Tailoring consumer resources to enhance self-care in chronic heart failure

Andrea Driscoll RN, CCCN, MEd, PhD,†,1,2, Patricia Davidson RN, BA, MEd, PhD,1,3, Robyn Clark RN, RM, ICU Cert, BN, MEd, PhD FRCNA,1,4, Nancy Huang,1,5, Zoe Aho1,5

a Dept of Epidemiology and Preventive Medicine, Monash University, Burnett Building, 3rd Floor, 89 Commerical Rd, Melbourne 3004, Australia
b Centre for Cardiovascular and Chronic Care, School of Nursing and Midwifery, Curtin University of Technology, Curtin House 39 Regent St Chippendale 2008, New South Wales, Australia
c Room 3 Level 2 Bonython Jubilee Building (BJ02-03), C/- School of Health Sciences Centre for Research into Sustainable Health Care City East Campus, University of South Australia, SA 5000, Australia
d Heart Foundation, Level 12, 500 Collins Street, Melbourne 3000, Australia

Received 12 December 2008; received in revised form 9 April 2009; accepted 8 May 2009

KEYWORDS
Heart failure; Self-care; Health literacy; Patient information

Summary
Background: Chronic heart failure (CHF) is associated with high hospitalisation and mortality rates and debilitating symptoms. In an effort to reduce hospitalisations and improve symptoms individuals must be supported in managing their condition. Patients who can effectively self-manage their symptoms through lifestyle modification and adherence to complex medication regimens will experience less hospitalisations and other adverse events.

Aim: The purpose of this paper is to explain how providing evidence-based information, using patient education resources, can support self-care.
Discussion: Self-care relates to the activities that individuals engage in relation to health seeking behaviours. Supporting self-care practices through tailored and relevant information can provide patients with resources and advice on strategies to manage their condition. Evidence-based approaches to improve adherence to self-care practices in patients with heart failure are not often reported. Low health literacy can result in poor understanding of the information about CHF and is related to adverse health outcomes. Also a lack of knowledge can lead to non-adherence with self-care practices such as following fluid restriction, low sodium diet and daily weighing routines. However these issues need to be addressed to improve self-management skills.

Outcome: Recently the Heart Foundation CHF consumer resource was updated based on evidence-based national clinical guidelines. The aim of this resource is to help consumers improve understanding of the disease, reduce uncertainty and anxiety about what to do when symptoms appear, encourage discussions with local doctors, and build confidence in self-care management.

Conclusion: Evidence-based CHF patient education resources promote self-care practices and early detection of symptom change that may reduce hospitalisations and improve the quality of life for people with CHF.

Background

Self-care in chronic heart failure (CHF) and health outcomes are closely linked. Mortality and hospitalisation rates remain high, particularly in the elderly. In Australia, approximately 40,000 patients were hospitalised with newly diagnosed CHF in 2003. Patients with CHF experience debilitating symptoms such as shortness of breath, increasing exercise intolerance and lethargy which impacts on their everyday day life. In an effort to reduce these symptoms and hospitalisations patients must learn how to manage their CHF through adhering to several self-management strategies. These include: a low sodium diet, engaging in physical activity, restricting their fluid and adhering to a complex medication regimen. Patients who can effectively self-manage their symptoms through lifestyle modification and adhere to complex medication regimens will experience fewer hospitalisations and improved quality of life.

Educating and supporting patients about optimal self-care behaviours is the cornerstone of effective CHF management. Self-care refers to the decision making process of patients concerning their choice of healthy behaviour and response to worsening symptoms when they occur. The science of self-care is rapidly growing. Both intrinsic factors, for example cognitive ability, and extrinsic factors such as access to appropriate and relevant information, impact on an individual’s capacity for self-care. The purpose of this paper is to explain how providing evidence-based information, using patient education resources, can support self-care.

The Heart Foundation has recently updated its national consumer resource entitled 'Living well with chronic heart failure', based on the current national clinical guidelines. The resource will be referred to in this paper to demonstrate principles of consumer engagement, mapping of evidence-based guidelines, and end-user feedback, in the development of consumer resources. This process was staged to include needs and barrier analysis through expert clinical and consumer consultation, content development and the use of medical writers, piloting and refinement and finally establishing a channel for resource dissemination. The paper will demonstrate how the principles of adherence, knowledge and health literacy underpinned the development of this product.

Self-care of heart failure

Self-care involves cognitive decision making, requiring the recognition of signs and symptoms that indicate a change in condition, which is based on knowledge and prior experiences of deterioration. It also refers to the ability to engage in constructive behaviours to monitor and maintain health.

