

**The Nexus Between Cognitive Function and Self-care Ability
in Patients with Chronic Heart Failure**

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Abstract

Background

The prevalence of chronic heart failure (CHF) within in the Western World remains high and is rapidly increasing in developing nations. The clinical trajectory of CHF is often characterised by chronic symptoms with periods of acute decompensation requiring hospitalisations for treatment. Yet almost half of these readmissions are potentially preventable through better adherence with self-care practices. For patients with CHF, self-care involves a level of confidence to adhere to behaviours that maintain physiological stability as well as recognising and making pertinent decisions in response to symptom changes. These self-care skills are not readily learnt and there are many barriers that account for this. Cognitive impairment occurs frequently in adults with CHF and is hypothesised to be a barrier in the acquisition of self-care skills.

Aims

The research program is a series of systematically designed studies the specific aims were to: Review the literature surrounding the management of heart failure and teaching patients self-care behaviours; Identify clinical tools that measure heart failure self-care; Identify factors that appear to hinder the practice of self-care; Develop (Phase 1) and test (Phase 2) a conceptual model of factors that predict CHF self-care; compare the Mini Mental State Exam (MMSE) with the Montreal Cognitive Assessment (MoCA) in screening for Mild Cognitive Impairment (MCI); Examine the influence experience with heart failure symptoms has on self-care behaviours.

Methods

The program consisted of comprehensive reviews of the literature, identification of clinical tools to measure self-care and cognitive function and two studies using descriptive survey methodology to develop (Phase 1) and test (Phase 2) a conceptual model of variables deemed to predict self-care. Patients were recruited for the studies

during their index hospital admission patients with CHF were assessed for self-care (Self-Care of Heart Failure Index) and screened for MCI and depressive symptoms (scores <83 on Cardiac Depression Scale). In Phase 1, patients were coded as MCI by scores <27 on the MMSE. In Phase 2, patients were coded as MCI by scores <27 on MMSE and/or scores <26 on the Montreal Cognitive Assessment (MoCA). Adequate self-care was indicated by scores >70 on self-care domains: maintenance, management and confidence of the SCHFI. These factors along with demographic and clinical characteristics (age, gender, social isolation, education level, new diagnosis and co-morbid illnesses) were tested in multiple regression models for self-care.

Results

In Phase 1 (n=50), seven variables (cognitive function, depressive symptoms, age, gender, social isolation, self-care confidence and co-morbid illnesses) explained 39% (F (7, 42) 3.80, p=0.003) of the variance in self-care maintenance and 38% (F (7,42) 3.73 p=0.003) of the variance in self-care management. Two variables were significant in predicting self-care maintenance: Age (p<0.01), and moderate-to-severe co-morbidity (p<0.05). Four variables were significant in predicting self-care management: Gender (p<0.05), moderate-to-severe co-morbidity (p<0.05), depression (p<0.05), and self-care confidence (p<0.01). Although cognitive function was not a significant variable in the models, when it was removed the remaining six variables explained less of the variance in self-care maintenance (35% (F (6, 43) 3.91 p=0.003) and management (34% F (6, 43) 3.71 p=0.005), suggesting that it helped in predicting self-care.

In Phase 2 (n=93), 68 (73%) patients were coded as having MCI. The MoCA identified 35 participants as having MCI not categorised by the MMSE, suggesting it was a more sensitive screening measure. Significant differences in self-care management (p<=0.01) and self-confidence scores (p=0.04) existed between patients coded with and without MCI. In multivariate analysis, time diagnosed was the most significant variable explaining 10% of the variance in self-care maintenance scores (F (1, 91) = 9.6, p<0.01). Co-morbid Index, NYHA class III or IV, and MCI explained 20% of the variance in self-care management (F (3,89) = 7.3, p<0.01) of which MCI made the largest contribution to the model explaining 10% of the variance. Age and depressive symptoms were significant

variables, explaining 13% of the variance in self-care confidence scores ($F(2,90) = 6.9$, $p < 0.01$).

Findings from Phase 2 suggested the need to further examine the influence of experience on self-care. By combining the data sets (Phase 2a) level of experience with CHF symptoms was found to be a major determinant of self-care maintenance behaviours and self-care management skills. On an adjusted basis, novices were less likely to have adequate self-care maintenance (OR, 0.3, 95% CI 0.1 to 0.8, $p < 0.01$) and self-care management (OR, 0.3, 95% CI, 0.1 to 0.8, $p = 0.02$) than patients with a diagnosis > 2 months.

Conclusion

This systematically designed research program enhances the knowledge of heart failure self-care and provides a unique contribution in understanding the relationship between this phenomena and cognitive function. Cognitive impairment is a hidden co-morbidity in patients with CHF and to reflect this, the research program has henceforth been named the 'The InCOGNITO Heart Failure Study'. This co-morbidity impacts negatively upon self-care actions and decisions, potentially increasing the risk of hospital readmissions or even premature death. Such evidence suggests that CHF patients with MCI require ongoing support in developing self-care skills and behaviours directed at reducing CHF symptoms and improving their health and quality of life. The research program provides further insight into the patient's experience of coping and adjusting to living with CHF. A number of other factors also help to predict self-care behaviours including the presence of symptoms causing functional limitations (NYHA class III or IV), higher co-morbidity, younger age and absence of depressive symptoms. These factors are a reflection of the complex nature of this syndrome and highlight the need for an integrated multidisciplinary health team in the long-term management of CHF. In order to clearly identify and articulate effective support and educational strategies directed at patients with CHF, ongoing research is required to further explore factors that hinder the application of teaching and counselling strategies and develop programs of care to specifically address these barriers.

Table 1: Relevant publications to the InCOGNITO Heart Failure Study

Chapter	Title
Chapter 2	Cameron, J., Worrall-Carter, L., Driscoll, A., New, G., & Stewart, S. (2007). Extent of Heart Failure Self-Care as an Endpoint to Patient Education: A Review of the Literature. <i>British Journal of Cardiac Nursing</i> , 2(4), 188-197.
Chapter 2	Cameron, J., Worrall-Carter, L., Driscoll, A., & Stewart, S. (2009). Measuring self-care in chronic heart failure: a review of the psychometric properties of clinical instruments. <i>Journal of Cardiovascular Nursing</i> , 24(6):E10-22.
Chapter 3	Cameron, J., Worrall-Carter, L., Riegel, B., Lo, SK., & Stewart, S. (2009). Testing a Model of Patient Characteristics, Psychological Status & Cognitive Function as Predictors of Self-care in Persons with CHF. <i>Heart & Lung the Journal of Acute & Critical Care</i> , Sept; 38(5):410-8.
Chapter 4	Cameron, J., Worrall-Carter, Page, K., Riegel, B., Lo, SK., & Stewart, S. (2010). Does cognitive impairment predict poor self-care in patients with chronic heart failure? <i>European Journal of Heart Failure</i> ; 12(5): 508-15.
Chapter 4	Cameron, J., Worrall-Carter, Page, K., Riegel, B., McLennan, S., & Stewart, S. (In progress). Comparison of the Montreal Cognitive Assessment and Mini Mental State Exam as a screening method for mild cognitive impairments in patients with chronic heart failure.
Chapter 5	Cameron. J., Worrall-Carter, L., Page, K., Stewart, S. (2010). Does experience with CHF symptoms really impact on self-care? <i>European Journal of Cardiovascular Nursing</i> ; 9(2):92-100.

Table 2: Associated publications during PhD

Chapter	Title
Chapter 1	Driscoll, A., Worrall-Carter, L., McLennan, S., Dawson, A., O'Reilly, J. , & Stewart, S. (2006). Heterogeneity of heart failure management programs in Australia. <i>European Journal Of Cardiovascular Nursing: Journal Of The Working Group On Cardiovascular Nursing Of The European Society Of Cardiology</i> , 5(1), 75-82.
Chapter 2	McLennan, S., Pearson, S., Cameron, J. , & Stewart, S. (2006). Prognostic importance of cognitive impairment in chronic heart failure patients: Does specialist management make a difference? <i>European Journal of Heart Failure</i> , 8(5), 494-501.
Chapter 3	Riegel, B., Driscoll, A., Suwanno, J., Moser, D., Lennie, T., Chung, M., Wu, JR., Dickson, V., Carlson, B., Cameron, J. , (2009). Heart Failure Self-care in Developed & Developing Countries Self-Care. <i>Journal of Cardiac Failure</i> , 15(6):508-16.
Chapter 3	Lee, C., Riegel, B., Driscoll, A., Suwanno, J., Moser, D., Lennie, T., Dickson, V., Cameron, J. , Worrall-Carter, L. (2009). Gender Differences in Heart Failure Self-Care: A Multinational Perspective. <i>International Journal of Nursing Studies</i> , 46(11):1485-95.
Chapter 3	Riegel, B., Dickson, V., Cameron, J. , Page, K., Johnson, J, Worrall-Carter, L (2010). "Symptom Recognition in Elders with Heart Failure." <i>Journal Of Nursing Scholarship: An Official Publication Of Sigma Theta Tau International Honor Society Of Nursing / Sigma Theta Tau</i> ; 42(1):92-100.

Candidates Statement of Originality

This thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma.

No other persons' work has been used without due acknowledgement in the main text of the thesis.

This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in this thesis received the approval of the relevant Ethics/Safety Committees (where required)

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Statements of Contributions to Jointly Published Work

It is acknowledged that I have worked within a research team and as such other members have mentored and supported my research training and work. However, the body of this research program has been conceptualised and undertaken for my PhD and is therefore my own intellectual property. It is also acknowledged that a number of researchers have contributed in part to the publications included in this thesis (see Table 1), the actual research undertaken and the preparation of the manuscripts for publication was solely my own work. It is acknowledged that all co-authors of jointly published papers included in this thesis provided their consent for the inclusion of each paper in this thesis and that the co-authors accept my contribution to the paper as described in the Statement of Contributions of Others. All other work included in this thesis, not part of published papers or those accepted for publication is entirely my own work, except where duly acknowledged. My contribution and the contribution of others to each of the published papers included in this thesis are outlined in the following statements.

Statement of Contributions for Chapter 2

Extent of Heart Failure Self-Care as an Endpoint to Patient Education: A Review of the Literature. British Journal of Cardiac Nursing 2006; 2(4), 188-197.

Janette Cameron Conception and design of literature search and data extraction

Analysis and interpretation of data

Drafting the article or revising it critically for important intellectual content

Final approval of the version for publication

Linda Worrall-Carter Advised on the search strategy

Made critical revisions to draft versions for important intellectual content

Andrea Driscoll Made critical revisions to draft versions for important intellectual content

Gishel New Made critical revisions to draft versions for important intellectual content

Simon Stewart Made critical revisions to draft versions for important intellectual content

Signed:

Ms Janette Cameron

Professor Linda Worrall-Carter

Date: _____

Statement of Contributions for Chapter 2

Measuring self-care in heart failure: A review of the psychometric properties of clinical instruments. Journal of Cardiovascular Nursing (2009); 4(6), E10-22.

Janette Cameron Conception and design of literature search and data extraction

Analysis and interpretation of data

Drafting the article or revising it critically for important intellectual content

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Andrea Driscoll Advised on analysis and interpretation of data

Made critical revisions to draft versions for important intellectual content

Linda Worrall-Carter Advised on the search strategy and interpretation of data

Made critical revisions to draft versions for important intellectual content

Simon Stewart Made critical revisions to draft versions for important intellectual content

Signed:

Ms Janette Cameron

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Date: _____

Statement of Contributions for Chapter 3

Testing a model of patient characteristics, psychological status and cognitive function as predictors of self-care in persons with chronic heart failure. Heart & Lung (2009); 8(5), 410 - 418.

Janette Cameron Conception and design of study, data collection, analysis and interpretation of data

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Made critical revisions to draft versions for important intellectual content

Barbara Riegel Advised on analysis and interpretation of data

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Sing Kai Lo Assisted in data analysis

Made critical revisions to draft versions for important intellectual content

Simon Stewart Advised on conception of study

Made critical revisions to draft versions for important intellectual content

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Ms Janette Cameron

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Does cognitive impairment predict poor self-care in patients with chronic heart failure? European Journal of Heart Failure (2010); 12(5): 508-15.

Janette Cameron Conception and design of study, data collection, analysis and interpretation of data

Drafting the article or revising it critically for important intellectual content

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Karen Page Advised on analysis and interpretation of data

Made critical revisions to draft versions for important intellectual content

Barbara Riegel Advised on analysis and interpretation of data

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Sing Kai Lo Assisted in data analysis

Made critical revisions to draft versions for important intellectual content

Simon Stewart Advised on analysis and interpretation of data

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Statement of Contributions for Chapter 4

Comparison of the Montreal Cognitive Assessment and Mini Mental State Exam as a screening for cognitive impairment in patients with chronic heart failure.

Journal of Nursing and Healthcare of Chronic Illness (In Progress).

Janette Cameron Conception and design of study, data collection, analysis and interpretation of data

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Does experience with heart failure symptoms really impact on self-care.

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List of Abbreviations Used in the Thesis

Angiotensin converting enzyme inhibitor – ACE-I

Angiotensin II receptor antagonists - ARB

Cardiac Depression Scale – CDS

Chronic Heart Failure – CHF

Chronic Heart Failure Management Programs – CHF-MPs

European Heart Failure Self-care Behaviour Scale – EHFS CBS

Impaired **COGNITiOn** in heart failure study – InCOGNITO study

Mild Cognitive Impairment – MCI

Mini Mental State Exam – MMSE

Montreal Cognitive Assessment – MoCA

New York Heart Association Classification – NYHA

Self-care Heart Failure Index – SCHFI

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Introduction to the Thesis

The concept of this research program developed around the issue of establishing whether cognitive impairment was a barrier to achieving optimal self-care skills in patients with chronic heart failure (CHF). The interest emerged from questioning personal clinical practice as to the effectiveness of education being provided and having a determination to improve the manner in which patients with CHF self-manage their syndrome. It was hypothesised that cognitive impairment would be a significant barrier in self-care. During analysis it was evident that mild cognitive impairment (MCI) was often not recognised and could be perceived as a “hidden” co-morbidity. The research program has therefore been named the ‘The InCOGNITO Heart Failure Study’ to reflect the concealed nature of Impaired **COGNITiOn** in patients with CHF.

The ‘InCOGNITO Heart Failure Study’ examines and tests a number of hypotheses. First, the research program examines the importance of self-care in the management of CHF and determines the role of patient education in improving self-care practices. The literature review also examines if changes in self-care can be accurately measured. It is evident in Chapter 2 that self-care is often sub-optimal and there are many barriers to explain this. However it is the role that cognitive function plays in self-care that is the focus of the research program. The primary hypothesis tested is whether cognitive function is a predictor of self-care, which is examined in Phase 1 and 2 of the research program. In developing a greater understanding as to the phenomena of self-care it was apparent that experience is an important aspect. Phase 2a of the research program tests the hypothesis that level of experience with CHF impacts on self-care.

