



Nationwide study of sudden cardiac death in persons aged 1–35 years

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Aims

The aim of this investigation was to study the incidence of sudden cardiac death (SCD) in persons aged 1–35 years in a nationwide setting (5.38 million people) by systematic evaluation of all deaths.

Methods and results

All deaths in persons aged 1–35 years in Denmark in 2000–06 were included. Death certificates were read independently by two physicians. The National Patient Registry was used to retrieve information on prior medical history. All autopsy reports were read and the cause of death was revised based on autopsy findings. We identified 625 cases of sudden unexpected death (10% of all deaths), of which 156 (25%) were not autopsied. Of the 469 autopsied cases, 314 (67%) were SCD. The most common cardiac cause of death was ischaemic heart disease (13%); 29% of autopsied sudden unexpected death cases were unexplained. In 45% of SCD cases, the death was witnessed; 34% died during sleep; 89% were out-of-hospital deaths. Highest possible incidence rate of SCD in the young was 2.8 per 100 000 person-years including non-autopsied cases of sudden unexpected death. Excluding those, the incidence rate declined to 1.9 per 100 000 person-years.

Conclusions

A total of 7% of all deaths in the young can be attributed to SCD, when including non-autopsied cases (autopsy ratio 75%). The incidence rate of SCD in the young of 2.8 per 100 000 person-years is higher than previously reported.

Keywords

Sudden death • Epidemiology • Young • Pathology • Registries • Autopsy

Introduction

Sudden cardiac death (SCD) in the young, although presumably rare, is always a tragic and devastating event often occurring in apparently healthy persons. Through the last decades, researches have been undertaken to estimate the incidence rate and underlying causes of these deaths. Nonetheless, the studies have been few, total number of deaths studied has been low, and the incidences of SCD together with the causes of death determined by autopsy have varied greatly among the studies.^{1–9} The discrepancy between the reported results might in part be explained by different study designs. For instance, incidence rates have often been based on findings in one forensic department or a region of a

country with data being obtained either prospectively or retrospectively and almost exclusively from autopsied decedents. Because autopsy is not always conducted, there is a potential bias in the incidence rates reported. To our knowledge, no prior study has systematically investigated all deaths in a nationwide setting by reviewing all death certificates, autopsy reports, and registry entries on previous known disease.

In this study, we chart nationwide incidence rates of SCD in the young in Denmark. We address the autopsy ratio in sudden unexpected death, differences among autopsied and non-autopsied cases, autopsy results among SCD cases, and describe differences between explained SCD and sudden unexplained death (SUD) cases.

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Methods

Study design

The study was a nationwide retrospective study using the availability of all death certificates, the registration of all in- and outpatient activity on Danish hospitals and emergency rooms together with access to medical records and autopsy reports. All deaths in persons aged 1–35 years in Denmark in 2000–06 were included. Death certificates, retrieved as scanned computer files, were read independently by two physicians to identify cases of sudden unexpected death. In cases of disagreement, the two investigators re-evaluated the death certificate together to reach a consensus.

Danish death certificates include a *supplemental information field* describing the circumstances surrounding the death including interview with eyewitnesses and relatives, previous medical conditions, an external examination of the body, and the preliminary conclusion before autopsy. The supplemental information field is large, giving space for a thorough description. This field is mandatory in all medico-legal external examinations, regardless of whether an autopsy is performed or not. A representative example of a Danish death certificate is provided as a supplementary file (see Supplementary material online, 1). In the example, 14 lines of text with a total word count of 226 are written in the field.

Information on prior medical history was retrieved both from the death certificate and from the National Patient Registry, which contains information on all in- and outpatient activity at Danish hospitals and emergency rooms including International Classification of Diseases (ICD)-10 diagnosis codes for each visit. The number of deaths autopsied was ascertained, and all autopsy reports were collected and read. The cause of death was revised based on autopsy findings. In case of uncertainty regarding the cause of death after review of the autopsy report, the entire case in all its contents was reviewed by and discussed with a forensic pathologist.

