Self-care management of heart failure: practical recommendations from the Patient Care Committee of the Heart Failure Association of the European Society of Cardiology

Mitja Lainscak, Lynda Blue, Andrew L Clark, Ulf Dahlström, Kenneth Dickstein, Inger Ekman, Theresa McDonagh, John J McMurray, Mary Ryder, Simon Stewart, Anna Strömberg and Tiny Jaarsma

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Mitja Lainscak,[1,2] Lynda Blue,[3] Andrew L. Clark,[4] Ulf Dahlström,[5] Kenneth Dickstein,[6] Inger Ekman,[7] Theresa McDonagh,[8] John J. McMurray,[9] Mary Ryder,[10] Simon Stewart,[11] Anna Strömberg,[5, 12] Tiny Jaarsma[13]

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

[2] Applied Cachexia Research, Department of Cardiology, Charité, Campus Virchow-Klinikum, Berlin, Germany

[3] British Heart Foundation, London, UK

[4] University of Hull, Hull, UK

[5] Department of Medicine and Health Sciences, Division of Cardiovascular Medicine, Linkoping University, Linkoping, Sweden

[6] University of Bergen, Stavanger University Hospital, Stavanger, Norway

[7] The Sahlgrenska Academy at Gothenburg University, Institute of Health and Care Sciences, Gothenburg, Sweden

[8] Cardiology Department, Royal Brompton Hospital, London, UK

[9] University of Glasgow, Glasgow, UK

[10] Heart Failure Unit, St. Vincent's Healthcare Group, Dublin, Ireland

[11] Preventative Health, Baker IDI, Heart and Diabetes Institute, Melbourne, Australia

[12] Department of Medicine and Health Sciences, Division of Nursing, Faculty of Health Sciences, Linkoping University, Linkoping, Sweden

[13] ISV, Department of Social and Welfare Studies, Faculty of Health Sciences, Linkoping University, Linkoping, Sweden and department of Cardiology, University Medical Centre Groningen, University of Groningen, the Netherlands

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Corresponding Author:

Mitja Lainscak, MD, PhD, FESC

Assistant Professor of Internal Medicine

Division of Cardiology, University Clinic of Respiratory and Allergic Diseases Golnik

Golnik 36, SI-4204 Golnik, Slovenia

Tel.: +386 31 379 533

Fax: +386 4 25 69 117

E-mail: mitja.lainscak@guest.arnes.si

ABSTRACT

Guidelines on Heart Failure (HF) stress the importance of lifestyle advice, although there is little evidence that such recommendations improve symptoms or prognosis. Patients are experiencing symptoms of different intensity which impairs their daily activities and reduces quality of life. To cope with their clinical condition, many patients seek advice about lifestyle and self-management strategies when in contact with medical care providers, particularly specialized HF services. Self-care management is an important part of HF treatment thus health professionals working with patients with HF have recognized the need for more specific recommendations on lifestyle advice. The present paper summarizes the available evidence, promotes self-care management, and aims to provide practical advice for health professionals delivering care to HF patients. It also defines avenues of research to optimise self-care strategies in a number of key areas to derive further benefits.

Keywords: compliance; heart failure; lifestyle; non-pharmacological measures; self-care

INTRODUCTION

Guidelines on Heart Failure (HF) stress the importance of lifestyle advice, although there is little evidence that such recommendations improve symptoms or prognosis [1]. Most of the advice was developed in an era before there was effective drug therapy and only a few randomized controlled trials on life-style interventions have been published [2-4]. Many patients seek advice about lifestyle and self-management strategies when in contact with medical care providers, particularly specialized HF services [5]. Although little evidence exists that lifestyle intervention is of benefit, it has been part of multicisciplinary intervention. Such services have led to improved adherence to self-management strategies and improved quality of life, and a clear benefit in terms of reduced number of hospitalizations [6, 7] and mortality [8]. Different models for HF services are tailored to local needs and the most efficient content and structure to deliver optimal health outcomes is yet to be defined. With increasing internet availability, patient literacy, and particularly as it has now been translated into five languages, the specifically designed and regularly updated web site (www.heartfailurematters.com) may prove to be very helpful both for patients and medical care providers. Regardless of efficacy, the challenge of HF to patients and their families mandates tailored education on self-care maintenance and management throughout the natural history of the syndrome with suitably altered recommendations on self-care and lifestyle [9]; from the disease management stage to a terminal care phase.

Health professionals working with patients with HF have recognized the need for more specific recommendations on lifestyle advice. The present paper

summarizes the available evidence, promotes self-care management, and aims to provide practical advice for those delivering care to HF patients. Current HF guidelines have identified several gaps in evidence. We have extended their list of common issues that deserve to be addressed in future clinical research (Table 1). We realize that when delivering patient education, health professionals need to be aware of the personal situation of patients and aim at tailored advice, considering how to optimally improve their quality of life.

