Diabetes among the Sami population of Sweden

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Abstract

**Background:** Diabetes is a significant health problem world-wide with an international prevalence of 2.8%, estimated to rise to 4.4% by 2030. Indigenous populations (meaning populations which inhabited an area prior to colonization or conquering by a subsequent group) are generally observed to have far worse health outcomes than their non-indigenous counterparts. This is true also for diabetes, where indigenous populations are generally observed to have higher rates of diabetes and its consequences. In Sweden, the Sami are the indigenous populations of the northern region, and have lived in northern Sweden and surrounding countries for many thousands of years. Despite international recognition of the needs of indigenous groups, relatively little research has been performed regarding the Sami population in Sweden, with what research has been done indicating that the health status between Sami and non-Sami are relatively the same. To date, no in-depth investigation of diabetes among the Sami population of Sweden has been performed. The purpose of this thesis is to investigate diabetes and its consequences among the Sami population of Sweden and compare it to non-Samis.

**Methods:** Through use of records of registered voters in the Sami parliament and registered reindeer herders, Hassler et al. have been able to create a dataset of an estimated Sami population in Sweden. By adding blood relatives of those identified, a group of 37,039 Sami has been created. After matching for location, age and gender a control group of 96,514 non-Sami was also created. By accessing available health records, hospital discharge forms and death records it was possible to extract 11,853 Sami and 34,184 non-Sami from these groups for whom a recording of the presence or absence of diabetes could be made. Using this data, prevalence and incidence measures were able to be calculated. For prevalence measures, the relative prevalence of diabetes between Sami and non-Sami (as well as further separating the Sami group into Reindeer Herding and non Reindeer Herding groups) as well as the relative prevalence for various complications of diabetes could be established. For incidence measures, the incidence of new cases of diabetes could be estimated and compared between groups, as well as the relative incidence of death between the Sami and non-Sami diabetics.

**Results:** The prevalence ratio of diabetes between Sami and non-Sami after adjusting for age was 1.03 (95% CI 0.92-1.15). No statistically significant difference was observed after separating by reindeer herding status. While stratifying for age, it was observed that there was a disproportionately high number of children under the age of ten from the Sami group in hospital who have a significantly lower rate of diabetes. Whether this represents a true difference in the prevalence of diabetes among this age group or is a result of the disproportionately high number of people in the Sami group is unclear. The prevalence of diabetic complications was equivalent for both Sami and non-Sami
groups. There was no statistically significant difference with regards to the incidence of new cases of diabetes or of death among diabetics.

**Conclusion:** No statistically significant difference has been found overall between the Sami and non-Sami groups for the prevalence of diabetes and its complications as well as for the incidence of new cases and death among diabetics. This is a very encouraging finding given that generally indigenous populations suffer far worse health than their non-indigenous counterparts. However, various practical limitations with regards to the data set and external applicability of this research means that its results must be interpreted with caution and that further research to confirm and further investigate these findings is required. An incidental finding of a disproportionately high number of Sami children being admitted to hospital requires further research to be fully understood.
List of Abbreviations

DKA - Diabetic Ketoacidosis
HHS- Hyperglycaemic Hyperosmolar State
ICD - International Classification of Disease
PCD - Peripheral Circulatory Disease
UN - United Nations
VIP - Västerbotten Intervention Programme
WHO - World Health Organization
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1. Introduction

1.1 Overview
The concept of what it means for a population to be considered "indigenous" to a region is multifaceted and complex. In general, an indigenous population is a group of people, who consider themselves distinct from other parts of the society in which they live who occupied a geographical location prior to (and generally speaking, during and after) invasion or colonization by a different group. Indigenous populations generally have distinct cultures, languages, histories and belief systems from those around them (1). Indigenous populations are widely observed to occupy lower levels of a nation's socio-economic structure and generally have markedly different health outcomes than non-indigenous populations. For example, in New Zealand, the indigenous Maori population has an average life expectancy eight years less than that of the colonial European population (2), and earn an average of 25% less than their European counterparts (3). In Australia, this difference in life expectancy extends to ten years for the native Aboriginal population (4), and they have unemployment rates three times that of their European counterparts (5). In the Scandinavian population, the Sami people are recognized as the indigenous population of the area (6), having occupied the northern region of Scandinavia many centuries prior to colonization from mainland Europe. Nowadays, the Sami either live integrated within "mainstream" Sweden or live working as reindeer herders (which is their traditional past-time).

Despite the international recognition that indigenous populations have unique and separate health needs in comparison to the colonial populations (7), and Sweden's support for the United Nations Declaration on the Rights of Indigenous People, (8) Sweden has relatively little to show in terms of investigating the health of their indigenous population. This has drawn criticism from the United Nations, notably from Special Rapporteur Paul Hunt, who in his 2006 report criticised Sweden for failing to identify and address any special health needs of the Sami population (9).

Work by Hassler et al. has taken some steps to address these criticisms and has already produced some knowledge of the health of the Sami population in Sweden. No difference in life expectancy has been observed between Sami and non-Sami. In terms of causes of mortality, there are several small differences between Sami and non-Sami. Sami men appear to have a slightly increased rate of death from subarachnoid haemorrhage and vehicle accidents, while having a decreased rate of death from cancer, while Sami women have increased rates of death from subarachnoid haemorrhage, ischemic heart disease and respiratory disease (and overall have a slightly higher rate of death than non-Sami women). If looking specifically at Reindeer Herding Sami, it is found that men have higher rates of death from subarachnoid haemorrhage and vehicle accidents (probably reflecting occupational hazards of reindeer herding) as well as a slightly increased rate of suicide and a reduced rate of death from gastrointestinal causes. Of particular relevance to this thesis, there did not appear to be any appreciable difference between Sami and non-Sami with regards to deaths related to diabetes (10), (11).

With regards to cancer, the Sami population in Sweden has been observed to have a lower overall rate of cancer than the non-Sami population (12). In particular, the Sami population was observed to have a higher rate of stomach cancer but had a lower rate of cancer of the
colon, lung, breast, prostate, kidney, bladder, skin and lymphoma. Investigations of cancer among the Sami throughout the Scandinavian region have indicated that these findings are consistent throughout Scandinavia (13).

As yet, no in-depth study of the burden of diabetes among the Sami population of Sweden exists. This thesis seeks to do such an investigation.

1.2 Historical Context
The Sami people have traditionally been nomadic, moving with herds of reindeer. They have become synonymous with reindeer herding, which has been their traditional occupation for hundreds, if not thousands of years. The right to herd reindeer in Sweden remains the exclusive right of Sami and is the most commonly known feature of the Sami population.

The historical region that the Sami people occupied is known as Sapmi (Figure 1). It covers the nations of Norway, Sweden, Finland and Russia. It is unclear for exactly how long the Sami people have been in residence. Archaeological findings have found evidence of peoples living in the Sapmi region as far back as 9000BC and there have been written references to peoples, with descriptions consistent with Sami, dating back as far as 98AD.

In Sweden, Sami persons have been referenced to in tax records since the mid 16th Century, in which they were referred to as a minority population of Sweden. Since the Sami people were considered to be Swedish subjects they were required to pay taxes for the use of their traditional lands, and at some times were required to pay taxes to multiple bodies (as their lands included the regions of Sweden, Finland and Russia). Settlers arrived into the northern region of Sweden during the 17th Century and the need for land and property was the source of some difficulty between the Sami population and Swedish settlers. Efforts were taken to assimilate the Sami people into society, largely through the use of Christian missionaries and, following an extensive effort during the 16th and 17th centuries, the majority of the Sami adopted Christianity as their primary faith. The influx of settlers into the northern region of Sweden continued and by the 19th century, the Sami found themselves outnumbered in their traditional homelands. As the population of settlers increased, so did the rate of conflicts between Sami and Europeans relating to land usage, hunting and fishing rights as well as conflicts over cultural, religious and linguistic matters. In an effort to control some of these conflicts, a regional Sami service was created in the northern part of Sweden. The main public role of these Sami services appears to have
been the supervision of the Sami population as well as the control and regulation of reindeer husbandry. However, the Sami service also had functions in the controlling of Sami issues and the proposing of new laws and regulations. This service continued in operation until 1971 when it was assimilated into the Swedish Department of Agriculture (which still deals with the majority of Sami related issues) (14).

