

## International exchange

# Chronic heart failure: the role of primary care – position paper of the European Forum for Primary Care

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## Introduction

Chronic heart failure (CHF) is a clinical or subclinical condition that results from different cardiac pathologies including myocardial infarction (MI) and is becoming a major problem in primary care. The condition occurs in around 2% of the adult population,<sup>1,2</sup> rising to over 8% of over 75 year olds and 15% of those over 85 years.<sup>2</sup> The incidence of CHF continues to increase, presumably due to improved survival following acute MI and an increasingly older population. Over 3.6 million new cases of CHF are reported each year in Europe.<sup>3,4</sup> CHF affects from 10 to 14 million patients in Western Europe and the United States alone,<sup>3,5</sup> and this number is forecast to increase to 30 million by the year 2020 in just Europe alone.<sup>3,5,6</sup>

CHF is more common than most cancers, including breast, testicular, cervical and bowel cancers.<sup>7</sup> Admission to hospital with CHF has more than doubled in the last 20 years.<sup>3</sup> CHF patients experience a lower quality of life than patients suffering from any other chronic disease.<sup>3</sup>

## Impact of CHF on patients

The New York Heart Association (NYHA) classification distinguishes four classes of severity of CHF: asymptomatic, mild, moderate and severe heart failure.

### Mortality

Mortality rates in CHF are high. In recent trials, annual mortality in a placebo group which was compared with groups treated by angiotensin-converting enzyme (ACE) inhibitors has ranged from 7% in mild CHF (NYHA II),<sup>8</sup> to 11–13% in moderate cases (NYHA III),<sup>3,9</sup> and to 20%,<sup>5</sup> 23%,<sup>10</sup> or 28%,<sup>11</sup> in severe CHF. Nearly 40% of CHF patients will die within one year of first hospitalisation, and only 25% of men and 38% of women will survive more than five years following diagnosis.<sup>12,13</sup> By 2020 the number of deaths in Europe attributed to CHF will be nine million each year.<sup>3</sup>

Mortality data from some recent epidemiological studies mainly report on CHF resulting from left ventricular systolic dysfunction (LVSD), or CHF in younger patients only,<sup>14</sup> or in patients presenting to hospital, usually with acute symptomatic CHF.<sup>7,15</sup> In

these studies, mortality is particularly high, with 50% two-year mortality, probably representing late presentations. A more accurate estimate of prognosis of CHF, across all ages and stages, is available from follow up of the ECHOES cohort (Echocardiographic Heart of England Screening).<sup>4</sup> Five-year survival rate of the general population was 93% compared to 58% of those with a diagnosis of LVSD and 58% for those with definite CHF. Those with a prior diagnostic label of CHF had the lowest survival compared with the general population, and survival improved significantly with increasing ejection fraction. Those persons with multiple causes of CHF had the poorest survival. Importantly, outcomes in CHF are improving, presumably due to better initiation and maintenance of evidence-based therapies.<sup>16</sup>

### Morbidity

Morbidity in CHF is considerable, whether measured by symptom severity, quality of life, need for consultation, treatment or hospital admission. The few existing publications with comparative data suggest that CHF worsens quality of life more than other chronic diseases,<sup>17</sup> and that women may suffer worse impairment.<sup>18</sup> Other studies have shown that CHF is associated with depressive illness,<sup>19–21</sup> and further, that this is then linked to a worse prognosis.<sup>22</sup> Those with CHF had significant impairment of all the measured aspects of physical and mental health, not only physical functioning. Patients with asymptomatic left ventricular dysfunction and patients rendered asymptomatic by treatment had similar scores to the random population sample. Those with CHF reported more-severe

impairment of quality of life than people giving a history of chronic lung disease or arthritis, with a similar impact to patients reporting depression.

### Importance of CHF in primary care

The above data suggest that CHF is increasingly frequent and, therefore, needs to be addressed in the community. This means that primary care must play an important role in the management of CHF.

Indeed, in many countries, general practice is the most frequent point of consultation of patients with CHF, and the role of general practitioners (GPs) and nurses is becoming a key element in the management of CHF.

## Diagnosis of CHF

### Clinical diagnosis

CHF is a common syndrome, a manifestation of underlying heart disease, like anaemia, thyroid disease and damage to the heart muscle by ischaemia (MI) or hypertension. There is no universally agreed definition of CHF.