Each Chapter presents a different Phase in the research program (See Figure 4: By undertaking a program of research in this manner it has the capacity to look more broadly at an issue. The research program contributes to new knowledge through such research and dissemination of findings is through writing a thesis and developing a number of manuscripts that have been published in peer reviewed journals (see Table 1: Relevant publications to the InCOGNITO Heart Failure Study). These manuscripts reflect the findings from each Phase of the research program. Figure 4 illustrates the Phases of the research program and summary of each Chapter.

Chapter 1 provides the background for undertaking the research program by presenting the burden of CHF. A diagnosis of CHF conveys a poor prognosis in relation to morbidity and mortality (McDonald, Conlon, & Ledwidge, 2007). It is within this context that a variety of strategies have been specifically developed and applied to improve health outcomes for the large numbers of people diagnosed with CHF (Krum et al., 2006; Wagner, Davis, Schaefer, Von Korff, & Austin, 1999). Figure 1 illustrates strategies that are recommended in the application of the long-term management of patients with CHF. The Chapter includes a synopsis of the Level 1 evidence for the application of multidisciplinary programs of care to typically older patients.

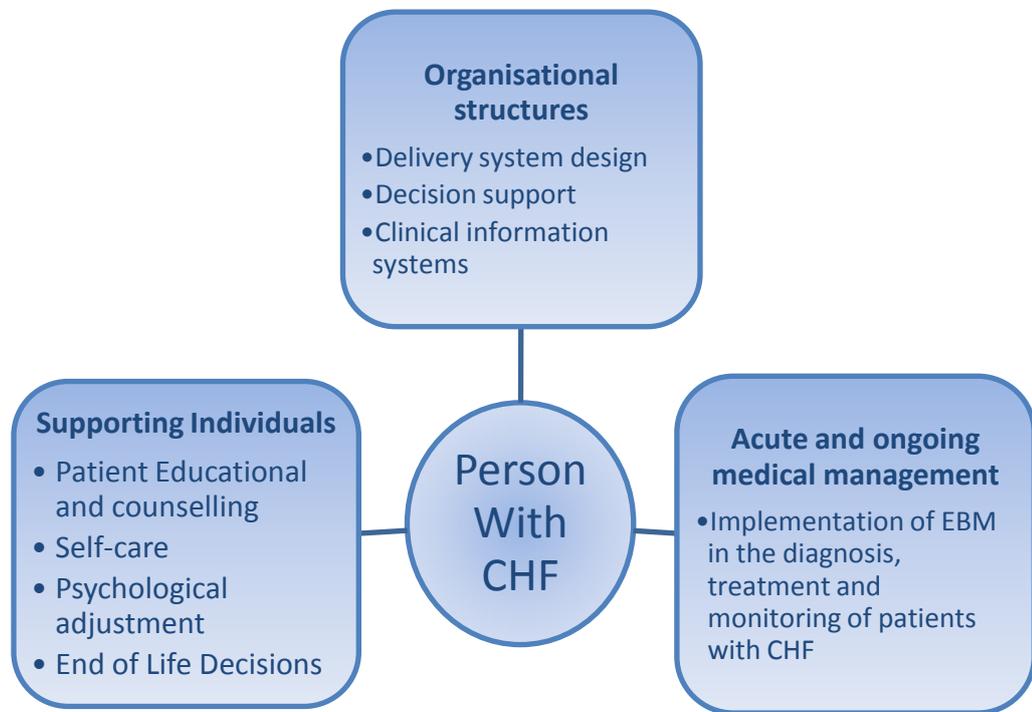


Figure 1: Illustration of strategies targeted to improve health outcomes in patients with Chronic Heart Failure

Legend: CHF – Chronic Heart Failure; EBM – Evidenced Based Medicine

It is now widely acknowledged that a fundamental strategy within a Chronic Heart Failure Management Program (CHF-MP) is to support and teach patients self-care skills (Dickstein, et al., 2008). Chapter 2 establishes the role of patient education in supporting patients in self-care (pg. 57). The first literature review conducted examines the outcomes of randomised control studies (RCTs) using patient education as the primary intervention (pg 64). The translation of the findings into 'new knowledge' resulted in the development of the manuscript 'Extent of heart failure self-care as an endpoint to patient education: a review of the literature' (Cameron, Worrall-Carter, Driscoll, New, & Stewart, 2007). This manuscript was published in the *British Journal of Cardiac Nursing* and is included in Appendix A. The literature review found that only three out of the ten studies identified, had utilised reliable and valid measures to report improvements in self-care as an outcome to patient education. The lack of reliable tools for such an important measure was the focus of the second review.

Chapter 2 also presents the findings from the second in-depth literature review (pg. 93) conducted to determine whether CHF self-care can be accurately measured. Only two disease specific measures of CHF self-care were found in the literature. An examination of their psychometric properties demonstrated the instruments measure differing aspect of CHF self-care skills. The European Heart Failure Self-care Behaviour Scale (EHFScBS) measures three aspects of health maintenance behaviours: compliance with the management regimen, asking for help and adapting daily activities (Jaarsma, Stromberg, Martensson, & Dracup, 2003). In contrast the Self-care Heart Failure Index (SCHFI) measures three dimensions related to self-care skills and behaviours: self-care maintenance behaviours, self-care management decisions and confidence with performing maintenance and management behaviours (Riegel et al., 2004). Information from this literature review provides the rationale for choosing the SCHFI to measure self-care in testing the conceptual model of barriers that predict this outcome. The translation of the findings into 'new knowledge' resulted in the development of the manuscript "Measuring self-care in heart failure: a review of the psychometric properties of clinical instruments". This manuscript has been published in the *Journal of Cardiovascular Nursing* (Cameron, Worrall-Carter, Driscoll, & Stewart, 2009) and is included in Appendix A.

Despite universal attention to educational strategies directed at improving self-care, overall it is still poorly understood and mastering these skills is not easy for many patients with CHF. There are many factors for this. The constellation of symptoms associated with CHF can impact on individuals' ability in performing everyday activities of daily living and contribute to the challenge of living with the syndrome (Stromberg, 2005). These functional limitations result in a poor quality of life and feelings of anxiety or depression (Lesman-Leegte et al., 2009). The syndrome requires a complex treatment regimen which may not be readily learnt or understood by individuals especially if they have low health literacy levels (Laramee, Morris, & Littenberg, 2007). Most CHF patients are at risk of other age-related disabilities (Moser, Doering, & Chung, 2005), including cognitive impairment (Bennett & Sauve, 2003; Sauve, Lewis, Blankenbiller, Rickabaugh, & Pressler, 2009), an increasing number of co-existing co-morbidities (De Geest et al., 2004) and inadequate social support (Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008) that can impact on the ability of patients to make independent and appropriate self-care decisions (Moser & Watkins, 2008). Chapter 2 examines factors that appear to impact on the achievement of adequate self-care skills, which serves as a basis for those included and tested in the conceptual model.

The InCOGNITO conceptual model developed for this thesis is considered a mid-range theory (Walker & Avant, 2005) that tests a number of factors related to the phenomena of CHF self-care. The development and testing of this conceptual model provides new insight into the phenomenon of CHF self-care. It is acknowledged that Moser & Watkins (2008) have also developed The Life Course Model of factors that affect decision making and self-care. Nonetheless, the 'InCOGNITO' model developed for this thesis contrasts to the Life Course Model because it demonstrates the clinical application of the conceptual model with clinical parameters applied to factors that predict self-care. It is the analytic focus of testing the conceptual model in clinical practice that provides another contribution to the body of knowledge in identifying barriers in the achievement of optimal self-care.

Chapter 3 presents Phase 1 of the 'InCOGNITO Heart Failure Study' research program. In Phase 1, a conceptual model of patient characteristics, psychological status and cognitive function was developed from the literature and tested to predict self-care

maintenance and management (See Figure 2: Initial conceptual model (Phase 1) of factors that help predict heart failure self-care). In Phase 1 of the research program, patients were defined as cognitively impaired if their score was <27 on the Mini Mental State Exam (MMSE)(Folstein, Folstein, & McHugh, 1975). In Phase 2 patients were defined as cognitively impaired if their cognitive test scores were <27 on MMSE and <26 on the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005). It was hypothesised that patients who were cognitively intact would perform superior self-care management on the premise that this behaviour requires the cognitive ability to learn, perceive, interpret and respond to symptom changes (Dickson, Tkacs, & Riegel, 2007). These are higher order cognitive functions that are associated with executive functioning or problem solving skills originating from the pre-frontal cortex of the brain (Naugle & Kawczak, 1989; Xu, Meyer, Thornby, Chowdhury, & Quach, 2002). The translation of the findings into 'new knowledge' resulted in the development of the manuscript 'Testing a model of patient characteristics, psychological status and cognitive functions as predictors of self-care' (Cameron, Worrall-Carter, Riegel, Lo, & Stewart, 2009) and is included in Appendix A.

A failure to support the hypothesis tested in Phase 1 may have been due to the manner in which cognition was measured. At the time of undertaking the study, the options for nurses in screening for cognitive changes were limited to general measures of cognitive decline such as the Mini-Mental State Examination. It is acknowledged that a limitation of this screening measure is that it does not assess higher order cognitive functions (Naugle & Kawczak, 1989) and may help to explain some of the findings from Phase 1.

Subsequent to the completion of Phase 1, the Montreal Cognitive Assessment (MoCA) emerged as a valid and reliable specific screening measure of mild cognitive impairment (MCI) (Nasreddine et al., 2005). Phase 2 revisits the particular hypothesis that cognitive function would predict self-care. The conceptual model is re-tested in a larger sample and includes two screening measures of cognitive function that were now available for use by nurses: MMSE and MoCA (see Figure 3). The MoCA was developed to specifically screen for MCI and demonstrates the changing paradigm that mild cognitive impairment can be considered a preclinical phase of Alzheimer-type dementia

affecting memory and executive functioning domains (Bisiacchi, Borella, Bergamaschi, Carretti, & Mondini, 2008; Gauthier et al., 2006).

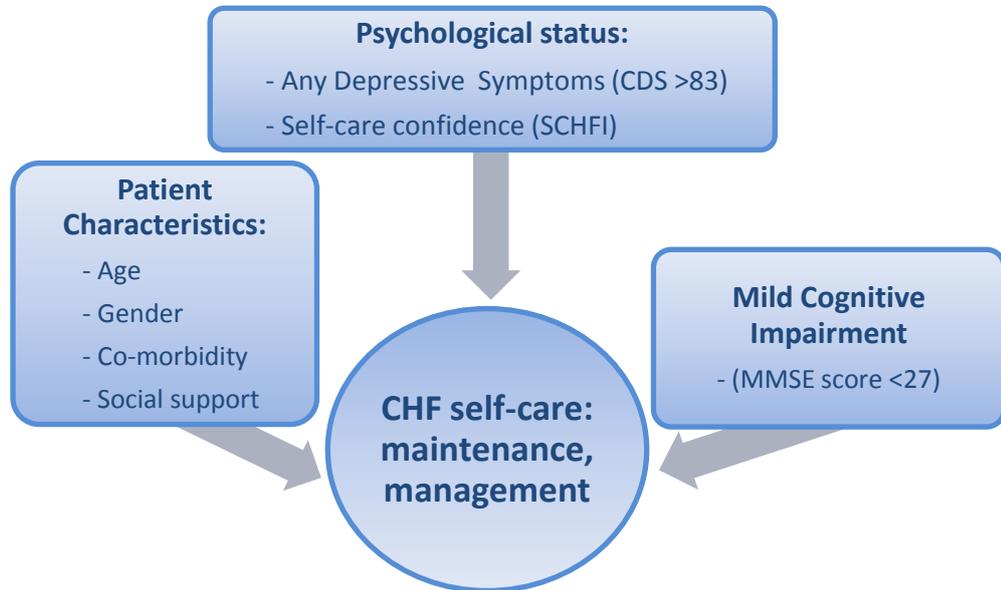


Figure 2: Initial conceptual model (Phase 1) of factors that help predict heart failure self-care

Legend: CHF – Chronic Heart Failure; CDS – Cardiac Depression Scale; MMSE – Mini Mental State Exam; SCHFI- Self-care Heart Failure Index

Chapter 4 advances our understanding as to the impact cognitive impairment has on self-care. In the second Phase of the study, the hypothesis is supported and establishes the link that MCI appears to impact on the self-care decision-making capacity of patients with CHF. The translation of the findings into ‘new knowledge’ resulted in the development of the manuscript ‘Does cognitive impairment predict self-care in persons with chronic heart failure’(Cameron, Worrall-Carter, Page, Riegel et al., In Press) and is included in Appendix A.

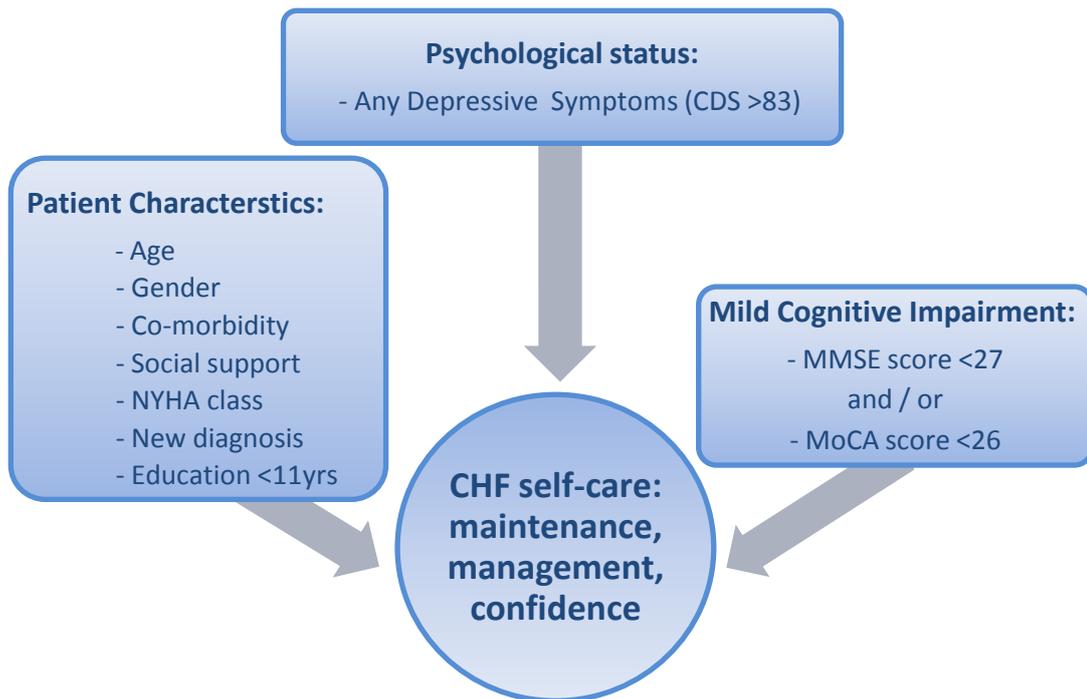


Figure 3: The refined conceptual model (Phase 2) of factors that help predict self-care in persons with heart failure

Legend: CHF – Chronic Heart Failure; CDS – Cardiac Depression Scale; MMSE – Mini Mental State Exam; MoCA – Montreal Cognitive Assessment; NYHA – New York Heart Association Functional Class

The implications of MCI for clinical practice are clear. Persons with CHF often have subtle cognitive impairments that are not readily apparent to clinicians. The use of screening measures to identify this feature may alert health professionals to those at greater risk of a reduced capacity to self-care. In this manner identifying patients with MCI may help us to more appropriately tailor patient education and support strategies. A further aim in Chapter 4 was to examine the utility of the two screening measures used to identify MCI and discuss the implications for clinical practice. The translation of these findings into ‘new knowledge’ has resulted in a paper presented at an international conference (Cameron, Worrall-Carter, Page, Riegel, & Stewart, 2009). This knowledge serves to fill a gap in the current literature in identifying an optimal

screening tool of MCI in the clinical setting that had been identified by Pressler (2008) as a research priority.

