

General public awareness of heart failure: results of questionnaire survey during Heart Failure Awareness Day 2011

Mitja Lainscak^{1,2}, Mitja Letonja³, Dragan Kovacic⁴, Lea Majc Hodoscek⁵, Apolon Marolt⁶, Cvetka Melihen Bartolic⁷, Marija Mulej⁸, Meta Penko⁹, Janez Poles¹⁰, Tinkara Ravnikar¹¹, Mojca Savnik Iskra¹², Cirila Slemenik Pusnik⁶, Borut Jug¹³

¹Division of Cardiology, University Clinic Golnik, Golnik, Slovenia

²Applied Cachexia Research, Division of Cardiology, Charite – Campus Virchow-Klinikum, Berlin, Germany

³Department of Internal Medicine, General Hospital Ptuj, Ptuj, Slovenia

⁴Department of Cardiology, General Hospital Celje, Celje, Slovenia

⁵Department of Internal Medicine, General Hospital Murska Sobota, Murska Sobota, Slovenia

⁶Department of Internal Medicine, General Hospital Slovenj Gradec, Slovenj Gradec, Slovenia

⁷Department of Cardiology, General Hospital dr. Franca Derganca, Sempeter pri Gorici, Slovenia

⁸Department of Internal Medicine, General Hospital Jesenice, Jesenice, Slovenia

⁹Clinic for Internal Medicine, Department of Cardiology, University Medical Center Maribor, Slovenia

¹⁰Department of Internal Medicine, Hospital Topolsica, Topolsica, Slovenia

¹¹Department of Internal Medicine, General Hospital Izola, Izola, Slovenia

¹²Department of Internal Medicine, General Hospital Brezice, Brezice, Slovenia

¹³Division of Internal Medicine, Department of Vascular Diseases, University Medical Center, Ljubljana, Slovenia

Author for correspondence:
Mitja Lainscak MD, PhD, FESC
Division of Cardiology
University Clinic Golnik
Golnik 36, SI-4204 Golnik,
Slovenia
Phone: +38631379533
Fax: +38642569117
E-mail: mitja.lainscak@guest.arnes.si

Submitted: 2 September 2013

Accepted: 20 December 2013

Arch Med Sci 2014; 10, 2: 355–360

DOI: 10.5114/aoms.2014.42589

Copyright © 2014 Termedia & Banach

Abstract

Introduction: General public views about heart failure (HF) alone and in comparison with other chronic conditions are largely unknown; thus we conducted this survey to evaluate general public awareness about HF and HF disease burden relative to common chronic disease.

Material and methods: This was a cross-sectional survey during European Heart Failure Awareness Day 2011. People visiting the stands and other activities in 12 Slovenian cities were invited to complete a 14-item questionnaire.

Results: The analysis included 850 subjects (age 56 ±15 years, 44% men, 55% completed secondary education or higher). Overall, 83% reported to have heard about HF, 58% knew someone with HF, and 35% believed that HF is a normal consequence of ageing. When compared to other chronic diseases, HF was perceived as less important than cancer, myocardial infarction, stroke and diabetes with only 6%, 12%, 7%, and 5% of subjects ranking HF as number 1 in terms of prevalence, cost, quality of life, and survival. A typical patient with HF symptoms was recognized by 30%, which was comparable to the description of myocardial ischemia (33%) and stroke (39%). Primary care physicians (53%) or specialists (52%) would be primary sources of information about HF. If experiencing HF, 83% would prefer their care to be focused on quality of life rather than on survival (14%).

Conclusions: Many participants reported to have heard about heart failure but the knowledge was poor and with several misbeliefs. Heart failure was

perceived as less important than several other chronic diseases, where cancer appears as a main concern among the general public.

Key words: attitudes, awareness, heart failure, knowledge, public health.

Introduction

Cardiovascular diseases are significant chronic conditions in terms of prevalence, outcome and quality of life [1, 2]. Heart failure (HF) represents a possible end stage of any cardiovascular disease; therefore its prevalence and clinical relevance are steadily increasing [3]. Hence, it would be expected that appropriate public health strategies are in place and that general public awareness about HF is high.

Information regarding public awareness about HF is scarce. To the best of the authors' knowledge, only the Study of Heart failure Awareness and Perception in Europe (SHAPE), which was conducted in 9 countries and included 7958 subjects, has addressed this topic in a comprehensive and sizeable manner [4]. Several misbeliefs were detected and awareness about HF was described as low. Although as many as 86% of respondents had heard of HF, only 3% identified the typical clinical presentation of HF, and 67% thought that HF patients live longer than cancer patients. When different chronic conditions were compared, only 9% believed that HF leads to higher costs than cancer, HIV and diabetes.

