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The influence of cultural background in intercultural dementia care: exemplified by Sami patients

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The influence of cultural background in intercultural dementia care: exemplified by Sami patients

Aim: To gain knowledge about how the original culture may influence communication and interaction with institutionalised patients with dementia and of what particular cultural aspects may come to the fore, exemplified by Sami patients.
Method: Qualitative narrative interviews with 15 interviewees, family members of Sami patients with dementia and nursing staff experienced with dementia care were conducted. Hermeneutic, thematic analysis was used.
Findings: Although the way dementia influence mental functions, language, etc. is universal, behaviours, reactions and responses may be coloured by the patient's background culture. Knowledge of language, cultural codes and the patient's former life are primary keys to understanding. Rhythm of life, spirituality, singing and tangible aspects of traditional culture like clothes and food constitute important aspects of culture-appropriate care.

Keywords: Sami, culture, dementia, communication, spirituality, food, cultural understanding, intercultural care.

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Introduction

As an increasing number of ethnic minority persons, whether belonging to immigrant or indigenous groups, grow old, health care professionals need to realise that cultural background may influence upon their needs and expectations. This is particularly so when ethnic minority persons develop dementia. The way the various forms of dementia affect people's mental functions, language, etc. is universal, while behaviours, reactions and responses may be coloured by the patient's background culture. This may add socio-cultural and linguistic challenges to that of caring for persons with dementia and make it more difficult for health care personnel to understand, communicate and care for patients with dementia who hail from different cultural backgrounds than themselves.

The purpose of this paper is to discuss how the original culture may influence communication and interaction with institutionalised patients with dementia and what cultural aspect may be particularly important. The hallmark of care 'is a deeper understanding of the wholeness of the patient's situation, which implies that nursing care requires interpretation, understanding, and hermeneutic experience' (1: p. 317). The paper is based on a study among the Sami concerning good dementia care. Findings will illustrate the importance of openness to foreign cultural expressions to be able to produce a caring and meaningful environment for patients as well as create reciprocal understanding between patients and health care personnel.

Cultural setting

'As a system of shared symbols and beliefs, culture supports a person's sense of security, integrity, and belonging and provides a prescription for how to conduct life and approach death' (2: p. 3). This does not mean that a culture is unchanging or that members of a particular cultural group make identical life choices. However, although there are great variations in life-styles and ideas among members of any given cultural group, there are symbolic features, traditions, etc., which make its members feel that in spite of different views and lifestyles, they have a common cultural identity.

The Sami are the indigenous people of northern Scandinavia and north-western Russia. The majority, between 50 000 and 65 000, live in Norway (3). The Sami 'are one people oriented towards many different vocational, linguistic and cultural adaptations which all have their individual needs based on their individual premises. The Sami society may be divided in various ways, linguistically, vocationally, geographically, and culturally, for instance Eastern Sami, Northern Sami, Lule Sami, Pite Sami, Southern Sami, city dwellers, agriculturalists, Coastal Sami, and Reindeer herding Sami. These groups have

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adapted differently to their common Sami culture and together they constitute the totality of the Sami culture' (3). Only about one-third of the Sami population speak a Sami language, but in 'our' town in Finnmark,[1] the local Sami language and culture are very much alive.

Some of the patients in this study had traditional backgrounds while others had held urban type jobs. But they were all raised in Sami communities, they were used to traditional Sami foods, although some were equally used to a 'Norwegian' diet, and they all had Sami as their first language and their primary means of communication.

The cultural meaning of the changed mental abilities in persons with dementia varies among various cultural groups (4). Traditional Sami cultural aspects will in this paper serve to illustrate how cultural background may influence behaviour and communication. Thusly, it is a patient's behaviour linked to culture, not the epidemiology of dementia which is focused, as 'the epidemiological evidence that race or culture influence on the development of the dementias is scanty' (5: p. 284).

Research approach

Family members of institutionalised patients with dementia and members of nursing staff experienced with dementia care were interviewed. The main question put to the interviewees was: 'According to your experience as a nurse/son/daughter of a patient with dementia in this institution, what constitutes good dementia care?' With this open, narrative approach, I wished to learn about the interviewees' personal experiences and thoughts concerning good dementia care.

The interviews, lasting 20–130 minutes, took form of an electronically recorded talk where the respondents were encouraged to recount their experiences. Follow-up questions depended on what the respective interviewee had to say. Questions and the 'mirroring' of statements were used to clarify and verify statements during the interviews.

