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Self-care and patient education

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Abstract: (150 words)

Self-care is a vital part of the comprehensive management of heart failure. Self-care includes behaviours of patients and caregivers that are aimed to maintain stability, that monitor changes in signs and symptoms behaviours that respond to changes. Optimal self-care improves patient outcomes and can prevent deterioration and exacerbations. With a greater emphasis on self-care, the ability to participate in daily life requires knowledge as well as interpretation, skills and action. All health care providers have the responsibility to optimally educate and support patients with heart failure and their caregivers. This chapter will explore a number of approaches to education to patients and caregivers, as well as the special considerations associated with health literacy. We also present a range of tools and resources that can be used in patient education. Furthermore, we describe the importance of including family members or other informal caregivers.

Keywords: self-care, patient education, information, health literacy, caregivers

1. Introduction

The successful delivery of modern healthcare requires the active involvement of patients and caregivers. Heart Failure (HF) management programs emphasize the role of self-care to improve patient outcomes and prevent HF deterioration and exacerbations. Effective communication and information by the multidisciplinary team across all care settings promote involvement. With a greater emphasis on self-care, the ability to participate in daily tasks requires knowledge as well as interpretation, skills and action. Patient education and self-care support is a responsibility of all health care providers taking care of patients with HF and within the HF team the roles and responsibilities should be clearly defined. There are several approaches to education to patients and caregivers. In this chapter we discuss these approaches and present some resources that can be used in education of patients and their family members or other informal caregivers.

Self-care in patients with Heart Failure

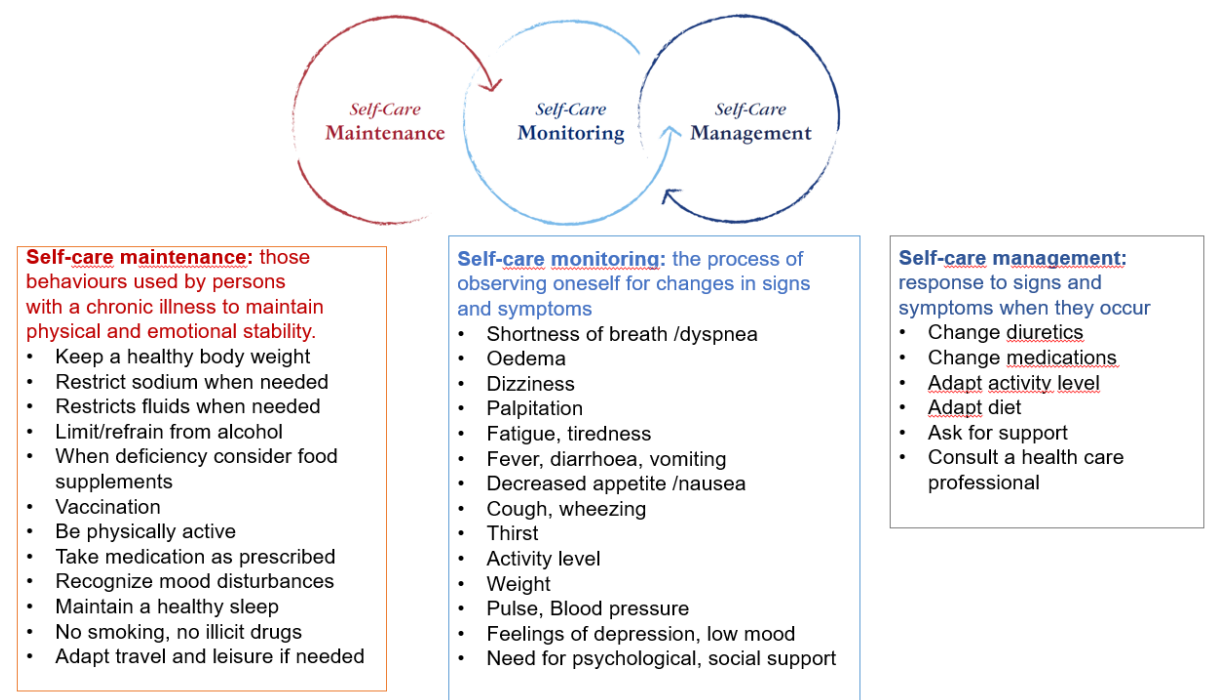
Self-care is essential in the long-term management of HF. Self-care is defined as process of maintaining health through health promoting practices and managing illness and is performed in both healthy and ill states.[1] Self-care is an overarching concept based on three key concepts: self-care maintenance, self-care monitoring and self-care management. [2]

- Self-care maintenance includes behaviors used by patients to preserve health, to maintain physical and emotional stability, or to improve well-being. These may be health-promoting behaviors (e.g., smoking cessation, preparing healthy food, physical activity, coping with stress) or illness-related behaviors (e.g., taking medication as prescribed).
- Self-care monitoring is the process of observing oneself for changes in signs and symptom, for example by checking body weight, monitoring symptoms or heart rate. The

goal of self-care monitoring is recognition that a change has occurred. The monitoring of symptoms is effective when the person or an informal caregiver is able to both recognize and interpret the sign or symptom. In other words, only checking for changes in symptoms or signs without interpreting the meaning or significance of the change is not sufficient.

