

# Differences in investigations of sudden unexpected deaths in young people in a nationwide setting

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## Abstract

**Background** Inherited disease may be causative in many young sudden unexpected death cases. Autopsy is essential in the counselling of the bereaved, as the family of the victim may be at risk too. In a nationwide setting operating under the same set of laws, we hypothesized that regional differences exist in the investigation of young persons dying suddenly and unexpectedly.

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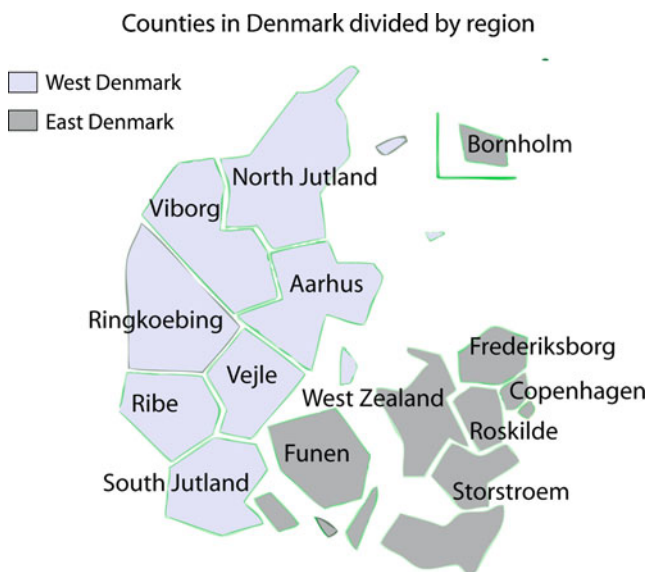
**Methods and results** All deaths in persons aged 1–35 years in Denmark in 2000–2006 were included. Death certificates were read independently by two physicians. External examination as well as autopsy status was retrieved. Significant regional differences were found regarding external examinations and autopsy frequencies. Ratios of conducted external examinations varied between 63% and 93% ( $p=0.004$ ). Autopsy ratios varied between 60% and 88% ( $p=0.001$ ). In urban areas, external examinations and autopsies were more often conducted than in rural areas. In East Denmark, there were more external examinations resulting in a forensic autopsy, and there was a higher overall autopsy rate compared to West Denmark.

**Conclusion** Despite operating under the same set of laws, we document significant regional differences in forensic investigations of young persons suffering a sudden unexpected death. This is probably not unique for Denmark although no data exist to confirm that. The results are worrying and call for a revision of the way these deaths are handled. Mandatory autopsy in sudden unexpected death in young persons is warranted as a thorough investigation of the death may help the clinician in guidance of the relatives in relation to hereditary diseases.

**Keywords** Sudden death · Epidemiology · Public health · Forensic medicine · Health law · Autopsy

## Introduction

Sudden unexpected death in the young is always a tragic and devastating event leaving the relatives not only with grief but also with the awareness that sudden death may strike the family again. Autopsy may reveal structural heart diseases like hypertrophic or dilated cardiomyopathy,

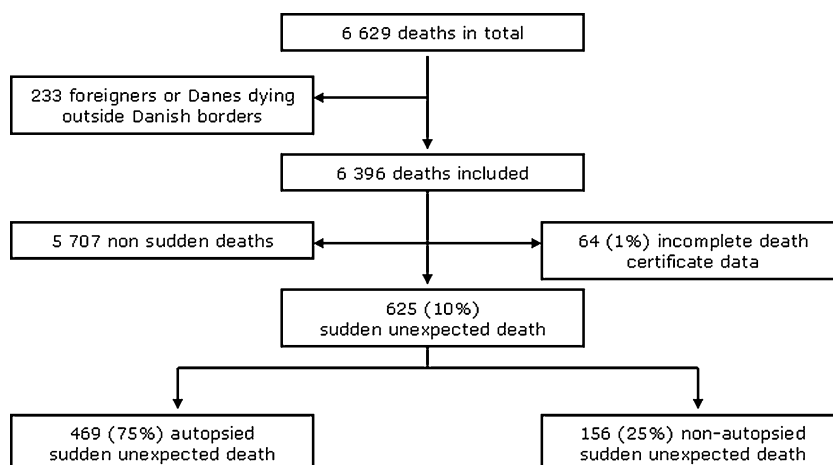


**Fig. 1** Map of Danish counties as of 2006. Denmark divided into West and East is also shown

arrhythmogenic right ventricular cardiomyopathy, or myocardial infarction. However, in many cases, autopsy will show a structurally normal heart and no plausible explanation of the death [1–4]. These deaths—termed Sudden Unexplained Deaths (SUD)—have previously been shown to be associated with mutations in genes encoding cardiac ion channels in about 20% of cases [5, 6]. In structural heart disease in young Sudden Cardiac Death (SCD) victims, disease-causing mutations may also be found [7–11].

