Self Managing Heart Failure in Remote Australia - Translating Concepts into Clinical Practice

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Abstract: Congestive heart failure (CHF) is an ambulatory health care condition characterized by episodes of decompensation and is usually without cure. It is a leading cause for morbidity and mortality and the lead cause for hospital admissions in older patients in the developed world. The long-term requirement for medical care and pharmaceuticals contributes to significant health care costs. CHF management follows a hierarchy from physician prescription to allied health, predominately nurse-led, delivery of care. Health services are easier to access in urban compared to rural settings. The differentials for more specialized services could be even greater. Remote Australia is thus faced with unique challenges in delivering CHF best practice. Chronic disease self-management programs (CDSMP) were designed to increase patient participation in their health and alleviate stress on health systems. There have been CDSMP successes with some diseases, although challenges still exist for CHF. These challenges are amplified in remote Australia due to geographic and demographic factors, increased burden of disease, and higher incidence of comorbidities. In this review we explore CDSMP for CHF and the challenges for our region.

Keywords: Chronic disease, Congestive Heart failure, Indigenous Australians, Remote, Self-care, Self-management.

INTRODUCTION

No health system to date has successfully developed and translated a chronic disease self-management program (CDSMP) for congestive heart failure (CHF). Positive findings can be found among some ambulatory chronic care conditions such as chronic pain syndromes, diabetes, hypertension and inflammatory arthritic conditions. Long-term disease control, resource utilization, program retention and outcomes have been more difficult to demonstrate. CHF, a leading cause for morbidity and mortality in Australia, has similarly seen attempts at CDSMP with varied success [1-16]. Governments continue to encourage these concepts that facilitate clients management of many more aspects of their illnesses to help curtail escalating health care costs. Clinicians and health administrators however are still struggling to find viable models to implement.

The standard CHF care model delivers guideline based care (therapeutics and rehabilitation) within a nurse-led CHF program, which is proven to improve morbidity and mortality [2]. Most tertiary institutes have such programs in place. While the principle of CDSMP, i.e. to reduce the role of health staff and increase the role of the patient, is outwardly simple, it has been difficult to implement [12]. This review addresses CDSMP for CHF, with a regional context. We explore:

- Why has this important concept failed to create an impact in health services to date?
- What could the future of self-management be?
- What entails effective, reliable and informing research in this area?
- Is the current paradigm effective or are new paradigms required?

The terms self-management, self-care, or maintenance are used interchangeably in the literature; we use the term
self-management broadly and self-care when focused on the patient.

WHAT IS SELF-MANAGEMENT AND DOES IT ACTUALLY WORK?

‘Self-management’ was introduced in the 1960’s to describe the active participation of pediatric patients with management of their chronic asthma. It is used more widely now, often in chronic disease management programs (CDMP) and is applied to all age groups, but remains poorly defined or conceptualized [17]. CDSMP is a problem based approach to medicine that is designed to encourage patients to engage with their disease management; success lies in achieving self-efficacy and self-tailoring. CDSMP comprises (Table 1):

- Four goals: performance mastery, modeling, interpretation of symptoms and social persuasion
- Three tasks: medical management, role management and emotional management
- Five skills: problem solving, decision making, resource utilization, forming a patient/health care provider partnership, and taking action

Several theoretical platforms guide the development and delivery of CDSMP (e.g. ‘Orem Model of Nursing/Self Care Deficit Nursing’ and ‘Naturalistic Decision Making Framework’). Cognitive behavioral theory and social learning theories provide frameworks for understanding behavior change through knowledge acquisition, attitude change, and social persuasion. These theoretical frameworks have helped shape self-management models, such as the Chronic Care Model, the Stamford Model, and the Flinders Program of Chronic Condition Self-Management (CFPI) [17], however, CDSMP can be quite different in practice. In general, CDSMP tends to involve an approach that emphasizes client education and knowledge transfer to achieve sustained behavioral change, health improvement and health care utilization. Health providers generally begin by implementing a needs assessment of client-focused concerns in the illness context; this flexibility is critical to ensure that complex care needs are addressed.

Positive outcomes of CDSMP have been reported in a variety of chronic conditions, such as asthma and chronic airways diseases, anxiety and depression, diabetes, hypertension, rheumatologic and chronic pain [19-30]. These studies have examined effects of nurse-led programs, educational materials, eHealth technologies (eg., telephone, mobile phone, web and applications), improved medication packaging, and social support (eg., group and family) to target a range of patient issues, including distance, education, disability, language and culture, staffing and resources [2, 31-45]. There are some fundamental self-management principles to understand. The balance for the specific program components has been a major stumbling block. Four points are worth considering for CHF:

1. Core Self-management principles: summarized in Table 1.
2. The patient: CHF is usually lifelong, where physiological and psychological wellbeing waxes and wanes. Where possible, it is important for patients to engage with the management of their condition; patient self-efficacy and capacity to self-manage are important considerations here. The gradient in a patients capacity, intensity and motivation, makes some good self-managers and others poor.
3. Health Professionals: Health prescription is often led by physicians and shared with allied health, delivery is often led by allied health and shared with clients, while ownership is shared variably. Standardizing these points so that each arm values components from the other should provide greater importance for self-management.
4. Health Systems: Remuneration for time-consuming self-management sessions [2].

SELF-CARE IN HEART FAILURE

There are no landmark studies to support the argument for CDMSMs as an independent predictor for improved major adverse cardiovascular events (MACE) [3-10, 20, 46-48]. There is a spectrum of published data drawn from quantitative and qualitative studies, including descriptive, observational, and randomized controlled trials, which have covered topics that include: clinical outcomes and QOL [49-69]; strategies to deliver [70-88], promote [89-105], predict [106-124], and support carers [125-136]; programs in non-western cultures, non-English languages, [137-149]; education/ literacy gaps [150-168]; age [50, 58, 150]; gender [152]; comorbid conditions [33, 169, 170]; depression [170-172], and; remoteness and Indigenous background [2, 173-181]. These studies point to a wide range of benefits. It is established that self-management reduces the incidence of CHF and all cause hospitalizations, improves quality of life, knowledge and disease specific behaviors (Table 2). Methodological shortfalls in the study design and poor replicability of findings undermine confidence in some of these outcomes, particularly MACE.

Comparing Generic CHF Programs and stand-alone CDSMP

Mortality benefits have been observed for CHF CDMP with self-management components. In this model, care is delivered most effectively when it is nurse led, and face-to-face. A minimum level of service intensity is required [2]. Supplementing face-to-face communication with technology-enabled delivery such as rehabilitation is also equally effective [2, 32].

For CDSMP as an independent tool, many grey areas still remain [48]. The HART study, which randomized 902 patients, identified no benefits of their self-management intervention compared to the control group [55, 59]. Nonetheless, there is evidence linking increased self-care behaviors with better composite endpoints of hospitalization or death [50, 51, 53, 54, 56-58, 62, 108, 158, 159]. Surrogates for poor self-care, such as impaired cognition or lower literacy, are concomitantly associated with poorer outcomes [154, 160]. Wu et al showed among 595 participants with at least moderate CHF that the 37% who had lowest literacy also had worse CHF, higher NYHA class and increased incidence ratio of hospitalization and death [158]. Gonzalez et al.
Table 1. CDSMP Components for Congestive Heart Failure.

| GOALS | Health System | Patient | Psychological Theories & Core Principals |
|-------|--------------|---------|-----------------------------------------|
| EDUCATION | PURPOSE | REQUIREMENT | DETERMINANT OF SUCCESS | |
| • Increase knowledge | • Active Client Participation | • Content | 1. Information giving model |
| • Increase Skills | | • Theoretical Framework | 2. Social Learning Theory |
| • Increase Motivation | | • Standardization of Curriculum | |
| • Increase Confidence | | • Intensity | |
| • Increase Compliance | | • Realistic selection of individual goal and capability | 1. Orem’s Theory |
| | | • Correct Delivery Method | 2. Naturalistic Decision Making Framework |
| | | • Age, anxiety, cognition, comorbidity, depression, health literacy, sleep disturbances, underlying support | 3. Social Learning Theory (Self Efficacy Theory) |
| | | | 4. CBT and Principles |
| | | | 5. Chronic Care Model |
| | | | 6. Transitional Care Model |
| DETERMINANT OF SUCCESS | | | |
| • Content | | • Education level | |
| • Theoretical Framework | | • Cultural Appropriateness | |
| • Standardization of Curriculum | | • Intensity | |
| • Intensity | | • Correct Delivery Method | |
| • Delivery Setting & Method | | • Age, anxiety, cognition, comorbidity, depression, health literacy, sleep disturbances, underlying support | |
| • Funding Model, remuneration & sustainability | | | |
| CONTENT & SKILLS | SKILLS | GOALS | SYNONYMS |
| • Training | • Problem solving | • Acquire, Learn, | • Acquire, Learn, |
| • Re-training intervals | • Decision making | • Action, action planning, manage, master, perform, | • Acquire, Learn, |
| • Basic Minimum Standards | • Resource utilization | • Monitor, observe | • Action, action planning, manage, master, perform, |
| • Generic or Disease Specific | • Form patient provider partnership | • Adjust, titrate | • Monitor, observe |
| CHF Skills Goals | • Action planning with Self-tailoring | • Adhere, comply | • Adjust, titrate |
| • Vital signs (G,M) | • Monitoring (G,M) | • Engage | • Adhere, comply |
| • Weight and weight change action plan (G) | • Monitoring with action (G) | | • Engage |
| • Medication (G,M,P) | • Exercise (G,M) | | |
| • Diuretic titration (G) | • RF Modification and preventive behaviors (G) | | |
| • Warning signs and symptoms of worsening CHF (G,M) | • Engaging health system (G,M) | | |
| • When to call provider (G,M,P) | • Compliance (G,M,P) | | |
| • Diet (G,M,P) | • Diet adherence (G,M,P) | | |
| • Activity/exercise/Fitness (G,M) | | | |
| • ADL & personal hygiene (G,M) | | | |
| • Stress management & Psychosocial Consequence (G) | | | |
| • Support systems (G,M,P) | | | |
| • Smoking cessation (G,M) | | | |
| • Alcohol consumption (G,M) | | | |
| • Lifestyle Changes (G,M) | | | |
| • Disease specific self-activities (G) | | | |
| Self-care Goals (minimum): | | | |
| • Assessment skills | | | |
| • Motivational interviewing | | | |
| • Information sharing | | | |
| • Problem solving/goal setting | | | |
| • Shared decision making | | | |
| • Self-efficacy assessment | | | |
| • Follow-up interventions | | | |
| DETERMINANT OF SUCCESS | | | |
| • As above | | | |
(Table 1) Contd….

