

ORIGINAL RESEARCH ARTICLE



Survival of Sami cancer patients

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Objectives. The incidence of cancer among the indigenous Sami people of Northern Finland is lower than among the Finnish general population. The survival of Sami cancer patients is not known, and therefore it is the object of this study.

Study design. The cohort consisted of 2,091 Sami and 4,161 non-Sami who lived on 31 December 1978 in the two Sami municipalities of Inari and Utsjoki, which are located in Northern Finland and are 300–500 km away from the nearest central hospital. The survival experience of Sami and non-Sami cancer patients diagnosed in this cohort during 1979–2009 was compared with that of the Finnish patients outside the cohort.

Methods. The Sami and non-Sami cancer patients were matched to other Finnish cancer patients for gender, age and year of diagnosis and for the site of cancer. An additional matching was done for the stage at diagnosis. Cancer-specific survival analyses were made using the Kaplan–Meier method and Cox regression modelling.

Results. There were 204 Sami and 391 non-Sami cancer cases in the cohort, 20,181 matched controls without matching with stage, and 7,874 stage-matched controls. In the cancer-specific analysis without stage variable, the hazard ratio for Sami was 1.05 (95% confidence interval 0.85–1.30) and for non-Sami 1.02 (0.86–1.20), indicating no difference between the survival of those groups and other patients in Finland. Likewise, when the same was done by also matching the stage, there was no difference in cancer survival.

Conclusion. Long distances to medical care or Sami ethnicity have no influence on the cancer patient survival in Northern Finland.

Keywords: *Sami; cancer; cancer survival; arctic population*

Received: 20 December 2011; Revised: 25 April 2012; Accepted: 25 May 2012; Published: 2 July 2012

The Sami are the indigenous people of Northern Finland, Sweden, Norway and Russia. Today there are about 70,000 Sami in these countries. In Finland, there were about 10,000 Sami in the year 2011, when they were counted for the election of the Sami Parliament. More than 65% of them were living outside of their traditional homeland, which consists of the 3 northernmost municipalities of Finland – Inari, Utsjoki, Enontekiö, and the northern part of the Sodankylä municipality. In the Inari municipality, there are 3 Sami groups – Inari Sami, Skolt Sami and Northern Sami – all with cultural, linguistic and health differences. In the same area, there are also non-Sami, some families have been there already for several generations. Utsjoki is the only municipality in Finland with a Sami majority. The living habits of the Sami nowadays are rather similar to those of the non-Sami, because both of them have been influenced from the other. The Sami are genetically different from the rest of the Finnish population.

Until about 1960s, the Finnish Sami were rather isolated and did not get many stimuli and influences from outside (1).

The disease pattern of the Sami differs from that of the general population in their countries and from the non-Sami in the same area (1–10). The mortality and cancer incidence of the Sami groups have been studied previously, and hence it is known that the Finnish Sami groups have cancer incidence patterns that are different from each other and from the non-Sami population (4,10). The cancer incidence of the Sami was significantly lower (SIR 0.64) than that of the Finnish general population and also lower than that of the non-Sami population in the same region (4). On the other hand, the total mortality of the Sami was higher due to non-disease mortality (10). It is not known if the survival of the Sami cancer patients differs from that of the general population. The survival of the non-Sami cancer patients from the same area has not been studied, either.

Until the 1990s the nearest oncologist worked in Oulu University Hospital and consulted from time to time in the main hospital of Lapland (Lapland Central Hospital) in Rovaniemi. The most remote village in “Samiland” is Nuorgam, about 500 km from Rovaniemi and 700 km from Oulu.

The aim of the study is to assess cancer patient survival among the Sami and non-Sami living hundreds of kilometers north from the nearest central hospital, and to compare it with the survival experience of average Finnish cancer patients. This setting allows estimation of the impacts of long distance, and of factors related to genetic background and/or lifestyle of the Sami to the survival of the cancer patients.

Material and methods

The cohort

All persons living in 2 Sami municipalities in northernmost Finland (Inari and Utsjoki) on 31 December 1978 were identified from the Finnish Population Information System. The Sami were identified by using the material of the Finnish International Biological Program, Human Adaptability section. Those data were produced by interviewing the Sami themselves and by genealogical sources (1,11). In the current study, a person representing at least 75% of any ethnic subgroup of Sami was classified as a Sami. A non-Sami is a person without any Sami ethnicity. The mixed group with 1–25% of Sami ethnicity was excluded. Because of historical computational reasons, the non-Sami were restricted to those born between the 1st and 24th day of any month of any year. The final cohort consisted of 2,091 Sami and 4,161 non-Sami people.

