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ORIGINAL ARTICLE

Health consumption in Sami-speaking municipalities with regard to cancer and radiotherapy

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ABSTRACT

Objectives. The objective of this study was to document that the Sami people, constituting an ethnic minority in northern Norway, experience an equally available specialist health care service as the one offered to Norwegians in general. We aimed to use cancer and radiotherapy treatment as the instrument to clarify the situation.

Study design. A retrospective registry-based study.

Methods. The 8 municipalities included in the administration area of the Sami language law were matched with a control group of 11 municipalities. Population data (numbers, sex and age) were accessed from Statistics Norway. Data on cancer incidence, prevalence and survival during the 10-year time period 1999–2008 were derived from the Cancer Registry of Norway (CRN). Five years overall survival was calculated for patients diagnosed in the time period 1999–2003. Furthermore, data on radiotherapy (RT) and treatment intention were recorded for the time period 1999–2008.

Results. The Sami-speaking municipalities had a significantly lower incidence of cancer. Breast (RR 0.82 [95% CI 0.76–0.89]) and lung cancer (females RR 0.55 [95% CI 0.52–0.58], males RR 0.64 [95% CI 0.60–0.68]) were significantly less frequent. The Sami group had experienced a significant increase (Sami 54.5% [95% CI 49.2–61.7], controls 24.1% [95% CI 21.7–26.5]) in the prevalence of cancer during the last 10 years. Five years overall survival was similar among both the Sami and control groups. In both groups, 28% of cancer patients underwent radiotherapy.

Conclusions. The Sami in northern Norway had a lower risk of cancer but experienced the same use of radiotherapy in their cancer treatment as Norwegians in general.

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Keywords: Sami, cancer, radiotherapy, Norway

INTRODUCTION

The Sami live in the northern regions of Fennoscandia in what today comprises the northern areas of Norway, Sweden, Finland and Russia's Kola Peninsula. The Norwegian government has ratified the Sami as the Indigenous people of Norway (1). They constitute an ethnic minority in the Norwegian community. No exact overview of the total number of Sami exists. The size of the Sami population has been reckoned to be approximately 75,000–100,000, but estimates vary in accordance with the criteria used such as genetic heritage, mother tongue and sense of belonging to the Sami. According to the definitions employed by the Sami Parliament, a Sami is a person who either speaks Sami or has at least 1 parent, grandparent or great-grandparent who spoke the Sami language. The majority of the Sami people in Norway live in the 3 northern counties named Finnmark, Troms and Nordland.

The Sami have their own language and culture. Traditionally, the Sami lifestyle diverges from that of the rest of the Norwegian population, but in relation to occupational expansion, traditions are changing. Until recently, research to understand health issues specifically for the Sami people has been lacking. No systematic registration of ethnicity that can be used for research purposes has existed except for the Census 1970 (2). This census information has been used in record-linkage studies of ethnicity and cancer incidence (3).

In Norway, all inhabitants have equal rights concerning the supply of primary and secondary health care, independent of their ethnic group (4). Norwegian health care authorities have been concerned about offering the Sami minority the same high-quality health care service received

by Norwegians in general. Several national reports have put Sami health care into focus (4–5). Furthermore, the topic has been discussed in the annual mission document from the Ministry of Health and Care Services to the Northern Norway Regional Health Authority (NNRHA) (6). This concern over Sami health care is based on prior research revealing that Sami people are less satisfied with the health care services offered to them than Norwegians in general (7–8).

Despite the fact that the Sami people are protected by the Sami Act, they have a different native language and culture that may cause several difficulties and challenges when assessing public health care services (4). The challenges have often been summarized as threshold, counter, queue and cultural challenges. These hindrances may have an influence on the time of diagnosis and treatment of cancer. With this as our starting point, we aimed to clarify the incidence and prevalence of cancer in the Sami-speaking municipalities in northern Norway and a selected control group. We also aimed to document survival figures and the use of radiotherapy.