In 2010, the Heart Failure Association of the European Society of Cardiology launched the Heart Failure Awareness Day to initiate public campaigns about HF awareness across Europe. In Slovenia, we conducted a nationwide survey among the general public during the 2011 campaign, aiming to evaluate general public awareness about HF and the HF disease burden relative to common chronic diseases.

Material and methods

Study design and subjects

This was a cross-sectional survey during Heart Failure Awareness Day 2011 in Slovenia. On May 7th and 8th, the local HF teams in 12 Slovenian cities organized promotional activities including educational lectures and stands, open-day clinics, and audio/video media and newspaper coverage [5]. A self-administered 14-item questionnaire (appendix) was distributed to people attending the activities, primarily when visiting the educational stands. Attending personnel were instructed to provide people with the questionnaire prior to any specific interaction with them or before providing them with material in order to minimize any

immediate learning effects. The National Medical Ethics Committee approved the survey protocol, including the verbal consent prior to participation in this anonymous and voluntary survey.

Data collection

An expert panel developed the questionnaire, which was pretested in a pilot sample of 30 subjects to assess whether questions were written in an understandable way and whether it was feasible to use the questionnaire in a field survey. No major modifications were made to the 14-item questionnaire consisting of questions related to several topics. After obtaining demographic characteristics, we assessed subjects' exposure to HF (2 questions), knowledge of symptoms of HF and intervention if symptoms would be present (7 questions), and management of HF (3 questions). An open-ended question describing a typical patient with angina pectoris, stroke, and HF asked respondents to name each of the conditions. Finally, we asked about the beliefs about most prevalent, most deadly, most costly condition and the condition associated with poorest quality of life; we provided a list of six chronic conditions (i.e. cancer, myocardial infarction, diabetes mellitus, HF, stroke and chronic obstructive pulmonary disease) to choose from.

Statistical analysis

Descriptive statistics was used to analyze the results. We applied number of subjects with proportion and mean with standard deviation as appropriate. All calculations were performed with the software package SPSS 18.0 (SPSS Inc., 2009, USA).

Results

This survey recruited 850 middle-aged participants who resembled the general Slovenian population (age: 56 ±15 years, 56% women, 55% completed secondary education or more). Most of them reported to have heard about HF and more than half stated they knew someone with HF (Table I).

A typical patient with HF, angina pectoris, and stroke was correctly recognized by 254 (30%), 282 (33%), and 334 (39%) of respondents, respectively. About a third (35%) of participants considered HF as a normal consequence of ageing (Figure 1 A). In case of HF, most would consult their general practitioner (GP, 53%) or specialist (52%) as a pri-

Table I. Characteristics of survey participants (N = 850)

Parameter	Results
Gender, n (%):	
Male	374 (44)
Female	476 (56)
Age, n (%) [years]:	
< 45	179 (21)
45–65	431 (51)
> 65	240 (28)
Level of education, n (%):	
Less than primary school	29 (3)
Primary school	87 (10)
Vocational school	161 (19)
Secondary school	306 (36)
College	98 (12)
University	169 (20)
Heard of heart failure, n (%)	706 (83)
Knows someone with heart failure, n (%)	493 (58)
Heart failure in family, n (%)	111 (13)

mary source of advice, whilst the internet (19%) would be the third most common way to obtain information, followed by the family, friends, pharmacist, and medical encyclopedia (all < 10%). If they experienced unusual dyspnea, fatigue or swollen ankles, most would make an appointment with their GP (78%) or seek additional information (14%), whilst only 3% would not do anything. When asked about treatment options, drugs, surgery, and pacemaker were the most frequent answers (64%, 6%, and 17%, respectively). Only 6 respondents considered HF as an untreatable condition and 14% were not sure how to treat HF. Moreover, 37% of respondents consider that HF patients should take it easy and rest (Figure 1 B). If diagnosed with HF, the vast majority would prefer their management to be focused on symptom relief rather than survival prolongation (83% vs. 14%) – Figure 1 C.

When asked about chronic disease burden in terms of prevalence, quality of life and disease-related costs, cancer most often ranked first (48%, 35%, and 59%, respectively), whilst myocardial infarction was considered most fatal (48%)—Figure 2. Generally, less than 10% of respondents ranked the following conditions as number one in any of the previous features: HF (except for quality of life – 12%), diabetes mellitus (except for prevalence – 14%), and chronic obstructive pulmonary disease.

