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**Heart failure patients' experiences of non-pharmacological self-care: A narrative
literature review.**

ABSTRACT

Background: Heart failure self-care is important yet often sub-optimal. This literature review identifies and analyses the literature on heart failure patients' experiences of non-pharmacological self-care.

Methods: The literature was searched on April 14th 2015 using EBSCO Host. The 'World Health Organisations' Dimensions of Adherence' (World Health Organisation, 2003) framework was used for data analysis.

Results: The identified literature (14 primary articles and four literature reviews) was heavily weighted towards patient-related factors, namely acceptance of diagnosis, bio-behavioural variables and decision-making characteristics. Poor symptom recognition/management and the presence of co-morbidities (specifically depression) were common condition-related factors highlighted as barriers to self-care. Lifestyle factors (therapy-related dimension) and professional support (health system/team dimension) were briefly described.

Conclusions: This narrative literature review highlighted that heart failure self-care regimes are complex and often challenging to maintain. Further qualitative research regarding the therapy-related and health system-related factors would shed light on individual variations of and barriers to self-care.

Keywords

Heart failure; self-care; patient adherence; patient compliance; health behaviour

INTRODUCTION

Heart failure is an internationally prevalent progressive and debilitating chronic syndrome. Patients, their carers and health care professionals alike are exposed to the negative, turbulent trajectory that is the patient journey in chronic heart failure, for example, the debilitating symptoms of breathlessness and oedema. Heart failure is, and will continue to be, a highly prevalent disease and a major burden to the healthcare system due to the increasing age of the population, prolonged survival of persons with heart failure and the high incidence of obesity and hypertension, among other factors (Heart Foundation of Australia, 2011).

Chronic illness management has become a major health focus in our ageing population (World Health Organisation, 2003). While heart failure often shows an adverse trajectory towards morbidity and mortality, self-care in heart failure is an important practice to improve patients' symptoms and quality of life. There is a strong association between heart failure self-care practices and health outcomes (Driscoll et al., 2009). Self-care (or self-management) involves the individual monitoring their own health (Heart Foundation of Australia, 2011). This fosters a greater sense of control and confidence with their health for the provision of appropriate health behaviour changes (The BACPR Standards and Core Components (2nd Edition) Primary Writing Group, 2012) with the aim include limit worsening of symptoms by daily symptom monitoring and addressing deterioration effectively (Heart Foundation of Australia, 2011). The National Institute for Health and Care Excellence (NICE, 2010) recommendation 1.3.1.1 states that patients with heart failure should have access to a heart failure specific rehabilitation program including exercise, psychological and educational component supporting ongoing self-care.

Nevertheless, the World Health Organization (WHO 2003) suggests adherence to long-term therapies, such as those in heart failure, is only approximately 50% in developed countries. Adherence is ‘the extent to which a person’s behaviour – taking medication, following a diet and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider’ (p. 3, World Health Organisation, 2003). Guidelines for the self-management of heart failure include sodium (salt) and fluid restriction, daily weighing, symptom monitoring, lifestyle adjustment and following a complex pharmacological regime in addition to periodic physician appointments, ever changing treatment plans and management of co-morbid conditions often prevalent in this population (van der Wal et al., 2006, National Heart Foundation of Australia, 2008, Heart Foundation of Australia, 2011, Conraads et al., 2012). The challenging practice of self-care is a multi-dimensional system of many intersecting factors (World Health Organisation, 2003), which when conducted ineffectively, often falls to a suboptimal level to maintain adequate quality of life and avoidance of unnecessary hospitalizations (National Heart Foundation of Australia, 2008, Sethares et al., 2014, National Heart Foundation of Australia, 2013).

AIM

The aim of this narrative literature review was to identify, critically appraise and analyse the literature on heart failure patients’ experiences of non-pharmacological self-care. The primary goal is to better understand heart failure patients’ experience of self-care, and the secondary goal is to determine barriers to adhering to self-care practices.