MATERIAL AND METHODS

Whereas 40 Norwegian municipalities have Sami settlers, 8 main municipalities have been included in the administration area of the Sami language law. The latter were selected as the Sami communities in this study. Despite that these municipalities employ the Sami language, the share of Sami people within them, or the percentage having Sami as their mother tongue, is not known. The coastal municipalities of northern Norway generally have few Sami residents and 11 of them were chosen as the control group. Details on Sami-speaking municipalities

and the control group are shown in Table I. Their names written in both Sami (when employed) and Norwegian were Deatnu/Tana, Unjárga/Nesseby, Porsanger/Porsángu/Porsanki, Kárásjohka/Karasjok, Guovdageaidnu/Kautokeino, Gáivuotna/Kåfjord, Ástávuona/Lavangen and Divtasvuona/Tysfjord. In 1998 and 2008, these municipalities had a total of 20,507 and 18,968 inhabitants, respectively. The cohort included in the control group is shown in Table I. They had a total population of 21,511 in 1998 and 18,931 inhabitants in 2008. As visualized in Table I, both groups experienced a reduction in the number of inhabitants (Sami group 8.1% and control group 13.6%) during the 10-year period. The female to male ratio was 0.94 and 0.95 in the Sami group and the control cohort, respectively. The age distribution according to gender and 5-year step intervals is shown in Figure 1.

The geographic locations of the 2 groups are shown in Figure 2. Traditionally, the coastal population has easier access to fishing resources than those living inland (the Sami group). However, except for the consumption of reindeer meat, ethnicity has not been shown to play a major role in predicting dietary patterns (9).

In Norway there are ongoing national

screening programs for breast and cervical cancers. All women aged 50–69 years are invited biannually to have a mammogram. In our region the program was initiated on 22 May 2000 and a “screening bus” has been employed to make the service available to all women. As all female candidates were invited, both groups had the same opportunity to take part in the screening program. Concerning the cervical cancer screening, all women were invited by a letter from the national CRN to have a Pap test performed every 3 years from the age of 25 until 69 years of age. The test is performed by general practitioners (GPs) and/or gynecologists who take smears from the participants’ uterine cervix. As all candidates were invited and had their own registered GP, both study cohorts could take part in the screening program. At present there is no national screening program for prostate or colorectal cancer.

In January 2010, we accessed data from the CRN. The following data on cancer were extracted: incidence, prevalence (31 December 1998 and 2008), type of cancer and age at diagnosis. Precancerous conditions, cervical carcinoma in situ, ovarian borderline tumours and basal cell carcinoma of the skin were excluded. Furthermore, we registered all radiotherapy

Table I. The Sami-speaking municipalities and the control group. The number of inhabitants is according to the 1998 and 2008 figures from Statistics Norway (<http://www.ssb.no>).

Sami-speaking municipalities			Control group		
Municipality	Inhabitants		Municipality	Inhabitants	
Year	1998	2008	1998	2008	
Tana	3,137	2,954	Vardø	2,913	2,190
Nesseby	1,035	856	Hasvik	1,245	998
Kautokeino	3,140	2,947	Nordkapp	3,606	3,219
Karasjok	2,857	2,866	Båtsfjord & Berlevåg	3,805	3,167
Kåfjord	2,484	2,248	Salangen	2,385	2,169
Porsanger	4,422	4,059	Lebesby-Gamvik-Måsøy	4,416	3,677
Lavangen	1,060	1,010	Bjarkøy	604	509
Tysfjord	2,372	2,028	Lødingen	2,537	2,279
Total	20,507	18,968		21,511	18,931

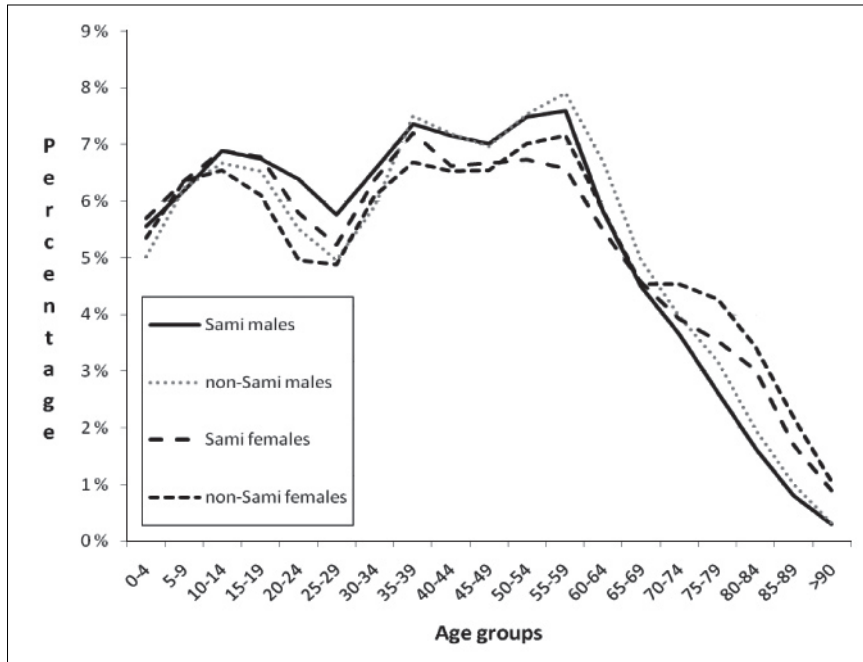


Figure 1. Mean percentage of the population (Sami and non-Sami groups) in each age cohort during the study period.