In selected cases, hospital records were also collected to further elucidate the circumstances relating to the death.

The observed incidence rate of SCD was compared with the official statistics in Denmark as provided in the Cause of Death Registry.

The study was approved by the local Ethics Committee (KF 01 272484), The Danish Data Protection Agency (2005–41–5237), and the Danish National Board of Health (7–505–29–58/1–5).

Death certificate data

All persons born in Denmark or living permanently in Denmark are given a unique National Person Registry ID. This ID is utilized for all healthcare-related services. When a person dies, a death certificate is always issued if the death occurred within Danish borders. The death certificate can only be issued by a medical doctor (physician). In case a person is found dead and/or the death is sudden and unexpected, a medico-legal external examination (in the following referred to as external examination) is mandatory. It is performed by the police and one of the 34 medical officers of public health (who are certified physicians) and includes a standardized 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. The medical officer of public health always has access to (i) first responder [emergency medical service (EMS)] records, (ii) the medical files related to the death (if any), (iii) the entire police record including all witness statements, and (iv) the body. Furthermore, additional data, i.e. medical files from previous admissions, are retrieved in cases where this is deemed necessary. Whenever an external examination is carried

out, the *supplemental information field* on the Danish death certificate, therefore, provides at a minimum (i) a summary of existing diseases and the physical condition prior to death as described by relatives, (ii) a description of the events immediately preceding the death as described by witnesses, (iii) a summary of the actions taken by the EMS on the scene, and (iv) what actions were taken at hospital (if any).

Conduction of autopsies

In Denmark, forensic autopsy is to be performed in cases where the external examination concludes that the mode of death is not established. There are three Departments of Forensic Medicine conducting together ~1500 autopsies/year. All autopsies are being supervised by another forensic pathologist. Forensic autopsies follow a standardized protocol, in which all organs are examined. Toxicology screens are performed in unexplained adolescent and adult cases of sudden unexpected death.

In addition to forensic autopsies, autopsies are also conducted at local hospital pathology departments. The *hospital autopsies* are conducted if the police did not request an autopsy (or an external examination was not performed), and it is requested by the relatives and the physician.

The diagnoses of arrhythmogenic right ventricular cardiomyopathy (ARVC), hypertrophic cardiomyopathy (HCM), myocarditis, fibrosis in the heart, connective tissue disease, Takayasu arteritis, and conduction abnormalities require confirmation by histopathology. Arrhythmogenic right ventricular cardiomyopathy requires fibrofatty replacements at histopathology. Hypertrophic cardiomyopathy requires the presence of the disarray of myofibrils.

Definitions

Applying the generally accepted criteria and current knowledge,^{10–12} we defined SCD in *autopsied cases* as the sudden, natural unexpected death of unknown, or cardiac cause; in *unwitnessed cases* as a person last seen alive and functioning normally <24 h before being found dead and in *witnessed cases* as an acute change in cardiovascular status with the time to death being <1 h.

The group of *autopsied SCD*, hence, was subdivided into two groups: (i) *explained SCD*, where a cardiac cause of death was established at autopsy, and (ii) *SUD*, where the cause of death remained unknown after autopsy.

In *non-autopsied deaths*, we used the same criteria as above in cases presumed to be of cardiac cause based on the circumstances relating to the death. A prior medical history was not an exclusion criterion, but was taken into account in every single case. If concurrent disease was considered to be a potential or likely causative explanation to death, the case was not considered an SCD. The group of *autopsied SCD* was pooled with the group of *non-autopsied sudden unexpected deaths* to give the highest possible estimate of SCD in the young. For descriptive purposes, this group is described as the SCD population in this study.

A previous medical history was defined as known heart disease, major mental and/or physical disabilities (i.e. birth defects), or chronic diseases associated with increased risk of cardiovascular disease (i.e. diabetes).

Explanations to the terms used are listed in *Table 1*.