In addition to the above Sami services, the 19th century also saw the implementation of segregation between the Sami and European populations. Under the "Sami should be Sami" policy the Sami were intended to remain as nomads and reindeer herders. Interestingly, the Swedish government only referred to those Sami who continued to herd reindeer in this policy and those who no longer herded reindeer were expected to assimilate into mainstream Swedish society.

In the early 20th century, racial intermixing was considered a danger to society. The Swedish Institute of Racial Biology undertook extensive research in the first half of the 20th century in an attempt to prove that racial intermixing was a danger to Swedish society through carrying out research on people of Sami descent. The research showed no such thing. After the Second World War, such policies and opinions were publicly unacceptable.

The latter half of the 20th century has been very powerful for the recognition of the Sami population in Sweden. The Swedish government officially recognized the Sami population as the indigenous population of Sweden in 1977. In 1986 the Sami flag (Figure 2) was adopted. In 1993, the Samitinget was established; this is the Sami parliament and has a role in the representing of Sami persons in Sweden. There are similar parliaments in Finland and Norway. Today Sami live in Sweden either assimilated with "mainstream" Swedish society or working in their traditional roles as Reindeer herders (15).

The current population of Sami persons is difficult to accurately estimate since information about ethnicity is not routinely collected in Swedish statistics. According to the Swedish Ministry of Agriculture, the total population of Sami persons throughout Scandinavia is 80,000, with 20,000 living in Sweden. Among those living in Sweden, 2,500 are estimated to be in the reindeer herding industry (15). The accuracy of this is uncertain though, since (as will be revealed in the methodology section) the estimate of Sami population created for use in this thesis is substantially different from that provided by the Swedish Ministry of Agriculture.
1.3 Ethnicity
It seems prudent to spend some time discussing ethnicity as a concept. The features that separate people into different ethnic groups is mainly one of socially constructed difference and geographic separation. There is little to no genetic basis for the classification of people into different ethnic groups (physical differences such as skin colour and facial shape are often the only notable genetic differences and generally have little to do with any other significant illness factors). It is generally considered that the inequity between those of different ethnic groups caused as the result of previous actions (such as loss of traditional lands and property or segregation) results in predispositions towards certain diseases. Therefore, the purpose of identifying differences in illness between ethnic groups is to identify areas of inequity between one group and another (16).

1.4 Diabetes Mellitus

1.4.1 Definition
Diabetes Mellitus is a term which refers to a heterogeneous group of metabolic disorders which all share hyperglycaemia (elevated blood sugar) as a common feature. There are four categories of classification for diabetes which are based upon the pathological process which leads to the development of hyperglycaemia (17).

Type 1 diabetes is typified by the destruction of β-cells in the pancreas (which are responsible for insulin production). This results in a near or total absence of insulin in an individual which results in hyperglycaemia. The cause of the destruction of these cells is generally considered to be immune mediated and frequently occurs when an individual is in childhood or early adulthood (usually before the age of thirty). Type 2 diabetes is a combination of insulin resistance in peripheral cells with or without a degree of deficient insulin production from the pancreas. There are a multitude of causes for this, including family history of diabetes, obesity, physical inactivity, hypertension, and hyperlipidaemia. This type of diabetes usually occurs in later adulthood (after the age of thirty) although there have been a notable number of cases where a younger person has developed type 2 diabetes (known as maturity onset diabetes in the young). Gestational diabetes can arise during pregnancy and is thought to relate to various metabolic changes which occur during later pregnancy, specifically increased insulin requirements which lead to impaired glucose tolerance and thus hyperglycaemia. Most women with gestational diabetes revert to normal after delivery although they do have an elevated risk of developing diabetes later in life. Other causes of diabetes refers to the wide range of relatively uncommon causes of diabetes. This can include such things as specific genetic conditions, metabolic abnormalities, pancreatic disease, endocrinological disorder or a result of medical therapy (such as surgical removal of the pancreas or use of steroid medication) (17).

1.4.2 Symptoms
One of the challenges of diabetes is that while there are symptoms to indicate that it is present, many of them are mild and often fail to be noticed or are considered to be harmless by those afflicted. According to the American Diabetes Association (18) the symptoms for diabetes include: frequent urination (polyuria), excessive thirst (polydipsia), extreme hunger, fatigue, irritability, weight loss, frequent or recurring infections, slow to heal wounds, or
tingling or numbness in the extremities. In many cases no symptoms are present at all and a diagnosis is made incidentally during a medical exam.

1.4.3 Diagnostic Criteria
The World Health Organisation (WHO) diagnostic criteria for a diagnosis of diabetes are as follows (19):

- Fasting plasma glucose $\geq 7.0$ mmol/L OR
- Glucose level $\geq 11.1$ mmol/L 2 hours after ingestion of 75g oral glucose load

The glucose level is tested through venous blood analysis.

The WHO also contains diagnostic criteria for what could be considered "pre-diabetes" where the blood sugar level is too high to be considered "normal" but is not high enough to be diagnostic of diabetes. They indicate an elevated future risk for development of diabetes (typically referring to the development of type 2 diabetes). These conditions are:

- Impaired glucose tolerance - Fasting glucose of $<7.0$ mmol/L AND glucose between 7.8 - 11.1 mmol/L 2 hours after ingestion of 75g oral glucose
- Impaired fasting glucose - Fasting glucose between 6.1-6.9 mmol/L AND glucose $<7.8$ mmol/L 2 hours after ingestion of 75g oral glucose

1.4.4 Consequences
The medical consequences of diabetes are varied but can be categorized into two groups, acute (referring to rapid onset of disease and generally high level of urgency) and chronic (referring to long term consequences) (17).

1.4.4.1 Acute Consequences
Diabetic ketoacidosis (DKA) almost exclusively occurs in those with type one diabetes. It arises in situations of insulin deficiency and relative glucagon excess (such as failure to take sufficient insulin, or new development of type one diabetes). This results in the production of glucose and ketone bodies in the liver, which leads to marked hyperglycaemia, dehydration and metabolic acidosis. This condition is immediately life threatening and requires hospitalization for rehydration and insulin therapy in order to preserve life.

Hyperglycaemic hyperosmolar state (HHS) generally occurs in those with type 2 diabetes and is usually occurs in situations with relative insulin deficiency and poor fluid intake. This results in increased glucose levels which produces a dehydrating effect (through driving urination) which is often inadequately replaced by the patient. There is no production of ketone bodies. Like DKA, this is a life threatening complication and requires immediate medical treatment with insulin and rehydration.

1.4.4.2 Chronic Consequences
The chronic consequences of diabetes are far more frequent than the acute consequences and account for a much larger portion of the associated morbidity and mortality from the disease. Chronic consequences can be classified as either vascular or non-vascular.
1.4.4.2.1 Vascular Complications

The term vascular complications refers to the effect upon the blood vessels caused by diabetes. It can be classified further by the size of the vessels that they damage. Macro-vascular complications affect the larger blood vessels and result in coronary artery disease, peripheral vascular disease and cerebro-vascular disease. Micro-vascular complications affect the smaller vessels and result in ophthalmopathy (damage to the eye), neuropathy (nerve damage) and nephropathy (kidney damage).

1.4.4.2.2 Non-vascular complications

Non-vascular complications of diabetes refer to complications associated with diabetes which are not associated with any blood vessels. They include problems such as gastro paresis (slowing down of the bowels), susceptibility to infection, and hearing loss.

Some diabetic complications occur as a combination of several other complications working in tandem. For example, though a combination of peripheral vascular disease, neuropathy and susceptibility to infection, individuals with diabetes are prone to the development of skin ulcers which frequently become infected, often require surgery and in extreme cases, require amputation of the affected limb.

1.4.4.3 Mechanism of complication

While the complications of diabetes are strongly associated with prolonged hyperglycaemia (usually presenting after years of hyperglycaemia) the physiological mechanism is less well understood. The current reasoning is that prolonged hyperglycaemia results in other bodily functions increasing in frequency and activity, resulting in disease over a prolonged period of time.

