

The Danish Heart Failure Registry

Inge Schjødt¹
Anne Nakano^{2,3}
Kenneth Egstrup⁴
Charlotte Cerqueira⁵

¹Department of Cardiology,
²Department of Clinical Epidemiology,
Aarhus University Hospital, ³Registry
Support Centre of Clinical Quality
and Health Informatics (West),
Aarhus, ⁴Department of Cardiology,
Odense University Hospital,
Svendborg Hospital, Svendborg,
⁵Registry Support Centre of
Epidemiology and Biostatistics (East),
Research Centre for Prevention and
Health, Capital Region of Denmark,
Glostrup, Denmark

Aim of database: The aim of the Danish Heart Failure Registry (DHFR) is to monitor and improve the care of patients with incident heart failure (HF) in Denmark.

Study population: The DHFR includes inpatients and outpatients (≥ 18 years) with incident HF. Reporting to the DHFR is mandatory for the Danish hospital departments treating patients with incident HF. Final decision to register a patient in the DHFR is made by a cardiologist to ensure the validity of the diagnosis. Approximately 42,400 patients with incident HF were registered in the DHFR in July 2015.

Main variables and descriptive data: The main variables recorded in the DHFR are related to the indicators for quality of care in patients with incident HF: performance of echocardiography, functional capacity (New York Heart Association functional classification), pharmacological therapy (angiotensin converting enzyme/angiotensin II antagonist inhibitors, beta-blockers, and mineralocorticoid receptor antagonist), nonpharmacological therapy (physical training, patient education), 4-week readmission rate, and 1-year mortality. Furthermore, basic patient characteristics and prognostic factors (eg, smoking and alcohol) are recorded. At the annual national audit in the DHFR, the indicators and standards for good clinical quality of care for patients with HF are discussed, and recommendations are reported back to clinicians to promote quality improvement initiatives. Furthermore, results and recommendations are communicated to the public in an annual report. All standards for the quality indicators have been met at a national level since 2014. Indicators for treatment status 1 year after diagnosis are under consideration (now prevalent HF).

Conclusion: The DHFR is a valuable tool for continuous improvement of quality of care in patients with incident HF in Denmark. Furthermore, it is an important resource for the Danish registry-based HF research.

Keywords: heart failure, registry, quality, indicators, processes of care, variables, quality improvement

Introduction

The Danish Heart Failure Registry (DHFR) is a nationwide registry established in 2003 as a part of a large nationwide quality improvement initiative aimed at monitoring and improving the quality of care for patients with specific severe diseases, including heart failure (HF).¹ Reporting to the DHFR is mandatory for all hospital departments treating patients with incident HF. The DHFR achieved complete nationwide coverage in 2005.

Aim of database

The aim of the DHFR is to monitor and support implementation of evidence-based treatment and care of patients with incident HF, and it is anticipated that it will improve the overall performance in patients with HF.

Correspondence: Inge Schjødt
Department of Cardiology, Aarhus
University Hospital, Palle Juul-Jensens
Boulevard 99, 8200 Aarhus N, Denmark
Tel +45 2927 0177
Fax +45 7845 2057
Email ingeschj@rm.dk



Study population

The DHFR includes data on inpatients and outpatients with incident HF. The HF diagnosis is made by a cardiologist using the criteria of the European Society of Cardiology.² At discharge or at the first outpatient contact, patients with one of the following diagnoses (primary diagnosis) are screened for inclusion in the DHFR: I11.0, I13.0, I13.2, I42.0, I42.6, I42.7, I42.9, I50.0, I50.1, and I50.9. All diagnoses are made in accordance with the International Classification of Diseases 10th edition, which has been used for all admissions and outpatient contacts in Denmark since 1995.

Patients enrolled in the DHFR have to meet the following inclusion criteria: age 18 years or older, a first time hospital contact with HF as the primary diagnosis, and

- symptoms of HF, usually dyspnea, increased fatigue, fluid retention, and
- objective signs of HF at rest, for example, reduced systolic function and/or diastolic dysfunction/elevated filling pressure and/or
- clinical response to specific HF treatment.

Thus, enrollment in the registry requires both manifestation of symptoms and objective signs of HF at rest and/or response to treatment of HF.

Exclusion criteria are previously verified diagnosis and treatment of HF, isolated right-sided HF, and HF secondary to valvular heart diseases, noncorrectable structural heart diseases, or tachycardia-induced HF (often atrial fibrillation). Furthermore, patients discharged with a diagnosis of acute myocardial infarction and concomitant HF are not included. These patients will be included if they are later hospitalized with HF or are referred to an outpatient cardiology clinic for treatment of HF.