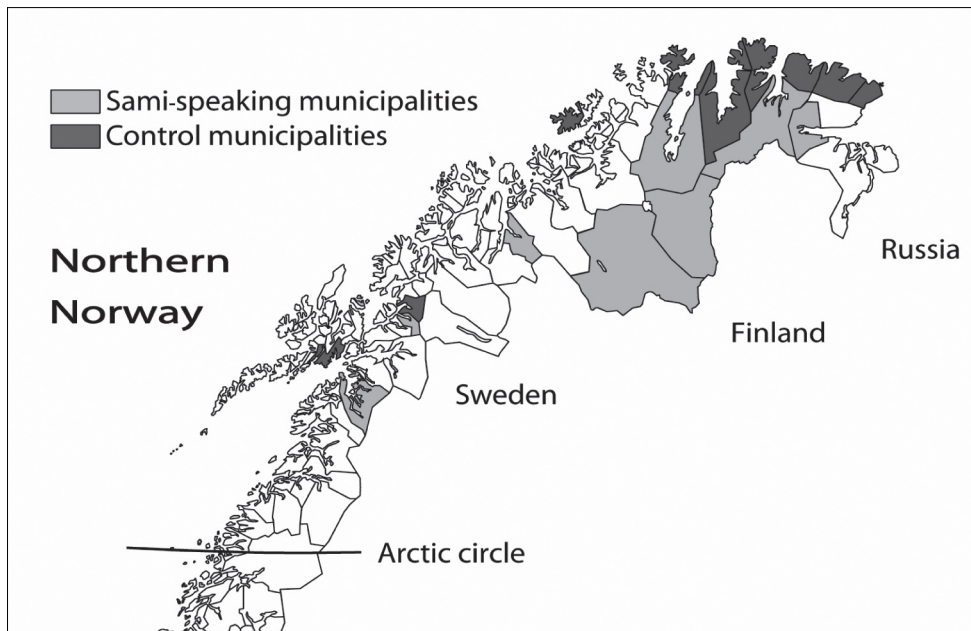


Figure 2. Sami- and non-Sami-speaking municipalities on a map of northern Norway.

administered and treatment intentions that were recorded. The 10-year time period between 1999 and 2008 was selected for study. As all radiotherapy units in Norway (according to law regulations) must export their treatment data to the CRN, data on any patient treated outside northern Norway will also be included in these figures. An overall survival figure of 5 years was recorded for the group of patients diagnosed with primary cancer in the time period 1999–2003. The time since diagnosis was calculated using the prevalence recorded on 31 December 2008 as its basis.

The age distribution among the 2 cohorts was imported from Statistics Norway (<http://www.ssb.no>). The data were organized in steps of 5 years each. The median age was located in the age group 40–44 years in both cohorts. Details are shown in Figure 1.

Statistical analysis and authorization

Microsoft Excel 2002 was employed for the calculations and final database. Descriptive statistics was used. Statistical Package for Social Science (SPSS) version 16.0 was employed for statistical calculations. Overall survival was calculated using the Kaplan-Meier method (crude, unadjusted cumulative survival). The Cancer Registry of Norway (CRN) employed their self-developed program for their calculations. The world standard was employed for the age-adjusted rates.

All data implemented were derived from national public resources and they were made anonymous before being exported to our database. We thus had no access to any individual patient data and no approval from the Regional Committees for Medical and Health Research Ethics (REK) was necessary.

RESULTS

A total of 875 and 1,071 cases of cancer were detected in the Sami-speaking municipalities and the control group, respectively. The age-adjusted annual incidence rate of cancer in the 2 groups per 100,000 women was 246.3 (95% CI 222.0–270.4) and 273.6 (95% CI 246.8–300.4 [RR 0.90]), respectively. The corresponding figures in males were 269.0 (95% CI 242.4–295.4) and 306.8 (95% CI 276.7–336.9 [RR 0.88]). This documents a significantly lower risk of cancer among people living in the Sami-speaking municipalities. Looking at the most frequent types of cancer (breast, lung, colon and prostate cancer), we discovered a statistically significant lower incidence of breast (females RR 0.82 [95% CI 0.76–0.89]) and lung cancer (females RR 0.55 [95% CI 0.52–0.58], males RR 0.64 [95% CI 0.60–0.68]) in the Sami cohort. The Sami group had a 45% (females) and 36% (males) lower incidence rate of lung cancer compared to the control group. Looking at breast cancer, the age-adjusted incidence was 18% lower. Details can be seen in Table II.