SYMPTOM RECOGNITION

RATIONALE

Symptoms not only reflect the physical aspects of a disease but also have an impact on lifestyle, anxiety and depression in patients. Breathlessness and fatigue are classical symptoms of HF and are often assessed and reported [10]. Other symptoms are rarely documented in patients with HF, but a broad range of symptoms (e.g. dizziness, oedema, loss of appetite) linked to HF has been reported [11, 12]. Although symptoms are subjective, and clinicians' and patients' assessment of the same symptom may differ, clinicians should recognise their importance to the affected individual [13-15] and evaluate them objectively [16].

EVIDENCE

While symptoms are hallmarks of HF severity, interpretation of symptoms is difficult [14, 15, 17, 18]. Individual experiences are still valuable and should be considered in clinical practice [19].

CURRENT GUIDELINES

The ESC guidelines [1] for HF treatment advocate that patients and/or caregivers understand that symptoms indicative of HF deterioration vary considerably. Furthermore, they should learn to rapidly detect and/or recognize warning symptoms in order to take appropriate action.

CLINICAL PRACTICE

- Obtain a comprehensive patient history and focus both on symptom frequency and intensity [20]
- Find out how patients describes symptoms when needing acute hospitalisation, and relate the symptoms to how they felt in the period leading to admission
- Useful keywords when discussing symptoms with patients are [21]:
  - Intensity
  - Rate (on how many occasions during a time interval)
  - Duration (how long)
  - Pattern (mornings, after activities etc)
  - Specificity (the whole body, arms etc)
  - Specific words (no energy, cannot concentrate, feeling of suffocation etc)

To improve evaluation of symptoms, standardized scales can be used [22]. Rating of intensity of symptoms can be done by the patients using a numeric rating scale, a visual analogue scale, or a Likert scale, for example to rate the intensity of shortness of breath: (1) Asymptomatic; (2) dyspnoea when walking upstairs at normal pace; (3) dyspnoea when walking at normal pace on the flat; (4) dyspnoea when walking slowly on the flat or during washing or dressing and (5) dyspnoea at rest.

FUTURE RESEARCH

The optimal method(s) to teach patients about their symptoms, and how to build their skills to recognize the significance of symptoms remains unknown. Since symptoms reflect the personal and the social experiences of illness, cultural differences exist in interpretation of symptoms which may lead to different

responses to the illness. Studies exploring and evaluating symptom burden and relief (particularly when language barriers exist) is important. Remote monitoring of symptoms in patients with HF has shown promising results to reduce events [23]. Given the volume of information derived from such monitoring, defining which variables should be assessed, which symptoms should be reported, which components are successful and feasible and the role and responsibility of the patients themselves needs to be studied [24, 25].

FLUID AND SODIUM MANAGEMENT

RATIONALE

Maintaining euvolaemia is one of key issues for patients with HF. Volume overload can worsen the symptoms of HF thus interventions to restore fluid balance are needed and many patients have to be hospitalized. They frequently require intravenous diuretics, modified sodium and fluid intake or additional procedures in cases of refractory volume overload. On the other hand, volume depletion due to various clinical conditions (fever, diarrhoea or vomiting), therapy (overuse of diuretics), or insufficient fluid intake by the patient, can lead to a different set of symptoms such as hypotension, dizziness and lethargy. Volume depletion also affects the renal function and electrolyte homeostasis.

EVIDENCE

There is limited research focussing on optimal fluid management in the HF patient. A recent study comparing fixed (1500ml) and flexible (30ml/kg body weight, 35ml/kg if body weight >85kg) fluid intake regimens, found no significant differences in quality of life, number of hospitalizations, and physical performance. However, thirst was less pronounced during a flexible regimen, and patients did not want to cross-over to the fixed regimen [26, 27]. In acutely decompensated patients admitted to hospital (N=67) there was no difference in time to discontinuation of parenteral diuretic therapy between fluid restricted and ad libitum group [28].

Sodium determines body fluid volume and it is therefore plausible, that sodium restriction might be beneficial [29]. In patients with advanced HF, it has been suggested that excessive sodium intake may cause diuretic resistance and deterioration which can trigger a hospital admission [30]. Poor knowledge about dietary sodium using standardized test was associated with 90-day hospital readmissions [31]. However, in a randomized trial which compared low (80mmol/l) vs normal (120 mmol/l) sodium diet in patients receiving high doses of furosemide, sodium restriction was associated with more readmissions over 180 days after an index hospitalization [32]. This could be due to enhanced activity of renin-angiotensin-aldosterone system and sympathetic nervous system, as previously reported in patients with HF exposed to a low sodium diet [33].

In a recently published prospective randomized pilot study, patients followed a sodium (2-3 g/day) and fluid (1.5 L/day) restricted diet and a significant reduction in fluid and sodium intake were found [34]. The effects in terms of patient perceptions and clinical outcomes need to be assessed in a larger study.