In a previous study, by combining cardiac causes of death that might harbour an inherited trait (unexplained deaths, ischaemic heart disease, thoracic aortic dissection, ARVC, DCM, and HCM including hypertrophic and fibrotic hearts), up to 54% of all autopsied sudden unexpected deaths had either a normal autopsy or a cardiac disease which could be linked to inheritability [1]. Thus, if a young person dies suddenly and unexpectedly, an autopsy (including blood or tissue samples for the purpose of genetic testing) is required

**Fig. 2** A flowchart of the initial review of death certificates. Adapted from Winkel et al. [1]



for the clinician to be able to manage the family in regard to inherited diseases [12]. Despite this, little is known as to what extent these young persons suspected of dying suddenly and unexpectedly are being autopsied. In Denmark, the nationwide autopsy rate in this group is 75% [1].

In this study, we hypothesize that despite working under the same set of laws, regional differences exist in the investigation of young persons dying suddenly and unexpectedly in Denmark.

## Methods

The identification of sudden unexpected deaths in the young in Denmark has previously been described in detail [1]. In short, death certificates on all persons aged 1–35 years, who died in 2000–2006, were reviewed independently by two physicians and tagged for sudden unexpected death. The death certificates in Denmark have a *supplemental information* field. This field describes the circumstances surrounding the death, thereby making them suitable for primary identification of sudden unexpected death. The number of persons autopsied was ascertained for all counties in Denmark.

### National Civil Registry ID and Death Certificate data

All persons born or living permanently in Denmark are given a unique National Civil Registry ID. All health care-related services are registered using this ID. When a person dies, a death certificate is always issued. The death certificate can only be issued by a medical doctor (physician), either (1) the physician who notes the death of the person, (2) the deceased's general practitioner, (3) by the medical officer of public health, or (4) a forensic pathologist. The medical officer of public health is a certified physician with specialty in juridical and the Danish health law. The medical officer of public health issues the death certificate in all cases where an external examination has been conducted (except for

**Table 1** County data on the 625 sudden unexpected death cases, showing for each county how many deaths were encountered, how many hospital and forensic autopsies were conducted, how many were not autopsied (divided into relatives' decision or other decision), and the autopsy rate

County	Total deaths, <i>n</i> (%)	Hospital autopsies, <i>n</i>	Forensic autopsies, <i>n</i>	No autopsy, other decision, <i>n</i>	No autopsy, relatives' decision, <i>n</i>	Autopsy rate, %
Copenhagen City/ Frederiksberg/ Bornholm	92 (15)	4	76	8	4	87
Frederiksborg	39 (6)	4	29	3	3	85
Funen	50 (8)	3	35	7	5	76
Copenhagen	73 (12)	2	62	6	3	88
North Jutland	60 (10)	9	27	18	6	60
Ribe	26 (4)	1	17	7	1	69
Ringkoebing	24 (4)	2	17	4	1	79
Roskilde	30 (5)	10	11	7	2	70
Storstroem	34 (5)	5	24	5	0	85
South Jutland	29 (5)	0	19	9	1	66
Vejle	44 (7)	2	26	13	3	64
West Zealand	26 (4)	0	18	6	2	69
Viborg	28 (4)	2	18	8	0	71
Aarhus	70 (11)	6	40	23	1	66
Total	625	50	419	124	32	75

*p*=0.001

Copenhagen City, where the external examination and the subsequent issuing of the death certificate are outsourced to the forensic pathologists). In Denmark, there are a total of 34 medical officers of public health.

The external examination is to be carried out if (1) a criminal act is suspected, (2) in all accidents and suicides, (3) if a person is found dead, and/or (4) the death is sudden

and unexpected. The external examination includes a thorough death scene investigation with particular focus on circumstances relating to the death, supplemented with data from hospital records, interviews with relatives and witnesses, and an external examination of the body. A summary of the examination is always written in the *supplemental information* field on the death certificate.