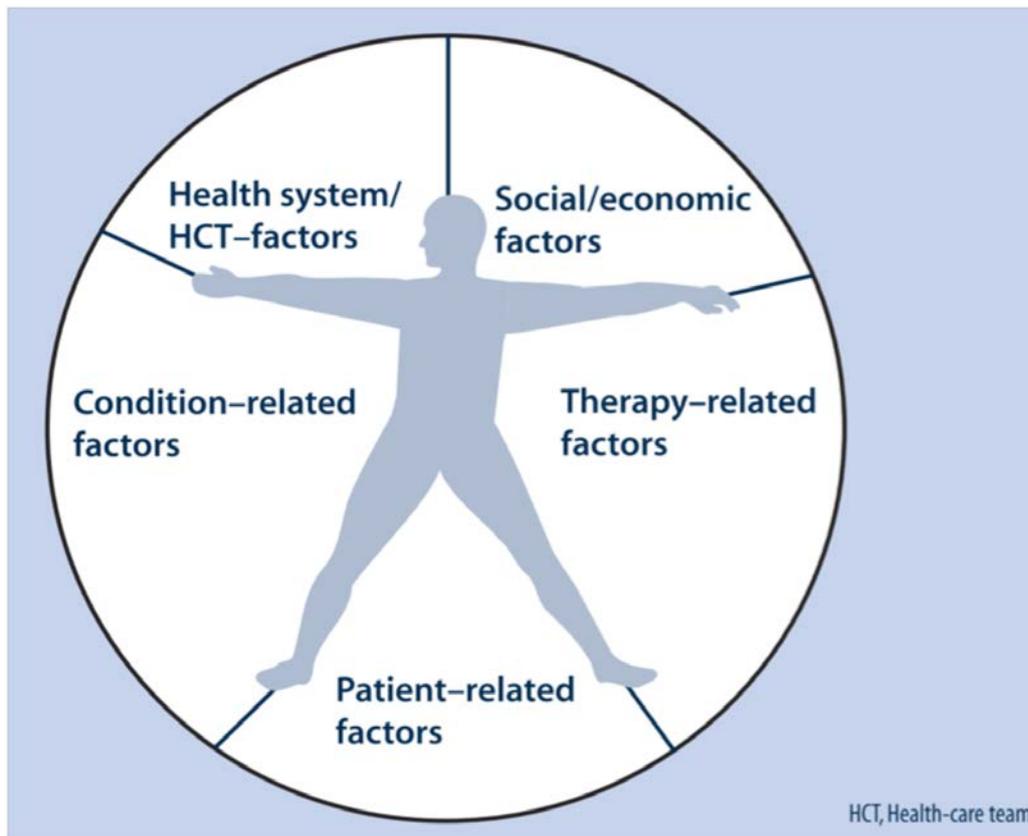
METHODS

The literature search was conducted on April 14th 2015 using the publisher EBSCO Host. Five databases were used; CINAHL Plus with Full Text, Medline Complete, Psychology and Behavioural Sciences Collection, PsycARTICLES and Biomedical Reference Collection: Comprehensive. Three search terms were used; (heart OR cardiac failure) AND (self care OR manag*) AND (experience). Major subjects headings were (heart failure) AND (self care) yielding 311 articles. English language articles with the major subject headings of ‘heart failure’ and ‘self care’ within the years 2000-2015 were included yielding 89 articles. Inclusion criteria were patient-focused, non-pharmacological, primary or review studies published in English from OECD countries. It was necessary that all included articles represented the patient’s perspective on their experience to as to describe the problem through eyes of the healthcare consumer. To provide context to the care received by patients with heart failure the ‘grey literature’ was also explored, namely guidelines, reports and updates from additional literature in the form of PDF documents downloaded from the World Wide Web (National Heart Foundation of Australia, 2008, Heart Foundation of Australia, 2011, National Heart Foundation of Australia, 2013, World Health Organisation, 2003, Australian Institute of Health and Welfare, 2015, The BACPR Standards and Core Components (2nd Edition) Primary Writing Group, 2012, National Institute for Health and Clinical Excellence, 2010)

Multiple, inter-playing factors affect heart failure patients’ experience of self-care. Therefore, the ‘WHO Dimensions of Adherence’ framework was used to analyse the data in this literature review. This model, developed in 2003, provides a focus on issues around self-care practices in chronic diseases under the dimensions of patient-related, condition-related, therapy-related,

health system/team-related and socio-economic related factors (World Health Organisation, 2003). See **figure 1**.