CURRENT GUIDELINES

In the ESC guidelines [1] it is advised that patients should monitor weight on a regular basis and respond to a sudden unexpected weight gain of >2kg in 3 days. There is no rationale for routine fluid restriction in stabilised patients with mild to moderate HF. Fluid restriction of 1.5-2l/day may be considered in patients with severe symptoms, particularly in concurrent hyponatremia. Studies supporting sodium restriction are lacking.

CLINICAL PRACTICE

The EuroHeart Failure survey reported that 12 weeks after discharge only half of patients with a clinical diagnosis of HF recalled receiving advice to weigh themselves regularly and about two thirds of them followed advice completely [35]. Instead of applying a strict fluid restriction, patients might be encouraged to monitor their weight regularly and to adopt self-management strategies to avoid deterioration if they experience weight gain. In current clinical practice not all patients receive advice to limit fluid and/or sodium intake [36].

FUTURE RESEARCH

Although guidelines suggest that excessive intake of fluids is not beneficial in HF patients, a scientifically rigorous study on the tolerated amount of fluids has never been performed; the feasibility of such a trial is questionable. However, to provide consistent and effective advice to patients, it is vital that an evidence base is developed. The value of weight monitoring as a surrogate marker of fluid balance is not clearly established and weight gain cannot be considered as a “gold standard” of clinically important fluid retention. It would also be worthwhile to study the potential benefits of salt restriction in HF. With evolving information technology, weight measurement using telemonitoring seems a potentially useful approach [37].

NUTRITION AND WEIGHT MANAGEMENT

RATIONALE

Obesity can increase the probability of developing HF and/or worsen the symptoms [38]. Alternatively, HF can cause body wasting and even cachexia, which carries a particularly grim prognosis. Nutritional intake is reduced due to lack of appetite, liver and gut dysfunction, systemic inflammation and activation of neurohormonal mechanisms [39].

EVIDENCE

HF is associated with elevated resting metabolic rate and catabolic/anabolic imbalance [39]. Around 10% of patients with advanced HF will develop cachexia. ACE inhibitors and beta-blockers seem to promote stable weight which could have ancillary protective effects [40, 41]. Preliminary results of nutritional intervention are encouraging but inconclusive [42].

CURENT GUIDELINES

Cardiac cachexia can be defined as weight loss of >6% of previous stable weight without evidence of fluid retention during the past 6 months [43]. In ESC guidelines [1] assessment of nutritional status is recommended. In moderate to severe HF, weight reduction should not routinely be recommended since anorexia and unintentional weight loss are common problems. Weight reduction in obese (body mass index >30kg/m2) persons with HF should be considered in order to prevent progression of HF, decrease symptoms, and improve well being.

CLINICAL PRACTICE

Anthropometric parameters are easily obtained in patients with HF but interpretation may be complex due to fluid overload and diuresis driven weight changes. Nutritional assessment and evaluation of body composition can be used to evaluate the nutritional status. There are no reports of a structured nutritional intervention aimed to maintain or improve nutritional status in HF patients. Patients need to receive advice on healthy food to maintain optimal nutritional status. In clinical practice general brochures, HF cookbooks or websites on healthy food are used to inform patients. Patients can be referred to a dietician and in some countries workshops on (sodium restricted) healthy cooking are available for patient and their caregivers. Patients can be advised to divide their daily menu into smaller but more frequent meals. For patients with body wasting and cachexia in particular, caloric and protein nutritional support may be beneficial [44].

FUTURE RESEARCH

Prospective observational studies using a new cachexia definition [45] will provide a more complete picture about its incidence and prevalence. To improve outcomes, studies on nutritional intake, appetite, and body composition in non-cachectic and cachectic patients with HF are needed. Dietary interventional studies have to define optimal quantity and form of nutritional support.

SMOKING AND ALCOHOL

RATIONALE

Smoking is the most important preventable risk factor for the development of cardiovascular disease [46]. It is also associated with the development of pulmonary disease and cancers which can worsen symptoms and reduce patient physical performance [47].

EVIDENCE

There are no prospective studies on the effects of smoking or alcohol consumption in patients with HF. Several observational studies support smoking cessation to reduce morbidity and mortality [48, 49]. A recent report from OPTIMIZE-HF, however, suggested that a smoker's paradox in respect to hospitalizations [50]. Some reports suggest that light to moderate alcohol consumption could confer a lower risk of HF [51]. Alcohol consumption is not associated with an adverse prognosis in patients with left ventricular systolic dysfunction, and it may reduce the risk of fatal myocardial infarction in patients with ischemic left ventricular dysfunction [52].

CURENT GUIDELINES

It is recommended that patients receive support and advice and be motivated to stop smoking. Due to potential risk of arrhythmias, increase in blood pressure, potential negative inotropic effect, and additional fluid burden, the daily alcohol intake should be limited to 10-20g or completely avoided in those who are thought to have alcohol-induced cardiomyopathy.