All persons in this cohort had personal identity codes given to all residents who have lived in Finland in 1967 or later and used in all person registers in Finland. The cohort was updated from Statistics Finland with information on dates and causes of death up to 31 December 2009. Dates of emigration were obtained from the National Population Register. The cohort was also linked with the Finnish Cancer Registry including incident cancer cases diagnosed during 1979–2009.

Statistical analyses

Cancer-specific survival analysis was employed. The outcome is a net survival measure representing survival from a specified cause of death, in this case the patient’s cancer, in the absence of other causes of death. The survival times of individuals who died from causes other than those specified are considered to be censored.

The cancer-specific survival experience of patients classified as Sami and non-Sami was compared with that of the Finns outside the cohort. The 5-year cancer-

specific survival was estimated only for all cancers combined because of the small numbers of individual cancers.

To produce comparative cancer-specific survival figures, the Sami cancer patients were matched to other Finnish cancer patients obtained from the Finnish Cancer Registry with respect to site, gender, age at diagnosis and year of diagnosis, and in a separate analysis also with respect to the stage. The stage was analyzed in five categories: (a) localized, (b) regional, (c) distant, (d) non-localized, not known whether regional or distant, and (e) unknown. All available controls were accepted into the analyses. A similar matching was also made for non-Sami cancer patients.

Cancer-specific analyses were conducted using the matched Cox regression model (12). Weighted survival analyses were made separately for Sami and non-Sami cancer patients using the Kaplan-Meier method. The weight for each matched control was calculated as the inverse of the number of controls for each case (i.e. weight = 1/number of controls for each case). The statistical software STATA was used to calculate 5-year cumulative weighted cause-specific survival figures.

In addition to the cancer-specific analyses, regular matched overall or all-cause survival analyses were also performed, disregarding the cause of death information.

Results

There were 204 cancer cases in the Sami cohort, 391 in the non-Sami cohort. The number of controls was 20,181 when cancer patients were matched with respect to site, gender, age at diagnosis and year of diagnosis and 7,874 when also matched with respect to stage. Survival until 5 years after diagnosis was first compared without considering the stage and later also matching for stage.

In the cancer-specific analysis without stage variable, the hazard ratio for Sami was 1.05 (95% CI 0.85–1.30) and for non-Sami 1.02 (0.86–1.20). When the Sami cancer patients were also matched according to the stage of the cancer, the cancer-specific analyses gave a hazard ratio for the Sami 1.02 (0.78–1.33) and for the non-Sami 1.10 (0.91–1.33).

The hazard ratios in the all-cause observed 5-year survival analysis were 1.13 (0.94–1.37) for the Sami and 0.97 (0.84–1.12) for the non-Sami.

In the survival curves (Fig. 1) a small difference can be seen between survival of the Sami and matched controls. This difference, however, is not statistically significant as the numbers above show. The survival curves for the non-Sami and matched controls are practically identical. The curves of Sami and non-Sami and their matched controls run at different levels in the figures.

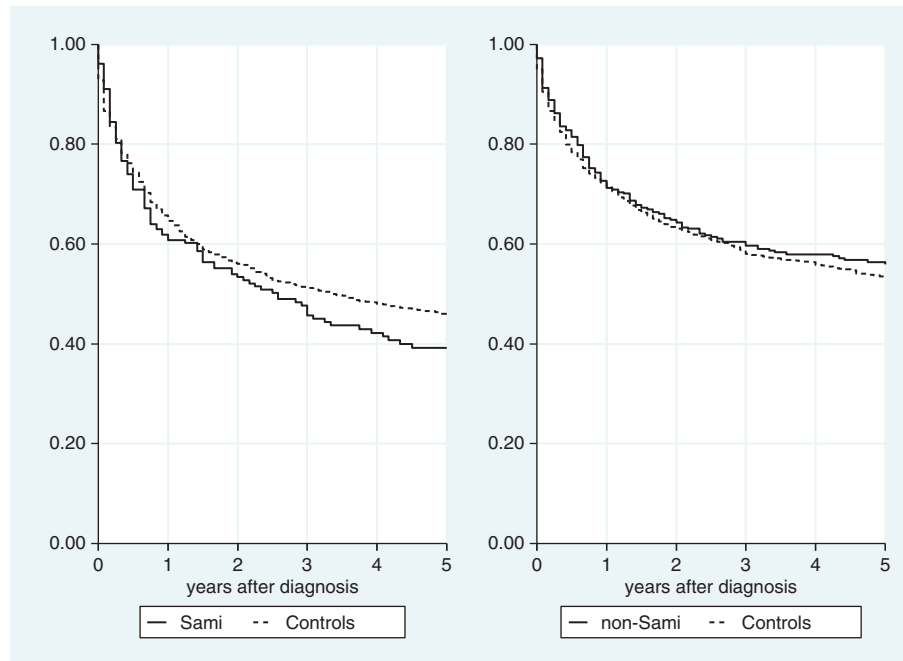


Fig. 1. Cumulative cancer-specific survival curves of all cancer sites combined for the Sami and non-Sami cancer patients in Inari and Utsjoki compared with controls of Finnish population, matched with respect to site, gender, age at diagnosis and year of diagnosis.