Chapter 5 expands on our understanding about barriers and enablers in achieving optimal self-care. In particular, it became apparent from Phase 2 of the 'InCOGNITO Heart Failure' research program that more than two months experience with CHF symptoms was a significant predictor of self-care maintenance. Although it is acknowledged that others (Francque-Frontiero, Riegel, Bennett, Sheposh, & Carlson, 2002; Moser & Watkins, 2008; Riegel & Dickson, 2008) have previously identified this variable as a predictor of self-care, it was decided to test whether in a contemporary sample where awareness is greater, that level of experience with CHF will impact on self-care. By combining the data sets from Phase 1 & 2, Phase 2a tests the hypothesis that experience is a significant factor in predicting of self-care. The translation of the findings from Phase 2a into 'new knowledge' has resulted in the development of the manuscript 'Self-care behaviours and heart failure: does experience with symptoms really make a difference?' (Cameron, Worrall-Carter, Page, & Stewart, In Press) and is included in Appendix A. Findings from both [*this*] and the previous Phases of the research program, helps to support the conceptual model that cognitive function, psychological status and a number of patient characteristics which are largely not modifiable, help predict self-care.

A summary of the key messages formulated in each chapter and acknowledgment of some of the limitations to the research program are presented in Chapter 6. Implications for clinical practice and recommendations for further research are made in light of the new knowledge that has emerged from the 'InCOGNITO Heart Failure' research program. This thesis will also demonstrate the growth in my capabilities as a researcher. During a four year period there has been substantiation of independent thinking, a culmination in high level skill development regarding statistical knowledge, database management as well as articulation of evidence through my publication record. My future goals and direction draw the thesis to a close but it is hoped that my future as an independent researcher is only just beginning.

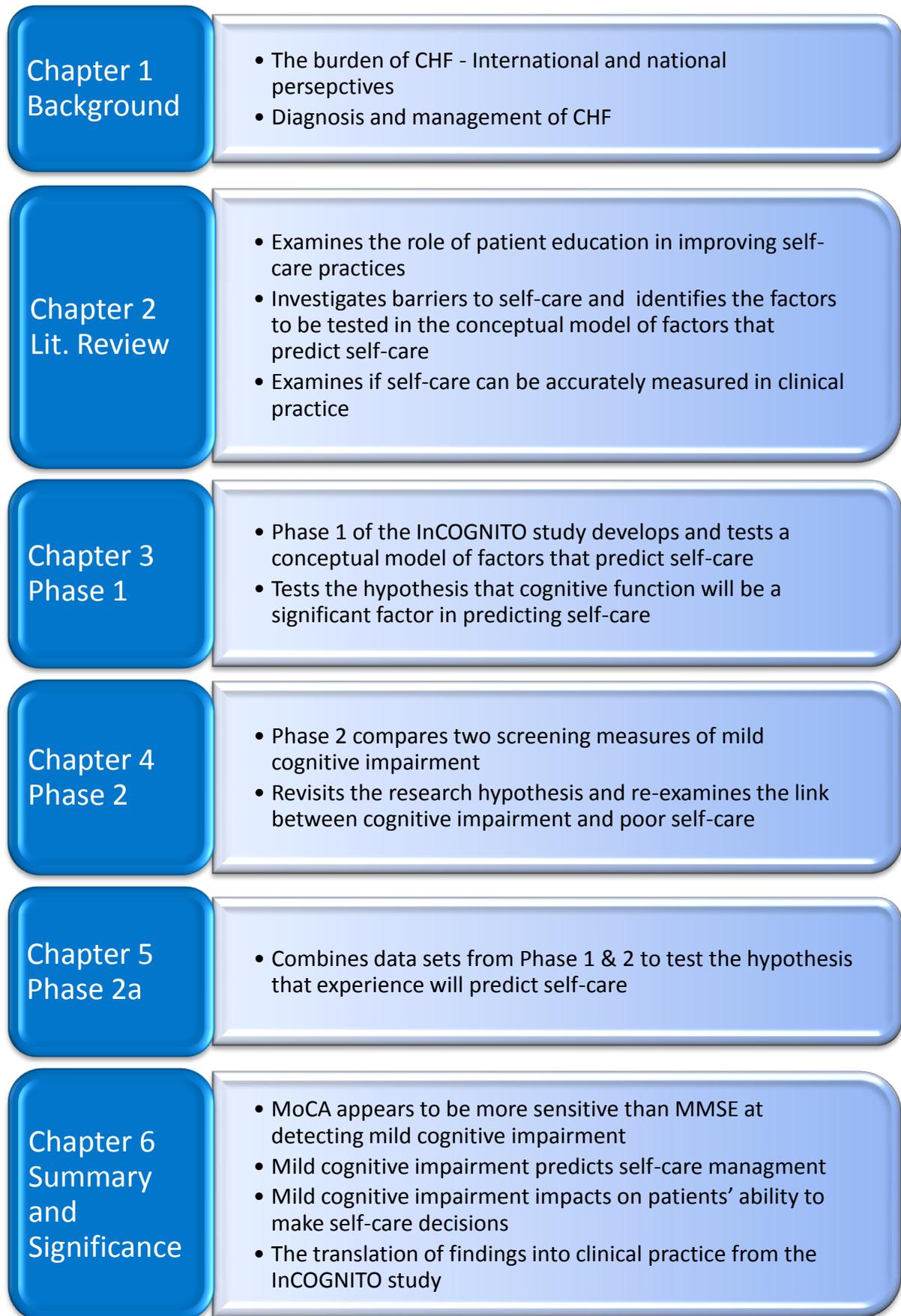


Figure 4: Overview of Chapters and each Phase of the research program

Chapter 1 – Chronic Heart Failure and its Burden

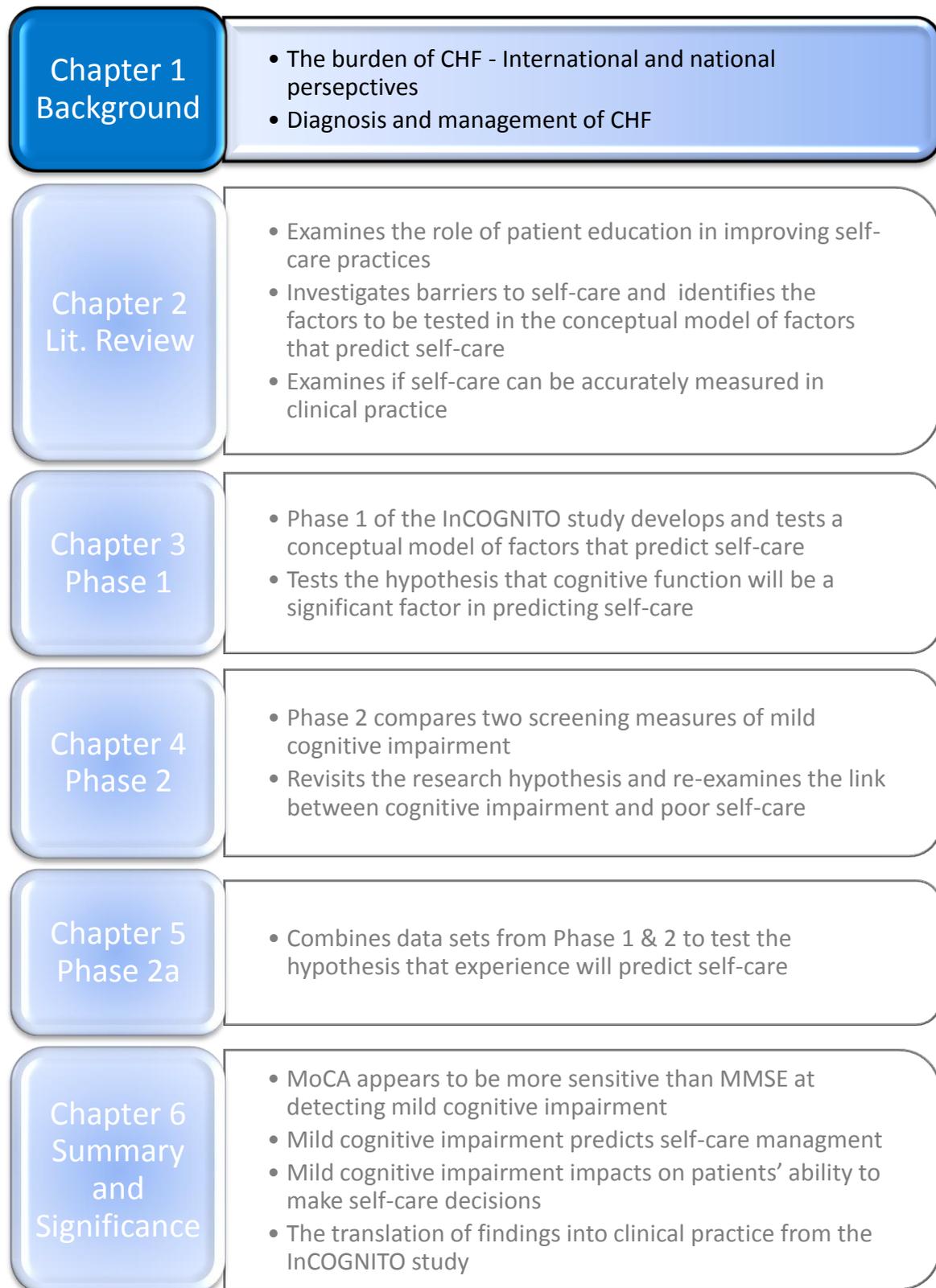


Figure 5: Overview of Chapter 1

Chapter 1 Background

The clinical syndrome, chronic heart failure (CHF) is a world-wide health problem that is associated with burgeoning health care costs (McMurray et al., 2006; Rosamond et al., 2008), significant morbidity and mortality (Ezekowitz, Lee, Tu, Newman, & McAlister, 2008; Rosamond et al., 2008; S. Stewart, 2008). It is widely acknowledged that CHF has a worse prognosis than many forms of cancer (S. Stewart, MacIntyre, Hole, Capewell, & McMurray, 2001) with only 20-30% of patients surviving five years from time of diagnosis (Goldberg, Ciampa, Lessard, Meyer, & Spencer, 2007; Ko et al., 2008). Moreover, the major cost of managing CHF is attributed to frequent hospital admissions (Hauptman, Swindle, Burroughs, & Schnitzler, 2008) in an elderly population with significant morbidity as a result of the syndrome and many co-existing chronic health problems (Krum & Gilbert, 2003). The constellation of symptoms associated with CHF can impact on individuals' ability in performing everyday activities of daily living and contribute to the challenge of living with the syndrome (Stromberg, 2005). These functional limitations together with periods of acute decompensation resulting in frequent hospital admissions can result in a poor quality of life and feelings of anxiety or depression for the individual (Lesman-Leegte et al., 2009; Rodriguez-Artalejo, Guallar-Castillon, & Otero, 2005). The burden of CHF to the individual, the community and the health care sector in both developed and developing nations are therefore significant.

The clinical diagnosis of CHF is problematic due to the complexity of signs and symptoms associated with the compensatory bodily changes that occur at a muscular, cellular and neurohormonal level, in an effort to preserve cardiac performance (Hunt, 2005; Jessup & Brozena, 2003).

It is the poor outcomes associated with a diagnosis of CHF that has been the catalyst for programs of research to improve not only our understanding of the syndrome but also its management. Chronic Heart Failure Disease Management Programs (CHF-MPs) have emerged as one solution in ensuring patients receive gold-standard treatments, and are adequately supported in learning to live with this syndrome (Sochalski et al., 2009; Yu, Thompson, & Lee, 2006). A number of large randomised controlled studies and meta-analyses have been undertaken in recent

years, which has resulted in Level 1 evidence (National Health & Medical Research Council, 1999) as to their effectiveness at addressing many of the poor health outcomes associated with CHF (R. A. Clark, Inglis, McAlister, Cleland, & Stewart, 2007; Duffy, Hoskins, & Chen, 2004; Göhler et al., 2008; Göhler et al., 2006; Gonseth, Guallar-Castillon, Banegas, & Rodriguez-Artalejo, 2004; Gustafsson & Arnold, 2004; Gwadrý-Sridhar, Flintoft, Lee, Lee, & Guyatt, 2004; Holland et al., 2005; McAlister, Lawson, Teo, & Armstrong, 2001; McAlister, Stewart, Ferrua, & McMurray, 2004; Phillips, Singa, Rubin, & Jaarsma, 2005; Phillips et al., 2004; Rich, 1999; Roccaforte, Demers, Baldassarre, Teo, & Yusuf, 2005; Whellan, Hasselblad, Peterson, O'Connor, & Schulman, 2005; Yu, Lee, Kwong, Thompson, & Woo, 2008; Yu et al., 2006). The application of CHF-MPs is dependent upon the local health-care environment (Jaarsma, Stromberg et al., 2006) which has resulted in diverse models of care (Driscoll, Worrall-Carter, McLennon, Dawson, & Stewart, 2004) ranging from multidisciplinary programs of care during the in-patient and out-patient phase (Holland et al., 2005; Rich et al., 1995), nurse-led clinics (Phillips et al., 2005; Stromberg et al., 2003), tele-monitoring services (R. A. Clark, Inglis et al., 2007), to specialist care provided by a pharmacist (Murray et al., 2007).

Although there is considerable heterogeneity within these programs of care, there is substantial evidence that specific interventions can improve mortality, reduce hospital admissions and subsequently health care costs, and improve patient's quality of life. A summary of components deemed essential to CHF-MPs will conclude this chapter. The aims of Chapter 1 are to provide the reader with a contemporary overview of CHF, its significance to the individual, the health care system and the community and its management.

Definition of Chronic Heart Failure

The classic definition of CHF indicates it is a state in which the heart is "unable to maintain adequate circulation for the needs of the body despite a satisfactory filling pressure" (Wood, 1968). This definition has practical limitations as it does not offer objective criterion on which to base a diagnosis. As a consequence of progressive cardiac dysfunction, patients can present with a constellation of signs and symptoms (breathlessness, fatigue, fluid retention) highlighting that it is a syndrome rather than a

primary diagnosis (Jessup & Brozena, 2003). In the past six years several definitions have been employed by expert panels worldwide to develop Evidenced-based Best Practice Guidelines in the diagnosis and treatment of CHF. These five definitions (See Table 3) illustrate that some clinical judgment is required, based on history, physical examination and appropriate investigations, in order to accurately diagnose CHF.