Only patients with a Danish unique personal identification number (CPR number) are enrolled in the database, allowing accurate linkage between the DHFR and other nationwide administrative registries at the individual level. The decision to register a patient in the DHFR is made by a cardiologist to ensure the validity of the incident HF diagnosis according to the inclusion and exclusion criteria. By July 2015, the DHFR contained data on ~42,400 patients with incident HF. Each year, 3,700–3,900 patients with incident HF are registered in the DHFR.

Patients in the DHFR are selected in accordance with the exclusion criteria to establish a homogeneous population with HF. Thus, the DHFR will not reflect the total incidence of HF in the general Danish population due to inclusion and exclusion criteria. Moreover, less-severe cases of HF may be treated in the primary health care sector (general practice) and these cases are not recorded in the DHFR.

Main variables

The variables recorded in the DHFR are related to basic characteristics, prognostic factors, diagnostic tests, functional capacity (symptom severity), pharmacological therapy, nonpharmacological therapy, readmission, and mortality (Table 1). The quality indicators consist of five processes and two outcome indicators³ defined by the DHFR multidisciplinary board to monitor good clinical quality of treatment and care for patients with incident HF. The indicators are echocardiography, New York Heart Association functional classification, medications, physical training, patient education, rate of readmission, and mortality (Table 2). Both the prognostic factors and the evidence-based quality indicators are based on national⁴ and international guidelines.^{2,5}

The use of echocardiography and New York Heart Association functional classification, 4-week readmission rate, and 1-year mortality are reported for all patients, whereas the use of angiotensin converting enzyme/angiotensin II antagonist inhibitors and beta-blockers, physical training, and patient education are evaluated in patients with systolic HF and left ventricular ejection fraction $\leq 40\%$. The use of mineralocorticoid receptor antagonist is evaluated in patients with left ventricular ejection fraction $\leq 35\%$.

Until now, the DHFR only contains information about patients with incident HF. At the audit conducted in 2015, the multidisciplinary board decided to supplement the registry with qualitative indicators for treatment status of the patients' treatment 1 year after diagnosis.

Data are registered for patients with HF admitted to hospital or at first outpatient visit by a cardiologist and the nursing staff. The process for registration of data has been developed to ensure data accuracy and for standardizing procedures for all clinicians.⁶

The DHFR board is obliged to ensure that the indicators reflect the quality of HF treatment and that the collection of data is simple and feasible in routine clinical settings. Systematic literature reviews are performed regularly, and the latest review was conducted in 2015.⁷

Local, regional, and national audits are conducted yearly. Performance data, completeness of registered patients, and variables are reported for each hospital department, region, and at a national level, making comparison of data possible.

At the annual national audit in the DHFR, the indicators and standards for good clinical quality in treatment and care for patients with HF are discussed and recommendations are

Table 1 Main variables in the Danish Heart Failure Registry

Main group	Variable	Description/comments
Basic characteristics	Civil registration number	Unique personal identification number including date of birth and sex
	Age	
	Sex	
	Status of hospital contact	Inpatient or outpatient
	Date of admission/outpatient contact	
	Date of discharge	Only hospitalized patients
	Status at discharge	Alive or dead
Prognostic factors	Discharge diagnosis	I11.0, I13.0, I13.2, I42.0, I42.6, I42.7, I42.9, I50.0, I50.1, and I50.9 (ICD-10)
	Acute myocardial infarction	Yes or no
	Stroke	Yes or no
	Diabetes	Yes or no
	COPD	Yes or no
	Hypertension	Yes or no
	Serum creatinine ≥ 150 $\mu\text{mol/L}$	Yes or no
	Electrocardiogram	Yes or no
	Heart rhythm	SR, AF/AFL, or other
Diagnostic test	Alcohol intake	$\leq 14/21$ units per week, $> 14/21$ units per week or na
	Smoking	Smoker, previous smoker, never smoker, or na
	Echocardiography	Yes, date for echocardiography or no. If yes, the exact value for LVEF or LVEF $< 25\%$, $25\% \leq \text{LVEF} \leq 35\%$, $35\% < \text{LVEF} \leq 40\%$, $40\% < \text{LVEF} < 50\%$, LVEF $\geq 50\%$
Functional capacity	NYHA functional classification	NYHA functional classification I, II, III, IV, or na
Pharmacological therapy	Status of ACE/ATII inhibitor treatment at first contact	Yes or no
	Initiation of ACE/ATII inhibitor treatment	Yes and starting date or no
	Status of beta-blocker treatment at first contact	Yes or no
	Initiation of beta-blocker treatment	Yes and starting date or no
	Status of MRA at first contact	Yes or no
Nonpharmacological therapy	Initiation of MRA treatment	Yes and starting date or no
	Physical training	Yes and starting date of training in hospital or date for referral to training in municipality or no
Readmission	Patient education	Yes and starting date or no
	4-week rate of acute readmission	Yes and date for readmission or no
Mortality	1-year mortality	Alive or dead according to the Danish Civil Registration System

