

SELECTION OF THE PRINCIPAL CAUSE OF DEATH

**Studies on the basis of mortality statistics
for rheumatoid arthritis**

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Huddinge 1985

III

This thesis is based on the following papers, referred to in the text by their Roman numerals:

- I. Lindahl, B.I.B.: On the selection of causes of death: An analysis of WHO:s rules for selection of the underlying cause of death. In Health, Disease, and Causal Explanations in Medicine, (eds.) L. Nordenfelt and B.I.B. Lindahl, D. Reidel Publishing Company, Dordrecht, 1984, pp. 137-152.
- II. Lindahl, B.I.B.: The reliability of Swedish mortality statistics for rheumatoid arthritis. Scandinavian Journal of Rheumatology 13:289-296, 1984.
- III. Lindahl, B.I.B. and Allander, E.: Problems in the classification of cause of death diagnoses affecting the reliability of mortality statistics for rheumatoid arthritis. Journal of Chronic Diseases, in press.
- IV. Lindahl, B.I.B.: The causal sequence on death certificates: Errors affecting the reliability of mortality statistics for rheumatoid arthritis. Journal of Chronic Diseases, in press.
- V. Lindahl, B.I.B.: In what sense is rheumatoid arthritis the principal cause of death? A study of the national statistics office's way of reasoning based on 1224 death certificates. Journal of Chronic Diseases, in review.

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1. INTRODUCTION

The national cause-of-death statistics, as well as the computer register on which these statistics are based, are principal sources for medical and social science research. It would not be presumptuous to say that no source of medical information has had, and still has, a greater significance to the formulation and testing of hypotheses in the search for health risk-factors. Information on causes of death are widely used in the evaluation of effects of treatment and preventive measures taken by the health care and other community services, and for establishing goals and overall policies. The cause-of-death statistics is one of the most widely used indicators of the morbidity in a population, and is therefore also vital for international comparisons.

Considering the wide utilization of the cause-of-death register and statistics for various scientific purposes, the number of validity studies has been small. In particular, very little attention has been paid in previous studies to the physicians' compliance with the official rules and concepts governing the completion of death certificates, and to the coders' medical interpretation problems when registering the diagnostic information from death certificates.

Acquaintance with the problems and actual use of the international instructions for the cause-of-death certification (68) and for the coders' processing of the death certificates (62,64), is vital not only to the persons responsible for the quality of the statistics, but also, as Hofsten (50) points out, to the users that have to interpret the data of the register and statistics.

In a special search, performed by Gittelsohn et al. (38), 128 published and unpublished papers in English on the quality of cause-of-death statistics throughout the world from 1958-1980 were identified. The reports were located through the current bibliographic sources, the Medical Literature Analysis and Retrieval System (MEDLARS) between 1966-1977, Index Medicus 1958-1980, and through letters to all the US State health department statistical offices, to selected departments of epidemiology in medical schools and schools of public health, and to workers in vital statistics in national and international agencies.

A majority of the studies were concerned with the diagnostic evidence supporting cause-of-death diagnoses. The two most frequent types of studies were (each study is here included in only one of the categories): (a) The causes of death on the death certificates are compared with diagnoses on clinical records and/or autopsy reports, 38 studies (30%)¹; and (b) The causes of death based on pre-mortem diagnoses are compared with diagnoses based on necropsy or autopsy, 21 studies (16%)². Most of the remaining 69 studies represent various approaches to the problem of assessing the accuracy or degree of completeness of the cause-of-death diagnoses on certificates or in the official statistics, e.g., by comparing different sources of information, or by investigating certifiers' diagnostic habits. The dominant interest in diagnostic evidence appears also from another comprehensive overview by Alderson (2).

Deficiencies in the Swedish cause-of-death statistics have been pointed out in various contexts in recent years (4,10,11,13,33,34,80,82), and studies have been initiated by the Swedish National Central Bureau of Statistics (NCBS) in order to improve the quality of the statistics (39-43,51).

Only one of the recent Swedish studies (51) investigates the certifiers' compliance with the official rules for making out of the certificates. The material of this study consisted of 994 randomly selected death certificates from 1979, i.e. 1.1% of all 91 054 deaths in Sweden that year. Some of the results from this study of relevance for the present thesis will be accounted for in what follows.

A comparison between Swedish and Norwegian coders' registration of the causes of death from Swedish certificates has been performed (40,42,43). The material consisted of 5 975 certificates from deaths in January 1976. The comparison showed that different codes were selected for the underlying cause of death in 1 106 (18.5%) of the cases. Most of the disagreements, 582 cases (53%), were due to diverging interpretations of the World Health Organization (WHO) rules for cause-of-death coding, issued in the International Statistical Classification of Diseases, Injuries, and Causes of Death (ICD) (62). The rest were attributed to "coding errors", 410 cases (37%), and "terminological differences or uncertainties", 114 cases (10%) (42; my translation).

1.1 Aims of the thesis

The present thesis focuses on the certifiers' and coders' adherence to the official instructions for cause-of-death reporting and registration, and analyses some of the central theoretical conceptual and causal problems inherent in these instructions and in the different steps of the data collecting process for the national cause-of-death statistics.

The point of departure of the present thesis was an observed 2.7-fold increase in mortality for men and a 3.0-fold increase for women attributed to rheumatoid arthritis (RA) as the underlying cause of death in the official

statistics for Sweden between 1971 and 1975 (18,19). (The observed increase for women was followed by a decrease in 1976-82, whereas for men the statistics show an increase throughout the 1970s and a decrease at the beginning of the 1980s. (17)).

The aims of the thesis were:

- (i) To explain the observed increase in mortality attributed to RA as the underlying cause of death;
- (ii) To identify physicians' inadequacies when making out death certificates, and assess how these inadequacies influence the coders' registration of the causes of death;
- (iii) To identify major interpretation problems facing the physicians and coders in their reporting and registering of causes of death for vital statistics' purposes, and assess how these problems influence the reliability of mortality statistics.

1.2 RA as cause of death

It is well known that the estimation of RA prevalence involves several methodological problems, which makes comparisons between different studies difficult. Hochberg (48) concludes, however, in an overview of studies on RA that the prevalence of definite RA is approximately 1.0 per cent in most Caucasian groups (cf. 55). Hochberg's overview also supports the general view that the prevalence of definite RA is about two to three times greater in females than in males (cf. 55): The prevalence of definite RA increases with increasing age in both sexes, approaching 2 per cent in males and 5 per cent in females over the age of 55 (48). The prevalence of classical and definite RA in Sweden has been estimated from a population of 39 418

persons to be 0.93%, (0.60% for males and 1.30% for women) (45). According to another estimation (3), based on a Swedish population of 15 268 persons, the crude prevalence for RA was 2.7%.

