



## 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.



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### 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

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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 CDSMPs 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
<p><b>EDUCATION</b></p>	<p><b>PURPOSE</b></p> <ul style="list-style-type: none"> <li>• Increase knowledge</li> <li>• Increase Skills</li> <li>• Increase Motivation</li> <li>• Increase Confidence</li> <li>• Increase Compliance</li> </ul> <p><b>DETERMINANT OF SUCCESS</b></p> <ul style="list-style-type: none"> <li>• Content</li> <li>• Theoretical Framework</li> <li>• Standardization of Curriculum</li> <li>• Intensity</li> <li>• Delivery Setting &amp; Method</li> <li>• Funding Model, remuneration &amp; sustainability</li> </ul>	<p><b>REQUIREMENT</b></p> <ul style="list-style-type: none"> <li>• Active Client Participation</li> </ul> <p><b>DETERMINANT OF SUCCESS</b></p> <ul style="list-style-type: none"> <li>• Education level</li> <li>• Cultural Appropriateness</li> <li>• Intensity</li> <li>• Realistic selection of individual goal and capability</li> <li>• Correct Delivery Method</li> <li>• Age, anxiety, cognition, comorbidity, depression, health literacy, sleep disturbances, underlying support</li> </ul>	<ol style="list-style-type: none"> <li>1. <b>Information giving model</b></li> <li>2. <b>Social Learning Theory</b></li> </ol> <p><b>KEY POINTS</b></p> <ul style="list-style-type: none"> <li>• 3 Core self-management tasks:                     <ul style="list-style-type: none"> <li>- Medical management</li> <li>- Role management</li> <li>- Emotional management</li> </ul> </li> <li>• Providing knowledge to gain self-care skills insufficient on its own to achieve and promote lasting behavioral change</li> <li>• Standardized curriculum not available</li> <li>• Content, process and format of CDSMP</li> </ul>
<p><b>CONTENT &amp; SKILLS</b></p>	<p><b>SKILLS</b></p> <ul style="list-style-type: none"> <li>• Training</li> <li>• Re-training intervals</li> <li>• Basic Minimum Standards</li> <li>• Generic or Disease Specific</li> </ul> <p><b>CHF Skills Goals</b></p> <ul style="list-style-type: none"> <li>• Vital signs (G,M)</li> <li>• Weight and weight change action plan (G)</li> <li>• Medication (G,M,P)</li> <li>• Diuretic titration (G)</li> <li>• Warning signs and symptoms of worsening CHF (G,M)</li> <li>• When to call provider (G,M,P)</li> <li>• Diet (G,M,P)</li> <li>• Activity/exercise/Fitness (G,M)</li> <li>• ADL &amp; personal hygiene (G,M)</li> <li>• Stress management &amp; Psychosocial Consequence (G)</li> <li>• Support systems (G,M,P)</li> <li>• Smoking cessation (G,M)</li> <li>• Alcohol consumption (G,M)</li> <li>• Lifestyle Changes (G,M)</li> <li>• Disease specific self-activities (G)</li> </ul> <p><b>Self-care Goals (minimum):</b></p> <ul style="list-style-type: none"> <li>• Assessment skills</li> <li>• Motivational interviewing</li> <li>• Information sharing</li> <li>• Problem solving/goal setting</li> <li>• Shared decision making</li> <li>• Self-efficacy assessment</li> <li>• Follow-up interventions</li> </ul>	<p><b>SKILLS</b></p> <ul style="list-style-type: none"> <li>• Problem solving</li> <li>• Decision making</li> <li>• Resource utilization</li> <li>• Form patient provider partnership</li> <li>• Action planning with Self-tailoring</li> </ul> <p><b>GOALS</b></p> <ul style="list-style-type: none"> <li>• Monitoring (G,M)</li> <li>• Monitoring with action (G)</li> <li>• Exercise (G,M)</li> <li>• RF Modification and preventive behaviors (G)</li> <li>• Engaging health system (G,M)</li> <li>• Compliance (G,M,P)</li> <li>• Diet adherence (G,M,P)</li> </ul> <p><b>SYNONYMS</b></p> <ul style="list-style-type: none"> <li>• Acquire, Learn,</li> <li>• Action, action planning, manage, master, perform,</li> <li>• Monitor, observe</li> <li>• Adjust, titrate</li> <li>• Adhere, comply</li> <li>• Engage</li> </ul> <p><b>DETERMINANT OF SUCCESS</b></p> <ul style="list-style-type: none"> <li>• As above</li> </ul>	<ol style="list-style-type: none"> <li>1. <b>Orem’s Theory</b></li> <li>2. <b>Naturalistic Decision Making Framework</b></li> <li>3. <b>Social Learning Theory (Self Efficacy Theory)</b></li> <li>4. <b>CBT and Principles</b></li> <li>5. <b>Chronic Care Model</b></li> <li>6. <b>Transitional Care Model</b></li> </ol> <p><b>GOALS &amp; STRATEGIES</b></p> <ul style="list-style-type: none"> <li>• Performance Mastery - Cognitive behavioral principles e.g. repetition, persuasion; Problem solving e.g. Role-modeling, mastery experience,</li> <li>• Modeling – teaching material reflect local culture; peer teaching;</li> <li>• Symptom interpretation –reinterpretation of physiology</li> <li>• Social persuasion - Providing mutual support e.g. social groups, engaging family</li> </ul> <p><b>KEY POINTS</b></p> <ul style="list-style-type: none"> <li>• Using and retaining acquired knowledge is key goal of CDSMP</li> <li>• Programs that understand the importance of this learning dynamic more likely to succeed</li> <li>• In simplistic terms clients need to learn, observe, perform, engage</li> </ul>

