of the fittest" (94). This means that the strongest should be strengthened as the weakest would die out anyway. According to this science, humans were grouped into different races. The Nordic race was regarded the best and strongest, whereas the Kven and Sami were regarded further down the scale. It was believed that these individuals had stopped at a lower stage of development. Much of the research was conducted to confirm the theory of ethnic dominance.

Schreiner's measurement of the human skull is an example of research methods that were conducted in Sami areas (Tysfjord and Kautokeino) from 1914 till 1921 (88, 95). Many photos were taken, and below the pictures, body measurements such as forehead lengths, skull sizes, and other intimate details were stated (95). The Sami were somewhat unwilling to be photographed

nude and take off their shoes. Later, the local population strongly condemned the results and photographic materials of this research due to the negative portrayal of the Sami (96). In addition, skeleton materials (skulls) were collected from pre-Christian graves in Finnmark and Nordland (1914-1939). These materials were sold to domestic and international institutes of anatomy, with the blessing of the authorities (88, 97).

The researchers' task was to define, classify, and typify the population into two main groups as well as several subgroups. Norwegians were classified as long skulls, and the Sami were classified as primitive short skulls having lappoloid traits (96). Friis (1821-1896), who was a professor in the Sami and Kven languages, described the Sami as *the Finn's weaker brother* (93). To regard some populations as primitive, was held to be scientifically true. This attitude formed the basis of physical anthropology and was used to legitimize the exercise of power such as colonialization and nationalization (97).

At the same time as the skeleton materials were collected and the skulls were measured (1900-1950), large parts of the Norwegian population was hit by tuberculosis. This led to high population mortality. The mortality rate was particularly high in Northern Norway, and in Finnmark the mortality rate was twice as high as the rates for the rest of the country. The Sami children who lived in residential schools were particularly susceptible to infections (98). The authorities regarded the Sami and Kven populations as unhygienic and uncivilized. Therefore, the fighting of the disease was used to cultivate and assimilate them into the Norwegian culture. Therefore, many Sami and Kven patients did not meet for medical examination due to distrust in the health services. This attitude may be directly related to the Norwegian authorities' treatment of this population in the 20th century (99).

Today, skull measurements, excavations, and research on skeleton materials as well as the "cultivation" of the Sami and Kven are regarded as abuse of these minorities (88). Furthermore, the research results have been used as the basis of assimilating them into the Norwegian culture (96). In recent years, new methods and principles in research have been developed to prevent additional abuse of minorities. Examples of this are user involvement in research and indigenous research methodologies.

11.3 User involvement and indigenous research methodology

The Norwegian Ministry of Health and Care Services wants to increase user involvement in research. This implies that the users of health services are to be included in the entire research process and not merely in the recruitment phase (100, 101). They state:

When the users are involved in the entire research process, the research will, to a larger extent, reflect the users' needs and points of view. This will provide new knowledge with greater certainty, that might be beneficial to the health and care services.

This approach is in line with the newly proposed ethical guidelines for health research on the Sami (88).

In this research project, we have included user involvement on several levels. We have included and interviewed health personnel, users, as well as healers about their experiences with traditional healing. The rationale for involving these participants is that it is the patients and their relatives who have the experience of how traditional healing and biomedical treatments are used in cases of illness. Health personnel have experience in how these treatments are handled by the public health services. The healers have clinical experience and knowledge of how traditional healing is practiced in their daily work with the patients.

Moreover, the interview guide was developed in cooperation with the users and healers who have experience of traditional healing. They commented on and gave advice about the questions in the interview guide. As previously mentioned, we cooperated closely with the community managers, the language centers, and key informants in both communities. This was important to build study legitimacy among the inhabitants in the communities.

User involvement is about building relationships between the researcher and the participants. This is also an important principle in indigenous research methodology (102). Indigenous research methodology was developed to create a more equal balance between the researcher and the study participants as there has been so much abuse of indigenous peoples and other vulnerable groups in research involving these groups (88, 103).

Even though the policy of Norwegianization is history, the consequences for the Sami and Kven populations have been feelings of shame and cultural degradation (36). Kirkengen is of the opinion that if you experience shame of belonging to a stigmatized group, the shame may be

characterized as dual. This is because you feel shame about yourself as well as shame for your parents. This may lead to self-contempt (104). Nergård supports this and adds that researchers need to be aware that the consequences of the Norwegianization policy still exist. Even though the colonial master is gone, the shame may have been embedded in the bodies. This might make the individuals continue to downgrade themselves as well as their ethnic group (36). Another consequence of the Norwegianization policy is that people may experience the question of ethnic affiliation as offensive and highly personal information (88). Several researchers are of the opinion that the policy of Norwegianization and the offensive research conducted on ethnic minorities in Norway, have contributed to creating a collective pain in the Sami and Kven populations. These conditions demand particular sensitivity in interactions with these people (88). Consequently, the need of an indigenous research methodology arises.

This is how Kuokkanen describes indigenous research ethics.

Indigenous research ethics are about establishing new, more respectful and responsible relationships, discourses and practices with indigenous communities and addressing the previous colonial, exploitative and asymmetrical relations of research (105) p. 55.

The aim of indigenous research methodology is to break with previous structures and rather promote more symmetrical relationships between researchers and participants (103). Previous research that has been conducted on indigenous peoples has tended to describe and explain other cultures based on preconceptions originating in customs of the researchers' own culture (ethnocentrism). The researchers need to reflect on this to avoid committing ethnocentric fallacies (106). An example of this is if a Norwegian researcher arrives at the conclusion that all British people drive on the wrong side of the road. Another consequence of ethnocentrism is the researchers' disparagement, rejection, and exclusion of the cultural knowledge and traditions of indigenous peoples. Moreover, they have been assessed as primitive, unreasonable, and irrelevant, based on the researchers' world view. In the worst cases, the researchers have taken out patents on their knowledge (107).

In our research project, we tried to establish good relationships between the researchers and the participants. We spent a lot of time establishing and maintain trust. The research fellow often visited the participants to talk with them. For two months, she lived in the communities when

conducting the interviews. She attended a dodge course, mushroom course, and a traditional handcraft course in both communities. She heard the greatest and most colorful stories when the tape recorder was turned off (mountain hiking or in private gatherings). The information she collected during these informal talks has undoubtedly helped her ask more proper and nuanced questions.

Wilson is of the opinion that indigenous research methods are about equivalence between paradigms, indigenous knowledge, and academic knowledge (108). This includes drawing attention to indigenous knowledge in academia, but on the terms of the indigenous peoples. Furthermore, he claims that researchers with indigenous background must become more self-confident and use the experience from their own culture as a resource in their research. An example of such work is the Árbiediehtu project in which the aim is to document, collect, and systematize traditional knowledge. The objective is to promote Sami knowledge as the basis for political and administrative decision making (56, 57).

An important characteristic of indigenous research methodology is that the participants are to benefit from the research. Moreover, the research results should be useful to the community in which the study was conducted (103). A seminar at Arran Lule Sami Center described previous research in Sami areas as: They came, they took, they left (109). It was a catching title. It is descriptive and refers to how researchers arrived, gathered lots of data, and then left. The research results were not shared with the local population. Moreover, the research provided no benefit to the local community(109).

When studying indigenous peoples, the research ought to be beneficial to the participants in the study. In our study, that was the two Sami Norwegian communities in which the study was conducted. In this research project, we have tried to comply with the requirements regarding the return of results through lectures held by the research fellow in the communities. In addition, she published an article in a popular local science journal (110). When the project is completed, we will continue to give lectures, workshops, invite the participants to meetings in which we will present additional research findings.

11.4 Methodological aspects

For this research project, we decided to use a qualitative design. This design is well suited to study experiences of social phenomena when little prior knowledge of the phenomena exists (79,

111). This approach can help the researcher to gain access to the view of participants and address how an intervention is used in practice (76). The focus is on the content, nature, and meaning (77, 78). Qualitative research can also generate hypotheses for quantitative research and test the theoretical framework for a quantitative method (75). In this research project, a qualitative design was used to examine primary health care providers' knowledge of traditional healing in two Sami-Norwegian communities in Northern Norway, and how they relate to patients who seek traditional healing in addition to conventional health care. The design was also applied to delineate the healers' perspective on the healing process, and investigate what the networks want the health personnel to know about how they handle disease. Content analysis is usually applied when prior research exists, but the research is sparse or would benefit from further research (112). This was the rationale for applying content analyses in this research project. Elements from both conventional and direct content analyses were used, hence a mixed type.