Several studies show that patients with RA have a reduced life expectancy compared with the general population (4,5,12,20,23,26,54,56,70,77-79,84). (For an overview see (1,24)). It has been concluded, however, that RA is on balance an essentially benign, nonfatal disease (1), and that the increased mortality recurrently observed is associated only with more severe forms of RA and/or complications of either the disease or its treatment (1,78).

Thus, besides the doubts concerning the applicability of the observed increased mortality for RA patients to cases of RA in general, there is also an uncertainty regarding the causal principality of RA even in the cases of more severe forms of RA.

A key question is whether death in these cases should be attributed to RA itself as the principal cause, or ascribed to complications of RA or to adverse effects of its treatment. This is a crucial medical question. Ultimately it is the purpose of the explanation that decides which of these causes should be selected as the principal one. For example, as Bohrod (9) points out, for a scientific purpose the physiologic event which caused a person to die at a particular time might be selected as the principal cause (i.e. often the immediate cause of death), whereas for a statistical purpose it is generally the first disease or link in the fatal sequence which is pointed out, and for a legal purpose it is the interest of legal responsibility that guides the choice of the principal cause.

In most cases of RA the disease is not mentioned on death certificates. The degree to which RA is entered on the death certificate varies from different studies. Linos et

al. (57) identified RA on death certificates for patients with RA in only 6% (8/143), Allebeck et al. (4) in 11% (9/84), Atwater et al. (7) in 45% (36/80), and Benn et al. (8) in 50%. When RA is entered on the death certificate it has been found to be certified as the underlying cause in between 17-18% (Paper II) and in 12% (8).

1.3 Problems in the data collecting process for the cause-of-death register and statistics

In Sweden the nationwide cause-of-death statistics dates back to 1751. The statistical accounts have become more and more comprehensive, both concerning the number of causes accounted for in the tables and regarding the amount of causes registered per individual. The quality of the data has gradually improved due to greater demands for professional medical knowledge when establishing the causes of death.

Since January 1st 1971 the causes of death of Swedish citizens deceased in Sweden or abroad must always be certified by physicians, and the diagnoses should be based on medical examination (81). Before 1971 the causes-of-death diagnoses could be also based on information from non-physicians. The death certificates are sent to the NCBS through the parish authorities where the deaths are first registered. In the processing of the certificates, the NCBS makes controls with other sources of information, such as the county registers, police records and documents obtained from the medical clinics.

Guidance for physicians and coders when dealing with the medical, taxonomic, semantic, and causal theoretical problems of certifying and registering the causes of death is provided by the international instructions for physicians (68) and coders (62,64) issued by the WHO. It should also be noted that the coders in Sweden are trained nurses.

When it is obvious that the death certificate has not been made out in accordance with the official instructions (68), and the conditions cannot be registered in the way they have been recorded on the certificate, the coder should seek further clarification of the certificate from the certifier (62,64). In cases when such information cannot be obtained, the coder is left to register the reported diagnoses solely from his own medical interpretations and by applying the ICD-rules (62,64). These rules aim at a medically and causally correct interpretation of the physicians' cause-of-death statements, and at optimizing the usefulness and precision of the statistics (62,64).

The major problems of the data collecting process are briefly accounted for in the following.

1.3.1 Epistemic quality of the diagnoses

Although the epistemic issues, i.e. the questions concerning on what kind of knowledge the cause-of-death diagnoses are based (e.g. pre-mortem or post-mortem observations, clinical or autopsy examination, medical documents etc.) are central to the evaluation of the quality of the statistics, they are beyond the scope of the present thesis. As mentioned earlier, questions regarding the evidence for cause-of-death diagnoses have hitherto attracted the greatest interest in studies pertaining to the quality of the statistics (2,38).

1.3.2 Amount of diagnostic information

Until 1965 only one cause of death (the principal cause) was tabulated from each certificate (16), and this despite the fact that secondary or contributory causes have been asked for on the form, besides the principal cause, for

more than a century (53). Today up to seven causes are tabulated from each certificate: the underlying cause and six others, either complications or contributory causes.

The amount of diagnostic information to be entered on the certificate is further limited by the design of the current death certificate form. The diagnostic part of the Swedish death certificate is designed in accordance with the WHO recommendations (Figure 1).

Figure 1.

INTERNATIONAL FORM OF MEDICAL CERTIFICATE OF CAUSE OF DEATH

CAUSE OF DEATH		Approximate interval between onset and death
I		
<i>Disease or condition directly leading to death *</i>	(a) due to (or as a consequence of)
<i>Antecedent causes</i>	(b) due to (or as a consequence of)
Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last		
	(c)
II		
<i>Other significant conditions contributing to the death, but not related to the disease or condition causing it</i>	{
<small>* This does not mean the mode of dying, e.g., heart failure, asthenia, etc. It means the disease, injury, or complication which caused death.</small>		

(Reproduced from (64)).

On this form, which came into use in Sweden in 1951 (14), the sequence leading from the underlying cause to death should be accounted for by one diagnosis on each line (from line c to a) in Part I of the certificate. If the sequence contains more than three conditions, extra lines may be added in Part I. The underlying cause of death should be stated on the last used line. If the course of events leading to death can be completely described by a single

diagnosis, only line (a) needs to be used in Part I. In Part II other contributory causes may be entered (62,64,68).

More than one diagnosis on each line in Part I have been shown to occur on 4.5% of Swedish death certificates, and on 4.6% of the certificates only a single diagnosis which did not completely describe the fatal course of events had been entered in Part I (51).

The amount of diagnostic information on RA death certificates are dealt with in paper IV.

1.3.3 Selection of causes

The international instructions for physicians (68) and coders (62,64) determine what kind of conditions may be reported on the certificate. 'Causes of death' are defined as "all those diseases, morbid conditions or injuries which either resulted in or contributed to death and the circumstances of the accident or violence which produced any such injuries" (62,64,68). The WHO concept 'causal sequence', refers not only to sequences "with an etiological or pathological basis" but also to sequences "where an antecedent condition is believed to have prepared the way for the more direct cause by damage to tissues or impairment of function, even after a long interval" (68; cf. 62,64). Modes of dying (e.g. anoxia, asphyxia, asthenia, collapse, exhaustion, heart failure, respiratory failure, and syncope), and symptoms (see ch. XVI in (62)) should not be reported on the certificate, since they are by definition not causes of death (62, p. 415; 64, p. 699; cf. 67, pp. 6,15 and 68, pp. 7,25). The only exceptions to this rule concerning modes of dying are cases of perinatal death when this "was the only fetal or infant condition known" (68, p. 25).