| GOALS                        | Health System                                                                 | Patient                                                                 | Psychological Theories & Core Principles |
|------------------------------|-------------------------------------------------------------------------------|-------------------------------------------------------------------------|------------------------------------------|
| INTENSITY & DURATION         | • Run in periods                                                             | • Individual Ability                                                     | CBT                                      |
|                              | • Frequency (Fatigue factors, signal to noise ratio)                          | • Motivation                                                            | • Regular follow-up required for self-care efficacy and retention |
|                              | • Duration                                                                   | • Fatigue                                                               | • Excess can lead to fatigue             |
|                              | • Feasibility & Sustainability                                               | • Geographic & Logistic                                                 |                                          |
|                              | • Self-management support                                                   |                                                                         |                                          |
| ASSESSMENT                   | • Accuracy - signal to noise ratio                                           | • Timing of contact                                                     | 1. Social cognition models              |
|                              | • Effectiveness                                                              | • Fatigue                                                               | 2. Health belief model                   |
|                              | • Feasibility                                                                | • Achieving agreed goals (self-efficacy; knowledge; behavior)           | 3. Locus of control                      |
|                              | • Cost                                                                       | • Compliance                                                            |                                          |
|                              | • Setting                                                                    | • Safety                                                                |                                          |
|                              | • Safety (e.g. Measures of Disease Control; Health outcomes measure; patient satisfaction measures; utilization and productivity measures; cost; patient Behavior; patient self-efficacy; patient knowledge) |                                                                         |                                          |
| DETERMINANT OF SUCCESS       | • Self-care maintenance                                                     | • Self-care management                                                  |                                          |
|                              | • Self-care confidence                                                      | • Self-care confidence                                                  |                                          |
| PEOPLE                       | • Health Care Providers (Doctor)                                             | Client                                                                  | CBT                                      |
|                              | • Nurse                                                                      | Family Supports                                                         | Deliver & retain self-care capacity      |
|                              | • AHW; OT; PT; SW                                                           | Social Network                                                          | Social support critical to encourage & maintain behavior |
|                              | • Pharmacist                                                                 | Carers                                                                  |                                          |
| DELIVERY METHODS, MONITORING TOOLS & INFORMATION SHARING | Education                                                                  | Variable depends on:                                                    | CBT                                      |
|                              | • Reading materials (leaflets, information sheets)                           | • Education levels                                                      | • Group support via face to face or with virtual online communities can address confidence, support, |
|                              | • Group Classes & Courses                                                   | • Availability                                                          | • Reminders                              |
|                              | • Rehab Program                                                              | • Preference                                                            | • Health literacy training              |
|                              | • Communication                                                             | • Motivation                                                            | • Individual care plans                 |
|                              | • Face-to-Face (verbal)                                                      | • Support                                                               |                                          |
|                              | • Group                                                                      | • Miscellaneous: unconventional approaches targeting pill size, burden, compliance, other factors making compliance harder |
|                              | • Phone                                                                      |                                                                         |                                          |
|                              | • Web portal & health apps                                                  |                                                                         |                                          |
|                              | • Video Conferencing                                                        |                                                                         |                                          |
|                              | • Monitoring & Treating                                                      |                                                                         |                                          |
|                              | • Clinician guidance                                                        |                                                                         |                                          |
|                              | • External or internal monitoring devices                                    |                                                                         |                                          |
|                              | • Web or mobile platforms                                                   |                                                                         |                                          |
|                              | • Algorithm based feedback                                                  |                                                                         |                                          |
|                              | • Automated telephone DMP                                                   |                                                                         |                                          |

Good (G), moderate (M), Poor (P) - are the minimum patient characteristics needed to achieve the highlighted self-management goal.

Abbreviation: AHW – aboriginal/allied health care worker; OT – occupational therapist; pt – patient; PT – physiotherapist; SW – social worker; Details of table compiled from ref [3-10, 17, 18, 47, 48, 221].
assessed 335 HF patients stratified into three educational groups and noted a significant improvement in patient self-care following a nurse-led education programme in all groups at 12 months [153].

The optimal balance of intensity within a CDMP and methods for delivering support needs to be defined [56]. CHF can be differentiated from other chronic diseases by its complexity and the skill level required for patients to achieve goals [56]. There are thus barriers to achieving this minimum self-efficiency, but it should be achievable by most. Negotiating components to share between health staff and patients is part of this learning curve. Finally all this should be achieved within a CHF CDMP, and not an independent CDSMP.

Practical and Psychological Barriers to Self-Management

Good CHF care requires that patients master several key skills, often with co-morbid illnesses. For example, Dickson et al. found that 79% of 114 patients reported 2 or more co-morbidities which influenced self-care [169]. Clark et al. reviewed 49 studies and noted that many patients were motivated and sought assistance to improve their adherence to care plans. However, deficiencies can exist in knowledge, training, and assessment. Moreover, there can be important mismatches between client, support group and health system beliefs, variable involvement of the family and, finally, failure to structure programs around patients’ normal routines [106, 139]. Marti et al. surveyed 308 CHF patients and showed that self-reported behavioral adherence can be low and selective in a variety of areas, including alcohol intake, smoking cessation and exercise [108]. Patients also go through a process of developing skills and understanding where these new skills sit with their health-related beliefs [113]. This process does not always occur within acceptable study timeframes, but rather relate to the length of time since CHF diagnosis. Thus behaviors which could lead to decompensation, such as excess salt and water intake, are also those with observable perceived benefits and are among the most amenable to change [92, 117]. Depressive symptoms can manifest as physical or intellectual impediments. Depression can be difficult to assess, is poorly detected and contributes to poor self-care [171, 172]. Other barriers include socioeconomic status, which can alter patient priorities, and communication barriers for which technology can be of benefit. Thus barriers to client self-management are important factors that can determine self-efficacy [32].

Non-modifiable Barriers to Self-Management

Age, sex, culture or language, ethnicity, educational status and cognition are important non-modifiable barriers to self-management. Poor outcomes in patients presenting with these characteristics can partly be attributed to suboptimal delivery of CDMP. Published reports from the Middle East, Asia and Europe show that these factors can be addressed [92, 138, 140, 145, 147]. In Australia, some of these issues have been addressed through multicultural health care workers, with significant improvements observed in patient self-care skills with positive outcome trends [142]. Multilingual patients with higher intelligence, or more cognizant, have an advantage, although a gradient of improvement can be seen across all spectra [144, 153, 156, 168]. Cognitive impairment is a predictor of poor self-care and should be screened for [154], although teaching patients self-care skills still has potential benefits [161]. Rigid definitions are thus counter-productive. Sampling of chronic diseases among lower SES in Singapore showed that older and female patients were more likely to utilize outpatient services [143]. Thus ensuring there are a basket of options to factor all these is important.

Self-management for Indigenous Patients

This is a difficult area for all health systems. There are some arguments for community developed models of chronic care [178], however, in the Northern Territory of Australia alone, there are > 130 discrete communities and >70 spoken languages. Many Aboriginal patients live remotely, which adds to the complexity of health service provision in Aboriginal cultures [181]. Indeed, the vulnerability of remotely located patients’ means that it is imperative that self-care programs work for these patients, however, delivery is constrained. A good starting point would be to implement a set of overriding principles:

I. Among the most important is to engage in a dialogue with the patient and the appropriate network and negotiate a suitable balance of care that can be shared.

II. Second is to understand the concept of ownership of health matters for chronic diseases within the Aboriginal context and translating this to patient interactions.

These principles should foster a platform for understanding cultural sensitivities and promoting respectful engagement. In a study of 49 indigenous patients with mental illness, Nagel et al. [179] provided a series of brief, culturally-focused interventions to promote self-care. The authors identified common goals and steps chosen by most patients. Nearly a third achieved their second goal after one session. The study identified goal setting as an acceptable self-management strategy for indigenous mental illness and provided insight into the strategies patients chose for change [179]. The AUSI-CDS is another example of a study designed to address some of these points [11]. In this case the CFPI is particularly useful as it provides a structure for client goal setting; how this program fits into CHF CDMP is an important point to explore in time.