11.4.1 Semi-structured interviews

Semi-structured individual interviews were used in this research project, as use of traditional healing is a sensitive theme to many users and a widespread practice in Northern Norway. Therefore, "one to one conversations" were a highly suitable methodological approach. The design includes open-ended questions, allows follow-up questions, and the participants are enabled to give nuanced answers (79). In addition, it enables the researcher to study the theme in depth and dwell on issues that might emerge during the interview. The semi-structured interview is therefore particularly suitable to examine the participants' in-depth understanding of a phenomenon. The design also gives room for personal stories (75).

A thematic interview guide including questions about healing traditions in Northern Norway was drafted by the research fellow. It was further developed together with the rest of the research team. The interview guide was developed according to previous knowledge about traditional healing established in other studies, and the candidates' own previous cultural knowledge from growing up in one of the communities under investigation. The interview guide was used as a checklist during the interviews. The research fellow conducted all of the 60 individual interviews herself, and she attempted to keep an open dialogue with the participants (76). The sequence or wording of the questions asked would therefore vary from interview to interview. Prior to the

study, a group of researchers with and without personal experience and knowledge of traditional healing, discussed the questions in the interview guide (strengthens inner validity).

11.4.2 Focus group interviews

Focus group interview is a research method that is well suited in conjunction with other methods. Therefore, we used this design in addition to individual interviews (81). A group interview resembles natural conversations between people, and is a method that is well suited for sharing experiences about culture sensitive issues (80). Focus group interviews may function as a concentrated conversation among participants that might never occur in the “real world” The ideal number of persons in the focus group is between six and twelve, but if the theme or topic is emotionally charged or sensitive, it might be better to have a smaller group (76). It is recommended that a mentor or moderator is present in focus group interviews. The person is to lead the discussion and takes care that everyone is asked and given the opportunity to contribute to the discussion (81, 113). In this research project, the research fellow functioned as an interviewer as well as a moderator as traditional healing is a confidential and sensitive theme. For this reason, we did not want to impair earned trust and confidence by introducing unfamiliar people in the interview situation. Group participants who feel safe to share their perspectives might provide the researcher with broader data and participation in other stories than what can be obtained from individual interviews with the identical sample of participants (81). The research fellow experienced that the participants in the group interviews communicated other stories with more nuances than the stories they told in the individual interview. The group dynamics made the participants share new thoughts and reflections and illuminate the themes from different angles. This was the case especially for the group of participants of different ethnicity and different health professional background. In this research project, a total of seven focus group interviews were conducted, including two to five participants in each group.

During a focus group interview with health personnel, the Sami participants expressed fear of having conveyed too much information about traditional healing to the researcher during the preceding individual interviews. The researcher had to make the informants feel confident to be able to conduct the interview. She spent 20-30 minutes listening to their fear as well as establishing trust before turning on the tape recorder. Reflexivity means not to interpret stories as resolute facts but rather try to understand what the stories mean to the informants (81). In this context, the fear might be an expression of having broken a collective norm of silence. When

conveying your own experiences of traditional healing, you simultaneously reveal information about the others in the collective community (Sami culture).

11.4.3 Internal validity

Validity is a term that is used to verify whether a study examines the issues intended (114). In this connection, the researcher should have continuous quality controls in all stages of the research process (79). The researcher should ask himself/herself if he or she has used the relevant terms and mapping methods to secure proper instruments when seeking answers to the questions. There is a considerable risk of using incorrect terms, especially when examining other cultures or countries with a different language from that of the researcher (75). As an example, Malterud mentions that a female researcher who studies female diseases will obtain other nuances in her interviews/data than a male researcher who studies the same themes. Likewise, it is presumed that a Sami researcher who knows the culture will obtain other nuances in the interviews/data than a researcher who is unfamiliar with the culture (75). Thus, it was an advantage that the researcher of this research project grew up in the Sami culture and was a qualified nurse. She was therefore familiar with the local terms and medical terminology.

The researcher's pre-understanding may be a source of bias. This means that the researcher's previous experience and knowledge may affect the results of the study (75). To become aware of her own pre-understanding, the research fellow wrote a research log during the entire process/study. In the research log, she recorded her thoughts prior to and after having conducted the interviews. In a research diary, she wrote down her thoughts and data analyses to validate herself as a researcher. In addition, she had professional discussions with the research group who provided input, other perspectives, and viewpoints, especially when analyzing the data. This might have increased the credibility and validity of the research (76).

In her master's thesis, the research fellow examined the patients' reasons for using traditional healing in today's technological society. The data contributed essentially to developing this research project and was used as background information in subsequent analyses. Researchers who familiarize themselves with the field have greater validity than those who do not (75). The quality of the interview (ask good questions) depends on the researchers' skills and knowledge of the theme (79). Through previous studies, the researchers have familiarized themselves with the literature on the relevant themes. Moreover, they have gained a deeper understanding of the field.

This enables them to ask more precise questions. However, if they think they know the theme and they are not curious enough to dig deeper into it, this may naturally represent a possible source of error. Thus, they might be blinded to nuances in the data.

During the interviews, the research fellow ensured that she had understood the participants correctly. In the interviews, the participants were asked if they would have answered differently if the researcher was not a Sami and did not know the culture. The participants answered quite differently. Some claimed they would have answered openly and honestly regardless, and others claimed that they would not have been open and honest if the researcher was not a Sami and did not know the culture. At the end of each interview, the participants were asked if there were issues that they wanted to elaborate on or if they had anything else to add. Quite often the researcher had to turn the tape recorder back on.

After the interviews had been transcribed, the transcriptions were sent to the participants for review, a so-called member check (114). This resulted in the inclusion of some supplementary answers from one of the participants. This did not however, change the meaning. Some key informants were interviewed several times to ensure correct understanding (79).

11.4.4 Recruitment (external validity)

To ensure the external validity of the research project, it is important to check if there is a representative selection, and if the instrument (questions used in the interviews) has been turned in the right direction for the issues to be examined (75). Previous research has shown that there is a strong prevalence of traditional healing and Laestadianism in communities with a large proportion of Sami inhabitants. For this research project, we therefore chose two Sami communities that were included in the Sami Language Management Area. The research fellow has previously examined these two communities (the master's thesis and the pilot survey). It was therefore sensible to build on former relationships and continue the research in an area that was familiar to her.

Prior to the initiation of the study, the research fellow visited both communities. She had an information and coordination meeting with the managers and health care managers of the communities. The health care managers provided concrete advice on how to conduct the study. She was advised not to stress that this research was merely on the Sami. The focus should rather

be on research in areas with a large proportion of Sami population as this is an area of mixed ethnic populations (Norwegian, Kven, and Sami).

The community managers gave permission to conduct the interviews during work hours, and the managers of the health and care sector in the communities were notified. In addition, information about the study was published on the communities' websites. The same information was published in the local newspapers. Moreover, information sheets about the study were posted in the libraries, shops, and on the communities' bulletin boards.

Furthermore, various meetings were arranged in both communities prior to initiating the study. In these meetings, people were informed of the upcoming study. In addition, information was provided about the results from two smaller studies that had previously been conducted in the communities. To obtain a locally rooted study, some key people as well as the managers of the cultural centers were involved in the planning. These key people provided concrete advice on how to build trust. The community managers helped the research fellow secure a representative selection of participants. The research team had developed some criteria for participation beforehand. These were the inclusion criteria:

- Qualified health personnel of both genders who worked in the community's primary health care services
- Different health professional background (physicians, dentists, nurses, social educators, and paramedics)
- Different positions in the primary health care services
- Different years of experience
- Different community affiliation

The users of traditional healing were recruited following the information meetings and according to the principle of snowball sampling. In this method some people recommend participation in the study to some of their acquaintances. This method of recruitment is well suited to recruit participants from hidden populations to for instance marginalized groups or to studies that include sensitive themes (81). These were the inclusion criteria for the users of traditional healing:

- persons older than 18 years who were consent competent

- both genders
- experience of traditional healing
- community residents
- not closely related to the research fellow

The study was important and approved by the managers of the communities. This made it easier to recruit participants to the study.