1.3.4 Causal classification

The causes are classified on the certificate into 'the direct cause', 'the intervening antecedent cause', 'the underlying cause' and 'other significant conditions contributing to the death' (62,64). The first three conditions form the principal course of events: the underlying cause giving rise to the intervening cause, giving rise to the direct cause, and this in its turn causing death.

'The underlying cause of death' is defined as "(a) the disease or injury which initiated the train of morbid events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury" (62,64,68).

The contributory causes should be such that they "unfavourably influenced the course of the morbid process, and thus contributed to the fatal outcome, but which [was/were] not related to the disease or condition directly causing death" (62,64,68). Thus, they are not supposed to be "directly part of the fatal sequence" (68). Their relation to the main sequence was to be even more restricted according to the first edition of the instructions for physicians, which implies that they were "not related to the direct or antecedent causes" (67; my italics). This seems to imply that the contributory causes should not be causally related to any condition in the main sequence.

The contributory causes should be entered in order of significance (68).

In paper II the physicians' causal classification is compared with the NCBS' causal classification.

1.3.5 Interval between onset and death

In order to facilitate the coders' interpretation of the causal sequence, the interval between the presumed onset of the conditions reported and death is asked for on the certificate (Figure 1). The instructions provide that this information "should be entered where known, even approximately, or 'unknown' should be written" (68).

Information on the interval between the onset of the causal conditions and death has been found to be missing completely or in part in 72.4% of Swedish certificates (51).

The coders' causal interpretation problems, due to lack of information on the duration of the causes reported on RA death certificates, are further commented upon in paper IV.

1.3.6 Terminology

The coders' problems of registering the causes of death are aggravated by the fact that the expressions on the death certificates are in Swedish, Latin or, as in most cases, a Swedish-Latin mixture, whereas the ICD used by the coders is in English. For example, the not uncommon diagnostic expression "Hjärtsvikt" can be interpreted either as heart failure 782.4 or heart decompensation 429.0. If it refers to heart failure, this condition should be avoided since it is a mode of dying, but if it refers to heart decompensation, it can be registered according to the ICD. Other examples appearing on death certificates are "Respirations insufficiens" (respiratory insufficiency) "Cirkulationsrubbning i hjärnan" (circulatory disorder of brain), and "Blodpropp" (clot of blood). The latin expressions are often grammatically incorrect or the endings ignored by the use of abbreviations (Paper III).

The problems with the Swedish diagnostic expressions are so common that the request for a Latin translation of Swedish expressions on death certificates is among the standard questions printed on the NCBS' queries to the certifiers (75)

The choice of terminology on the certificate has been a bone of contention for more than a century. It is interesting to note that already when the demand for the causes of death to be certified by physicians was first subject of legislation in 1860 (52), involving then only the major cities, and when the idea to transfer the task of the nationwide collection and registration of causes of death from the clergymen to special registrators was first contemplated, attention was also drawn to the necessity of a uniform terminology (36). As a guidance for the making out of the death certificates a special diagnostic nomenclature in Swedish and Latin was compiled by the Swedish Society of Medical Sciences (36,53). The number of diagnostic expressions to be used was then fairly manageable. The nomenclature contained 115 diagnoses (with 21 subcategories), including also "Rheumatism. Rheumatismus acutus vel chronicus" (53). Today, the classification contains 999 main categories (the three-digit level) and thousands of subcategories (the four-digit level) (62,64).

Physicians' choice of diagnostic terminology and its consequences for the coding of causes of death are treated in paper III.

1.3.7 Semantic precision

The certifier is requested to "record diagnoses as precisely as the information permits, incorporating relevant details from histological or autopsy reports" (68).

The rules for the coders concentrate on the precision of the diagnosis for the underlying cause of death. Four rules in particular aim at improving the degree of detail of the diagnosis, rules 4, 5, 7, and 8 (62,64). Rules 4 and 5 state that diagnoses for symptoms and ill-defined conditions (ch. XVI in (62,64)) should be disregarded in the registration of the underlying cause of death, unless information on these conditions modifies the coding of the preferable diagnosis. Rule 7 concerns cases when the diagnosis for the underlying cause can be linked with another diagnosis on the certificate into one code. This more inclusive code, containing both conditions, should then be used in the registration of the underlying cause of death. Rule 8 deals with the specificity of the diagnosis for the underlying cause in general, and states that out of two diagnoses referring to the same condition, the one providing more information about the site or nature of the condition should be selected, even if this more informative diagnosis was not reported on the last used line in Part I of the certificate.

The coders' application of the semantic ICD-rules when registering the causes of death from RA certificates is treated in paper V.

1.3.8 Medical classification

Though the medical classification today is not, as in the 19th century, primarily a task of the certifier, but of the coder, it is still necessary that the diagnostic distinctions and the degree of semantic precision of the diagnoses entered on the certificate comply with the ICD. The coder must be able to find a code in the ICD for the conditions referred to without the need for medical speculations.

The problems of medical classification when RA is involved are analysed in paper III.

1.3.9 Further clarification

Supplementary information from the certifiers regarding incomplete or vague diagnoses are obtained by the NCBS in approximately 1.5% of the certificates processed every year (51,75).

The information most commonly asked for is (i) the cause of a reported injury; (ii) the condition that brought about a reported surgical operation; (iii) the nature of a reported tumour (malign/benign, primary/secondary), and/or its anatomic site; (iv) the cause/aetiology of a condition reported, in order to establish the underlying cause of death; (v) the latin translation of a Swedish diagnostic expression used; and (vi) the final version of a preliminary certificate (75).

The clarification of RA death certificates sought by the NCBS are examined in paper V.

2. MATERIAL AND METHODS

2.1 Definitions

The following definitions are used in the thesis.

Diagnosis = def. a statement referring to a cause of death.

Diagnostic expression = def. a term or a set of terms used for a statement referring to one or several cause(s) of death.

Physician's underlying cause of death = def. each of the conditions referred to by the diagnoses on the last used line in Part I of the certificate.