Figure 1 World Health Organisation Five Dimensions of Adherence



In this narrative review, the literature was examined by the researcher through the lens of these dimensions. Therefore all the studies which met the inclusion criteria were considered relevant for inclusion and are presented using the format of the World Health Organisation dimensions of adherence.

RESULTS

Eighty-nine articles were exported to Endnote X7.1 and duplicates were removed resulting in 62 articles for further analysis by title and abstract alone. Studies were omitted if they did not meet the inclusion criteria, yielding a final number of 14 primary articles and four literature or

systematic reviews. Of the 14 primary studies published between years 2005 to 2014, quantitative studies made up the largest group in terms of methodology (n=6). Qualitative studies make up five of 14 studies, and mixed method studies were chosen by three of the research teams.

The six quantitative studies included outcome-specific questionnaires. In the nature of investigating the patient experiences of heart failure self-care the questionnaires gathered self-reported data. The largest study included 689 participants (Riegel et al., 2011). The sample was collected from the inpatient, clinic and home setting from three health care facility locations across the United States (Riegel et al., 2011). The second largest study (n=501) comes from the only European research on the topic where participants completed a variety of questionnaires around compliance, beliefs, knowledge and self-care behaviour (van der Wal et al., 2006). Most qualitative studies contained demographic and clinical data providing context for research findings. The most common form of quantitative data analysis was use of the SPSS software (n=5).

Three mixed methods studies were identified. Each included B. Riegel as an author and two included VV. Dickson as an author, displaying the concordance of researchers in this field. Mixed method sample sizes were 27 participants (Riegel et al., 2010), 41 participants (Dickson et al., 2008) and 77 participants (Jurgens et al., 2009). The results of the mixed method studies were analysed for commonality of themes related to the WHO dimensions and are described using a subjective, descriptive process.

North American studies dominated the research landscape within this literature search (n=8). United Kingdom (Thornhill, 2008), Netherlands (van der Wal et al., 2006) and Japan (Kato et al., 2009) were represented by one study each, while two Australian studies were identified (Cameron et al., 2010, Riegel et al., 2010). Additionally, a combined Australia-USA study sample was evidenced in the study by Riegel et al. (2013).

Recent literature supports the consensus that multiple, interacting factors affect self-care (Wingham et al., 2014). We analysed the data using the World Health Organisation's Five Dimensions of Adherence (World Health Organisation, 2003), explicated commonalities in the studies and summarised the findings. See table 1. Improvement in the understanding of the patients' experiences around heart failure self-care can be seen through five inter-related factors; social/economical factors, therapy-related factors, patient-related factors, condition-related factors, and health system/team factors.

Patient-related factors are heavily reported and descriptively explained in this patient experience investigation of heart failure self-care. All 14 primary studies plus the literature reviews with various methodologies and across geographic locations included a detailed examination of the multiple patient-related factors. Diagnosis acceptance, bio-behavioural variables, decision-making characteristics and action taking are major factors. Fourteen of 18 studies displayed the importance of social factors in self-care with all three mixed methods studies emphasising the major significance of social support (Dickson et al., 2008, Jurgens et al., 2009, Riegel et al., 2010). Condition-related factors were explained in 14 of 18 papers, as equally reported as socio-economic factors and second to patient-related factors. Symptom recognition/management is the primary condition-related theme. The presence of co-

morbidities was a variable that was measured (Meyerson and Kline, 2009, Riegel et al., 2010, Riegel et al., 2011), with depression a common barrier to self-care in four of the 14 studies (van der Wal et al., 2006, Kato et al., 2009, Cameron et al., 2010, Piamjariyakul et al., 2012). Within the therapy-related dimension participants reported the impact of lifestyle factors (n= 5) yet the studies failed to provide details of the patient experience of maintaining specific treatments. Whilst highlighted in 13 papers health system/team support was not well described in the results findings.

DISCUSSION

Each WHO Dimension includes factors impacting on the experience of self-care. It is worth noting that the relative division of data in each section may be misleading as per the World Health Organisation (2003). Adherence should not be viewed like it traditionally was, that is, as a ‘patient problem’ (World Health Organisation, 2003). As more evidence from the literature is available in the patient-related domain, this does not necessarily mean more emphasis should be placed on this dimension, but simply more clearly defines one section within the broad picture of adherence. An understanding of each and every category supports a greater understanding of the patient experience holistically.