Discussion

This is the first assessment of the cancer survival of the Sami. Only the survival of all sites of cancer could be assessed because of the low number of cancer cases. Because the different Sami groups could only be assessed together due to the small numbers of cancer cases in each of them, the possible survival differences between the Sami categories could not be assessed.

The starting assumption of this study was that both genetic or lifestyle features of the Sami, and long distances to the medical care and to hospitals could have an influence on the survival of cancer. The results, however, do not support these hypotheses.

About half of the Sami people in this cohort were born before 1950, and hence have been living according to the traditional Sami culture. The main livelihoods were reindeer herding, fishing and hunting. The quality of food was healthy, including reindeer meat, fish and berries. Before the era of cars and other motor vehicles, the Sami had to do a lot of exercise. The increased communication between the Sami area and other districts brought along more smoking, alcohol drinking, and unhealthy eating habits, but also a higher living standard, better health care and facilities, making life easier. Finnish legislation since 1969 has made it possible to get a 75% subsidy for the costs for building new reindeer farms, and in that way affecting the well-being and health of reindeer herders. The Skolt Sami have their own legislation, which helps their living conditions. From the 1970s, the ways of life of the Sami

and the non-Sami have been very much alike, also with regard to how they seek health services.

There is very little cancer survival data concerning arctic indigenous populations. A publication from the USA describes and compares cancer-specific survival ratios of patients of 6 major racial or ethnic groups during the years 1975–1997 in the USA (13). In 1975–1987, the cancer survival ratio of American Indian and Alaskan Native patients was the lowest; 25% in males and 36% in females (13). The respective ratios for the non-Hispanic Whites were 35% and 46%. Although the 5-year survival ratios of cancer patients during 1988–1997 in any group were more favourable than in 1975–1987, the differences between ethnic groups persisted. An 11 percent-unit lower all-site cancer survival ratio was reported in a comparison between the Alaska Natives and the USA Caucasian cancer patients in 1984–1994 (14). There are no data on the survival of Sami cancer patients before 1979. However, the mortality/incidence ratios in the Northernmost Finland in the 1950s suggest that the survival of cancer patients in that area was worse than in the rest of Finland, but the difference disappeared before the 1970s, thanks to a more rapid decrease in the mortality/incidence ratio in the North (15). It is likely that the survival of patients with cancer (and other diseases) improves when the living standard increases and the living conditions get better. They are rather good today in Finnish Lapland. One has to remember that the living circumstances such as distances, living standards,

and social situations of Indians and Alaskan natives are quite different from those of the Sami in Finland.

The explanation for the similar cancer survival of Sami and non-Sami and the Finnish population might be the similar possibilities to get physician consultations and care everywhere in Finland. When the sickness insurance act came into force 1964, it recognized the need for travelling to the medical doctor. From that time on it was possible to get reimbursement for travelling costs. For those who lived far from services (health centre, shops, banks etc.), it was practical to also manage other things such as shopping when coming to visit the doctor. Hence, the threshold to visit the doctor was rather low, similarly for the Sami and non-Sami from the Northernmost Finland.

In the past, language has been a problem, because all the 3 Sami groups in Finnish Lapland speak different Sami languages, and it is clear that physicians and public health nurses, who came from the South did not speak Sami at all, and Sami nurses spoke only their own Sami language. The Utsjoki municipality later got Northern-Sami speaking general practitioners (GP) and nurses. Today all Sami are bilingual; they understand and speak Finnish. Inari has 3 official Sami languages and Utsjoki 1 official language. Health care workers receive a salary increment if they speak a Sami language.

When the Public Health Act came into force in 1972, it was a big step towards better health care, especially in the sparsely populated rural areas. New health centres, often with beds, were built, more posts for medical doctors and other staff were established, and especially, the health education and early detection of diseases was prioritized. The equality in health care should have been realized, providing the same system and same rules for everybody. In the Inari health centre during the time of this study, there were 6 GP posts and 35 beds. The health centre in Utsjoki has 1.5 GP posts and 15 beds. A local deviation or application from the Public Health Act was that the doctors met patients not only in health centres but also in remote Sami villages. The patients did not need to travel, because the GP travelled. When travelling to the remote villages, the GP also made home visits on the way.

In the Inari municipality and partly also in Utsjoki, there were the same GPs working from the beginning of the 1970s until they gradually retired from 2005. These GPs knew well the population and circumstances, which benefits the early diagnosing of diseases, also cancer. There was not a high threshold to contact the GP in case of symptoms. The Sami and non-Sami in Utsjoki and Inari had all possibilities for early detection, which is an important reason for better survival. From the present study we see that there was no difference between the results with and without adjustment for the stage.