1.4.5 Treatment

There is a slight variation in treatment depending upon the subtype of diabetes. In Type 1 diabetes, there is an absolute absence of insulin. Therefore, the primary therapy at present is to replace the insulin. This is done through the use of regular self administered injections of insulin and in concurrence with regular self testing of blood sugars is intended to simulate the normal function of the body in the management of sugar and the function of insulin. In Type 2 diabetes, the therapy takes several parts. First, dietary changes and lifestyle changes are advised, in order to reduce the intake of sugars, reduce weight, and increase exercise. Second, oral medications are frequently used. These various medications work in various ways depending upon their purpose. Commonly used medications in Type 2 diabetes include Metformin, which reduces glucose production in the liver and reduces insulin resistance, and Glipizide which forces the pancreas to produce a higher amount of insulin. Third, injections of insulin are frequently used as well in order to effectively bring blood sugars under control. Gestational diabetes frequently just needs dietary alteration and should resolve at the end of pregnancy. The treatment of the "other" causes of diabetes is highly varied but generally involves some combination of the above therapies (17).

In all these types of diabetes, in addition to controlling blood sugar, persons with diabetes are regularly monitored for signs of complications, the intention being to identify any complications at an early stage and begin appropriate therapy before the complications become too advanced.
1.4.6 Epidemiology

The epidemiology of diabetes mellitus shows an increasing prevalence of the disease worldwide. With estimates placing an international prevalence at 2.8%, estimated to increase to 4.4% by 2030 (20). Both type 1 and 2 diabetes are both increasing world-wide, however, type 2 diabetes is increasing much more rapidly than type 1. This is probably in a large part due to the worldwide trends in diet changes, an increase in obesity and decreasing activity levels.

In Sweden the prevalence of diabetes is approximately 5% (21). An in depth investigation exploring any difference in diabetes between non-Sami and Sami in Sweden does not yet exist. The diet of Samis (most notably the reindeer herding Sami) is considered to be notably different to that of non-Sami, with higher levels of fats and carbohydrates being taken in the diet than non-Sami (22). Given these differences in diet, it is reasonable to consider that the risk of the development of diabetes could be higher among the Sami population.

1.5 Diabetes and indigenous populations

The available evidence suggests that, generally speaking, indigenous populations suffer from worse health than their colonial counterparts. This appears to be true for diabetes and its consequences. In Australia, the indigenous aboriginal population have three times the prevalence of diabetes than their European counterparts (4). In the United Stated of America, the indigenous population has twice the prevalence of diabetes than the non-indigenous population (23). If we were to focus for a moment upon type 2 diabetes and its consequences (which is the most frequently researched subtype with regards to indigenous populations), it is possible to find a modest array of research conducted upon the disease burden of diabetes between the indigenous and colonial populations. Naqshbandi et al. (24) have collated much of the available research with startling results. Research from New Zealand, Australia, Canada and the United States of America has consistently shown a clear difference between indigenous and colonial complications in diabetes. In all of these instances, the indigenous populations have experienced worse outcomes than their colonial counterparts. For example, in New Zealand, the indigenous Maori population has six times the rate of diabetic nephropathy than non-Maori and 16 times the rate of end-stage kidney failure. The mortality rate for Maori diabetics in New Zealand is almost six times that of non-Maori. The indigenous population in Canada and the USA has a death rate associated with diabetes twice that of the general population. In Australia, the Aboriginal population with diabetes has a death rate nine times that of the general population (5).

1.6 Aim of thesis

The aim of this thesis is to investigate diabetes among the Sami population of Sweden and to compare it to that of the non-Sami population. Included in this comparison will be the overall prevalence and incidence of diabetes as well as the degrees of complications that occur.
2. Methods

2.1 Study Design
The primary purpose of this thesis is to compare the prevalence of diabetes and its complications between Sami and non-Sami in Sweden. This will be achieved by an epidemiological study of diabetes in Sweden using population registers and medical records. The primary measures will be the relative prevalence of diabetes and its complications between Sami and non-Sami alive in Sweden as well as the prevalence of diabetes among the Reindeer Herding Sami of Sweden in comparison to both non-Sami and non Reindeer Herding Sami. Secondary measures will be the relative incidence of death among diabetics between Sami and non-Sami and the relative incidence of new cases of diabetes between Sami and non-Sami.

2.2 Study Population

2.2.1 Identification of Sami population
It is not legal in Sweden to directly collect and record ethnicity data, so an alternative methodology was required to produce a group of Sami for study. Hassler et al. (14) produced an index of Sami in Sweden. This index was made available for use in this thesis. The creation of this group was as follows (25):

Step 1: Only people of Sami descent are permitted to register and vote in the Samitinget (Sami parliament). By accessing the registration records, one source of identifying Sami persons was identified.

Step 2: Only Sami people are permitted to farm reindeer and all farmers of reindeer must be registered as such. By accessing the records of all registered reindeer farmers a second source of Sami persons was identified. The fact that these people were reindeer farmers was also recorded for use in future analysis. This was done because the lifestyle of reindeer herding Sami is considered to be notably different from non-reindeer herding Sami.

Step 3: Steps one and two created what we can consider to be a group of "index Sami" - those who are directly identified as Sami. Under the logical assumption that the blood relatives of these index Sami must also be Sami, the parents, siblings and descendants of those people gained from steps one and two were identified.

2.2.2 Creation of a Control Population
The three previous steps produced a total of 41,721 persons and are summarized in Figure 3. In order to
accurately get an understanding of Sami health, a control "non-Sami" group must be created in order to find a point of comparison. The Sami group produced was matched for age, gender and location to a randomly selected group of the general Swedish population who had not been identified as Sami (25). This provided 144,930 non-Sami to act as a control group. Since the primary purpose of this research has generally been to investigate Sami health among the living, both groups were compared to the 1999 Swedish census and all those who were deceased at that point were removed. This reduced the Sami group to 37,039 and the non-Sami group to 96,514.

2.3 Data Sources
Both study populations provided basic demographic information but did not contain information about diabetes. In order to address this, access to medical records was sought. For use in this thesis three sources of medical information were available: hospital data, death record data and information from the Västerbotten Intervention Programme.

2.3.1 Hospital discharge data
Hospital discharge data was available for between the years 1999 and 2003, and contained every recorded incident of hospital admission (and subsequent discharge) for all persons. The hospital data contains a yes/no component for the diagnosis of diabetes as well as International Classification of Disease (ICD) 10 coding of diseases. The ICD coding system is the international standard for the recording of diagnoses (26). The "10" refers to the tenth edition of this classification system. Diseases are given specific codes based upon a general classification. Diabetes is coded under the "endocrine, nutritional and metabolic disorders" section with the prefix code E1. It then goes on to add further subtypes, E10 is the code for insulin-dependent diabetes mellitus, E11 codes for non-insulin-dependent diabetes mellitus, E12 codes for malnutrition-related diabetes mellitus, E13 codes for "other" specified diabetes mellitus and E14 codes for "unspecified" diabetes mellitus. Many people have more than one admission to hospital. Care was taken to ensure that no person was inadvertently counted twice.

2.3.2 Death Records
Death records between years 1990 and 2002 were available. The death records contain not only the primary cause of death, but also the recorded diagnoses of the deceased. These recordings were undertaken using either the ICD 9 (the previous edition) or ICD 10 method of diagnostic coding (which method used dependent upon location and time of death). Since all those deceased prior to 1999 had been removed from the study population, the death records only indicated those who had died subsequent to 1999.

2.3.3 Västerbotten Intervention Programme
Information from the Västerbotten Intervention Programme (VIP) between years 1990 and 1999 was made available. The Västerbotten Intervention Programme is a long running primary health care intervention which originally started in 1985 in a small Swedish municipality and subsequently spread throughout the Västerbotten region from 1987 onwards. The programme was introduced in response to a finding that people in the Västerbotten County had a notably higher rate of cardiovascular disease than the rest of Sweden. The Programme involves persons being interviewed regarding their health and having various screening tests performed. The people involved are seen at the ages of 40, 50
and 60 years (27). Those results are able to be tabulated into an overall health "pattern" which can then be targeted for future interventions or programmes. Of relevance to this project is an indication of whether the person has a diagnosis of diabetes (recorded in "yes/no" fashion).

2.3.4 Applying Data Sources to Study Population

The 37,039 Sami and 96,514 non-Sami in the study population were checked against these data sources and those who had a record of the presence or absence of diabetes were then extracted for use in this thesis. The death records were used for two purposes. The first use was that those who were deceased were excluded from the calculation of prevalence measures. This gave a total of 10,735 Sami and 28,979 non-Sami which we could use to study the prevalence of diabetes. The VIP provided 1,250 Sami and 5,159 non-Sami. Hospital records gave 9,860 Sami and 25,409 non-Sami. Some people were included in both the VIP records and hospital records but it was ensured that they were only counted once. The second use of the death records was in the calculation of the incidence of death among diabetics, those who had died were then used in these calculations.