**Table 2** County data on the 625 sudden unexpected death cases, showing for each county how many external examinations were performed, the rate of external examinations of total deaths, and the rate of external examinations resulting in a forensic autopsy

County\Autopsies	Total deaths, <i>n</i> (~%)	External examinations, <i>n</i>	Forensic autopsies, <i>n</i>	External examinations of total deaths (%)	External examinations resulting in forensic autopsy (%)
Copenhagen City/ Frederiksberg/ Bornholm	92 (15)	79	76	86	96
Frederiksborg	39 (6)	33	29	85	88
Funen	50 (8)	41	35	82	85
Copenhagen	73 (12)	66	62	90	94
North Jutland	60 (10)	42	27	70	64
Ribe	26 (4)	24	17	92	71
Ringkoebing	24 (4)	20	17	83	85
Roskilde	30 (5)	19	11	63	58
Storstroem	34 (5)	26	24	76	92
South Jutland	29 (5)	27	19	93	70
Vejle	44 (7)	39	26	89	67
West Zealand	26 (4)	22	18	85	82
Viborg	28 (4)	23	18	82	78
Aarhus	70 (11)	65	40	93	62
Total	625	526	419	84	80

*p*<0.004      *p*<0.0005

## Conduction of autopsies

Forensic autopsy is to be performed if an external examination concludes that (1) a criminal act is suspected (including all cases of potential drug abuse), (2) mode of death is not well established (natural death, accident, suicide, or homicide), or if (3) cause of death is not well established, and the police solicits the autopsy. Hence, it is ultimately the police that make the decision to perform a forensic autopsy.

In addition to forensic autopsies, autopsies are also conducted at local hospital pathology departments. The *hospital autopsies* are conducted if the police did not solicit the autopsy (or an external examination was not carried out), and it is requested by the relatives and/or the physician. A forensic autopsy always follows a standardized protocol in which all organs are examined, including histopathology. In case of unexplained deaths, a toxicology screen is routinely performed.

## Definitions

Denmark was at the time of the study divided into 13 counties and Copenhagen City (including Frederiksberg and Bornholm). For descriptive purposes, Copenhagen City in this study was considered a county as well, bringing the total number of counties to 14. See Fig. 1 for a graphical overview of Denmark and the counties.

We defined urban counties as counties in which the largest city is inhabited by more than 100,000 persons and comprised at least one third of the total population in the county. Rural counties were those that did not meet the criteria for an urban county. West Denmark was defined as counties in Jutland. East Denmark was defined as the rest of Denmark.

Sudden unexpected death was defined as all sudden deaths of presumed natural cause, in *witnessed cases* as an acute change in cardiovascular status with time to death being less than 1 h and in *unwitnessed cases* as death in a person last seen alive and functioning normally less than 24 h before being found.

## Statistical analysis

Differences between the counties were tested with the chi-square test or Fisher's exact test for categorical data where appropriate.

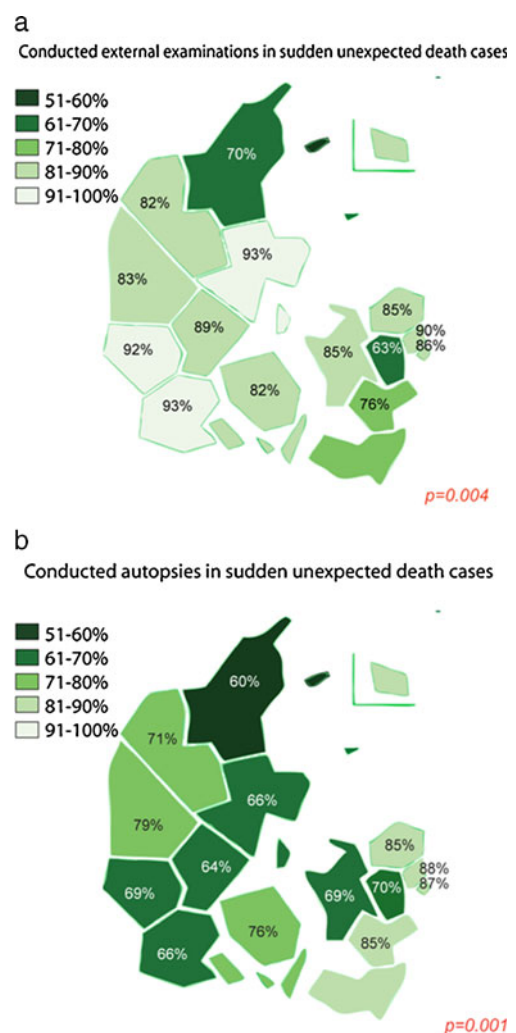
## Results

The 14 counties in Denmark had between 224,000 and 619,000 inhabitants as of January 2006. In the study period, Denmark had a mean population of 5.38 million inhabitants, of whom 2.38 million were in the age group 1–35 years. Four counties were defined as urban.