MEASURING OUTCOMES

A number of tools, using quantitative or qualitative formats, are used to assess CHF self-efficacy and quality of life (QOL) based on patient-reported outcomes (PRO) [182-200]. Cameron et al. identified 21 instruments measuring aspects of self-care, however, only two tools have been validated; the European Heart Failure Self-care Behavior Scale [EHFSeBS] and Self-care Heart Failure Index [SCHFI] [190]. These tools were based on Orem’s theory and definition of self-care and a naturalistic decision-making framework. Shuldam et al. noted that the two measures were not significantly correlated, suggesting that they measure different self-care elements [198]. A third option, the CFPI, which has an advantage being developed in Australia with remote collaborating Universities and research institutes is available.
online and has proven reproducibility for other ambulatory health conditions. The scoring system is simple [18]. While it provides comprehensive assessment of self-management, it lacks disease specific integration and has not been evaluated in CHF. Its relevance could increase significantly by minor modifications of questions for greater disease specific focus. Targeting groups from the current individual focus is also important. This planning is currently underway.

CDMPs can also be measured for health systems (ACIC) or clients (PACIC, PSQ-18, CAHPS). Chronic condition QOL PRO tools include the SF-12 or 36, EQ-5D, CAHPS, Health Utilities Index, The Nottingham Health Profile and Quality of Well Being Scale; CHF specific QOL tools include the MLHFQ, KCCQ and the NYHA. Tools such as these can provide information regarding quality adjusted life years (QALY) and health care costs. These tools have their strengths and weaknesses, one being the length of time for clients or staff to complete. One study showed that in the SF-36, more than 65% of respondents did not complete the questionnaire [201-209]. The issues of validity and reliability have largely been resolved. Regional applicability is best defined within each health system. User-friendliness and significance is best defined within each health system (Table 3).

### Table 2. Breakdown of the published evidence.

| Study Details | References | Population | Outcomes | Notes |
|---------------|------------|------------|----------|-------|
| MA            | [33, 35, 41, 37, 39, 109] | • Homogenous population  
• Most have comorbidity | • Reduce hospitalization | • Significantly decreased hospitalization for telephone, home visit, specialists clinic follow-up, but not for primary care supervised (2 studies only)  
• Significant heterogeneity in results unable to comment on other parameters  
• Multiple chronic conditions increase vulnerability to poor self-care.  
• Adherence to diet, symptom monitoring, and differentiating symptoms from multiple conditions were the most challenging self-care skills. |
| SR, RV        | [2, 4, 5, 6, 7, 12, 17, 34, 54, 68, 69, 86, 87, 89, 92, 97, 99, 100, 106, 113, 117, 119, 125, 126, 142] | • Homogenous population  
• Most have comorbidity | • Reduce hospitalizations  
• NS reduction in mortality | • Methodological shortfalls in many studies impairing validation  
• Research is needed to develop and test tailored and inclusive CVD self-care interventions. Attention to rigorous study designs and methods including consistent outcomes and measurement is essential  
• Case management, and patient education with behavioral support all improved medication adherence for more than 1 condition. Evidence is limited on whether these approaches are broadly applicable or affect long-term medication adherence and health outcomes.  
• Telehealth could improve self-care, small sample sizes  
• Carer support could be developed further  
• Further research needed on the barriers and facilitators of self-care in HF, to provide an appropriate guide to any intervention strategy.  
• Address specific client issue to improve self-care |
| Ont Health Technol Assess Ser (SR, MA) | [48] | 10 RCT (n = 6074) | • Significant/small ↑ some health status outcomes  
• Significant/small ↑ some healthy behavior outcomes:  
• Significant/small ↑ self-efficacy:  
• NS health care utilization outcomes | • Data reporting poor. No intention to treat principles  
• Stanford models had small short term gains  
• Greater research needed to identify responders and non-responders, effect on clinical outcomes and across a wider demographic. |
| Guideline     | [3, 18, 20, 23, 47, 220] | Consensus & other Statements on CDSMP | NA | • Outlines principles of self-care to integrate with HF CDMP |

CDMP – chronic disease management program; CVD – cardiovascular disease; HF – heart failure; hr-QOL – health related quality of life; MA – meta-analysis; n – number of participants; NA – not applicable; NS – not significant; RCT – randomized controlled trial; Ref – references; RV – review; SR – systematic review.
STRUCTURING CDSMP TRIALS FOR REMOTE AUSTRALIA

Many health systems, including our own, continue to raise the question of how to structure CDSMPs for CHF, effectively allocate resources, and obtain evidence of program efficacy. CHF management is expensive, poor compliance is more common than is acknowledged and self-efficacy is among the best surrogates for compliance. It is important then for health professionals to have the confidence to tell their patients ‘I want you to learn about your disease and its management’ and the health system adequately prepared to say ‘we can help you achieve this’. These points could form the basis of structuring self-management components of CHF CDMP:

- CDSMP aims – achieving self-efficacy. Improved self-care behaviors is synonymous with improved compliance, thus better outcomes and cost savings [2, 210-213].
- CDSMP or CDMP with self-management components? We believe that the evidence supports self-management as an essential component of any chronic disease program. A stand-alone CDSMP may work for other conditions but is not recommended in CHF.
- What, who and how much self-management? Reinforcing client’s core belief on the benefits of their therapy, disease specific knowledge and educational parameters listed in Table 1. Patients and nominated carers should both be approached by health staff. The intensity of CDSMP should be tailored to the needs of the patient. While scoring systems are important to be able to quantify progress, actual success will depend on the experience of the staff and rapport they build with patients. This rather than fixed time structure should be encouraged. CDSMP remains a learning process for the majority, thus implementation in the early phases should be an exercise to identify the successful and failing components, not a rigid structure and timeline to target.
- How long should the client receive support? Program intensity is greatest at the start of the illness and subsequently wanes. Systems do not often provide a description of non-pharmacological supports the clients received and what level many aspects of their chronic disease understanding is at. Consistency and continuity of chronic disease care could thus be improved. Self-management supports have to be factored within this context.
- What are suitable research studies? A lot of lessons can be taken from the literature however more work is needed. For example, there are many shortcomings, such as inadequate detail in study methods; we reference only nine studies with detailed methods [11, 182-189]. The main consideration is the need for randomization and controlling bias. Quasi-experimental or non-randomized studies allow for observations on real world treatment protocols. Biases could be controlled by pseudo-randomization techniques such as regression adjustment, propensity matching, inverse probability weighting and instrument variables as examples. A combination of qualitative and quantitative data is most likely to provide a robust dataset. It could also be important that we start viewing these studies as phase 4 research addressing effectiveness and subsequently cost-effectiveness. We also feel it is important to ensure representation from administrative personnel, clinicians and research groups when developing research methods.
- What are appropriate surrogate end-points? CHF management includes robust prognostic pharmacotherapy, implantable devices and established CDMPs. Postmarketing studies such as the OPTIMIZE-HF study show that programs targeting measures to increase patient compliance improves outcomes [2]. It is thus not necessary to explore these endpoints again. As self-care is expected to be part of a program, endpoints could include: patient self-efficacy, staff and client satisfaction, health care utilization and hospitalization and cost efficacy. Major adverse cardiovascular events could then be explored as part of that comprehensive CHF CDMP, rather than as self-care independently [214-220].

CONCLUSION

Is it possible to achieve successes with CDSMP? With escalating health care costs it is imperative we do so. CHF can largely be managed in the communities. Health policy and planners have however found it difficult to uniformly increase patient responsibilities and reduce tertiary level support. CDSMP were initiated to transfer some of the care responsibilities to the patient. Independent CDSMP for CHF is unlikely to be of benefit. CHF management is complex and requires a CDMP in its own right. Self-management as part of a CHF CDMP should be explored further. Achieving patient self-efficacy will improve compliance, reduce hospitalizations and MACE. It will remain difficult to develop programs to achieve sustained behavioral changes for all the variable demographics. A broad canvas with generic content, supplemented with specific focus, would be a good start. Efficacy monitoring should ask valid questions, set realistic goals and utilize appropriate research techniques. There is certainly a need for a paradigm change in the way we view self-management from evidence generation to implementation. We believe all systems will come to accept that investments in self-management strategies are essential for long-term planning.