The healers were recruited through snowball sampling and the research fellow's network that she had built through her previous studies. These were the inclusion criteria:

- persons older than 18 years who were consent competent
- both genders
- healers who were well known in their local community
- community residents
- not closely related to the research fellow

It was easier to recruit the Sami participants than the Norwegians. One of the reasons might be that the research fellow is a Sami herself which enabled her to get along better with the Sami participants.

11.4.5 External validity and generalizability

External validity refers to whether results obtained from a study can be applied in other settings, for example other and larger populations (76). Our findings cannot readily be applied to other populations. However, Krueger and Malterud (59, 111) suggest the concept of the study transferability. The study may for example contribute to more open-minded health care workers in their encounters with Sami patients who use traditional healing in handling their illness. In addition, other indigenous communities might have similar parallel health care systems that include traditional healers. Researchers may benefit from our findings when comparing different indigenous communities.

The results of this research project may contribute to better communication between health personnel and patients who use traditional healing. Moreover, this might lead to increased patient satisfaction with the health care services and improved culturally competent health care systems.

Furthermore, the study may provide increased understanding and better handling of illness from the perspective of resources and coping. In addition, it may contribute to reveal more invisible, relational, and environmental aspects of the use of traditional medicine, improved multi ethnic (Sami, Kven and Norwegian) understanding and handling connected to illness and suffering.

11.4.6 Reliability

Reliability refers to the consistency and credibility of the research results. Ideally, the results of a study should be universal, regardless of the researcher. Therefore, it is important that the researcher is able to describe the research process in detail (75, 79). According to Creswell (114), reliability can be enhanced if the researcher writes down detailed field notes. Before and after the interviews, the research fellow took field notes to become aware of her own pre-understanding and new thoughts. In addition, she recorded methodological issues.

Disclosing the data to other researchers with different research background, may contribute to reveal other perspectives and nuances of knowledge. This may increase the reliability and credibility of the research results (115). This is called triangulation when the researcher makes use of multiple and different investigators with different views to provide corroborating evidence (114). After the interviews, two researchers (the research fellow and the supervisor) listened to the tape recordings and reviewed the interview transcriptions. The interview transcriptions were thematically analyzed. This is a well suited method for analyzing large amounts of interview data. The data were coded in the computer program NVivo. This is a computer program that can handle large amounts of qualitative data. The program provides possibilities for storing all the research data in one place, as well as providing many researchers with access to these data. In this way, NVivo makes it easier for other researchers to follow the analysis process (116). This makes the research process more available. Using NVivo, other researchers can gain insight into the research process. In addition, NVivo enhances the transparency of the research process. This is in line with the requirements for validation of research (117). Overgaard is of the opinion that the quality of research is enhanced by increased transparency and testability (increased reliability).

11.4.7 Perspective for future research and practice

Our studies were conducted in two coastal communities with mixed ethnicity in Northern Norway. There could be differences within Northern Norway or in the Sami and Kven cultures,

and various Sami groups have different cultural expressions and healing traditions. Different healing traditions and patient coping strategies in traditional network within the Sami culture should be investigated using qualitative designs. The focus should be on similarities and differences in traditional medicine, patient coping strategies, and conventional health care between various Sami populations (North Sámi, Lule Sámi, Pite Sámi, Ume Sámi, and South Sámi). To gain increased knowledge of the similarities and differences, future studies should include healers, patients, and conventional health personnel from several Sami areas and across the national borders within Sapmi (the land of the Sami across Norway, Sweden, Finland, and Russia). They should also include questionnaires combined with qualitative interviews of healers and users of traditional medicine in the entire Sami area. A similar study could also be conducted at hospitals, interviewing health personnel and patients about the use of traditional healing.

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En kvalitativ studie av helsepersonell sin kunnskap om og håndtering av "læsing" i
en norsk-samisk kommune

"There are more things in heaven and earth!" How knowledge about traditional healing affects clinical practice: Interviews with conventional health personnel

"The prayer circles in the air": A qualitative study about traditional healers from
Northern Norway

"We own the illness": A qualitative study of networks in two communities with
mixed ethnicity in Northern Norway

Appendix 20.1

- a) Information and consent letter to health care personnel

Forespørsel om deltakelse i forskningsprosjektet

En kvalitativ undersøkelse av helsepersonell i møte med pasienter som kombinerer samisk tradisjonell helbredelse og skolemedisin.

I denne undersøkelsen ønsker vi å komme i kontakt med helsepersonell i primærhelsetjenesten, for å undersøke hvordan helsepersonell forstår, forholder seg til læsing og hvilken erfaring de har med pasienter som søker hjelp hos tradisjonelle helbredere og skolemedisin. Forskningsprosjektet gjennomføres av Nasjonalt Forskningscenter innen Komplementær og Alternativ Medisin, Universitetet i Tromsø (NAFKAM).

I Nord- Norge har helbredertradisjonen en lang historie, fra lenger før vestlig medisins inntog i nord. Tidligere forskning har vist at tradisjonell helbredelse fortsatt blir brukt og praktisert. Forskning på psykiatriske pasienter bruk av tradisjonell helbredelse viser at samiske pasienter søker hjelp hos læsere oftere enn norske pasienter, men at dette ofte underkommuniseres til helsepersonell. Helsepersonell i primærhelsetjenesten er den delen av helsesektoren som står sentralt i det offentlige helsetilbudet til befolkningen. Det er hit den første henvendelsen til helsesektoren går, og det er også i denne delen av helsetjenesten enkeltpersoner og familier følges opp over tid.

Studien vil bidra til:

- 1) Å øke forståelse av hvordan helsepersonell i primærhelsetjenesten møter pasienter som søker hjelp hos både tradisjonell samisk helbredelse/læsing og skolemedisin.
- 2) Å gi kunnskap og forståelse for hvordan kulturelt nedarvete helbredertradisjoner oppleves og forstås av ansatte i primærhelsetjenesten.
- 3) Å gi innsikt i om helsearbeidernes egen etniske og kulturelle bakgrunn har betydning for hvordan bruk av tradisjonell helbredelse håndteres i møter med pasienter. Dette gjelder for pasienter med både fysiske og psykiske helse-problemer.
- 4) At helsearbeidere øker sin kompetanse på å ivareta pasienter som også søker tradisjonell helbredelse på profesjonelt gode, og kulturelt sensitive måter.

Metode

I studien ønsker vi å intervju deg som er ansatt i kommunehelsetjenesten om din opplevelse og erfaring med pasienter som kombinerer samisk tradisjonell helbredelse/læsing og skolemedisin. Intervjuene ønskes gjennomført i løpet av februar 2013 og vil vare ca 1 time.

Vi ønsker i tillegg å gjennomføre et fokusgruppeintervju med dem som er intervjuet individuelt. Spørsmål til fokusgruppen vil utvikles basert på funn i de individuelle intervjuene.

Opplysninger du gir om deg selv vil oppbevares konfidensielt i prosjektperioden. Lydbåndopptak transkriberes i etterkant. NAFKAM vil oppbevare opptak til prosjektslutt ved utgangen av 2014, deretter vil de slettes. I transkripsjoner og notater fra intervjuer vil ditt navn erstattes med en kode som viser til en atskilt navneliste. Transkripsjoner, notater og navneliste lagres i 5 år etter prosjektslutt av hensyn til en mulig oppfølgingsstudie. Når/dersom oppfølgingsstudien gjennomføres, vil du få ny informasjon og forespørsel om å delta. Hvis du ikke hører noe, eller ikke ønsker å delta, vil alle opplysninger om deg anonymiseres innen 31.12.2019.

Publisering og anonymisering

Ved publisering av materiale vil det tilstrebes at identitet til de inkluderte anonymiseres. Det er kun Prosjektansvarlig og forsker ved NAFKAM som har adgang til navnelisten og kan finne tilbake til deg. Navn, alder og annen sensitiv informasjon vil bli fjernet eller endret i publikasjoner. Det er allikevel alltid en mulighet for at detaljer i publisert materiale vil gjenkjennes lokalt. Du vil ha mulighet for å lese gjennom artikler før publisering, og du vil motta kopi av ferdige publikasjoner om ønskelig.