Dimension one: social/economic factors

Socio-economic factors influence the experience of self-care in heart failure patients. These ‘competing factors’ include culture, employment, education and family demands (World Health Organisation, 2003). Social relationships and increased age were the main categories from the literature.

Dominating the literature in this dimension, social relationships have significant impact on adjustment to adequate self-care behaviours (Thornhill, 2008). Participants in the recent study by Piamjariyakul et al. (2012) consistently agreed that caregiver involvement was essential. For example, one participant said ‘family is motivation’ (Piamjariyakul et al., 2012). It was found that family actually gave a wide range of self-management and support to the patient (Piamjariyakul et al., 2012), and contribute to the care seeking decisions in 25% of cases (Jurgens et al., 2009).

Increased age is a socio-economic factor affecting self-care. Specific to the inclusion criteria, only adults with heart failure were studied, however three studies specifically investigated aged participants (Cameron et al., 2010, Riegel et al., 2010, Jurgens et al., 2009). Whilst sub-optimal self-care affects all age groups, older patients are particularly likely to show self-care deficits (World Health Organisation, 2003). The impact on health care treatment is therefore affected. The older patient’s illness experience may be classified as ‘geriatric’ in the health care setting and as a result such patients may have restricted access to specialised cardiac treatment (Falk et al., 2013). Exploration of the older patient’s experience in heart failure was examined through an integrative literature review (Falk et al., 2013). Symptoms, illness experience and self-care management were three key components of the review of 23 qualitative and quantitative papers between the years 2001-2011, for persons aged ≥ 75 . Poor self-care management and symptom monitoring was discovered within this patient group, caused by a multitude of factors, namely, their ‘illness understanding’ (Falk et al., 2013). Degenerative cognitive impairment and functional decline are two reasons offered by the World Health Organisation (2003) to adversely affect self-care. These two factors classified as cognition in this literature review and may be additionally considered a patient-related factor showing the overlap of dimensions and associated complexity of self-care practices in older patients.

Socio-demographic particulars play a significant role within this domain (World Health Organisation, 2003). For example, financial concerns was represented as the seventh major theme in the Northern American study reporting that heart failure management is 'very expensive', a burden on the family and a barrier to self-care in some of this patient group (Piamjariyakul et al., 2012). Interestingly, employment was an independent determinant of poorer self-care in the Japanese study (Kato et al., 2009). Structure and funding of health systems for individual countries no doubt affect the financial impact of treatment costs and loss of income often associated with living with heart failure.

Dimension two: therapy-related factors

There is limited investigation of therapy-specific issues from the patient's perspective yet the treatments and guidelines for the non-pharmacological management of heart failure are many and varied in the grey literature. Fluid restriction, daily weighing, symptom monitoring, lifestyle adjustment, periodic physician appointments, managing frequently changing treatment plans, coping with unwanted side effects and management of co-morbid conditions are examples (Heart Foundation of Australia, 2011, National Heart Foundation of Australia, 2008, World Health Organisation, 2003). These specifics however, were not defined in the literature. Only one single therapy-related theme identified was that of 'lifestyle changes' which related to four of 18 articles. Twenty-one of 25 participants in the Thornhill (2008) study felt restricted in many aspects of their life. Yet, adjusting to the changing lifestyle of diet, exercise and daily weighing empowered their management in the home (Piamjariyakul et al., 2012). One participant reported he does 'use song and dance for exercise' (Piamjariyakul et al., 2012), highlighting adaptation to their therapy.

Lifestyle changes may be considered both a therapy-related factor and condition-related factor referring to whether it was directly related to the illness or the associated treatments required to manage the illness. Nevertheless, further investigation of this domain is recommended.