The NCBS' underlying cause of death = def. the condition(s) referred to by the ICD-code(s) on the first line in the special square for the NCBS' notations on the certificate.

(In cases of injuries the NCBS register the underlying cause of death by two ICD-codes: An N-code for the nature of the injury and an E-code for the external cause).

2.2 Collection of RA death certificates

Paper II-V are based on one and the same material of death certificates.

For a larger study on the mortality of rheumatic diseases, involving also systemic lupus erythematosus (SLE) we collected all Swedish death certificates for the years 1971 and 1975, where "rheumatoid arthritis and allied conditions" (code 712 in the 8th revision of the ICD) and "diffuse diseases of connective tissue" (ICD 8 code 734) were registered by the NCBS in the official statistics as the underlying cause of death, complication or contributory cause of death. 1 541 such death certificates were identified. Of these, 1 224 were RA death certificates, i.e., certificates where RA (ICD 8 code 712.3) was registered by the NCBS as the underlying cause, complication or contributory cause of death. This RA population contained in 1971: 171 men and 413 women, and in 1975: 159 men and 481 women.

2.3 Coding

The NCBS' notations concerning which diagnoses had been registered for tabulation, which ICD 8 codes had been used, and in what order of causal priority they had been registered, was coded in its entirety. All information was coded as originally written on the death certificates and computerized, taking into account demographic data, date of birth and death, place of death, hospital, clinic, medical speciality, form of medical examination, certifier's title and age, duration of causes, sequences of causal conditions and the whole spectrum of different diagnostic expressions used.

In order to include all the physician's diagnoses, up to 16 "underlying causes of death and complications" in Part I of the death certificate and up to 13 "contributory causes" in Part II could be coded from each certificate. Space was reserved for 4 diagnoses from each line in Part I, (a) to (c), as well as for an extra line (d). The causal relations between the underlying causes and complications were also coded, independently of where (on which line, etc.) they were mentioned in the medical Part I of the certificate (see Figure 1). The diagnoses were registered en clair, exactly in the wording used on the certificates. Each diagnosis was given a unique code and was also coded according to the 8th revision of the ICD. Special codes were added to (i) diagnoses for which no ICD code could be found, and (ii) when the diagnosis could be coded by several ICD codes. In the latter case, the additional separate code indicates which, if any, of the ICD codes the ICD give priority to.

Physicians' non-underlying RA diagnosis was coded according to whether this condition could be accepted as the underlying cause, according to the ICD. Physicians' non-RA underlying diagnoses were coded according to whether the condition could be rejected as the underlying cause,

according to the ICD. The qualifications used for this coding, (A-M, accounted for in the following sections 2.3.1 and 2.3.2), were drawn partly from relevant Selection rules and Modification rules of the ICD (qualifications A-D, F-I, M), partly from Rules embedded in the ICD text or mentioned in the instructions for physicians (E, L), and partly from Problems of medical classification (J, K). In order to come as close as possible to the NCBS' registration practice, some of these qualifications were based on alternative interpretations of one and the same ICD-rule.

2.3.1 Coding of physicians' non-underlying RA diagnosis

The diagnosis for non-underlying RA was coded according to whether this condition:

(A) is the first mentioned of the conditions which can be considered, without presupposing an intermediate cause, to have caused a condition mentioned on the last used line in Part I of the certificate (i.e. RA is a more primary condition than the stated underlying cause, in a strict interpretation of ICD-rule 3);

(B) is the first mentioned of the conditions which can be considered, only if an intermediate condition is presupposed, to have caused a condition mentioned on the last used line in Part I (i.e. RA is a more primary condition in a less strict interpretation of ICD-rule 3);

(C) is the underlying cause of the first mentioned sequence when the sequence from the last used line in Part I is broken (i.e. does not terminate in any condition mentioned on the first used line) (i.e. RA is the underlying cause according to ICD-rule 1);

(D) is the first mentioned condition in Part I when there is no sequence terminating in any condition mentioned on the first used line (i.e. RA is the underlying cause according to ICD-rule 2).

2.3.2 Coding of physicians' non-RA underlying diagnoses

The diagnoses for non-RA underlying conditions were coded according to whether the condition:

(E) is the only condition mentioned in Part I and the diagnosis does not completely describe the train of events leading to death (62 p. 416);

(F) is stated by a diagnosis D₁ which describes the condition C₁ in general terms, and there is another diagnosis D₂ outside that line which provides more precise information about the site or nature of this condition C₁ (ICD-rule 8);

(G) is stated by a diagnosis D₁ which describes the condition C₁ in general terms (i.e. the diagnosis can only be coded by a rest-category ICD-code), and there is another diagnosis D₂, not describing C₁ but another condition C₂, (RA), and D₂ provides more precise information about the site or nature of C₂ than D₁ does of C₁ (a qualification inspired by ICD-rule 8);

(H) is stated by a diagnostic expression which can be coded both as one diagnosis and as several diagnoses (ICD-rule 7);

(I) is stated by an ill-defined diagnosis (ICD-rules 4 and 5);

(J) is stated by a diagnostic expression which can be coded by several ICD 8 codes, and one is preferable to the others according to the ICD;

(K) is stated by a diagnostic expression without ICD 8 code;

(L) is a mode of dying (68, pp. 7,25; 62, p. 415; 67, pp. 6,15);

(M) is a trivial condition: "unlikely itself to cause death" (the quotation is from the ICD rule 6 and is here interpreted as that the degree of seriousness (predictable lethality) varies considerably from case to case (e.g.

Bronchopneumonia, Insufficiencia cordis)), and is not reported as the cause of a more serious complication (an interpretation of ICD-rule 6).

The certificate was regarded as satisfying a qualification E-M only if all diagnoses on the last used line in Part I of the certificate were of a kind E-M.

The ICD coding of all the diagnoses, and the (A-M) coding of the diagnoses for non-underlying RA and for non-RA underlying conditions, was developed and performed in consultation with the ICD-coding expertise of the NCBS. The previous NCBS notations concerning which diagnoses had been originally registered for tabulation in 1971 and 1975, respectively, and in what order of causal priority they had then been registered, and the year of the certificate, were blanked out from the certificates during the coding.

The NCBS' original registration of physicians' non-underlying RA as the underlying cause of death in 1971 and 1975 was then compared with whether the physicians' reported non-underlying RA, or the non-RA underlying condition(s), satisfied the ICD qualifications for being registered as the underlying cause of death, (A-M).