(Table 1) Contd....

GOALS	Health System	Patient	Psychological Theories & Core Principals
<b>INTENSITY &amp; DURATION</b>	<ul style="list-style-type: none"> <li>Run in periods</li> <li>Frequency (Fatigue factors, signal to noise ratio)</li> <li>Duration</li> <li>Feasibility &amp; Sustainability</li> <li>Self-management support</li> </ul>	<ul style="list-style-type: none"> <li>Individual Ability</li> <li>Motivation</li> <li>Fatigue</li> <li>Geographic &amp; Logistic</li> </ul>	<p><b>CBT</b></p> <ul style="list-style-type: none"> <li>Regular follow-up required for self-care efficacy and retention</li> <li>Excess can lead to fatigue</li> </ul>
<b>ASSESSMENT</b>	<ul style="list-style-type: none"> <li>Accuracy - signal to noise ratio</li> <li>Effectiveness</li> <li>Feasibility</li> <li>Cost</li> <li>Setting</li> <li>Safety</li> </ul> <p>(e.g. Measures of Disease Control; Health outcomes measure; patient satisfaction measures; utilization and productivity measures; cost; patient Behavior; patient self-efficacy; patient knowledge)</p>	<ul style="list-style-type: none"> <li>Timing of contact</li> <li>Fatigue</li> <li>Achieving agreed goals (self-efficacy; knowledge; behavior)</li> <li>Compliance</li> <li>Safety</li> </ul> <p><b>DETERMINANT OF SUCCESS</b></p> <ul style="list-style-type: none"> <li>Self-care maintenance</li> <li>Self-care management</li> <li>Self-care confidence</li> </ul>	<ol style="list-style-type: none"> <li><b>Social cognition models</b></li> <li><b>Health belief model</b></li> <li><b>Locus of control</b></li> </ol> <p><b>KEY POINTS</b></p> <ul style="list-style-type: none"> <li>Self-Care Measurement Tools</li> <li>Stepping stones to Quality</li> </ul> <p><b>GOALS</b></p> <ul style="list-style-type: none"> <li>Change behavior</li> <li>Change health status</li> <li>Change health care utilization</li> </ul>
<b>PEOPLE</b>	<ul style="list-style-type: none"> <li>Health Care Providers (Doctor)</li> <li>Nurse</li> <li>AHW; OT; PT; SW</li> <li>Pharmacist</li> </ul>	<ul style="list-style-type: none"> <li>Client</li> <li>Family Supports</li> <li>Social Network</li> <li>Carers</li> </ul>	<p><b>CBT</b></p> <ul style="list-style-type: none"> <li>Deliver &amp; retain self-care capacity</li> <li>Social support critical to encourage &amp; maintain behavior</li> </ul> <p><b>KEY POINTS</b></p> <ul style="list-style-type: none"> <li>With advent of technology personnel and site of delivery less an issue</li> </ul>
<b>DELIVERY METHODS, MONITORING TOOLS &amp; INFORMATION SHARING</b>	<p><b>Education</b></p> <ul style="list-style-type: none"> <li>Reading materials (leaflets, information sheets)</li> <li>Group Classes &amp; Courses</li> <li>Rehab Program</li> </ul> <p><b>Communication</b></p> <ul style="list-style-type: none"> <li>Face-to-Face (verbal)</li> <li>Group</li> <li>Phone</li> <li>Web portal &amp; health apps</li> <li>Video Conferencing</li> </ul> <p><b>Monitoring &amp; Treating</b></p> <ul style="list-style-type: none"> <li>Clinician guidance</li> <li>External or internal monitoring devices</li> <li>Web or mobile platforms</li> <li>Algorithm based feedback</li> <li>Automated telephone DMP</li> </ul>	<p><b>Variable depends on:</b></p> <ul style="list-style-type: none"> <li>Education levels</li> <li>Availability</li> <li>Preference</li> <li>Motivation</li> <li>Support</li> <li>Miscellaneous: unconventional approaches targeting pill size, burden, compliance, other factors making compliance harder</li> </ul>	<p><b>CBT</b></p> <ul style="list-style-type: none"> <li>Group support via face to face or with virtual online communities can address confidence, support,</li> <li>Reminders</li> <li>Health literacy training</li> <li>Individual care plans</li> </ul> <p><b>KEY POINTS</b></p> <ul style="list-style-type: none"> <li>System of care – cost, feasibility, effectiveness, protocols, etc</li> <li>Goal targeted - skill development, behavioral change, family support, etc</li> <li>Staffing; content; pt population served; information support; protocols; staff training;</li> </ul> <p><b>MODELS</b></p> <ul style="list-style-type: none"> <li>Primary Care (Internal)</li> <li>On the Ground (External)                         <ul style="list-style-type: none"> <li>Telephone Call center</li> <li>Remote model</li> </ul> </li> <li>Hospital Specialist</li> <li>AHW</li> </ul>

