Heart failure describing the underlying cause of death – a misconception, lack of

information on the true underlying causes or both?

Running title: HF as underlying cause of death

Gerhard Sulo^{1,2} MD, PhD; Christian Lycke Ellingsen^{2,3} MD; Enxhela Sulo⁴ MD, PhD;

Mohsen Naghavi⁵ MD, PhD; Stein Emil Vollset⁵ MD, Dr.PH.

1. Centre for Disease Burden, Division of Mental and Physical Health, Norwegian Institute of

Public Health, Norway

2. Department of Global Public Health and Primary Care, University of Bergen, Norway

3. Department of Pathology, Stavanger University Hospital, Norway

4. Department of Heart Disease, Haukeland University Hospital, Bergen, Norway

5. Institute for Health Metrics and Evaluation (IHME), University of Washington, WA, US.

Corresponding author

Gerhard Sulo, MD, PhD

Centre for Disease Burden, Division of Mental and Physical Health, Norwegian Institute of

Public Health, Norway

Zander Kaaesgate 7, 5015 Bergen, Norway

Phone: +47 21 07 80 17

E-mail: Gerhard.Sulo@fhi.no

1

ABSTRACT

Aim: The underlying cause of death (UCoD) represents the most important information on death certificates. Often, conditions that cannot represent a true UCoD are listed as such. This phenomenon affects the quality of vital statistics and results of studies using cause-specific mortality endpoints. We aimed at exploring the magnitude and factors associated with use of HF to describe the UCoD.

Methods: In this cross-sectional, register based study we linked data from Cause of death Registry and Norwegian Patient Registry. We used logistic regression models to analyze the association between external factors and HF listed as the UCoD.

Results: HF was listed as the UCoD in 3.6% of all deaths. The odds of HF increased i) by 35% for 5-year increment in age, ii) by 78% for deaths occurring at nursing homes (compared to in-hospital deaths) and iii) by 602% for deaths not followed by an autopsy (compared to those followed by an autopsy). Deceased with a previous hospitalizations with HF as discharge diagnosis had 514% higher odds of having HF listed as their UCoD.

Of the deceased with HF listed as the UCoD, 9.4% did not have, and, 69.2%, had only irrelevant additional information for assessing the true UCoD in their death certificates.

Conclusions: HF listed as the UCoD was associated with age, place of death, autopsy and previous hospitalizations – all factors that should not influence coding procedures. Better completion of death certificates in accordance with the WHO rules will help reduce use of HF to describe the UCoD.

Key words: Heart failure, garbage codes, mortality, Norway, underlying cause of death

INTRODUCTION

Effective strategies to prevent deaths require sufficient information on conditions causing them. In this context, the underlying cause of death (UCoD) is a key concept. The UCoD is defined as 'the disease or injury which initiated the train of morbid events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury'.

The International Classification of Diseases (ICD), 10th revision, published by World Health Organization (WHO) provides guidance and explains the rules and procedures for correctly selecting the UCOD.¹ However, these rules are not properly followed in many cases. Consequently, conditions that cannot represent the true UCoD are listed as such in death certificates. In the context of the Global Burden of Disease (GBD) Study, Murray and Lopez introduced the term 'garbage codes' (GC) to describe the practice of assigning the UCoD to causes that are not useful for public health analysis² due to the fact that they are not specific enough, represent an immediate or intermediate cause or are simply incapable of causing death.³

Heart failure (HF) is a clinical syndrome complicating various conditions such as coronary artery disease, systemic hypertension, diabetes mellitus, atrial fibrillation, and ventricular systolic dysfunction. In terms of *morbidity*, HF is a frequent source for hospitalization. It is often used as a quality indicator of hospital performance⁴ and an attractive cardiovascular endpoint in randomized controlled trials and other clinical studies. In terms of *mortality*, HF can only indicate an intermediate factor between the true underlying cause and death. As such, HF should not be used to describe the underlying cause of death (UCoD). This is explicitly emphasized in the volume 2 of the WHO's publication '*ICD-10*: *International Statistical Classification of Diseases and related health problems*'. Where HF is included in the 'Ill-defined cause of death' group. Similarly, the Global Burden of Disease (GBD) study classifies HF as a 'major garbage code' that should not be used to describe the UCoD.

Despite these instructions, HF continues to be used incorrectly as UCoD,⁵⁻⁸ indicating the global nature of this phenomenon.