Dimension three: patient-related factors

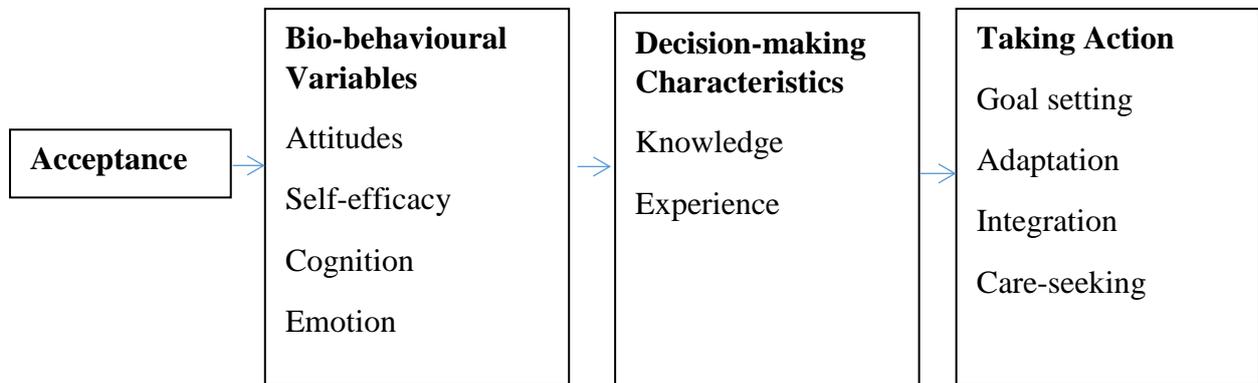
The most heavily identified dimension in heart failure self-care is the patient-related factors. The World Health Organisation (2003) contends that patient-related factors are primarily concerned with the value the individual places on the treatment regime. However, the literature highlights the complexities.

First and foremost was patient acceptance of the heart failure diagnosis. This metaphorical 'gateway' to self-care practices is explicated by Scotto (2005), Thornhill (2008), Piamjariyakul et al. (2012). In the 18-paper integrative review by Welstand et al. (2009) the first of five conceptual dimensions which emerged was the diagnosis (Welstand et al., 2009). With the emphasis on this 'concept of self' throughout the review, the conclusion highlights the necessity of patients taking on a 'new self' in this acceptance process (Welstand et al., 2009).

Further to acceptance, patient-related factors are represented by ten main categories in the literature. The Decision-making Model of Heart Failure Self-care Management Dickson 2007 cited in Dickson et al. (2008) is a condition-specific adaptation of the naturalistic decision-making theory which provides an understanding of some of these patient-related factors. Firstly, bio-behavioural variables affect self-care decisions and are identified by the categories; attitudes, self-efficacy and cognition (Dickson et al., 2008). Emotion may also be categorised as a bio-behavioural variable. Following these, decision-making characteristics (knowledge

and experience) impact on the final step of taking action (goal setting, adaptation, integration and care-seeking). See figure 2.

Figure 2 Collection of patient-related variables from the literature in a proposed model of heart failure patients' experience of self-care.



Attitudes, self-efficacy and cognition are three pivotal components as bio-behavioural variables. Self-efficacy and positive attitudes enabled persistence of optimal self-care (Dickson et al., 2008), where barriers included lack of confidence (Meyerson and Kline, 2009), denial and anger (Piamjariyakul et al., 2012), and type-D personalities (Oosterom-Calo et al., 2012). In relation to cognition, some patients were deemed to be unaware of their worsening symptoms and this physiological impairment in cognition in heart failure is an area for further investigation (Jurgens et al., 2009). A lack of emotional response to deteriorating symptoms negatively influences appropriate care-seeking (Jurgens et al., 2009). This may be related to the patient's perceptions of their symptoms, for example, exertional dyspnoea and fatigue being dismissed as 'unimportant' or 'unworthy of medical attention', especially with elderly patients (Jurgens et al., 2009).

Subsequent to these findings, certain decision-making characteristics are suggested to affect the implementation of self-care practices. Two key components emerged from the literature:

knowledge and experience. In order to make appropriate self-management decisions a patient needs to be first aware of the symptom, interpret the symptom, understand its importance, in order to develop a plan and finally evaluate the outcome (Riegel et al., 2013) all of which are key components in the decision-making process.

The idea that experience equals appropriate decision-making, however, remains unsubstantiated. The 26 article systematic review by Oosterom-Calo et al. (2012) implied improvements in self-care performance were related to increased length of time from diagnosis (Dickson et al., 2008). High overall compliance was demonstrated in participants with significantly more knowledge (van der Wal et al., 2006). Improvements in knowledge by education and counselling were recommended to improve self-care adherence in this study (van der Wal et al., 2006), and therefore knowledge may be considered a modifiable health system/team factor.