Statistical analysis

Incidence rates were calculated based on the mean resident population of Danes aged 1–35 years in 2000–06 as provided by Statistics Denmark.¹³

Table 1 Explanation of the different terms used

Term	Explanation
Sudden unexpected death	Sudden unexpected death possible due to a cardiac cause, after review of death certificate
Non-autopsied sudden unexpected death	Non-autopsied cases of sudden unexpected death, after review of death certificates and previous medical history
Autopsied SCD	SCD concluded after review of autopsy report, consists of cases of both explained SCD and sudden unexplained death
Explained SCD	Subgroup of autopsied SCD where cardiac cause of death is established at autopsy
Sudden unexplained death, SUD	Subgroup of autopsied SCD where cause of death remains unknown after autopsy
SCD population	Autopsied SCD and non-autopsied sudden unexpected death pooled together

SCD, sudden cardiac death.

Differences between explained SCD and SUD as well as autopsied SCD and non-autopsied sudden unexpected death were tested with the χ^2 test or Fisher's exact test for categorical data, and for continuous data with Student's *t*-test or Wilcoxon rank-sum test. All tests were two-sided and a significance level of $P = 0.05$ was used. We used Stata 11 (Statacorp, USA) for all analyses.

Results

Review of death certificates

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. The population was predominantly white (88%).¹³ In the 7-year study period from 2000–06, there were 6629 deaths among persons aged 1–35 years. In total, 6396 death certificates were issued during this period. The 233 missing death certificates represented Danes dying outside Danish borders, and deaths in Greenland, which is part of Denmark but not included in this study. We reviewed all 6396 death certificates. A total of 64 deaths were excluded due to incomplete death certificates. The remaining 6332 deaths (99%) were included in the study.

Sudden cardiac death population

From the review of death certificates, we identified 625 sudden unexpected death cases (flowchart provided in Figure 1). In 526

