Published in final edited form as:
Eur J Heart Fail. 2021 June ; 23(6): 917–918. doi:10.1002/ejhf.2148.

Making heart failure count

Boback Ziaeian[1,2], **Gregg C. Fonarow**[2,*]

[1]Division of Cardiology, David Geffen School of Medicine at University of California Los Angeles, Los Angeles, CA, USA;

[2]Division of Cardiology, Veteran Affairs Greater Los Angeles Healthcare System, Los Angeles, CA, USA

> 'Many of the things you can count, don't count. Many of the things you can't count, really count.'
>
> —Albert Einstein

Counting is fundamental to public health and medical research. We group and categorize elements of the world to better understand them. Fundamental to language is grouping similar objects or ideas and drawing contrasts between their differences. Without the ability to count, we are blind to many natural phenomena. Accurate assessment of disease burden is vital to allocation of research funding and prioritization of public health, prevention, and treatment efforts. During the COVID-19 pandemic, diagnosing, counting, tracing, and isolating were fundamental tools for understanding transmission dynamics, infection control strategies, and eventually the effectiveness of treatments and vaccines. The urgency and importance of counting COVID-19 cases, hospitalizations, and deaths directed the response of governments and public health officials.

The epidemic that the cardiovascular community has faced for decades is heart failure (HF). A slow and steady growth of underlying cardiovascular risk factors, aging demographics, and poor uptake of preventative strategies has led to the prevalence of a chronic disease that is a leading cause of hospitalization risk for adults in the developed world.[1,2] Yet, despite the known burdens and mortality risk observed for patients with HF, accurate epidemiologic estimates at the national level remain elusive. In the U.S., estimates of HF prevalence are based on cross-sectional survey and self-report from the National Health and Nutrition Examination Survey (NHANES).[3] Self-report of HF is insensitive and is known to severely under count active HF diagnoses.[4] A healthy selection bias related to non-response and non-institutionalized populations skew U.S. national estimates from NHANES.[5] The recent cross-sectional NHANES survey interviewed around 16 000 study participants to understand the disease prevalence for over 320 million Americans. The few hundred participants that mention HF as a self-reported diagnosis are scaled to an NHANES estimated 6.0 million Americans with HF between 2015 and 2018, which likely remains a profound

---

[*]Corresponding author. Ahmanson–UCLA Cardiomyopathy Center, Ronald Reagan UCLA Medical Center, 10833 LeConte Avenue, Room A2-237 CHS, Los Angeles, CA 90095-1679, USA. Tel: +1 310 206-9112, Fax: +1 310 206-9111, gfonarow@mednet.ucla.edu.

Conflict of interest: B.Z.: none declared. G.C.F.: consulting: Abbott, Amgen, AstraZeneca, Bayer, CHF Solutions, Edwards, Janssen, Medtronic, Merck, and Novartis.

underestimate.[3] A clear remedy to the poor epidemiologic data is immensely challenging in a nation with fragmented health data and delivery systems.

Further complicating matters of the basic epidemiology of HF is the coding of death certificates. By convention, HF is treated as a ‘garbage code’ meaning that it should never be the primary cause of death. Attempts are made to reassign HF to sudden cardiac death, respiratory failure, or ischaemic heart disease. This approach to classification of mortality leads to near complete obfuscation of HF contribution to the leading causes of all-cause and cardiovascular mortality. The clinical phenotype clinicians see regularly, and that patients live with, is largely scrubbed from death certification at the end of life based on currently recommended documentation and coding practices.

In this issue of the Journal, the Heart Failure Association (HFA) Atlas in collaboration with the European Society of Cardiology (ESC), the European Heart Health Institute, and the National Heart Failure Societies (NHFS) have spearheaded an international epidemiologic survey to standardize reporting of the burden of HF across ESC member nations.[6] We are now provided detailed national estimates for 32 countries that include HF incidence, prevalence, as well as access to HF centres, testing, medications, and advanced treatments. We see remarkable variation in the burden of HF and ability to access evidence-based treatments. It is very important to acknowledge not all data elements are reported by each nation and data sources are of variable, if not questionable, quality and not entirely nationally representative. Some of the striking variability observed may reflect differences in data sources, definitions, and quality rather than true intercountry variability.

With respect to prevalence, the HFA Atlas reports that Germany leads the included nations with a prevalence of 39 per 1000 person-years compared to 10 per 1000 person-years for Greece. The German data were obtained from a published manuscript covering the years of 2009 to 2013 using claims data from the German Health Risk Institute on individuals with statuary health insurance. For Greece, data were obtained from national coordinators for 2015 without a clear methodology identified by the HFA Atlas. At the current stage, neither the German or Greek estimates are age-adjusted nor do they provide sex-specific estimates. Why there might be a 3.9-fold difference in HF burden is not clear for two nations with similar age distributions. Understanding both reporting differences and underlying factors in these estimates should hopefully improve future epidemiologic reporting practices.