3. RESULTS

3.1 The WHO's concepts and rules for causal selection and classification (Paper I)

Paper I calls attention to some basic theoretical problems inherent in the international concepts and rules governing the coders' registration of the diagnostic information from death certificates. The study is based on the current revision (64) of the ICD, which is planned will come into use in Sweden from January 1st 1986. The concepts are the

same, however, and the rules have not changed between the 8th (62) and the 9th (64) revision regarding the aspects focused on in paper I, and from which the conclusions are drawn.

The aims of the study were to examine how these concepts and rules can be interpreted, and what criteria of selection of the underlying cause of death may be derived from them.

A principal source for this study is the causal analysis by Nordenfelt (74), from which some central ideas have been developed with special reference to ICD 9.

The WHO definition of the concept of the underlying cause of death is scrutinized and compared with the ICD-rules, using a basic causal theoretical distinction between two dimensions of causal multiplicity derived from Nordenfelt (74) and White (86). A discrepancy between the WHO's definition of 'the underlying cause of death' and how this notion appears from the ICD-rules is pointed out: The definition restricts the concept of the underlying cause of death only in relation to other causes in the same chain of events (dimension 1), whereas the rules also identify the underlying cause among non-interdependent causes, in, for instance, different parallel chains of events (dimension 2). It is concluded that, since the ICD-rules are not included in the instructions for the making out of death certificates, it is not possible for the certifier to fully understand the WHO concept of the underlying cause of death.

A theoretical difference between what is here called "dimension 2" and what Nordenfelt (74) and White (86) refer to as "vertical" principality and multiplicity of causes should perhaps be mentioned. The 'second dimension' implies that the causes selected between are causally non-inter-dependent, e.g., that they are parts of two different, and

in some instances in themselves sufficient, causal sequences (cf. ICD-rules 1 and 3 (64)), whereas the 'vertical' dimension refers to causes that are not by themselves sufficient for bringing about the effect (74, p. 84; 86, pp. 60, note 2, 142).

In order to capture the overall purpose(s) of the selection procedure prescribed by the WHO, the functions and general characteristics of the ICD-rules are mapped out, including also of the 62 'Notes for use in underlying cause mortality coding'.

The semantic, causal, and purely conventional functions of the rules are discerned. It is pointed out that not only the causal characteristics of the conditions referred to in the death certificate, but also the semantic qualities of the diagnostic expressions themselves and the order in which they are entered on the certificate, are taken into consideration in the instructions for selection and causal classification.

The significance of two traditional criteria of selection and causal classification, the criteria of severity and manipulability, which have been recurrent in manuals for selection of the principal cause of death since the end of the 19th century (74), is underscored. A potential conflict is found between the rules requiring that the cause should be the most serious, and at the same time possible to intervene against in order to prevent untimely death.

An interpretation is given of the concept of modes of dying, and the possible reasons for the WHO's exclusion of these conditions from the definition of 'causes of death'. It is conjectured that these conditions lack explanatory value, since they do not make the difference between the particular death to be explained and what always (or generally) precedes death or through which death always (or generally) ensues.

In conclusion, the concepts and rules of the ICD are shown to be vague and open to a variety of interpretations. (The arbitrariness of the rules is even explicitly pointed out in the ICD, as a reason for the coders' obligation to first of all ask for further clarification of the certificate from the certifier (64, pp. 702-703)). But there is also an uncertainty in the instructions as to the overall purpose(s) of the selection of the principal cause of death.

3.2 A comparison between the physicians' and the NCBS' causal classification of RA (Paper II)

The point of departure of paper II was an observed 2.7-fold mortality increase for men and a 3.0-fold increase for women attributed to RA as the underlying cause of death in the official statistics for Sweden between 1971 and 1975 (18,19). The increase is here estimated in proportion to all deaths from all causes (PMR), as reported in the official statistics. The number of men with RA as the underlying cause of death was in per cent of all deaths from all causes in 1971, 0.040 (18/45561) and in 1975, 0.106 (51/48322), and the corresponding figures for women were 0.186 (69/37173) and 0.567 (226/39880).

A comparison between physicians' stated underlying cause of death on the RA death certificates for 1971 and 1975, and the NCBS' notations on the certificates regarding the registration of the underlying cause of death, showed that the physicians had reported a slight decrease for men between the years, from 0.057 to 0.043 and practically no change at all for women, from 0.213 to 0.216, whereas the NCBS had registered an increase for men from 0.044 to 0.112, and for women, from 0.180 to 0.577. (The number of individuals with RA as the underlying cause of death according to the NCBS' notations on the certificates were

found to be two more men and two less women in 1971, and three more men and four more women in 1975 compared with the official statistics).

Thus, the observed increase was found to be due to an increased tendency by NCBS to favour RA in the registration of the underlying cause of death. The total number of altered certificates were 94 (16%) in 1971 and 205 (32%) in 1975. The NCBS was found to have registered physicians' underlying RA as complication or contributory cause less often in 1975 (21%) than in 1971 (56%), and physicians' RA as complication and contributory cause of death was more often registered as the underlying cause of death in 1975 (37%) than in 1971 (8%). The net effect of both these changes is an increase in deaths attributed to RA as the underlying cause of death.

In this paper a first examination of the certificates showed that there was no noticeable difference in the percentage of inadequately made out death certificates between the years, 34% in 1971 and 31-36% in 1975. In papers III-V the inadequacies on the death certificates, and how these influence the coders' registration of the causes, are analysed in greater detail.

3.3 Problems of medical classification (Paper III)

In paper III physicians' diagnostic language on RA death certificates and its consequences for the coders' medical classification is studied.

Physicians' notations of causal conditions on death certificates were found to be strongly individualistic. In total 1 666 diagnostic expressions were identified, out of which 76% were used only once in 1971 and 73% in 1975. These

1 666 expressions could be coded by 287 ICD 8 codes. 139 different expressions had been used for rheumatoid arthritis.

156 (13%) of the death certificates contained diagnostic expressions encumbered with one or more of four major kinds of classification problem:

- (1) There is no ICD 8 code for the diagnostic expression (24 certificates);
- (2) The expression can be coded by several ICD 8 codes, but the ICD-rules give no guidance about which to select (45 certificates);
- (3) Several alternative ICD 8 codes can be found for the expression, one is preferable to the others according to the ICD (39 certificates);
- (4) The diagnostic expression can be coded both as one diagnosis and as several diagnoses (60 certificates).