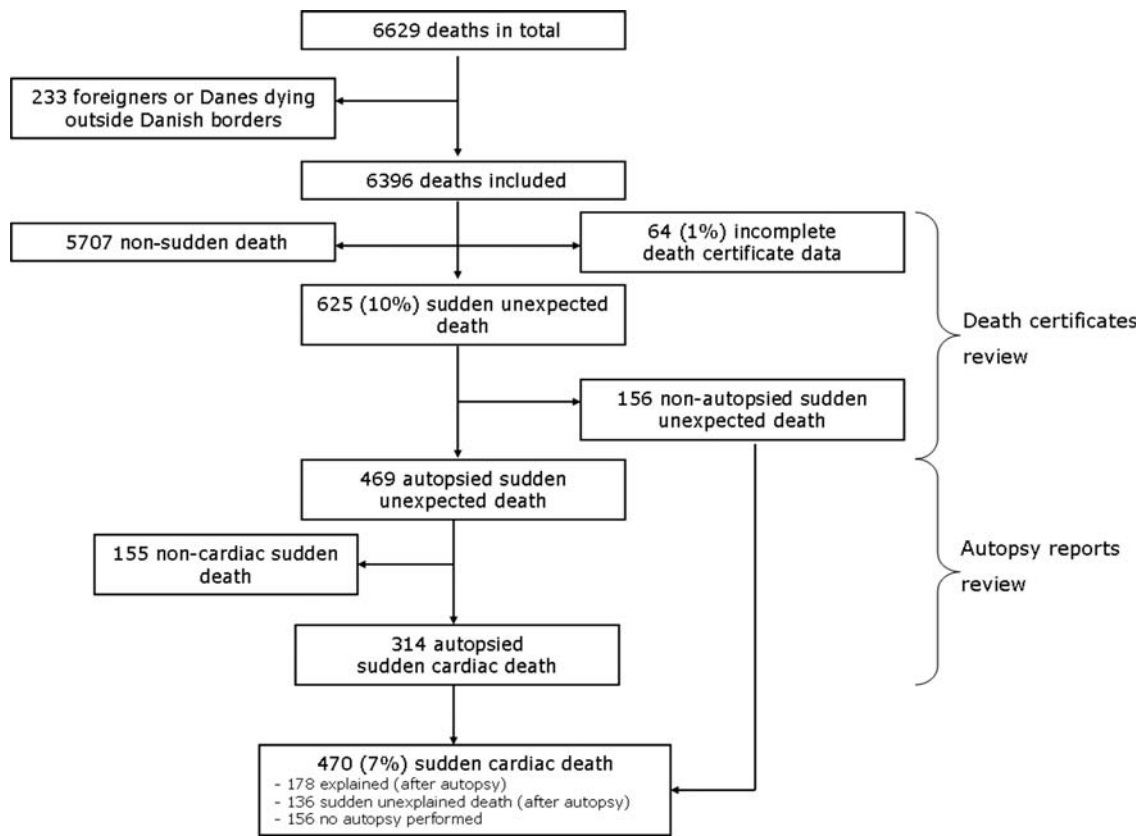


Figure 1 Flowchart of the review of death certificates and autopsy reports in persons aged 1–35 years in Denmark 2000–06.

of these (84%) an external examination was conducted. Of the 625 sudden unexpected death cases, 156 were not autopsied, 469 were autopsied. Thus, the autopsy ratio was 75%. Of the autopsied cases, 419 (89%) autopsies were conducted in one of the three Forensic Pathology Departments in Denmark, while the remaining 50 (11%) were conducted in a hospital pathology department.

After reviewing all autopsy reports on those with sudden unexpected death ($n = 469$), 155 (33%) were found to have died a sudden non-cardiac death. We identified a total of 470 SCD (7.3% of all deaths): 314 autopsied cases and 156 non-autopsied cases. Of the autopsied SCD cases, histopathology was done in 301 cases (96%); 4 cases of SUD (3%) did not have histopathology performed. A toxicology screen was performed in 112 of the 136 (82%) SUD cases. None of the SUD cases had a toxicological profile that the forensic pathologists concluded could explain their death. Of the performed toxicology screens, 71 (63%) was negative. A total of 7 cases (6%) had alcohol detected, 10 (9%) had traces of cannabis, and 2 (2%) had traces of cocaine. Of prescribed drugs, 13 (12%) had methadone detected and 28 (25%) had other prescribed drugs detected. In total, 16 (14%) had one compound detected at the toxicology screen, while 25 (22%) had more than one compound detected.

There was a male predominance (67% male vs. 33% female). The median age of the SCD population was 29 years; see age distribution in Figure 2. No difference in age distribution between males and females was found (not shown). Of the SCD group, 61% had no previous medical history.

Increasing age was associated with significantly increased risk of dying from SCD as shown in Figure 2. For every decade, the risk of SCD roughly doubled in relation to the previous decade. The risk of dying of SCD was >10 times higher for persons aged 30–35 years than for persons aged 1–10 years.

Place of death was in 68% of SCD cases at home; 11% were in-hospital deaths. Of these in-hospital deaths, 27% collapsed and died in the emergency room, while 63% died sudden and unexpectedly during hospitalization. Table 2 provides details on the

SCD population. Cause of death was structural heart disease in 178 of the autopsied cases; in 136 autopsied cases the death remained unexplained. The causes of death in the 314 autopsied cases of SCD are shown in Figure 3.

Autopsied sudden cardiac death vs. non-autopsied sudden unexpected death

Comparing the autopsied SCD cases with the non-autopsied sudden unexpected death cases (Table 3), there was a higher percentage of witnessed deaths in the autopsied group than in the non-autopsied group (50 vs. 35%, $P = 0.002$). Autopsied cases had no previous medical history more frequently than non-autopsied cases (74 vs. 37%, $P < 0.0005$) and more frequently died during sleep (33 vs. 24%, $P = 0.036$). Autopsied cases were also younger (28 vs. 30 years, $P = 0.0039$).

Explained sudden cardiac death vs. sudden unexplained death

Likewise, comparing the cases of SCD explained by autopsy with the SUD cases, we found a higher proportion of the explained deaths being witnessed (62 vs. 34%, $P < 0.0005$), fewer of the explained deaths died during sleep (24 vs. 46%, $P < 0.0005$), and more male deaths were explained (72 vs. 60%, $P = 0.023$).