When the nearest central hospital in Rovaniemi got its own oncologist in the beginning of 1990s, most cancer

patients no longer needed to travel to Oulu (another 200 km further), unless a specialized treatment such as radiotherapy was required. Because of the experienced GPs and good cooperation with the central hospital oncologist, it was possible to follow the treatment plan in the local health centre and carry out such cancer treatments (e.g. chemotherapy), which normally are implemented in central hospitals. Special investigations such as tomography, MRI and ultrasound were done in the central hospital.

The survival curves of the Sami cancer patients and their control cancer patients – matched according to sex, age and cancer type – were on a lower level than the respective curves for the non-Sami and their controls (Fig. 1). The reason for this difference is the different cancer type distribution of the Sami and non-Sami. The Sami have a lower incidence of cancers with high survival (cancers of the skin, breast, prostate, testis, kidney, bladder and thyroid, and Hodgkin lymphoma) than the non-Sami, while the incidence of more lethal common cancer types such as stomach cancer or lung cancer is not lower (4). The Sami persons were also older than the non-Sami, and older cancer patients tend to have lower relative survival rates than young ones.

There was no difference between the all-cause survival of Sami and non-Sami and other patients in Finland. The higher mortality hazard in the Sami patients may well also reflect a higher mortality from the other causes of death (10), which may as well be partly due to the higher age of the Sami compared to the non-Sami.

During the study period (1979–2009), the survival of cancer patients in the far north has been the same as in Finland generally. That concerns both Sami and non-Sami patients, which means that neither long distances in Finland nor ethnic background have an effect on surviving. These results might also tell something about good and persistent patient-physician relationships (early detection), which are known to advance the surviving of all diseases.

Conflict of interest and funding

The authors have not received any funding or benefits from industry or elsewhere to conduct this study.

References

1. Eriksson AW. Anthropology and health in Lapps. *Coll Antropol.* 1988;2:197–235.
2. Wiklund K, Holm LE, Eklund G. Mortality among Swedish reindeer breeding Lapps in 1961–85. *Arctic Med Res.* 1991;50:3–7.
3. Hassler S, Sjölander P, Barnekow-Bergqvist M, Kadesjö A. Cancer risk in the reindeer breeding Sami population of Sweden 1961–1997. *Eur J Epidemiol.* 2001;17:969–76.
4. Soininen L, Järvinen S, Pukkala E. Cancer incidence among Sami in Northern Finland, 1979–1998. *Int J Cancer.* 2002;100:342–6.

5. Haldorsen T, Tynes T. Cancer in the Sami population of North Norway, 1970–1997. *Eur J Cancer Prev.* 2005;14:63–8.
6. Hassler S, Soininen L, Sjölander P, Pukkala E. Cancer among the Sami – a review on the Norwegian, Swedish and Finnish Sami Populations. *Int J Circumpolar Health.* 2008;67:421–32.
7. Hassler S, Sjölander P, Grönberg H, Johansson R, Damber L. Cancer in the Sami population of Sweden in relation to lifestyle and genetic factors. *Eur J Epidemiol.* 2008;23:273–80.
8. Hassler S, Johansson R, Sjölander P, Grönberg H, Damber L. Causes of death in the Sami population of Sweden, 1961–2000. *Int J Epidemiol.* 2005;34:623–9.
9. Tynes T, Haldorsen T. Mortality in the Sami population of North Norway, 1970–98. *Scand J Public Health.* 2007;35:306–12.
10. Soininen L, Pukkala E. Mortality of the Sami in Northern Finland 1979–2005. *Int J Circumpolar Health.* 2008;67:43–55.
11. Nickul E. Suomen saamelaiset vuonna 1962 (The Sami of Finland in the year 1962). Master's graduate study. Helsinki: University of Helsinki, Department of Statistics; 1968. 118 p. [in Finnish]
12. Cox DR. Regression models and life table (with discussion). *J R Stat Soc B.* 1972;34:187–220.
13. Clegg LX, Li FP, Hankey BF, Chu K, Edwards BK. Cancer survival among US whites and minorities. A SEER (Surveillance, Epidemiology, and End Results) program population-based study. *Arch Intern Med.* 2002;162:1985–93.
14. Lanier AP, Holck P, Kelly J, Smith B, McEvoy T. Alaska native cancer survival. *Alaska Med.* 2001;43:61–83.
15. Pukkala E, Patama T. Small-area based map animations of cancer incidence in the Finland, 1953–2008. Helsinki: Finnish Cancer Registry; 2010 [cited 2012 June 7]. Available from: <http://astra.cancer.fi/cancermaps/suomi5308>

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