Excessive use of HF (and other GCs) to describe the UCoD is an important quality indicator of mortality data. Further, extensive use of GCs distort the true pattern of cause-specific mortality. Studies have shown that replacement of HF with the true UCoD, results in important changes in the magnitude and ranking of cause-specific mortality. This is especially important for cardiovascular mortality as HF represent the most frequent GC within CVD chapter.

The main objective of our study to analyze the magnitude and identify factors associated with incorrect use of HF listed as the UCoD. The second objective was to assess the quantity and quality of information in death certificates of deceased in whom HF was incorrectly used to describe the UCoD.

MATERIALS AND METHODS

Data sources

Data from the Norwegian Cause of Death Registry (NCDR)¹¹ and the Norwegian Patient Registry (NPR)¹² were linked at the individual level using a project-specific unique ID. The NCDR contains information on sex, date, age at death, place of death, underlying and contributing causes of death and whether an autopsy (forensic or medical) was performed. The NPR contains information on patient's age, sex, admission and discharge dates as well as primary and (several) secondary discharge diagnoses.

Study design, period, and outcome

Of all deaths occurring in Norway during 1986-2015 (our study population), we identified those with a HF code [ICD-9 codes; 416-416.9, 428-428.9 and ICD-10 codes; I50-I50.9, J81-J81.1]³ listed as the underlying cause. Deaths with HF as the underlying case were the outcome of the study. The associations of various factors of interest (age at death, sex, place

of death, autopsy and previous hospitalizations) with study outcome in our cross-sectional, register-based study were explored using logistic regression analyses.

Age, place of death, autopsy, prior hospitalizations and odds of HF listed as the UCoD We reported odds ratios (OR) and 95% confidence intervals (CI) from logistic regression models for i) five-year increment in age at death; ii) out-of-hospital, compared to in-hospital deaths and iii) deaths without, compared to those followed by an autopsy.

The association between previous hospitalizations and odds of HF listed as the UCoD was explored using data from 2009 onward. This was done to allow for a minimum lookback period of one year, given that information on hospitalizations in the NPR is only available from January 1, 2008. We conducted two sets of analyses: in the first set, the odds of HF listed as the UCoD among deceased *without* a hospitalization (reference category) were compared to those *with* a non-CVD hospitalization and those *with* a CVD hospitalization. In the second set of analyses the reference category was compared with deceased who had an other-than-HF hospitalization and those *with* a HF hospitalization. Lastly, we explored whether the timing of hospitalization with regard to death date was associated with odds of HF being listed as the UCoD.

Hospitalizations during the last year of life among deceased with HF listed as UCoD We scrutinized the principal (main) discharge diagnosis of hospitalizations preceding death and qualitatively described whether these diagnoses might be of help in correctly identifying the true UCoD in these cases.

Death certificates (DC) of deceased in whom HF was listed as the UCoD

Based on the information in DC, we first identified cases without any other information beside the HF code listed as the UCoD. Of the remaining cases, we then distinguished between those *without* and *with* a 'target code' listed as immediate or intermediate cause of death. The term 'target code' refers to medical conditions, to which the 'HF deaths' should in

principle be reassigned to, based on pathophysiology or an assessment of certification practice. A list of 'target codes' for HF is provided here and summarized in the footnote of Table 4. The study was approved by the Regional Committee for Medical and Health Research Ethics South-East Norway, reference number 2013/2394. Analyses were performed using STATA software version 16.

RESULTS

HF was listed as the UCoD in 3.6% (46 808) of deaths occurring in Norway during 1986-2015 (Table 1). These deaths occurred at an older age, more often involved females and were followed less frequently by an autopsy compared to deaths coded otherwise in Norway (Table 1). The proportion of deceased with a previous hospitalization due to CVD or more specifically, to HF was also higher among deaths with HF coded as underlying cause compared to other deaths (25.3% vs 16.8% for CVD hospitalizations and 13.1% vs 2.5% for HF hospitalizations (Table 1).

The proportion of cases with HF listed as the UCoD was fairly stable over time but varied widely with age (Figure S1).