CLINICAL PRACTICE

Previous or current smoking is common in patients with HF. In clinical practice, the message about smoking cessation has not been optimally implemented. The EuroHeart Failure study showed that fewer than half of patients recalled receiving advice about smoking and only three quarters of them reported following that advice. Only about one third recalled any advice about alcohol, although most of them did follow the advice given [53].

FUTURE RESEARCH

Prospective observational studies about the effects of smoking cessation on outcome in patients with HF or a retrospective analysis of smoking cessation or a propensity score matched study is needed. With even less information about alcohol consumption in patients with established HF, similar suggestions would apply.

PHYSICAL ACTIVITY

RATIONALE

The cardinal symptom of chronic HF is limitation of exercise capacity. Many patients have been told by family and health professionals that they should “take it easy” and have been advised to reduce their physical activity. However, this approach can lead to a spiral of deconditioning and paradoxical worsening of exercise-related symptoms and further inactivity.

EVIDENCE

Research has demonstrated that physical activity is of benefit to all patients with chronic HF unless they are in NYHA class IV or have other limiting symptoms such as angina [54-56]. Benefits of physical activity include: an increase in exercise capacity; reduction in symptoms during exercise; improvement in quality of life. In addition, indices associated with worse outcome such as heart rate variability and neurohormonal activation are also improved by regular exercise and there is provisional evidence that regular exercise improves survival [56].

The largest randomized trial to date, the HF-ACTION trial, showed improvment in physical performance and quality of life but failed to confirm a survival benefit [57, 58]. The lack of mortality effect may be due to suboptimal adherence to exercise training rather than due to true lack of benefit. In patients unable or unwilling to perform exercise, electrical muscle stimulation is a possible alternative to a formal training programme, and may confer similar benefits without any negative effects in terms of muscle injury [59-61].

CURRENT GUIDELINES

Regular moderate daily activity is recommended for all patients with HF. Exercise training is recommended, if available, to all stable chronic HF patients. There is no evidence that exercise training should be limited to any particular HF patient subgroup. Hospital-based and home-based exercise training programmes appear to have similar beneficial effects.

CLINICAL PRACTICE

Structured exercise training programmes are usually limited to specialized HF centres or rehabilitation services. Most patients are not at present encouraged to take regular exercise and do not have the opportunity to join exercise training programmes. The intense, highly supervised and structured intervention used in HF-ACTION is not really applicable to the wider population of patients with chronic HF [57]. However, unsupervised exercise is safe, and a regime of approximately 20 minutes of exercise at around 60-70% of maximal heart rate, three times a week, is associated with improved exercise capacity.

FUTURE RESEARCH

There are no data for patients with HF and normal ejection fraction. There is no specific advice for patients with asymptomatic left ventricular dysfunction, but there is no reason to believe they would not benefit in the same way as either the normal population or patients with overt HF.

IMMUNIZATION

RATIONALE

Patients with cardiovascular diseases, diabetes and especially those older than 65 years, are vulnerable to a greater extent to complications secondary to an influenza infection. These complications can lead to premature deaths and excess hospitalisations [62] with strong seasonal patterns [63]. This may be due to inflammatory response and generation of atherosclerotic vascular injury or to local cell autoimmune reactions caused by direct colonization of the vessel wall [64].

EVIDENCE

There are no HF specific randomized studies about immunization. In patients with acute coronary syndrome, influenza immunization reduced the relative risk of cardiovascular mortality at one year [65]. Non-randomized studies have shown beneficial effects in terms of reduced hospitalisations, especially in elderly patients suffering from HF [66]. Additionally, no increased risk in terms of more major cardiovascular effects has been reported [67]. However, in younger patients, no protective effects of immunization were found [68]. In a recent observational study, data were suggestive that there were benefits from influenza vaccination in patients >65 years with chronic cardiac disease [69].

CURRENT GUIDELINES

ESC guidelines [1] suggest yearly influenza vaccination and vaccination against pneumococcal disease in patients with symptomatic HF without known contraindications yet the evidence is far from robust.

CLINICAL PRACTICE

Since influenzas are major causes of death and hospitalizations in many countries, and because non-randomized studies have shown protective and no harmful effects, immunization for influenza has been recommended in patients aged > 65 years. However, as indicated in the guidelines [1], there are no documented effects of immunization in patients with HF. This may be the reason for the low recall (38%) of vaccination advice as reported by patients being recently hospitalized for HF [53]. In several countries a system to identify systematically risk groups that need immunization is in place.

FUTURE RESEARCH

There is a need for a prospective and preferably randomized trial in patients with HF evaluating the benefit of influenza or pneumococcal vaccination.