ABBREVIATIONS

ACIC = Assessment of chronic illness care
CAHPS = Consumer Assessment of Healthcare Providers
CDMP = chronic disease management program
CDSMP = chronic disease self-management program
CFPI = Flinders Program of Chronic Condition Management
CHF = congestive heart failure
DMP = disease management program
Table 3. Qualitative Tools Measuring outcomes for HF and Self-care programs.

| Tool          | Type of Measure | Summary of Instrument/Tool                                                                 | Dimensions                                           |
|---------------|-----------------|-------------------------------------------------------------------------------------------|------------------------------------------------------|
| ACIC          | Health Systems  | The components of ACIC was derived after specific evidence-based interventions from the six components of the Chronic Care Model. Thus similar to this model, the ACIC addresses the main elements for improving chronic illness care at the community, organization, practice and patient level. | ➢ Community resources  
➢ Health organization  
➢ Self-management support  
➢ Delivery system design  
➢ Decision support  
➢ Clinical information systems |
| PACIC         | Patient Satisfaction | 20 or 26 item patient report instrument to rate chronic illness care over a 6 month period. Cover 5 dimensions of care | ➢ Patient activation  
➢ Delivery system design  
➢ Goal setting  
➢ Problem solving  
➢ Follow-up/coordination |
| PSQ-18        | Patient satisfaction | Short form of PSQ-III using Likert scale questionnaire evaluating 18 items from 7 dimensions of patient satisfaction directed toward doctors | ➢ General satisfaction  
➢ Technical quality  
➢ Interpersonal manner  
➢ Communication  
➢ Financial aspects  
➢ Time spent with doctor  
➢ Accessibility and convenience |
| CAHPS         | Patient satisfaction | Survey for consumers and patients to report on and evaluate their experiences with health care from 12 dimensions | ➢ Getting Timely Care  
➢ Provider Communication  
➢ Rating of Provider  
➢ Access to Specialists  
➢ Health Promotion and Education  
➢ Shared Decision-making  
➢ Health Status/Functional Status  
➢ Courteous/Helpful Office Staff  
➢ Care Coordination  
➢ Between Visit Communication  
➢ Education About Medication Adherence  
➢ Stewardship of Patient Resources |
| SF-36v2       | Patient reported outcomes | Patient reported 5 point survey covering mental and physical health over eight scaled scores. Each question has equal leaving final score from 0-100 scale. Lower scores associated with greater disability. | ➢ Physical functioning  
➢ Physical role functioning  
➢ Bodily pain  
➢ General health perceptions  
➢ Vitality  
➢ Emotional role functioning  
➢ Social role functioning  
➢ Mental health |
| EQ-5D         | Patient reported outcomes | Most used self-administered survey, for > 70 languages, that can be completed within minutes. Scoring based on 3 point descriptive questionnaire and 20cm vertical visual analogue scale with best health (top) or worst (bottom). | ➢ Mobility  
➢ Self-Care  
➢ Usual Activities  
➢ Pain/Discomfort  
➢ Anxiety/Depression |
| QWB-SA        | Patient reported outcomes | Survey of interview of 71 items scored 0 (death) to 1.0 (full function) taking 10-15 minutes. Can be translated into QALY. Requires training. | ➢ Acute and Chronic Symptoms  
➢ Self-Care  
➢ Mobility  
➢ Physical Activity  
➢ Usual activity |
| Tool     | Type of Measure | Summary of Instrument/Tool                                                                                                                                                                                                                                                                                                                                 | Dimensions                                                                 |
|----------|-----------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------|
| HUI      | Patient reported outcomes | Family of generic health profiles and preference-based systems measuring health status, reporting health-related quality of life, and producing utility scores. Explores: 1) experience of patients undergoing therapy; 2) long-term outcomes of disease or therapy; 3) the efficacy, effectiveness and efficiency of interventions; and 4) health status of general populations. Each HUI attribute (dimension) has 3–6 levels of discrimination and is very responsive to changes in health caused by treatment therapies or other influences. | 8 attributes vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain – each with 5 or 6 levels of ability/disability. |
| KCCQ     | Disease specific QOL | The Kansas City Cardiomyopathy Questionnaire (KCCQ) is a new, self-administered, 23-item questionnaire developed to provide a better description of HRQoL in patients with CHF. It quantifies, in a disease-specific fashion, physical limitation, symptoms (frequency, severity and recent change over time), QoL, social interference and self-efficacy. | Physical limitations, Symptoms stability, frequency, severity, change over time Self-efficacy and knowledge Social interference/limitation Quality of Life: |
| MLHFQ    | Disease specific QOL | Self administered, 5-10 minutes, 21 item 5 point Likert variable, to measure the effects of symptoms, functional limitations, psychological distress on an individual's quality of life, the MLHF questionnaire asks each person to indicate using a 6-point, zero to five, Likert scale how much each of 21 facets prevented them from living as they desired. The MLHFQ is designed to measure the effects of heart failure and its treatments on an individual's quality of life. MLHFQ measures the effects of symptoms, functional limitations, and psychological distress on an individual's quality of life. It consists of questions that assess the impact of frequent physical symptoms, the effects of heart failure on physical/social functions, and side effects of treatments, hospital stays, and costs of care. | |
| NYHA     | Disease specific QOL | Standardised health care provider assessment of heart failure severity. Dyspnoea grading with varying states of rest and exercise. Range 0-4. Higher scores are worse. | One component - Universal |
| CFPI     | Self-care understanding and goals | Partners in Health Scale, self-efficacy for managing chronic disease 6 – item Scale Energy/Fatigue Scale, Cue & Response Score, Problems & Goals Score. Training required for use. | PIH Cue & Response P & G |
| EHFScBS  | CHF self-care | The EHFScBS is a 12-item questionnaire that measures 3 aspects of health maintenance behaviors: compliance with their management regimen, asking for help, and adapting daily activities. Responses are on a 5-point Likert-type scale indicating how often each behavior is performed, ranging from “I completely agree” to “I don’t agree at all.” Scores are summed. Lower scores indicate better self-care. The instrument has subsequently been revised into a 9-item instrument. | Translated into 14 languages: Swedish (161) The Netherlands (1241) United Kingdom (177) Italian (173) German (285) Spanish (553) |
| SCHFI    | CHF self-care | The SCHFI consists of 15 items that measure 3 subscales: behaviors undertaken to maintain clinical stability (self-care maintenance), the decision-making process with regard to symptom changes (self-care management), and confidence to manage symptoms and evaluate any actions implemented (self-care confidence). Self-care management can only be computed if patients have been symptomatic in past month. Summary scores for the 3 subscales are used by transforming each subscale to scale from 0 to 100. Adequate scores are more than 70 on any subscale. | Officially translated into Spanish and Thai languages and requests to use it in 24 other countries: United States (453) Australian (1095) Thai (400) Mexican (134) |

2DE, BNP and 6MWT are simple reproducible qualitative tools that can be combined with routine biochemistry. Abbreviations: CAHPS - Consumer Assessment of Healthcare Providers and Systems; EQ-5D - EuroQOL five dimensions questionnaire; HUI – health utility index; KCCQ - Kansas City Cardiomyopathy Questionnaire; MLHFQ - Minnesota Living with Heart Failure questionnaire; PACIC - Patient Assessment of Chronic Illness Care; PSQ-18 - The Patient Satisfaction Questionnaire Short Form; PRO – patient reported outcomes; QOL – quality of life; QWB-SA - quality of well-being self-administered version. Details of table compiled from references 182-200.

EHFScBS = European Heart Failure Self-care Behavior Scale
EQ-5D = EuroQOL five dimensions questionnaire
KCCQ = The Kansas City Cardiomyopathy Questionnaire
MACE = major adverse cardiovascular events
MLHFQ = Minnesota Living with Heart Failure questionnaire
NYHA = New York Heart Association
OPTIMIZE-HF = Organized Program to Initiate Lifesaving Treatment in Hospitalized Patients
PACIC = Patient Assessment of Care for Chronic Conditions
PRO = patient reported outcomes
PSQ-18 = The Patient Satisfaction Questionnaire Short Form
QALY = Quality Associated Life Years
QOL = quality of life
RCT = randomized controlled trial
SCHFI = Self-care Heart Failure Index
SF-12 or 36 = Short Form Health Survey

DISCLOSURES

All co-authors have won independent and governmental research funding. Professor Batterby is co-inventor of the CFPI. None pose a conflict of interest for this paper.

CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

ACKNOWLEDGEMENTS

Declared none.