As Candida Fonseca states in one of her review articles on CHF:

... improving the reliability of diagnosis in primary care is essential since determining the aetiology and stage of CHF leads to different management choices to improve symptoms, quality of life and disease prognosis. Early diagnosis is beneficial, also in asymptomatic cases, since treatment can delay or reverse disease progression.<sup>31</sup>

### Box 1 Specific high-risk groups for CHF

The risk of death is significantly elevated in elderly patients and those affected with sleep apnoea syndrome (SAS) with CHF, independent of ventricular function and CHF severity, and these patients must be treated with special attention.<sup>23,24</sup> Sleep apnoea prevalence in CHF exceeds 50% in series but often goes unrecognised and, even when detected, it is often not treated. Screening for CHF is recommended, mainly in those more severely affected by SAS and when patients do not improve with correct treatment.<sup>25</sup> Sleep apnoea in patients with CHF is frequently unrecognised, perhaps because its associated symptoms (fatigue, impaired physical performance, poor quality of life, and cognitive impairment) are attributed to CHF.<sup>26</sup>

SAS may contribute to CHF progression by exposing the heart to intermittent hypoxia, increasing preload and afterload, sympathetic activation, and vascular endothelial dysfunction. Sleep apnoea is common, readily diagnosed, and usually treatable. It frequently co-exists undiagnosed in patients with cardiovascular disease, activates disease mechanisms known to elicit cardiac and vascular damage, and may be implicated in the progression of cardiovascular disease and resistance to conventional therapeutic strategies.<sup>27</sup>

Treatment of SAS with continuous positive airway pressure (CPAP) in the home setting has been shown to alleviate sleep apnoea, and to improve left ventricular ejection fraction (LVEF), decrease urinary and plasma norepinephrine (noradrenaline) concentrations, and improve symptoms of CHF.<sup>28,29,30</sup> Although survival studies have not yet shown significant mortality difference between treated and control groups, CPAP probably can prolong survival in patients with both CHF and SAS. Larger series are needed, and many authors conclude that early diagnosis of SAS and initiation of effective CPAP therapy are of paramount importance in patients with co-existent CHF and SAS.<sup>2,4</sup>

Individual signs and symptoms may result from other pathologies and mistakenly be attributed to CHF. In countries where self-referral to a specialist is an option, a not-well-informed patient with dyspnoea may visit either the cardiologist or the lung specialist, or a patient with hepatic enlargement may consult an internist. Spontaneous access of the patient to secondary care may lead to unnecessary costs.<sup>32</sup> The role of the family physician is crucial in early detection and diagnosis of CHF, on condition that they are well trained in the subject. However, for some, the role of primary care is controversial: Cowie *et al* in 1997 stated that delegating the responsibility of the initial diagnosis to the family medicine-led community services is not an effective approach, as reports have demonstrated incorrect diagnoses in as many as 60% of cases.<sup>33</sup> This may be partly explained by the difficulty in diagnosing CHF in its earliest stages due to the often non-specific nature of presentation.

Indeed, other studies exploring the validity of a clinical diagnosis of CHF in primary care report high rates of misdiagnosis when patients are assessed against objective criteria (rates of 25–50% accuracy reported in different series). In a study in Scotland, only 26% of patients referred to a rapid-access echocardiography clinic with suspected CHF were confirmed after investigation.<sup>34</sup> However, clinical diagnosis by hospital physicians is just as poor.

## Imaging and laboratory

While the correct clinical diagnosis of CHF is indeed difficult to make, especially in the early cases, the need for reliable diagnostic tools is evident.

Cardiac imaging is required, also in early cases. Suggested alternatives in primary care include electrocardiography (ECG), since a normal recording will, in most cases, exclude left ventricular dysfunction.<sup>35</sup> However, changes may be subtle and the lack of ECG interpretation skills may still require referral for specialist opinion. Another test often advocated, but with few supporting data, is the use of the chest X-ray (CXR). Both ECG and CXR are relatively inexpensive, and recent evidence confirms that they should not act as 'rule-out-tests'.<sup>36</sup> Echocardiography is considered as the gold standard only in CHF caused by LVSD, so this also is not entirely specific.

The degree to which GPs can access ECG, echocardiography and laboratory tests, therefore, is an important determinant of their capacity to correctly diagnose and follow up on CHF. In some countries these essential investigations may not be readily available to GPs.