IMPROVING SELF-CARE IN HEART FAILURE

RATIONALE

Adequate self-care behavior related to HF reflects the actions that a patient undertakes to maintain healthy functioning and well being [70]. This includes adherence to medication, diet and exercise, as well as monitoring and self-management of symptoms and daily weighing to assess fluid retention and seeking assistance when symptoms occur. Patients who are actively involved in their own care and treatment and adhere to the regimen have improved outcomes, in terms of improved survival and decreased readmissions [71, 72].

EVIDENCE

There are different strategies to improve self care capabilities, but it is not always clear which intervention is the most successful [73, 74]. HF management programmes can reduce hospital readmission rates and mortality, but results are not always easy to interpret [4, 75]. Providing information alone might not be enough to give patients confidence to carry out self-care and thereby reduce hospital readmission [4, 76]. Identifying patients at highest risk for poor self-care and subsequent poor outcomes continues to challenge the health care community [77, 78].

Various psychosocial variables complicate self-care behavior in HF patients [79]. Depression may interfere with the ability to learn, perceive symptoms, judge the severity of symptoms, and make decisions about symptoms. Anxiety may affect patients' willingness and ability to perform self-care, because it impairs cognition, energy, and motivation. Impaired cognition, poor understanding of health

information, illiteracy and sleep disturbances might also be barriers for effective self-care in HF patients [80].

CURRENT GUIDELINES

The ESC guidelines [1] stress the importance of self-care as part of successful treatment and needed to decrease symptoms, improve functional capacity, wellbeing, morbidity, and prognosis. The guidelines recommend that health professionals provide comprehensive HF education and counseling that is not only focusing on knowledge but also on skills and behavior.

CLINICAL PRACTICE

To improve self care the following strategies can be used in practice:

- Screen routinely for barriers to self-care (e.g., inability to read medication and food labels) so that solutions can be developed before poor self-care is evident.
- Provide structured and individually reinforced education, tailored at previous knowledge, literacy level and cultural background
- Adapt communication to patient's history, view of HF and treatment and expectations of the patient related to the treatment.
- Include family, friends, and other care-givers in education and counseling activities.
- Provide educational material and create a non-threatening climate and an inspiring learning atmosphere. Ask each patient what they would like to know more about.

- Use different educational materials (such as brochures, verbal education or/and computer-based education) and methods (such as support groups) to address different learning styles and needs
- Set mutual goals for learning, viewed as an on-going process of continuously learning by the patient as well as the health care provider
- Teach skills (e.g. how to read food labels) rather than only providing information
- Consider flexible diuretic regimen

FUTURE RESEARCH

Future research in the area of self-care should be focused at identifying and targeting risk groups for poor self-care. Prospective studies evaluating the short and long term outcomes of tailored programmes targeted to improve self-care are needed. This includes the evaluation of specific educational strategies and the effectiveness of innovative ways of communication.

SEXUAL ACTIVITY

RATIONALE

Sexual problems are common in patients with HF and adversely affect the quality of life of the patients and of their partners [81, 82]. HF symptoms and cardiac medications can cause sexual problems and could make patients consider stopping the medications on their own initiative [83]. Furthermore, certain cardiac medications (nitrates) might interact with one type of treatment for erectile dysfunction (e.g. phosphodiesterase 5 inhibitors). Self-prescribing of increasingly easy available products (e.g. on the internet) may become a risk to patients, who may not be aware of drug interactions [83, 84]. Finally, patients with HF and their partners might be insecure about sexual activity fearing increased symptoms or cardiac death [85].

EVIDENCE

Like all physical activity, sexual activity might trigger exacerbation of symptoms, although the specific risk is unknown [82-84]. The metabolic requirements of sexual activity are comparable to light exercise (during the pre-orgasmic phase the metabolic requirement of sexual responses is equivalent to 2 to 3 METs, similar to walking 2 to 3 miles per hour on a level surface [83]). The energy expended during the orgasmic phase of sexual activity is 3 to 4 METs, which is less than activities such as cycling at 10 miles per hour (6 to 7 METs).

The importance of patient education and counselling with regard to return to sexual activity in myocardial infarction patients had been described in a limited number of studies [86, 87] but not specifically in HF patients.

CURRENT GUIDELINES

In guidelines [1, 88], the occurrence of sexual problems is recognized and individualized counselling is recommended for male and female HF patients and their partners. Additionally, treatment with nitro-glycerine as prophylaxis against dyspnoea and chest pain during sexual activity may be advised according to potential treatment of erectile dysfunction.

CLINICAL PRACTICE

Most health care providers do not routinely assess sexual problems and may experience barriers to providing sexual counseling related to available time, lack of knowledge or training, negative attitudes about sexuality, not feeling responsible for this topic or perceiving barriers in the condition of the patient [89]. Patients themselves might be reluctant to initiate discussions for reasons of shyness and embarrassment [90]. However, HF patients do report sexual concerns and sexual problems [81, 82] and have a need for information. In daily practice, booklets, websites and videotapes might be helpful in discussing sexual activity. It might also help if health care providers discuss the topic of sexual concerns within the context of exercise or in a general discussion on the consequences of the disease and its treatment in daily life.