REFERENCES

[1] Jordan JE, Osborne RH. Chronic disease self-management education programs: challenges ahead. MJA 2007; 186: 84-7.
[2] lyngkaran P, Harris M, Ilton M, et al. Implementing Guideline Based Heart Failure Care in the Northern Territory: Challenges and Solutions. Heart Lung Circ 2014; 23(5): 391-406.
[3] Riegel B, Moser DK, Anker SD, et al. State of the Science: Promoting self-care in persons with heart failure-A scientific statement from the American Heart Association. Circulation 2009; 120: 1141-63.
[4] Riegel B, Lee CS, Dickson VV. Self-care in patients with chronic heart failure. Nat Rev Cardiol 2011; 19(8): 644-54.
[5] Ward AM, Heneghan C, Perera R, et al. What are the basic self-monitoring components for cardiovascular risk management? BMC Med Res Methodol 2010; 10: 105.
[6] Moser DK, Dickson V, Jaarsma T, Lee C, Stromberg A, Riegel B. Role of self-care in the patient with heart failure. Curr Cardiol Rep 2012; 14(3): 265-75.
[7] Gardetto NJ. Self-management in heart failure: where have we been and where should we go? J Multidiscip Healthc 2011; 4: 39-51.
[8] Davidson PM, Inglis SC, Newton PJ. Self-care in patients with chronic heart failure. Expert Rev Pharmacoecon Outcomes Res 2013; 13(3): 351-9.
[9] Roccaforte R, Demers C, Baldassarre F, Teo KK, Yusuf S. Effectiveness of comprehensive disease management programs improving clinical outcomes in heart failure patients. A meta-analysis. Eur J Heart Fail 2005; 7: 1133–44.
[10] Dickson VV, Clark RA, Rabelo-Silva ER, Buck HG. Self-Care and Chronic Disease. Nurs Res Pract 2013; 2013: 827409.
[11] lyngkaran P, Majoni V, Haste M, et al. AUSTRALian Indigenous Chronic Disease Optimization Study (AUSI-CDS) Prospective observational cohort study to determine if an established chronic disease health care model can be used to deliver better heart failure care among Remote Indigenous Australians: Proof of concept. Study Rationale and Protocol. Heart Lung Circ 2013; 22(11): 920-9.
[12] Bos-Touwen I, Jonkman N, Westland H, et al. Tailoring of Self-Management Interventions in Patients With Heart Failure. Curr Heart Fail Rep 2015; 12: 223–35.
[13] Trappenburg J, Jonkman N, Jaarsma T, et al. Self-management: one size does not fit all. Patient Educ Couns 2013; 92: 134-7.
[14] lyngkaran P, Brown A, Cass A, Battersby M, Nadaranjan K, Ilton M. Why it Remains Difficult for Remote Cardiologists to Obtain the Lucrative of Control for Ambulatory Heart Care Conditions Such as Congestive Heart Failure? J Gen Pract 2014; 2: 146.
[15] Ross JS, Chen J, Lin ZQ, et al. Recent National Trends in readmission Rates after Heart Failure Hospitalization. Circ Heart Fail 2010; 3(1): 97-103.
[16] Dunlay SM, Redfield M, Weston S, et al. Hospitalizations After Heart Failure Diagnosis - A Community Perspective. J Am Coll Cardiol 2009; 54: 1695-702.
[17] Lorig KR, Holman HR. Self-Management Education: History, Definition, Outcomes, and Mechanisms. Ann Behav Med 2003; 26(1): 1-7.
[18] http://som.flinders.edu.au/FUSA/CCTU/Home.html (The Flinders Program™ for Chronic Condition Management: Information Paper)
[19] Clark AM, Savard LA, Thompson DR. What Is the Strength of Evidence for Heart Failure Disease-Management Programs? J Am Coll Cardiol 2009; 54: 397-401.
[20] Pearson ML, Matte T, Shaw R, Ridgely MS, Wiseman SH. Patient Self-Management Support Programs: An Evaluation (Final Contract Report). AHRQ Publication No. 08-0011 November 2007 (Prepared by: RAND Health Santa Monica, CA for Agency for Healthcare Research and Quality U.S. Department of Health and Human Services 540 Gaither Road Rockville, MD 20850)
[21] Schulman-Green D, Jaser S, Martin F, et al. Processes of self-management in chronic illness. J Nurs Scholarsh 2012; 44(2): 136-44.
[22] Lindsay S. Prioritizing illness: lessons in self-managing multiple chronic diseases. Can J Sociol 2009; 34(4): 983-1002.
[23] Center for the Advancement of Health: Essential Elements of Self-Management Interventions. Washington, DC: Center for the Advancement of Health, 2002.
[24] Briggs AM, Slater H, Bunzl H, et al. Consumers’ experiences of back pain in rural Western Australia: access to information and services, and self-management behaviours. BMC Health Serv Res 2012; 12: 357.
[25] Walters JA, Turnock AC. Walters EH. Wood-Baker R. Action back pain in rural Western Australia: access to information and services, and self-management behaviours. BMC Health Serv Res 2012; 12: 357.
[26] Cuijpers P, Donker T, Johansson R, Mohr DC, van Straten A, et al. Computer-based depression treatments for depression: a systematic review and meta-analysis. J Cult relativ 2014; 62: 1005-26.
[27] Cuijpers P, Donker T, Johansson R, Mohr DC, van Straten A, Andersson G. Self-guided psychological treatment for depression: a meta-analysis of randomized controlled trials. Ann Behav Med 2010; 39(1): 97-109.
[28] Lewis C, Pearce J, Bisson J. Efficacy, cost-effectiveness and acceptability of self-help interventions for anxiety disorders: a systematic review. Br J Psychiatry 2012; 200(1): 15-21.
[29] Bray EP, Holder R, Mant J, McManus RJ. Does self-monitoring reduce blood pressure? Meta-analysis with meta-regression of randomized controlled trials. Ann Med 2010; 42(5): 371-86.
[30] Walker J, Turnock AC. Walters EH. Wood-Baker R. Action plans with limited patient education only for exacerbations of chronic obstructive pulmonary disease. Cochrane Database Syst Rev 2010: 5: CD006074.
[31] Polykarpov I, Mitchell J, Hunt S, et al. Self-help interventions for anxiety disorders: systematic review and meta-analysis. Patient Educ Couns 2011; 85(3): e299-310.
[32] Boekeloe B, Holman HR, Self-Management: a systematic review. Br J Psychiatry 2012; 200(1): 15-21.
and meta-analysis of individual patient data. Lancet 2012; 379(9813): 322-34.

32. Lyngkaran P, Toukhssai SR, Biddagardi N, Zimmel H, J Atherton J, Hare DL. Technology-assisted congestive heart failure care. Curr Heart Fail Rep 2015; 12(2): 173-86.

33. Dickson VV, Buck H, Riegel B. A Qualitative meta-analysis of heart failure self-care practices among individuals with multiple comorbid conditions. J Cardiac Fail 2011; 17: 413-9.

34. Viswanathan M, Golin CE, Jones CD, et al. Interventions to Improve Adherence to Self-administered Medications for Chronic Diseases in the United States A Systematic Review. Ann Intern Med 2012; 157: 785-95.

35. Brady TJ, Murphy L, O’Colmain BJ, et al. A meta-analysis of health status, health behaviors, and healthcare utilization outcomes of the Chronic Disease Self-Management Program. Prev Chronic Dis 2013; 10: 120112.

36. Free C, Phillips G, Galli L, et al. The effectiveness of mobile-health technology-based health behavior change or disease management interventions for health care consumers: a systematic review. PLoS Med 2013; 10(1): e1001362.

37. Farrand P, Woodford J. Impact of support on the effectiveness of written cognitive behavioural self-help: a systematic review and meta-analysis of randomised controlled trials. Clin Psychol Rev 2013; 33(1): 182-95.

38. de Jongh T, Girol-Urganci I, Vodopive-Jamsek V, Car J, Atun R. Mobile phone messaging for facilitating self-management of long-term illnesses. Cochrane Database Syst Rev 2012; 12: CD007459.

39. Rusch FR, Dattilo J. Employment and self-management: a meta-evaluation of seven literature reviews. Intellect Dev Disabil 2012; 50(1): 69-75.

40. Piette JD, Rosland AM, Marinec NS, Striplin D, Bernstein SJ, Silveira MJ. Engagement With Automated Patient Monitoring and Self-Management Support Calls Experience With a Thousand Chronically Ill Patients. Med Care 2013; 51: 216-23.

41. Gherman A, Schnur J, Montgomery G, Sassu R, Versesi I, David D. How are adherent people more likely to think? A meta-analysis of health beliefs and diabetes self-care. Educator 2011; 37(3): 392-408.

42. Ryan R, Santesso N, Hill S, Lowe D, Kaufman C, Grimshaw J. Consumer-oriented interventions for evidence-based prescribing and medicines use: an overview of systematic reviews. Cochrane Database Syst Rev 2011; (5): CD007768.

43. Wolfe, Jennifer L, Roter, Debra L. Family presence in routine medical visits: a meta-analytical review. Soc Sci Med 2011; 72(6): 823-31.

44. Samoosta D, Brinvels DJ, Elbers NA, Anema JR, van der Beeck et al. Self-care Management of Heart Failure. Practical Recommendations From the Patient Care Committee of the Heart Failure Association of the European Society of Cardiology. Eur J Heart Fail 2011; 13(2): 115-26.

45. Franck J. Self-management support interventions for persons with chronic disease: an evidence-based analysis. Ont Health Technol Assess Ser 2013; 13(9): 1-60.

46. Shao JH, Chang AM, Edwards H, Shyu YI, Chen SH. A randomized controlled trial of self-management program improves health-related outcomes of older people with heart failure. J Adv Nurs 2013; 69(11): 2458-69.

47. El Badawy AM, El Heftawy KA. Randomized controlled trial of a comprehensive nursing intervention on readmission, mortality and quality of life among Egyptian heart failure patients: A 12 month follow up study. J Nurs Educ Pract 2013; 3(5): 14-30.

48. Kommuri NV, Johnson ML, Koelling TM. Relationship improvements in heart failure patient disease specific knowledge and clinical events as part of a randomized controlled trial. Patient Educ Couns 2012; 86(2): 233-8.

49. Jones CD, Holmes GM, Dewalt DA, et al. Is adherence to weight monitoring or weight-based diuretic self-adjustment associated with fewer heart failure-related emergency department visits or hospitalizations? J Card Fail 2012; 18(7): 576-84.

50. Otsu H, Moriyama M. Follow-up study for a disease management program for chronic heart failure 24 months after program commencement. Jpn J Nurs Sci 2012; 9(2): 136-48.

51. Ditewig JB, Blok H, Havers J, van Veenendaal H. Effectiveness of self-management interventions on mortality, hospital readmissions, chronic heart failure hospitalization rate and quality of life in patients with chronic heart failure: A systematic review. Patient Educ Couns 2010; 78: 785-95.