Age, place of death, education, autopsy and odds of HF listed as the UCoD (Table 2) The odds of HF being listed as the UCoD were higher among women (OR=1.08; 95% CI, 1.06-1.11) and increased with age (five years increment; OR=1.35; 95% CI, 1.34-1.36). The odds were also higher for deaths occurring in nursing homes (OR=1.78; 95% CI, 1.74-1.83) or at home (OR=1.81; 95% CI, 1.75-1.87) compared to in-hospital deaths, though these differences tended to decrease toward the end of the study period (2009-2015) compared to early years (1986-2008) (Figure S2). However, the differences in the frequency of using The odds were substantially higher (OR=6.02; 95% CI, 5.39-6.73) among cases without an autopsy compared to those followed by an autopsy. The strength and the direction of these associations were very similar in men and women (Table 2, sex-specific analyses)

Prior hospitalizations and odds of HF listed as the UCoD (Table 3)

Compared to deceased *without* a prior hospitalization, the odds of HF being listed as the UCoD were higher among deceased with a previous CVD-related hospitalization (Table 3, set one: OR=1.59, 95% CI: 1.42-1.77). The association was even stronger for previous hospitalizations with HF as the main discharge diagnosis (Table 3, set two: OR=4.98, 95% CI: 4.43-5.58). We did not observe an association between timing of hospitalizations preceding death and odds of HF listed as underling cause (Figure S2).

Last year hospitalizations among deceased with HF listed as the UCoD (Figure S3, Tables S2 & S3)

Overall, 85.2% of males and 72.9% of females had a hospitalization during their last year of life. Often, (55.6 % in males and 44.6 % in females) the hospitalization was registered during the last month of life (Figure S3).

In men, diseases of the circulatory system topped the list of reasons for hospitalizations (30.0%) (Table S2). The most frequent conditions were HF, atherosclerosis and atrial fibrillation (Table S3). Diseases of the respiratory system ranked second (26.5%) (Table S2) with the most frequent causes being bacterial pneumonia, unspecified pneumonia and respiratory failure (Table S3). Diseases of genitourinary system ranked third (7.6%) (Table S2) and included chronic kidney disease, acute renal failure and other disorders of the urinary system (Table S3).

In women, diseases of the circulatory system topped the list of hospitalizations (28.9%) (Table S2) and included HF, acute myocardial infarction and cerebral infarction (Table S3). Diseases of respiratory system ranked second (22.5 %) (Table S2) and included bacterial pneumonia, unspecified pneumonia, and respiratory failure (Table S3). Injury-related hospitalizations ranked third (12.8 %) (Table S2) and included hospitalizations due to

fractures of femur, superficial injuries of hip and thigh and fractures of lumbar spine and pelvis (Table S3).

Information on death certificates of deceased in whom HF was listed as the UCoD (Table 4) Overall, 9.4% of death certificates did not have any other information beside the HF code that was used to describe the UCoD. In another 69.2% of death certificates, there was additional information but such information was not relevant and could not help determine the true UCoD. Only in 21.4% of cases did the death certificates contain at least one 'target code'. The quality of information was poorer among women compared to men, for out-of-hospital compared to in-hospital deaths and for deaths not followed compared to those followed by an autopsy.

DISCUSSION

HF was listed as the UCoD in 3.6% of all deaths in Norway. This proportion was similar to that reported in other countries including the US during 1999-2011 (2.3%),⁶ Brazil during 2008-2012 (3.7%),⁷ Australia during 1997-2003 (3.2%)⁸ and in a multinational study of 142 million deaths conducted in 2009 (3.1%).⁵ The similar proportion of deaths with HF incorrectly listed as UCoD in countries that differ from one another in many aspects may point to a global rather than local nature of this phenomenon.

The quality of information and logical sequence of events registered in death certificate are crucial elements in the process of correctly identifying the UCoD. Of deceased with HF listed as the UCoD in our study, 9.4% lacked any other information in the death certificate (beside the HF code used to describe the UCoD). Another 69.2%, had additional information in their death certificates; however, the information was not related to HF and could not help in identifying the true UCoD. Hence, taken together, the substitution of the HF code with another, a plausible UCoD was not possible in 78.6% of the cases. Of note, this phenomenon was observed even among deaths occurring in hospitals; where in 4.9% of cases the death

certificates lacked any other information (beside the HF code used to describe the UCoD) and in 62.7% of cases, the death certificates missed relevant information. This was surprising to us, given that for deaths occurring in hospitals, medical charts contain sufficient information on patient's history of disease, examination results and sequence of events leading to death. Taken together, these findings point to the first limiting step and source of error, namely suboptimal information on death certificates, possibly due to lack of information, lack of training in completing the death certificate or both.

Of note, the introduction of the software application 'Automated Classification of Medical Entities' (ACME) to code the UCoD in 2005¹⁴ was not associated with changes in the proportion of deaths with HF listed as underlying cause. While electronic programs for coding death certificates and identifying the UCoD were intended to increase quality by avoiding human errors and standardizing the process, they cannot make up for lack of, inconsistent and/or illogical information provided in death certificates.