## *B-type natriuretic peptide and pro-peptide N-terminal B-type natriuretic peptide tests*

In this context, the potential role of B-type natriuretic peptide (BNP) and its pro-peptide N-terminal fragment (NT-proBNP) in diagnosing CHF on the basis of a simple and inexpensive blood test has emerged. BNP is a substance secreted from the ventricles or lower chambers of the heart in response to changes in pressure that occur when heart failure develops and worsens.

Numerous studies have confirmed the stability and feasibility of BNP testing, although there are relatively few data testing the peptides in the clinical setting where they would be most used, i.e. in adults in the community presenting with persisting breathlessness. Also, there is some controversy on the specificity and sensitivity and thereby of the use of the test: is it useful for screening or early diagnosis purposes?<sup>37,38</sup> A normal level of BNP virtually guarantees that CHF is not present, but echocardiography is needed in patients with elevated BNP to confirm the diagnosis. However, there are still questions about the diagnostic accuracy of BNP and NT-proBNP arising from systematic reviews: most of the diagnostic studies were conducted in secondary or emergency care, and results of the primary care studies showed significant heterogeneity.<sup>39</sup> Relevant cut-offs and how these are affected by age, sex and possibly comorbidity conditions are still under discussion.<sup>40</sup> Recent studies suggest that clinical information is as effective as NT-pro BNP in ruling out LVSD.<sup>41</sup> However, some smaller follow-up studies suggest that it may also have an important role in guiding therapy, at least in specialist settings.<sup>42</sup>

In conclusion, CHF represents a complex disorder to diagnose, requiring a mix of careful clinical assessment and objective evidence of structural cardiac problems alongside. The probability of CHF in patients with typical symptoms is significantly increased in those patients with a previous history of MI, with concurrent symptoms of ischaemic heart disease, with existing hypertension, or suffering diabetes (in descending order of likelihood). Therefore, the primary care physician requires a structured approach to CHF diagnosis, taking into account at-risk groups. Further guidelines or protocols for the approach by GPs in primary care, adjusted to their context, would be welcome.

## Management of patients with CHF

Caring for patients with CHF often involves a host of medical, behavioural, psychological, social and economic factors, and appropriate attention must therefore

## Box 2 Clinical practice guidelines (CPGs) and diagnostic tests for CHF

In 2007, a systematic review of evidence-based CPGs has been conducted, in preparation for the development of a new guideline on CHF for German primary care physicians.<sup>43</sup> During the review, a total of 16 guidelines fulfilled the predefined inclusion criteria, and 10/16 addressed diagnostics in CHF. Of these, seven provided recommendations for the use of BNP/NTproBNP tests, but their content and grading were completely different:

- one CPG from the UK suggested the use of BNP or NTproBNP tests and/or a 12-lead ECG to rule out CHF before a patient with suspected CHF was referred for echocardiography<sup>44</sup>
- three CPGs from Canada, the US and Finland considered the tests to be helpful in patients with acute dyspnoea and suspected CHF in addition to symptoms and clinical signs. One of them graded the recommendation as 'A', based on evidence level I,<sup>45</sup> a second did not weight the strength of recommendation but assessed the evidence as levels 'A and C',<sup>46</sup> and the last graded the recommendation as 'B'<sup>47</sup>
- the guideline from the European Society of Cardiology endorsed the use of the tests in the text but did not formulate an explicit recommendation<sup>48</sup>
- two CPGs from New Zealand and the US disapproved of the use of the test in the primary care setting because of the lack of strong evidence (in this setting).<sup>49,50</sup>

There was a very low literature overlap between the guidelines, which raises questions on their evidence base, and none of them undertook a systematic evaluation of existing studies. Apart from that, reasons other than evidence may have been responsible for the recommendations. It was explicitly stated in one CPG that the limited availability of echocardiography led to a positive recommendation on the use of the BNP/NTproBNP test.<sup>43</sup> Restricted access to echocardiography for health economy reasons also may have influenced the decisions of other guideline-development groups. Based upon the variations of CPG recommendations on this point, a systematic evaluation was carried out for the German guideline. It did not identify strong evidence for the use of these tests in the primary care setting. Since availability of and access to echocardiography are fairly high in Germany, the use of this test was not recommended in the guideline. However, in settings where GPs have no access to echocardiography, use of this test may be warranted.

be directed to all aspects of care, both pharmacological and non-pharmacological.<sup>51,52</sup>

## Pharmacological treatment

CHF is treated in various ways. The aims of pharmacological treatment are to counteract the pathophysiological mechanisms underlying CHF and thereby to reduce symptoms and delay progression of the disease, reduce hospitalisation, and extend and improve the quality of life.<sup>32</sup> The GP can achieve these aims and is also able to treat CHF effectively in the early stages, in the elderly and in homecare outpatients. Over the past years, treatment options have increased. Clinical guidelines are available for GPs in Europe (for example the NICE guideline).<sup>44</sup> However, some drugs are not easy to prescribe or available in primary care in all European countries: national regulations, in some cases, keep some drugs to be prescribed just in secondary care or under inspection seal (drugs not covered by public finance and only authorised in specific circumstances).