2.4 Definition of Variables

2.4.1 Definition of diabetes

The available medical records were inconsistent in their method of recording of diabetes. A combination of ICD coding and simple yes/no responses were used. Additionally, the ICD coding system refers to "insulin dependent" (E10) and "non-insulin dependent" (E11) diabetes. This method of referring to diabetes can be confusing as insulin is a common manner of therapy in many subtypes of diabetes and therefore fails to properly record the actual type of diabetes present. Because of these difficulties, it was decided to include all subtypes of Diabetes Mellitus in the analysis. This meant that any record which contained a "yes" response to a diagnosis of diabetes, or an ICD code with a prefix of E1 would be considered a positive diagnosis of diabetes.

2.4.2 Definition of Complications of diabetes

2.4.2.1 Directly Coded Complications

The ICD coding system includes codes for complications which are recorded to have occurred directly as a result of diabetes. The codes are written so that a diagnosis of diabetes is recorded first and then a suffix is inserted to identify complications. These codes are (x indicates the space for the subtype of diabetes):

- E1x0 - with coma
- E1x1 - with ketoacidosis
- E1x2 - with nephropathy (kidney damage)
- E1x3 - with ophthalmopathy (eye damage)
- E1x4 - with neuropathy (nerve damage)
- E1x5 - with peripheral circulatory complications
- E1x6 - with "other" unspecified complications
- E1x7 - with multiple complications
- E1x8 - with unspecified complications
- E1x9 - without complications

Due to the highly non-specific nature of codes 6 and 8 they will not be included in analysis.
2.4.2.2 Other Complications

In addition, we were able to search the hospital records for indications of other diseases known to be associated with diabetes but not directly coded as such in the ICD system. The diseases selected for study were: cardiovascular disease, stroke, and skin ulcers. These diseases were selected for two reasons. Firstly they are all established complications of diabetes (28). Secondly, they are frequent enough diseases to be able to potentially provide meaningful findings. To allow for the possibility that diabetic nephropathy was incorrectly being coded as chronic kidney disease, an additional evaluation of the prevalence of kidney disease was undertaken.

The presence or absence of history of stroke was recorded directly in the hospital records as a "yes/no" record. The presence of skin ulcers, heart and kidney disease were detected using appropriate ICD codes. The code for heart disease used was I25 which codes for chronic cardiac disease. The code for kidney disease used was N18 which codes for chronic kidney failure and the code for skin ulcer used was L89 which codes for De Cubitius ulcers (also known as pressure ulcers, this disease can be exacerbated by diabetes through a combination of nerve damage and circulatory disease (29)).

2.5 Data Analysis

2.5.1 Prevalence Measures

The primary intention of this thesis is to be able to gain an understanding of how the prevalence of diabetes among the Sami population is in comparison to non-Sami. This will be achieved through the usage of prevalence measures and prevalence ratios to compare Sami and non-Sami. "Prevalence" refers to the proportion of people in a particular population who have a predetermined disease at a particular point in time (30). Prevalence ratios are calculated by dividing the prevalence calculated in the Sami group by the prevalence of the non-Sami group. 95% confidence intervals will be constructed to test for statistical significance, with a confidence interval that excludes one being considered statistically significant (with a ratio above one indicating that the Sami have higher levels while below one indicates lower levels). Prevalence will be calculated for the point at the end of 2002 (where the available records end for the study group). Since diabetes generally does not "go away" any record of diabetes in a person will be considered to indicate that the diagnosis remains for the purpose of calculating prevalence.

2.5.1.1 Reindeer Herding Sami

Of particular interest are the reindeer herding Sami, who in many ways continue their traditional lives, culture and diet. The initial data set has recorded which Sami were identified through the reindeer herding measure and has thus provided 6,474 persons identified as Reindeer herders. Of this 6,474 persons, 2,065 had a record of their diabetes status and were included in analysis of the relative prevalence of diabetes between groups.

2.5.1.2 Measurement of complications

The identification of diabetic complications was only established through the use of hospital data. Therefore the prevalence measures here will only be among the diabetics in the 10,585 Sami and 28,945 non-Sami identified from the hospital data. The prevalence and prevalence ratios for the complications of diabetes was calculated.
2.5.2 Incidence Measures

Since the data gathered covers a period of time with many people being recorded more than once it has been possible to make estimates of incidence measures for the group with regards to the relative incidence of diabetes and the incidence of death among diabetics. Incidence refers to the number of new cases of a disease which occur in a population at risk of that disease over a period of follow-up (30). Relative incidence refers to dividing the incidence among the Sami group by the incidence among the non-Sami group. 95% confidence intervals will be created for the relative incidence to calculate for statistical significance. The period of follow-up for the persons involved in this study are the years 1990 to 2003. Not all of the available data sources followed all of the involved persons through this entire period. The VIP data carried information for persons between the years 1990 to 1999 and was used in the calculation of the incidence of new cases of diabetes and the incidence of death among diabetics. The Hospital discharge data was provided between the years 1999 to 2003 and was only used in the calculation of death among diabetics. Death register data was available between 1990 to 2002.

2.5.2.1 Calculation of Incidence of New Cases of Diabetes

Using the data from the Västerbotten Intervention Programme it was possible to estimate the relative incidence of diabetes among the Sami and non-Sami populations. In the Sami group there were 1268 persons registered in the programme. Of those 1227 (96.7%) did not have a diagnosis of diabetes. Each person had only one recorded entry in the Västerbotten programme. Using hospital data and death data it was possible to identify persons who had subsequently gained a diagnosis of diabetes. Persons not found to have developed diabetes through these data sets were assumed to have not developed diabetes. People were followed from the point in which they were entered into the Västerbotten programme (any year between 1990 and 1999) up until the point where they either: developed diabetes, died or, until the end of the cohort in 2002.

2.5.2.2 Calculation of Incidence of Death among diabetics

Since the groups were designed in order to study those alive, all those deceased prior to 1999 had been removed. However, a number of persons died subsequently to 1999. This provided an opportunity to assess the incidence of death among diabetics in both the Sami and non-Sami groups. This was done as follows: all diabetics from both Västerbotten study data and hospital data were identified and separated. Those identified as diabetics will then be followed from the earliest point in the records indicating that they have diabetes until either the point of their death or until the end of the time period for which data has been collected. It is then possible to calculate the relative incidence rate of death among the diabetics.

2.6 Ethical Approval

This project has been undertaken using the design and data provided through Sjölander et al. who had ethical approval provided by the ethics committee of Umeå University (14). That ethical approval has been considered to extend to this research project. All analyses have been performed at the group level and there is no data on personal identity available in the database. At no point can any individual be recognised or traced through the use of this data set.
Additionally, given the sensitive nature that the study of ethnicity can entail, the explicit purpose of this research is to explore the differences in health between these two groups with the express intention of maximising health for all. No interventions or actions should be taken towards any group in this study without the prior informed consent of the affected group.
3. Results

3.1 Demographic Features
The demographics of the two groups are available in Table 1. There was a higher proportion of females to males in both groups (57% females in the Sami group compared to 58% in the non-Sami group). The Sami group had an average age six years less than that of the non-Sami group.