As mentioned previously, the literature review findings in the decision-making category remain inconsistent. For example, Kato et al. (2009) found that previous hospitalisations for heart failure were *not* a determinant of decision-making behaviour for their Japanese participants and Cameron et al. (2010) found experience-level did not correspond to more self-confidence with the management of heart failure. In this Australian secondary analysis paper the majority of ‘experienced’ heart failure patients actually lacked adequate skills in self-care decisions (Cameron et al., 2010).

Taking action in self-care practices is considered a patient-related factor. Taking action requires adaptation to and integration of optimal self-care practices. Goal-setting was demonstrated to be useful to move towards adoption of optimal self-care behaviours (Meyerson and Kline,

2009), namely with a focus on personal goals (Riegel et al., 2013) and perceived areas of self-management improvements (Meyerson and Kline, 2009). Emphasis is placed on understanding the non-linear trajectory of this adaptation process coupled with the individual experience of each and every patient especially with the unpredictability of symptoms (Wingham et al., 2014).

Dimension four: condition-related factors

Heart failure symptoms are often debilitating in themselves. In addition to the adjustment to the severity and progression of disease, the physical and psychological limitations (World Health Organisation, 2003) of heart failure affects patients' self-care experience. Severe and frequent heart failure symptoms plague patients thereby limiting many aspects of their lives and directly negatively affecting illness self-care (Falk et al., 2013). Though some patients did not classify their condition as a serious illness others realised the seriousness of the condition (Thornhill, 2008).

Symptom recognition is the condition-related mainstay of self-care in this literature review. Dyspnoea (shortness of breath), exertional dyspnoea and fatigue are the most commonly reported symptoms and the longer the patient experienced these symptoms the more distress was encountered (Jurgens et al., 2009). Making sense of these symptoms proved challenging for most patients with the complexity of the condition causing, for example, inappropriate delay in care-seeking (Jurgens et al., 2009). Purportedly, care-seeking is a commonly investigated subject in this patient group with the aim of decreasing frequency and duration of hospitalisations resulting less health care expenditure. Jurgens et al. (2009) looked at the association between symptom recognition and delay in responding to heart failure symptoms finding elderly patients specifically, had problems with sensing and attributing worsening heart

failure symptoms to their condition. Further, Riegel et al. (2010) backed up this finding in their mixed methods study conducting six-minute walk tests and analysing the reported perceived shortness of breath using the Borg Measure of Perceived Exertion (a 0-10 rating scale). Older patients found it more challenging to detect and interpret their shortness of breath than their younger counterparts (Riegel et al., 2010). With less insight into their symptom recognition, self-care management is compromised.

Further to heart failure specific demands, co-morbidities in this patient group are common. The World Health Organisation (2003) supports the idea that depression is an important modifier of adherence behaviours in chronic diseases and this is demonstrated in the results. Diabetes mellitus and depression pose specific challenges for patients in their self-care journey and are categorised as condition-related factors affecting adherence (World Health Organisation, 2003). Measurement of depressive symptoms was investigated in the literature to determine the extent of the problem in this patient group (van der Wal et al., 2006, Kato et al., 2009, Cameron et al., 2010, Piamjariyakul et al., 2012). Many (41%) patients with depressive symptoms were represented in the van der Wal et al. (2006) study. Diabetes mellitus was an independent risk factor for suboptimal self-care in the Japanese study (Kato et al., 2009), but remains undefined by other studies. Piamjariyakul et al. (2012) found patients who could manage their stress were better able to deal with the symptoms they were experiencing. Support from others was the common thread in this domain.

Impact on lifestyle was a significant literature finding, as previously reported as a therapy-related factor. The impact of heart failure on patients was demonstrated by 21 out of 25 participants surveyed in the study by Thornhill (2008) who felt restricted in many aspects of

their daily lives. It is undefined if the majority of these feelings are condition-related, therapy-related or inter-related.

Dimension five: health system/team factors

Re-hospitalisation rates for heart failure are between 29 and 49% within 3-6 months post initial discharge (National Heart Foundation of Australia, 2013). The National Heart Foundation of Australia (2013) identifies that some of these ‘admissions were preventable, and therefore avoidable’. With a focus on managing this condition at home by improving self-care practices, an understanding of the patient experience in relation to health system/health care team factors was important in this review yet yielded no descriptive results. One reason for this may be due to the exclusion criteria omitting interventional studies (n=9) and health care provider studies (n=7). Regardless, limited health system/team factors were yielded from the patient perspective in this narrative review.