Mulige fordeler og ulemper Fordeler ved å delta i studien vil være å bidra til økt forståelse av helsepersonell sine erfaringer med pasienter som søker hjelp også hos tradisjonelle helbredere. Det kan bidra til mer kulturelt sensitiv profesjonell kompetanse overfor denne pasientgruppen. Ulemper for den enkelte deltaker kan være ubehag ved å være i en intervjusituasjon.

Frivillig deltakelse

Det er frivillig å delta i studien. Du har mulighet til å trekke deg fra prosjektet uansett tidspunkt, under eller intervju. Om du sier ja til å delta nå, kan du senere trekke tilbake ditt samtykke. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte NAFKAM på tlf 77 64 66 50, eller seniorforsker Nina Foss, NAFKAM, mail: nina.foss@uit.no, tlf: 776 60 723, mobil 938 01 728.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

b) Information and consent letter to traditional healers and users

Forespørsel om deltakelse i forskningsprosjektet: Brukere, tradisjonelle helbredere og helsesenteret: hjelp-søking i to samisk- norske kommuner i Nord -Norge

I denne undersøkelsen ønsker vi å komme i kontakt med helsepersonell i primærhelsetjenesten, for å undersøke hvordan helsepersonell forstår, forholder seg til tradisjonell helbredelse/ læsing og hvilken erfaring de har med pasienter som søker hjelp hos tradisjonelle helbredere og skolemedisin.

Forskningsprosjektet er et doktorgradsprosjekt som gjennomføres av Nasjonalt Forskningscenter innen Komplementær og Alternativ Medisin, Universitetet i Tromsø (NAFKAM). Prosjektet har feste i et samarbeid mellom tre sentre ved Norges arktiske Universitet(UiT); Nasjonalt forskningscenter innen komplementær og alternativ medisin ved Institutt for samfunnsmedisin (NAFKAM), Senter for omsorgsforskning ved Institutt for helse- og omsorgsfag (SOF) og Senter for samiske studier ved Fakultet for humaniora samfunnsvitenskap og lærerutdanning (SESAM), og med Memorial University, Environmental Policy Institute (EPI), Kanada. Prosjektet vil lokaliseres til NAFKAM. NAFKAM er det sentrale forskningsmiljøet i Norge innen forskning komplementær og alternativ medisin.

I Nord- Norge har helbredertradisjonen en lang historie, fra lenger før vestlig medisins inntog i nord. Tidligere forskning har vist at tradisjonell helbredelse fortsatt blir brukt og praktisert. Forskning på psykiatriske pasienter bruk av tradisjonell helbredelse viser at samiske pasienter søker hjelp hos tradisjonelle helbredere oftere enn norske pasienter, men at dette ofte underkommuniseres til helsepersonell.

Helsepersonell i primærhelsetjenesten er den delen av helsesektoren som står sentralt i det offentlige helsetilbudet til befolkningen. Det er hit den første henvendelsen til helsesektoren går, og det er også i denne delen av helsetjenesten enkeltpersoner og familier følges opp over tid.

Studien vil bidra til:

- 1) Å øke forståelse av hvordan helsepersonell i primærhelsetjenesten møter pasienter som søker hjelp hos både tradisjonell samisk helbredelse/læsing og skolemedisin.
- 2) Å gi kunnskap og forståelse for hvordan kulturelt nedarvete helbredertradisjoner oppleves og forstås av ansatte i primærhelsetjenesten.
- 3) Å gi innsikt i om helsearbeidernes egen etniske og kulturelle bakgrunn har betydning for hvordan bruk av tradisjonell helbredelse håndteres i møter med pasienter. Dette gjelder for pasienter med både fysiske og psykiske helse-problemer.
- 4) At helsearbeidere øker sin kompetanse på å ivareta pasienter som også søker tradisjonell helbredelse på profesjonelt gode, og kulturelt sensitive måter.

Metode

I studien ønsker vi å intervju deg som er ansatt i kommunehelsetjenesten om din opplevelse og erfaring med pasienter som kombinerer samisk tradisjonell helbredelse og skolemedisin. Intervjuene ønskes gjennomført i løpet høst 2014 vår 2015 og vil vare ca 1 time.

Vi ønsker i tillegg å gjennomføre et fokusgruppeintervju med dem som er intervjuet individuelt. Spørsmål til fokusgruppen vil utvikles basert på funn i de individuelle intervjuene.

Opplysninger du gir om deg selv vil oppbevares konfidensielt i prosjektperioden. Lydbåndopptak transkriberes i etterkant. NAFKAM vil oppbevare opptak til prosjektslutt ved utgangen av 2022, deretter vil de slettes. Anonymiserte transkripsjoner og notater fra intervjuer vil oppbevares i 5 år, før materialet ødelegges.

Publisering og anonymisering

Ved publisering av materiale vil det tilstrebes at identitet til de inkluderte anonymiseres. Det er kun Prosjektansvarlig og forsker ved NAFKAM som har adgang til navnelisten og kan finne tilbake til deg. Navn, alder og annen sensitiv informasjon vil bli fjernet eller endret i publikasjoner. Det er allikevel alltid en mulighet for at detaljer i publisert materiale vil gjenkjennes lokalt. Du vil ha mulighet for å lese gjennom artikler før publisering, og du vil motta kopi av ferdige publikasjoner om ønskelig.

Mulige fordeler og ulemper Fordeler ved å delta i studien vil være å bidra til økt forståelse av helsepersonell sine erfaringer med pasienter som søker hjelp også hos tradisjonelle helbredere. Det kan bidra til mer kulturelt sensitiv profesjonell kompetanse overfor denne pasientgruppen. Ulemper for den enkelte deltaker kan være ubehag ved å være i en intervjusituasjon.

Frivillig deltakelse

Det er frivillig å delta i studien. Du har mulighet til å trekke deg fra prosjektet uansett tidspunkt. Om du sier ja til å delta nå, kan du senere trekke tilbake ditt samtykke. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side.

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte NAFKAM på tlf 77 64 66 50, eller Stipendiat Anette Langås Larsen, NAFKAM, mail: anette.l.larsen@uit.no. Tlf 776 49 284, mobil 916 12 680.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien og er villig til å delta

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Appendix 20.1

c) Interview guide, health care personnel

Intervju guide helsepersonell

Alder, Profesjon, tilhørighet til kommunen, etnisk og kulturell bakgrunn

Erfaring med læsing/ tradisjonell helbredelse

Profesjonelt

- opplevelser, blitt fortalt, vært til stede, kontaktet helbreder

Privat

- Egne, eller familie, sambygdinge, kjenninger erfaringer med tradisjonell helbredelse.

- Har det hendt at folk i bygda forteller til deg når du ikke er på jobb, men som privatperson.

Kunnskap om læsing/ tradisjonell helbredelse

- Formell, utdanning kurs, el uformell kjennskap

Kommunikasjon – med pasienter, som privatperson og med kolleger, dokumenteres dette?

Skolemedisin- tradisjonell helbredelse/læsing- årsaksforståelse

- Er det det noen lidelser du tenker at pasienter heller søker hjelp hos helbredere? / søker hjelp hos skolemedisin i stedet for helbredere?
- Tenker du at lokal forståelse av sykdom kan være annerledes enn skolemedisins forståelse?
- Sykdomsforklaring, hender det at du opplever at pasienter forklarer sykdom annerledes enn skolemedisins forståelse? Sykdom satt på, varsel osv.
- Helbredelsesforklaring
- Religiøst/ åndelig, Natur, Etnisitet, samisk, kvensk, kristen tradisjon

Relasjoner:

- Innenfor skolemedisinen er det pasienten selv som søker hjelp og som samtykker til behandling. I en studie er det kommet frem at den syke trenger ikke å vite at helbreder er kontaktet, er det noe som du kjenner deg igjen på? hva tenker du om det?

Egen etnisk /relasjonell bakgrunn:

- Egen etniske og kulturelle bakgrunn har for forståelse og håndtering av pasienter som også søker hjelp hos tradisjonelle helbredere.

- Å komme fra bygda for forståelse av temaet?
- Er det forskjell å snakke om temaet med helsepersonell fra kommunen enn de som ikke er vokst opp i kommunen, men for eksempel kommer fra de større byene i sør?

Åpenhet? - Endring i åpenhet?

- Opplever du noen endring i helsepersonell forståelse og praksis overfor pasienter som kombinerer skolemedisin og tradisjonell.
- Har det noen ganger vært problematisk for deg å kombinere roller som helsepersonell og være en del av en kultur hvor helbredelse regnes som å være vanlig? På hvilken måte?