Acute versus Chronic Heart Failure

Often in the literature ‘chronic heart failure’ and ‘heart failure’ are used interchangeably. However, it is important to delineate the two given that acute heart failure is the rapid onset of signs and symptoms secondary to cardiac dysfunction that presents with one of several clinical conditions:

- Acute de-compensated congestive heart failure
- Acute heart failure with hypertension/hypertensive crisis
- Acute heart failure with pulmonary oedema
- Cardiogenic shock
- Severe cardiogenic shock
- High output failure
- Right-sided acute heart failure (Nieminen & Harjola, 2005)

Chronic heart failure is often punctuated by episodes of acute heart failure requiring hospitalisations for treatment (Swedberg et al., 2005). As this research program is more concerned with the “chronic” form of heart failure, ongoing aspects of living with this syndrome and attempts to prevent acute episodes, it is not appropriate to further discuss the management of acute heart failure.

Table 3: Definitions of chronic heart failure

Source	Definition of CHF
ESC, 2008	A syndrome in which the patients should have the following features: symptoms of HF, typically shortness of breath at rest or during exertion, and/or fatigue, signs of fluid retention such as pulmonary congestion or ankle swelling; and objective evidence of an abnormality of the structure or of the heart at rest” (Dickstein et al., 2008, p.2390-1)
NHF and CSANZ, 2006	A complex clinical syndrome with typical symptoms (eg dyspnoea, fatigue) that can occur at rest or on effort and is characterised by objective evidence of an underlying structural abnormality or cardiac dysfunction that impairs the ability of the ventricle to fill or eject blood (particularly during physical activity). A diagnosis of CHF may be further strengthened by improvement in symptoms in response to treatment (Krum et al., 2006, p. 9)
HFSA, 2006	Heart failure is a syndrome caused by cardiac dysfunction, generally resulting from myocardial muscle dysfunction or loss and characterised by left ventricular dilation or hypertrophy. Whether the dysfunction is primarily systolic or diastolic or mixed, it leads to neurohormonal and circulatory abnormalities, usually resulting in characteristics symptoms such as fluid retention, shortness of breath and fatigues, especially on exertion (Adams et al., 2006b, p.13)
AHA / ACC, 2005	A complex clinical syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the ventricle to fill with or eject blood (Hunt, 2005, p. e5)
NICE, 2003	Heart failure is a complex syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the heart’s to function as a pump to support a physiological circulation. The syndrome of heart failure is characterised by symptoms such as breathlessness and fatigue, and signs such as fluid retention (National Institute of Clinical Excellence (NICE) & National Collaborating Centre for Chronic Conditions, 2003, p.4)

Systolic versus Diastolic Heart Failure

Diastolic heart failure and systolic heart failure are essentially two clinical subsets of the syndrome used to delineate differences in myocardial functioning. Systolic heart failure occurs from impaired left ventricular contraction and in most cases affects young and middle-aged persons. In contrast, diastolic dysfunction occurs subsequent to impaired ventricular relaxation, compliance or filling and is more common in the elderly (Chatterjee & Massie, 2007). A diagnosis of either systolic or diastolic heart failure is determined from an echocardiogram which is discussed later in this Chapter. There are few differences in presenting signs and symptoms for diastolic or systolic heart failure. The pathophysiology of CHF will now be presented to explain the symptoms patients develop symptoms.

Pathophysiology of Chronic Heart Failure

Primarily CHF develops because the myocardium sustains some injury or stress that results in impairment of the left ventricle. A cycle of adaptive responses occur at a muscular, cellular and neurohormonal level, in an attempt to preserve cardiac output (Jessup & Brozena, 2003). Initially the failing heart attempts to *remodel* the ventricles by changing their shape and dimension in an attempt to maintain the force of contraction. The cardiac remodelling process increases hemodynamic stresses on the walls of the failing heart, depressing its mechanical performance even further and causing mitral valve incompetence, which in turn adds to the risk of irregular heart rhythms (Hunt, 2005). As the ventricles enlarge their compliance decreases. This means that the ventricles are unable to adequately fill with blood during diastole; the phase when the heart chambers should be passively filling with blood. This causes an increase in pulmonary capillary pressures, resulting in shortness of breath and pulmonary oedema during an acute exacerbation (Swedberg et al., 2005).

A second process that occurs from cardiac remodelling is activation of both the sympathetic nervous system and renin-angiotensin system. Figure 6 illustrates the pathophysiology of ventricular modelling adapted from Carelock and Clark (2001). Neurohormones are released from the renin-angiotensin system to increase the

circulating blood volume through the retention of sodium and water. In contrast, unopposed activation of the sympathetic nervous system causes intense constriction of the systemic and pulmonary veins that augment venous return and exacerbates hypoperfusion to vital organs such as the brain and kidneys (Coats, 2000). Although the activation of these neurohormonal systems are initially adaptive and serve to restore cardiac function, the chronic activation of neurohormones has dire consequences (Cahalin, 1996).

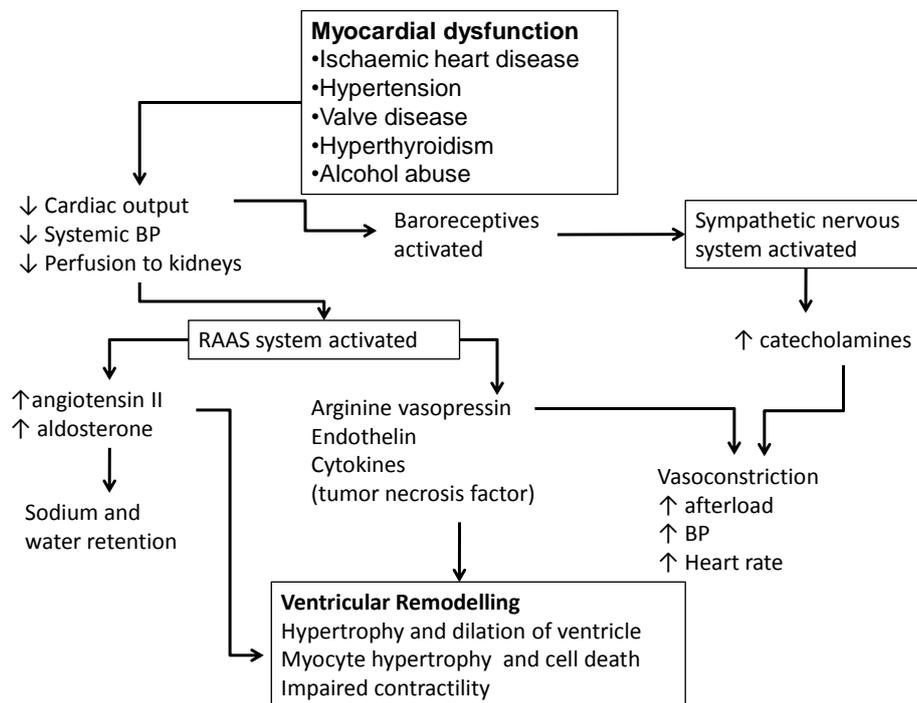


Figure 6: Pathophysiology of Ventricular Modelling

Legend: RAAS – Renin-angiotensin-aldosterone-system, BP – Blood Pressure

(Carelock & Clark, 2001)

In a poorly functioning heart increased venous pressures forces blood backwards into the lungs and other tissue spaces, resulting in peripheral oedema and congestion in the lungs. Further, neurohormonal activation results not only in death of the cardiac muscle cells but musculoskeletal abnormalities that further reduce the patients exercise tolerance (Coats, 2000; Krum, 2001). Hence the complex pathophysiology of CHF has a

progressive detrimental effect that in the long-term results in a chronic deterioration of cardiac performance.

By the time symptoms develop and individuals present to their doctor, the heart has been failing for some time and compensatory mechanisms have been triggered. Once patients have structural cardiac abnormalities the outcome can be dire. They may die before developing symptoms. They may develop symptoms that are controlled by treatment or they may die of progressive heart failure (Hunt, 2005).

Signs and Symptoms of Chronic Heart Failure

Patients with either systolic or diastolic heart failure may report symptoms of dyspnoea on exertion, advancing dyspnoea when lying recumbent (orthopnea) and dyspnoea after a few hours sleep (paroxysmal nocturnal dyspnoea), a dry irritating cough, fatigue and weakness, dizzy spells and palpitations, (Krum et al., 2006). Signs of fluid retention such as peripheral oedema, hepatomegaly, pulmonary oedema, and ascites result in a sudden weight gain. The clinical manifestation of CHF can impact on patients' ability to perform everyday activities and ultimately impair their quality of life (Carlson, Riegel, & Moser, 2001; Heo, Doering, Widener, & Moser, 2008). The severity of symptoms is often used as a means to classify the gravity of the disease. Two classifications are widely used in practice.

Classification of Heart Failure

As seen in Table 3 (p.38) there are two established methods for classifying the severity of CHF. The New York Heart Association (NYHA) is a measure of functional class. It has four grades that equate to symptoms of breathlessness with varying degrees of activity. In Australian clinical practice, NYHA classification is used. In contrast, the American College of Cardiology and American Heart Association have graded CHF according to the level of cardiac dysfunction and symptoms. This classification includes patients who may not have any symptoms of CHF but are at risk of developing heart failure. Recommendations for the treatment of asymptomatic patients (level A & B)

appear in the guidelines because their clinical outcomes may be improved through both lifestyle behaviour changes and pharmacotherapy treatment (Hunt, 2005).

Table 3: Classifications used to distinguish severity of heart failure

NYHA Classification for Heart Failure (The Criteria Committee of the New York Heart Association, 1964)		The American College of Cardiology and American Heart Association Classification for heart failure (Hunt, 2005)	
I	No limitations. Ordinary physical activity does not cause undue fatigue, dyspnoea or palpitations.	Level A	At high risk for heart failure but without structural heart disease or heart failure symptoms
II	Slight physical limitations. Ordinary physical activity results in some symptoms of fatigue, dyspnoea, palpitations or angina	Level B	Structural heart disease but without signs or symptoms of heart failure
III	Marked physical limitations. Less than ordinary physical activity leads to symptoms.	Level C	Structural heart disease with prior or current symptoms of heart failure
IV	Unable to perform any physical activity without symptoms. Symptoms of HF present at rest	Level D	Refractory end stage heart failure requiring specialized interventions

Essential to the management of patients with CHF is objective clinical evidence that symptoms, such as breathlessness, are related to either systolic or diastolic dysfunction rather than some other primary cause. The single most useful diagnostic test in the evaluation of patients is an echocardiogram.

Echocardiography in the Diagnosis of CHF

Echocardiography is the cornerstone in the non-invasive assessment of cardiac function which can provide measures of: systolic and diastolic function of both the left and right ventricles; ventricular size, volumes and wall thickness; structure and functioning of the valves; and pressure of blood within both the heart and lungs. All of these measures not only help to confirm a diagnosis but also determine the aetiology of CHF which may guide the management plan (Krum et al., 2006).

A calculated left ventricular ejection fraction (LVEF) is the ratio of the volume of blood ejected during a heartbeat to the volume at the end of heart filling (end diastole). In general, an LVEF of < 40% is taken as evidence of CHF because it indicates significant left ventricular systolic dysfunction (Sweitzer, Lopatin, Yancy, Mills, & Stevenson, 2008). It is often seen when heart muscle is damaged as in a myocardial infarction. Alternatively, individuals who have clinical signs of congestive heart failure with a preserved left ventricle may have diastolic heart failure. Limiting the diagnosis of CHF to evidence of an ejection fraction below normal can potentially exclude 40% of the elderly population from appropriate clinical management (Cleland & MacFadyen, 2002; Goble, Worcester, Bunker, & Campbell, 2003). Dickstein (2005) further argues that physicians need to incorporate all the clinical information available in order to make an accurate diagnosis and develop an appropriate treatment plan. As there is no single investigation that is specific for making such a diagnosis a thorough assessment must include: a physical examination; an electrocardiogram; a chest x-ray; laboratory tests; natriuretic peptides; an echocardiogram.

Electrocardiogram (ECG)

An ECG can help provide information about the aetiology of CHF. It will demonstrate the presence, both past and current, of coronary artery disease and brady or tachy arrhythmias (Dickstein, 2005).

Chest X-ray

A chest x-ray can identify pulmonary congestion, cardiomegaly, the presence of pleural effusions and pneumonia. It can also help in the differential diagnosis of patients with breathlessness due to chronic obstructive airways disease (Dickstein, 2005).

Laboratory Tests

Routine blood tests can detect a number of co-morbid conditions (anaemia, hyponatremia, renal dysfunction, diabetes, neoplasm and infection) which have significant ramifications in the ongoing management of CHF (Dickstein, 2005).

B-Type Natriuretic Peptides

Brain natriuretic peptides (BNP) are released by cardiac cells, in particular the ventricular myocytes, as a response to volume expansion and/or pressure overload causing cardiac wall stretch (Krupicka, Janota, Kasalova, & Hradec, 2009). In recent times BNP testing is not only used as to identify heart failure in dyspneic patients but may also be used to help guide the treatment of the syndrome (Green, Green, & Januzzi, 2009; Pandeli et al., 2007). Typical cut-points used to diagnose heart failure are BNP levels <100pg/ml or NT-proBNP <300pg/ml (Krupicka et al., 2009). As a result of the high-negative predictive value, all contemporary guidelines now discuss the role that BNP have in improving the diagnostic accuracy for CHF (van Kimmenade et al., 2006).

Despite discrepancies in the diagnosis of CHF it is recognised that it is a world-wide health problem associated with burgeoning health care costs, significant morbidity and mortality. The global of CHF will be presented from an international perspective before presenting the National burden.

The Global Burden of Chronic Heart Failure

The estimated population prevalence of CHF in industrialised countries is significant. In the United States, CHF affects over 5 million people (2.5% of the population). Furthermore, the syndrome is a feature of ageing with its incidence

doubling for each decade of life. The incidence of new heart failure events per 1000 population is 15.2 in white males aged 65-74 and 8.2 in white females of same age, increasing to 65.2 in white males and 45.6 in white females over 85 years of age (Rosamond et al., 2008). Similar to the United States, the estimated prevalence of CHF in Europe is 15 million (4% of the population). Once again it appears a feature of ageing with the prevalence dramatically rising from 0.4% in people younger than 65, up to 20% in persons 70-80 years old (Dickstein et al., 2008).

