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Coding ill-defined and unknown cause of death is 13 times more frequent in Denmark than in Finland

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ABSTRACT

Exact cause and manner of death determination improves legislative safety for the individual and for society and guides aspects of national public health. In the International Classification of Diseases, codes R00–R99 are used for "symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified" designated as "ill-defined" or "with unknown etiology". The World Health Organisation recommends avoiding the use of ill-defined and unknown causes of death in the death certificate as this terminology does not give any information concerning the possible conditions that led to the death.

Thus, the aim of the study was, firstly, to analyse the frequencies of R00–R99-coded deaths in mortality statistics in Finland and in Denmark and, secondly, to compare these and the methods used to investigate the cause of death.

To do so, we extracted a random 90% sample of the Finnish death certificates and 100% of the Danish certificates from the national mortality registries for 2000, 2005 and 2010. Subsequently, we analysed the frequencies of forensic and medical autopsies and external clinical examinations of the bodies in R00–R99-coded deaths.

The use of R00–R99 codes was significantly higher in Denmark than in Finland; OR 18.6 (95% CI 15.3–22.4; $p < 0.001$) for 2000, OR 9.5 (95% CI 8.0–11.3; $p < 0.001$) for 2005 and OR 13.2 (95% CI 11.1–15.7; $p < 0.001$) for 2010. More than 80% of Danish deaths with R00–R99 codes were over 70 years of age at the time of death. Forensic autopsy was performed in 88.3% of Finnish R00–R99-coded deaths, whereas only 3.5% of Danish R00–R99-coded deaths were investigated with forensic or medical autopsy. The codes that were most used in both countries were R96–R99, meaning "unknown cause of death". In Finland, all of these deaths were investigated with a forensic autopsy.

Our study suggests that if all deaths in all age groups with unclear cause of death were systematically investigated with a forensic autopsy, only 2–3/1000 deaths *per* year would be coded as an ill-defined and unknown cause of death in national mortality statistics. At the same time the risk to overlook unnatural deaths is decreased to a minimum. To achieve this in Denmark requires that the existing legislation on cause of death investigation would need to be changed to ensure that all deaths with unknown cause of death are investigated with a forensic autopsy.

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1. Introduction

Despite that it is well known that an autopsy is the ultimate method to achieve accurate information on cause of death (CoD) and manner of death (MoD) [1–10], the national legislation and practice governing CoD investigation is different in Finland (FI) [11] compared with Denmark (DK) [12]. This is reflected in a high

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autopsy rate in FI and low in DK [13], although they belong to the socially and politically similar Nordic countries, which use national CoD statistics to guide the health and preventive practices in public health care system [14].

Ill-defined and unknown CoDs are described in Chapter XVIII of the 10th revision of the International Classification of Diseases (ICD-10) [15]. All ill-defined and unknown CoDs begin with the letter R and are coded using numbers from R00 to R99. The precise title for these R00–R99 codes is "symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified". The only exception is code R95 for Sudden Infant Death Syndrome (SIDS) which is not regarded as an ill-defined CoD [16].

Both in DK and in FI, death certificate forms are made using the World Health Organization's (WHO) templates [17]. The WHO recommends avoiding the use of R00–R99 codes in the death certificate because R00–R99 codes point equally to two or more conditions in the systems of the body [16]. If the CoD is ill-defined on the death certificate, the statistical office reselects a CoD from the other reported conditions that may lead to death. If no other conditions reported on the certificate are more precise, an ill-defined or unknown condition is registered as an underlying CoD in national mortality statistics. MoD is registered as natural (disease) in these cases, although original death certificate was with unnatural MoD, e.g. accident, suicide or unknown. An underlying unknown CoD does not give any information concerning the possible conditions that led to the death.

Among the Nordic countries, FI has the highest total autopsy frequency and DK the lowest [13,14,17]. Both countries have about 50,000 deaths *per* year. The total autopsy rate is about 3000/10,000 deaths *per* year in FI whereas in DK, CoD is investigated with an autopsy in only about 500/10,000 deaths *per* year.