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 [EHFScBS] 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. Shuldham *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

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

Study Details	References	Population	Outcomes	Notes
MA	[33, 35, 41, 37, 39, 109]	<ul style="list-style-type: none"> <li>• Homogenous population</li> <li>• Most have comorbidity</li> </ul>	<ul style="list-style-type: none"> <li>• Reduce hospitalization</li> </ul>	<ul style="list-style-type: none"> <li>• Significantly decreased hospitalization for telephone, home visit, specialists clinic follow-up, but not for primary care supervised (2 studies only)</li> <li>• Significant heterogeneity in results unable to comment on other parameters</li> <li>• Multiple chronic conditions increase vulnerability to poor self-care.</li> <li>• Adherence to diet, symptom monitoring, and differentiating symptoms from multiple conditions were the most challenging self-care skills.</li> </ul>
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]	<ul style="list-style-type: none"> <li>• Homogenous population</li> <li>• Most have comorbidity</li> </ul>	<ul style="list-style-type: none"> <li>• Reduce hospitalizations</li> <li>• NS reduction in mortality</li> </ul>	<ul style="list-style-type: none"> <li>• Methodological shortfalls in many studies impairing validation</li> <li>• 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</li> <li>• 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.</li> <li>• Telehealth could improve self-care, small sample sizes</li> <li>• Carer support could be developed further</li> <li>• Further research needed on the barriers and facilitators of self-care in HF, to provide an appropriate guide to any intervention strategy.</li> <li>• Address specific client issue to improve self-care</li> </ul>
Ont Health Technol Assess Ser (SR, MA)	[48]	10 RCT (n = 6074)	<ul style="list-style-type: none"> <li>• Significant/small ↑ some health status outcomes</li> <li>• Significant/small ↑ some healthy behavior outcomes:</li> <li>• Significant/small ↑ self-efficacy:</li> <li>• NS health care utilization outcomes</li> </ul>	<ul style="list-style-type: none"> <li>• Data reporting poor. No intention to treat principles</li> <li>• Stanford models had small short term gains</li> <li>• Greater research needed to identify responders and non-responders, effect on clinical outcomes and across a wider demographic.</li> </ul>
Guideline	[3, 18, 20, 23, 47, 220]	Consensus & other Statements on CDSMP	NA	<ul style="list-style-type: none"> <li>• Outlines principles of self-care to integrate with HF CDMP</li> </ul>

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.

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 or36, 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).