Table 1 - Demographic Features of the Sami and non-Sami groups

<table>
<thead>
<tr>
<th></th>
<th>Sami (n=10,735)</th>
<th>Non-Sami (n=28,979)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender mix% (m/f)</td>
<td>43/57</td>
<td>42/58</td>
</tr>
<tr>
<td>Mean age (years)</td>
<td>43</td>
<td>49</td>
</tr>
<tr>
<td>Mean age men</td>
<td>44</td>
<td>49</td>
</tr>
<tr>
<td>Mean age women</td>
<td>42</td>
<td>48</td>
</tr>
</tbody>
</table>

3.2 Prevalence Measures

3.2.1 Prevalence of Diabetes among Sami and non-Sami
The available populations were explored to find their absolute prevalence of diabetes. Once the prevalence was established they were compared and a relative prevalence (with 95% confidence interval) was calculated. The findings are summarized in Table 2. In the VIP group, there were 24 diabetics in the Sami group out of 1250 available, giving a prevalence of 1.92%. The non-Sami group had 75 diabetics out of 5159 persons giving a prevalence of 1.45%. This gave a prevalence ratio of 1.32 (95% CI 0.84 - 2.08). In the hospital group, there were 428 Sami identified as diabetic out of a total of 9860, giving a prevalence of 4.34%. The non-Sami group had 1301 persons identified as diabetic out of a total of 25,409, giving a prevalence of 5.12%. This gave a prevalence ratio of 0.85 (95% CI 0.76 - 0.94). In combining the two groups, a number of people were found to have been in both the hospital and VIP data sets. Duplicate records were removed, leaving only one occurrence of each person. In the combined dataset there were 441 Sami diabetics out of 10,735 available, giving a prevalence of 4.11%. Among the non-Sami, there were 1352 diabetics out of 28,979 giving a prevalence of 4.67%. This gave a prevalence ratio of 0.88 (95% CI 0.79-0.98) which indicates that the Sami population have a statistically significantly lower overall prevalence of diabetes. Interesting points to notice from here are that the hospital discharge data dominates the overall data set and the figures are as yet unadjusted for any possible confounding factors.

Table 2 - Prevalence and Prevalence Ratios of Diabetes

<table>
<thead>
<tr>
<th></th>
<th>Diabetics</th>
<th>Available</th>
<th>Prevalence</th>
<th>Prevalence Ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>VIP</td>
<td>Sami</td>
<td>24</td>
<td>1250</td>
<td>1.92</td>
</tr>
<tr>
<td></td>
<td>Non-Sami</td>
<td>75</td>
<td>5159</td>
<td>1.45</td>
</tr>
</tbody>
</table>
The data was then stratified by age group (Table 3), which revealed a major role of the under 10 age group where a far higher number of Sami children (without diabetes) have been enrolled than non-Sami. Since the only source of people under the age of 50 is hospital data (the other source is VIP) there appears to be a notably larger number of children admitted to hospital from the Sami group than the non-Sami. A pooled estimate gave a prevalence ratio of 1.03 with 95% confidence interval 0.93 to 1.6.

Table 3 - Prevalence and Prevalence Ratios Stratified by Age

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Diabetes</th>
<th>Total</th>
<th>Prevalence</th>
<th>Diabetes</th>
<th>Total</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>7</td>
<td>699</td>
<td>1.00%</td>
<td>14</td>
<td>259</td>
<td>5.41%</td>
</tr>
<tr>
<td>10-19</td>
<td>29</td>
<td>1093</td>
<td>2.65%</td>
<td>64</td>
<td>2666</td>
<td>2.40%</td>
</tr>
<tr>
<td>20-29</td>
<td>10</td>
<td>1446</td>
<td>0.69%</td>
<td>30</td>
<td>3299</td>
<td>0.91%</td>
</tr>
<tr>
<td>30-39</td>
<td>25</td>
<td>2012</td>
<td>1.24%</td>
<td>49</td>
<td>4284</td>
<td>1.14%</td>
</tr>
<tr>
<td>40-49</td>
<td>37</td>
<td>1234</td>
<td>3.00%</td>
<td>82</td>
<td>3773</td>
<td>2.17%</td>
</tr>
<tr>
<td>50-59</td>
<td>64</td>
<td>1485</td>
<td>4.31%</td>
<td>222</td>
<td>5051</td>
<td>4.40%</td>
</tr>
<tr>
<td>60-69</td>
<td>111</td>
<td>1434</td>
<td>7.74%</td>
<td>343</td>
<td>4959</td>
<td>6.92%</td>
</tr>
<tr>
<td>70-79</td>
<td>97</td>
<td>805</td>
<td>12.05%</td>
<td>303</td>
<td>2625</td>
<td>11.54%</td>
</tr>
<tr>
<td>80-89</td>
<td>49</td>
<td>446</td>
<td>10.99%</td>
<td>207</td>
<td>1753</td>
<td>11.81%</td>
</tr>
<tr>
<td>90+</td>
<td>12</td>
<td>81</td>
<td>14.81%</td>
<td>38</td>
<td>310</td>
<td>12.26%</td>
</tr>
</tbody>
</table>

Stratification by gender (Table 4) revealed that Sami males had a similar level of prevalence of diabetes than non-Sami males (prevalence ratio 1.01, 95% CI 0.88-1.10). Sami females appeared to have a lower prevalence of diabetes relative to non-Sami females (prevalence ratio 0.71, 95% CI 0.60-0.84).

Table 4 - Prevalence and Prevalence Ratios Stratified by gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Diabetics</th>
<th>Available</th>
<th>Prevalence</th>
<th>Prevalence ratio (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>Sami</td>
<td>276</td>
<td>4664</td>
<td>5.92%</td>
</tr>
<tr>
<td></td>
<td>Non-Sami</td>
<td>705</td>
<td>12044</td>
<td>5.85%</td>
</tr>
</tbody>
</table>
Stratification further by age and gender (Table 5) revealed again the major role which the under 10 age group played in both genders, but most notably females where a prevalence ratio of 0.09 was revealed. A pooled estimate gave a ratio of 1.03 with 95% confidence interval 0.92 to 1.15

Table 5 - Prevalence Ratios Stratified by Age and Gender

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Sami Diabetics</th>
<th>Available</th>
<th>Non-Sami Diabetics</th>
<th>Available</th>
<th>Prevalence Ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>5</td>
<td>382</td>
<td>6</td>
<td>139</td>
<td>0.30 (0.09, 0.98)</td>
</tr>
<tr>
<td>10-19</td>
<td>21</td>
<td>604</td>
<td>32</td>
<td>1344</td>
<td>1.46 (0.85, 2.51)</td>
</tr>
<tr>
<td>20-29</td>
<td>7</td>
<td>476</td>
<td>16</td>
<td>1055</td>
<td>0.97 (0.40, 2.34)</td>
</tr>
<tr>
<td>30-39</td>
<td>16</td>
<td>557</td>
<td>29</td>
<td>1258</td>
<td>1.25 (0.68, 2.28)</td>
</tr>
<tr>
<td>40-49</td>
<td>23</td>
<td>534</td>
<td>49</td>
<td>1671</td>
<td>1.47 (0.90, 2.39)</td>
</tr>
<tr>
<td>50-59</td>
<td>45</td>
<td>724</td>
<td>140</td>
<td>2372</td>
<td>1.05 (0.76, 1.46)</td>
</tr>
<tr>
<td>60-69</td>
<td>64</td>
<td>689</td>
<td>214</td>
<td>2298</td>
<td>1.00 (0.76, 1.30)</td>
</tr>
<tr>
<td>70-79</td>
<td>62</td>
<td>441</td>
<td>151</td>
<td>1184</td>
<td>1.10 (0.84, 1.45)</td>
</tr>
<tr>
<td>80-89</td>
<td>26</td>
<td>222</td>
<td>65</td>
<td>629</td>
<td>1.13 (0.74, 1.74)</td>
</tr>
<tr>
<td>90+</td>
<td>7</td>
<td>35</td>
<td>3</td>
<td>94</td>
<td>6.27 (1.72, 22.89)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Sami Diabetics</th>
<th>Available</th>
<th>Non-Sami Diabetics</th>
<th>Available</th>
<th>Prevalence Ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>2</td>
<td>317</td>
<td>8</td>
<td>120</td>
<td>0.09 (0.02, 0.44)</td>
</tr>
<tr>
<td>10-19</td>
<td>8</td>
<td>489</td>
<td>32</td>
<td>1322</td>
<td>0.68 (0.31, 1.46)</td>
</tr>
<tr>
<td>20-29</td>
<td>3</td>
<td>970</td>
<td>14</td>
<td>2244</td>
<td>0.50 (0.14, 1.72)</td>
</tr>
<tr>
<td>30-39</td>
<td>9</td>
<td>1455</td>
<td>20</td>
<td>3026</td>
<td>0.94 (0.43, 2.05)</td>
</tr>
<tr>
<td>40-49</td>
<td>14</td>
<td>700</td>
<td>33</td>
<td>2102</td>
<td>1.27 (0.69, 2.37)</td>
</tr>
<tr>
<td>50-59</td>
<td>19</td>
<td>761</td>
<td>82</td>
<td>2679</td>
<td>0.82 (0.50, 1.33)</td>
</tr>
<tr>
<td>60-69</td>
<td>47</td>
<td>745</td>
<td>129</td>
<td>2661</td>
<td>1.30 (0.94, 1.80)</td>
</tr>
<tr>
<td>70-79</td>
<td>35</td>
<td>364</td>
<td>152</td>
<td>1441</td>
<td>0.91 (0.64, 1.29)</td>
</tr>
<tr>
<td>80-89</td>
<td>23</td>
<td>224</td>
<td>142</td>
<td>1124</td>
<td>0.81 (0.54, 1.23)</td>
</tr>
<tr>
<td>90+</td>
<td>5</td>
<td>46</td>
<td>35</td>
<td>216</td>
<td>0.67 (0.28, 1.62)</td>
</tr>
</tbody>
</table>
3.2.2 The Prevalence of Diabetes in the Reindeer Herding Sami

Of the 10,735 available Sami, 2,065 (19%) were reindeer herding. Of this 2,065, 101 (4.9%) had a diagnosis of diabetes, compared to 3.9% of the non-reindeer herding Sami, and 4.67% of the non-Sami. Comparing the reindeer herding Sami directly to non-Sami gives us a prevalence ratio of 0.84 with 95% confidence interval 0.75-0.94 (Table 6).