Little is known about the prevalence and incidence of CHF in developing countries. However, in one of the largest studies undertaken in Africa it was revealed that whilst the aetiology of CHF may differ somewhat, the syndrome is not only associated with westernised nations. Stewart et al (S. Stewart et al., 2008) prospectively collected clinical data from one hospital servicing 1.1 million Africans in Soweto, South Africa. In 2006, there were 1,960 cases of heart failure arising from five different causes: 33% of cases were from hypertensive cardiomyopathies, 28% were idiopathic causes, 27% were from right sided heart failure, 9% were from ischemic cardiomyopathies and 8% were the result of valvular problems. Black Africans had less ischemic cardiomyopathy (adjusted odds ratio, 0.12; 95% CI, 0.07 to 0.20) but more idiopathic and other causes of cardiomyopathy (adjusted odds ratio, 4.80; 95% CI, 2.57 to 8.93). This suggests that CHF has significant ramifications for both developed and developing nations.

National Burden of Chronic Heart Failure

Despite the minimal and inconsistent collection of data surrounding the incidence and prevalence of CHF in Australia (Tofler, 2004) it is recognised that in a population of approximately 20 million, the burden to both the community and the health care sector is not dissimilar to other developed nations.

By combining data from the Australian Bureau of Statistics together with well-validated population-based epidemiological data Clark, McLennan, Dawson, Wilkinson & Stewart (2004), estimated that 325,000 Australians had symptomatic heart failure, resulting in 22,000 admissions and contributing to over 1.4 million days of

hospitalisation, at a cost of more than \$1 billion per year. Moreover, mortality and readmission rates for CHF appear significantly higher in the winter months, suggesting the demand on hospital beds have seasonal variations (Inglis et al., 2008). Unfortunately prevalence rates of CHF in rural and remote regions within Australia is considerably high (R. A. Clark et al., 2005) where access to CHF specialist services is very limited (R. A. Clark, Driscoll et al., 2007). Furthermore, there is compelling evidence that up to 214,000 Australians have latent CHF and are at high risk for developing symptoms in the near future (R. A. Clark et al., 2004). This assumption was also supported in a cross sectional survey of elderly residents residing in Canberra (Abhayaratna et al., 2006), where 0.6% of subjects had evidence of cardiac dysfunction with symptoms and yet had not previously been diagnosed with clinical heart failure. This suggests that diagnosed cases represent only the 'tip of the iceberg' when examining the national burden of disease within Australia.

Whilst these data provide a snapshot for the incidence and prevalence of CHF, others have suggested that there have been some improvements in health outcomes across Australia with hospital separations for CHF falling from 1996 to 2004 (Najafi, Dobson, & Jamrozik, 2007) and mortality rates over the past twenty years also decreasing (McLean, Eslick, & Coats, 2007). Although these statistics appear promising, some of these results may be attributed to altered admission thresholds and changes in the diagnosis and coding of hospital admissions and death with CHF as a primary or secondary factor over time. Despite some data from the UK linking improved population outcomes related to the application of proven treatments (see Jhund et al. 2009 below), overall CHF still represents a significant health problem to the Australian nation. Similar to other developed countries the burden is expected to escalate over the foreseeable future. A national strategy is required to improve the management of CHF in order to address the huge burden this syndrome incurs on both the individual and the health system.

Future Burden of Chronic Heart Failure

Despite the issues in diagnosing CHF, it would appear that the incidence of the syndrome is expected to double over the next twenty five years as medical progress continues to prolong longevity in patients with cardiovascular diseases (McMurray & Stewart, 2001; Rosamond et al., 2008). This has significant ramifications in regards to the need for health care services demanded by this health problem.

Mortality

Whilst the population death rate has declined 2% over the decade from 1994-2004, deaths from CHF have increased 28% during this period (Rosamond et al., 2008). The 1-year mortality for CHF is high; one in five persons will die as a result of the syndrome (Rosamond et al., 2008) and this will more often be the result of systolic rather than diastolic heart failure (Ezekowitz et al., 2008). In a study of 9943 Canadian patients newly diagnosed with CHF between 1999 and 2001, the 5-year mortality rate was 68.7% with a median survival of only 2.4 years (Ko et al., 2008). Similarly, in 2445 patients admitted to hospitals in Massachusetts during 2000 with a confirmed diagnosis of acute heart failure, over a third (37.3%) had died within the first year after hospitalisation and 78.5% died during the 5-year follow-up period (Goldberg et al., 2007). Despite these alarming statistics, evidence from two large population studies have found that survival rates appear to be improving.

In the Framingham Heart Study conducted from 1950 through to 1999 (Levy et al., 2002) the age-adjusted survival rates have improved over time. For the 1075 participants who were diagnosed with CHF, there was an overall 12% decline in the risk of death per decade. For males, 1-year mortality declined from 30% to 28% and 5-year mortality declined from 70% to 59%, over the 50 year period. Similarly 1-year mortality rates for women declined from 28% to 24% and the 5-year rates declined from 57% to 45%. Subsequently, in a study involving 116 556 individual patients discharged from Scottish hospitals with a first-time diagnosis of heart failure (Jhund et al., 2009), survival rates increased for males from 1.33 years (95% CI 1.17 to 1.50 years) in 1986 to 2.34 years (95% CI 2.15 to 2.56 years) in 2002 ($p < 0.0001$). Similarly, female survival rates

improved from 1.32 years (95% CI 1.19 to 1.44 years) in 1986 to 1.79 years (95% CI 1.50 to 1.98 years) in 2003 ($p < 0.001$). Moreover, there were significant improvements in the adjusted 30-day, 1- and 5-year survival rates (Jhund et al., 2009). Despite this encouraging evidence, only a quarter to one half of patients will survive five years from their first hospital presentation (Goldberg et al., 2007; Jhund et al., 2009; Ko et al., 2008), making the mortality from CHF worse than many forms of cancer (S. Stewart et al., 2001). These alarming statistics indicate that management of CHF still deserves significant research attention if the number of premature deaths attributable to the syndrome is to be reduced.

The Economic Costs of Chronic Heart Failure

The direct costs of managing CHF have been estimated to be more than US\$33 billion (Rosamond et al., 2008). The major cost of managing CHF is attributed to frequent hospital admissions in an elderly population that have many co-existing chronic health problem and a poor quality of life as a result of significant morbidity. In an ageing population, CHF has become one of the most common causes of hospital admission in patients over 65 years of age (Ahmed, 2007). In developed nations, CHF as a primary diagnosis consumes 1- 2% of health care expenditure (W. C. Lee, Chavez, Baker, & Luce, 2004) but this estimate can rise to 4% when the cost of hospitalisation with a secondary diagnosis of heart failure is calculated (S. Stewart, Jenkins et al., 2002). Several factors account for the economic drain on the health care system in managing CHF:

Re-admissions occur frequently with up to two thirds of patients being re-admitted within 30-180 days of their index hospital admission (Ahmed et al., 2008; Hamner, Ellison, & Alabama, 2005; Krumholz et al., 1997; Schwarz & Elman, 2003; Tsuchihashi et al., 2001; Vinson, Rich, Sperry, Shah, & McNamara, 1990)

Patients are elderly and often have many co-existing cardiac (Galvao & Adhere Scientific Advisory Committee Investigators, 2005) and non-cardiac co-morbidities (Braunstein et al., 2003; Fonarow et al., 2008)

The fragility of these patients can prolong the length of time spent in hospital (De Geest et al., 2004; Hauptman et al., 2008).

As almost 70% of the management costs are attributable to hospital admissions (Göhler et al., 2008; S. Stewart, 2005a), it is not surprising that over the past two decades a great deal of attention has been focused on ways to improve the economic burden to the health care sector and improve health outcomes for individuals living with CHF.

The Individual Impact of Heart Failure

Although it is important to review the dollar cost in the burden of CHF, it is the impact of the syndrome on the individual and their family that has a substantial human cost. Patients report an array of symptoms associated with CHF including shortness of breath, fatigue, a dry mouth and day time sleepiness (Bekelman et al., 2007; Brostrom, Stromberg, Dahlstrom, & Fridlund, 2004). The increasing number of symptoms patients report, the more likely they will feel depressed and experience a poor quality of life (Bekelman et al., 2007; Muller-Tasch et al., 2007). The multitude of symptoms associated with CHF can result in functional impairments that interfere with normal activities of daily living, social and sexual interactions (A. L. Stewart et al., 1989). Functional limitations correlate with higher NYHA class and a worse quality of life (De Jong, Moser, & Chung, 2005) to the extent that for many patients, they would willingly trade at least half their remaining life expectancy in order to feel better (Lewis et al., 2001). The burden on the caregiver is also substantial with many reporting changes in their own lives and daily routines as they take on responsibility for supporting the patient with personal and daily living needs (Luttik, Blaauwbroek, Dijker, & Jaarsma, 2007), medical and self-care decisions (Sayers et al., 2008). In Chapter 2 the role that self-care behaviours and skills have in managing CHF symptoms will be discussed at greater length.

Aims of Heart Failure Management

The management aims of CHF address the burden of the disease by alleviating symptoms, improving functional capacity and quality of life, prolonging survival, reducing acute exacerbations and related hospital admissions (Rich, 2002). This is achieved through a holistic and systematic approach that includes both pharmacotherapy and lifestyle measures, from a range of health professionals to address both medical and non-medical aspects of health (Rich, 2002). According to Wagner et al (Wagner, Austin, & Von Korff, 1996; Wagner et al., 2005), effective interventions fall into one of five areas: the use of evidence-based, planned care; reorganization of practice systems and provider roles; improved patient self-management support; increased access to expertise; and greater availability of clinical information. These components have been integrated into a Model of Effective Chronic Illness Care (Wagner et al., 1999) and have informed the development of Chronic Heart Failure Management Programs (CHF-MPs) which have been adopted both nationally (Krum et al., 2006) and internationally (Adams et al., 2006d; Hunt, 2005).

The Role of Heart Failure Management Programs in Improving Health

It is the poor outcomes associated with a diagnosis of CHF that has been the catalyst for programs of research to improve not only our understanding of the syndrome but also its management. Heart failure disease management programs have emerged as a means to address the poor health outcomes associated with CHF and from the number of large randomised controlled studies and meta-analyses that have been undertaken in recent years (Holland et al., 2005; Jovicic, Holroyd-Leduc, & Straus, 2006; McAlister et al., 2004; Rich, 2003), there is little doubt as to their effectiveness.

The landmark study by Rich et al. (1995) was the first large scale, randomised trial to ascertain the impact of a nurse-directed, multidisciplinary intervention on a group of elderly patients who were at a high risk of readmission for de-compensated heart failure, within 90 days of hospital discharge. The intervention consisted of several strategies prior to the patient's discharge: Delivery of intense education from a nurse specialist which was supported by a patient resource booklet; an individual nutritional

assessment by a dietician; a social worker assisted in the discharge planning process ensuring patients had appropriate community supports; a review of prescribed medications by a geriatric cardiologist. In addition, patients received intensive follow-up both by the hospital's home-care services and members of the study team, who re-enforced patient education and emphasised the need for compliance with CHF self-care behaviours. Ninety day survival without readmission was greater in the treatment group than those receiving conventional care ($p=0.09$) and a 56% reduction in heart failure readmissions in the treatment group ($p=0.04$). The reduction in hospital admissions resulted in a cost saving benefit of US\$460 per patient ($p=0.1192$). The intervention was proven to be beneficial with the effects persisting for up to one year. It was concluded that a nurse-directed, multidisciplinary intervention improved several health outcomes for elderly patients with CHF.

Subsequently there have been an abundance of published randomised and non-randomised studies demonstrating significant improvements in a number of health outcomes: Reduced healthcare utilisation (Doughty et al., 2002; Riegel, Carlson et al., 2002); Reduced healthcare costs (Krumholz et al., 2002); Reduction in mortality (S. Stewart, Marley, & Horowitz, 1999). These significant improvements in health outcomes have been qualified by at least 17 systematic reviews and meta-analyses to qualify that CHF-MPs improve health outcomes for patients diagnosed with CHF (R. A. Clark, Inglis et al., 2007; Duffy et al., 2004; Göhler et al., 2008; Göhler et al., 2006; Gonseth et al., 2004; Gustafsson & Arnold, 2004; Gwady-Sridhar et al., 2004; Holland et al., 2005; McAlister et al., 2001; McAlister et al., 2004; Phillips et al., 2005; Phillips et al., 2004; Rich, 1999; Roccaforte et al., 2005; Whellan et al., 2005; Yu et al., 2008; Yu et al., 2006). This has established the Level 1 evidence as to application of CHF-MPs.

The Impact of CHF-MPs on Hospital Utilisation

It is clear that CHF-MPs have a beneficial impact on reducing hospital utilisation. The relative risk reductions from pooled randomised controlled studies report a reduction in all-cause readmissions between 12% (Gonseth et al., 2004) and 21% (Gwady-Sridhar et al., 2004) and a 35% relative risk reduction in heart failure

readmissions (Phillips et al., 2004). The absolute risk reduction has been estimated to be 11%, indicating that to prevent one readmission only eleven patients are required to be treated (Gwady-Sridhar et al., 2004). Furthermore, Roccaforte et al. (2005 p.1139) found that the total number of days spent in hospital for any cause is significantly reduced (WMD = -1.49, CI -2.03 to -0.95, $p < 0.00001$) when patients are managed within CHF-MPs.

The Impact of CHF-MPs on Mortality

Stewart, Marley and Horowitch (1999) were the first to demonstrate in a large-scale randomised trial that a CHF-MP with a home-based intervention was capable of prolonging survival. Although smaller published studies are not always powered sufficiently to report on mortality as an endpoint there is evidence from larger studies that patients managed within CHF-MPs have a 13% relative risk reduction in mortality and a 27% reduction in the combined endpoint of death or readmission (Phillips et al., 2004). However, there is wide heterogeneity in CHF-MPs (Driscoll et al., 2006) and so it is often difficult to identify which components are crucial to improve these health outcomes. To overcome this problem, McAlister et al. (2004), compared the outcomes among homogenous programs: multi-disciplinary teams with or without specialised clinics, telephone follow-up and primary care physician, enhanced self-care. This meta-analysis showed that a specialised multidisciplinary program had a superior effect over the other two models in reducing mortality (RR 0.75, 95%CI 0.59 to 0.96). Therefore, it appears that patients managed in comprehensive CHF-MPs after discharge from hospital, have a significant improvement in survival.

The Cost Benefits of CHF-MPs

It is difficult to generalise cost benefit effects of CHF-MPs as health care costs vary greatly throughout the world. In ten observational studies reviewed by Rich (1999), despite an increase in outpatient overheads there was a reduction in in-patient expenditure, yielding an average cost saving of US\$8,000 per patient. Subsequently Phillips, Singa, Rubin & Jaarsma (2005) estimated the potential cost benefit from three

studies in their meta-regression analysis to be US\$277.88 per patient, per month for medical care relative to usual care, although this difference was not statistically significant. On the other hand, Stewart & Horowitz (2002b) found a statistically significant ($p < 0.01$) cost difference in the long-term analysis of a home-based nurse intervention. The home-based intervention resulted in 78 fewer unplanned readmissions compared with usual care and this computed to a cost difference of AU\$325/month in the intervention group versus AU\$660/month in the usual care ($p < 0.01$). Notwithstanding these discrepancies, it appears that CHF-MPs need only treat 17 patients to prevent 1 death and only 11 patients to prevent one readmission, suggesting they have similar effects to established pharmacotherapies for CHF (McAlister et al., 2004).