Self-management of CHF depends on patient adoption of healthy behaviours and manage-
Tailoring consumer resources to enhance self-care

Adherence with self-care

Adherence with self-care is vital in chronic disease management and has been shown to reduce morbidity and mortality. The capacity to adhere with recommended treatment strategies is often suboptimal in individuals with CHF, especially in those who are recently diagnosed. A study by Michalsen et al. surveyed 179 patients admitted to hospital with an exacerbation of HF. All of the patients had a previous diagnosis of HF. No education about heart failure was given to patients prior to their survey. Results showed that only 26% of patients knew about the importance of restricting fluid intake. While the majority of the patients (87%) had weighing scales, only 38% of patients weighed themselves regularly. Van Der Wal et al. examined compliance and self-care behaviour in patients with a pre-existing diagnosis of heart failure. All patients were administered a questionnaire on admission to hospital with heart failure and prior to receiving education about heart failure. They found that 73% of patients restricted their fluid intake, 39% were compliant with exercise and only 35% of patients were compliant with daily weighs.

Adhering to treatment recommendations can be improved through providing information and strategies to the patient and their family to support self-care. Furthermore adherence is encouraged if consumer information or strategies are directed at those patients who need it most especially in newly diagnosed patients recently hospitalised with an exacerbation of CHF. There is some evidence to show that people diagnosed with long standing CHF are more likely to report or act on their weight gain than those who are newly diagnosed. This was supported by a study showing that initiation of self-care strategies was higher in patients with CHF for several years, and postulated that this may be related to experience with previous hospital admissions, or past education interventions.

The evidence reflecting poor adherence with treatment recommendations and adverse health outcomes demonstrates that there is a need to implement strategies to improve adherence such as improving patient understanding of CHF, particularly those who are newly diagnosed and those who have experienced deterioration in their condition.

For these target groups the Heart Foundation CHF resource provides an easy to read day-to-day reference for patients learning about symptoms, lifestyle, and medicines. Testing with consumers during the development stage ensured the resource was tailored to patient needs. The resource uses large font, pictures and simple language. Furthermore information is focused on patient information needs such as tips for recognising symptom changes, while minimising overly detailed or complex information. This approach aims to overcome some of the barriers to adherence.

Knowledge of self-care

Knowledge and understanding are essential elements for patient empowerment and successful self-management. Information and resources used to provide this knowledge should be evidence-based to maximise opportunities for improving patient satisfaction and health outcomes.

A lack of knowledge can lead to non-adherence with self-care practices such as following fluid restriction, low sodium diet and daily weighing routines. Ni et al. investigated 41 hospitalised heart failure patients and found that knowledge was significantly correlated with adherence with self-care behaviour.

Educational interventions to provide information and support knowledge acquisition have shown promising results for CHF. Results from a meta-analysis of CHF management programs has shown that an emphasis on self-care and patient education improved outcomes; all-cause hospitalisations were reduced by 32% (RR 0.68, 95%CI 0.54–0.87) and CHF-related hospitalisation by 40% (RR 0.60, 95%CI 0.41–0.88). These programs included the provision of guideline-based information on disease.
Health professional support of self-care practices

Health care providers can influence adherence to treatment. Simpson describes a constructive patient—provider relationship as one of trust that motivates patients to adhere to lifestyle changes and complex medication regimes. In spite of the importance of providing timely and relevant information, there is evidence to suggest that health care providers do not always use consumer resources within education opportunities. For example the results of a recent survey of 496 general practitioners concerning the use of resources for CHF patients found that 74% of general practitioners did not routinely provide written information to patients. Of the health professionals that were aware of online resources very few used these, with 60% of them never accessing the resources. Whether this relates to scepticism of the benefit of these resources, lack of awareness of available resources or time limitations is unclear.

In the hospital setting, patient and carer education opportunities can be limited by a reduced length of stay and the patient’s physical and cognitive status during the acute care episode. This may result in patients being discharged from hospital with an inadequate level of knowledge to support self-care. In spite of the limitations associated with in-patient education, this is an ideal opportunity to provide patients and carers with a consumer resource. Ideally the clinician can emphasise important aspects of the resource. Although numerous information resources are available, providing evidence-based information is important, as incorrect or contradictory advice can lead to uncertainty about what should or should not occur and impede decision making processes about when to seek medical help.