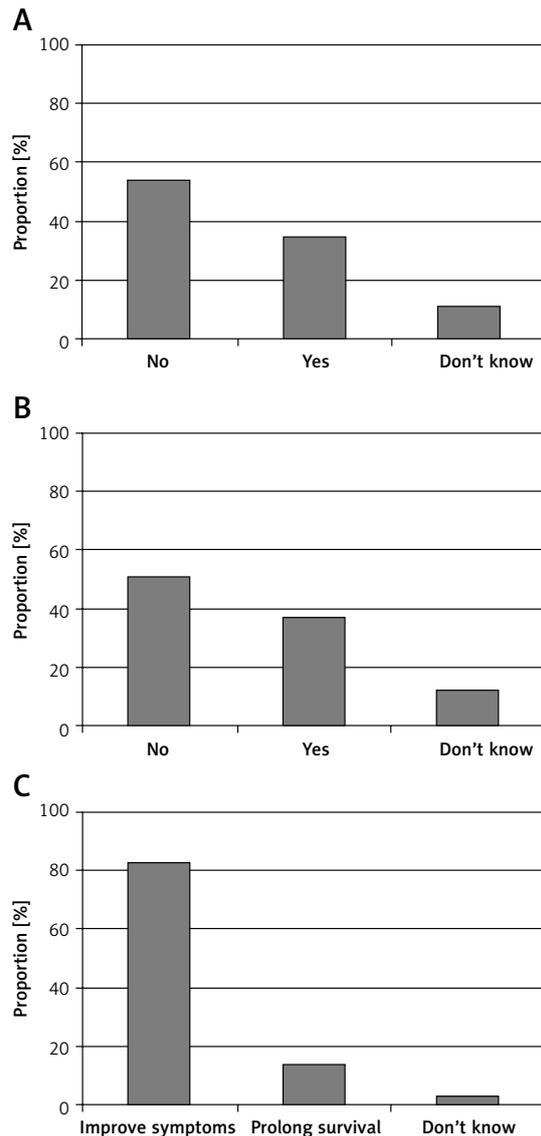


Figure 1. Proportion of participants considering heart failure: **A** – as a normal consequence of aging, **B** – as a condition when it is better to take it easy and rest, and **C** – their preferences regarding the heart failure treatment effects

Discussion

After the SHAPE study, this is the first study of comparable individual country size and wealth of information describing awareness about HF in the community. We demonstrated that all aspects of HF are largely unknown to or neglected by the general public in Slovenia and that several misbeliefs exist. Additionally, HF is perceived as a less dangerous and burdensome condition than other common chronic diseases, particularly when compared to cancer.

Generally, poor knowledge and several misbeliefs about HF are the key findings of this survey. Although 83% of respondents have heard about HF, only 30% identified a typical HF description of

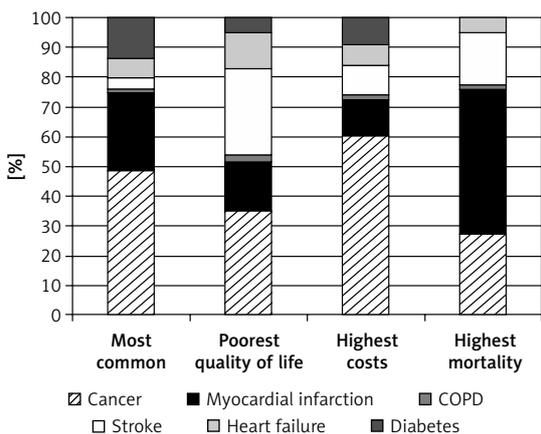


Figure 2. Proportion of participants when asked the question: *In your opinion, which disease is/has...*

symptoms. Most of the respondents would make an appointment with their general practitioner when experiencing some symptoms, and only 3% would do nothing; this is not what we usually experience in clinical practice where many patients with HF are either unrecognized or receive medical attention with full-blown disease [3]. Development of the society and respondents' average age is nicely reflected by the finding that the internet with 19% of respondents would be the third most frequent site of information request, after general practitioner and specialist but ahead of medical encyclopedia, family, or pharmacist. Only a few considered HF as an untreatable condition and drugs were the first choice of treatment modalities, which actually is in line with current guidelines and the situation in daily practice. The most prominent misbeliefs, in our opinion, were those about HF association with ageing and about physical activity: overall, more than one third considered HF as a normal consequence of ageing and as a condition where rest is better than physical activity. Both beliefs are of course wrong and could reflect the expectation that with age something will go wrong with the health, and once this happens it may be better to take it easy to prevent further deterioration. It should be emphasized that ageing itself does not cause heart failure or functional limitations but is a risk factor for development of diseases or conditions that impair health status with or without limitations for the subject.