Data in the last decade show a progressive improvement in the use of recommended drugs prescribed by GPs. However, statistics collected by GPs show that the proportion of patients with CHF who currently receive drug prescriptions under differing guidelines

varies widely.<sup>53–55</sup> Further analysis should be carried out, leading to more effective implementation of clinical guidelines in CHF at the primary health level in Europe. This includes permanent updating of knowledge and skilful use of all drug treatment alternatives in primary care.

A brief overview of the existing treatment options is given next.

Angiotensin-converting enzyme (ACE) inhibitors were an important addition to the classic diuretics: they improve both morbidity and mortality in all grades of symptomatic CHF due to LVSD, and in patients with asymptomatic LVSD they can delay or prevent progression to symptomatic CHF. Beta-blocker therapy in CHF due to LVSD has also been demonstrated to improve prognosis and reduce admission rates, against a background of ACE inhibition.<sup>56</sup> Both these drug classes have also been shown to improve global quality of life in sufferers.<sup>57,58</sup>

Aldosterone receptor antagonists, which are potassium-sparing diuretics, reduce hospitalisation and mortality in severely symptomatic (NYHA grade III and IV) patients,<sup>10</sup> or in post-MI LVSD.<sup>59</sup> However, they should be used in low doses in the elderly population since they may be associated with raising mortality if not used carefully in routine practice (only

in low doses and withdrawn during periods of illness especially when dehydrated).<sup>60</sup> More recent data have demonstrated the general utility of angiotensin-receptor blockers in patients who are intolerant of ACE inhibitors in people with impaired LV function.<sup>61</sup>

Despite this rich evidence base on effective interventions, CHF remains suboptimally diagnosed and treated in many countries,<sup>62</sup> due at least in part to many patients with suspected CHF not receiving formal assessment of LV function.

## Non-pharmacological treatment

The non-pharmacological treatment of CHF can be divided into changes in lifestyle and symptom monitoring. To encourage patients to make lifestyle changes is a form of secondary prevention. It includes dietary changes such as restricted fluid, sodium and alcohol intake, and individually adjusted energy intake in order to reduce overweight or prevent malnutrition. It also includes smoking cessation, exercise in stable CHF and infection prophylaxis with vaccinations.<sup>18</sup> Symptom monitoring is the ability to recognise symptoms indicating a change in the condition of the patient and symptoms of CHF, i.e. increased shortness of breath, weight gain and oedema.<sup>63,64</sup> Symptom monitoring includes daily weighing and monitoring of fatigue, shortness of breath and peripheral oedema.

## Patient education

In western societies empowerment has become the philosophy of patient educators. The empowerment approach assumes that the person with a chronic illness takes personal responsibility for his or her health and self-cares as much as possible. The goal of education is then to help the person to make informed choices and reach the self-selected goals regarding their self-care.<sup>65,66</sup>

CHF has an impact on physical and psychological wellbeing, social functioning and daily life activities.<sup>67–69</sup> As CHF progresses, patients have to make adjustments in their lives and learn to live with the consequences of CHF. The aim of the education is primarily to make the disease and its symptoms more comprehensible to the patient. Knowledge increases the sense of personal control and helps the patient to adapt to the chronic illness and the prescribed treatment.<sup>70</sup> Adapting to the consequences of having CHF can be a difficult process for the patients. Many patients with CHF consider themselves as healthy until they deteriorate and become acutely ill, and so they may find it unnecessary to take drugs and make

lifestyle changes.<sup>71</sup> Guidelines on patient education have been frequently used and are an important tool in the follow-up (see Box 3).<sup>16,72</sup>

There have been quite a few examples of a positive effect of programmes on symptoms and the evolution of CHF, such as exercise training,<sup>74</sup> and intensive nurse-led discharge and outreach programmes.<sup>75</sup>