52. Powell LH, Calvin JE, Richardson D, et al. Self-management counselling in patients with heart failure: The Heart Failure Adherence and retention Randomized Behavioral Trial. JAMA 2010; 304: 1331-8.

53. Kfoury AG, French TK, Horne BD, et al. Incremental Survival Benefit With Adherence to Standardized Heart Failure Core Measures: A Performance Evaluation Study of 2958 Patients. J Cardiac Fail 2008; 14: 95e102.

54. Lee CS, Moser D, Lenneia TA, Riegel B. Engaging in self-care management improves event-free survival in adults with heart failure. Circulation 2008; 118(suppl2): S769. Abstract.

55. Jovicic A, Holroyd-Leduc JM, Straus SE. Effects of self-management intervention on health outcomes of patients with heart failure: a systematic review of randomized controlled trials. BMC Cardiovasc Disord 2006; 6: 43.

56. Grady KL, Mendes de Leon CF, Kozak AT, et al. Does self-management counseling in patients with heart failure improve quality of life? Findings from the Heart Failure Adherence and Retention Trial (HART). Qual Life Res 2014; 23(1): 31-8.

57. Vellone E, Chung ML, Coccchiere A, Rosco G, Alvaro R, Riegel B. Effects of Self-Care on Quality of Life in Adults With Heart Failure and Their Spousal Caregivers: Testing Dyadic Dynamics Using the Actor-Partner Interdependence Model. J Fam Nurs 2014; 20(1): 120-41.

58. Tung HH, Lin CY, Chen KY, Chang CJ, Lin YP, Chou CH. Self-management intervention to improve self-care and quality of life in heart failure patients. Congest Heart Fail 2013; 19(4): E9-E16.

59. Buck HG, Lee CS, Moser DK, et al. Relationship Between Self-care and Health-Related Quality of Life in Older Adults With Moderate to Advanced Heart Failure. J Cardiovasc Nurs 2012; 27(1): 8-15.

60. Du H, Everett B, Newton PJ, Salamonson Y, Davidson PM. Self-efficacy: a useful construct to promote physical activity in people with stable chronic heart failure. J Clin Nurs 2012; 21(3-4): 301-10.

61. Seto E, Leonard KJ, Caafazzo JA, Masino C, Barnsley J, Ross HJ. Self-care and Quality of Life of Heart Failure Patients at a Multidisciplinary Heart Failure Clinic. J Cardiovasc Nurs 2011; 26(5): 377-85.

62. Peters-Klimm F, Kunz CU, Laux G, Szeszenyi J, Muller-Tasch T. Patient and provider related determinants of generic and specific health-related quality of life of patients with chronic systolic heart failure in primary care: a cross-sectional study. Health Qual Life Outcomes 2010; 8: 98.

63. Agudo O, Morciano D, Delas J, et al. Long-term implications of a single home-based educational intervention in patients with heart failure. Heart Lung 2010; 39: S14-22.

64. Grady KL. Self-care and quality of life outcomes in heart failure patients. J Cardiovasc Nurs 2008; 23(3): 285-92.

65. Welsh D, Lenneia TA, Marcinek R, et al. Low-sodium diet self-management intervention in heart failure: pilot study results. Eur J Cardiovasc Nurs 2013; 12: 87.

66. Du H, Everett B, Newton PJ, Salamonson Y, Davidson PM. Self-efficacy: a useful construct to promote physical activity in people with stable chronic heart failure. J Clin Nurs 2012; 21(3-4): 301-10.

67. Larsen P, Pedersen PU. Stimulation to self-care in patients with chronic heart failure hospitalizations? J Card Fail 2012; 18(7): 576-84.

68. Karin AI, Kornreich M, Czyzewski M, et al. Do interventions to improve self-care and quality of life in chronic heart failure patients: A comprehensive systematic review. Eur J Cardiovasc Nurs 2013; 12(2): 159-66.

69. Mussi CM, Ruschel K, de Souza EN, et al. Home visit improves knowledge, self-care and adherence in heart failure: Randomized Clinical Trial HELEN-I. Rev. Latino-Am. Enfermagem 2013; 21: 20-8.
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[73] Higgins RO, Navaratnam HS, Murphy BM, Walker S, Worcester M. Outcomes of a chronic heart failure training program for health professionals. J Nurs Educ Pract 2013; 3(7): 68-74.

[74] Boyde M, Song S, Peters R, Turner C, Thompson DR, Stewart S. Pilot testing of a self-care education intervention for patients with heart failure. Eur J Cardiovasc Nurs 2013; 12(1): 34-36.

[75] Pina IL, Bruckman D, Lance C, et al. Quality Improvement in Heart Failure: A Randomized Educational Intervention to Change Provider Behavior. Congest Heart Fail 2012; 18(5): 245-53.

[76] Rodriguez-Gazquez M, Arredondo-Holguin E, Herrera-Cortes R. Effectiveness of an educational program in nursing in the self-care of patients with heart failure: randomized controlled trial. Rev Latino-Am Enfermagem 2012; 20(2): 296-306.

[77] Arredondo-Holguin E, Gavazquez M, Urrego L. Improvement of self-care behaviors after a nursing educational intervention with patients with heart failure. Invest Educ Enferm 2012; 30(2): 188-97.

[78] Jaarsma T, Nikolaova-Simons M, van der Wal MH. Nurses' strategies to address self-care aspects related to medication adherence and symptom recognition in heart failure patients: an in-depth look. Heart Lung 2012; 41(6): 583-93.

[79] Tiessen AH, Smit AJ, Broer J, Gronier KH, van der Meer K. Randomized controlled trial on cardiovascular risk management by practice nurses supported by self-monitoring in primary care. BMC Fam Pract 2012; 13: 90.

[80] Domingues FB, Chassell N, Aliti GB, Dominguez DR, Rabelo ER. Education and Telephone Monitoring by Nurses of Patients with Heart Failure: Randomized Clinical Trial. Arq Bras Cardiol 2011; 96(3): 233-9.

[81] Baker DW, DeWalt DA, Schillinger D, Hawk V, Ruo B, Bibbings-Domingo K, et al. The Effect of Progressive, Reinforcing Telephone Education and Counseling Versus Brief Educational Intervention on Knowledge, Self-Care Behaviors and Heart Failure Symptoms. J Cardio Fail 2011; 17: 789e796.

[82] Wong FYY, Chan FWK, You JHS, Wong ELY, Yeoh EK. Patient self-management and pharmacist-led patient self-management in Hong Kong: A focus group study from different healthcare professionals' perspectives. BMC Health Serv Res 2011; 11: 121.

[83] Smeulders E, van Haastregt J, Ambergen T, Smit AJ, Broer J, Gronier KH, van der Meer K. Ran-...
[117] Oosterom–Calo R, van Balleghoijken AJ, Terwee CB, et al. Determinants of heart failure self-care: a systematic literature review. Heart Fail Rev 2012; 17: 367-85.

[118] Gravely S, Tamim H, Smith J, Daly T, Grace SL. None Symptom-Related Factors Contributing to Delay in Seeking Medical Care by Patients With Heart Failure: A Narrative Review. J Cardiac Fail 2011; 17: 779e787.

[119] Jeon YH, Krauss SG, Jowsey T, Glasgow NJ. The experience of living with chronic heart failure: a narrative review of qualitative studies. BMC Health Serv Res 2010; 10: 77.

[120] Annema C, Luttik ML, Jaarsma T. Reasons for readmission in heart failure: Perspectives of patients, caregivers, cardiologists, and heart failure nurses. Heart Lung 2009; 38: 427-34.

[121] Fonarow GC, Yancy CW, Heywood JT. Adherence to heart failure quality-of-care indicators in US hospitals. Arch Intern Med 2005; 165: 1469-77.

[122] Riegel B, Carlson B. Facilitators and barriers to heart failure self-care. Patient Educ Couns 2002; 46: 287-95.

[123] Artinian NT, Magnan M, Sloan M, Lange P. Self-care behaviors among patients with heart failure. Heart Lung 2002; 31: 161-72.

[124] Rockwell JM, Riegel B. Predictors of self-care in persons with heart failure. Heart Lung 2001; 20: 18-25.

[125] Buck HG, Harkness K, Wion R, et al. Caregivers’ contributions to heart failure self-care: A systematic review. Eur J Cardiovasc Nurs 2015; 14(1): 79-89.

[126] Graven LJ, Grant JS. Social support and self-care behaviors in individuals with heart failure: An integrative review. Int J Nurs Stud 2014; 51(2): 320-33.

[127] Cené CW, Haymore LB, Dolan-Soto D, et al. Self-care confidence mediates the relationship between perceived social support and self-care maintenance in adults with heart failure. J Card Fail 2013; 19(3): 202-10.

[128] Retrum JH, Nowels CT, Bekelman DB. Patient and caregiver congruence: the importance of dyads in heart failure care. J Cardiovasc Nurs 2013; 28(2): 129-36.

[129] Shahriari M, Ahmadi M, Babaei S, Mehrabi T, Sadeghi M. Effects of a family support program on self-care behaviors in patients with congestive heart failure. Iran J Nurs Midwifery Res 2013; 18(2): 152-7.