Incidence rates

The highest possible annual incidence rate of SCD in persons aged 1–35 years in Denmark was 2.8 per 100 000 person-years with a higher male than female incidence rate (3.7 vs. 1.9; Table 4). Excluding non-autopsied sudden unexpected death cases, the incidence rate declined to 1.9 per 100 000 person-years. Of these, 1.1 per 100 000 were explained SCD upon autopsy.

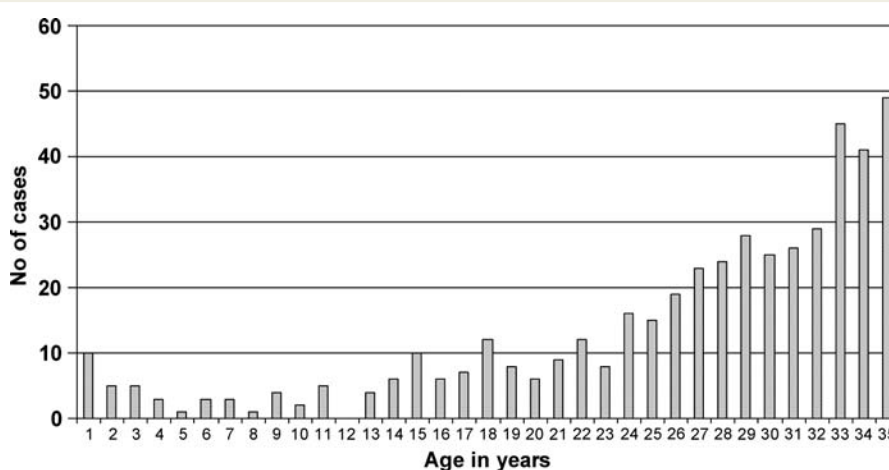


Figure 2 Age-related distribution of 470 sudden cardiac deaths in persons aged 1–35 years in Denmark 2000–06. Male deaths constituted 67% of all sudden cardiac deaths. There were no differences in the age distribution between males and females (data not shown).

Table 2 Results from autopsy reports. Places of death and activity at time of death in cases of sudden cardiac death in persons aged 1–35 years in Denmark in 2000–06

SCD (n = 470)	n	%
Explained SCD (after autopsy)	178	
Sudden unexplained death (SUD)	136	
Non-autopsied sudden unexpected death	156	
Total SCD	470	7.3
Ratio of explained SCD or SUD after autopsy (%)	67	
Median age, years	29 (IQR: 22–33)	
Witnessed deaths, n (%)	211 (45)	
Place of death, (n = 417)	n	~%
At home	285	68
In-hospital deaths	44	11
of which death in emergency room	12	3
of which death during hospitalization	32	8
Public area	73	18
At work	15	4
Activity at death, (n = 409)	n	~%
Awake and relaxed	206	50
Sleeping	141	34
Eating	7	2
Moderate to high intensity activity including sport	43	11
At general practitioner	4	1
Waken up by loud noise	2	0
Aroused state of mind (exaltated)	3	1
Shower	3	1

IQR, inter-quartile range.

Validation of the Danish Cause of Death Registry and the use of death certificates as a predictor of the incidence of sudden cardiac death

We validated the Cause of Death Registry by comparing the cause of death after reading the autopsy report in those deaths that were explained SCD (i.e. cardiac cause of death was established at autopsy; $n = 178$) with the ICD-10 criteria denoting cardiovascular or ill-defined causes (I10–52, I70–99, Q20–28, R00–53, and R55–99) in the Cause of Death Registry. The registry correctly categorized 146 of the 178 explained SCD cases (82%), 3 of which were ill-defined causes (R00–53 and R55–99). In 32 cases (18%), the above-mentioned ICD-10 classification codes were not used; instead there was an even distribution throughout the ICD-10 coding system (except cancer diagnoses). When including the deaths that were termed SUD after autopsy (autopsy-

negative), the Cause of Death Registry correctly grouped 238 of the 314 cases (76%). Ill-defined causes accounted for 22% of the deaths in this group.