Concerning stomach cancer, the figures are low and thus must be handled with caution. The incidence rates in the Sami and control groups during the 10-year period (1999–2008) were 46 and 38 cases. The corresponding mean annual age-adjusted incidence rate per 100,000 inhabitants among males and females were 10.5 and 6.9 (control group) and 15.2 and 12.5 (Sami group), respectively. This may indicate a higher frequency of stomach cancer in the Sami group.

Despite a significantly lower incidence of lung cancer (usually having a poor outcome) in the Sami group, the 5-year rate of overall

Table II. Cancer incidence and prevalence in the Sami-speaking-municipalities and the control group.

	Sami-speaking municipalities			Control group			Ratio	
	No.	Age adj. [#]	95% CI	No.	Age adj. [#]	95% CI	(##)	95% CI
Incidence (females)								
Total	415	246.3	222.0–270.4	499	273.6	246.8–300.4	0.90*	0.82–0.98*
Colon	41	19.8	17.9–21.7	45	18.5	16.7–20.3	1.07	0.96–1.19
Lung	32	18.7	16.9–20.5	57	34.0	30.7–37.3	0.55*	0.52–0.58*
Breast	80	54.8	49.4–60.2	107	66.6	60.1–72.8	0.76	0.89*
Incidence (males)								
Total	460	269.0	242.4–295.4	572	306.8	276.7–336.9	0.88*	0.81–0.96*
Colon	33	19.4	17.5–21.3	41	21.0	18.9–23.1	0.92	0.84–1.00
Lung	67	36.6	33.0–40.2	115	57.2	51.6–62.8	0.64*	0.60–0.68*
Prostate	116	61.2	55.3–67.1	113	54.3	49.0–59.6	1.01	1.26*
Prevalence (31.12.1998)								
	Sami		Control group		Ratio	95% CI		
Total	422		634		0.67*	0.63–0.72*		
Breast	69		98		0.70*	0.65–0.75*		
Prostate	30		54		0.56*	0.53–0.59*		
Colon	17		52		0.33*	0.32–0.35*		
Prevalence (31.12.2008)								
	Sami		Control group		Ratio	95% CI		
Total	652		787		0.83*	0.80–0.86*		
Breast	109		125		0.87*	0.80–0.95*		
Prostate	84		78		1.08	0.97–1.21		
Colon	37		63		0.59*	0.57–0.61*		

[#] Age adjusted = age-adjusted incidence rates per 100,000.

* Statistically significant difference ($p < 0.05$).

survival was similar in both groups, with a slightly better survival rate among women in the Sami cohort. The figures were 43.6% (95% CI 39.3–47.9 [males]) and 63% (95% CI 56.8–69.2 [females]) in the Sami group and 45.7% (95% CI 41.2–50.2 [males]) and 56.2% (95% CI 50.7–61.7 [females]) among the others, respectively. This could indicate a later disclosure of cancer among the Sami people leading to more serious prognoses. However, the prevalence (as of 31 December 2008) of cancer had increased by 54.5% (Sami) and 24.1% (controls) in the time period between 1999 and 2008. This indicates an improvement in early diagnosis and not simply an increasing number of new cases in the Sami-speaking municipalities. This was also supported by the fact that, when comparing the period 1999–2003 with the period 2004–2008, the age-adjusted incidence rates increased more

in the control group than the Sami group. The changes in incidence rates among females and males were -4.1% and +7.8% (Sami group) and +4.8% and +7.3% (control group), respectively.

Looking at the participants' ages at diagnosis, the Sami municipalities had a lower age-specific incidence rate than the control group, except for males older than 80 years (Figure 3). Looking at the most frequent cancer diagnoses for this group, prostate cancer was clearly the culprit.

The share of cancer patients undergoing radiotherapy (28%) was equal in both groups. Details are visualized in Table III. Curative radiotherapy was the most common treatment intention. Palliative radiotherapy was less frequently employed in the Sami-speaking municipalities, probably due to the lower incidence of lung cancer. Lung cancer patients are commonly offered palliative radiotherapy.