The alternative interpretations of all these expressions differed in most cases on a three-digit level and in some cases on chapter level in the ICD.

The diagnostic expressions with problems of medical classification referred to an underlying cause of death in 55 of the certificates, 30 in 1971 and 25 in 1975.

These difficulties could, however, not explain the NCBS' increased registration of RA as the underlying cause of death between 1971 and 1975. The classification problems concerned physicians' underlying arthritis and rheumatism diagnostic expressions on only 2 of the certificates in 1971, and none in 1975, where RA was not registered by the NCBS as the underlying cause of death. Correspondingly, the expressions used for the non-arthritis and non-rheumatism underlying conditions caused problems of classification on

only 2 of the certificates in 1971 and on 8 in 1975, where these diagnoses were rejected in favour of RA in the NCBS' registration of the underlying cause of death.

3.4 The causal sequence on death certificates (Paper IV)

In paper IV physicians' amount of diagnostic information and the adequacy of the causal sequence(s) on RA death certificates were studied. Physicians' reporting was compared with the NCBS' registration of the causal conditions, particularly the underlying cause of death.

Only 1.6% of the certificates contained in total more than 7 diagnoses. There was, however, a noticeable excess of diagnoses on each line in Part I of the certificates. More than one diagnosis on each line appeared on 28% of the certificates, 29% in 1971 and 26% in 1975. In 17% more than one underlying cause of death was stated on the certificates, 19% in 1971 and 15% in 1975.

The causal sequences were inadequate in 35% of the certificates, 37% in 1971 and 33% in 1975. Ten types of inadequate sequences were identified. The NCBS rejected physicians' underlying cause of death in 56% of the inadequate sequences and in 52% of the adequate sequences. This rejection implies that the NCBS registered another four-digit ICD 8 code for the underlying cause of death than what could be used for the condition(s) stated by the physician on the last used line of the certificate. When the comparison was made on a three-digit level, and certificates with only one cause in Part I were included, there was no difference at all between the percentage of rejected underlying causes on causally adequate certificates as compared with causally inadequate certificates, 54% in both cases.

The inadequate sequences were not considerably more frequent on the certificates where the NCBS rejected physicians' non-RA underlying cause of death in favour of RA (23% in 1971 and 28% in 1975), than they were on the certificates where the NCBS accepted physicians' non-RA underlying cause of death (18% in 1971 and 19% in 1975). Nor was there any noticeable difference between the years that could explain the observation (paper II) that the NCBS rejected physicians' non-RA underlying cause in favour of RA in 8% in 1971 and 37% in 1975.

The percentage of inadequate sequences was greater on the certificates where the NCBS rejected physicians' underlying RA (66% in 1971 and 70% in 1975) compared with the certificates where the underlying RA was accepted (28% in 1971 and 31% in 1975). But there was no noticeable difference between the years that could explain the observation (paper II) that the NCBS rejected physicians' underlying RA less often in 1975 (21%) than in 1971 (56%).

3.5 RA as the principal cause of death (Paper V)

Paper V investigates the applicability of the ICD-rules and principles for registration of the underlying cause of death, and compares this with the actual NCBS registration of the underlying cause, in the cases when the NCBS rejected physicians' non-RA underlying cause of death in favour of RA (the first kind of change), or rejected the stated RA underlying cause in favour of some other condition (the second kind of change), in 1971 and 1975. (In the second kind of change physicians' underlying RA was registered by the NCBS as a contributory cause of death).

When the inadequacies in the completion of the death certificates, pointed out in paper II-IV, were added together, 62% of the certificates for each year respectively were found to be inadequately made out in one or several aspects.

None of the ICD qualifications (ICD-rules and principles A-M; see p. 17-19 above) could alone or in combination explain the more than fourfold (4.6) increase in the NCBS' registration of physicians' non-underlying RA as the underlying cause between 1971 and 1975. Nor was any decrease in the number of inadequacies to be found, such as broken causal sequences, ambiguous diagnostic expressions for the stated underlying arthritis and rheumatism condition, or the occurrence of conditions reported besides RA on the last used line, which could explain the NCBS' decreased rejection of physicians' underlying RA between 1971 and 1975.

No inadequacy, or other reason based on the ICD, was found that was sufficient for the NCBS to reject the physician's non-RA underlying condition in favour of RA or to reject the reported underlying RA in the registration of the underlying cause of death.

Some qualifications were, however, noticeably more frequently satisfied (i.e., some of the ICD-rules and principles were more often applicable) in the cases where the NCBS registered physician's non-underlying RA as the underlying cause of death, compared with the cases where a non-RA condition was registered as the underlying cause. RA appeared to have been favoured to the greatest extent by the NCBS (i) when RA was likely to have caused physician's underlying cause of death, (ii) when there is only one non-RA diagnosis reported in Part I of the certificate, and this diagnosis does not completely describe the train of events leading to death, (iii) when the diagnosis for the non-RA underlying condition provides less precise informa-

tion about the site or nature of the underlying condition, compared with another diagnosis for another condition, RA, stated on the certificate, or (iv) when the reported non-RA underlying condition could not itself be considered lethal, and was not reported as a cause of a more serious condition.

The first qualification, (i), was satisfied 5.8 times as often when the non-underlying RA was registered by the NCBS as the underlying cause, compared with when a non-RA condition was registered as the underlying cause; the qualification (ii) 3.2 times as often, (iii) 2.8 times, and (iv) 4.1 times.

Only one type of inadequacy was identified which could explain the second kind of changes by the NCBS: The causal sequences were broken almost ten (9.6) times as often on the certificates where the NCBS rejected physicians' underlying RA and registered RA as a complication or contributory cause, as compared with when physicians' underlying RA was registered as the underlying cause by the NCBS.

However, the percentage of broken sequences could not explain the NCBS' decreased rejection of physicians' underlying RA between 1971 and 1975.

4. GENERAL DISCUSSION

The problems of the different steps in the data collecting process for the cause-of-death statistics investigated in the present thesis may be summed up as concerning mainly two issues: The problem of giving formally adequate (according to the design of the certificate) and relevant cause-of-death explanation, and the problem of using an appropriate diagnostic language in this explanation. The first issue concerns the selection of causes and the causal

classification, and the second issue concerns the agreement between the diagnostic expressions on death certificates and the terminology of the ICD. In the following a few comments will be made on these issues.