Table 6 - Relative prevalence Reindeer Herding Sami compared to non-Sami

<table>
<thead>
<tr>
<th></th>
<th>Diabetic</th>
<th>Non-Diabetic</th>
<th>Total</th>
<th>Prevalence</th>
<th>Prevalence Ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Sami</td>
<td>1352</td>
<td>27628</td>
<td>28979</td>
<td>4.67%</td>
<td>1.00</td>
</tr>
<tr>
<td>Reindeer Herding</td>
<td>101</td>
<td>1964</td>
<td>2065</td>
<td>4.89%</td>
<td>1.05 (0.86, 1.28)</td>
</tr>
<tr>
<td>Sami</td>
<td>340</td>
<td>8330</td>
<td>8670</td>
<td>3.92%</td>
<td>0.84 (0.75, 0.94)</td>
</tr>
</tbody>
</table>

We then repeat our earlier efforts and stratify by age again. This time, separating the Sami population further by herding status and then comparing the prevalence to that among non-Sami we find once again that the dominance of the under ten age group is largely responsible for the observed difference (Table 7).

Table 7 - Reindeer Herding Sami and Non Reindeer Herding Sami compared to non-Sami

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Non-Sami</th>
<th>Reindeer Herding Sami</th>
<th>Non-Reindeer Herding Sami</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>14</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>5.41%</td>
<td>0.00%</td>
<td>1.04%</td>
</tr>
<tr>
<td>10-19</td>
<td>64</td>
<td>2</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>2.40%</td>
<td>4.00%</td>
<td>2.59%</td>
</tr>
<tr>
<td>20-29</td>
<td>30</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>0.91%</td>
<td>0.52%</td>
<td>0.72%</td>
</tr>
<tr>
<td>30-39</td>
<td>49</td>
<td>4</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>1.14%</td>
<td>1.13%</td>
<td>1.27%</td>
</tr>
<tr>
<td>40-49</td>
<td>82</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td></td>
<td>2.17%</td>
<td>2.68%</td>
<td>3.10%</td>
</tr>
<tr>
<td>50-59</td>
<td>222</td>
<td>10</td>
<td>54</td>
</tr>
<tr>
<td></td>
<td>4.40%</td>
<td>2.66%</td>
<td>4.87%</td>
</tr>
<tr>
<td>60-69</td>
<td>343</td>
<td>22</td>
<td>89</td>
</tr>
<tr>
<td></td>
<td>6.92%</td>
<td>6.45%</td>
<td>8.14%</td>
</tr>
<tr>
<td>70-79</td>
<td>303</td>
<td>33</td>
<td>64</td>
</tr>
<tr>
<td></td>
<td>11.54%</td>
<td>12.04%</td>
<td>12.05%</td>
</tr>
<tr>
<td>80-89</td>
<td>207</td>
<td>17</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td>11.81%</td>
<td>12.78%</td>
<td>10.22%</td>
</tr>
<tr>
<td>90+</td>
<td>38</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>12.26%</td>
<td>23.53%</td>
<td>12.50%</td>
</tr>
</tbody>
</table>

If we directly compare reindeer herding Sami to non-reindeer herders, we find a prevalence ratio of 0.80 with 95% confidence interval of 0.65 to 1.00. Stratifying this by age once again reveals the role that the under ten age group plays, this time with zero Reindeer Herding...
Sami having a diagnosis of diabetes (Table 8). Pooling the age stratification gives us a ratio of 1.12 with 95% confidence interval 0.89 to 1.42

Table 8 - Reindeer Herding Sami stratified by age and compared to non-Reindeer Herders

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Reindeer Herders</th>
<th>Non-Reindeer Herders</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Diabetics</td>
<td>Total</td>
</tr>
<tr>
<td>0-9</td>
<td>0</td>
<td>28</td>
</tr>
<tr>
<td>10-19</td>
<td>2</td>
<td>50</td>
</tr>
<tr>
<td>20-29</td>
<td>1</td>
<td>194</td>
</tr>
<tr>
<td>30-39</td>
<td>4</td>
<td>353</td>
</tr>
<tr>
<td>40-49</td>
<td>8</td>
<td>299</td>
</tr>
<tr>
<td>50-59</td>
<td>10</td>
<td>376</td>
</tr>
<tr>
<td>60-69</td>
<td>22</td>
<td>341</td>
</tr>
<tr>
<td>70-79</td>
<td>33</td>
<td>274</td>
</tr>
<tr>
<td>80-89</td>
<td>17</td>
<td>133</td>
</tr>
<tr>
<td>90+</td>
<td>4</td>
<td>17</td>
</tr>
</tbody>
</table>

3.2.3 The Prevalence of Diabetic Complications

The 428 Sami and 1301 non-Sami identified with diabetes from the hospital data set were investigated further for diagnoses commonly associated with diabetic complications.

3.2.3.1 Directly Coded Complications

Acute Complications

Using the ICD codes 1x0 and 1x1 to represent the two major acute diabetic complications (ketoacidosis and coma) we were able to establish the prevalence of these complications among the diabetic population and compare them between the Sami and non-Sami population. Note that these diagnoses will refer to those who have a diagnosis of the complication and might not represent an acute admission but instead refer to a previous admission that occurred prior to the follow-up period. As such, this section should be considered to represent a history of acute diabetic consequences. Also, this only counts individuals who have had one or more event. It does not count the number of events in itself. So an individual who has had 4 events is only counted once, as is a person who has only had one event.

Coma

The Sami group had 24 persons with and identified diagnosis of coma (5.61%), compared to 67 among the non-Sami group (5.15%). It is not specified in the ICD coding whether or not the coma is concurrent with acidosis or not. This provided a prevalence ratio of 1.09 (95% confidence interval 0.69-1.71)
**Ketoacidosis**

Nine Sami (2.10%) and 40 Non-Sami (3.07%) had diagnoses of ketoacidosis. This provided a prevalence ratio of 0.68 with 95% confidence interval 0.33-1.40.

It should be noted though, that several of these diagnoses were coded E111, which in the ICD 10 indicated ketoacidosis in an individual with non insulin dependent diabetes (which is itself an outdated term, but generally indicates type 2 diabetes). This seems to potentially indicate a miscoding as, generally speaking, those with type 2 diabetes do not develop acidosis.

**Chronic Complications**

Continuing the usage of the ICD codes to identify directly coded diabetic complications we were able to look at chronic complications of diabetes. The complications under focus were: Nephropathy (1x2), Ophthalmopathy (1x3), Neuropathy (1x4), peripheral circulatory disorder (1x5) and "multiple" complications (1x7).