FUTURE RESEARCH

Evidence-based approaches to address sexual problems of patients and partners and effectively integrate counselling in daily practice are still scarce. Further research is needed to validate specific content and instructions for HF.

DEPRESSION

RATIONALE

The prevalence of depressive symptoms in HF patients is significantly higher compared to age- and sex-matched norms [91, 92]. Approximately 20% of patients with HF are thought to be depressed although this could prove to be a conservative estimate if a more sensitive instrument were to be used to screen for depression on a regular basis. Depression is associated with differences in self-care, hospitalization and survival in HF [93]. Patients might become increasingly uninterested and non-compliant with self-care practices and carer responsibilities might increase accordingly; requiring encouragement to persist while treatment for the depression is being applied.

EVIDENCE

The support for pharmacological intervention for depressive symptoms in HF patients is still limited. However, data from studies in other cardiac populations [94] support the idea that pharmacological and non-pharmacological interventions can decrease depressive symptoms, improve quality of life and physical functioning. The application of a collaborative care model to tackle depression is promising in this context.

CURRENT GUIDELINES

The ESC guidelines [1] indicate there is limited evidence regarding screening and assessment tools as well as of the efficacy of psychological and

pharmacological interventions in patients with HF. Screening for depression and initiating appropriate treatment is, however, still advised.

CLINICAL PRACTICE

Health professionals should ensure regular screening tools are administered to help identify depression in HF patients. Patients should routinely be screened for depressive symptoms. Treatment of depression can vary depending on local services and can incorporate non-pharmacological and pharmacological treatment. Since there is an association between SSRI use and hyponatremia, patients receiving such treatment require regular monitoring of sodium levels during active treatment [95].

FUTURE RESEARCH

Limited evidence based interventions are available to treat HF patients for their depression, either pharmacological or non pharmacological. Current HF management programmes might not be best suitable for depressive HF patients and therefore tailored approaches need to be investigated [96].

REMOTE PATIENT MONITORING

RATIONALE

Systematic reviews have shown that multidisciplinary disease management programmes for HF have a positive effect on patient outcomes by reducing all-cause and HF related admissions [8, 97] and are cost effective [98]. Although the most optimal model and minimal components have not been determined, in several countries HF clinics or other HF disease management programmes have been successfully applied. Unfortunately, the number of people affected by HF, together with geographical and cost constraints, present major challenges in providing equitable provision of structured disease management programmes.

EVIDENCE

Previous systematic reviews have suggested benefits associated with a range of remote telemonitoring interventions, without providing definitive evidence in favour of this approach to management [24, 25]. However, a recently completed Cochrane systematic review [99] examined the outcomes of 25 randomised controlled trials (16 involving structured telephone support, 11 involving telemonitoring and 2 evaluating both) involving a total of 8,323 patients. Overall, telemonitoring was found to reduce the risk of all-cause mortality by 34% (RR 0.66, 95% CI 0.54-0.81), whilst structured telephone support resulted in a more modest (and non-significant) reduction of 12%, relative to usual care. Alternatively, both approaches significantly reduced the risk of a HF-related hospitalization by 21-23% with additional benefits reported in respect to improved quality of life and reduced health care costs [100].

CURRENT GUIDELINES

Remote monitoring may decrease healthcare utilization through fewer hospitalizations for chronic HF, fewer HF related re-admissions and more efficient device management.

CLINICAL PRACTICE

Telemonitoring has mainly featured in research trials but is increasingly becoming integrated into every day HF practice, enabling a higher proportion of people with HF to be monitored by specialist services. It is particularly helpful for those living in remote and rural areas, the elderly and frail who are housebound, and those at high risk of clinical deterioration.

FUTURE RESEARCH

The recently updated Cochrane review of the literature [99, 100] now provides the highest level of evidence in support of this type of management (particularly telemonitoring) being applied to those patients not able to access face-to-face management. To enable clinicians and managers to translate an already extensive and expanding body of evidence into routine healthcare delivery requires further research in a number of areas [101]. Further research is required to provide information on the components which make a programme effective, the optimal duration and intensity patients should be monitored, which patients benefit most in comparison to face-to-face programmes, value in different ethnic and socioeconomic groups, geographical locations and the experiences of users and health professionals. A key issue, as the volume of data derived from

telemonitoring increases, is the sensitivity and specificity of responding to monitored events that may (or may not) lead to a morbid or fatal event.