In order to address some of these challenges, the Heart Foundation developed a resource to support self-care that is not only evidence-based but incorporates input from patients and health professionals to target known limitations to accessing accurate and relevant information. For example feedback from health professionals in the testing phase emphasised the importance of nurses and pharmacists in addition to doctors as important sources of medicines information, and to include information on “webster packs” as a simple way to help patients remember medicine instructions. Furthermore, through considering the role of health literacy in promoting self-care, information is presented in a simple way to assist patient understanding. For instance information about salt intake is enhanced through definition of “low salt” and information on how to read food nutrition panels and tips on healthy food choices.

Health literacy in supporting self-care

Health literacy refers to an individual’s ability to use and interpret information relating to health issues. Low health literacy can result in poor understanding of the information about CHF and is related to adverse health outcomes. Approximately 83% of Australians aged over 65 years have a health literacy level that is below the minimum required to meet the complex demands of everyday life. The elderly population also has the poorest health literacy skills and are the biggest users of the health care system. Heart failure was one of the most common causes of hospitalisations in people aged over 70 years.

Previous research has shown that poor health literacy is related to adverse health outcomes. Low health literacy has been shown to be an independent predictor of mortality and hospitalisations. One study investigated health literacy in people hospitalised in a public hospital. Over a 12-month period, they found that patients with a low health literacy were 69% more likely to be hospitalised compared with patients with high health literacy. Another study by Baker et al. also found similar results among Medicare patients. Those with a low health literacy score were 29% more likely to be hospitalised than patients with high health literacy after adjusting for age, gender, race and education status. Another study investigating the impact of health literacy on asthma outcomes showed that patients with poor health literacy were more likely to attend the Emergency Department for management of their asthma.

Low health literacy needs to be addressed to improve capacity for self-management. However it
is unknown as to whether poor health literacy is a primary cause of poor health outcomes or whether it is an underlying problem of other issues such as low socioeconomic status, inadequate access to health services or a low trust in health care providers. Nevertheless, low health literacy needs to be addressed in an effort to improve knowledge and self-management skills.33–35

Health literacy can be improved through consumer resources that are easy to read, both in terms of the language and format used. Visual content is far superior to other forms of communication for memory retention,36 therefore pictures and images in a resource will help to enhance patient understanding. Ensuring that consumer resources are developed with an awareness of the health literacy levels of the target audience is critical to its effective use and adoption of healthy behaviours and can improve health outcomes.37

**Living well with chronic heart failure**

‘Living well with chronic heart failure’ consumer resource has been developed as a companion to the CHF guideline and as such communicates management strategies that are well known to optimise health outcomes.10 The consumer oriented approach to resource development ensures information is tailored to patient needs. Table 1 gives examples of how the clinical content and format and layout has been adapted for consumers.

One important component of the consumer resource is the action plan (Fig. 1). The action plan outlines recommended daily activities to assist the patient with managing their heart failure. It also stipulates when the patient should notify their local doctor, heart failure nurse or ambulance should their symptoms deteriorate. This action plan was developed as a stand-alone resource following

<table>
<thead>
<tr>
<th><strong>Table 1</strong> Adapting evidence for a consumer resource.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>’The evidence’</strong></td>
</tr>
<tr>
<td>Recommendations, such as: multidisciplinary programs for high risk chronic heart failure patients prolong survival and improve quality of life</td>
</tr>
<tr>
<td>Clinical definition and aetiology of chronic heart failure</td>
</tr>
<tr>
<td>Detailed diagnostic information. Echocardiograms are recommended as the ‘single most useful investigation’ in chronic heart failure patients</td>
</tr>
<tr>
<td>Non-pharmacological management, for example fluid restrictions, and monitoring of weight can lead to improved outcomes</td>
</tr>
<tr>
<td>Benefits of specific pharmacological treatment of symptomatic chronic heart failure</td>
</tr>
<tr>
<td>Management of acute exacerbations of CHF</td>
</tr>
<tr>
<td>Format and layout to enhance communication of key messages</td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited amount of information per page and lots of white space to assist comprehension</td>
<td>Use of pictures to communicate key messages, such as a picture of measuring jug to monitor water intake and a picture of scales</td>
</tr>
<tr>
<td>Lift out summary sheet/action plan for easy reference</td>
<td>Translated versions of resource into 15 community languages</td>
</tr>
</tbody>
</table>
Chronic heart failure action plan

**Note:** It is important that you develop an individualised action plan with your healthcare team that takes into account the severity of your heart failure, any other health problems you may also have, and your healthcare preferences.