The 15 interviewees, eight family members and nine members of nursing staff, were chosen by a representative of the Health Centre in question. Two of the nursing staff doubled as family respondents as they had close family members with dementia. Of the interviewees, there were three men and 12 women. All but two of the nursing staff were Sami.

Data analysis

All interviews and the verbatim transcriptions were conducted by the author. This gave intimate knowledge of the data from the very start and became the first two steps of the hermeneutic analytic process. A hermeneutic analytic approach was chosen to place the research question at the immediate locality of daily life (6). Through reading and re-reading the interview texts, I tried to 'remain open to the meaning of the other person or the text' (7: p. 268). This was important as I have studied intercultural health care and Sami culture for years and thus risked being blinded by my preunderstanding.

Gadamer (7) points out that interpretive analysis is a creative activity, striving for depth of understanding through a circular investigation of situations. The interviews were read and re-read, while conceptions were re-evaluated and understanding grew. I wished to explore the thoughts, feelings and cultural meaning described in the interviews. Gadamer teaches us to be open, curious, communicate authentically and realise that the fusion of horizons through the reading of texts leads to the creation of something new.

Through this process, themes were elicited from each interview based on the interview statements (8). A content-focused approach was chosen where I attempted to formulate themes that touched the core of the situations or meanings found in the texts (8). The various interviews' themes were then compared. Related themes were coalesced into common themes, the most central ones being: the need of a common language; the need of cultural understanding; the importance of traditional foods; rhythm of life; spirituality; Sami singing traditions.

Ethical aspects

Interviewees gave their written informed consent to participate. They were informed in writing and orally that they were free to withdraw from the project at any time. Transcriptions are stored according to ethical research guidelines (9). Recorded interviews were deleted after transcription. The project is approved by the Regional Committee for Research, South-Eastern Norway, and The Norwegian Social Science Data Services.

Findings

General caring issues will not be discussed in this paper. The focus will be on culture specific aspects in dementia care.

The need of a common language

Language was the very first issue mentioned by all family interviewees when asked about good dementia care. One said: 'What is extremely important is the language, the mother tongue. …. To be cared for, nursed, in your own mother tongue. Not having to try to stammer something in a foreign language.' She had seen patients asking for more food be lead away from table because nurses thought they signalled that they were finished eating.

[1]Finnmark is Norway's northernmost and largest county (48 637 km^2) with a population of <73 000 inhabitants. In the town of this study, 85–90% of the population is Sami.

Nurses who did not speak Sami well found communicate difficult. They tried to make up for the language problem by way of sign language and patience. One said: 'One must not give up in spite of lack of words. And we show them that we have patience, so that they feel safe.'

As opposed to this, several of the Sami nurses said it was very important '… that one speaks the same language to be able to give good care to patients with dementia'. Their experience told them that 'if you do not speak the patient's language, the patient becomes restless and worried when you are to nurse him or her. You need to be able to explain what you do, and you cannot do that unless you speak the language well.' Furthermore, lack of a common language tends to make patients fret and be less cooperative, which may cause procedures to become more painful, according to Sami nurses. A family interviewee concurred saying: '… what (matters) is that (people) can speak the language – the same language and culture. … we have quite a few nurses who do not really speak any Sami, and that is a problem. Many of them are capable, competent people and give very good care and help and that kind of thing, but even so they fall short when it comes to the language and the language barrier becomes very evident.'

The need of cultural understanding

Several of the Sami nurses emphasised the importance for health care personnel to have 'the same cultural background as the patient and know the different cultural codes. … there are various codes that one has to understand to be able to interpret what the patient wants' and why persons with dementia behave the way they do. An example may illustrate the latter point:

> Two ladies, both with nomadic backgrounds, had one day rushed around removing the duvets from all the beds on the ward and put them in duvet covers. They had been so quick about it that the staff had not been able to stop them. When a daughter came to the rescue, it turned out that they were making ready for the seasonal reindeer trek and were in a hurry to 'strike camp' as they believed the animals were approaching.