Etnisitet/ bakgrunn

Hvordan påvirker det din forståelse?

Tror du det har noe å si for hva pasienter forteller? Eller hvordan du håndterer temaet.

Avslutning

Er det noe som du synes at jeg ikke har gått inn på som du synes er viktig å få frem?

Appendix 20.1

d) Interview guide, traditional healers

Intervju guide Helbredere

Alder, tilhørighet til kommunen, etnisk og kulturell bakgrunn

Helbrederoppgaven:

- Hva skal til for å være helbreder?
- Når oppdaget du at du hadde evnene?

Erfaringer med hva, når, og hvordan søker folk hjelp? Og hva går de til offentlig helsevesen med?

- Hvem kontakter deg?
- Hvordan vet de at du kan hjelpe?
- Er det andre utenfor ditt nærområde/ nær familiær krets som kontakter deg?
- Hender det at du må dra til helsesenter, legesenter sykehus?
- Hender det at du selv forteller at du kan helbrede?

Forståelse av sykdom og helbredelse

- Religiøst/ åndelig, Natur, Etnisitet, samisk, kvensk, kristen tradisjon
- Tenker du at lokal forståelse av sykdom kan være annerledes enn skolemedisins forståelse?
- Sykdomsforklaring, hender det at du opplever at pasienter forklarer sykdom annerledes enn skolemedisins forståelse? Sykdom satt på, varsel osv.

Hvilken hjelp gir du?

- Hvilke metoder bruker du til å helbrede? For eksempel stål, ulltråd, "medisin", urter, kopping ild, leser i naturen, i vann alkohol etc.

Hvordan deles og videreføres kunnskapen?

- Evner/ eller tillært
- Hvordan lærte du det, kan du fortelle?
- Opplæring, eldre, yngre, kjente ukjente?
- Har du lært dette videre?
- Hva ser du etter når du velger noen til å helbrede? Egenskaper?

Hvordan forholder du deg til det offentlige helsevesenet?

- Vet helsepersonell at du kan helbrede?
- Og hvordan forholder de seg til deg?
- Har det hendt at du har blitt vist ut av helsepersonell? kan du fortelle om dette?
- Er det annerledes på hjemplass enn på for eksempel sykehus?

- Hender det at du sender folk videre til andre helbredere? Andre spesialister?

Relasjoner:

- Innenfor skolemedisinen er det pasienten selv som søker hjelp og som samtykker til behandling. I en studie er det kommet frem at den syke trenger ikke å vite at helbreder er kontaktet, er det noe som du kjenner deg igjen på? hva tenker du om det?

Åpenhet? - Endring i åpenhet?

Etnisitet/ bakgrunn

Avslutning

- Er det noe som du synes at jeg ikke har gått inn på som du synes er viktig å få frem?

Appendix 20.1

e) Interview guide, users

Intervju guide vanlige folk

Erfaring med læsing/ tradisjonell helbredelse

- Kjenner du til læsing, blåsing, kurering, tradisjonell helbredelse eller håndspåleggelse
- Hvordan forstår du det?
- Benytter du ditt nettverk familie læsing?

Kunnskap om læsing/ tradisjonell helbredelse?

- For hva?
- Når kontaktes helbredere? Hvor tidlig kontaktes helbreder? / lege?

Hvordan kontaktes disse?

- Livstruende sykdom? mindre alvorlige plager?
- Psykiske lidelser?

Kommunikasjon

- Hvem tar kontakten
- Hender det at de som du kontakter helbreder for ikke vet om det?
- Fortelles det til helsepersonell?
- Hender det at du selv har blitt kontaktet i forbindelse med andres sykdom med tanke på andre som trenger formidling av helbrederhjelp?
- Ringer du å forteller til helbreder hvordan det gikk?
- Hvordan reagerer folk utenfra kommunen når du forteller om tradisjonen?

Relasjoner

- Hvem tar kontakt, hvordan vet du hvem du skal ta kontakt med?
- Kjenner du noen som kan helbrede? Stoppe blod, ta bort verk, vorter, lette på psykiske lidelser.

Skolemedisin- folk forståelse – årsaksforståelse

- Hva hjelper deg når du eller dine nærmeste er syk?
- Forståelse av sykdom
- Forståelse av måter å bli frisk på
- Hvor henter du dine nærmeste styrke til å håndtere sykdom?

Etnisitet/ relasjonell bakgrunn?

- På hvilken måte har det noe å si for hvordan du tenker om helbredelse, måter å bli frisk på?

Helsepersonell

- Har det noe å si hvor helsepersonellet kommer fra, for hva man forteller til dem?
- Har det noe å si om etnisitet for helsepersonellet for hva man forteller?

Appendix 20.2

Registration Norwegian Centre for Research Data (NSD)



MELDESKJEMA

Meldeskjema (versjon 1.4) for forsknings- og studentprosjekt som medfører meldeplikt eller konsesjonsplikt (jf. personopplysningsloven og helseregisterloven med forskrifter).

| 1. Prosjekttittel | | |
|---|---|---|
| Tittel | Brukere, "læsere" og helsesenteret: Hjelp-søking i to samisk-norske kommuner i Nord-Norge. En kvalitativ studie av folk, helbredere og helsepersonells forståelse og bruk av tradisjonell helbredelse og skolemedisin i områder med stor andel samisk befolkning. | |
| 2. Behandlingsansvarlig institusjon | | |
| Institusjon | UiT Norges arktiske universitet | Velg den institusjonen du er tilknyttet. Alle nivå må oppgis. Ved studentprosjekt er det studentens tilknytning som er avgjørende. Dersom institusjonen ikke finnes på listen, vennligst ta kontakt med personvernombudet. |
| Avdeling/Fakultet | Det helsevitenskapelige fakultet | |
| Institutt | Institutt for samfunnsmedisin | |
| 3. Daglig ansvarlig (forsker, veileder, stipendiat) | | |
| Fornavn | Anette Iren Langås | Før opp navnet på den som har det daglige ansvaret for prosjektet. Veileder er vanligvis daglig ansvarlig ved studentprosjekt. Veileder og student må være tilknyttet samme institusjon. Dersom studenten har ekstern veileder, kan biveileder eller fagansvarlig ved studiestedet stå som daglig ansvarlig. Arbeidssted må være tilknyttet behandlingsansvarlig institusjon, f.eks. underavdeling, institutt etc. NB! Det er viktig at du oppgir en e-postadresse som brukes aktivt. Vennligst gi oss beskjed dersom den endres. |
| Etternavn | Larsen | |
| Akademisk grad | Høyere grad | |
| Stilling | Stipendiat | |
| Arbeidssted | NAFKAM Nasjonalt forskningssenter innen komplementær og alternativ medisin | |
| Adresse (arb.sted) | NAFKAM, Det helsevitenskapelige fakultet UiT Norges arktiske universitet | |
| Postnr/sted (arb.sted) | 9037 Tromsø | |
| Telefon/mobil (arb.sted) | 77649284 / 91612680 | |
| E-post | anette.l.larsen@uit.no | |
| 4. Student (master, bachelor) | | |
| Studentprosjekt | Ja <input type="radio"/> Nei <input checked="" type="radio"/> | |
| 5. Formålet med prosjektet | | |
| Formål | Utvikle kvalitativ kunnskap om sosiale prosesser og fortæleser knyttet til bruk av tradisjonell helbredelse og konvesjonell helsehjelp: -Undersøke forståelse og erfaring i tre grupper, folk som søker hjelp, ansatte i primærhelsetjenesten, og tradisjonelle helbredere. - sammenligne prosesser og forståelse i to kommuner Mulige spørsmål; hvilke helbrederfortellinger sirkulerer, åpenhet – lukkethet, hvordan ulik hjelpsøking inngår i sosiale relasjoner, er knyttet til religiøs, eller geografisk tilhørighet, identitet og språk. Spørsmål og metodisk tilnærming vil være dels overlappende for de tre gruppene. (se prosjektbeskrivelse pgt. 3 forskningsspørsmål, metode og analytisk tilnærming). | Redegjør kort for prosjektets formål, problemstilling, forskningsspørsmål e.l. Maks 750 tegn. |
| 6. Prosjektomfang | | |
| Velg omfang | <input type="radio"/> Enkel institusjon <input type="radio"/> Nasjonalt samarbeidsprosjekt <input checked="" type="radio"/> Internasjonalt samarbeidsprosjekt | Med samarbeidsprosjekt menes prosjekt som gjennomføres av flere institusjoner samtidig, som |