Abbreviations: ACE/ATII, angiotensin converting enzyme/angiotensin II antagonist; AF/AFL, atrial fibrillation/atrial flutter; COPD, chronic obstructive pulmonary disease; ICD-10, International Classification of Diseases 10th edition; LVEF, left ventricular ejection fraction; MRA, mineralocorticoid receptor antagonist; na, not available; NYHA functional classification, New York Heart Association functional classification; SR, sinus rhythm.

reported back to clinicians and communicated to the public in the final annual report. Furthermore, the board decides whether any changes to the quality measures are warranted, and discusses potential new indicators.

In 2014 and 2015, all indicators were met at a national level.⁸ The coverage and completeness of indicator variables and prognostic factors from 2004 to 2015 are shown in Table 3. The completeness of the reported variables for each indicator was between 91% and 100% in 2015.⁸

Only patients with a first time primary diagnosis of HF are included in the registry. We assume that careful screening of the patients by a cardiologist means that virtually all patients

included in the database have HF. But a precise validation of the accuracy has not been performed.

The coverage of the DHFR is routinely evaluated by matching data with the administrative data in the Danish National Patient Register,⁹ which includes data on all hospital contacts in Denmark since 1977. A total of 82% of incident HF cases had been recorded in the DHFR in 2015.⁸ This relatively low coverage may partly be explained by patients being treated for HF in the hospital and, thus, registered accordingly in the Danish National Patient Register, but not meeting the inclusion/exclusion criteria for entry into the DHFR. To obtain high coverage of the registry, a continuous

Table 2 Process and outcome indicators in the Danish Heart Failure Registry

Indicator area	Indicator	Time frame	Type	Standard (%)
Echocardiography	Proportion of patients who undergo echocardiography	≤6 months before or ≤7 weekdays after admission or first outpatient contact	Process	≥90
NYHA functional classification	Proportion of patients who undergo NYHA functional classification	≤12 weeks after admission or first outpatient contact	Process	≥90
Medication	Proportion of patients with reduced systolic function (LVEF ≤40%) treated with ACE/ATII inhibitors	≤8 weeks after admission or first outpatient contact	Process	≥90
	Proportion of patients with reduced systolic function (LVEF ≤40%) treated with beta-blockers	≤12 weeks after admission or first outpatient contact	Process	≥80
	Proportion of patients with reduced systolic function (LVEF ≤35%) treated with MRA	≤12 weeks after admission or first outpatient contact	Process	≥35
Physical training	Proportion of patients with reduced systolic function (LVEF ≤40%) referred to individual physical training	≤12 weeks after admission or first outpatient contact	Process	≥30
Patient education	Proportion of patients with reduced systolic function (LVEF ≤40%) who were started on a structured patient education	≤12 weeks after admission or first outpatient contact	Process	≥80
Readmission	Proportion of patients hospitalized acutely within 4 weeks after discharge or first outpatient contact	≤4 weeks after discharge from the hospital or first outpatient contact	Outcome	≤10
Mortality	Proportion of patients who die 1 year after admission to hospital or first outpatient contact	≤1 year after admission or first outpatient contact	Outcome	≤20

Abbreviations: ACE/ATII, angiotensin converting enzyme/angiotensin II antagonist; LVEF, left ventricular ejection fraction; MRA, mineralocorticoid receptor antagonist; NYHA functional classification, New York Heart Association functional classification.