This difference in autopsy rate is rooted in national legislation and practices in CoD investigation. In FI, the police investigate deaths if MoD is unclear, if the deceased does not have a known medical history, if the deceased was not under medical treatment for a possible disease, or if death was sudden and unexpected. A medical doctor makes a statement to the police after having performed a clinical examination of the body. If CoD remains unclear after these investigations, a forensic autopsy is mandatory. The possibility for relatives to refuse a forensic autopsy does not exist [11].

In DK, a medical doctor has to inform the police of all deaths where there is suspicion of an unnatural MoD or when death was sudden and unexpected. The police investigate first all these deaths. After consulting a Medical Officer of Health, investigation proceeds only in case of an unnatural or unknown MoD. In such cases, an external forensic examination of the body is performed by the police and a Medical Officer of Health. Investigation proceeds with a forensic autopsy only if the MoD is uncertain. If the MoD is resolved, but the CoD is not certain, a forensic autopsy is only performed if a crime is suspected. The police makes the final decision whether a forensic autopsy is needed. It is possible for the relatives of the deceased to refuse a forensic autopsy, but this can be overruled by the court [12], and this right to refuse is only seldom used.

Subjects who have died a natural death may undergo medical autopsy to achieve more precise information about the CoD in FI and in DK. Medical autopsy for this reason is most often used if a person dies at the hospital, but it can also be arranged for people who have died outside hospital. Permission from the relatives of the deceased or, if this is not possible, from the authorities, is mandatory to perform a medical autopsy [11,12].

Published national mortality statistics show that the frequency of ill-defined and unknown CoDs is low in FI [18] and high in DK [19]. Previous study made by Saukko [14] has shown that the number of ill-defined and unknown CoDs seems to correlate inversely with the autopsy frequencies of each Nordic country. Both FI and DK have adopted the use of ICD-10 and WHO's modification rules to avoid ill-defined and unknown CoDs. According to the WHO, R00–R99 codes should only be used in death certificates if all available investigation methods have been exhausted [15–17]. Even so, the difference in legislations governing the medico-legal CoD investigation makes it possible that an autopsy is not performed in all cases with ill-defined and unknown CoD. To the best of our knowledge, no studies comparing the methods used to investigate deaths with certified ill-defined and unknown CoD in FI and DK have been performed.

2. Materials and methods

The study material consists of data extracted from the Finnish and Danish National Mortality Registers, i.e. Statistics Finland and the Division of Health Surveillance and Research at "Statens Serum Institut" Denmark. The study uses a cross-sectional design for the years of 2000, 2005 and 2010.

Both countries publish annual national CoD reports. Data on CoD is extracted from death certificate codes. Coding is done in accordance with the International Classification of Diseases, 10th revision (ICD-10) issued by the WHO [16]. Because of different summary lists in CoD statistics, national CoD statistics are not directly comparable [17–19]. To make comparison possible, data from Finnish and Danish mortality registers were extracted without their own summary lists. Study variables were extracted from death certificates and included CoD, age in years and gender of the deceased person and the method used to investigate his or her death. Additionally, the Danish death certificate data contained information whether the relatives of the deceased had refused to grant permission to perform the autopsy, or if the relatives were not asked for their permission. All statistical analyses were conducted using IBM SPSS Statistics software (Statistical Package for the Social Sciences, version 20).

The sampling process for Finnish and Danish R00–R99-coded deaths is shown in Table 1. Data from FI covered 90% of all deceased persons where death had occurred after 4 weeks of age and for

Table 1
Sampling process for Finnish (FI) and Danish (DK) deaths.

Study years		2000		2005		2010	
Number (n)		FI	DK	FI	DK	FI	DK
Total deaths		49,316	57,204	47,751	54,670	50,910	54,027
Exclusion:	No death certificate (FI)	40	–	87	–	84	–
	Deaths 0–28 days (FI)	136	–	125	–	91	–
	Random sampling 10% (FI)	4914	–	4753	–	5073	–
	Deaths >4 weeks<1 year (FI)	63	–	49	–	42	–
	Deaths <1 year of age (DK)	–	333	–	280	–	139
	R990 deaths (DK)	–	160	–	508	–	2135
Total deaths in the study		44,163	56,711	42,737	53,882	45,620	51,753

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