SLEEP DISORDERED BREATHING

RATIONALE

Sleep disordered breathing (SDB) may occur in up to 50% of patients with moderate to severe HF [102]. Patients are diagnosed when they have >10-15 apnoea-hypopnoea episodes per hour of sleep. It can present as obstructive sleep apnoea (OSA) in which increased inspiratory efforts against an occluded pharynx generate enhanced negative intra-thoracic pressure that increases left ventricular pressure and thereby after-load. It also increases venous return, distending the RV, and displaces the IV septum in diastole-impeding left ventricular filling. Associated hypoxia may impair cardiac contractility and precipitate ischaemia. Hypoxia, hypercapnoea, and arousal from sleep trigger sympathetic nervous system outflow with its resultant deleterious effects in HF [103]. A second form of SDB is central sleep apnoea (CSA), which is related to chronic hypocapnoea due to increased left ventricular end diastolic pressure and pulmonary congestion that may provoke hyperventilation in HF. The hyperventilation reduces pCO2 below the apnoeic threshold. When this happens chronically there is enhanced chemosensitivity, so the resultant fall in pO2 and rise in pCO2 with apnoea causes ventilatory overshoot leading to a further reduction in pCO2 and hence cyclical alternation of apnoea and hyperventilation. The enhanced sympathetic nervous system activity may decrease survival in patients with HF and CSA may lead to progression of the syndrome and reduced survival.

EVIDENCE

The gold standard for diagnosis of SDB is nocturnal polysomnography which remains expensive, time consuming and not widely available. Respiratory screening devices which measure oro-nasal airflow, chest and abdominal wall movement and pulse oximetry usually suffice: they have a high sensitivity and specificity for detecting SDB in HF patients. Home pulse oximetry can also be used with a sensitivity of 85% and specificity of 93% for detecting SDB in HF. In patients with OSA, treatment with continuous positive airway pressure (CPAP) via a nasal or facemask is well established. It reduces episodes of apnoea-hypopnoea, the number of arousals, daytime somnolence, and improves LVEF, and quality of life [104]. For patients with CSA the treatment remains unclear. Optimization of HF therapy may improve apnoea-hyponoea index. CPAP is not advised for the treatment of CSA in HF as small studies with bi-level non-invasive ventilation and adaptive servo-ventilation (ASV) have shown improvements in arousals.

CURRENT GUIDELINES

SDB may be associated with increased morbidity and mortality. Guidelines recommend weight loss in severely overweight patients, smoking cessation, and alcohol abstinence. Treatment with CPAP should be considered in polysomnography confirmed OSA.

CLINICAL PRACTICE

Few centers perform systematic screening to identify patients eligible for additional testing. The resources of sleep laboratories are limited and cannot meet the challenges of this common problem.

FUTURE RESEARCH

The feasibility of large scale screening for SDB should be investigated. Interventions to treat reversible causes (e.g. co-morbidity, severe obesity) are lacking. There is an ongoing trial of adaptive servoventilation – SERVE-HF.

TRAVEL

RATIONALE

Travel arrangements are complex for patients with HF. It is important to emphasise that travel is possible but preparation is key. There is an increased incidence of cardiovascular events amongst travellers who have existing cardiovascular disease [105].

EVIDENCE

Evidence specifically pertaining to travel advice for HF patients is limited and relies on that derived for cardiac patients in general and the elderly. Any intention to travel should be discussed with a healthcare professional prior to making any arrangements [105, 106]. HF patients are at higher risk of developing deep vein thrombosis and pulmonary emboli during prolonged periods of air travel [107, 108]. A meta-analysis identified that although there appears to be a weak link between prolonged travel and embolic events, many of the randomised controlled studies showed the study populations had fewer risk factors than most and therefore the risks are often underestimated in a HF population. The risk of cardiovascular events is a concern for all patients travelling. Exposure to hypoxia during a flight is more likely to cause adverse cardiopulmonary events in patients with cardiovascular disease than in healthy subjects. The risk of altitude-induced hypoxia must be individualised taking into account all co-existing diseases, and supplemental oxygen during flight may be required. Colder climates can increase peripheral vascular resistance and thereby increase myocardial oxygen demand,

making it easier to reach ischaemic threshold, resulting in worsening angina symptoms for patients with ischemic cardiomyopathy.

CURRENT GUIDELINES

The ESC guidelines [1] recommend that travel at high altitudes (>1500m) and travelling to very hot and humid destinations for symptomatic HF patients should be discouraged. Planned travel should be discussed with the HF team. As a rule, air travel is preferable to long journeys by other means of transport. There is no class of recommendation or level of evidence to support this advice in the recent guidelines.

CLINICAL PRACTICE

Patients who have experienced a cardiovascular event within a few weeks should be discouraged from travelling. For HF patients travelling distances by car or bus, taking diuretics may become more of an issue due to limited toilet facilities during travel. If possible, patients could be advised to take diuretics after arrival to final destination. Air travel is associated with long walking distances in short periods of time, and lifting heavy luggage: these physical activities may exceed an individuals' exercise capacity.

FUTURE RESEARCH

Research on long-term consequences of traveling and patient experience with traveling is needed.