Professional support was the main category in this dimension. Ongoing professional support was a common theme in the home management study by Piamjariyakul et al. (2012), yet it was found that seeking help with worsening heart failure was poor in the Japanese study (Kato et al., 2009) and delayed (Jurgens, 2006) especially in the older population (Jurgens et al., 2009). The complexities of chronic illness management were highlighted. The paper by Thornhill (2008) identified patients felt under-informed about the physical illness, had poor understanding behind the justification of their treatment and their prognosis. Some felt unsupported by health care professionals who hoped for a more holistic approach to their care (Boyd et al., 2004, cited in Thornhill, 2008). Patients required ongoing learning from health care professionals beyond hospitalization where the information given to them was ‘confusing’, ‘too rushed’ and ‘not understood’ (Piamjariyakul et al., 2012). The medical terminology on the

written information was reflected upon as being too complex by some participants and seeking information from a variety of sources was a strategy adopted by others (Piamjariyakul et al., 2012). Further to medical support, professional psychological support proved beneficial in heart failure management (Thornhill, 2008). Whilst 'knowledge' may be considered a modifiable factor and has been included as a patient-related factor in this review, it is necessary to understand the importance of shared responsibility by the patient and the health system/team to address self-care deficits.

The WHO framework has proven beneficial in examining existing literature around heart failure patients' non-pharmacological self-care. An understanding of each and every dimension supports a greater understanding of the patient experience holistically, especially significant for clinicians working with patients to improve guideline adherence. Further, the advantage of including all methodological articles in this narrative review is the exposure to the many, various factors affecting an individual's ability to adhere to a guideline, contextually significant to improve healthcare delivery. A limitation of the WHO dimensions report is the omission of the explanation of the initiation of adherence and describing the short-term determinants of adherence. This critique is consistent with a review of systematic reviews around patient adherence to pharmacological regimes which yielded no publications identifying the short-term determinants and only three describing the initiation of adherence (Kardas et al., 2013). An understanding of these two stages of adherence may provide more context to the often analysed, long-term adherence behaviours of patients with chronic illnesses.

CONCLUSION

Heart failure is a serious, debilitating, progressive chronic condition. Self-care regimes to improve quality of life and reduce costly re-hospitalizations are complex and often challenging

to maintain with adherence to an appropriate regime the cornerstone of treatment. The literature is heavily weighted towards patient-related factors affecting self-care, namely acceptance of diagnosis, bio-behavioural variables and decision-making characteristics. Understanding the patient experience is the first step in tailoring effective strategies to help manage these complex self-care behaviours yet little is known about the therapy-related factors which affect self-care practices. Further qualitative research in the day-to-day patient experience of adherence to specific therapies, such as fluid restriction guideline adherence, would shed light on individual variations of and barriers to self-care.

Traditionally generalised as a 'patient problem', self-care is also affected by other factors. This literature review highlighted a major result deficit in therapy-specific factors and this dimension is poorly understood.

More research is required for health care teams to improve adherence. Persisting long-term with an optimal non-pharmacological treatment plan proves to be challenging for patients yet improvements in self-care adherence are our best investment in chronic illness management (World Health Organisation, 2003). This is especially significant in our ageing population as we strive to improve out-patient chronic disease management. The first step is 'assessing the extent of adherence using non-threatening questions' (World Health Organisation, 2003). Health care professionals need to be armed with more insight into the patient's illness experience to tailor effective self-care management plans to address individualised self-care deficits for patients and their caregivers throughout the journey of their illness. Therefore further research into the patients' perception of health system/team factors is necessary.

Acknowledgements

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Key Point Sentences

- Heart failure self-care regimes are complex and often challenging to maintain.
- Adherence to an appropriate regime can improve quality of life and reduce costly re-hospitalisations.
- Traditionally generalised as a 'patient problem', self-care is also affected by other factors.
- The literature is heavily weighted towards patient-related factors affecting self-care, namely acceptance of diagnosis, bio-behavioural variables and decision-making characteristics.
- Social relationships have significant impact on self-care behaviours.
- Understanding the patient experience is the first step in tailoring effective strategies to help manage these complex self-care behaviours.
- This literature review highlighted a major result deficit in therapy-specific factors and this dimension is poorly understood.