| | | |
|-----------------------------------|--|--|
| Oppgi øvrige institusjoner | Prosjektet har feste i et samarbeid mellom tre sentre ved Norges arktiske Universitet(UiT); Nasjonalt forskningscenter innen komplementær og alternativ medisin ved Institutt for samfunnsmedisin (NAFKAM), Senter for omsorgsforskning ved Institutt for helse- og omsorgsfag (SOF) og Senter for samiske studier ved Fakultet for humaniora samfunnsvitenskap og lærerutdanning (SESAM), og med Memorial University, Environmental Policy Institute (EPI), Kanada. | har samme formål og hvor personopplysninger utveksles. |
| Oppgi hvordan samarbeidet foregår | <p>Prosjektet vil lokaliseres til NAFKAM. NAFKAM er det sentrale forskningsmiljøet i Norge innen forskning komplementær og alternativ medisin. Seniorforsker Nina Foss (PhD) vil lede prosjektgruppen, og være hovedveileder i prosjektet. Hun har erfaring innenfor medisinsk antropologi, interkulturelle prosesser, kvalitativ metode og i deltakende arbeidsmåter. Hun har studert mønstre i sykdom og hjelpesøking i bygder i Nord Norge.</p> <p>SESAM er et internasjonalt senter for studier og samiske spørsmål så vel som globale problemstillinger relatert til urfolk og minoriteter generelt. UiT har et nasjonalt ansvar for samisk og urfolks forskning og høyere utdanning i Norge. SESAM har som mål å styrke forskning og utdanning knyttet til samiske og urfolks spørsmål. Professor Bjørg Evjens vil bidra med veiledning og inngå i prosjektgruppen. Hennes viktigste forsknings emner er historien om samer og urfolk, kjønn, polar og industri historie, særlig i lulesamiske områder. SOF er et forsknings og kompetansesenter for helseregion Nord-Norge støttet av Norsk Forskningsråd. Professor Torunn Hamran er forskningsleder for senteret og professor i helsevitenskap ved Institutt for helse- og omsorgsfag. Hennes viktigste forskningstema er forholdet mellom nasjonal velferdspolitik og helsevesenet og hvordan den overføres til praksis i helsevesenet. Hamran vil være en del av prosjektgruppa, og vil bidra i veiledning for PhD kandidaten. EPI er internasjonal samarbeidspartner. EPI forsker på miljø- og politiske prosesser, inkludert helse, og er aktive i kommunikasjon mellom akademia og sivilt samfunn. Adj Professor Maura Hanrahan (PhD), Division of Community Health and Humanities, Faculty of Medicine og spesialrådgiver for "President on aboriginal affairs", vil delta i prosjektgruppen. Hun har bl a forsket på helseforståelse og erfaringer med helsevesenet blant labrador Metis og inuit grupper. De tre sentrene ved UiT vil gi et godt forskningsmiljø for PhD studenten, og kan bidra med nødvendig metodisk så vel som teoretisk opplæring. De tre forskerne danner prosjektgruppen for min pågående studie. De har sagt seg interessert i å videreføre det faglige samarbeidet i PhD prosjektet. Gruppen vil møtes 1gang pr halvår. Målet med disse møtene er å sikre fremdriften i prosjektet og å utvikle analyser. Alle fire partnerne vil delta i «kick-off workshop» i løpet av de første tre månedene. I tillegg vil at EPI representanten delta på 1møte /år og i planlegging og gjennomføring av et internasjonalt seminar i 2016. EPI vil være vert for mitt 5 måneders forskningsopphold i løpet av PhD studiet.</p> | |
| 7. Utvalgsbeskrivelse | | |
| Utvalget | Det er ønskelig med jevnt antall kvinner og menn, fra 18 år og oppover, med samtykkekompetanse. Utvalg fra tre ulike grupper: 1. brukere Jeg søker ikke deltakere med spesifikke diagnoser, ettersom et av målene i denne studien er å lære mer om hva folk søker hjelp hos ulike hjelpere for. Jeg søker særlig personer som har søkt hjelp hos tradisjonell helbreder på egne, eller andres vegne, og som kan dele helbrederhistorier. 2. Helsepersonell fra ulike profesjoner i primærhelsetjensten og 3. Tradisjonelle helbredere. | Med utvalg menes dem som deltar i undersøkelsen eller dem det innhentes opplysninger om. F.eks. et representativt utvalg av befolkningen, skoleelever med lese- og skrivevansker, pasienter, innsatte. |

| | | |
|--|---|--|
| Rekruttering og trekking | Rekruttering av deltakere til studien vil bli gjort ulikt i de tre ulike gruppene i studien. Basert på erfaringer fra egne tidligere studier vil jeg initiere et informasjonsmøte i hver kommune for å starte og rekruttere deltakere i brukergruppen, siden vil jeg rekruttere folk fra brukergruppen gjennom relasjoner og nettverk. Helsepersonell vil bli rekruttert gjennom helse og omsorgssjef i kommunene. Helbredere vil primært bli rekruttert gjennom brukergruppen. | Beskriv hvordan utvalget trekkes eller rekrutteres og oppgi hvem som foretar den. Et utvalg kan trekkes fra registre som f.eks. Folkeregisteret, SSB-registre, pasientregistre, eller det kan rekrutteres gjennom f.eks. en bedrift, skole, idrettsmiljø, eget nettverk. |
| Førstegangskontakt | Førstekontakt gjøres av stipendiat Anette Langås Larsen, pr telefon til Ordfører, Rådmann og til Helse og omsorgssjef i hver kommune. Basert på erfaringer fra egne tidligere studier vil jeg initiere et informasjonsmøte i hver kommune for å starte og rekruttere deltakere. | Beskriv hvordan førstegangskontakten opprettes og oppgi hvem som foretar den. Les mer om dette på våre temasider. |
| Alder på utvalget | <input type="checkbox"/> Barn (0-15 år) <input type="checkbox"/> Ungdom (16-17 år) <input checked="" type="checkbox"/> Voksne (over 18 år) | |
| Antall personer som inngår i utvalget | Brukere 10 fra hver kommune. Offentlige helsepersonell 12 . Helbredere ca 3-5 . | |
| Inkluderes det myndige personer med redusert eller manglende samtykkekompetanse? | Ja <input type="radio"/> Nei <input checked="" type="radio"/> | Begrunn hvorfor det er nødvendig å inkludere myndige personer med redusert eller manglende samtykkekompetanse. |
| Hvis ja, begrunn | | Les mer om Pasienter, brukere og personer med redusert eller manglende samtykkekompetanse |
| 8. Metode for innsamling av personopplysninger | | |
| Kryss av for hvilke datainnsamlingsmetoder og datakilder som vil benyttes | <input type="checkbox"/> Spørreskjema <input checked="" type="checkbox"/> Personlig intervju <input checked="" type="checkbox"/> Gruppeintervju <input type="checkbox"/> Observasjon <input type="checkbox"/> Psykologiske/pedagogiske tester <input type="checkbox"/> Medisinske undersøkelser/tester <input type="checkbox"/> Journaldata <input type="checkbox"/> Registerdata <input type="checkbox"/> Annen innsamlingsmetode | Personopplysninger kan innhentes direkte fra den registrerte f.eks. gjennom spørreskjema, intervju, tester, og/eller ulike journaler (f.eks. elevmapper, NAV, PPT, sykehus) og/eller registre (f.eks. Statistisk sentralbyrå, sentrale helseregistre). |
| Annen innsamlingsmetode, oppgi hvilken | | |
| Kommentar | | |
| 9. Datamaterialets innhold | | |