CONCLUDING REMARKS

Self-care management is an important part of HF treatment. Health professional should promote non-pharmacological management to all patients with HF in an intelligent and individualized fashion. They should also be aware of potential patient limitations to adequate implementation where involvement of carers is warranted. By doing so, a significant advance in quality of life can be achieved, with further benefits in terms of decreased burden for health care providers and health care system. Further research to optimise self-care strategies is required in a number of key areas to derive further benefits.

Table 1. Practical recommendations for self-care management.

Topic	Goal	Actions

Symptom recognition	anticipate or recognize deterioration	○ Take patient history
		○ Assess symptoms
		  ○ Frequency (how often)
		  ○ Intensity
		  ○ Rate(on how many occasions during a time interval)
		  ○ Duration (how long)
		  ○ Pattern (mornings, after activities etc)
		  ○ Specificity (the whole body, arms etc)
		  ○ Specific words (no energy, cannot concentrate, feeling of suffocation etc)
		○ Use standardized scales, if possible.
		○ Explore the possibilities of telemonitoirng to enhance symptom monitoring and therapeutic response (self-care or health professional initiated)

Fluid and sodium management	Manage fluid status	○ Assess fluid intake over 24hours
		  ○ 1 cup = 200ml, 1000 ml = 1000g
		  ○ Consider all fluids (for medication, alcohol) and certain fruits and vegetables
		○ Routine fluid restriction not advisable
		○ Avoid excessive salt intake, particularly in symptomatic patients
		○ Advise weight monitoring as a daily routine
		○ Once daily in same conditions (e.g. after morning toilet, in light clothes), using same weighing scale
		○ Arrange for support for reading and interpreting the results if necessary
		○ Avoid hypovolemia (febrile state, humid and hot environment, diarrhoea and vomiting))
		○ Advise patients that in case of sudden unexpected weight gain (>2kg in 3 days) they should
		  ○ Inform the medical care provider
		  ○ Adjust diuretics
		  ○ Adjust fluid/salt intake

Nutrition and weight management	Keep a healthy body weight	○ Advise to lose weight should be reserved to patients with obesity associated symptoms ○ Advise patients to monitor for weight loss (see fluid and sodium management) ○ Assess nutritional status ○ Advise patients and family of healthy food habits
Smoking and alcohol	Smoking cessation and prevention of excessive drinking	○ Advise smoking cessation using appropriate methods. ○ Advise patients to avoid passive smoking. ○ Advise to limit alcohol intake to 2 (women) to 3 (men) units* of alcohol daily. ○ Advise patients with alcohol-induced cardiomyopathy to abstain from alcohol.
Physical activity	Maintain physical activity	○ Advise exercise and when to stop exercise as appropriate. ○ Advise at least 20 minutes, minimum of three times a week aiming to achieve modest breathlessness during exertion.
Immunization	Prevent infection-associated deteriorations	○ Advise annual (influenza) and regular (pneumococcal vaccine) immunization.
Improving self-care in heart	Optimize self care	○ Screen routinely for barriers to self-care ○ Provide structured and tailored education

failure		○ Include family and friends in education and counseling activities. ○ Provide educational material; use different educational materials; the interactive webpage www.heartfailurematters.org can be used ○ Set mutual goals for learning ○ Teach knowledge and skills
Sexual advice	Acceptable sexual relationship	○ Define sexual concerns ○ Inform patients about energy consumption/exercise tolerance ○ Inform patients about the relationship between sexual problems and heart failure ○ Use education material (e.g. www.heartfailurematters.org)
Depression	Recognize and treat depression	○ Screen for depression using standardized tools at least once a year ○ Management of depression as appropriate ○ Recognize the role of depression in adherence ○ Support of caregiver if needed
Remote patient monitoring	Anticipation of deterioration	○ Advise patients to perform measurements (e.g. body weight, blood pressure, heart rate) and to transfer them to central monitoring ○ Advise patients how to manage device alarms
Sleep-disordered breathing	Detection and treatment of Sleep-disordered breathing	○ Identify patients with sleep-disordered breathing with questionnaires and appropriate referral for investigation and treatment.
Travel	To ensure safe travel	○ Conduct a pre-travel risk assessment ○ Advise regarding the use of flight socks (appropriately fitting, before travelling and for several hours after arrival at destination) ○ Provide written documentation of medical history and current medication regimen. ○ Carry extra medication and multiple lists of medications, but not kept in the same piece of luggage ○ Ensure patients have adequate prescription medication for duration of travel ○ Possibly carry a recent ECG, and contact details of medical advisors ○ Help to adjust medication time slowly to fit a new time zone ○ Advise patients to request mobility assistance at airports ○ Monitor fluid intake particularly during flights and in hot climates ○ Advise to maintain their normal fluid restriction ○ Adivise to take appropriate protection in the sun particularly if on medication with adverse reactions to sun exposure ○ Provide advice about travel insurance ○ Provide individual advice relating to specific travel arrangements

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