Comparing our findings to the SHAPE [4] results, there are many similarities and only a few differences. Quality of life and not prolonged survival appears to be the main expectation of HF management, which could be due to inclusion of mostly healthy people in this survey, in whom quality of life may have priority over longevity. Along with SHAPE, respondents had difficulties

with ways and modalities how to treat HF, as only a few knew more sophisticated and novel approaches. Most prominent was the difference in the proportion of respondents recognizing the typical clinical presentation of HF symptoms (30% vs. 3%), which likely reflects the Heart Failure Awareness Day activities along with our survey as all respondents were exposed to HF specific information, including symptoms and signs. SHAPE also included more subjects; however, when numbers per individual country are compared, they are very similar.

From a broader perspective, it was important to compare perception of HF with several chronic diseases in terms of prognosis and disease burden. In this context, a key finding was that neither cardiovascular conditions nor diabetes or chronic obstructive pulmonary disease was perceived as a major threat. Instead, cancer was regarded as the main and most relevant concern among the survey population, which is not very different from the findings reported by the SHAPE investigators [4]. This does not reflect the epidemiological situation or clinical practice and actually shows many misconceptions about chronic diseases among the general public. Whilst similar in many aspects, including mortality [6], there are some important differences between HF and cancer that are relevant for clinical practice and public health interventions. Advances in treatment over the last decades [3] translated into a significant survival benefit for patients with HF, whereas cancer patients' prognosis did not improve comparably [7], despite the higher investments [8]. Also, we have more information about the awareness of cancer in the lay population, which is generally considered satisfactory [9–11] and comparable to patient's knowledge [12]. Whether this reflects better strategies or public perception of cancer as a more important disease remains unknown. Such findings, however, may partly be due to an estimated 2% prevalence of HF, mostly in elderly people, which can result in low penetration to the general public. However, this is not the case for cancer, where similar prevalence results in higher awareness [9–12], or for chronic obstructive pulmonary disease, where higher prevalence is not associated with better awareness [13].

Our findings should also be put into the perspective of HF perception and understanding amongst patients and health care professionals. Clinical practice could be improved as there appears to be a certain level of non-adherence to guidelines throughout the last decade [14–16]. In particular, beliefs of primary care practitioners have revealed considerable gaps, especially in terms of HF management [17]. Nurses represent

key professionals for patient education and delivery of HF-focused care [18, 19]; however, a recent survey demonstrated a lower-than-expected confidence of nurses in HF-related issues [20]. Apparently, HF remains a difficult clinical issue and represents an ongoing challenge for health care providers [21, 22]. This calls for interventions in these populations to improve guideline implementation as appropriate.

Per survey design and recruited sample size, it is possible that HF awareness information is incomplete. The sample size, however, needs to be interpreted in comparison with the studies in the field and is very similar to the individual country sample in the SHAPE study [4]. Conduction of an awareness and perception survey along with educational activities may have skewed the real dimension, as people are likely to give socially desirable answers when asked about perception and beliefs.

In conclusion, current perception about HF amongst the general public and civil initiatives appear, in contrast to some other diseases, to be insufficient to generate appropriate actions by healthcare authorities, medical professionals and other stakeholders. Our results, along with the SHAPE survey [4], should encourage HF awareness activities for the general public and beyond. The Heart Failure Awareness Day initiative launched by the Heart Failure Association at the European Society of Cardiology is a genuine strategy to make the general population and key stakeholders aware of this deadly and debilitating condition. In 3 years the initiative has developed continuously, both in quantitative and qualitative terms [23]. The present report and studies such as SHAPE provide us with necessary insight for future planning of our efforts in order to optimize outcomes and benefits. Ideally, activities should not be limited to day- or week-long events like European Heart Failure Awareness Day but should rather evolve into a continuous effort for the general public, healthcare communities and also policy decision makers. Simultaneously, changes in national health care policies should be pursued to entrust the health care institutions with continuous promotion and iterative campaigns about healthy lifestyle and preventive activities to reduce disease-associated costs and disability. Infrastructure with potential for implementation across most of Europe appears to be in place [24], ready for a coordinated and guideline-based initiative.

Acknowledgments

The present study was not funded. None of the authors have any conflicts of interest directly relevant to the content of this study.