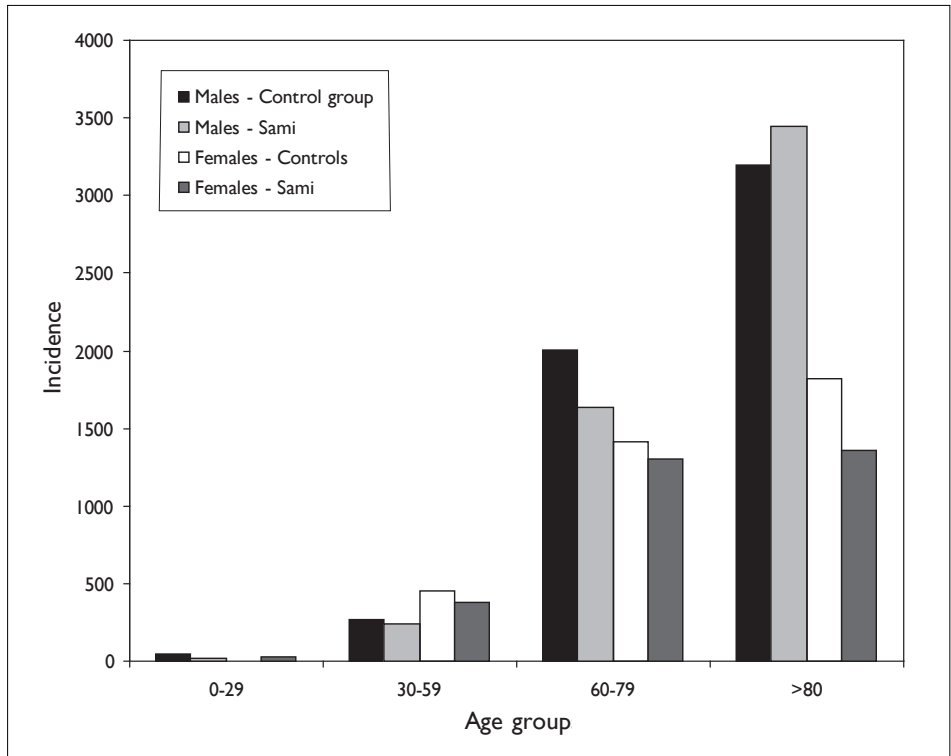


Figure 3. Age-specific incidence rates per 100,000 person-years among male and female cancer patients in the Sami municipalities and the control group.

Table III. Radiotherapy (RT) given to cancer patients in the Sami-speaking municipalities and the control group.

	Sami-speaking municipalities		Control group	
	No.	% (n=875)	No.	% (n=1.071)
Prophylactic RT	1	0	1	0
Curative RT	137	16	138	13
Palliative RT	91	10	136	13
Unknown	16	2	27	3
Total (nRT)	245		302	
Percentage (nRT/N)		28		28

RT = Radiotherapy.

DISCUSSION

In this study, we have found that the Sami-speaking municipalities had a significantly lower incidence of cancer. Breast and especially lung cancer were less common in the study group. No difference was revealed with regard to colon and prostate cancer. Furthermore, the Sami cohort had experienced a significant increase in the prevalence of cancer, indicating earlier diagnosis and/or improved overall survival during the study period. The Sami group experienced a similar use of radiotherapy as the control group. Less use of palliative radiotherapy in the Sami cohort was probably due to fewer cases of lung cancer. However, the long distance between the Sami studied and the University hospital of North Norway in Tromsø or the Nordland hospital in Bodø may also have influenced this group's use of palliative radiotherapy.

Data quality

The study was based on the total populations of 2 groups of municipalities in northern Norway. Data were extracted from the CRN. The Nordic cancer registries are known for their high quality (10). This is due to the fact that all Norwegian hospitals and medical doctors, according to Norwegian law, have to report any case of cancer to the CRN. In Norway, data on minorities such as the Sami people are not available as registering people based on ethnicity is not permitted. Therefore, those living in the administration area of the Sami language law were selected as a surrogate for the Sami people in this survey. Whereas there is, without any doubt, a high percentage of Sami people living in these municipalities, the exact percentage is not known. Similarly, the percentage of Sami people among the control group, consisting of coastal municipalities, is

certainly low. However, the exact percentage is not known.