With respect to treatment availability and access to care, the HFA Atlas provides visuals for the variation in access to evidence-based drug classes (beta-blockers, angiotensin-converting enzyme inhibitors/angiotensin receptor blockers, ivabradine, mineralocorticoid receptor antagonists, and sacubitril/valsartan), HF centres, and advanced therapies. Many nations provide medical therapies with complete reimbursement to patients with HF while others are classified as partial or no reimbursement. Evaluations of how variations in medication coverage/payment/copayment policies may influence receipt of medical therapies from a national perspective may inform future health policy work.

The ambitiousness of the HFA Atlas to highlight the reporting of these epidemiologic data will hopefully encourage more work to improve data standardization, data quality, and the comprehensive measurement of the HF burden. Research that will help clarify where the reported differences in care burden and access to treatments should encourage either improved reporting or public health efforts. This in turn can facilitate the prioritization and funding necessary to deliver primary and secondary preventative strategies more effectively to advance national cardiovascular health. Future iterations should prioritize the inclusion of HF performance measures for guideline-recommended medical therapies as emphasized by U.S. professional societies.[7] Making HF count will hopefully turn the rising tide of a preventable and treatable chronic disease epidemic.

Funding

B.Z.'s research is supported by AHA SDG 17SDG33630113 and the NIH/National Center for Advancing Translational Science (NCATS) UCLA CTSI Grant Number KL2TR001882. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

References

1. Heidenreich PA, Albert NM, Allen LA, Bluemke DA, Butler J, Fonarow GC, Ikonomidis JS, Khavjou O, Konstam MA, Maddox TM, Nichol G, Pham M, Piña IL, Trogdon JG. Forecasting the impact of heart failure in the United States: a policy statement from the American Heart Association. Circ Heart Fail 2013;6:606–619. [PubMed: 23616602]
2. Ziaeian B, Fonarow GC. Epidemiology and aetiology of heart failure. Nat Rev Cardiol 2016;13:368–378. [PubMed: 26935038]
3. Virani SS, Alonso A, Aparicio HJ, Benjamin EJ, Bittencourt MS, Callaway CW, Carson AP, Chamberlain AM, Cheng S, Delling FN, Elkind MS, Evenson KR, Ferguson JF, Gupta DK, Khan SS, Kissela BM, Knutson KL, Lee CD, Lewis TT, Liu J, Loop MS, Lutsey PL, Ma J, Mackey J, Martin SS, Matchar DB, Mussolino ME, Navaneethan SD, Perak AM, Roth GA, Samad Z, Satou GM, Schroeder EB, Shah SH, Shay CM, Stokes A, Van Wagner LB, Wang NY, Tsao CW; American Heart Association Council on Epidemiology and Prevention Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics – 2021 update: a report from the American Heart Association. Circulation 2021;143:e254–e743. [PubMed: 33501848]
4. Camplain R, Kucharska-Newton A, Loehr L, Keyserling TC, Layton JB, Wruck L, Folsom AR, Bertoni AG, Heiss G. Accuracy of self-reported heart failure. The Atherosclerosis Risk in Communities (ARIC) study. J Card Fail 2017;23:802–808. [PubMed: 28893677]
5. Fakhouri TH, Martin CB, Chen TC, Akinbami LJ, Ogden CL, Paulose-Ram R, Riddles MK, Van de Kerckhove W, Roth SB, Clark J, Mohadjer LK, Fay RE. An investigation of nonresponse bias and survey location variability in the 2017–2018 National Health and Nutrition Examination Survey. Vital Health Stat 2 2020;185:1–36.
6. Seferović PM, Vardas P, Jankowska EA, Maggioni AP, Timmis A, Milinković I, Polovina M, Gale CP, Lund LH, Lopatin Y, Lainscak M, Savarese G, Huculeci R, Kazakiewicz D, Coats AJ. The Heart Failure Association Atlas: Heart Failure Epidemiology and Management Statistics 2019. Eur J Heart Fail 2021 Feb 26. 10.1002/ejhf.2143 [Epub ahead of print].
7. Heidenreich PA, Fonarow GC, Breathett K, Jurgens CY, Pisani BA, Pozehl BJ, Spertus JA, Taylor KG, Thibodeau JT, Yancy CW, Ziaeian B. 2020 ACC/AHA clinical performance and quality measures for adults with heart failure: a report of the American College of Cardiology/American Heart Association Task Force on Performance Measures. Circ Cardiovasc Qual Outcomes 2020;76:2527–2564.