4.1 Cause-of-death explanation

Two elementary requirements for the explanatory value of causal explanations are obvious: That the statement is accurate (true), and that it is relevant to the purpose of the explanation. Attention will here only be paid to the second requirement. The first requirement, regarding the accuracy of the diagnoses and of the establishing of the causal relations will not be commented upon here. It is, as mentioned earlier, beyond the scope of the present thesis.

Moriyama (71) questions whether the traditional way of cause-of-death explanation, the attribution of death to a single cause as the underlying cause is really adequate to current needs. The focusing of interest on a single cause derives from an era when public health was chiefly concerned with infectious and acute communicable diseases (71,76,83). In a society with a high standard of living and a well developed public health planning, there is a need for deeper study of chronic diseases (83), and of complex combinations of diseases (30).

In 1967 the WHO was recommended to initiate trials with different forms of death certificates designed to elicit more complete information on the pathological conditions present at death, and to investigate the advisability of dropping the distinction between 'underlying cause', 'conditions contributing to death' and 'other conditions present at the time of death' (29, pp. 8, 30-31).³

Treloar (83) suggests that the certifier should be exempted from the obligation to identify a single (underlying) cause of death for tabulation purposes. Instead the tabulations should "be extended to cover all entries on the medical certification of cause of death that meet desirable standards in defining important diseases". These conditions should be accounted for without relative order of precedence, only by the frequency with which they appeared among those deceased (83).

Angrist (6) goes a step further and suggests a causal classification for the certification of the causes of death, taking into account both what is called in paper I "dimension 1" (pathogenesis) and "dimension 2" (causal significance). Angrist (6) shows how such a certificate form could be designed and gives an example of its completion. The first listing should answer the question "'Which was the initiating disease entity, and what was the relationship in the order of their development of the subsequent complications or the simultaneous existing entities?'" (6). The second separate listing should answer the question "'What are the disease entities or complications in order of magnitude, i.e., without which death would have been delayed the longest or life prolonged the most?'" (6).

As mentioned earlier, the want of multiple cause tabulation has been complied with in Sweden since 1965 (16). Information on complications and contributory causes of death for deaths occurring as from 1961 are available on tapes (15,49). From these tapes it is possible not only to assess the relative frequency of causes recorded besides the underlying cause, but also to assess the frequency of combinations of causes jointly causing death (15,49). This renders a more complete picture of the mechanisms behind particular deaths. But the task of singling out one cause as the underlying cause has not been abandoned, and the selection of the greater amount of diagnostic information

is still itself a selection. The basic question of causal selection remains unsolved: What conditions are relevant for tabulation? Ultimately it is always the purpose that delimits the range of causes relevant for the explanation (58, pp. 161 ff.)

The WHO instructions (62,64,68) do not explicitly state what causes of death should be reported on the certificates and registered in the statistics. What is said about the contributory causes is merely a repetition of the definitions of 'causes of death' (see the citations in section 1.3.3 and 1.3.4). It seems like any (well-defined) cause of death, in the WHO sense of 'causes of death', may be reported on the certificate besides those in the main sequence.

However, the practical significance of more than one cause being mentioned on the certificate is evident. Besides the advantages of multiple cause-of-death registration, mentioned earlier, it also enables the coder to get a more complete picture of the course of events, and in many cases to improve the coding of the underlying cause of death. In this way diagnostic information may often be available that modifies the coding of the underlying cause of death, and a more informative code for the underlying cause can be selected.

Information on the complications and contributory causes are thus of important indirect interest, for the clarification and coding of the underlying cause of death. If the present causal classification were to be abandoned, as Treloar (83) and the WHO report (29) suggest, another order of significance would be necessary, such as for example Angrist (6) suggests. Otherwise there would be no explicit guidance at all for a consistent judgement of what conditions should be considered relevant for tabulation. It

appears that Treloar (83) is aware of this fact, from his call for "desirable standards in defining important diseases".

As it is now, the overall purpose(s) of the causal selection derives in practice from the interest in the underlying cause of death. The relevance of the causes to be selected is thus determined by the purpose(s) of the selection of the underlying cause.

The problem of singling out a cause as the principal cause is pertinent not only to the context of cause-of-death explanation in medicine, but is a central issue of the theory of explanation in general. The criteria used for pointing out one cause, among several established causes, as the principal cause has been subject to analysis in previous studies in a number of scientific fields - in medicine (9,27,28,30-32,46,47,74,83,87,88), social science (58), jurisprudence (44), history research (37,86), and in philosophy of science, regarding causal explanations in general (59,60,66,72,73). Traditionally the issue of pointing out the cause has been analysed in terms of the cause in contrast to merely (necessary) background conditions (21,22,25,35,37,44,58,60,69,72,85). These two issues are not always clearly separated. The latter issue is often connected with the question of defining 'causation' i.e., what constitutes 'causal' relations.

The theoretical basis for the selection of the underlying cause of death certainly merits further analysis and clarification. It is only possible here, however, to call attention to what has already been pointed out in paper I, that the selection is made from a point of view of prevention. It is stated in the ICD that "From the standpoint of prevention of deaths, it is important to cut the chain of events or institute the cure at some point. The most effective public health objective is to prevent the precipitating cause from operating". (62, p. 415;

64, pp. 699-700; cf. 68, p. 5). This is the reason given for the WHO's definition of 'the underlying cause of death' in the ICD.

The preventability does not seem, however, to be a criterion of selection used in practice. This criterion is not underscored in any of the examples of certification in the instructions for the certifiers, and it does not appear in the ICD-rules. The main concern lies in defining the degree to which the underlying cause should have contributed to the fatal outcome.

One could question whether preventing the condition initiating the fatal sequence from operating really always is the most effective way to prevent untimely death. Knowledge of how fatal sequences are initiated might, however, be an appropriate point of departure in the epidemiological search for factors best suited for prevention.

4.2 Diagnostic nomenclature

When considering the problems of medical classification, a central question is whether the ICD should in practice be used as a nomenclature for the making out of death certificates.

It is stated in the introduction of the ICD that it is not intended to be a medical nomenclature. A statistical classification and a medical nomenclature usually serve different purposes. A medical nomenclature differs from a disease classification in that a nomenclature is a list of approved terms to be used for describing specific clinical and pathological conditions, whereas a classification provides a system of categories for grouping of conditions, and need not be prescriptive as to what terms should be used for specific conditions. In contrast to a nomenclature

a statistical classification need not have a separate title and code for each particular condition included in the list.

