

After fifty years we now have a register of the one disease that claims most lives

## Finally a Norwegian registry of myocardial infarctions

The post-war years witnessed a dramatic increase in ischaemic heart disease. From 1947 to 1960 its prevalence quintupled, and this gave rise to major concerns. The government appointed a committee, which in 1963 delivered its recommendations regarding the correlation between the consumption of fat in our diet and cardiovascular disease (1). The committee proposed dietary changes that could prevent the disease, but also suggested that the authorities should monitor the population's morbidity and mortality from cardiovascular disease. The idea of registering cardiovascular diseases was proposed at the very establishment of the Norwegian Council for Cardiovascular Disease in 1955, and in 1961 the council entered into a cooperation agreement with the Cancer Registry of Norway (2). Disagreement later arose on the location as well as the nature of the registry. Only in 2010 did the Storting decide that a nationwide registry of personally identifiable data should be established. Since 1 January 2012 all hospitals have an obligation to report health data on patients admitted with a diagnosis of acute myocardial infarction to the Norwegian Myocardial Infarction Registry. In this issue of the *Journal of the Norwegian Medical Association* we can read the first article from this registry (3).

The lethality of a disease is a function of the risk it involves and the effectiveness of the treatment provided. Changes in incidence reflect changes in the causal factors in the population. In the 1960s, mortality from heart infarction was a good substitute for incidence, and the considerable geographical variations that could be observed between Finnmark county, which headed the list along with Oslo, and Sogn og Fjordane county, which had stabilised at the lowest level, most likely reflected real differences in the risk of disease (4). The treatment provided was in principle without any effect, and luck and coincidence chiefly determined whether the patients would survive and avoid becoming part of the statistics.

There was also an awareness, however, that statistics on causes of death have their limitations. A clinically based registry linked to a registry of causes of death is required to describe incidence, mortality and treatment effects.

The main purpose of the Norwegian Myocardial Infarction Registry is to collect and present data that can be used to improve the quality of the treatment provided to patients with myocardial infarction in Norway. An important objective is to provide better and comparable information on the number and treatment of myocardial infarctions in Norwegian hospitals and thus help provide good treatment services and clinical pathways. The treatment of patients with acute coronary disease has been developed into a sophisticated clinical and technological activity. Algorithms and guidelines intended to ensure the best possible outcome for each patient have been prepared. The Norwegian Myocardial Infarction Registry will allow monitoring of the extent to which such guidelines are being followed up, and thus ensure equality of treatment all over the country. The precondition is that the data entered into the registry are valid, and the data producer and the central recipient both have a substantial responsibility. Jortveit and collaborators have studied the year 2013, the first year with near-complete data (3). Some hospitals have failed to meet their obligations, and the reporting remains somewhat uneven. This reduces the value of the registry, making it difficult for individual hospitals to evaluate their own

treatment outcomes. The methods used for data registration still vary between the hospitals, and this issue ought to be addressed in the future. In other respects, the data sets for each individual patient are nearly complete in terms of risk factors, treatment and previous illness. At the same time, it is a paradox that smoking, which is the variable that has the greatest effect on the subsequent course (in the smoker), is also the most poorly registered variable.

One of the most important findings in the article is that the 30-day mortality is approximately identical all over the country. Approximately one in ten patients admitted with acute myocardial infarction had died within 30 days. This should be evidence that Norwegian hospitals do well in international comparisons. At the same time, the authors point out that there is uncertain information regarding the time that has elapsed from the onset of symptoms to hospitalisation. If this is not taken into account, a nearly identical lethality may conceal differences in treatment outcome between different hospitals. As a rule, it is estimated that two-thirds of those who die within 30 days of an acute heart infarction do so outside hospital. If this proportion varies from one region to another because of distances and transport opportunities, the mortality risk will vary among those who are admitted to hospital. For this reason, we should seek to obtain better information on the time from onset of symptoms to initiation of treatment. Another matter is that an improvement in the survival rate in hospitals will mean that deaths outside hospitals will have a relatively greater importance (5).

Since the Norwegian Myocardial Infarction Registry is a hospital-based registry it does not provide an exhaustive overview of the frequency of myocardial infarction in Norway. We will obtain information on changes in the incidence of myocardial infarction, and not least in its lethality, from the Norwegian Cardiovascular Disease Registry, in which the Norwegian Myocardial Infarction Registry is included as one of several quality registries along with the Cause of Death Registry. In Sweden, it has been shown that the 28-day mortality for all patients with infarction seen as a whole, both those admitted to hospital and those who die outside hospital, varies from 20% to somewhat more than 40%, depending on their age at the first infarction (5). In other words, far more than one in ten succumb to their first infarction.

In addition to monitoring of quality, the registry can also be used for specific research purposes, as an end-point registry in clinical trials or to search for possible interactions and adverse effects by linking it to other registries. A recent review article of the epidemiology of coronary disease in the USA situates such registries in a wider perspective (6). The development over time of cause-specific mortality and lethality must be seen in the context of new knowledge on development of atherosclerosis, risk factors and treatment interventions. Longitudinal studies of clinical pathways and development are necessary instruments to ensure an optimal treatment of the patients. In a few years we may start to derive serious benefit from the Norwegian Myocardial Infarction Registry.

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