Factors associated with incorrect use of HF to describe UCD

The use of HF to describe the UCoD increased with age. This finding was in line with reports from US¹⁵ and Brazil¹⁶ and may be explained – at least partially - by presence of multiple medical conditions among elderly, which may mimic or serve as intermediate causes for one-another. Thus, the correct completion of the death certificate in elderly requires a great deal of understanding of the sequence of events leading to death.

HF was most frequently listed as the UCoD among individuals who died outside hospitals compared to those who died in a hospital, although these differences attenuated (but not disappeared) toward the end of the study period.

Similarly, a publication from the US¹⁵ reported a lower probability of listing HF as the UCoD among deaths occurring in a hospital as opposed to out-of-hospital death. For deaths occurring in nursing homes, we may speculate that suboptimal coverage, with only a minority

of family doctors being fully (100%) employed in these structures¹⁷ may play a role. Another plausible mechanism involves lack of training in death certificate completion. We don't have information on age distribution and/or level of formal training in death certificate completion among doctors in this project. However, based on internal routines, death certificates are usually completed by young doctors, often during their residency period. It seems plausible that other tasks and duties are formally prioritized over training on death certificate completion. Alternatively, doctors may tend to focus on the terminal phase and 'distance' themselves from these last events and correctly identifying the true UCoD.

In the absence of an autopsy, the odds of HF listed as the UCoD increased substantially. A previous study reported that autopsy results led to changes in the UCoD in 61% of deaths, ¹⁴ pointing to the potential positive role of performing autopsies with regard to the quality of mortality data.

The presence of a previous hospitalization due to CVD, and, more importantly, HF, was associated with higher odds of HF listed as the UCoD. We were not able to identify other studies exploring this association. A few international studies have reported on the agreement between hospital records and the UCoD in death certificates. Johansson et al. reported a 89% compatibility between the hospitalization's main condition and the UCoD. In cases of incompatibility, further analyses of case summaries were an important source of information for determining the true UCoD. Another study from Norway reported that 80.9% of all deceased during 2009-2011 were admitted to a hospital or attended an outpatient consultation during their last year of life. However, there was a lot of variability between the UCoD and diagnostic codes of hospitalizations, being as high as 55.1 % for deaths coded as 'Other cardiovascular diseases (130 - 133, 139 - 152)'. 20

Hospitalizations during the last year of life in deceased with HF listed as the UCoD

These analyses revealed at least two important patterns. *First*, the majority of these individuals had a hospitalization during their last year of life, often due to HF as the primary discharge diagnosis. This may point to difficulties in distinguishing the two different aspects of HF as i) a cause of hospitalization and ii) cause of death. It seems that a recent hospitalization with a HF diagnosis misled the doctors responsible for completing the death certificates to conclude that the same condition can describe the UCoD as well. This becomes even more 'tempting' when the time lag between two events (discharge from hospital and death) is short. *Second*, the principal hospital discharge diagnosis in many cases is a broad, unspecified entity (e.g. 'atherosclerosis' or 'bacterial pneumonia'), often reflecting either the inability to identify the correct diagnosis for hospitalization or problems coding the discharge diagnoses. However, in some cases, clear diagnoses such as acute myocardial infarction should have been noted as plausible UCoD, especially when death occurred shortly after hospital discharge.

Strength and limitations

This is to the best of our knowledge the most recent study to report on the burden of deaths with HF listed as the underlying cause of death. We conducted sex-specific analyses and identified factors associated with incorrect use of HF to describe the UCoD. Our data span over thirty years and were not restricted with regard to age, geography sex or socioeconomic status. Taking advantage of the unique identification number, we linked information from national data sources at the individual level exploring for the first time the role of previous hospitalizations in correctly assigning the UCoD.

Our study is prone to limitations characterizing register-based studies. Such registers do not include dynamic information regarding individuals' life, living arrangements or detailed sequence of events around deteriorating health. Further, a hospital record (especially the last one prior to death) may not always capture the complexity and severity of the medical

condition(s) in a given individual and the threshold for hospitalizing patients differs by age, sex and living conditions.

Conclusions: The magnitude of HF used to describe the UCoD remained stable over time and was comparable to that reported from other countries, pointing to a global rather than local misconception. This incorrect use, was associated with age, place of death, autopsy and history for previous hospitalizations – all factors not directly related to the disease mechanisms, physiopathology or coding procedures. In most cases, total lack of information or irrelevant information on death certificates seemed to hinder the identification of the true UCoD. Formal training of health personnel responsible for completing death certificates and better use of medical reports from recent hospitalizations would help reducing the usage of HF as the UCoD.