Obviously if the most costly aspect to health care is related to patient bed days, then programs that are able to reduce hospital utilisation in an elderly population that would normally have frequent and lengthy admissions, have the potential to reduce the overall expenditure for this syndrome. Based upon this assumption an analysis of the implementation of a specialist nurse CHF-MP (S. Stewart, Blue, Walker, Morrison, & McMurray, 2002), it was projected that the implementation of a National program across the UK would reduce all-cause readmissions by 50%. For every 1000 patients subject to a home-based program the prevention of 2400 days of hospitalisations would result in a cost-saving of £169,000. When these results are also combined with improved quality of life, reduced general practice and outpatient visits and potentially pro-longed survival the overall benefits would potentially save £60.0 million per annum in health care expenditure (S. Stewart, Blue et al., 2002). It is therefore clear that nurse-led CHF-MPs combined with optimal pharmacological management improve health outcomes. Despite the evidence regarding CHF-MPs there is no consensus in regards to the most cost effective and essential components to these models of care.

Components to Heart Failure Management Programs

Although there is wide variability in these programs of care (Driscoll et al., 2006; Jaarsma, van der Wal, & van Veldhuisen, 2006), there is substantial evidence that

specific interventions together can improve health outcomes. These interventions have been set out in a variety of management guidelines to ensure that CHF-MPs achieve evidenced-based standards of care (Adams et al., 2006a; Bonow et al., 2005; Dickstein et al., 2008; Goble et al., 2003; Hunt, 2005; Krum et al., 2006; National Institute of Clinical Excellence (NICE) & National Collaborating Centre for Chronic Conditions, 2003) which are summarised in Table 4.

Table 4: Standards of care and strategies for CHF-MPs

Standards of care	Strategies
An accurate clinical diagnosis and Utilisation of evidenced based pharmacotherapy and other treatment modalities	Meticulous clinical assessment and investigations to confirm diagnosis and underlying aetiology Titration of anti-failure therapy Vigilant prescribing to optimal doses of medications proven to prolong survival and reduce symptoms Appropriate use of devices (bi-ventricular pacemakers / internal cardio defibrillators)
Integrated care management and a smooth transition from acute to primary care	A multi-disciplinary team to consider an holistic approach to the patient's medical, physical, educational and psychosocial needs Changes to delivery of health care system to improve communication and increase access to primary care
A heart-failure co-ordinator (nurse) to support the non-pharmacological management of patients	A heart failure nurse specialist is deemed pivotal for discharge planning and coordination of post hospitalisation care
Development of an individual program of activity and exercise to maintain muscle strength required for activities of daily living	Referral to an appropriate exercise training programs (community or home-based) so that patients can achieve realistic and sustainable levels of physical activity
Support patients and their carers to achieve and maintain self-care	Intense, ongoing education and counselling that encourage self-care behaviours and address barriers to compliance with management plan Address the psychosocial needs of the patient's to overcome anxiety and depression Referrals to social services that can support patients and families in their community
Prevention and deterioration of CHF	Education and counselling of patients at risk and those diagnosed with CHF about lifestyle behaviours that can maintain health and prevent clinically deterioration

(Adams et al., 2006a; Bonow et al., 2005; Dickstein et al., 2008; Goble et al., 2003; Hunt, 2005; Krum et al., 2006; National Institute of Clinical Excellence (NICE) & National Collaborating Centre for Chronic Conditions, 2003)

Pharmacological Strategies

Utilisation of pharmacotherapy is directed at reducing mortality, improving symptoms and preventing further myocardium damage (Dickstein et al., 2008). The need for differing classes of medications is dependent on symptomology. Table 5 (p. 53) is a synthesis of recommended pharmacotherapy derived from Clinical Practice Guidelines for the treatment of symptomatic heart failure (Dickstein et al., 2008; Hunt, 2005; Krum et al., 2006).

The prescribing of evidenced-based pharmacotherapy for the treatment of CHF requires careful vigilance during their introduction, up-titration to the maximal doses and ongoing monitoring (McMurray et al., 2005). This surveillance and adherence in prescribing recommended pharmacotherapy is one of the strategies within a CHF-MP, as previously discussed. However, in order for these pharmacotherapies to have maximal benefits they need to be accompanied by other strategies that encourage adherence with the regimen and support self-care. These additional strategies are deemed non-pharmacological strategies and are discussed at greater length in Chapter 2.

Table 5: Recommended pharmacotherapy for the treatment of symptomatic heart failure

Drug Class	Rationale	Recommendations
Angiotensin Enzyme Converting Inhibitors (ACE-I)	Prolongs survival, improves symptoms and LV function, reduces hospitalisations	Mandatory for all patients with systolic LV dysfunction, unless not tolerated or contra-indicated. The aim is to increase doses to higher levels shown to be of benefit in major trials
Loop diuretics	Symptom benefit. Increases urine sodium excretion which relieves symptoms of fluid overload resulting in systemic and pulmonary congestion.	Prescribed to achieve euvolemia in combination with ACE-I. In fluid overloaded patients dose is increased to achieve an increase in urine output and weight reduction of 0.5-1kg daily
Beta-blockers	Improves ventricular function and reduces LV re-modelling. Prolongs survival, reduces hospitalisations and improves symptoms.	Prescribed for patients NYHA class II-IV (unless contra-indicated or not tolerated) with optimal dose of ACE-I
Angiotensin II Receptor Antagonists (ARB)	Improves ventricular function, survival and reduces hospitalisations in patients with CHF already prescribed an ACE-I	Prescribed in patients with systolic heart failure who remain symptomatic despite optimal doses of ACE-I and Beta blocker
Aldosterone Antagonists	Reduce hospitalisations, prolongs survival	Prescribed for patients NYHA class III-IV, with no evidence of hyperkalemia or significant renal dysfunction
Digoxin	Inotropic agent that slows ventricular rate in patients with atrial fibrillation Improves well-being and hospitalisations	Prescribed in patients with advanced heart failure or patients with reduced LV function and atrial fibrillation
Nitrates	Improves ventricular function, exercise tolerance and survival	Prescribed when patients do not tolerate an ACE-I or ARB, when no other therapeutic option exists

(Dickstein et al., 2008; Hunt, 2005; Krum et al., 2006)

Conclusion

The burden of CHF to the individual, their family, the community and the health care sector warrants the significant attention that is being directed at improving health outcomes for the large numbers of people diagnosed with this syndrome. This chapter has provided an overview of CHF, illustrating it is a complex syndrome that makes diagnosis problematic. Once diagnosed with CHF the outlook can be dismal for many patients. Up to two-thirds will be readmitted for worsening symptoms within 180 days of diagnosis and at best only half will survive five years (Goldberg et al., 2005; Ko et al., 2008; Levy et al., 2002). Programs of care have emerged over the past 20 years to improve the health outcomes associated with CHF. There are a variety of strategies that are considered integral to CHF-MPs, one aspect being the prescribing of medications that have been shown to improve survival, reduce symptoms and prevent ongoing myocardial damage. The following Chapter will discuss the support and education required to promote self-care care, which is perceived to compliment and help achieve maximal benefits from the pharmacological management.

Chapter 2: The Contemporary Issues on Self-care in Patients with Chronic Heart Failure

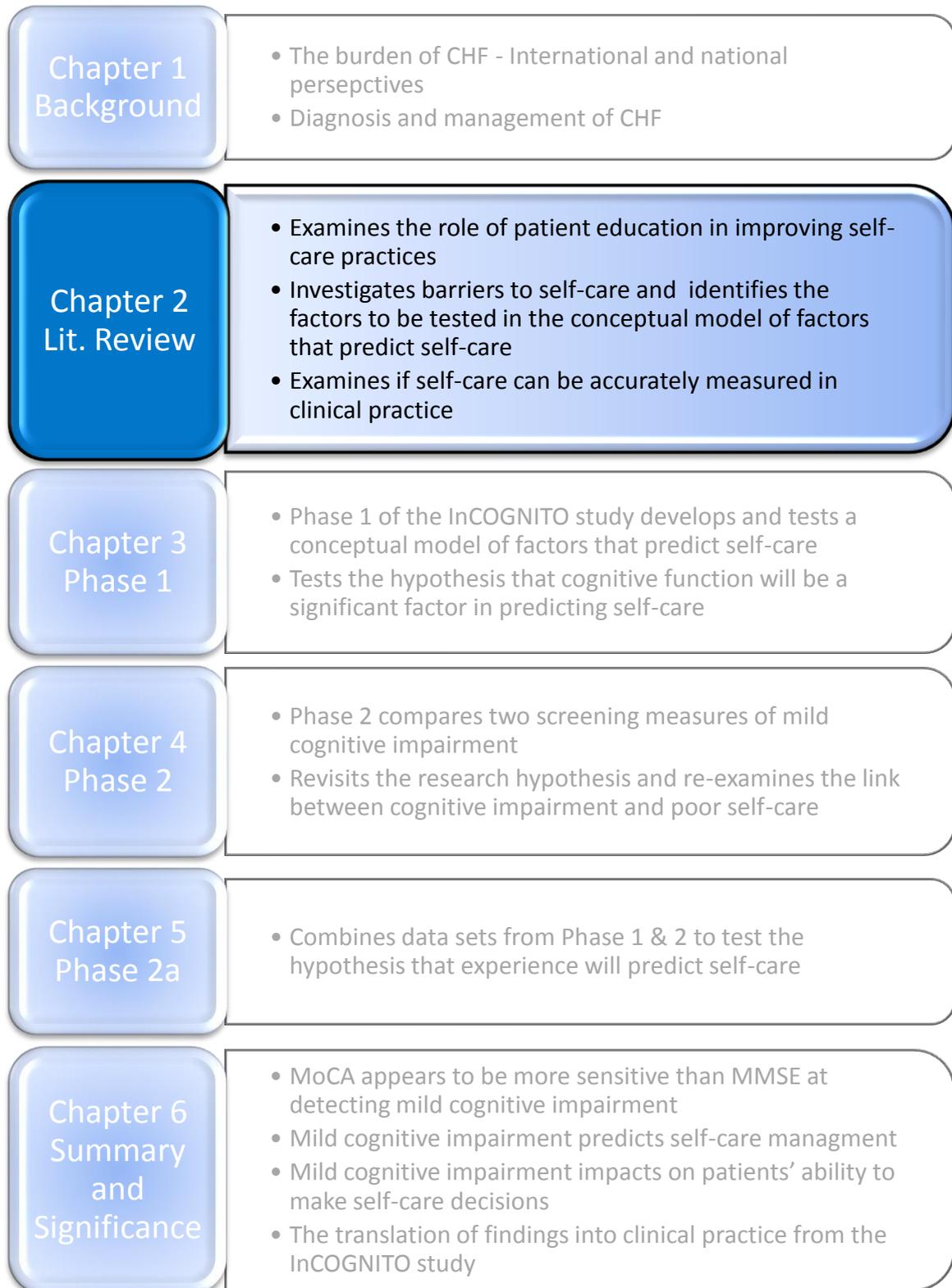


Figure 7: Overview of Chapter 2

Overview of Chapter 2

The aims of the Chapter are to establish the role of self-care in the long-term management of patients with CHF. The first comprehensive literature review was undertaken to demonstrate changes in self-care practices from patient education strategies applied in randomised controlled studies. In examining the literature it became evident that a myriad of factors help to explain why self-care is often less than adequate. Therefore, barriers that may impede teaching efforts directed at achieving optimal self-care will also be examined in this Chapter. This evidence will establish the variables included in testing the 'InCOGNITO' conceptual model (Phase 1 and 2). In the first literature review, it was difficult to reach firm conclusions as to improvements in self-care skills as valid instruments to measure this construct were infrequently used. This led to a second in-depth literature review which aimed to identify psychometrically sound instruments that have been developed to measure changes in self-care skills and behaviours. From the second literature review it became evident that the European Heart Failure Self-care Behaviour Scale (Jaarsma et al., 2003) and the Self-care Heart failure Index (Riegel et al., 2004) are the only two reliable and valid instruments currently available to assess changes in self-care. In this chapter, the psychometric attributes of these measures will be described. The second literature review provides the rationale for the instrument chosen to measure self-care in the conceptual model for the present study. While the aim of developing a conceptual model was to identify factors that predict self-care, there was a strong clinical justification behind this rationale. By reviewing the tools that have been developed to measure self-care behaviours it was deemed important that such information would be relevant to nurses working in CHF-MPs (Cameron, Worrall-Carter, Driscoll et al., 2009).

As previously alluded to, the overall aim to the research program was to develop a conceptual model of factors predicting self-care. A secondary aim was to establish whether a link exists between cognitive impairment and inadequate self-care. This Chapter therefore, presents the literature surrounding barriers to self-care and establishes why cognitive impairment is such a significant issue in patients with CHF. By synthesising the literature it will become evident as to the inclusion of factors examined

in the 'InCOGNITO' conceptual model. The testing of the conceptual model will be presented in Chapter 3 (Phase 1) and Chapter 4 (Phase 2).

Introduction to Chapter 2

Inadequate scare has been identified as a proximate reason why patients often present to hospital for admission (Bennett et al., 1998; Krumholz et al., 2000). Consequently patient education and counselling is deemed an essential strategy in CHF-MPs to support patients and their families in adopting self care behaviours (Adams et al., 2006c; Krum et al., 2006). In a number of randomised controlled studies it has been demonstrated that self-management interventions applied have a significant cost saving benefit by reducing the number of hospital readmissions (Jovicic et al., 2006). Yet despite the attention that is given to this health outcome, achievement of optimal self-care is difficult for most patients to attain (Riegel, Driscoll et al., 2009). Consequently, a gap remains in the literature as to the optimum timing and intensity required to teach self-care and to determine the most efficacious strategies that should be applied in CHF-MPs (Jaarsma et al., 2008).

The Emergence of Self-care in Chronic Diseases

The term 'self-care' has been used for almost fifty years to represent the active participation of patients' in their treatment (Creer & Burns, 1979). The World Health Organisation (1983) perceive self-care as the process of engaging individuals, families or communities to take responsibility for managing aspects of their health and adopting behaviours that prevent disease, limit illness, and restore health. Likewise Dorothy Orem (2001), also recognises that humans function with a deliberate intention towards maintaining healthy functioning and well-being. Nursing interventions are required when self-care needs arising from health problems or specific life stages, exceed their own self-care ability. Corbin and Straus (1988) identify three tasks for self-care:

1. The medical management of the condition such as taking medications,
2. Actions that involve maintaining, changing and creating new meaningful behaviours,
3. Dealing with the emotional sequela

Self-care has emerged as a means of empowering patients to have more control over their daily lives through active participation in their management by purposely engaging in healthy behaviours, symptom monitoring and implementing a course of actions that can lessen debilitating symptoms (Connelly, 1993; Lorig, 2003; Orem, 2001; Thorne, Paterson, & Russell, 2003; Wilson & Mayor, 2006).