In total, the Cause of Death Registry registered 716 deaths with cardiovascular or ill-defined causes, but no information exists in the registry as to whether a death is sudden and unexpected, and thus this aspect could not be validated.

We identified a total of 625 sudden unexpected death cases from the review of death certificates. Of these, 314 deaths were SCD after autopsy. Thus, the positive predictive value of the initial review of death certificates was 50%.

Discussion

The diagnosis of SCD can be elusive and the incidence in the young has been difficult to establish. Incidence rates have varied greatly possibly due to geographically, ethnically, socioeconomically, and culturally distinct patterns influencing disease and death in different parts of the world in combination with different designs of the studies.^{1–9,14–19} The aim of our study was to chart SCD in the young in a nationwide setting and provide figures for the incidence rate of SCD.

Previously, it has been shown that the use of death certificate-derived data for identifying SCD in the USA yielded a sensitivity of 59% and a positive predictive value of a mere 19%.²⁰ Even though that study had a different study population (mean age of 81 vs. ours mean age of 29 years), this would naturally lead to concern whether our initial use of death certificates would be a reliable method. However, the Danish death certificate, unlike the USA death certificate,²¹ allows for extensive additional information, thereby making the Danish death certificates suitable to be a primary screening tool for identification of sudden unexpected death in the young. This information is always provided in the case of an external examination and is usually provided to some extent also in the absence of an external examination. It is noteworthy that an external examination was carried out in 84% of all sudden unexpected death cases and the autopsy ratio was 75% in our study.

The positive predictive value of identifying SCD from death certificates was 50% in our study. This was calculated using only autopsied cases as the numerator and as such could never exceed the autopsy ratio of 75%. In essence, this suggests that death certificates contain a high level of information in our study. While this is sufficient information with regard to identifying *sudden unexpected death* cases, it is insufficient information to identify SCD cases, especially SUD cases, as one-third of autopsied sudden unexpected death cases turned out not to be SCD but rather sudden death by other causes. With the method we used, we were able to go beyond the inherent weaknesses of using only death certificates or the Cause of Death Registry as the means of describing SCD.

We found a significant proportion of deaths (11%) occurring in-hospital. In addition, 34% died during sleep. Taken together, this warrants for caution in the interpretation of figures that rely solely on out-of-hospital deaths and/or witnessed deaths as they are likely to underestimate the incidence of SCD.

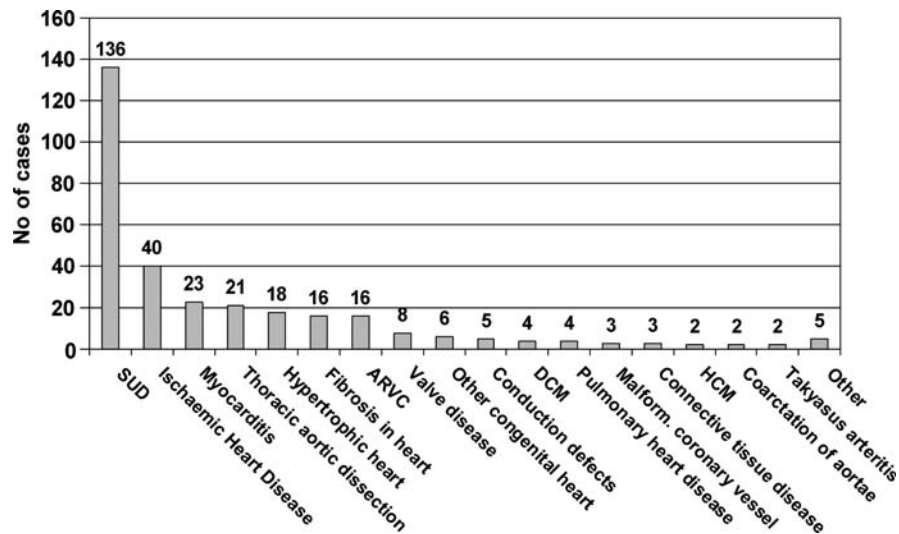


Figure 3 Distribution of the causes of death in the 314 autopsied cases of sudden cardiac death in persons aged 1–35 years in Denmark in 2000–06. SUD, sudden unexplained death; ARVC, arrhythmogenic right ventricular cardiomyopathy; DCM, dilated cardiomyopathy; HCM, hypertrophic cardiomyopathy.

