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Registers in cardiovascular epidemiology

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INTRODUCTION, OBJECTIVES AND OUTLINE

Cardiovascular diseases kill over 50,000 people each year in the Netherlands, more than any other group of diseases.¹ They are responsible for one fifth of all disability adjusted life years, a measure that combines both years of life lost and years lived in disability rather than in full health.² In a report on the cost of diseases in the Netherlands, cardiovascular disease accounted for about 11% of all health care costs in 1994, ranking second only after the group of mental disorders.³ Cardiovascular disease constitute a major burden both from a patient, a public health and an economic perspective.

Cardiovascular disease has not always been so dominant. At the beginning of the 20th century, infectious and pulmonary diseases were the major causes of death.⁴ Since then cardiovascular disease have become more prevalent and took more and more lives. Mortality from cardiovascular disease reached its peak in the early 1970s, and the whole Western world was concerned about what was by then called the 'epidemic' of cardiovascular disease. Large research projects were started to gain knowledge about the mechanisms of cardiovascular disease and ways to reduce its impact. These efforts were successful. Most Western countries experienced a welcome decline in cardiovascular mortality, especially from coronary and cerebrovascular causes.

The case of cardiovascular disease illustrates how major changes can emerge within a relatively short period. Registers have played and will continue to play a major role in describing the occurrence of diseases within and across countries and to monitor changes over time. The last two decades saw an explosion of registers in health care, many of them with an administrative background rather than a disease-specific interest. Registers have a natural attractiveness to epidemiologists and, consequently, they are increasingly being used. Their use is no longer restricted to research with a typical public health perspective, but extended to clinical research as well. Although attractive, the use of registers poses many difficulties.

OBJECTIVES

This thesis explores the use of registers in cardiovascular epidemiology. We look at this central theme from two perspectives. Monitoring cardiovascular disease in the Netherlands by means of national registers is our first perspective. We examine trends over time for different cardiovascular diseases based on national hospital discharge and mortality data. For this perspective, the following objectives apply:

- ◆ *To assess the burden of cardiovascular disease in the Netherlands, as measured by the number of hospital admissions and deaths caused by different cardiovascular diseases*
- ◆ *To describe trends over time in the number of hospital admissions and deaths due to different cardiovascular diseases and to provide possible explanations for the observed changes*

In the second perspective, our focus is on the role of registers in epidemiological research. We compare the data requirements of various types of epidemiological research with the actual data characteristics of register data, and elaborate on their interaction. The following objectives apply:

- ◆ *To examine the possibilities and limitations of register data, in particular hospital statistics and mortality data, in describing and explaining trends in cardiovascular disease*
- ◆ *To give an overview of the potential sources of problems in epidemiological research involving registers, and to derive general guidelines for the employment of register data in various types of epidemiological research*
- ◆ *To describe new possibilities to extend the role of registers in epidemiological research, in particular the prospect of using register data in longitudinal analyses by employing medical record linkage techniques*

OUTLINE

Chapter 1 provides an overview of the role of registers in epidemiological research. It discusses the various sources of problems when registers are used to answer different types of research questions.

The next four chapters are all empirical studies in which registers have been used to study cardiovascular disease in the Netherlands. Trends in the number of hospital admissions and deaths caused by different cardiovascular diseases are examined and possible explanations explored. Stroke is analysed in *chapter 2*, aneurysms of the abdominal aorta in *chapter 3*, heart failure in *chapter 4*, and the total group of cardiovascular disease in *chapter 5*.

Chapter 6 introduces the principles of medical record linkage and its applications. The aim in record linkage is to connect information of the same person recorded at two different sites or at two different times without the help of a unique identification number. The added value of linked data sources revealing longitudinal information is illustrated in *chapter 7*. A cohort of patients with acute myocardial infarction is traced over time within and across registers with the help of record linkage to identify readmissions and death within this cohort.

Chapter 8, by way of encore, examines the current use of direct standardisation in the medical literature. Direct standardisation, as applied in *chapters 2 through 5*, is a popular way of addressing differences in confounding factors in studies examining trends over time, such as the changing age structure of the population.

The *general discussion* elaborates on the two perspectives. The changing pattern of cardiovascular morbidity and mortality, as described in *chapters 2 through 5*, is annotated and emerging topics of interest are indicated. The pros and cons of register data in studies analysing trends over time and beyond are discussed. The outline of a current pilot study is given, in which hospital discharge data and mortality data are linked on a national level, an illustration of the extended use of registers in epidemiological research.

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