**Every day:**
- Weigh yourself and keep track of your weight.
- Restrict your fluid intake and salt intake as recommended by your doctor.
- Take your medicines as prescribed.
- Be physically active.
- Remember to call for medical assistance when the need arises (see below).

**Call your doctor or heart failure nurse as soon as possible if:**
- you gain or lose more than 2 kilograms over 2 days
- you have worsening shortness of breath with your normal activities
- your heart is beating very quickly
- you are very dizzy, or you pass out (faint)
- your angina is getting worse
- there is increased swelling in your ankles, legs or abdomen
- you are coughing a lot – especially at night
- you are generally feeling more tired or sad than usual.

*If calling 000 does not work on your mobile phone, try 112.*

**When you have angina:**
- Immediately stop and rest.
- If rest alone does not bring rapid or effective relief, take a dose of your angina medicine
- If the angina is not relieved within 5 minutes, take another dose of your angina medicine
- If the angina is not completely relieved within 10 minutes of onset by rest and medicine OR is severe OR gets worse quickly, **this is an emergency. Get help fast. Call triple zero (000)* and ask for an ambulance. Don’t hang up. Wait for advice from the 000 operator.**

**Call triple zero (000)* and ask for an ambulance if:**
You suddenly have severe shortness of breath, or you are experiencing new ‘blackouts’
*If calling 000 does not work on your mobile phone, try 112.*

For more information, refer to the source of this action plan—the Heart Foundation booklet ‘Living well with chronic heart failure’.

© 2016 National Heart Foundation of Australia, CE 179

Terms of use: This material has been developed for general information and educational purposes only. It does not constitute medical advice. Please consult your healthcare provider if you have, or suspect you have, a health problem. The information contained in this material has been independently reviewed and developed by the National Heart Foundation of Australia and includes or is derived from the available scientific evidence at the time of writing. It is not an endorsement of any organization, product or service. While care has been taken in preparing the content of this material, the National Heart Foundation of Australia and its employees cannot accept any liability, including for any loss or damage resulting from the reliance on the content, or for its accuracy, currency or completeness. This material may be found in third-party programs or materials (including but not limited to show bags or advertising items) but does not imply an endorsement or recommendation by the National Heart Foundation of Australia for such third party organizations, products or services, including the names, logos or addresses. Any use of National Heart Foundation of Australia material for another person or organization is done at the user’s own risk. The entire contents of this material are subject to copyright protection.

Figure 1  ‘Living well with chronic heart failure’ action plan. Reproduced with permission from the Heart Foundation

patient input for this type of format in the piloting phase.

The booklet can be used as a resource to improve communication between the consumer and their health care provider especially when developing an individualised action plan. A partnership based on effective communication skills will help to improve adherence to healthy lifestyle behaviours and self-management strategies.

**Conclusion**

Patients in contemporary health care systems, together with their health care provider, need to engage in partnerships to promote self-care strategies. In order to be effective partners, patients need and want accurate, practical information and advice; ‘Living well with chronic heart failure’ underpinned by a robust evidence-base on self-
care, has been developed to address this need. In particular, this resource targets newly diagnosed or hospitalised people with heart failure. As a practical communication tool, it can enhance information sharing between health professional and patient. As an evidence-based resource that is easy to read it can promote health literacy and adherence to self-care practices by people with CHF and result in better day-to-day management and early detection of symptoms change.

Acknowledgements

"Living well with chronic heart failure" (2008) Members of the Heart Failure Consumer Resource Working Group: Roshmeen Azam, National Prescribing Service; Meredith Cameron, National Institute of Clinical Studies; Eleanor Clune, National Heart Foundation of Australia; James McVeigh, Prince of Wales Hospital, Sydney; Vilma Paguio, National Heart Foundation of Australia; Graeme Percival, of Wales Hospital, Sydney; Agnes Vitry, University of South Australia; Sepehr Shakib, Royal Adelaide Hospital; Heart Foundation of Australia; Graeme Percival, Consumer; Sue Phillips, National Institute of Clinical Studies; Sepehr Shakib, Royal Adelaide Hospital; Agnes Vitry, University of South Australia; Jill Waddell, National Heart Foundation of Australia. The Joint Heart Failure Program Steering Committee: For further information on initiatives of the Joint Heart Failure Program (a collaboration between NICS/NHMRC, NHFA and NPS), visit http://www.heartfoundation.org.au/Professional_Information/Clinical_Practice/CHF/Pages/default.aspx.

References