Do the study cohort and the control group differ in any way, other than being mostly Sami and mostly non-Sami, which could possibly affect their risk of cancer? They differ in geographical setting. Whereas the Sami group is located inland, the control group is located in the coastal areas. However, both groups live in rural areas. Despite that both Vardø and Honningsvåg (in Nordkapp municipality) are registered as Norwegian towns, we argue that the number of inhabitants (about 2,000 in each town) and their location support their classification as rural areas. Data have also indicated that the 2 groups differ in dietary pattern, as the Sami have a tendency to consume reindeer meat (9).

Risk of cancer

A reduced risk of cancer among Sami people has been reported in prior studies (4,11). A Swedish study (11) analysed the cancer risk among Sami who breed reindeer. They studied a cohort of 2,034 persons and observed a total of 100 cases of cancer during the time period 1961–1984, whereas 163 cases were expected. Statistically significantly decreased risks were found for cancers of the colon, respiratory organs, female breast, male genital organs and kidneys, and for malignant lymphomas. The stomach was the only site with a significantly increased risk. This could be because reindeer-breeding Sami have ingested fallout products from nuclear weapon testing via the lichen-reindeer-man food chain since the 1950s. However, no increased risk was found for the cancer sites considered to be most sensitive to radiation.

A Norwegian study by Haldorsen and co-workers (4) followed a cohort of 19,801 people of Sami origin. The cohort was followed for cancer

incidence over the period 1970–1997 by the CRN. Among the Sami, 1,340 cases of cancer were observed, versus the 1,658 that were expected based on a regional reference population. For both sexes a significantly decreased incidence of colon cancer was observed. The standardized incidence ratio (SIR) for men was 0.50 and for women, 0.62. Looking at our figures, a notable difference in the prevalence of colon cancer was observed in 1998, but the difference was minimized during the study period. Low SIRs were also observed for lung cancer (4). The figures were 0.63 and 0.60 for men and women, respectively. This is in accordance with our ratios of 0.58 and 0.56. This is an important observation as both current and past smoking habits are frequently reported among the Sami population, especially among men (8). Whereas Haldorsen and colleagues (4) observed 127 cases of breast cancer, 150 cases were expected. This was confirmed in our study. There are no national data on the number of births per Sami woman. However, looking at Figure 1, there seem to be somewhat more children in the Lappish municipalities. This could be 1 of the possible explanations for a lower risk of breast cancer, as the number of children per woman is correlated to a lowered risk of breast cancer.

Men of Sami ancestry have been reported to have a decreased risk of prostate cancer (SIR 0.57) (12,13). Looking at our prevalence figures, a shift in the diagnosis of prostate cancer seems to have occurred between 1998 and 2008. This could be due to “wild screening” performed by GPs employing the PSA test. Despite several efforts to clarify this topic, the suggestion cannot be confirmed. However, this should be analysed in a future study.

The low risk of cancer in the Lappish municipalities is notable. A relatively high amount of physical activity, a different diet (reindeer dietary

content) and genetic causes have been suggested as explanations for the low cancer incidence in Sami municipalities (12).

The Sami municipalities we studied are located far from the 2 regional radiotherapy units in Bodø and Tromsø. Despite this distance, there was no difference in the use of radiotherapy between groups. This is in accordance with a recent study by Nieder and co-workers (14). They concluded that the distance to radiotherapy units in northern Norway was of no importance concerning access to care. The lesser use of palliative radiotherapy in the Sami cohort was probably due to the low risk of lung cancer in this group, rather than distance. However, this should be further investigated in future studies. Furthermore, only 28% of patients underwent radiotherapy in both groups. The figure is low and indicates insufficient use of this treatment modality. The corresponding figure in the South-Eastern Norway Regional Health Authority was 39% (range 33–44% between counties) in the time period 2003–2007 (15).

Mortality

With a reduced risk of cancer, mortality among Sami people should also be reduced. This was not investigated in our survey, but several other studies (16–18) have revealed a decreased mortality rate among Sami people. The low mortality from cancer constituted half of this difference in the study by Soininen and Pukkala (16). The reasons for reduced mortality among Sami people may be related to their diet, which is rich in reindeer meat and fish; their physically active way of life; and their genetic background.

Conclusion

Sami-speaking municipalities still experience a reduced risk of cancer. Lung and breast cancers were especially infrequent in this cohort. Prior

differences observed in colon and prostate cancer were not found in this study. Despite a low risk of cancer, the Sami patients experienced similar levels of radiotherapy use as others. This indicates that the NNRHA has achieved its goal of equal access to specialist health care for all inhabitants in the region, Sami people included.

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