There were a total of 6,396 young Danes (1–35 years of age) dying within Danish borders in the 7-year study period. A flow chart is provided in Fig. 2. We identified a total of 625 sudden unexpected deaths, 469 (75%) of which underwent autopsy (Table 1). Autopsy rate was higher for the 1–19 years old (81%) than for the 20–35 years old (73%).

## External examinations

A total of 526 external examinations were conducted (84% of all sudden unexpected deaths). Of these, 419 (80%) resulted in a forensic autopsy (Table 2 and Fig. 3a). The ratio of external examinations conducted varied between 63% and 93%, mean 84%. The ratio of external examinations resulting in a forensic autopsy varied between 58% and 96%, mean 80%.



**Fig. 3** The counties in Denmark are shown in scaled colours. **a** Conduction of external examinations in sudden unexpected death, i.e. in how many deaths were the police requesting a death scene investigation thereby involving the medical officer of public health ensuring a thorough examination of the death and **b** total autopsy rate (forensic and hospital autopsies) of sudden unexpected death, i.e. how many of the sudden unexpected death cases were autopsied in each county

External examinations were conducted more frequently in urban counties than in rural counties (88% vs. 81%,  $p=0.014$ ; Fig. 3). No statistic difference was present between East and West Denmark (83% vs. 85%,  $p=0.44$ ).

Urban counties and counties in Eastern Denmark both had significantly higher ratios of external examinations, resulting in forensic autopsy, than their counterparts (85% vs. 75%,  $p=0.005$ , and 89% vs. 68%,  $p<0.0005$ , respectively; Table 3).

#### Distribution of autopsy rates

There was a statistically significant difference in autopsy ratio between the Danish counties (varying between 60% and 88%, Table 1 and Fig. 3b). Significant differences between autopsy ratios were also found when comparing urban vs. rural areas (autopsy ratios of 80% and 71%, respectively;  $p=0.009$ ) as well as Eastern Denmark vs. Western Denmark (82% vs. 66%,  $p<0.0005$ ; Table 3).

## Discussion

Ideally, all sudden unexpected deaths in young persons should undergo a thorough investigation, including an

autopsy [13–15]. This is obvious because young persons dying a sudden (cardiac) death are often harbouring a genetic predisposition for the death [5, 7, 9–11, 16, 17]. Hence, trying to establish a cause of death is important because family members may be eligible for life-saving therapy. In addition, establishment of a non-inherited cause of death is equally important in the subsequent advice of the family of the deceased [18, 19].

Each country has its own law stating who should be autopsied [20]. In Denmark, we have 34 medical officers of public health and a few forensic pathologists, who together carry out all external examinations. In addition, we have three forensic institutes carrying out autopsies in a very standardized and thorough manner. Together, these three forensic institutes cover the entire Denmark.

By law, all sudden and unexpected deaths must undergo at least an external examination. All taken together, this should ensure a high quality in the investigation of sudden unexpected death victims in Denmark. Despite this, we document significant differences in both external examinations as well as conducted autopsies.

We found significant differences between counties in regard to conducted external examinations, how many of these were autopsied in a forensic setting and the overall

**Table 3** Subdivision of Denmark in urban vs. rural counties and East vs. West Denmark for means of comparison

<b>Difference in conducted external examinations (625 sudden unexpected deaths)</b>	<b>Conducted examinations/total</b>	<b>% conducted</b>	<b><i>p</i> value</b>
Urban areas	251/285	88	
Rural areas	275/340	81	0.014
East Denmark	286/344	83	
West Denmark	240/281	85	0.44
<b>Difference in external examinations resulting in forensic autopsy (526 examinations)</b>	<b>Conducted for. autopsies/total exams</b>	<b>% conducted</b>	<b><i>p</i> value</b>
Urban areas	213/251	85	
Rural areas	206/275	75	0.005
East Denmark	255/286	89	
West Denmark	164/240	68	<0.0005
<b>Difference in autopsy ratios (625 sudden unexpected deaths)</b>	<b>Autopsy/Total sudden unexpected death</b>	<b>% autopsied</b>	<b><i>p</i> value</b>
Urban areas	228/285	80	
Rural areas	241/340	71	0.009
East Denmark	283/344	82	
West Denmark	186/281	66	<0.0005