Declaration of conflicting interest:

The authors declare that there are no conflicts of interest.

REFERENCES

- World Health Organization (WHO). ICD-10: International Statistical Classification of Diseases and related health problems: fifth revision, 2016. Available online at https://icd.who.int/browse10/Content/statichtml/ICD10Volume2_en_2016.pdf.
- 2. Murray CJL, Lopez AD. The Global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020: summary / edited by Christopher J. L. Murray, Alan D. Lopez. World Health Organization. 1996.
- 3. Johnson SC, Cunningham M, Dippenaar IN, et al. Public health utility of cause of death data: applying empirical algorithms to improve data quality. *BMC Med Inform Decis Mak.* 2021;21:175.
- 4. Fischer C, Steyerberg EW, Fonarow GC, et al. A systematic review and meta-analysis on the association between quality of hospital care and readmission rates in patients with heart failure. *Am Heart J*. 2015;170:1005-U202.
- 5. Ahern RM, Lozano R, Naghavi M, et al. Improving the public health utility of global cardiovascular mortality data: the rise of ischemic heart disease. *Popul Health Metr.* 2011;9:8.
- 6. Foreman KJ, Naghavi M and Ezzati M. Improving the usefulness of US mortality data: new methods for reclassification of underlying cause of death. *Popul Health Metr.* 2016;14:14.
- 7. Bierrenbach AL, Alencar GP, Martinez C, et al. Redistribution of heart failure deaths using two methods: linkage of hospital records with death certificate data and multiple causes of death data. *Cadernos de saude publica*. 2019;35:e00135617.
- 8. Najafi F, Dobson AJ and Jamrozik K. Is mortality from heart failure increasing in Australia? An analysis of official data on mortality for 1997-2003. *Bull World Health Organ*. 2006;84:722-8.
- 9. Mathers CD, Fat DM, Inoue M, et al. Counting the dead and what they died from: an assessment of the global status of cause of death data. *Bull World Health Organ*. 2005;83:171-7.
- 10. Stevens GA, King G, Shibuya K. Deaths from heart failure: using coarsened exact matching to correct cause-of-death statistics. *Popul Health Metr.* 2010;8:6.
- 11. Pedersen AG, Ellingsen CL. Data quality in the Causes of Death Registry. *Tidsskr Nor Laegeforen*. 2015;135:768-70.
- 12. Bakken IJ, Suren P, Haberg SE, et al. The Norwegian patient register--an important source for research. *Tidsskr Nor Laegeforen*. 2014;134:12-3.

- 13. Naghavi M, Makela S, Foreman K, et al. Algorithms for enhancing public health utility of national causes-of-death data. *Popul Health Metr.* 2010;8:9.
- 14. Alfsen GC, Maehlen J. The value of autopsies for determining the cause of death. *Tidsskr Nor Laegeforen*. 2012;132:147-51.
- 15. Murray CJ, Kulkarni SC, Ezzati M. Understanding the coronary heart disease versus total cardiovascular mortality paradox: a method to enhance the comparability of cardiovascular death statistics in the United States. *Circulation*. 2006;113:2071-81.
- 16. França E, Ishitani LH, Teixeira R, et al. Changes in the quality of cause-of-death statistics in Brazil: garbage codes among registered deaths in 1996-2016. *Popul Health Metr.* 2020;18:20.
- 17. Melby L, Ågotnes G, Ambugo EA, Førland O. Kartlegging av medisinskfaglig tilbud i sykehjem og heldøgns omsorgsboliger. Senter for omsorgsforsknings Vest, 2019. Available online at https://ntnuopen.ntnu.no/ntnu xmlui/bitstream/handle/11250/2596428/Rapport%2003_19_web

Final.pdf? sequence = 1 & is Allowed = y.

- 18. Johansson LA, Westerling R. Comparing hospital discharge records with death certificates: can the differences be explained? *J Epidemiol Community Health*. 2002;56:301-8.
- 19. Johansson LA, Bjorkenstam C, Westerling R. Unexplained differences between hospital and mortality data indicated mistakes in death certification: an investigation of 1,094 deaths in Sweden during 1995. *J Clin Epidemiol*. 2009;62:1202-9.
- 20. Bakken IJ, Ellingsen CL, Pedersen AG, et al. Comparison of data from the Cause of Death Registry and the Norwegian Patient Register. *Tidsskr Nor Laegeforen*. 2015;135:1949-53.