Table 3 Coverage and completeness of indicator variables and prognostic factors 2004 to 2015

Annual report, year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
Number of patients	2,598	2,452	2,429	2,731	2,996	3,229	3,447	3,876	3,909	3,957	3,631	3,735
Coverage, national level (%)	na	76*	69*	73*	72**	79	84	82	83	84	81	82
Completeness of indicator variables*** (%)												
Echocardiography	94	100	100	100	100	99	100	99	100	100	100	100
NYHA functional classification	94	100	100	100	99	100	100	100	100	100	100	100
ACE/ATII inhibitors	na	67	81	85	85	87	86	89	92	93	93	94
Beta-blockers	na	36	52	60	87	90	87	89	92	93	93	94
MRA	na	6	17	24	85	89	86	87	90	90	91	92
Physical training	51	68	83	83	86	87	84	87	89	89	88	91
Patient education	63	78	89	88	87	88	85	88	91	91	92	93
Readmission	na	100	100	100	99	100	100	99	99	100	100	100
Mortality	na	100	100	100	100	100	100	100	100	100	100	100
Completeness of prognostic factors (%)												
Smoking	na	na	79	82	85	84	86	88	89	92	93	92
Alcohol	na	na	71	75	78	80	82	83	85	89	88	89
LVEF	72	73	81	86	90	92	93	97	98	99	99	99
Creatinine	na	na	na	na	na	na	100	100	100	100	100	98
AMI	80	81	89	92	98	98	98	99	98	99	99	99
Stroke	72	72	85	88	98	98	98	99	98	98	98	98
Hypertension	76	77	87	91	99	99	99	99	99	99	99	99
COPD	71	72	85	88	98	98	98	99	98	99	99	98
Diabetes	76	77	89	93	99	99	99	99	99	99	99	99

Notes: *Self-reported coverage. From 2009, coverage is estimated from the registration of patients in the Danish National Patient Register. **Self-reported coverage. In 2008, coverage was also estimated from the Danish National Patient Register, reaching only 43%. ***Data completeness refers to whether or not all the information necessary to estimate the indicator was available in the data resource.

Abbreviations: ACE/ATII, angiotensin converting enzyme/angiotensin II antagonist; AMI, acute myocardial infarction; COPD, chronic obstructive pulmonary disease; LVEF, left ventricular ejection fraction; MRA, mineralocorticoid receptor antagonist; na, not available; NYHA functional classification, New York Heart Association functional classification.

effort by the departments is performed to review the lists of inpatients and outpatients with the primary diagnosis of HF and to assess whether the inclusion and exclusion criteria in the DHFR are fulfilled.

Follow-up

Six of the seven indicators selected in the DHFR are related to care processes and outcome within a period of 12 weeks from the date for first contact to either hospital or outpatient clinic. Information on the seventh indicator on 1-year mortality is obtained from the Danish Civil Registration System,¹⁰ where vital status is updated continuously.

The participating departments receive regular feedback on their performance regarding the process indicators to ensure data validation and to support quality improvement.

Examples of research

The population-based data and a high number of patients with incident systolic and nonsystolic HF makes the DHFR data suitable for clinical epidemiology research. A study has shown a substantial improvement in the DHFR process indicators from 2003 to 2010 among patients diagnosed with incident HF. In the same period, the 1-year mortality decreased from 20.5% to 12.8%.¹¹

An analysis based on the DHFR and demographic data indicates that HF is not diagnosed and treated adequately in people above 75 years.¹² Studies on patients with systolic HF in the DHFR indicate equal effect of different types of angiotensin converting enzyme inhibitors and beta-blockers on mortality in patients with HF.^{13,14}

Administrative issues and funding

The DHFR is funded and operated by the Danish Clinical Registries,¹⁵ which are financed and owned by the five Danish regions. A clinical epidemiologist and a quality consultant from the Danish Clinical Registries are affiliated to the DHFR. The epidemiologist has the responsibility for the analytical methods, analysis of data, and interpretation of results in the DHFR. The quality consultant is responsible for communication and support to the DHFR as well as communication with the participating hospitals.

Conclusion

The DHFR is a valuable tool for improving the quality of care for patients with HF and a valuable source for research. Since the establishment in 2003, the care of

patients with incident HF admitted to the Danish hospitals and registered in the DHFR has improved with a higher level of achievement of quality indicators and declining 1-year mortality.

Acknowledgments

The DHFR exists only due to the continued efforts and contributions from the staff working with patients with HF. This paper was funded by the Program for Clinical Research Infrastructure (PROCRIN) established by the Lundbeck Foundation and the Novo Nordisk Foundation and administered by the Danish regions.

Disclosure

The authors report no conflicts of interest in this work.