References

1. Lopez AD, Mathers CD, Ezzati M, Jamison DT, Murray CJL. Global and regional burden of disease and risk factors, 2001: systematic analysis of population health data. *Lancet* 2006; 367: 1747-57.
2. Abegunde DO, Mathers CD, Adam T, Ortegon M, Strong K. The burden and costs of chronic diseases in low-income and middle-income countries. *Lancet* 2007; 370: 1929-38.
3. 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: 803-69.
4. Remme WJ, McMurray JJV, Rauch B, et al. Public awareness of heart failure in Europe: first results from SHAPE. *Eur Heart J* 2005; 26: 2413-21.
5. <http://www.escardio.org/communities/HFA/heart-failure-awareness-day-2011/Pages/country-programmes-2011.aspx> (last viewed 30.8.2013).
6. Stewart S, MacIntyre K, Hole DJ, Capewell S, McMurray JJV. More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *Eur J Heart Fail* 2001; 3: 315-22.
7. Lenfant C. Clinical research to clinical practice – lost in translation? *N Engl J Med* 2003; 349: 868-74.
8. Weinstein MC, Skinner JA. Comparative effectiveness and health care spending – implications for reform. *N Engl J Med* 2010; 362: 460-5.
9. Robb K, Stubbings S, Ramirez A, et al. Public awareness of cancer in Britain: a population-based survey of adults. *Br J Cancer* 2009; 101: S18-23.
10. Fitzpatrick JM, Kirby RS, Brough CL, Saggerson AL. Awareness of prostate cancer among patients and the general public: results of an international survey. *Prostate Cancer Prostatic Dis* 2009; 12: 347-54.
11. McMenamin M, Barry H, Lennon AM, et al.; the Irish National Cancer/Cardiac Awareness (INCA) survey. A survey of breast cancer awareness and knowledge in a western population: lots of light but little illumination. *Eur J Cancer* 2005; 41: 393-7.
12. Kozłowska E, Szewczyk MT, Banaszkiewicz Z, Jawien A, Cierzniańska K, Jarmocik P. Knowledge of symptoms and diagnostic possibilities of cancer diseases. *Arch Med Sci* 2011; 7: 304-9.
13. Sayiner A, Alzaabi A, Obeidat NM, et al. Attitudes and beliefs about COPD: data from the BREATHE study. *Respir Med* 2012; 106: S60-74.
14. Maggioni A, Anker SD, Dahlstrom U, et al. Are hospitalized or ambulatory patients with heart failure treated in accordance with ESC guidelines? Evidence from 12,440 patients of the ESC Heart Failure Long-Term Registry. *Eur J Heart Fail* 2013; 15: 1173-84.
15. Lainscak M, Cleland JG, Lenzen MJ, Follath F, Komajda M, Swedberg K. International variations in the treatment and co-morbidity of left ventricular systolic dysfunction: data from the EuroHeart Failure Survey. *Eur J Heart Fail* 2007; 9: 292-9.
16. Lainscak M, Cleland JG, Lenzen MJ, et al. Nonpharmacologic measures and drug compliance in patients with heart failure: data from the EuroHeart Failure Survey. *Am J Cardiol* 2007; 99: 31D-7D.
17. Lainscak M, Keber I; the Working Group on Heart Failure at the Slovenian Society of Cardiology. Primary care physicians' beliefs concerning heart failure management:

- results of a cross sectional survey. *Slov Kardiol* 2006; 3: 4-12.
18. McDonagh TA, Blue L, Clark AL, et al.; the Heart Failure Association Committee on Patient Care. European Society of Cardiology Heart Failure Association Standards for delivering heart failure care. *Eur J Heart Fail* 2011; 13: 235-41.
 19. Lainscak M, Blue L, Clark AL, et al. Self-care management of heart failure: practical recommendations from the Patient Care Committee of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail* 2011; 13: 115-26.
 20. Zontar T, Glavic T, Hostar H, et al. Knowledge about heart failure among Slovenian nurses. *Eur J Heart Fail* 2012; 11 (Suppl. 1): S218.
 21. Anker MS, von Haehling S, Springer J, Banach M, Anker SD. Highlights of mechanistic and therapeutic cachexia and sarcopenia research 2010 to 2012 and their relevance for cardiology. *Arch Med Sci* 2013; 9: 166-71.
 22. Roblek T, Trobec K, Mrhar A, Lainscak M. Potential drug-drug interactions in hospitalized patients with chronic heart failure and chronic obstructive pulmonary disease. *Arch Med Sci* in press.
 23. <http://www.escardio.org/communities/HFA/heart-failure-awareness-day-2012/Pages/european-heart-failure-awareness-day-2012.aspx> (last viewed 30.8.2013).
 24. Seferovic PM, Stoerk S, Filippatos G, et al. Organization of Heart failure Management in European Society of Cardiology Member Countries: Position Statement of the Heart Failure Association of the European Society of Cardiology in Collaboration with the Heart Failure National Societies/Working Groups. *Eur J Heart Fail* 2013; 15: 947-59.