### Box 3 Patient education: subjects to discuss with a CHF patient and his or her family

#### General advice

- Explanation of CHF and why symptoms occur
- Causes of CHF
- How to recognise symptoms
- What to do if symptoms occur
- Self-weighing
- Rationale for treatments
- Importance of adhering to pharmacological and non-pharmacological prescriptions
- Refrain from smoking
- Prognosis

#### Drug counselling

- Effects
- Dose and time of administration
- Side-effects and adverse effects
- Signs of intoxication
- What to do in case of skipped doses
- Self-management

#### Activity, exercise and rest

- Work, leisure activities and travel
- Rest
- Energy-conserving strategy
- Daily physical activity
- Sexual activity
- Rehabilitation; exercise programme

#### Vaccinations

#### Symptom assessment and management

- Expected symptoms versus symptoms of worsening CHF
- Self-monitoring of daily weights
- Actions in case of increased symptoms
- Dealing with psychological symptoms
- Self-management (for example, diuretics)

#### Dietary and social habits

- Control sodium intake when necessary
- Avoid excessive fluids in severe CHF
- Avoid excessive alcohol intake
- Smoking cessation
- Compliance strategies

#### Box 4 The European CHF Self-care Behaviour Scale (EHFScBS)

The goal of several non-pharmacological interventions for patients with CHF is improved self-care behaviour. These interventions are often evaluated based on their effects on readmission, costs and quality of life. However, it is also important to know if and how patients changed their self-care behaviour as a result of such interventions. In addition to a general approach to enhance compliance to the medical regimen and improve healthy behaviours amongst CHF patients, CHF-specific behaviours can be evaluated to gain insight about the measures required to improve patient education or support behavioural change.

The European CHF Self-care Behaviour Scale (EHFScBS) comprises 12 items rated on a five-point scale between 1 (I completely agree) and 5 (I completely disagree), which was developed, tested and published in 2003. The EHFScB is available in 14 languages. It has shown to be an internally consistent and valid scale to measure self-care behaviour related to CHF. The EHFScBS may well be used to establish the effectiveness of CHF-management programmes and to gain insight into the mechanisms by which such programmes achieve their behavioural goals.<sup>73</sup>

### Co-ordination of care in CHF: integrated care and disease-management programmes

Care that aims at maintaining or improving the quality of life of people with CHF and the end-of-life care in CHF should be seen as part of an integrated care approach.

In the late 1990s, Ed Wagner *et al* developed their Chronic Care Model (CCM),<sup>76</sup> which summarised the evidence for effective changes in healthcare systems – largely designed for acute illness – to improve chronic care. *Productive interactions* between ‘prepared proactive practice teams’ and ‘informed activated patients’ are at the core of CCM, and these consistently provide the positive assessments, support for self-management, optimisation of therapy, and follow-up associated with good outcomes. Ensuring productive interactions that consistently result in evidence-based clinical care and promote self-management has proved to be extremely difficult in current medical practice. In order to re-design delivery systems to meet the needs of chronically ill patients, Wagner *et al* clustered interventions into six areas: healthcare organisation, community resources, self-management support, delivery system design, decision support, and clinical information systems.<sup>76</sup> In accordance with these categories a systematic review including meta-analyses was conducted by the RAND Corporation and others.<sup>77</sup> Interventions with at least one CCM element had consistently beneficial effects on clinical outcomes and processes of care, and the 21 studies included for CHF additionally showed beneficial effects on quality of life. Nevertheless, the overall evidence on the effectiveness of CCM-interventions is still limited: most studies were undertaken within high-performing organisations like the US Health Maintenance Organizations.<sup>78</sup> Further research is needed on how to put CCM into practice in the small or even solo practices that are typical for most European countries.

The development of organised health systems, with integration of care across different levels of care and services, means that patients have to go to several services for various aspects of their health needs. In some countries, the GP conducts the referral and counter-referral process, and in others the patient chooses the specialists without a referral from the GP. Co-ordination requires a key element – the transfer of information generated in different places.<sup>79</sup> It is well reported that it is better to manage specific chronic diseases by involving several professionals and services. Because of that the development of disease-management programmes (DMPs) has proved to be a good tool for co-ordination in a cost-effective way. Therefore, DMPs may be defined as a complete approach to care of a particular disease encompassing prevention, treatment, follow-up care, and including implementation of guidelines.<sup>80</sup> The involvement of different professionals and levels of care and giving a special role to patients improves the quality, efficiency of care delivery and health outcomes.<sup>81</sup> In parallel with other chronic disease programmes, CHF DMPs have been recently established in some countries in Europe and they are well disseminated and evaluated in the US. These DMPs have shown a reduction in mortality and hospitalisations in heart failure patients. Because various types of DMP appear to be similarly effective, the choice of a specific programme depends on local health services characteristics, patient population, and resources available.<sup>82</sup>