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Table 1: Literature summary

Study	Design	Participants	Setting	Method/Measures	WHO Dimension(s)
Scotto (2005)	Qualitative	14	United States of America	Face-to-face interviews	Social/economic Patient-related
Jurgens (2006)	Quantitative	201	United States of America	Heart Failure Specific Somatic Awareness Modified Somatic Perception Questionnaire Mishel Uncertainty In Illness Scale-Community Form	Patient-related Condition-related Health system/team
van der Wal et al. (2006)	Quantitative	501	Netherlands	Centre for Epidemiology Surveys-Depression Scale (CAS-D) (Revised) Heart Failure Compliance Scale Dutch Heart Failure Knowledge Scale Heart Failure Belief Scale	Social/economical Patient-related Condition-related Health system/team
Dickson et al. (2008)	Mixed methods	41	United States of America	Self-care in Heart Failure Index (SCHFI) Various cognition tests Duke Activity Status Index Semi-structured interviews	Social/economical Patient-related Health system/team
Thornhill (2008)	Qualitative	25	United Kingdom	Face-to-face interviews	Social/economical Therapy-related Patient-related Condition-related Health system/team

Jurgens et al. (2009)	Mixed methods	77	United States of America	Heart Failure Somatic Perception Scale Specific Activity Scale Response to Symptom Questionnaire Charlson Comorbidity Index Interviews	Social/economical Patient-related Condition-related Health system/team
Kato et al. (2009)	Quantitative	116	Japan	(Version of the) European Heart Failure Self-Care Behavior Scale (EHFScBS) Heart Failure Knowledge Scale (Japanese version) Health Locus of Control Scale (originally by Watanabe 1985)	Patient-related Condition-related
Meyerson and Kline (2009)	Qualitative	27	United States of America	Analytical review of anecdotal records from a mutual goal-setting intervention study	Social/economical Therapy-related Patient-related Condition-related
Cameron et al. (2010)	Quantitative	143	Victoria, Australia	Self-care Heart Failure Index (SCHFI) Mini Mental State Exam Cardiac Depression Scale Charlson co-morbidity Index	Social/economical Therapy-related Patient-related Condition-related Health system/team
Riegel et al. (2010)	Mixed methods	29 (27 completed the interview)	Victoria, Australia	6-minute Walk Test Borg Measure of Perceived Exertion Interviews	Social/economical Patient-related Condition-related Health system/team

Riegel et al. (2011)	Quantitative	689	United States of America	Self-care Heart Failure Index (SCHFI) Duke Activity Status Index (Revised) Beck Depression Inventory ii Brief Symptom Inventory (BSI) (Revised) Control Attitudes Scale Multidimensional Scale of Perceived Social Support	Social/economical Patient-related Condition-related Health system/team
Piamjariyakul et al. (2012)	Qualitative	30 Patients 17 Health-care Professionals 17 Caregivers	United States of America	Telephone interviews and eight focus group discussions of patients and health care professionals	Social/economical Therapy-related Patient-related Condition-related Health system/team
Riegel et al. (2013)	Qualitative	120 data set 36 data saturation	Australia and United States of America	Secondary analysis of interviews in their study investigating naturalistic decision making	Social/economical Patient-related Condition-related Health system/team
Sethares et al. (2014)	Quantitative	131	United States of America	Neecham Confusion Scale Modified Response to Symptoms Questionnaire Heart Failure Somatic Awareness Scale Mishel Uncertainty in Illness Scale-Community (MUIS-C)	Social/economical Patient-related Condition-related Health system/team
Welstand et al. (2009)	Qualitative	Various	Various	Integrative review	Social/economical Patient-related Condition-related Health system/team

Oosterom- Calo et al. (2012)	Quantitative	Various	Various	Systematic literature review	Patient-related
Falk et al. (2013)	Qualitative and qualitative studies	Various	Various	Integrative literature review	Patient-related Condition-related
Wingham et al. (2014)	Qualitative studies	Various	Various	Meta-ethnographic qualitative synthesis	Social/economical Therapy-related Patient-related Health system/team