All patients at the Health Center's dementia ward had private apartments. The communal room was a combination of kitchen, dining room and lounge, large and high ceilinged. All windows ran floor to ceiling, which made patients repeatedly walk straight into them when focused on the outside scenery. Doors were leading to the various apartments, the nurses' office and the outdoors; doors everywhere making it difficult for patients to find their bearing. Disorientation is a universal problem in people with dementia. The many doors did not help, and the architecture of this room was furthermore very foreign to these patients. Although the communal room was adorned with wooden pillars that were to mimic the wooden supports used in the Sami 'lavvos[2]', these inclining pillars were seemingly placed unsupported on the floor instead of supporting the walls as they would in a 'lavvo'. Some patients who had lived their lives in the mountains therefore worried that the pillars would keel over and cause the ceiling to fall in their heads.

The importance of traditional foods

The nurses found that patients looked happy and would eat much more when served traditional foods rather than 'Norwegian' meals. They loved the familiar smells and tastes. Even otherwise mute patients would sometimes say a word or two when such meals were served. Once when they served their patients traditional blood or black pancakes in the Health Centre's 'gamme[3]', one of these suddenly said: 'You must sprinkle more sugar on the pancakes so that they taste good'. 'And what do I do afterwards?' the nurse asked. 'Then you fold them'. And that was it. No more comments from her, although she enjoyed the meal and the stay in the 'gamme' immensely and only reluctantly returned to the Health Centre building.

Several nurses were sad about traditional foods being served only occasionally and wished it was possible to prepare meals on the ward together with patients. Although they often served fish, this was not the fresh water fish patients were used to from the local lakes and rivers.

Rhythm of life

As the patients had held different kinds of jobs in younger days, this influenced on their respective behaviours and life rhythms: 'You have for instance the reindeer herders, they are used to watch over their flock at night in spring and in autumn (in connection with calving season and gathering of the flock). The farmers are early risers as they want to see to their animals. And the townspeople have a nine-to-four work rhythm. It is therefore very important to know their backgrounds.'

Nurses who did not realise these background influences tended to try to make former reindeer herders sleep by giving them sleep medication if they still 'kept nighty vigil' spring and autumn. Also some of the Sami nurses tried to adjust these patients' sleep rhythms while others tended to let them be as 'they sleep more during the day and will

[2] Tipi-like tent, the summer abode for many of the old reindeer herders in childhood and even later as they followed the flock's seasonal trek in the mountains. Lavvos are still in use in the mountains.

[3] Turf house, formerly the winter abode for many of the old reindeer herders. In the Health Centre's out-door area both a 'lavvo' and a 'gamme' are to be found.

sleep long when the calving season is over'. As to the latter view, a nurse said that 'if we could adjust our routines to the life rhythm of the individual patient, I think that patients would be much happier and we had perhaps avoided a lot of medications. You should be able to keep your life rhythm.'

Every season has its rhythm and designated activities: 'For instance working the 'sennegress[4]' and treating animal hides. Such activities – culture based activities – are important to consider: in what season does one do what? One needs that kind of knowledge in dementia care. … In the autumn let them work with 'sennegress', … collect berries and such like. Let them do what they are used to do.'

Spirituality

The majority of the Health Centre residents had been church-goers all their lives. As a Sami nurse put it: 'Church – to go to church – that was part of Sunday. That is lost when you stay in a geriatric institution and you are not able to get to church on your own. One should have been able to take them to church and then serve a tasty meal afterwards. Dress them in their Sunday best as they would at home – some in 'normal' clothes, by that I mean Norwegian clothes, some in their gækti (traditional female garb), and some in a little of each.'

Both the local pastor and deacon visited the Health Centre regularly to hold prayer meetings and devotional services. These visits were very much appreciated by the residents.

Sami singing traditions

Yoik, the old Sami form of song, was discussed by four family interviewees. To those who uphold this ancient singing tradition, yoiking (the act of singing a yoik) is an important part of their identity. These interviewees told how their old, demented relatives were not able to recognise or remember them when they came to visit, but through yoiking memory and recognition returned: '(Mother) recognises her own yoik. When I visit her and yoik her, even her facial colour changes. I can clearly see that she recognises it' and the yoiks of family members (10).

Many Sami perceive yoik as belonging to the old, heathen religion and therefore as sinful (10). Whether they yoik or not, singing plays an important role in Sami spirituality and culture, and the residents at the Health Centre love to sing hymns and religious songs.

[4] Dried bladder-sedge or blister sedge (Carex vesicaria), e.g. used as isolation in winter boots.