**Nephropathy**

The hospital data revealed 25 persons from the Sami group with a recorded diagnosis of nephropathy (5.84% of the total), this compared to 52 persons from the non-Sami group (4.00%). This gave a prevalence ratio of 1.46 with 95% confidence interval 0.92-2.33

**Ophthalmopathy**

Data revealed 28 persons in the Sami group with ophthalmopathy (6.54%), compared to 65 persons in the non-Sami group (5.00%). This gave a prevalence ratio of 1.31 with confidence interval 0.85-2.01

**Neuropathy**

14 Sami were identified as having neuropathy (3.27%) compared to 35 non-Sami (2.69%), giving a prevalence ratio of 1.22 with 95% confidence interval of 0.66-2.24

**Peripheral circulatory disease**

This diagnosis revealed 21 Sami (4.91%) and 101 non-Sami (7.76%) which gave a prevalence ratio of 0.63, with 95% confidence interval 0.40-1.00

**Multiple complications**

31 Sami were identified as having multiple complications (7.24%), compared to 130 non-Sami (9.99%). This gave a prevalence ratio of 0.72 with 95% confidence interval of 0.50-1.06

These findings (acute and chronic) are illustrated in Figure 4.
3.2.3.2 Indirect Consequences

While the above complications are directly linked into the diagnostic coding for diabetes, other complications may occur and not be coded as directly. To address this and search for further differences, we have identified particular medical conditions known to be associated with diabetes and investigated for them.

Stroke

Vascular disease is a widely recognized complication of diabetes. Stroke, a complication from cerebrovascular disease is a widely recognized complication of diabetes. The hospital data contained records on history of stroke among the groups.

Among the Sami with a diagnosis of diabetes, 83 (19.39%) also had a diagnosis of stroke. Among non-Sami, 291 individuals (22.37%) among the diabetics had a diagnosis of stroke while only 4.6% of those without diabetes had a history of stroke. Comparing the diabetic groups to each other gives a prevalence ratio of 0.87 with 95% confidence interval 0.70-1.08

Cardiovascular Disease

Taking the ICD coding of I25, which specifies for chronic cardiovascular disease, we are able to investigate the groups for any evidence of chronic heart disease and inspect for any difference between the groups. The Sami group had 59 individuals with this diagnosis (13.79%) while the non-Sami group had 236 individuals (18.14%). This gives a prevalence ratio of 0.76 with 95% confidence interval 0.58-0.99
Kidney Failure
The ICD code of N18 codes for chronic renal failure. Among the Sami diabetic group 13 individuals (3.04%) had chronic renal failure. 43 (3.31%) of the non-Sami diabetic group had chronic kidney failure. This gave a prevalence ratio of 0.92 with 95% confidence interval 0.50-1.69

Ulceration
Skin ulceration is a consequence of diabetes through the combined deficiencies of blood supply and peripheral neuropathy. The ICD code L89 refers to De Cubitus ulcers which includes skin ulcers caused as a result of sustained pressure. Among the Sami diabetics, only 3 persons had this diagnosis coded (0.70%). The Non-Sami group had a far higher 16 persons with a recorded diagnosis of ulceration (1.23%). This provided a prevalence ratio of 0.57 with 95% confidence interval 0.17-1.95

3.3 Incidence Measures

3.3.1 Incidence of new diabetes
The Sami group revealed 6 incident cases of diabetes from a total of 9,889 person years of follow up, giving an incidence rate of approximately 61 cases per 100,000 person-years. Among the non-Sami group, 40 incident cases of diabetes were identified out of a total of 41,885 person-years of follow up, giving an incidence rate of approximately 95 cases per 100,000 person-years. Comparing these incidence rates revealed an incidence rate ratio for diabetes among the Sami population of 0.63 times that of the non-Sami population. This ratio failed to meet statistical significance though, as the 95% confidence interval was 0.27 to 1.49.

There were no measures of incidence within the hospital data during the period of follow-up, i.e. there were zero cases of an individual changing from a "negative" to a "positive" diagnosis of diabetes.

3.3.2 Incidence of death among diabetics.
By taking those identified as diabetic during either the VIP or through hospital discharge data, we were able to calculate a rate of death, and compare it between Sami and non Sami. Among the Sami, 14 deaths were observed during 1078 person-years of follow-up. Among the non-Sami, 40 deaths were observed during 3446 person-years of follow-up, giving a relative incidence of death among Sami diabetics of 1.12 (95% confidence interval: 0.61 - 2.06).
4. Discussion

4.1 Discussion of the main findings of the thesis

The results indicate that there is no statistically significant difference between the Sami and non-Sami populations of Sweden with regards to the prevalence of diabetes. There was some initial suggestion that a difference might be forthcoming, but after stratification for age, it appeared that these differences were only present in the under ten age group where there was a disproportionately high number of young Sami children (who did not have diabetes) being admitted to hospital. The reason for this high level of hospitalization is unclear.

Looking briefly at the admitting diagnoses of these children it is found that among the Sami children, the top five diagnoses are: concussion (4.5% of admissions) abdominal pain/colic (4.4%), enlarged tonsils and adenoids (3.8%), unspecified viral haemorrhagic fever (3.5%) and unspecified viral infection (3%). Among the non-Sami group the top five diagnoses are: abdominal pain/colic (5%), concussion (4.7%), enlarged tonsils and adenoids (3.7%), unspecified viral haemorrhagic fever (3.2%) and unspecified viral infection (2.2%). This sheds no light on why so many more Sami children are admitted to hospital and most definitely warrants further investigation. With respect to diabetes, there is some possibility that this finding does in fact represent a significant difference in the levels of type 1 diabetes. If we were to assume that the main reasons for admission among the under ten age group were essentially the same (and that simply more Sami children were admitted), then it would follow that it should be expected that each group has equivalent levels of diabetes. This was not what was observed, with the Sami group having significantly lower diabetes than the non-Sami group. This may represent a very important finding, and if an understanding for the disproportionately high number of young person’s admissions can be found, this might then go on to establish a lower level of type 1 diabetes among the Sami.

In investigating diabetes among the reindeer herding population it was found that there was no statistically significant overall difference in the prevalence of diabetes among the Reindeer Herding Sami in comparison to either non-Reindeer Herding Sami or to non-Sami. Stratification by age again gave the same finding as before, this time with no children under the age of ten with diabetes. This may be due to the relatively small size of the population which was being studied or it may represent a true difference in diabetes. It is difficult to accurately tell from the information currently available and further research is certainly needed.

In investigating the complications of diabetes there was no statistically significant difference observed between the Sami population and the non-Sami population. This is an especially important finding given the international context which generally finds that indigenous populations have a notably higher level of diabetic complications than their colonial counterparts (24).

Examining the incidence of new cases of diabetes was consistent with the other main findings of the thesis. No statistically significant difference in the incidence of diabetes was observed between groups. It is worth noting though, that the persons at risk for diabetes used in this analysis were all selected from the VIP data set. This means that all of the persons involved here would be at least 40 years old, thus meaning that this incidence measure is most likely indicative of type 2 diabetes in particular. Given that we have previously discussed the lower
prevalence of diabetes among the under 10 age group (which would almost exclusively have type 1 diabetes), a study of the incidence of diabetes among young Sami might have notably different results.

The incidence of death among diabetics was not significantly different between groups, and this finding is of reasonable importance. Since the prevalence measures performed were among the living, there is a possibility that an excessive mortality among the Sami would mask a difference in prevalence, thus giving an unremarkable prevalence ratio while the Sami population still suffer a higher burden of disease via excess mortality. The finding of equivalent rates of mortality between Sami and non-Sami is reassuring because it indicates that the equivalent prevalence of diabetes among the living is not related to an unequal rate of mortality. In combination with equivalent prevalence ratios for complications of diabetes this would go on to suggest that the accessibility of health services for Sami persons would be roughly the same as the non-Sami since unequal accessibility would likely manifest itself in higher death rates or higher levels of complications.

These findings are highly encouraging. Given that the international trend is for indigenous populations to suffer worse health outcomes than their colonial counterparts (1) it is refreshing to find that this does not appear to be occurring in Sweden. The findings here are consistent with the other studies thus far performed indicating that the Sami population in Sweden (and possibly even in the whole Scandinavian region) enjoys a similar level of health to that of the general population (10), (14). It is not immediately clear why Sweden and other Scandinavian countries would have such positive health outcomes for their indigenous populations. Health policy in Sweden seems to be focussed upon accessibility and affordability of health care with more recent focus upon improved choice of health care provider (31). How (or whether) this plays a role in the state of indigenous health is unclear and deserves further investigation.

4.2 Limitations of the study
While the results for this thesis are encouraging with regards to the health of the indigenous population, and are in general, consistent with other studies which have indicated there is little difference between the health of the Sami and non-Sami groups in Sweden, there are many serious limitations to this study.