A primary objective of self-care is to promote the health status of individuals and reduce the need for acute health-care services. These objectives are achieved through a range of behaviours, knowledge and attitudes that enable individuals to cope with the impact of their chronic condition on physical functioning, emotional and social health (Lorig, Mazonson, & Holman, 1993). The development of collaborative relationships between primary care physicians, patients and their families is integral to supporting individuals to participate in their care, goal-setting and planning of treatment (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997; Wagner et al., 2005).

Health programs that aim to teach self-care have emerged as a result of the increasing prevalence of chronic conditions which have the potential to cause significant disability, premature mortality and a poor quality of life (Lorig & Holman, 2003). In comparison to usual care, these self-management programs have demonstrated long-lasting health outcomes, including a decrease in severity of symptoms, reduction in visits to the doctor and increased self-efficacy to self-manage their chronic condition (Lorig, Ritter, Laurent, & Fries, 2004).

On a daily basis patients have to make a range of decisions in response to changes in their health status, these decisions are often made in the context of other life influences and without input from health professionals (Schnell, Naimark, & McClement, 2006). A range of health skills are deemed essential in order for patients to adequately perform self-care tasks; problem solving, decision making, accessing health resources,

developing a patient/health care provider partnership, taking action (Lorig & Holman, 2003). Consequently, patient education has been directed to increasing knowledge as well as the application of supporting strategies directed at improving health skills.

The Construct of Self-care in Chronic Heart Failure

For the purpose of this thesis it is important to discuss in detail the construct of self-care for patients with CHF. The Situation Specific Theory of CHF self-care developed by Riegel & Dickson (2008) describes the decisions made by patients with CHF in self-managing their symptoms. This conceptual model informed the development of the SCHFI as a measure of self-care behaviours and decisions in persons with CHF (Riegel et al., 2004). Naturalistic Decision-making (Lipshitz, Klein, Orasanu, & Salas, 2001) underpins the conceptual model which helps to explain how individuals' make decisions and why different actions may be undertaken for the same problem. Five characteristics exemplify naturalistic decision-makers:

- These individuals are skilled decision-makers
- They use decision rules that match the situation and the action
- They let the context influence decisions made
- They focus on process rather than outcomes
- They base practical decisions on the empirical information available at that moment (Lipshitz et al., 2001, p. 332)

In reality, naturalistic decision-makers develop expertise over time and use this knowledge to make cognitive decisions and anticipate the outcome of such actions. Factors most influential in developing expertise are knowledge, experience, skill and behaviours that are compatibility with personal values. These four factors will influence the cognitive decisions made by individuals (Riegel & Dickson, 2008). Riegel et al (2004) identifies three domains to CHF self-care: self-care maintenance, self-care management and self-care self-confidence (See Table 6: Behaviours, decisions and scoring for SCHFI). Each domain of CHF self-care is associated with different behaviours and skill sets. These three domains are measured in the Self-care Heart Failure Index (SCHFI).

Table 6: Behaviours, decisions and scoring for SCHFI

SCHFI Domain	Behaviours assessed	Scoring
Self-care maintenance	<p>Adherence with:</p> <ul style="list-style-type: none"> • Daily weighing and checking ankles for swelling • General health maintenance behaviours • A low sodium diet • Physical activity and exercise • Medications and methods used to help with compliance 	<p>10 items with likert scale ranging from 1-4. Summary scores transformed to a range from 0 to 100</p>
Self-care management	<p>Trouble breathing or ankle oedema in past 3 months</p> <p>Recognition of symptoms (ankle oedema or trouble breathing)</p> <p>Assessment of self-care actions implemented (reduce salt or fluids, take an extra water pill, call health professional for guidance)</p> <p>Evaluation of the effectiveness of remedy implemented</p>	<p>If no symptoms are reported in the past 3 months this domain is not computed. Otherwise summary scores from all items are transformed to a range from 0 to 100</p> <p>1 item with a Likert scale ranging from 1-4</p> <p>4 items with a Likert scale ranging from 1-4</p> <p>1 item with a Likert scale ranging from 1-4</p>
Self-care self-confidence	<p>Level of confidence to:</p> <ul style="list-style-type: none"> • Keep free of CHF symptoms • Follow treatment advice given • Evaluate importance of symptoms • Recognise changes in health • Do something to relieve symptoms • Evaluate how well remedy works 	<p>6 items with a Likert scale ranging from 1-4. Summary scores transformed to a range from 0 to 100</p>

(Riegel et al., 2004)

It appears that CHF self-care is not purely learning appropriate behaviours but is a complex decision making process that requires patients to develop capacity to observe themselves, make sensible judgments about symptom changes, implement an action or remedy and feel confident to recognise desired outcomes (Carlson et al., 2001; N. Clark & Gong, 2000; Riegel et al., 2004; Riegel & Dickson, 2008).

Patient Educational and Counselling Strategies in CHF-MPs

In order for patients with CHF to acquire the skills and knowledge to master self-care it is considered crucial that education is commenced in hospital and supplemented with continued reinforcement, on an ongoing basis (Edwardson, 2007). Patient education topics that are recommended from Best Practice Clinical Guidelines in Australia (Krum et al., 2006), Europe (Dickstein et al., 2008) and the United States (Adams et al., 2006c; Hunt, 2005) are summarised in Table 7 (p.62).

While best-practice guidelines provide recommendations on the content of CHF education, they do not guide the methodological approach to teaching patients self-care skills. As previously mentioned, symptom management is very complex for patients with CHF. Table 8 (p. 63) provides a synthesis of self-care decisions that may be required in response to symptom monitoring behaviours (Adams et al., 2006c; Dickstein et al., 2008; Krum et al., 2006; Riegel, Moser et al., 2009). These self-care skills are deemed pivotal in optimising the health of patients with CHF.

Table 7: Summary of self-care behaviours recommended

Education Topic	Self-care behaviours modification
General advice	Physiology of CHF, Signs and symptoms of congestive heart failure, self-monitoring, how to recognise symptom changes, rationale of medical treatments, importance of compliance with treatments, prognosis
Medications	Effects, dose and timing, side effects and adverse effects, what to do in case of skipped dose, self-management Drugs to avoid Importance of annual vaccinations
Weight control	Regular weighing, when to report sudden increases or decreases Ideal body weight and importance of maintaining ideal BMI (>20 and <40)
Sodium restriction	Rationale and how to restrict sodium intake to 2000mg/day
Fluids	Importance of monitoring fluid intake, when to increase or decrease fluid intake Limiting alcohol intake and why
Smoking	How and why to quit smoking
Rest and exercise	Energy conservation and pacing Importance of exercise Exercise training and benefits of rehabilitation Sexual Activity
Travel	Places to avoid, means of travel and how to avoid complications during journey Adapting to climatic changes

(Krum et al., 2006; Dickstein et al., 2008; Adams et al., 2006c; Hunt, 2005)

Table 8: Symptom monitoring, behaviours and self-care for CHF

Behaviour	Symptoms for patients to observe	Self-care decisions /action
Fluid Management and Symptom Monitoring	<ul style="list-style-type: none"> • Sudden increase in weight of >1.5kg • Increasing peripheral oedema • Abdominal bloating and loss of appetite / nausea • Fingerprint indentations left on skin after pressure applied • Worsening breathlessness, especially at night and difficulty holding a conversation • Nocturnal cough and sleeping on an increasing number of pillows • Reduced exercise capacity • Increased lethargy and excessive daytime drowsiness • Sudden weight loss of >2 kg, dry mouth, increased thirst and reduced urine output 	<ul style="list-style-type: none"> • Reduce fluid intake to 1.5-2.0 litres • Reduce sodium intake <2 g/day • Continue to take all medications as instructed by your doctor but consider taking an extra diuretic • Sleep on extra pillows or in recliner • Report symptoms if no improvement • Pace yourself • Report symptoms and seek help with any psychological problems • Temporarily cease fluid restriction and report symptoms
Maintenance of a regular exercise program	<ul style="list-style-type: none"> • Lethargy, reduced exercise capacity and lack of motivation to undertake exercise • Need for more rest periods • Increasing angina 	<ul style="list-style-type: none"> • Attend cardiac rehabilitation program and maintain regular aerobic and strength training exercise program • Plan your day and pace yourself (energy conservation and pacing) • Keep as active as possible but ask for help to attend with heavy activities • Discuss symptoms with your doctor / physiotherapist
Adherence with prescribed medications	<ul style="list-style-type: none"> • Repeat prescriptions not obtained • Confusion due to polypharmacy and frequent changes to doses • Increased dizziness, especially on standing up quickly • Side effects of medications interferes with social activities • Occasionally missing medications 	<ul style="list-style-type: none"> • Make regular appointments with your doctor/cardiologist to review medications • Ask for clear written medication instructions to help in understanding your medications • Understand your medications and establish best timing for diuretic and cardiac medications • Discuss alternative times of taking medications • Use dosette box or daily reminders • Involve pharmacist in solving medication problems

Behaviour	Symptoms for patients to observe	Self-care decisions /action
Nutritional management	<ul style="list-style-type: none"> • Acknowledgement of being overweight • Abnormal weight loss and muscle wastage • Constipation 	<ul style="list-style-type: none"> • Set goal weight, reduce calorie and fat intake, exercise regularly • Eat small high calorie meals frequently • Discuss nutritional problems with a dietician • Use vitamin supplements • Maintain high fibre diet • Eat small regular portions
Reduce alcohol and avoid tobacco use	<ul style="list-style-type: none"> • Unable/ unmotivated to quit smoking and/or reduce alcohol intake 	<ul style="list-style-type: none"> • Ask for help in refraining from the use of these substances • Talk to your doctor/nurse about learning to live with CHF
Yearly flu vaccination	<ul style="list-style-type: none"> • Readmissions to hospital during winter months with chest infections 	<ul style="list-style-type: none"> • Maintain regular follow-up with local doctor

(Adams et al., 2006c; Dickstein et al., 2008; Krum et al., 2006; Riegel, Moser et al., 2009)

The previous two tables highlight the need for intensive education and counselling directed to supporting patients achieve adequate skills and the capacity to make appropriate self-care decisions on an independent basis. In view of the significant attention paid to teaching and supporting patients to practice self-care, a literature review was conducted to explore if patient education resulted in changes to self-care practices. The outcome of this literature review was the publication of the manuscript 'Extent of Heart Failure Self-Care as an Endpoint to Patient Education: A Review of the Literature' (Cameron et al., 2007) which is presented in Appendix A.

Method of the Literature Exploring Randomised Controlled Studies of Patient Education

Comprehensive literature searches using CINAHL (January 1982 to November 2006); Medline, (January 1966 to November 2006) and FullText Clinicians Health Channel databases were carried out to find relevant articles. Further publications were identified by reviewing the reference lists of all previously obtained articles. The key words used in the searches were *heart failure, education, self-care, self-management* and *measures*.

Inclusion criteria comprised of: randomised controlled studies (RCTs) with patient education as the only intervention and study cohort of patients with CHF. The outcome that was investigated was improved self-care behaviours. Two of the reviewers, blinded to each others choices determined which RCTs met the inclusion criteria for this review.

Results

Ten studies met the inclusion criteria and are summarised in Table 9: Summary of randomised studies of heart failure patient education. Thirty-two studies were excluded because they did not meet the inclusion criteria. Outcomes measured were: clinical events such as hospital readmissions and mortality (Harrison et al., 2002; Krumholz et al., 2002; Sethares & Elliott, 2004); changes in patients' knowledge in regards to their management plan (Bjorck Linne, Liedholm, & Israelsson, 1999; Caldwell, Peters, & Dracup, 2005; Serxner, Miyaji, & Jeffords, 1998; Stromberg, Dahlstrom, & Fridlund, 2006); changes in self-care behaviours (Caldwell et al., 2005; DeWalt et al., 2006; Jaarsma et al., 1999; Koelling, Johnson, Cody, & Aaronson, 2005; Serxner et al., 1998; Sethares & Elliott, 2004); changes in quality of life (DeWalt et al., 2006; Harrison et al., 2002; Jaarsma et al., 1999; Koelling et al., 2005; Sethares & Elliott, 2004; Stromberg, 2006). Overall, the studies differed from one another in five critical areas: patient population; health outcomes measured; quality of the study; who provided the education; and timing of the intervention.

Table 9: Summary of randomised studies of heart failure patient education

Author	Sample Population	Randomisation	Intervention Time Period / where occurred	Educational intervention	Theoretical framework	When and what Outcomes Measured	Summary of Results
Serxner et al. (1998) USA	n= 109 Exclusions not recorded 42% >75 years	Randomisation by admin staff in the quality improvement department	16 weeks Post discharge	Personalised letter, pamphlets and booklets sequentially mailed to patients. Topics covered: management of CHF, healthy eating, risk factors, lifestyle behaviours, medications and a resources guide for seniors.	Behavioural model but not specified	Pre and post interventions Investigator developed CHF knowledge, attitudes, self-efficacy and self-care behaviours questionnaires. Hospital readmissions Return-on-investment analysis	Significantly more of the intervention group reported changes in CHF self-care (positive dietary changes, reported weighing practices and knowledge of symptom changes to report). Patients in the intervention group reported significantly more confidence in their ability to manage CHF and rated themselves healthier than did the control group. The return on investment was \$19:1 from fewer hospital readmissions.
Bjorck Linne et al. (1999) Sweden	n=130 345 excluded Mean age 71 years 47% Females	Computer generated randomisation occurred after a control visit 1 week after hospital discharge	Two individual hour-long sessions delivered at week 3 and 4 post discharge	Small group counselling sessions by CHF nurse specialist then by a pharmacist. Patients used an interactive CD-Portfolio program to re-evaluate all the information that had been provided. Topics covered: information on CHF symptoms, self-adjustment of diuretics, effects and side-effects of medications used to treat CHF.	Patient education and counselling using oral, written and an interactive CD-program	At 10 weeks and 6 months Knowledge of symptoms and medications for CHF	Knowledge scores were significantly higher in the intervention group than the control at 1 month and at 6 months.

Author	Sample Population	Randomisation	Intervention Time Period / where occurred	Educational intervention	Theoretical framework	When and what Outcomes Measured	Summary of Results
Jaarsma et al. (1999)	n= 179 458 excluded Mean age 73 years NYHA classification III & IV	Method not discussed Efforts to ensure patients in the differing groups were not nursed in the same room.	Average of 4 hospital visits, 1 telephone call and 1 home visit In hospital and 2 weeks post discharge	Study nurse assessed self-care deficits and developed an education plan based upon them. Topics discussed included recognition of symptom changes, sodium and fluid restrictions, compliance with medications. Patient card with warning symptoms provided and information reiterated at home visit.	Orem's General Theory of Nursing	At 1, 3 and 9 months Self-care abilities using psychometrically validated tools (ASA, EHFSBS) Functional Status (PAIS) Psychosocial Adjustment to Illness (Cantril's Ladder)	At one month self-care behaviours improved in both groups, but control group performed statistically less behaviours than intervention. The initial improvements in self-care behaviours decreased over time but the intervention group continued to perform statistically significant better self-care than control at the 9 months follow-up.
Harrison et al. (2002)	n= 157 exclusions not recorded Mean age 75 years 45% females	A computer-generated schedule	In hospital and for 2 weeks post discharge	Individual structured education-counselling protocol delivered by primary hospital nurse. Topics covered include heart function; self-monitoring; medication management, diet, and exercise, support systems and community resources. PCCHF included an educational plan and transfer letter to the home care nurse.	Patient education and counselling	At 6 and 12 weeks HRQoL (MLWHF and SF-36) ED presentations All-cause hospital readmissions	Quality of life scores on MLWHF improved in both groups over time but at 12 weeks improvement for TC was statistically greater than usual care. TC had significantly fewer visits to the emergency room and less multiple visits compared with usual care. Fewer hospital admissions in TC compared with usual care but this was not statistically significant.