- Self-care management is the response to occurring signs and symptoms. Self-care management involves an evaluation of changes in physical and emotional signs and symptoms to determine if action is needed. These changes may be due to illness, treatment, or the environment (e.g. changing diuretic dose in response to symptoms).

Figure 1.



For patients with HF it might be necessary to regulate and adapt self-care during the course of the disease, for example in times of deterioration, if co-morbidities occur, or in case of specific advanced treatment. Self-care is found to be important to influence outcomes in patients with HF; those who report more effective self-care have better quality of life, lower

mortality and hospital readmission compared to those who report poor self-care.[3].

Education and support are essential to enhance self-care behavior that aims to improve HF - related outcomes.[4][5]

Having support from a family member or informal carer is very important for patients with HF. Family caregivers have been found to be crucial for supporting and improving patient self-care. As the other side of the coin there is an increasing awareness that caregiving could affect the caregiver's health negatively and cause physical, and financial burden as well as psychosocial distress. [6]

3. Education on self-care to patients and their caregivers

Recent guidelines and position papers recommend all health care professionals within the patient's multidisciplinary team, have a role in education of patients and their caregivers as part of their vital remit in care provision [3, 7, 8]. For many health care professionals, patient education relates to verbal dialogue, perhaps with information repeated on a number of occasions or reinforced by a written booklet or handout. However, this may not always ensure adequate comprehension and understanding. It is often assumed that patients and family members, when provided with the necessary knowledge, are motivated to become actively involved and improve their self-care behaviour, including adherence with pharmacological and non-pharmacological treatment [9]. This may work in the initial days' post discharge, however for continued adherence supportive interventions can ensure patients and informal caregivers continue to remain engaged. Indeed, studies that evaluated patient discharge education when combined with a support program, have found positive benefits. A meta-analysis noted that comprehensive discharge planning (including one-on-one teaching sessions, discharge protocols, and home care coordination) combined with post-discharge

support resulted in a 25% relative reduction in hospital readmissions over 3–12 months after discharge [10].

Additional strategies have been implemented to compliment the information provided by professionals.

Health literacy can be defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”[11] A recent systematic review stated that the level of health literacy was found to be low in patients with HF. Further inadequate health literacy has been found to be associated with lower quality of life and survival and higher health care utilisation. [12]

New approaches and techniques need to be considered and tools and resources need to be tailored to the patient and caregivers. Successful improvement of the level of health literacy in chronic conditions may be achieved with a combination of several strategies, and structured education and information contributing to shared decision making.[13]

A recent scientific statement from American heart Association summarized that there have only been a handful of intervention trials evaluating support to caregivers. The studies included a large majority of female family caregivers and the educational intervention and skill training were mainly delivered face-to-face[6].

3.1 Techniques and approaches

One techniques, for example ‘Teach-back’, is recognised as a best practice strategy [14] to improve disease-specific knowledge, and understanding, treatment adherence and self-efficacy leading to reduced hospital readmissions [15, 16]. Consultations whereby information is provided to the patient and informal caregiver should employ such a technique. Existing literature indicates that the most important time to provide HF patients with relevant information and ensure understanding is pre-discharge [17].

A successful approach to elicit behaviour change is that of Motivational Interviewing (MI) [18]. Defined as ‘a person-centred counselling style for addressing the common problem of ambivalence about change’, it’s benefit in comparison to informational sessions within HF management is becoming increasingly evidenced [19]. For self-care interventions to be effective, there must be a supportive relationship with the professional, an individualized approach, efforts to promote self-efficacy, practical information and ongoing support from informal caregivers [20]. Unsurprisingly, the incorporation of MI within a randomised control trial to improve self-care management, found positive results particularly regarding the inclusion of caregivers to improve patients’ self-care management.[19] In a systematic review published in 2020, eight randomised control trials involving 758 patients, found MI was better than simple advice-giving. This systematic review concluded that MI interventions had the potential to improve the immediate risk of hospital readmission as well as long-term outcomes through better medication adherence and self-care behaviours.

It is important both the patient and caregiver feel they can initiate questions during consultations. The ‘ASK ME 3’ (<http://www.ihl.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx>), is an online educational program to encourage patients to ask questions about their condition to promote healthy lifestyle. Driven by patient autonomy, the education of patients and informal caregivers will promote shared healthcare decision-making, alongside agreed management plan which will have greater likelihood of successful.