Table 1. Characteristics of deceased with heart failure listed as underlying cause versus overall mortality in Norway, 1986-2015.

Study population characteristics	Deaths with heart failure listed as the underlying cause			All other deaths		
	Men (n = 18 059)	Women $(n = 28749)$	Total (n = 46 808)	Men (n = 642 627)	Women (n = 619 140)	Total (n = 1 243 767)
Age at death, mean (SD)	83.2 (9.0)	87.1 (7.5)	85.6 (8.3)	73.0 (16.3)	79.2 (14.7)	76.1 (15.8)
Age at death, median (IQR)	84 (79 - 89)	88 (83 - 92)	87 (81 - 91)	77 (67 - 84)	83 (74 - 89)	80 (70 - 87)
Place of death, %						
Hospital	25.6	17.8	20.8	43.6	37.7	40.6
Nursing home	53.3	68.3	62.5	29.1	46.6	37.8
Home	17.8	11.9	14.2	19.6	12.8	16.2
Other	3.3	2.0	2.5	7.7	2.9	5.3
Autopsy, %	0.9	0.6	0.7	13.4	7.8	10.6
Hospitalizations prior to death*, %						
No	4.8	8.8	7.2	6.4	7.5	6.9
Due to other-than-CVD	67.9	67.2	67.5	77.0	75.5	76.2
Due to CVD-related*	27.3	24.0	25.3	16.6	17.0	16.8
Due to HF**	15.7	11.5	13.1	2.4	2.5	2.5

SD - standard deviation; IQR - interquartile range; HF - heart failure. $\mbox{*}$ Main discharge diagnosis coded as I00-I99

^{**} Main discharge diagnosis coded as I50.x, J81, J81.1

Table 2. Association between death characteristics and use of heart failure codes to describe the underlying cause of death in Norway, 1986-2015.

	Odds ratio (95% confidence interval)*							
	All		Men		Women			
	Unadjusted	Adjusted*	Unadjusted	Adjusted*	Unadjusted	Adjusted*		
Sex				-	-	-		
Men	1 ref	1 ref	-	-	-	-		
Women	1.61 (1.58 - 1.64)	1.08 (1.06 - 1.11)	-	-	-	-		
Age (5 year increase)	1.44 (1.42 - 1.44)	1.35 (1.34 - 1.36)	1.43 (1.42 - 1.44)	1.36 (1.04 - 1.07)	1.42 (1.41 - 1.43)	1.35 (1.34 - 1.36)		
Place of death								
Hospital	1 ref	1 ref	$1^{\text{ ref}}$	1 ref	$1^{\text{ ref}}$	1 ref		
Nursing home	3.23 (3.16 - 3.31)	1.78 (1.74 - 1.83)	3.11 (3.00 - 3.22)	1.78 (1.72 - 1.85)	3.08 (3.01 - 3.32)	1.80 (1.74 - 1.86)		
Home	1.71 (1.65 - 1.76)	1.81 (1.75 - 1.87)	1.54 (1.48 - 1.62)	1.71 (1.63 - 1.79)	1.97 (1.81 - 2.06)	1.91 (1.83 - 2.00)		
Autopsy	,	,	, , , , , , , , , , , , , , , , , , ,	,	, , ,	,		
Yes		1 ref	1 ref	1 ref	1 ref	1 ref		
No	16.10 (14.58 - 18.06)	6.02 (5.39 - 6.73)	16.22 (13.95 - 18.87)	6.41 (5.48 - 7.50)	14.27 (12.27 - 16.61)	5.58 (4.77 - 6.53)		

^{*}Model includes all four variables.

Table 3. Association between previous hospitalizations and use of heart failure to describe the underlying cause of death, 2009-2015.

Hospitalization prior to death	Odds ratio (95% confidence interval)					
	A	11	Men		Women	
	Unadjusted	Unadjusted Adjusted		Adjusted	Unadjusted	Adjusted
Set one						
No	1 ref	1 ref	1 ref	1 ref	1 ref	1 ref
Due to other than CVD	0.85 (0.76 - 0.95)	1.01 (0.92 - 1.09)	1.17 (0.96 - 1.44)	0.95 (0.81 - 1.11)	0.76 (0.68 - 0.85)	1.03 (0.93 - 1.14)
Due to CVD	1.44 (1.25 - 1.65)	1.59 (1.42 - 1.77)	2.19 (1.73 - 2.77)	1.69 (1.41 - 2.04)	1.20 (1.06 - 1.36)	1.51 (1.35 - 1.68)
Set two						
No	1 ref	1 ref	1 ref	1 ref	1 ref	1 ref
Due to other than HF	0.84 (0.75 - 0.94)	0.98 (0.90 - 1.07)	1.16 (0.95 - 1.42)	0.92 (0.83 - 1.14)	0.75 (0.67 - 0.84)	1.01 (0.91 - 1.12)
Due to HF	5.11 (4.44 - 5.88)	4.98 (4.43 - 5.58)	8.60 (6.72 - 11.01)	5.68 (4.68 - 6.89)	3.93 (3.41 - 4.52)	4.43 (3.87 - 5.08)

CVD-cardiovascular disease; HF-heart failure.