| | | |
|---|--|---|
| Redegjør for hvilke opplysninger som samles inn | <p>Kvalitative intervjuer som etterspør de intervjuedes erfaringer og forståelse om tradisjonell helbredelse/læsing, helse og sykdom.</p> <p>Spørsmål og metodisk tilnærming vil være dels overlappende for de tre gruppene.</p> <p>Overordnede spørsmål til folk som søker hjelp: For hva og når søkes det hjelp i de to helsesystemene? Hvem deltar i hjelpsøking? Hvordan henger hjelpsøking sammen med forståelse av helse og sykdom? Fortellinger om helseproblemer, håndtering, hjelpsøking og evt helbredelse vil stå sentralt.</p> <p>Helsepersonell i primærhelsetjenesten: Hva søker folk hjelp til i offentlig helsevesen og hos læsere? Hvilke erfaringer har de med pasienter som også søker hjelp hos tradisjonelle helbredere? Hvordan de kommuniserer med denne pasientgruppen? Hvordan kommuniserer de med kolleger om tradisjonell helbredelse? Egen etnisk og kulturell bakgrunn, hvordan virker den inn? Fortellinger om møter med pasienter og deres sykdomsforløp vil inngå i materialet.</p> <p>Læsere: Forståelse av sykdom og helbredelse? Hvilken hjelp gir de? Hvordan deles og videreføres kunnskapen? Erfaringer med for hva, når og hvordan folk søker hjelp hos dem, og hva de går til offentlig helsevesen med? Hvordan de forholder de seg til det offentlige helsesystemet?</p> | <p>Spørreskjema, intervju-/temaguide, observasjonsbeskrivelse m.m. sendes inn sammen med meldeskjemaet.</p> <p>NB! Vedleggene lastes opp til sist i meldeskjema, se punkt 16 Vedlegg.</p> |
| Samles det inn direkte personidentifiserende opplysninger? | Ja ● Nei ○ | Dersom det krysses av for ja her, se nærmere under punkt 11 Informasjonssikkerhet. |
| Hvis ja, hvilke? | <input type="checkbox"/> 11-sifret fødselsnummer <input checked="" type="checkbox"/> Navn, fødselsdato, adresse, e-postadresse og/eller telefonnummer | Les mer om hva personopplysninger er |
| Spesifiser hvilke | navn, alder (ikke fødselsdato), bosted | NB! Selv om opplysningene er anonymiserte i oppgave/rapport, må det krysses av dersom direkte og/eller indirekte personidentifiserende opplysninger innhentes/registreres i forbindelse med prosjektet. |
| Samles det inn indirekte personidentifiserende opplysninger? | Ja ● Nei ○ | En person vil være indirekte identifiserbar dersom det er mulig å identifisere vedkommende gjennom bakgrunnsopplysninger som for eksempel bostedskommune eller arbeidsplass/skole kombinert med opplysninger som alder, kjønn, yrke, diagnose, etc. |
| Hvis ja, hvilke? | bostedskommune, alder, kjønn, etnisitet og historier om sykdommen og helbredelse. | Kryss også av dersom ip-adresse registreres. |
| Samles det inn sensitive personopplysninger? | Ja ● Nei ○ | |
| Hvis ja, hvilke? | <input checked="" type="checkbox"/> Rasemessig eller etnisk bakgrunn, eller politisk, filosofisk eller religiøs oppfatning <input type="checkbox"/> At en person har vært mistenkt, siktet, tiltalt eller dømt for en straffbar handling <input type="checkbox"/> Helseforhold <input type="checkbox"/> Seksuelle forhold <input type="checkbox"/> Medlemskap i fagforeninger | |
| Samles det inn opplysninger om tredjeperson? | Ja ○ Nei ● | Med opplysninger om tredjeperson menes opplysninger som kan spores tilbake til personer som ikke inngår i utvalget. Eksempler på tredjeperson er kollega, elev, klient, familiemedlem. |
| Hvis ja, hvem er tredjeperson og hvilke opplysninger registreres? | | |
| Hvordan informeres tredjeperson om behandlingen? | <input type="checkbox"/> Skriftlig <input type="checkbox"/> Muntlig <input type="checkbox"/> Informeres ikke | |
| Informeres ikke, begrunn | | |

| 10. Informasjon og samtykke | | |
|--|---|--|
| Oppgi hvordan utvalget informeres | <input checked="" type="checkbox"/> Skriftlig <input checked="" type="checkbox"/> Muntlig <input type="checkbox"/> Informeres ikke | Vennligst send inn informasjonsskrivet eller mal for muntlig informasjon sammen med meldeskjema. |
| Begrunn | | NB! Vedlegg lastes opp til sist i meldeskjemaet, se punkt 16 Vedlegg. Dersom utvalget ikke skal informeres om behandlingen av personopplysninger må det begrunnes. Last ned vår veiledende mal til informasjonsskriv |
| Oppgi hvordan samtykke fra utvalget innhentes | <input checked="" type="checkbox"/> Skriftlig <input checked="" type="checkbox"/> Muntlig <input type="checkbox"/> Innhentes ikke | Dersom det innhentes skriftlig samtykke anbefales det at samtykkeerklæringen utformes som en svarslipp eller på eget ark. Dersom det ikke skal innhentes samtykke, må det begrunnes. |
| Innhentes ikke, begrunn | | |
| 11. Informasjonssikkerhet | | |
| Direkte personidentifiserende opplysninger erstattes med et referansenummer som viser til en atskilt navneliste (koblingsnøkkel) | Ja <input checked="" type="radio"/> Nei <input type="radio"/> | Har du krysset for ja under punkt 9 Datamaterialets innhold må det merkes av for hvordan direkte personidentifiserende opplysninger registreres. |
| Hvordan oppbevares navnelisten/koblingsnøkkelen og hvem har tilgang til den? | koblingsnøkkelen oppbevares i låsbart skap på låsbart kontor, separat fra opplysningene. | NB! Som hovedregel bør ikke direkte personidentifiserende opplysninger registreres sammen med det øvrige datamaterialet. |
| Direkte personidentifiserende opplysninger oppbevares sammen med det øvrige materialet | Ja <input type="radio"/> Nei <input checked="" type="radio"/> | |
| Hvorfor oppbevares direkte personidentifiserende opplysninger sammen med det øvrige datamaterialet? | | |
| Oppbevares direkte personidentifiserbare opplysninger på andre måter? | Ja <input type="radio"/> Nei <input checked="" type="radio"/> | |
| Spesifiser | | |
| Hvordan registreres og oppbevares datamaterialet? | <input type="checkbox"/> Fysisk isolert datamaskin tilhørende virksomheten <input checked="" type="checkbox"/> Datamaskin i nettverkssystem tilhørende virksomheten <input type="checkbox"/> Datamaskin i nettverkssystem tilknyttet Internett tilhørende virksomheten <input checked="" type="checkbox"/> Fysisk isolert privat datamaskin <input type="checkbox"/> Privat datamaskin tilknyttet Internett <input type="checkbox"/> Videoopptak/fotografi <input checked="" type="checkbox"/> Lydopptak <input checked="" type="checkbox"/> Notater/papir <input type="checkbox"/> Annen registreringsmetode | Merk av for hvilke hjelpemidler som benyttes for registrering og analyse av opplysninger. Sett flere kryss dersom opplysningene registreres på flere måter. |
| Annen registreringsmetode beskriv | | |
| Behandles lyd-/videoopptak og/eller fotografi ved hjelp av datamaskinbasert utstyr? | Ja <input type="radio"/> Nei <input checked="" type="radio"/> | Kryss av for ja dersom opptak eller foto behandles som lyd-/bildefil. Les mer om behandling av lyd og bilde. |
| Hvordan er datamaterialet beskyttet mot at uvedkommende får innsyn? | Datamaskin er beskyttet med brukernavn og passord, og står i låsart rom. Bærbar PC oppbevares i låsbart rom. Utskrifter og opptak oppbevares i låsbart skap i låsbart rom- (separat fra kodenøkkel). | Er f.eks. datamaskintilgangen beskyttet med brukernavn og passord, står datamaskinen i et låsbart rom, og hvordan sikres bærbare enheter, utskrifter og opptak? |