3.2 Tools and resources

Patients might prefer a multi-model style of learning including e-health [21]) ranging from more ‘basic/traditional’ material to more innovating ones. Resources include hard copy

education with printed education materials (brochures, flyers, leaflets), teaching sessions, telemedicine and digital health (websites and video education) telephone interventions, interactive voice response reminder systems, gaming and computer-aided learning application. [21, 22]

Brochures, flyers and leaflets.

Printed education materials consisting mostly of booklets allowing patients to easily have access to information over time.[4] Using printed material with verbal instructions either personally or in groups such an approach can enhance self-care behaviours.

Websites and video education

The Internet has become a powerful, accessible resource for many patients to use for their own medical management and comprehension. [8] It is also a practical method as patients can replay the videos whenever they desire or go back to read the information again.[18] The HeartFailurematters website (www.heartfailurematters.org) provides practical information from diagnosis, medications, lifestyle recommendations to palliative care, that patients and informal caregivers can readily access. It has a number of communication prompts and tools to enable the patients to ask questions on topics he/she is uncertain.

Adding images related to the words can contribute to involvement of the learner's mind and his/her active learning. Video education may enhance retention of health information. The visual absorb of information increases patients' confidence by showing actual persons living with HF, modelling healthy behaviors and the same time demonstrating that healthy behaviors are achievable. Using visual role modelling to demonstrate self-care behaviors seems to stimulate learning, health literacy and improve clinical outcomes in chronic diseases including heart failure.[23]

Internet access has opened up a plethora of resources to use as education materials, but the writing style and language of most medically relevant articles favour a small percentage of the general public and at the same time, not all e-health materials have been assessed for the quality of the information provided (e.g. DISCERN and CUA quality rating tool). [24, 25]

Gaming

Historical strategies to educating our patients is moving from a written or verbal format to a more digital format, facilitated by smartphones, APPs and innovative software. [26] With the current advances in technology, more innovative ways are possible to educate and develop patients' skills to enable successful self-care behaviour. Studies are using Artificial Intelligence to engage the patient to learn through 'Gaming' or provision of information through Aviator type interactions [27].

Other technologies used in self-care education

Technology that can support HF self-care range from invasive devices that monitor lung impedance and pulmonary artery pressure to mobile applications that track HF symptoms, blood pressure, heart rate and rhythm and adherence to medications. The digital solutions rarely target support to caregivers in their role and life situation despite the impact they have on a daily basis to support self-care so this is an area in need of further development.

Special considerations

Special attention is warranted in particular to those patients showing poor adherence to medical therapy or unpredictable self-care pattern [28, 29]. This may indicate some degree of cognitive impairment, with older patients with more severe HF found to have poorer

executive functioning. In addition the more severe the HF, it was associated with poorer total recall memory, poorer visuospatial recall ability, psychomotor slowing, and poorer executive function [30]. The provision of information and re-checking comprehension may not be sufficient if the patient is aware of what he/she needs to undertake but is physically, socially or psychologically challenged to do so.

With advanced technology, many professionals become caught up in the jargon, using complex terminology to explain pending investigations or technology. During the Covid pandemic as we have learnt how to use technology more effectively within the clinical environment, such may be simply extended to provide a visual overview of the, for example catheterisation room, the device clinic. This reinforces the importance of learning not just through words but images, pictures and real-life scenarios. Once again the valuable role of the family members and informal caregivers cannot be under-estimated and should be included, in as much as possible, information giving sessions [31].

Using technology, consideration of patients' perceived electronic health (eHealth) literacy skills or digital health literacy skills are crucial for improving the delivery of health information and instruments to assess eHealth literacy scale can be used [32].

4. Future directions

Adequate patient self-care is essential in the effective management of HF. Patient education allows patients to understand what is beneficial and to help to jointly with their health care professionals make decisions about their self-care. Education to improve self-care should be tailored to the individual patient and based on, where available, scientific evidence or expert opinion. A personalized and tailored approach to self-care support is needed. This includes using a range of teaching and educational techniques and optimal use of communication skills

and where relevant technological support and tools. Training in communication skills should be structurally intergrated in education of health care professionals and educational seminars.

5. Chapter summary and key messages

Optimal self-care improves patient outcomes and can prevent deterioration and exacerbations. With a greater emphasis on self-care, the ability to participate in daily life requires knowledge as well as interpretation, skills and action. New patient teaching strategies are needed to support the development of tactical and situational skills, foster coherence, and use trusted resources. As HF management programs develop, including coaching interventions that target skill-building tactics, such as role-playing in specific situations, may be one option [33]. Gone are the days when education relies on verbal and written information alone. Patients with HF as well as their caregivers require tailored information that is delivered in a format and engaging way that they can understand, and which will lead to positive behaviour changes.

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