Table 3 Comparison of cases of young autopsied sudden cardiac death and non-autopsied sudden unexpected death, as well as explained sudden cardiac death and sudden unexplained death cases in Denmark in 2000–06

SCD (n = 470)	Autopsied (n = 314) (%)	Non-autopsied (n = 156) (%)	P-value
No previous medical history	232 (74)	57 (37)	<0.0005
Male	211 (67)	105 (67)	0.981
Female	103 (33)	51 (33)	
Median age (years)	28 (IQR: 21–33)	30 (IQR: 26–33)	0.0039
Witnessed deaths	157 (50)	54 (35)	0.002
Death during sleep	104 (33)	37 (24)	0.036
Previous medical history, groups (%)	26	63	
Known disease	51 (16)	48 (31)	
Congenital heart disease	19 (6)	21 (13)	
Acquired heart disease	12 (4)	30 (19)	
Autopsied SCD (n = 314)	Explained SCD (n = 178) (%)	Sudden unexplained death (n = 136) (%)	P-value
No previous medical history	128 (72)	104 (76)	0.362
Male	129 (72)	82 (60)	0.023
Female	49 (28)	54 (40)	
Median age (years)	28 (IQR 22–33)	27 (IQR 20.5–32.5)	0.57
Witnessed deaths	111 (62)	46 (34)	<0.0005
Death during sleep	42 (24)	62 (46)	<0.0005
Previous medical history, groups (%)	28	24	
Known disease	21 (12)	30 (22)	
Congenital heart disease	18 (10)	1 (1)	
Acquired heart disease	11 (6)	1 (1)	

IQR, inter-quartile range.

Table 4 Incidence rates for sudden cardiac death in persons aged 1–35 years

Annual incidence rates of SCD (per 100 000)	Total	Male	Female
1–35 years old (population 2.38 million)			
SCD, including non-autopsied cases	2.8	3.7	1.9
Autopsied SCD	1.9	2.5	1.3
of which unexplained after autopsy (SUD)	0.8	1.0	0.7
Out-of-hospital SCD	2.6		
Autopsied, witnessed SCD	0.9		

Consistent with previous data ischaemic heart disease was the most frequent cause of SCD in our study (11%).¹ The incidence of HCM <1% ($n = 2$) in our data was seemingly low compared with previous studies, who report incidences between 6 and 13%.^{6,8,15,18} However, these studies did not report idiopathic fibrosis (IF) and left ventricular hypertrophy (LVH), except for one study, which reported HCM to be 6% and LVH to be 3%.⁶ If we include LVH and IF in the definition of HCM, our incidence would increase to 9% ($n = 18$ and $n = 16$, respectively), thereby being in concert with the other studies. It has previously been shown that some of these LVH and IF may clinically have been diagnosed as HCM.^{22,23}

Arrhythmogenic right ventricular cardiomyopathy accounted for 5% of autopsied SCD in our study. Although less frequent when compared with the Italian Veneto region (13% of sudden cardiovascular deaths),¹⁵ it is a significant cause of SCD in the young in Denmark.

Like previous studies, SUD is frequent in our study (29% of autopsied sudden unexpected death cases).^{4–6,14} This high frequency might in part reflect the young median age, as older populations have fewer unexplained cases.²⁴ Even though 37% of the SUD cases had a positive toxicology, in the majority of cases, it was either prescribed drugs in therapeutic concentrations or illegal drugs in trace amounts. It could be speculated, though, that some drugs, even in therapeutic concentrations, could have caused a fatal arrhythmia through i.e. prolongation of the QT interval.^{25,26} The SUD victims in our study were the same median age as the explained SCD victims (27 vs. 28 years), but the deaths were less likely to be witnessed (34 vs. 62% SCD cases). In addition, a larger proportion of SUD died during sleep (46 vs. 24%). A similar observation has been reported previously.⁵ Some of these persons may harbour disease causing mutations in, for instance, the *KCNQ1* and *SCN5A* genes known to be associated with death during sleep due to primary arrhythmogenic diseases like the long QT syndrome and the Brugada syndrome.^{27,28} In line with this, previous studies have demonstrated that in case of an SUD, a close family evaluation and/or a genetic testing might determine the aetiology of the death.^{27,29–31}