Currently, there are basically two approaches in DMPs in CHF. One aims at the sicker group of the CHF population, and the benefits of a DMP will only benefit these patients when their condition deteriorates to a stage that requires hospitalisation.<sup>83</sup> The second approach should work towards the development of an expanded DMP,<sup>83</sup> in which CHF is a chronic disease and not a terminal disease, and taking into account patients with established CHF and those at risk of its development. Hence, the majority of care

should be organised from the community setting led by the GP and nurse. As for much of the natural evolution of CHF the patient is clinically stable, the focus of primary care should be directed at maintaining this relative wellbeing.

Facilitating access to the asymptomatic and minimally symptomatic sections of the CHF population is another important challenge within an expanded model of disease management. The most successful strategy in this regard will be the ongoing and continuing education of the GP in CHF. In doing so, the GP will become more aware of those needing referral, and will become more confident in dealing with certain CHF issues that should not require referral. Formal shared-care protocols have been developed in many DMPs and they involve close ongoing liaison between cardiologists and GPs and nurses.<sup>84</sup>

Finally, a well-developed integrated care system and DMP needs a centralised information system. An electronic internet-based system, with shared and confidential clinical records should be the goal (primary care, secondary care, emergency care), but most European countries are still in early stages of the development of a comprehensive IT system. Other programmes that contribute to the integrated approach of CHF are programmes that include telemedicine and telemonitoring (structured telephone support programmes) for patients with CHF. These work in a proactive way in the follow-up of patients, from the clinically mild ones to the severe acute patient, and in the detection of non-respondent patients with CHF. These programmes have been reported to have a positive effect on clinical outcomes in community-dwelling patients.<sup>85,86</sup>

## Citizen awareness of CHF

How far is the general public aware of causes, symptoms and consequences of CHF? How important is awareness of CHF?

The SHAPE survey (Study group on CHF Awareness and Perception in Europe), which was carried out in nine European countries (France, Germany, Italy, The Netherlands, Poland, Romania, Spain, Sweden and the UK) in April 2002, analysed the following areas:

- 1 *recognition of CHF by citizens*: 86% of people surveyed had heard of CHF. However, only 3% could correctly identify the signs and symptoms of CHF. More than 70% of respondents did not consider CHF to be a serious condition – despite the fact that the disease is extremely debilitating, causing a high rate of hospitalisation. Over 65% believed that survival rates from CHF were better than those for cancer – in fact the survival rates are considerably bleaker, with only 25% of men and 38% of women living longer than five years after diagnosis; 34% believed CHF to be a natural consequence of ageing – yet 40% of those affected die within a year of first hospitalisation, the opposite of a gentle decline into old age
- 2 *comparison with other healthcare conditions*: only 43% thought CHF was more common than cancer in their country; 67% wrongly believed CHF patients lived longer than cancer patients; 66% wrongly thought chances of survival were higher in CHF patients than in HIV patients

### Box 5 Riksvikt: a quality registry to improve the management of patients with CHF

With the purpose to improve the management of patients CHF by following guidelines more strictly regarding diagnosis and treatment, a national quality registry (Riksvikt) was created by a group of experts in Sweden in 2003. Together they built a protocol, which shows aspects of aetiology, diagnostics, medical treatment and follow-up. The long-term goals of this guideline are to contribute to reduced mortality and morbidity, increased quality of life in patients with CHF, and more cost-effective CHF care.

Patients with a diagnosis of CHF admitted to hospitals, outpatient clinics or primary care centres are included in the registry (currently nearly 20 000 patients), and the information recorded from each patient consists of carefully selected and pre-defined variables to be filled in either by a nurse or by discharging physician. The registry covers background factors, performed diagnostics procedures, other investigations, medical therapy and follow-up. The register also has a special formula for primary care centres in which some of these variables are excluded. Data can also be imported from computer-based journals.