[130] Heisler M, Halasayani M, Cowen ME, et al. Randomized controlled effectiveness trial of reciprocal peer support in heart failure. Circ Heart Fail 2013; 6(2): 246-53.

[131] Labruneé M, Pathak A, Locsos M, Coudeyre E, Casillas J-M, Gremaux V. Therapeutic education in cardiovascular diseases: State of the art and perspectives. Ann Phys Rehabil Med 2012; 55: 322-41.

[132] Salyer J, Schubert C, Chiaranai C. Supportive Relationships, Self-care Confidence, and Heart Failure Self-care. J Cardiovasc Nurs 2012; 27(5): 384-93.

[133] Agren S, Evangelista LS, Hjelm C, Stromberg A. Dyads Affected by Chronic Heart Failure: A Randomized Study Evaluating Effects of Education and Psychosocial Support to Patients With Heart Failure and Their Partners. J Cardiac Fail 2012; 18: 359e366.

[134] Gallagher R, Luttik ML, Jaarsma T. Social Support and self-care in heart failure. J Cardiovasc Nurs 2011; 26(6): 439-45.

[135] Yehle KS, Sands LP, Rhynders PA, Newton GD. The effect of shared medical visits on knowledge and self-care in patients with heart failure: A pilot study. Heart Lung 2009; 38: 25-33.

[136] Sayers SL, Riegel B, Pawlowski S, Coyne JC, Samaha FF. Social Support and Self-Care of Patients with Heart Failure. Ann Behav Med 2008; 35: 70-9.

[137] Aliti GB, Rabelo ER, Domingues FB, Clausell N. Educational settings in the management of patients with heart failure. Rev Latino-am Enfermagem 2007; 15(2): 344-9.

[138] Baghianimoghadam MH, Shogafard G, Sanati HR, Bahianimoghadam B, Mazloomy SS, Askarshahi M. Application of the Health Belief Model in Promotion of Self-Care in Heart Failure Patients. Acta Medica Iranica 2013; 51(1): 52-8.

[139] Mirzaei M, Aspin C, Esseue B, Jean VH, Usherwood T, Leeder S. A patient-centered approach to health service delivery: improving health outcomes for people with chronic illness. BMC Health Serv Res 2013; 13: 251.

[140] Dickson VV, McCarthy MM, Howe A, Schipper J, Katz SM. Sociocultural influences on heart failure self-care among an ethnic minority black population. J Cardiovasc Nurs 2013; 28(2): 111-8.

[141] Tung HH, Chen SC, Yin WH, Cheng CH, Wang TJ, Wu SF. Self-care behaviour in patients with heart failure in Taiwan. Eur J Cardiovasc Nurs 2012; 11: 175.

[142] Goris J, Komaric N, Guandalini A, Francis D, Hawes E. Effectiveness of multicultural health workers in chronic disease prevention and self-management in culturally and linguistically diverse populations: a systematic literature review. Aust J Prim Health 2013; 19(1): 14-37.

[143] George P, Heng BH, Molina J, Wong LY, Lin NCW, Cheah TS. Self-reported chronic diseases and health status and health service utilization - Results from a community health survey in Singapore. Int J Equity Health 2012; 11: 44.

[144] Henderson S, Kendall E, See L. The effectiveness of culturally appropriate interventions to manage or prevent chronic disease in culturally and linguistically diverse communities: a systematic literature review. Health Soc Care Community 2011; 19(3): 225-49.

[145] Yang J, Toth J, Yoo H. Similarities and differences of self-care behaviors between Korean Americans and Caucasian Americans with heart failure. J Transcult Nurs 2012; 23(3): 246-54.

[146] Percival M, Cottrell WN, Jayasinghe R. Exploring the beliefs of heart failure patients towards their heart failure medicines and self-care activities. Int J Clin Pharm 2012; 34(4): 618-25.

[147] Shojaei F, Ebrahimi SM, Assemi S. Self-care behavior and affecting factors among patients with heart failure in Iran. Saudi Med J 2011; 32(10): 1027-34.

[148] Jeon YH, Esseue B, Jan S, Wells, Whitworth JA. Economic hardship associated with managing chronic illness: a qualitative inquiry. BMC Health Serv Res 2009; 9: 182.

[149] Dungbo F, Hua F, McGowan P, et al. Implementation and quantitative evaluation of chronic disease self-management programme in Shanghai, China: randomized controlled trial. Bull World Health Organ 2003; 81: 174-82.

[150] Curtis LH, Greiner MA, Hammill BG, et al. Early and Long-term Outcomes of Heart Failure in Elderly Persons, 2001-2005. Arch Intern Med 2008; 168(22): 2481-8.

[151] Phibin EF, Dec GW, Jenkins PL, DiSalvo TG. Socioeconomic Status as an Independent Risk Factor for Hospital Readmission for Heart Failure. Am J Cardiol 2001; 87: 1367-71.

[152] Heo S, Moser DK, Lennie TA, Riegel B, Chung ML. Gender differences and in factors related to self-care behaviors: A cross-sectional, correlational study of patients with heart failure. Int J Nurs Stud 2008; 45: 1807-15.

[153] Gonzalez B, Lupon J, Domingo M, et al. Educational level and self-care behaviour in patients with heart failure before and after nurse educational intervention. Eur J Cardiovasc Nurs 2014; 13(5): 459-65.

[154] Hajduk AM, Lemon SC, McManus DD, et al. Cognitive impairment and self-care in heart failure. Clin Epidemiol 2013; 5: 407-16.

[155] Schrepcman JP, Gathright EC, Goldstein CM, et al. Health Literacy and global Health Literacy Influence Heart Failure Self-care Maintenance in Adults. J Card Failure 2012; 18: 1367-71.

[156] Chen AM, Yehle KS, Albert NM, et al. Health Literacy Influences Heart Failure Knowledge Attainment but Not Self-Efficacy for Self-Care or Adherence to Self-Care over Time. Nurs Res Pract. 2013; 2013: 352920.

[157] Chen A, Yehle K, Albert N, et al. Relationships between health literacy and heart failure knowledge, self-efficacy, and self-care adherence. (2014). School of Nursing Faculty Publications. Paper 15.http://dx.doi.org/10.1016/j.sapharm.2013.07.001

[158] Wu JR, Holmes GM, DeWalt DA, et al. Low literacy is associated with increased risk of hospitalization and death among individuals with heart failure. J Gen Intern Med 2013; 28(9): 1174-80.

[159] Evangelista LS, Shinnick MA. What Do We Know About Adherence and Self-Care? J Cardiovasc Nurs 2008; 23(3): 250-7.

[160] Westlake C, Sethares K, Davidson P. How can health literacy influence outcomes in heart failure patients? Mechanisms and interventions. Curr Heart Fail Rep 2013; 10(3): 232-43.

[161] Chen AM, Yehle KS, Albert NM, et al. Health Literacy Influences Heart Failure Knowledge Attainment but Not Self-Efficacy for Self-Care or Adherence to Self-Care over Time. Nurs Res Pract. Nurs Res Pract 2013; 2013: 352909.

[162] Davis KK, Mintzer M, Himmelfarb CR, Hayat M, Rotman S, Allen J. Targeted intervention improves knowledge but not self-care or readmissions in heart failure patients with mild cognitive impairment. Eur J Heart Fail 2012; 14(9): 1041-9.
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[163] Peterson PN, Shetterly SM, Clarke CL, et al. Health Literacy and Outcomes in Patients With Heart Failure. JAMA 2011; 305(16): 1695-701.

[164] Macasbasco-O’Connell A, DeWalt DA, Brouckou KA, et al. Relationship Between Literacy, Knowledge, Self-Care Behaviors, and Heart Failure-Related Quality of Life Among Patients With Heart Failure. J Gen Intern Med 2011; 26(9): 979-96.

[165] Chen AM, Yehle KS, Plake KS, Murawski MW. Health Literacy and Self-care of Patients With Heart Failure. J Cardiovasc Nurs 2011; 26(6): 446-51.

[166] Smeulers E, van Haastregt J, Amberger T, et al. Heart failure patients with a lower educational level and better cognitive status benefit most from a self-management group programme. Patient Educ Couns 2010; 81: 214-21.

[167] Dennison CR, McIntee ML, Samuel L, et al. Adequate Health Literacy Is Associated With Higher Heart Failure Knowledge and Self-care Confidence in Hospitalized Patients. J Cardiovasc Nurs 2011; 26(5): 359-67.

[168] DeWalt DA, Malone RM, Bryant ME, et al. A heart failure self-management program for patients of all literacy levels: A randomized, controlled trial. BMC Health Serv Res 2006; 6: 30.

[169] Dickson VV, Buck H, Riegel B. Multiple comorbid conditions challenge heart failure self-care by decreasing self-efficacy. Nurs Res 2013; 62(1): 2-9.

[170] Cha E, Clark PC, Reilly CM, et al. Educational needs for improving self-care in heart failure patients with diabetes. Diabetes Educ 2012; 38(5): 673-84.

[171] Hwang B, Moser DK, Drapeau K. Knowledge Is Insufficient for Self-Care Among Heart Failure Patients with Psychological Distress. Health Psychol 2014; 33(7): 588-96.

[172] Dickson VV, McCarthy MM, Katz SM. How do depressive symptoms influence self-care among an ethnic minority population with heart failure? Etnh Dis 2013; 23(1): 22-8.