Urban counties were Copenhagen City/Frederiksberg/Bornholm, Copenhagen, Aarhus, and Funen. Rural counties were all others. East Denmark comprised Copenhagen City/Frederiksberg/Bornholm, Copenhagen, Frederiksborg, West Zealand, Storstroem, Roskilde, and Funen counties. West Denmark comprised North Jutland, Aarhus, Ribe, Ringkoebing, South Jutland, Vejle, and Viborg counties.

autopsy rates. These differences appear to be explained in part by population density and geographical issues.

The rate of external examinations conducted can be seen as a marker for how many deaths had involvement of the police and the medical officer of public health with the subsequent potential of being autopsied in a forensic setting. Because the Danish Health Law is very precise in describing which deaths should be thoroughly investigated by means of an external examination, we were surprised and worried to find significant differences in this aspect.

The interpretation of the Danish Health Law in regard to when to perform a forensic autopsy is more complex. While *mode of death* is typically well established, *cause of death* is not. Uncertainty in regard to *cause of death*, however, does not automatically result in a forensic autopsy—the police have to solicit it. This decision might be influenced by several parties such as the medical officer of public health, the relatives, and/or the head of police: The medical officer of public health will provide the police with a medical point of view; the relatives might be reluctant to have an autopsy performed and perhaps forbid it (forcing the police to present the case to a judge if they still want to proceed with a forensic autopsy), and the local head of police might have a general opinion as to how the law is interpreted and what is traditionally done in a case like this.

To our knowledge, no other study has looked at regional differences in autopsy rates among young sudden unexpected death cases, but one previous study from Ireland reported an autopsy rate in young sudden unexpected death cases to be 76%, which is similar to ours, 75% [1, 4]. In our study of SCD in the young, we found the incidence rate to be higher than previously reported (2.8 per 100,000 person-years vs. 1.0–1.9 per 100,000 person-years in Italy, Netherlands, and UK) when including the non-autopsied cases [1, 21–23]. Interestingly, when we subtracted the non-autopsied cases, we got an incidence rate of 1.9 per 100,000 person-years, thereby being in concert with the previously reported rates. Non-autopsied cases therefore might play a significant role not only in Denmark. We do not know whether the Danish system is better or worse than other countries' way of handling these deaths, but at least in the Scandinavian countries, the medico-legal investigative system is to some extent comparable [24].

In our study, we document large differences between the counties. For instance, in Copenhagen City, where the external examination is carried out by the forensic pathologists, there were a high autopsy ratio (87%), high ratio of external examinations (86% of all sudden unexpected deaths), and a high ratio of external examinations resulting in a forensic autopsy (96% of all external examinations). In contrast, North Jutland had an autopsy

ratio of 60%; external examinations were carried out in 70% of sudden unexpected death cases, and 64% of all external examinations resulted in a forensic autopsy. The regional differences found in our study suggest that the same law is not uniformly respected and interpreted throughout a country. This might not be unique for Denmark. Possible explanations, although it remains speculative, could be socioeconomic factors and/or local factors (i.e. local police). Socioeconomic factors are known to be associated with the risk of cardiovascular disease and SCD with a more marked effect among individuals younger than 65 years [25–27]. It is, however, unknown whether socioeconomic factors influence the autopsy ratio of sudden unexpected deaths in the young. Unfortunately, we were not able to adjust for socioeconomic status in the present paper. It is a potential weakness of the Danish forensic system that the police will have to solicit the autopsy of a sudden natural unexpected death, when in fact they might not have any interest in this from a police investigative point of view. A system that grants more decisive weight to the medical perspective would perhaps be beneficial. In addition, the information to the relatives underlining the importance of an autopsy needs to be optimized and, ideally, should be carried out by qualified physicians.

## Conclusion

For the first time, we demonstrate that despite a uniform law, there are regional differences in the rates of external examinations and autopsy rates in cases of young sudden unexpected death. Rates are greater in urban than rural areas, and in Eastern Denmark. We believe that autopsy should be mandatory in all cases of sudden unexpected death in the young. The final decision in this aspect should be made by a qualified physician.

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