4.2.1 The role of Sami and non-Sami ethnicity
The definition of Sami ethnicity in this research paper differs slightly from the definition that is generally used for the recognition of indigenous populations in other nations. According to the United Nations, a person who identifies as part of a particular group is generally considered to be part of that group (1). The definition used in this thesis, in the process of creating a Sami group for study, differs slightly from the UN definition. Initially our definition includes self-recognition of ethnicity through using electoral records and reindeer herding records to identify those who identify themselves as Sami sufficiently to publicly identify themselves as such. We then shift our definition to include those who are biologically related to those initial people. Therefore our definition of Sami includes both a component of self identification and biological determinism of ethnicity. A biological definition of ethnicity can be of use if searching for conditions which have a strong genetic base and for which one ethnic group may have a genetic predisposition, but, as these conditions are less common
than conditions associated with lifestyle (which reflects potential inequities between groups) a biological definition of ethnicity can be limited. In this thesis, using a definition of Sami which includes a biological component has increased the sample size substantially but the trade off for this has been a degree of uncertainty as to whether those identified as biologically Sami carry out a “normal” Sami lifestyle. A counter argument to this criticism though, would be that it would be reasonable to assume that someone who is directly related (i.e. a sibling, child or parent) to someone who identifies as Sami would also be likely to self-identify as Sami and therefore be likely to carry out a Sami lifestyle.

The non-Sami group would represent a heterogeneous selection of people from multiple ethnic and racial backgrounds. In this sense it is important to remember that we have not merely compared one ethnic group to another but instead have compared one single group to an amalgamation of all other ethnic groups in Sweden. There is no evidence to support an assumption that the ethnic makeup of the non-Sami group represents the ethnic makeup of Sweden in general. Future research would benefit from being able to differentiate ALL study participants by ethnicity in order to further understand if any clear difference in disease rates exists between any two or more ethnic groups.

The size of the Sami population created for use in this thesis is twice of that provided by the Swedish Ministry of Agriculture (15). This indicates the difficulty in properly establishing the true size of the Sami population in Sweden. This might mean that the data in this thesis overestimates the size of the Sami population in Sweden and therefore is unable to provide an accurate picture of Sami health (the same criticism can also be levelled at other research performed using this same dataset). Alternatively, it may be that the Swedish Ministry of Agriculture has significantly underestimated the true population of Sami in Sweden. If this is the case, then there might be wider implications for the accurate representation and portrayal of Sami people throughout Scandinavia.

4.2.2 Generalisability to general population
As the data sets gathered were from groups visiting health centres and hospitals, it would be unadvisable to compare outcomes with the general population. This especially applies to the measures of prevalence and incidence which can only be said to apply to those who have either been seen as a part of the VIP or have been admitted to hospital. The most important aspect of this thesis is the use of the ratios, which is able to give a reflection upon the differences between Sami and non-Sami groups. This in itself may not be a truly accurate reflection of the general population though as it is assuming that both Sami and non-Sami groups have equivalent access to medical services, which may or may not be true, but cannot be established for certain. While efforts were made while constructing the study groups to match for geographic location (which would at least indicate the proximity of medical services) it is impossible to know anything about the health status of those who did not seek medical care.

4.2.3 Data source
This thesis has been very reliant upon proper documentation and keeping of records. A failure to correctly record a diagnosis of diabetes on any one patient would lead to notable changes in the results. Inconsistencies in the different records being kept, as well as the imprecision of the use of terms such as “insulin dependent” and "non-insulin dependent"
made it difficult to give a single and precise definition of diabetes for use in this study. Being able to clearly separate people into the various subtypes of diabetes would have been ideal in this study but, due to the imprecision of the records, was unable to be done. Given that type 1 diabetes usually affects the young, and type 2 the old, we could have assumed that all within certain age groups had those types. The stratification by age done in this study could certainly be used to that effect. Given that type 1 diabetes usually occurs before the age of 30 and type 2 diabetes usually after, stratification into under and over 30 age groups could have been performed as a proxy for type 1 or type 2 diabetes. However, this is unreliable as type 1 diabetics do grow to become adults and type 2 diabetes is gradually increasing in frequency among the young.

There is also the possibility that differing levels of admissions to hospital for different causes would impact the findings with regards to diabetes. For example, if one group were to have substantially higher admissions with cancer or stroke than another, this might "dilute" the findings for diabetes. Research thus far on Sami though, has indicated that assuming a similar rate of hospital admissions between groups for diseases should be a reasonable assumption given that rates of cancer and cardiac disease should be roughly the same between groups. We do note the slightly higher rate of accidents and suicides among the Sami group, which might artificially reduce the recorded prevalence of diabetes but we remain relatively confident that this would represent a small enough proportion of people to not have any major bearing on the study's findings.

The data source used in analysis is of course, an amalgamation of data from hospital and community sources. The hospital group is much larger than the VIP group and covers all age ranges while the VIP group only includes those of middle age and higher (although is likely to be representative of the general population within those age ranges). The combination of these two datasets has led to improvement of the power of the study but does lead to some limitations in the study with regards to the generalisability of the findings. An alternative would be to carry out separate analyses of each dataset. This had been done at the level of the overall prevalence of diabetes and had been displayed in Table 2.

A further difficulty with the data source was that it was limited in the scope of available data. While there was information regarding various diagnoses there was limited information on lifestyle factors clinical history, medical examination findings and laboratory tests. Many of these, such as diet, body mass index, blood pressure and cholesterol levels have an important role in the development and complications of diabetes and would have provided valuable information if they had been available.

4.2.4 Sample Sizes
In the investigations of consequences of diabetes we found that there appeared to be no statistically difference between Sami and non-Sami with regards to complications. It is worth noting that several of the findings did come relatively close to reaching statistical significance (namely, PCD, heart disease, "multiple" and stroke) and that it is possible that the failure to reach statistical significance may have more been a feature of the relatively low numbers of persons involved in those aspects of the analysis than a true lack of statistical significance. This is supported by noting that PCD, heart disease and stroke all refer to disorders of a similar body system, the vascular system, which is what would be expected if a true difference
existed. Further research with larger sample sizes may reveal a statistically significant finding.

4.3 Future research
While no statistically significant difference has been observed overall, there are several interesting findings in this thesis which need some follow-up.

This thesis has indicated that there is no appreciable difference between an indigenous population and its colonial counterpart with regards to diabetes and its consequences. This finding is at odds with the international state of indigenous population which generally finds indigenous groups severely disadvantaged. The Swedish health system is comparable in function to the New Zealand, Australian and Canadian systems, yet seems to have remarkably different outcomes with regards to indigenous health. There would be great value in further investigating the manner in which Sweden acts towards and treats its indigenous populations in an effort to establish whether or not there are "lessons" that can be taught to the international community.

As discussed, there is a high level of reliance upon hospital data for the proper understanding of diabetes. Any difference in the availability or usage of hospital services would have immediate impacts upon the results of this study. It would be of benefit to investigate whether there was any notable difference in the availability and accessibility of hospital services between the Sami and the non-Sami population. Theoretically there might be a difference, given that the Reindeer herding Sami are likely to be more isolated and rurally based than their non-Sami alternatives.

Further on from the limitation of the data source, it would be of great benefit to be able to investigate the general community as a whole. A population based study, focussing on differences in diabetes at the community level (using clearly defined definitions of diabetes and its subtypes) would assist in confirming or refuting any of the major findings in this study.

Given the interesting findings regarding the under ten group, further study investigating this finding of increased hospital admission is definitely required. It would also provide a good opportunity to further investigate type 1 diabetes and try to establish more clearly whether or not a difference exists between Sami and non-Sami after the excess hospital admissions have been accounted for.
5. Conclusions

This thesis has made some interesting findings regarding diabetes among the indigenous population of Sweden. It appears that, while diabetes remains a health problem of significant proportion in Sweden, there does not appear to be any clear difference in the prevalence or consequences of diabetes between the indigenous Sami population and the non-Sami population. Additionally, there appears to be no appreciable difference between the Reindeer Herding Sami and the non-Reindeer Herding Sami with regards to the prevalence of diabetes. Observing the incidence of diabetes and death among diabetics has revealed no difference between Sami and non-Sami.

Despite these encouraging findings, there remain several limitations of this thesis largely related to the identification of people based upon their ethnicity and the reliance upon often inconsistent records. Further research to further clarify these findings, as well as understanding how they came to exist is warranted.
6. References


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