| | | |
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| Dersom det benyttes mobile lagringsenheter (bærbar datamaskin, minnepenn, minnekort, cd, ekstern harddisk, mobiltelefon), oppgi hvilke | bærbar datamaskin | NB! Mobile lagringsenheter bør ha mulighet for kryptering. |
| Vil medarbeidere ha tilgang til datamaterialet på lik linje med daglig ansvarlig/student? | Ja ● Nei ○ | |
| Hvis ja, hvem? | Hovedveileder Seniorforsker (PhD) Nina Foss, UiT, NAFKAM, og Biveileder Professor Torunn Hanman, UiT, SOF. | |
| Overføres personopplysninger ved hjelp av e-post/Internett? | Ja ○ Nei ● | F.eks. ved bruk av elektronisk spørreskjema, overføring av data til samarbeidspartner/databehandler mm. |
| Hvis ja, hvilke? | | |
| Vil personopplysninger bli utlevert til andre enn prosjektgruppen? | Ja ○ Nei ● | |
| Hvis ja, til hvem? | | |
| Samles opplysningene inn/behandles av en databehandler? | Ja ○ Nei ● | Dersom det benyttes eksterne til helt eller delvis å behandle personopplysninger, f.eks. Questback, Synovate MMI, Norfakta eller transkriberingsassistent eller tolk, er dette å betrakte som en databehandler. Slike oppdrag må kontraksreguleres |
| Hvis ja, hvilken? | | Les mer om databehandleravtaler her |
| 12. Vurdering/godkjenning fra andre instanser | | |
| Søkes det om dispensasjon fra taushetsplikten for å få tilgang til data? | Ja ○ Nei ● | For å få tilgang til taushetsbelagte opplysninger fra f.eks. NAV, PPT, sykehus, må det søkes om dispensasjon fra taushetsplikten. Dispensasjon søkes vanligvis fra aktuelt departement. Dispensasjon fra taushetsplikten for helseopplysninger skal for alle typer forskning søkes |
| Kommentar | | Regional komité for medisinsk og helsefaglig forskningsetikk |
| Søkes det godkjenning fra andre instanser? | Ja ● Nei ○ | F.eks. søke registreiere om tilgang til data, en ledelse om tilgang til forskning i virksomhet, skole, etc. |
| Hvis ja, hvilke? | Prosjektet har søkt om godkjenning hos REK. REK fant at prosjektet ikke inngår i deres mandat, men at det kun er meldeplikt til NSD/ REK svar vedlagt | |
| 13. Prosjektperiode | | |
| Prosjektperiode | Prosjektstart:01.02.2014 Prosjektslutt:03.03.2022 | Prosjektstart Vennligst oppgi tidspunktet for når førstegangskontakten med utvalget opprettes og/eller datainnsamlingen starter. Prosjektslutt Vennligst oppgi tidspunktet for når datamaterialet enten skal anonymiseres/slettes, eller arkiveres i påvente av oppfølgingsstudier eller annet. Prosjektet anses vanligvis som avsluttet når de oppgitte analyser er ferdigstilt og resultatene publisert, eller oppgave/avhandling er innlevert og sensurert. |
| Hva skal skje med datamaterialet ved prosjektslutt? | <input checked="" type="checkbox"/> Datamaterialet anonymiseres <input type="checkbox"/> Datamaterialet oppbevares med personidentifikasjon | Med anonymisering menes at datamaterialet bearbeides slik at det ikke lenger er mulig å føre opplysningene tilbake til enkeltpersoner.NB! Merk at dette omfatter både oppgave/publikasjon og rådata. Les mer om anonymisering |

| | | |
|--|--|---|
| Hvordan skal datamaterialet anonymiseres? | Kodenøkkel destrueres. Kun avidentifiserte utskrifter beholdes. Lydfiler destrueres. | Hovedregelen for videre oppbevaring av data med personidentifikasjon er samtykke fra den registrerte. |
| Hvorfor skal datamaterialet oppbevares med personidentifikasjon? | | Arsaker til oppbevaring kan være planlagte oppfølgingsstudier, undervisningsformål eller annet. |
| Hvor skal datamaterialet oppbevares, og hvor lenge? | | Datamaterialet kan oppbevares ved egen institusjon, offentlig arkiv eller annet. Les om arkivering hos NSD |
| 14. Finansiering | | |
| Hvordan finansieres prosjektet? | Prosjektet er finansiert av Norges Forskningsråd. | |
| 15. Tilleggsopplysninger | | |
| Tilleggsopplysninger | Kontakt er opprettet med kommunene i planleggingsfasen av prosjektet, under forutsening av godkjenning REK/NSD | |
| 16. Vedlegg | | |
| Antall vedlegg | 5 | |



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9037 TROMSØ

Vår dato: 04.04.2014

Vår ref: 38334 / 3 / AMS

Deres dato:

Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 27.03.2014. Meldingen gjelder prosjektet:

38334

Brukere, "læsere" og helsesenteret: Hjelp-søking i to samisk-norske kommuner i Nord-Norge. En kvalitativ studie av folk, helbredere og helsepersonells forståelse og bruk av tradisjonell helbredelse og skolemedisin i områder med stor andel samisk befolkning

*Behandlingsansvarlig
Daglig ansvarlig*

*UiT Norges arktiske universitet, ved institusjonens øverste leder
Anette Iren Langås Larsen*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 03.03.2022, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Anne-Mette Somby

Kontaktperson: Anne-Mette Somby tlf: 55 58 24 10

Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Avdelingskontorer / District Offices

OSLO NSD Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo Tel +47-22 85 52 11 nsd@uio.no

TROMSØ NSD Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim Tel +47-73 59 19 07 kyrre.svarva@svt.ntnu.no

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PROSJEKTDESIGN, FORMÅL OG SAMARBEID

Prosjektet er en internasjonal samarbeidsstudie. UiT Norges arktiske universitet er behandlingsansvarlig institusjon for den norske delen. Personvernombudet forutsetter at ansvaret for behandlingen av personopplysninger er avklart mellom institusjonene. Vi anbefaler at det inngås en avtale som omfatter ansvarsfordeling, ansvarsstruktur, hvem som initierer prosjektet, bruk av data og eventuelt eierskap.

Hovedveileder seniorforsker (PhD) Nina Foss, UiT, NAFKAM og biveileder professor Torunn Hamran, UiT, SOF er oppgitt som prosjektmedarbeidere med tilgang til datamaterialet.

Formålet er å utvikle kvalitativ kunnskap om sosiale prosesser og forståelser knyttet til bruk av tradisjonell helbredelse og konvensjonell helsehjelp ved:

- Å undersøke forståelse og erfaring i tre grupper; folk som søker hjelp, ansatte i primærhelsetjenesten, og tradisjonelle helbredere, samt ved å sammenligne prosesser og forståelse i to kommuner.

UTVALG, REKRUTTERING OG SAMTYKKE

Utvalg fra tre ulike grupper:

1. brukere av tradisjonell helbredelse og skolemedisin
2. Helsepersonell fra ulike profesjoner i primærhelsetjenesten
3. Tradisjonelle helbredere

Rekruttering av deltakere til studien vil bli gjort ulikt i de tre ulike gruppene i studien. Basert på erfaringer fra forskers tidligere studier vil hun initiere et informasjonsmøte i hver kommune for å starte og rekruttere deltakere i brukergruppen, siden vil hun rekruttere folk fra brukergruppen gjennom relasjoner og nettverk. Helsepersonell vil bli rekruttert gjennom helse og omsorgssjef i kommunene. Helbredere vil primært bli rekruttert gjennom brukergruppen.

Utvalget informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er godt utformet, og det informeres om at det i publikasjonen kan være potensiale for gjenkjennelse. Deltakerne gis mulighet til å lese artikler før publisering.

METODE OG DATA

Opplysningene skal innhentes gjennom intervjuer og gruppeintervjuer. Det behandles sensitive personopplysninger om etnisk bakgrunn, religiøs oppfatning og helseforhold, jf. personopplysningsloven § 2 nr. 8 a og c.

DATATSIKKERHET

Personvernombudet legger til grunn at forsker etterfølger UiT Norges arktiske universitet sine interne rutiner for datasikkerhet. Dersom personopplysninger skal lagres på privat pc/mobile enheter, bør opplysningene krypteres

tilstrekkelig.

Datamaterialet behandles aidentifisert i prosjektperioden, og koblingsnøkkel skal lagres atskilt fra øvrige opplysninger.

Personvernombudet finner at konfidensialiteten ivaretas ved at data behandles aidentifisert i prosjektperioden.

PROSJEKTSLUTT

Forventet prosjektslutt er 03.03.2022. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å slette direkte personopplysninger (som navn/koblingsnøkkel) og slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn) samt slette lydopptak.

ANDRE VURDERINGER

REK har vurdert at prosjektet ikke er framleggingspliktig, jf. brev 3.1.2014 (ref. 2014/309/REK nord).