Including the non-autopsied deaths in our incidence rates is somewhat controversial, especially when comparing our figures with studies that report from autopsied cases only. It was imperative for us, though, to report as true figures as possible on the magnitude

of SCD in the young, and based on the information on the death certificates and prior disease as recorded in the National Patient Registry, we are certain that these 156 non-autopsied cases died suddenly and unexpectedly. Even though our non-autopsied group was not directly comparable with the autopsied group, it is likely that the majority of the non-autopsied cases of sudden unexpected death would in fact have been attributed to SCD or SUD if they had been autopsied. In support of this, we found that 67% of the autopsied sudden natural deaths were categorized as SCD when data from autopsies were reviewed. These findings are consistent with previous studies of sudden deaths in the young.^{1,6,15}

The highest possible incidence rate of SCD we report are 2.8 per 100 000 person-years. Although still low, this is higher than previously reported. In the Italian studies from the Veneto region, there was an incidence rate of 1.0 per 100 000 person-years,¹⁵ in the Netherlands, it was 1.6,¹ and in the UK 1.8 per 100 000 person-years.¹⁷ The discrepancy might not be so surprising, since we have included non-autopsied cases of sudden unexpected death. Excluding those would make the incidence rate decline to 1.9 per 100 000 person-years in our study. This is in concert with reported incidence rates from The Netherlands and the UK but not from the Veneto region (1.6–1.9 vs. 1.0). This is probably because some non-athlete deaths are overlooked in the Italian study as pointed out by the authors themselves.¹⁶ A contributing factor might also be the difference in time limits (ours <24 h vs. the Italian study's <1 h). The difference in age ranges studied (1–35 vs. 12–35 years), though, should have produced higher incidence rates in the Italian study.

On the basis of the validation of the Cause of Death Registry, we conclude that we in Denmark cannot rely solely on the information on the cause of deaths in the registry when it comes to identifying SCD cases. We found that 24% of all autopsied cases of SCD or SUD were not categorized in the Cause of Death Registry with an ICD-code denoting cardiac or ill-defined cause of death. This might not be a unique problem for Denmark. Careful measures therefore should be taken when information is retrieved only from selected deaths derived from cause of death registries. In addition, most cause of death registries suffer from the inherent weakness of not registering whether a death was sudden and unexpected.

It is a limitation of the study that it is retrospective in design. While it was easy to extract data on whether or not a death was witnessed and the person was seen alive <24 h prior to death, it was difficult to assess more precise time limits (i.e. <1 h) in many of the unwitnessed cases. A prospective design would have had a more uniform registration of relevant data. Likewise, we are using the extraction of data done by the medical officers of public health (as provided on the death certificates) for the identification of sudden unexpected death cases. The officers of public health, however, are highly skilled within their field. We therefore rely on these data being as accurate as if we had read the EMS records, the hospital files, and the police records ourselves.

Conclusion

This nationwide study of SCD in the young found a higher than previously reported incidence rate of SCD—up to 2.8 per

100 000 person-years—including non-autopsied cases (autopsy ratio 75%). This corresponds to 7% of all deaths in persons aged 1–35 years. In 29% of autopsied sudden unexpected deaths, no cause of death was found, suggesting a primary arrhythmogenic cause of death. The most common cause of SCD was ischaemic heart disease. The Cause of Death Registry failed to identify one in four young SCD cases.

Supplementary material

Supplementary material is available at *European Heart Journal* online.

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Conflict of interest: none declared.

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