Though the ICD is not intended to be a nomenclature, the titles of the classification categories nevertheless ultimately decide the degree of detail possible to code. It is in practice necessary to conform to the diagnostic distinctions and the degree of detail of the classification when coding the causes of death. In this sense the ICD is prescriptive. Each condition included in the classification does not have a separate code. Some conditions have four-digit codes, but the Alphabetical Index (63,65) also contains a comprehensive list of expressions for specific conditions for which the classification provides only a three-digit code, i.e., a category code, which includes other specific conditions as well. The Alphabetical Index is compiled with the ambition to include not only the restricted set of titles used in the Tabular List (62,64), but also "most of the diagnostic terms given in the standard or official nomenclatures, as well as terms commonly used in different countries", i.e., even "many obsolete and unsatisfactory terms still stated on medical records and death certificates" (61, p. xxxiii).

The expressions listed in the Alphabetical Index are detailed, and the list contains synonyms. It has been pointed out that many of the categories of the ICD are too detailed for cause-of-death statistical purpose (71). In the statistics the causes of death are often presented in broader classes. The degree of detail in the ICD is needed, however, for morbidity statistics (71), and it is also of value for the cause-of-death register for research into particular diseases.

If the certifier fails to adhere to the diagnostic distinctions and degree of detail of the ICD, it can cause classification difficulties (paper III) and queries might

be sent to the clinic for clarification of the certificate. Adherence to the ICD in the completion of the certificates need not imply that the certifier should go as far as applying the ICD-rules, but adherence to the ICD terminology would facilitate and improve the coders' application of these rules when coding the conditions reported.

The procedure of medical classification involves medical judgements, and these are of course best done by the certifying physician, who has first hand knowledge of the deceased. The coder should not be left to make medical speculations when coding the certificates, and it is of interest both to the coder and the certifier that queries for supplementary information and clarification of the certificates are avoided.

5. SUMMARY AND CONCLUSIONS

In the present thesis the certifiers' and coders' adherence to the official instructions for cause-of-death reporting and registration have been investigated. Analysis has been made into some of the central conceptual and causal theoretical problems inherent in these instructions and in the different steps of the data collecting process for the national cause-of-death statistics.

The starting point was an observed 2.7-fold mortality increase for men and a 3.0-fold increase for women attributed to RA as the underlying cause of death in the official statistics for Sweden between 1971 and 1975. An investigation of all the Swedish RA death certificates for these years (N=1224) showed that the increase was due to changes in the NCBS' registration procedure: An increased tendency by the NCBS to favour RA in the registration of the underlying cause of death between the years. The increased registration of RA as the underlying cause of death could not be fully explained by physicians' inade-

quacies in completing the death certificates, nor by a strict and consequent application of the ICD-rules for selection of the underlying cause of death.

The major inadequacies identified on the certificates were (1) an inadequate causal sequence, (2) diagnoses making the underlying conditions difficult or impossible to code, (3) more than one diagnosis for each link in the principal causal chain, and (4) an underlying condition not stated in accordance with other provisions of the official WHO instructions. Though the increased registration of RA could not be explained by inadequate certificates or an applicability of ICD-rules, some reasons for the coders to favour RA in the registration in general were discerned. Physicians' non-RA underlying conditions were rejected by the NCBS, and instead RA was registered as the underlying cause (i) when RA was likely to have caused the stated underlying condition, (ii) when the non-RA diagnosis was the only diagnosis in part I of the certificate and this rendered an incomplete description of the fatal course of events, (iii) when the non-RA condition could only be classified by a rest-category code of the ICD, and (iv) when the non-RA condition was considered 'trivial'.

Interpretation problems were identified and different interpretations were discussed. Some of these problems were caused by inadequacies on the certificates. Others concerned incompleteness, ambiguities, and manifold meanings of the basic concepts and official rules governing the reporting and registration of causes of death. An uncertainty in the instructions for physicians and coders as to the overall purpose(s) of the selection of the principal cause of death also appeared. It was concluded that since the ICD-rules are not included in the instructions for the making out of death certificates, it is not possible for the certifiers to fully understand the WHO concept of the underlying cause of death.

It can further be concluded from the results of the present thesis that more elaborate instructions for the certifying physicians and for the coders are needed. An increased utilization of the ICD at the completion of the certificates would reduce the coders' problems of medical classification. It is also evident that the coders could make queries for clarification of inadequate and ambiguous statements on the certificates to a greater extent than hitherto.

ACKNOWLEDGEMENTS

My sincere thanks are due to all those who worked at the Department of Social Medicine 1980-84 for being a source of inspiration and encouragement, and for their willingness to assist in every way.

Many people have contributed to my work. I stand in particular debt to Erik Allander for his committed tutorship, and for initiating this study and generously giving me support and guidance in its realization. I am also greatly indebted to my teacher and tutor in philosophy, Lennart Nordenfelt, for arousing my interest in theory of medicine, and for giving valuable advice and criticism throughout this work.

I have benefited immeasurably from the expert knowledge and ready assistance of the staff of the Swedish National Central Bureau of Statistics - especially Anne-Marie Bolander, MariAnn Evers, Barbro Loogna, Yvonne Lönn, and Lars Age Johansson.

I thank Ulla König for assistance in the data collection, and Gunnar Ringmarck for programming and computer processing.

Philip H. N. Wood of the University of Manchester has read and criticized paper I, and Anders Ahlbom and Peter Allebeck the whole manuscript. Though I did not adopt all their suggestions, their comments have improved the clarity and accuracy of the text.

My gratitude also to Karin Lundström for the painstaking care she expended on typing all versions of the manuscript, and to Jennifer J. Wheeler, Paul Needham and Fredrik Ulfhielm for revising my English in different papers.

Above all, I am grateful to my wife Yoshiko, who has sustained me during all the many throes of this work.

This study was financially supported by the Swedish Medical Research Council and the Swedish Association Against Rheumatism.

NOTES

1. The numberings of these studies in the bibliography of Gittelsohn et al. (1982) are: 3,5,8,14,16,22,23,26-28, 31,34,35,38,43,49,52,55,62-64,66-68,70,78,87,89,95-97, 102,109,112,113,115,117,128.
2. Numberings in Gittelsohn et al. (1982): 12,17,18,20,24, 29,39,40,45,51,53,57,77,79,104,105,108,119-121,126.
3. The wording of this distinction is the one used in the report referred to (29). This distinction is formulated differently in the ICD (see above Fig. 1, p. 4 and section 1.3.4, pp. 10-11).

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