A very important purpose of the register is also to give continuous feedback to every centre on their data about diagnosis and treatment compared to the national average. By participating in the registry the participating units have immediate data entry over the internet or data transfer from local databases; access to information about all previously registered patients; and access to reports, lists and statistical analyses of selected patient groups in comparison to the average of other participating centres.<sup>87</sup>

### Box 6 The Expert Patient Programme for patients with CHF

The Catalan Health Institute, the biggest healthcare provider in Catalonia, has developed an Expert Patient Programme for CHF adapted to the Catalan environment in which primary care is the main player. This programme is the result of a shift in health education from a paternalistic model in which the health professional manages patient care, to a patient-empowerment model in which patients make decisions concerning their own health care. This new role is given to a selection of patients with CHF who have good communication skills and the motivation to follow a training programme, given by medical professionals. Once these expert patients have been trained, they conduct a scheduled programme with other patients with CHF. In these sessions, the health professional plays the role of observer and does not intervene in the meeting. He observes the dynamics of the meeting, and afterwards with the expert patient he analyses the meeting and proposes changes for follow-up meetings. The initiative for the meetings comes from the patients, and doubts, myths and management of the illness are discussed by the expert patient. One of the advantages of this model is that the expert patient has experienced the symptoms of CHF him/herself, and it is therefore easier to explain the experience and how he/she has learnt to manage their illness in everyday life. Evidence shows that information given by the expert patient is more readily interiorised by the CHF patient than when the same information is given by a health professional, and many myths and fears about CHF disappear.

The main objectives of the programme were: (i) to improve the understanding of CHF; (ii) to learn how to respond to different symptoms of the illness and how to cope in different situations; (iii) to learn how to interact within their family and society; (iv) to be able to make their own decisions and improve self-care; and finally (v) to rationalise the use of the healthcare services.

To evaluate the impact of the programme various indicators were analysed before and after the programme. Indicators evaluated: (i) the frequency of visits to the primary health centre, hospital admissions and emergency visits to hospital units due to CHF; (ii) the number of homecare visits by the doctor and nurse related to CHF; (iii) the number of follow-up visits to the nurse's office; and (iv) the call centre follow-up results of patients with CHF.

The results show that patient satisfaction has increased and there is a more-rational use of health services by the patients as they feel more confident in dealing with their illness.<sup>86</sup>

- 3 *treatment*: 65% believed that CHF could be treated by drugs and 38% by pacemakers; 18% wrongly thought that modern drugs could not improve CHF survival, and 30% wrongly thought that drugs could not prevent the development of CHF; 61% of respondents wrongly thought that CHF patients should live quietly and avoid any form of exercise; 67% would prefer to feel better and improve their quality of life than live longer if they were diagnosed with CHF
- 4 in terms of *costs*, there was a general misperception that CHF results in lower healthcare expenditure than cancer or HIV, although there were equal scores for the cost of HIV and CHF in the UK and Poland.<sup>3</sup>

As a result of the studies to date, we believe that a priority should now be the dissemination of information to the public at large regarding the disease. This should be carried out mainly by primary care professionals, especially the family doctor, with a view to empowering the public in practicing self health care.

The above data, in the context of sustainability of health systems in Europe, reflect that primary care must play a determinant role in the management of

CHF, and the professionals and policy makers at this health level will have to rethink their tasks, level of knowledge and how they deal with CHF. There is still a long way to go for both professionals and policy makers, and a new challenge will be to incorporate citizens in this debate.

## Conclusions

Literature and population-based studies on CHF and primary care are scarce. There are no specific data on CHF in primary care reported by international organisations such as the World Health Organization (WHO) and the World Organization of Family Doctors (WONCA), and by scientific societies in spite of the high incidence and prevalence of CHF in the population. Most of the literature and papers about CHF in indexed journals are written by cardiologists, and the studies that have been published are particularly difficult to compare because of differences in methodology.

General practitioners are the clinicians who most frequently make the diagnosis of CHF, and diagnostic

and therapeutic protocols, adjusted to country context, should support them.

Access to further investigation of CHF by GPs such as laboratory measurements, ECG, chest X-ray and cardiac imaging, is required for improved diagnosis, leading to successful management.

There is a large potential for prevention and early diagnosis of CHF in primary care. Treatment of hypertension should prevent long-term damage to the heart muscle, thereby reducing the burden of CHF in future years.

As for most chronic diseases, correct filing and exchange of information between professionals and with the patient is essential. Electronic tools offer greater opportunity to do this and their development will facilitate the role of primary care.

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