[173] Van Kuiken DM. The Role of Hope in Self-care in Person with Heart Failure. PhD Dissertation University of Cincinnati.

[174] Drapeau K, Moser DK, Pelter ME, et al. Rural Patients’ Knowledge About Heart Failure. J Cardiovasc Nurs 2014; 29(5): 423-8.

[175] Liaw ST, Lau P, Pyett P, et al. Successful chronic disease care for Aboriginal Australians requires cultural competence. Aust NZ J Public Health 2011; 35(3): 238-48.

[176] Ward NJ, Jowsey T, Haora PJ, Aspin C, Yen LE. With good intentions: complexity in unsolicited informal support for Aboriginal and Torres Strait Islander peoples. A qualitative study. BMC Public Health 2011; 11: 686.

[177] Aspin C, Brown N, Jowsey T, Yen L, Leeder S. Strategic approaches to enhanced health service delivery for Aboriginal and Torres Strait Islander people with chronic illness: a qualitative study. BMC Health Serv Res 2012; 12: 143.

[178] Skinner TC, Ellis IK. Tale of two courthouses: A critique of the underlying assumptions in chronic disease self-management for Aboriginal people. AMJ Public Health 2009; 109(2): 233-49.

[179] Nagel T, Thompson C. Motivational care planning - Self management in indigenous mental health. Aust Fam Physician 2008; 37(12): 996-1001.

[180] Caldwell MA, Peters KJ, Drapeau KA. A simplified education program improves knowledge, self-care behaviour, and disease severity in heart failure patients in rural settings. Am Heart J 2005; 150: 983e7-e12.

[181] Mahler P. A review of ‘Traditional’ Aboriginal health beliefs. Aust J Rural Health 1999; 7: 229-36.

[182] Smeulers E, van Haastregt J, van Hoef EFM, van Eijk JTM, Kempen GJM. Evaluation of a self-management programme for congestive heart failure patients: design of a randomised controlled trial. BMC Health Serv Res 2006; 6: 91.

[183] Meng K, Musekamp G, Seekatz B, et al. Evaluation of a self-management patient education program for patients with chronic heart failure undergoing inpatient cardiac rehabilitation: study protocol of a cluster randomized controlled trial. BMC Cardiovasc Disord 2013; 13: 60.

[184] Koehler F, Winkler S, Schieber M, et al. Telemedial Interventional Monitoring in Heart Failure (TIM-HF), a randomized, controlled intervention trial investigating the impact of telemedicine on mortality in ambulatory patients with heart failure: study design. Eur J Heart Fail 2010; 12(12): 1354-62.

[185] Pascual CR, Galan EP, Guerrero JLG, et al. Rationale and methods of the multicenter randomised trial of a heart failure management programme among geriatric patients (HF-Geriatrics). BMC Public Health 2011; 11: 627.

[186] Sherwood A, O’Connor C, Routledge FS, et al. Coping Effectively With Heart Failure (COPE-HF): Design and Rationale of a Telephone-Based Coping Skills Intervention. J Cardiac Fail 2011; 17: 206-210.

[187] Du HY, Newton PJ, Zecchin R, et al. An intervention to promote physical activity and self-management in people with stable chronic heart failure The Home-Heart-Walk study: study protocol for a randomized controlled trial. Trial 2011; 12: 63.

[188] Freund T, Peters-Klimm F, Rochon J, et al. Primary care practice-based care management for chronically ill patients (PrACMaN): study protocol for a cluster randomized controlled trial. Trials 2011; 12: 163.

[189] Peters-Klimm F, Campbell S, Hermann K, Kunz CU, Muller-Tasch T, Szczesny J. Case management for patients with chronic systolic heart failure in primary care: The HICMan exploratory randomised controlled trial. Trials 2010; 11: 56.

[190] Cameron J, Worrall-Carter L, Driscoll A, Stewart S. Measuring Self-care in Chronic Heart Failure - A Review of the Psychometric Properties of Clinical Instruments. J Cardiovasc Nurs 2009; 24(6): E10-22.

[191] Lee CS, Lyons KS, Gelow JM, et al. Validity and reliability of the European Heart Failure Self-care Behavior Scale among adults with heart failure from the United States with symptomatic heart failure. Eur J Cardiovasc Nurs 2013; 12: 214.

[192] Kato N, Kinugawa K, Nakayama E, et al. Development and Psychometric Properties of the Japanese Heart Failure Knowledge Scale. Japanese Heart Failure Knowledge Scale. Int Heart J 2013; 54: 228-33.

[193] Vellone E, Riegel B, Cocchieri A, et al. Psychometric Testing of the Self-Care of Heart Failure Index Version 6.2. Res Nurs Health 2013; 36: 500-11.

[194] Avila CW, Riegel B, Pokorski SC, Caney S, Silveira LC, Rabelo-Silva ER. Cross-Cultural Adaptation and Psychometric Testing of the Brazilian Version of the Self-Care of Heart Failure Index Version 6.2. Nurs Res Pract 2013; 2013: 178976.

[195] Oberich S, Glattacker M, Jaarsma T, Lohrmann C, Dassen T. Validity and reliability of the German version of the 9-item European Heart Failure Self-care Behaviour Scale. Eur J Cardiovasc Nurs 2013; 12: 150.

[196] Rabelo ER, Mantovani VM, Aliti GB, Domingues FB. Cross-cultural adaptation and validation of a disease knowledge and self-care questionnaire for a Brazilian sample of heart failure patients. Rev. Latino-Am. Enfermagem 2011; 19(2): 277-84.

[197] Hattori Y, Taru C, Miyawaki I. Development of an Evaluation Scale for Self-Monitoring by Patients with Heart Failure. Kobe J Med Sci 2011; 57(2): E63-74.

[198] Riegel B, Lee SC, Dickson VV, Carlson B. An update on the self-care of heart failure index. J Cardiovasc Nurs 2009; 24(6): 485-97.

[199] Jaarsma T, Stromberg J, Martensson J, Drapeau K. Development and testing of the European Heart Failure Self-care Behaviour Scale. Eur J HF 2003; 5: 363-70.

[200] Riegel B, Carlson B, Glaser D. Developing and testing of a clinical tool measuring self-management of heart failure. Heart Lung 2000; 29: 4-12.

[201] Eton DT, Eliahy TA, Montori VM. A systematic review of patient-reported measures of burden of treatment in three chronic diseases. Patient Relat Outcome Meas 2013; 4: 7-20.

[202] http://www.improvingchroniccare.org/index.php?p=ACIC_Survey &s=35

[203] http://www.improvingchroniccare.org/index.php?p=PACIC_survey &s=36

[204] http://www.rand.org/health_surveys_tools/psq.html

[205] http://www.sf-36.org/

[206] http://www.euroqol.org/

[207] http://www.rehabmeasures.org/Lists/RehabMeasures/PrintView.aspx?ID=1037

[208] https://hoap.ucsd.edu/qwb-info/

[209] http://www.scireproject.com/outcome-measures/quality-of-well-being

[210] van der Wal MH, Jaarsma T, van Veldhuisen DJ. Non-compliance in patients with heart failure; how can we manage it? Eur J Heart Fail 2005; 7(1): 5-17.

[211] Leykum LK, Parchment M, Pugh J, Lawrence V, Noel PH, McDaniel RR Jr. The importance of organizational characteristics for im-
proving outcomes in patients with chronic disease: a systematic review of congestive heart failure. Implement Sci 2010; 5: 66.

[212] Bodenheimer T, Chen E, Bennett HD. Confronting the growing burden of chronic disease: Can the US health care workforce do the job? The answer is ‘no’ – not as currently constituted. Health Affairs 2009; 28(1): 64-74.

[213] Konstam M, Varda Konstam V. Heart Failure Disease Management. A Sustainable Energy Source for the Health Care Engine. JACC 2010; 56(5): 379-81.

[214] Konstam MA, Greenberg B. Transforming Health Care Through the Medical Home: The Example of Heart Failure. J Cardiac Fail 2009; 15: 736e738.

[215] Alspach JG. The Patient's Capacity for Self-Care: Advocating for a Predischarge Assessment. Crit Care Nurse 2011; 31: 10-3.

[216] Manning S. Bridging the Gap Between Hospital and Home A New Model of Care for Reducing Readmission Rates in Chronic Heart Failure. J Cardiovasc Nurs 2011; 26(5): 368-76.

[217] Vellone E, Riegel B, Cocchieri A, et al. Validity and reliability of caregiver contribution to self-care of HF. J Cardiovasc Nurs 2013; 28(3): 245-55.

[218] Mahramus TL, Penoyer DA, Sole ML, Wilson D, Chamberlain L, Warrington W. Clinical Nurse Specialist Assessment of Nurses’ Knowledge of Heart Failure. Clin Nurse Spec 2013; 27(4): 198-204.

[219] Delaney C, Apostolidis B, Lachapelle L, Fortinsky R. Home care nurses’ knowledge of evidence-based education topics for management of heart failure. Heart Lung 2011; 40(4): 285-92.

[220] Chronic Care: Self-Management Guideline Team, Cincinnati Children's Hospital Medical Center: Evidence-based care guideline for Chronic Care: Self-Management. Guideline 30, pages 1-32, March 9, 2007. www.cincinnatichildrens.org/svc/alpha/h/health-policy/evbased/chronic