Discussion

Caring can only be complete if all aspects of person and context are considered. 'It involves body, mind and soul, as well as cultural and social aspects of caring for the human body' (11) Cultural background influences the experiences of care and how people with dementia react. Culture specific issues are significant for creating trust in care (12). It is necessary to understand individuals with dementia to be able to help them continue what for each person is his or her normal, culturally appropriate life as far and as long as possible, even when living in a geriatric institution.

The need of a common language

In a review of research literature, Lee (13) found that '[l]anguage differences are reported as the most frequently experienced stressor' and that a lack of proficiency in speaking the majority language 'is the most common of all adaptation difficulties' (pp. 404–405) in immigrants. A Norwegian report comments that 'when the old person more and more often mingle Sami and Norwegian language without being understood, one appreciates that this will create frustration, uneasiness, and other psychological reactions' (14). Language difficulties, then, constitute a central challenge in intercultural geriatric care, particularly in relation to dementia, either when minority elders loose whatever of the majority language they once knew [e.g. (15, 16)], or when ethnic minority health care personnel's majority language skill is limited.

In persons with dementia not only the ability to speak languages learned in adulthood may be lost. The mother tongue and nonverbal expression also gradually deteriorate. Face and gestures become less expressive than in healthy older people, and they have problems reading other people's facial expressions (17). Hence, it becomes progressively more difficult for patients to understand and be understood in general, but even more so by health care personnel who do not have the necessary intrinsic knowledge of the patient's background, verbal symbolism and nonverbal communication. An example of this was a family interviewee's relative who was tested and observed by ethnic Norwegian geriatrics experts. They found it difficult to assess the gravity of her dementia as they had minimal knowledge of the Sami culture at best, and none of them spoke the language.

In a study on Finnish- and Swedish-speaking nursing staff's care for Finnish patients with dementia in Swedish nursing homes, Ekman (18) found that while able to communicate adequately with the Finnish nursing staff, many patients had problems communicating with the Swedish speaking staff. Numerous misunderstandings caused nursing staff to communicate by giving patients

orders and repeatedly interrupting them. The demented Finnish immigrant patients communicated on a much lower level when they had to speak Swedish than when speaking Finnish. The presence of Finnish speakers among the nursing staff contributed positively to the quality of these patients' care and their ability to communicate. This corresponds with my findings.

Patients who do not speak the majority language are much less involved in conversation and much more left to their own devises than are majority ethnic patients. In long-term geriatric care, this constitutes a great problem as communication is important to maintain mental functioning and integrity (12, 18). Both Sami family members and Sami nurses claimed that lack of a communal language between patient and nurse reduces quality of treatment and care, particularly towards patients with dementia. 'A consumer study conducted by The Centre for Sami Health Research shows dissatisfaction with health care personnel's Sami language competency …. When health care personnel do not understand the language this may cause erroneous medical treatment and that symptoms of serious illness are not detected early enough' (3).

The need of cultural understanding

Often the difficulty within intercultural communication is not so much language as the misunderstanding of customs (19). However, the difference in culture tends not to be recognised (3).

Language and culture is very much part of a person's identity. So are clothes, and for patients used to wearing traditional clothes, whether they are Sami or of immigrant background, clothes are powerful reminders of who they are and used to be. To have to wear Norwegian or Western clothes in the institution if used to wear traditional dress may cause a person to loose a bit of his/her identity.

Many of the patients at the Health Centre hail from modest homes. Nurses complained that the dementia ward's architecture had an alienating influence on patients. Instead of creating an atmosphere of homeliness and safety, the large, high-ceilinged communal room with its multitude of doors made some patients restless and troubled with difficulty sleeping, while the traditional 'gamme[2]' and 'lavvo[1]' in the Health Center's out-door area contributed to recognition and a feeling of home. So did the old local pictures and traditional objects in the institution's communal areas.

The importance of traditional foods

Also traditional foods created a feeling of home in the Sami patients and were powerful reminiscence tools. The nurses took the patients' obvious delight in familiar smells and tastes as an indication that traditional foods awoke pleasant memories.

Food does not only bear upon well-being and health but is also important to psycho-social health and the quality of life, and old people may feel disappointed and unloved when served food foreign to them (20). Studies show that many ethnic minority patients are not used to the food served at the institution in which they live. Jewish, Muslim and Hindu patients alike may furthermore worry that meals may contain foods prohibited by their religion, and members of the two former religious groups may worry that animals are not slaughtered as religion prescribes. Hence, for some patients, food is not only a question of habit, likes and dislikes but also of religious purity. Food, then, is an important part of patient care in many respects.