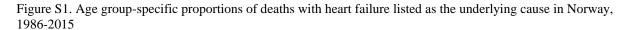
^{*}Model adjusted for age, sex, place of death and autopsy.

Table 4. Information from death certificates of 16 224 deceased in whom heart failure was listed as the underlying cause of death

_	All deaths	Proportion of deaths without additional information on death certificates	Proportion of deaths with additional information on death certificates		
			No target codes*	Target codes*	
All	16 225	9.4 %	69.2 %	21.4 %	
By sex					
Males	6253	8.1 %	64.9 %	27.0 %	
Females	9971	10.3 %	71.8 %	17.9 %	
By place of death					
In-hospital	4118	4.9 %	62.7 %	32.4 %	
Out-of hospital	12 106	10.9 %	71.4 %	17.7 %	
By autopsy					
Yes	88	9.3 %	69.3 %	21.4 %	
No	16 136	25.0 %	52.3 %	22.7 %	

^{*} Target codes for heart failuere are: congenital heart anomalies, cardiomyopathies, rheumatic heart disease, non-rheumatismal valvular heart disease, aortic aneurism, chronic kidney disease, endocrine, metabolic, blood, and immune disorders, endocarditis, ischemic heart disease, cirrhosis and other chronic liver diseases, hypertensive heart disease, chronic obstructive pulmonary disease, diabetes mellitus, tracheal, bronchus, and lung cancer, colon and rectum cancer, intracerebral hemorrhage.

SUPPLEMENTAL MATERIAL- ONLINE ONLY



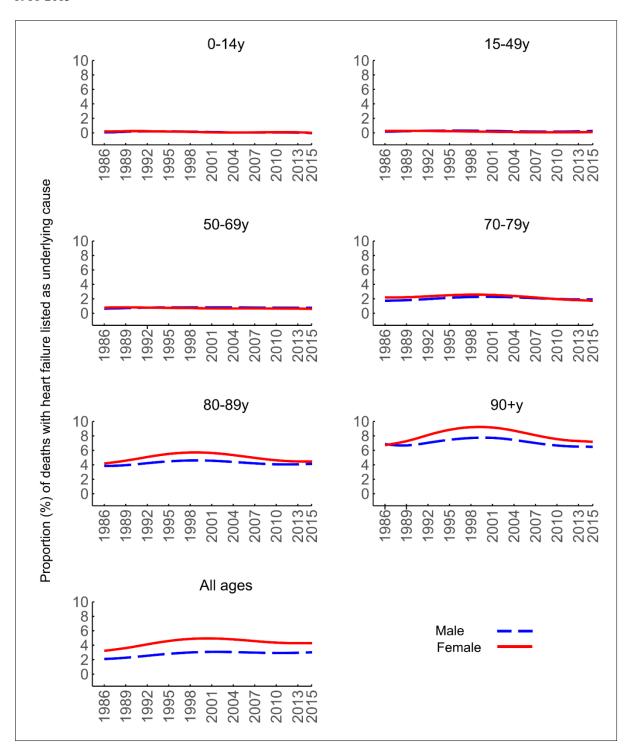
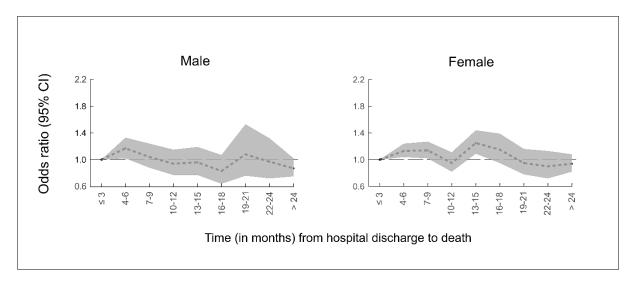


Figure S2. Association between timing of hospitalization preceding death and odds of heart failure listed as underlying cause of death in Norway, 2009-2015