## 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. Post-marketing 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
<b>ACIC</b>	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.	<ul style="list-style-type: none"> <li>➤ Community resources</li> <li>➤ Health organization</li> <li>➤ Self-management support</li> <li>➤ Delivery system design</li> <li>➤ Decision support</li> <li>➤ Clinical information systems</li> </ul>
<b>PACIC</b>	Patient Satisfaction	20 or 26 item patient report instrument to rate chronic illness care over a 6 month period. Cover 5 dimensions of care	<ul style="list-style-type: none"> <li>➤ Patient activation</li> <li>➤ Delivery system design</li> <li>➤ Goal setting</li> <li>➤ Problem solving</li> <li>➤ Follow-up/coordination</li> </ul>
<b>PSQ-18</b>	Patient satisfaction	Short form of PSQ-III using Likert scale questionnaire evaluating 18 items from 7 dimensions of patient satisfaction directed toward doctors	<ul style="list-style-type: none"> <li>➤ General satisfaction</li> <li>➤ Technical quality</li> <li>➤ Interpersonal manner</li> <li>➤ Communication</li> <li>➤ Financial aspects</li> <li>➤ Time spent with doctor</li> <li>➤ Accessibility and convenience</li> </ul>
<b>CAHPS</b>	Patient satisfaction	Survey for consumers and patients to report on and evaluate their experiences with health care from 12 dimensions	<ul style="list-style-type: none"> <li>➤ Getting Timely Care</li> <li>➤ Provider Communication</li> <li>➤ Rating of Provider</li> <li>➤ Access to Specialists</li> <li>➤ Health Promotion and Education</li> <li>➤ Shared Decision-making</li> <li>➤ Health Status/Functional Status</li> <li>➤ Courteous/Helpful Office Staff</li> <li>➤ Care Coordination</li> <li>➤ Between Visit Communication</li> <li>➤ Education About Medication Adherence</li> <li>➤ Stewardship of Patient Resources</li> </ul>
<b>SF-36v2</b>	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.	<ul style="list-style-type: none"> <li>➤ Physical functioning</li> <li>➤ Physical role functioning</li> <li>➤ Bodily pain</li> <li>➤ General health perceptions</li> <li>➤ Vitality</li> <li>➤ Emotional role functioning</li> <li>➤ Social role functioning</li> <li>➤ Mental health</li> </ul>
<b>EQ-5D</b>	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).	<ul style="list-style-type: none"> <li>➤ Mobility</li> <li>➤ Self-Care</li> <li>➤ Usual Activities</li> <li>➤ Pain/Discomfort</li> <li>➤ Anxiety/Depression</li> </ul>
<b>QWB-SA</b>	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.	<ul style="list-style-type: none"> <li>➤ Acute and Chronic Symptoms</li> <li>➤ Self-Care</li> <li>➤ Mobility</li> <li>➤ Physical Activity</li> <li>➤ Usual activity</li> </ul>



(Table 3) Contd....

Tool	Type of Measure	Summary of Instrument/Tool	Dimensions
<b>HUI</b>	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.	<ul style="list-style-type: none"> <li>➤ 8 attributes vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain – each with 5 or 6 levels of ability/ disability.</li> </ul>
<b>KCCQ</b>	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.	<ul style="list-style-type: none"> <li>➤ Physical limitations,</li> <li>➤ Symptoms stability , frequency, severity, change over time</li> <li>➤ Self-efficacy and knowledge</li> <li>➤ Social interference/limitation</li> <li>➤ Quality of Life:</li> </ul>
<b>MLHFQ</b>	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 individuals 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.	
<b>NYHA</b>	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
<b>CFPI</b>	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.	<ul style="list-style-type: none"> <li>➤ PIH</li> <li>➤ Cue &amp; Response</li> <li>➤ P &amp; G</li> </ul>
<b>EHFScBS</b>	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: <ul style="list-style-type: none"> <li>• Swedish (161)</li> <li>• The Netherlands (1243)</li> <li>• United Kingdom (177)</li> <li>• Italian (173)</li> <li>• German (285)</li> <li>• Spanish (553)</li> </ul>
<b>SCHFI</b>	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: <ul style="list-style-type: none"> <li>• United States (453)</li> <li>• Australian (1095)</li> <li>• Thai (400)</li> <li>• Mexican (134)</li> </ul>

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 Life-saving 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 Battersby 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.

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