Rhythm of life

A life based on the rhythm of animals and nature may collide with a health care institution's routines. As seen in the findings section, nurses disagreed whether it was better to let the sleep pattern of previous years prevail or whether one should help patients adapt to the rhythm of the institution. There is probably no right or wrong concerning this; also in this respect, patient care needs to be individualised.

As many of the old Sami patients with dementia had spent great parts of their lives out-of-doors in close communion with nature (21), it is important to accommodate for seasonal activities and thusly to some extent support their previous rhythm of life as well as contribute to remembrance (22). It is for instance possible to remind patients of the current season by looking for budding branches or yellowing leaves, to talk with patients about calving and work with 'sennegress[3]', as well as serving season-specific foods more often. Certain types of food mirror particular seasons. Salted meats are traditionally eaten in spring and fresh and smoked meats and food made from animal blood in autumn. Dried meat has its season, so have fresh water fish and freshly picked cloudberries. A nurse pointed out the importance of serving traditional foods in the correct season as patients with dementia for instance may think that 'oh, it's autumn now' if served smoked meat in summer.

Spirituality and singing traditions

Sunday morning church used to be part of the rhythm of life for many patients. At the Health Center, there are regular devotional services, and several nurse and family interviewees mentioned that the residents love to sing hymns. A focus on spirituality 'enables us to remember dimensions of the experience of illness and, indeed, of being human which patients' (23: p. 918), and Zahn et al. (24) found in their review of various international studies that spirituality promotes mental well-being in elderly people.

As shown in the findings section, yoik may be a powerful and positive communication tool when communi-

cating with patients with dementia (10). Graff (25) holds that yoiking may be seen as a 'memory art' through its referencing function as the yoik makes 'the referenced objects present in the mind of the yoiker' (p. 35) and of the listener. Although the singing of hymns and religious songs do not have the same personalised effect, these also are important memory tools besides the fact that the act of singing gives great joy.

Study strengths and limitations

Although most Sami interviewees spoke excellent Norwegian, they would perhaps have felt more comfortable if interviewed in their native language. The data reflect that the focus of the interviews was the personal experiences and thoughts of the respective interviewees. As Sami culture and Sami patients' care in the Health Centre were in the forefront of all interviews, these have become central features in this paper rather than a more general discussion on mental changes in persons with dementia. Although qualitative research data may not be generalised, I will suggest that the cultural influences on the behaviour in patients with dementia discussed in this paper have *transferability* value (26) to other contexts where patient and health care worker hail from different cultural backgrounds.

Conclusion

Although 'there are no cultural facts, only cultural possibilities, and … as much as there is inter-group variation there may be important intra-group variations in behaviour and belief around needs and health-related experiences' (5: p. 288), to be able to uphold one's rhythm of life, spirituality, memories and feeling of safety in familiar surroundings and being understood both linguistically and culturally are universal needs, although their cultural expression may vary.

As individuals with dementia gradually loose their feeling of self and the ability to recognise and relate to the surrounding world, this current and other studies (e.g. 22) show the importance of helping persons with dementia to hold on to their identity and to whatever cultural features are important to them personally. As exemplified by Sami patients, the more the patient's communicative skills deteriorate the more important health care personnel with an intimate understanding of the patient's language and culture becomes for the patient to be understood and to receive culture-appropriate care.

Even small cultural differences, as between Swedish and Finnish culture, may influence to what degree patients trust the persons they rely on for treatment and care (12). It is therefore important that health care personnel realise that different cultural backgrounds may create different needs and do their utmost to learn what thoughts and expectations this particular patient/client has. That will help create a safe environment for the patient and improve reciprocal understanding.

In a Norwegian report is stated: 'There are far too many examples of situations where … language and cultural background have not been understood or taken into adequate consideration, particularly in institutions' (14). As the number of ethnic minority patients with dementia is steadily growing, it is important to learn more about their various culture related needs through collaboration with their respective families and through more research. Furthermore, the health care systems need to respond to the challenges of intercultural dementia care, and more intercultural caring research is needed (26).

Author contributions

The author has contributed all text to this paper.

Ethical approval

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