Models adjusted for age, education, place of death and reason for hospitalization (cardiovascular versus non-cardiovascular)

Figure S3. Hospitalizations during the last year of life by time lag (in months) between discharge date and date of death in Norway, 2009-2015

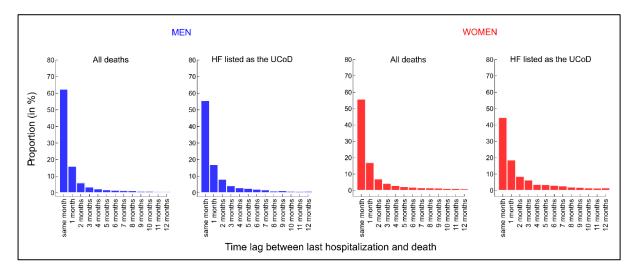


Table S1. Association* between death characteristics and use of heart failure codes to describe the underlying cause of death in Norway, 1986-2008 vs 2009-2015

	Odds ratio (95% confidence interval)			
	1986 - 2008	2009 - 2015		
Sex				
Men	1 ref	1 ref		
Women	1.11 (1.09 - 1.14)	1.05 (1.03 - 1.31)		
Age (5 year increase)	1.34 (1.32 - 1.35)	1.41 (1.24 - 1.76)		
Place of death				
Hospital	1 ref	1 ref		
Nursing home	2.01 (1.94 - 2.52)	1.28 (1.74 - 1.83)		
Home	1.95 (1.65 - 2.36)	1.24 (1.09 - 2.17)		
Autopsy				
Yes		1 ref		
No	5.96 (5.58 - 7.86)	6.12 (4.89 - 8.43)		

^{*}Model includes all four variables.

Table S2. Hospitalizations during the last year of life among individuals with heart failure listed as underlying cause of death in Norway, 2009-2015

Hospitalizations preceding death	Males	Females
by cause for hospitalization (main ICD-10 chapters)	(n = 3402)	(n = 4632)
Infectious diseases	177 (5.2)	163 (3.5)
Neoplasms	99 (2.9)	102 (2.2)
Diseases of the blood/blood-forming organs & disorders of immune mechanism	37 (1.1)	64 (1.4)
Endocrine, nutritional and metabolic diseases	42 (1.2)	74 (1.6)
Mental disorders	43 (1.3)	44 (0.9)
Diseases of the nervous system and the sense organs	109 (3.2)	198 (4.3)
Diseases of the circulatory system	1021 (30.0)	1339 (28.9)
Diseases of the respiratory system	903 (26.5)	1040 (22.5)
Diseases of the digestive system	126 (3.7)	171 (3.7)
Diseases of the skin and subcutaneous tissue	47 (1.4)	112 (2.4)
Diseases of the musculoskeletal system & connective tissue	43 (1.3)	80 (1.7)
Diseases of the genitourinary system	258 (7.6)	315 (6.8)
Symptoms, signs and abnormal clinical and laboratory findings	137 (4.0)	160 (3.5)
Injuries, poisoning & other consequences of external causes	257 (7.5)	596 (12.8)
Factors influencing health status and contact with health services	103 (3.1)	183 (4.0)

ICD: international classification of diseases

Table S3. Most frequent conditions for hospitalization within each top-three ICD-10 chapters in males and females

Cause for hospitalization (main ICD-10 chapters)	Sex	Most frequent reasons for hospitalization within each top-three ICD-10 chapter (in %)						
		First condition	%	Second condition	%	Third condition	%	
Diseases of the	Male	Heart failure	59.2	Atherosclerosis	7.4	Atrial fibrillation/flutter	4.4	
circulatory system	Female	Heart failure	50.7	50.7 Acute myocardial infarction		Cerebral infarction	6.4	
Diseases of the	Male	Bacterial pneumonia, not	47.3	Unangaified meaumonia	20.2	Acute or chronic respiratory	11.2	
respiratory system	Female	elsewhere classified	44.6	Unspecified pneumonia	18.7	failure	13.1	
Diseases of the	Male	Chronic kidney disease	33.7	Acute renal failure	24.0	Other disorders of urinary system	19.4	
genitourinary system	Female	Acute renal failure	28.9	Chronic kidney disease 25.1		Other disorders of utiliary system	21.3	
Injuries, poisoning & other	Male	Fracture of femur	28.3	Superficial injury of hip and thigh		Fracture of lumbar spine and	6.9	
consequences of external causes	Female	Tracture of Telliul	24.7	Superficial injury of hip and ungil	7.7	pelvis	7.2	

ICD: international classification of diseases