References

1. Mainz J, Hansen AM, Palshof T, Bartels PD. National quality measurement using clinical indicators: The Danish National Indicator Project. *J Surg Oncol*. 2009;99(8):500–504.
2. McMurray JJ, Adamopoulos S, Anker SD, et al. ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2012: the task force for the diagnosis and treatment of acute and chronic heart failure 2012 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association (HFA) of the ESC. *Eur J Heart Fail*. 2012;14(8):803–869.
3. Mainz J. Defining and classifying clinical indicators for quality improvement. *Int J Qual Health Care*. 2003;15(6):523–530.
4. Nielsen OW, Egstrup K, Køber L; for Danish Society of Cardiology. National cardiologisk behandlingsvejledning (NBV), 5. kronisk hjertesvigt (National guidelines in cardiology (NBV), 5. Chronic Heart Failure Updated June 2015). Available from: <http://nbv.cardio.dk/chf>. Accessed July 13, 2015.
5. Yancy CW, Jessup M, Bozkurt B, et al. 2013 ACCF/AHA guideline for the management of heart failure: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. *J Am Coll Cardiol*. 2013;62(16):e147–e239.
6. Registry Support Centre of Clinical Quality and Health Informatics (West). Datadefinitioner for NIP-hjerteinsufficiens (Data definitions for NIP-Heart Failure (The Heart Failure Registry)). Available from: <http://www.kcks-vest.dk/kliniske-kvalitetsdatabaser/hjertesvigt/>. Accessed December 6, 2015. [Danish].
7. Dansk Hjertesvigt-database. Dokumentalistrapport, Version 1, August 2015 (Manual for the Danish Heart Failure registry, August 2015). Available from: <http://www.kcks-vest.dk/kliniske-kvalitetsdatabaser/hjertesvigt>. 2015. [Danish]. Accessed April 8, 2016.
8. Dansk Hjertesvigt-database (DHD). National årsrapport 2015, 1. juli 2014 – 30. juni 2015. 2015. (Danish Heart Failure Registry (DHFR) National annual report 2015, July 1, 2014–June 30, 2015). Available from: <https://www.sundhed.dk/sundhedsfaglig/kvalitet/kliniske-kvalitetsdatabaser/hjerte-kar-sygdomme/hjertesvigt-nip/>. Accessed February 18, 2016. [Danish].
9. Schmidt M, Schmidt SA, Sandegaard JL, Ehrenstein V, Pedersen L, Sorensen HT. The Danish National Patient Registry: a review of content, data quality, and research potential. *Clin Epidemiol*. 2015;7:449–490. doi: 10.2147/CLEP.S91125.
10. Schmidt M, Pedersen L, Sorensen HT. The Danish Civil Registration System as a tool in epidemiology. *Eur J Epidemiol*. 2014;29(8):541–549. doi: 10.1007/s10654-014-9930-3.

11. Nakano A, Johnsen SP, Frederiksen BL, et al. Trends in quality of care among patients with incident heart failure in Denmark 2003–2010: a nationwide cohort study. *BMC Health Serv Res.* 2013;13:391. Available from: <http://www.biomedcentral.com/1472-6963/13/391>. Accessed December 6, 2015.
12. Olesen LL. Dansk Hjertesvigts Database tyder på underrapportering og underbehandling blandt ældre (The Danish National Quality Project about heart failure indicates lack of reporting and treatment of the elderly). *Ugeskr Laeger.* 2014;176(39). pii: V05140288. [Danish].
13. Svanstrom H, Pasternak B, Melbye M, Hviid A. Use of different types of angiotensin converting enzyme inhibitors and mortality in systolic heart failure. *Int J Cardiol.* 2015;182:90–96.
14. Pasternak B, Mattsson A, Svanstrom H, Hviid A. Comparative effectiveness of bisoprolol and metoprolol succinate in patients with heart failure. *Int J Cardiol.* 2015;190:4–6.
15. Danish Quality Improvement Program (RKKP). Internet homepage. Available from: <http://www.rkkp.dk/in-english/>. Accessed December 6, 2015. [Danish].

Clinical Epidemiology

Publish your work in this journal

Clinical Epidemiology is an international, peer-reviewed, open access, online journal focusing on disease and drug epidemiology, identification of risk factors and screening procedures to develop optimal preventative initiatives and programs. Specific topics include: diagnosis, prognosis, treatment, screening, prevention, risk factor modification,

Submit your manuscript here: <http://www.dovepress.com/clinical-epidemiology-journal>

systematic reviews, risk & safety of medical interventions, epidemiology & biostatistical methods, and evaluation of guidelines, translational medicine, health policies & economic evaluations. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use.

Dovepress