Author	Sample Population	Randomisation	Intervention Time Period / where occurred	Educational intervention	Theoretical framework	When and what Outcomes Measured	Summary of Results
Krumholz et al. (2002)	n= 88 248 excluded Median age 74 years 57% males	Randomisation not discussed	Initially hour long face-to-face then phone contact on weekly basis for four weeks, biweekly for eight weeks, monthly for remaining twelve months. Post discharge	Individualised one-to-one education session with an experienced cardiac nurse developed from the patient's understanding of the 5 sequential care domains for chronic illness. Telephone follow-up reviewed knowledge of care domains and provided support for patients to apply their knowledge, participate in managing these domains and effectively seek access care. Strategies were offered to empower patients and improve their compliance.	Patient educational and counselling based on 5 sequential care domains for chronic illness	1 year Mortality Readmissions (all-cause and HF-related) Cost benefit	Fewer patients in the intervention group than the control died but this was not statistically significant. Statistically fewer patients in the intervention group had at least one readmission or died during follow-up. Significantly more patients in the control group experienced greater than one readmission. The intervention resulted in a significant reduction in HF or other CVD readmissions. Hospital readmission costs were statistically higher in the control group by an average of \$7,515 per patient.
Sethares et al (2004)	n=70 Numbers excluded not recorded Mean age 76yrs 53% males	Randomisation by sealed envelope	In hospital, at 1 week and at 1 month after discharge The tailored messages were delivered by the research nurse and took an average of 15 minutes to deliver.	A tailored message delivered by the research nurse based upon on the patient's beliefs about dietary compliance, medication compliance and self-monitoring compliance. Three validated Health Belief Scales were used. Persons scoring above 3 on a barrier question and below 4 on a benefit question received a tailored message to that item.	Health Belief Model	At 1 and 3 months HRQoL (MLWHF) Readmissions Changes in scores on 3 Benefits and Barriers scales were recorded in the intervention group.	Fewer individuals in the intervention group were readmitted than in the control but this was not statistically significant. There were significant within-subject differences in quality of life measures at the 2 time points but differences in quality of life scores between the intervention and the treatment groups were not significantly different. Benefits of medication scores did not change significantly during the study. There were significant changes in all other benefit and barrier items in the direction hypothesized.

Author	Sample Population	Randomisation	Intervention Time Period / where occurred	Educational intervention	Theoretical framework	When and what Outcomes Measured	Summary of Results
Koelling et al. (2005)	n= 223 367 excluded Mean age 65 years 34% females	By computer program	1 hour In hospital	One-to-one education session with a nurse educator. Topics covered: causes of CHF and its management, specific instructions to reduce sodium and fluid intake, rationale for self-care behaviours	Patient education and counselling	At 30, 90 and 180 days Disease specific HRQoL (MLWHF) investigator developed 6-item questionnaire assessing self-care behaviours 180 day event free survival and days of hospitalisation Cost benefit	Initial improvements in quality of life in the education group compared to control but at 180 days this difference was not statistically significant. Sum of 6 self-care measures significantly higher for education group than control. Event free survival significantly longer for education group. Cost of care higher in control group by \$2823 per subject
Caldwell et al. (2005)	n = 36 Mean age 71yrs 31% females	Randomisation not discussed	1 education session conducted in their physician's office or the patient's home. 1 Telephone follow-up call a month later	One-to-one education using a high-impact flip chart. Topics covered causes of CHF, signs and symptoms, importance of daily weights and when to seek help. Potential barriers to care were also discussed. Patients received written information and a weight chart.	Patient education and counselling	At 3 months. CHF knowledge. Self-care behaviours using an abbreviated version of a psychometrically validated questionnaire. Severity of CHF (BNP level)	Knowledge level significantly higher in intervention group (p=0.01). Total score for self-care behaviours significantly higher in the intervention group (p=0.03). Although weighing behaviours were better in the intervention group there were no differences between the groups related to seeking help with worsening symptoms. Severity of CHF was NS different between the groups

Author	Sample Population	Randomisation	Intervention Time Period / where occurred	Educational intervention	Theoretical framework	When and what Outcomes Measured	Summary of Results
DeWalt et al. (2006)	n=123 801 excluded Mean age 62.5yrs 50% females	Randomisation by concealed allocation based on a random number generator	1 hour education session with a clinical pharmacist or health educators conducted in the General Internal Medicine clinic. 9x 5-15 minute follow-up calls	One-to-one education using educational booklet designed for low literacy patients used to teach signs of exacerbation, assessment of daily weight and adjusting diuretic dose. Patient's ideal weight established and baseline diuretic dose and self-adjustment regimen. Follow-up calls made by program co-ordinator	Pedagogic education and counselling strategies	6 and 12 months Death or all-cause readmission QoL (MLHF) Self-efficacy, knowledge and weighing behaviours using investigator developed tools	Patients in the intervention group had a lower rate of hospitalisation or death (crude incidence rate ratio =0.69; CI 0.4, 1.2). Differences in improved QoL were not statistically significant between the two groups. Knowledge of CHF improved more in the intervention group (p<0.001) as did self-efficacy (p=0.0026). Significantly more patients in the intervention group recorded a daily weight (79% vs 29%p<0.001).
Stromberg et al. (2006)	n=72 Mean age 70yrs 29% females	Randomisation by computer-generated list of random numbers	30-45 minute inter-active CD-ROM education program in addition to patient education from a CHF nurse	Animated CD-ROM program with touch screen buttons	Patient education and counselling	CHF knowledge and compliance questionnaire using investigator developed tools QoL (EuroQoL) 1 month and 6 months	The increase in knowledge was significantly higher in the intervention group. Changes in compliance were not statistically different between the control and intervention groups at 1 or 6 months. Improvements in quality of life were not statistically significant between the groups at 1 or 6 months

Legend: ED- Emergency Department, PCCHF – Partner is Care for Congestive Heart Failure; BNP – Brain natriuretic peptide; NS- Not Statistically Significant; HRQoL – Health Related Quality of Life; MLWHF – Minnesota Living With Heart Failure Questionnaire; EHFS CBS – European Heart Failure self-care Behaviour Scale; ASA – Appraisal of Self-care Agency Scale; PAIS – Psychosocial Adjustment to Illness Scale; NHYA – New York Heart Association functional class; SF-36 – Medical Outcome Study Short Form; TC – Transitional Care

The Sample Population

Despite the ten studies recruiting 1064 elderly patients (mean ages 62 -76 years) with CHF, fundamental differences existed in patients' experience with the syndrome. Three studies (DeWalt et al., 2006; Jaarsma et al., 1999; Sethares & Elliott, 2004) recruited patients who had been diagnosed for more than three months (n= 372) whereas six studies recruited only those patients who were newly diagnosed (n=692). One study (Caldwell et al., 2005) had not specified the length of time that patients had been diagnosed but indicated that patients with NYHA I classification were included as long as they had an unplanned admission to emergency department within the previous twelve months for CHF. According to current guidelines (Krum et al., 2006) such patients may not be considered to have CHF, although it can be argued that they may have become symptom free because of optimal therapy.

Health Outcomes Measured

There was some consistency in measuring health related quality of life with four out of the six studies utilising the Minnesota Living with Heart Failure questionnaire (DeWalt et al., 2006; Harrison et al., 2002; Koelling et al., 2005; Sethares & Elliott, 2004). Generally it was reported that over time there were improvements in health related quality of life, irrespective of being randomised to an intervention. Only one study reported significant differences in quality of life scores between the control and intervention groups (Harrison et al., 2002). This suggests that perceived quality of life improves over time, independent to the education intervention. Indeed some authors would argue that the dose effect of education and counselling strategies directed at elderly patients with advanced heart failure is not sufficient to result in improvements in quality of life (Jaarsma et al., 1999; Riegel, Moser et al., 2002).

Although seven studies identified a link with self-care management as an outcome only three used validated instruments to measure change (Caldwell et al., 2005; Jaarsma et al., 1999; Sethares & Elliott, 2004). Jaarsma et al. (1999) utilised the Heart Failure Self care Behaviour Scale (HFScBS) which consists of 19 items that cover three dimensions of

CHF self-care: compliance with self-care maintenance behaviours such as fluid and sodium restriction; seeking help when symptoms change; and adaptive activities such as eating a low salt diet. The maximum score is 60 and is obtained from 12-items with a five-point Likert-scale that rates how much the patient agrees with each of the twelve statements. Cronbach's α ranged from 0.62 to 0.68 indicating it was a valid and reliable scale. Initially, changes in self-care behaviours in both groups were evident however, it was the intervention group that complied with more behaviours than the control (14.2 ± 2.9 vs. 12.2 ± 2.9 , $t=3.8$, $p<0.001$). Over time CHF self-care behaviours decreased in both groups. Nevertheless, the intervention group continued to comply with more self-care behaviours than did the control group although this difference was not statistically significant (11.2 ± 3.1 compared with 10.3 ± 2.8 , $t=1.6$, $p=0.11$). Although the inpatient education intervention resulted in superior CHF self-care behaviours these were not sustained over time.

Caldwell, Peters and Dracup (2005) had also used the HFScBS (albeit an abbreviated version using only four of the self-care statements) with no indication that the shortened version was equally reliable. The intervention influenced patient's daily weight monitoring however, this did not translate to improved self-reported behaviours related to seeking help with shortness of breath, swollen feet or weight gain. Sethares and Elliott (2004) also reported significant improvements in beliefs as to the benefits of taking medications, following a sodium-restricted diet and self-monitoring for signs of fluid overload. Changes in beliefs were measured using scales to measure the benefits and barriers to the three self-care behaviours. Psychometric evaluation of the tools had previously proven satisfactory internal consistencies (0.87 for benefits of medications, 0.91 for barriers to medication, 0.84 for benefits of diet and 0.69 for barriers of diet) and confirmatory factor analysis had shown a 2-factor solution for each of the scales (Bennett et al., 2001). Scores on the three scales were recorded at baseline and one month follow-up. There were statistically significant decreases in barrier scores to taking medications ($p<0.01$), sodium restricted diet ($p<0.01$) and self-monitoring ($p<0.01$). Similarly, the changes in benefit scores on two of the three scales significantly improved from baseline to one-month follow-up: sodium restricted diet ($p<0.01$), self-monitoring ($p<0.01$) (Sethares, 2003).

Although four researchers (DeWalt et al., 2006; Koelling et al., 2005; Serxner et al., 1998; Stromberg et al., 2006) had also reported improvements in self-care, they had implemented an investigator developed tool to measure self-care without necessarily emphasising the instruments' reliability and validity. This was a limitation to their studies and may have resulted in biased results in regards to changes in self-care (LoBiondo-Wood & Haber, 2002).

Changes in Knowledge

Knowledge is an essential factor in the development of self-care skills. Four of the studies reviewed measured changes in knowledge (Bjorck Linne et al., 1999; Caldwell et al., 2005; DeWalt et al., 2006; Stromberg et al., 2006). Knowledge levels increased after one month in both groups who received a standard education program (Stromberg et al., 2006). However over a six month period, there were statistically higher increases in knowledge ($p=0.03$) in patients who received the standard education which had been supplemented with a computer-based education intervention (Stromberg et al., 2006). Likewise, Caldwell, Peters and Dracup (2005) reported significantly higher ($p=0.01$) knowledge levels in the intervention group, three months after receiving an education program and one follow-up call that focused on symptom management advice. At the 12-month follow-up period (DeWalt et al., 2006), patients who had received a picture-based education intervention had significantly higher heart failure related knowledge scores than patients in the control group ($p<0.01$). Patients who received the application of a 3-hour interactive CD-Portfolio education program had higher knowledge scores ($p<0.01$) than patients in the control group (Bjorck Linne et al., 1999). Some caution is required in interpreting these positive findings as only one group of researchers (Caldwell et al., 2005) reported the reliability or validity of the instrument used to assess changes in knowledge.

Improved Health Outcomes

Many of the studies reviewed measured improvements in other important health outcomes such as hospital readmissions (DeWalt et al., 2006; Jaarsma et al., 1999;

Krumholz et al., 2002; Serxner et al., 1998), mortality (Koelling et al., 2005; Krumholz et al., 2002) and cost savings (Koelling et al., 2005; Krumholz et al., 2002; Serxner et al., 1998).

Using an intervention of educational materials posted out to patients over a three month period Serxner et al., (1998) reported the intervention resulted in 52% fewer hospital admissions with a cost-saving to the hospital of \$172,790. Likewise, DeWalt et al (2006) reported their education intervention resulted in a significant reduction in hospitalisation or death in comparison to the control group (adjusted incident rate ratio=0.53, CI 0.32 to 0.89). In an evaluation of a 1-hour education session as a component of the discharge process (Koelling et al., 2005), patients who received the intervention had a lower risk of death or hospitalisation compared with the control group (RR, 0.65; 95% CI, 0.45 to 0.93, $p < 0.02$), resulting in significantly reduced health care costs ($p < 0.05$). An intensive education program delivered over a 12-month period (Krumholz et al., 2002) resulted in a reduced risk of readmission (hazard ratio=0.56, 95% CI: 0.32 to 0.96, $p = 0.03$) but not a reduction in mortality (RR=0.69, 95% CI: 0.33 to 1.45; $p = 0.33$). The reduction in hospital admissions resulted in significantly lower costs per patient ($p = 0.04$) (Krumholz et al., 2002).

Although three studies (Harrison et al., 2002; Jaarsma et al., 1999; Sethares & Elliott, 2004) reported that their education interventions resulted in a trend towards a reduction in hospital readmissions, the differences were not statistically significant. Reasons given to account for these findings were that the sample sizes were not significantly powered to detect this health outcome.

Educational Intervention Applied

Only three of the studies had clearly identified the model or theory that underpinned the development of the education interventions (Jaarsma et al., 1999; Krumholz et al., 2002; Sethares & Elliott, 2004). For example, Sethares and Elliott's (2004) developed educational interventions underpinned from the Health Belief Model (Rosenstock, 1974), whereby patient's health beliefs were assessed in regards to three CHF self-care behaviours: adhering to a low sodium diet; complying with their medication

regimen; and self-monitoring symptoms. Education interventions were then applied according to patients' responses on the health belief scales. Persons scoring above a cut-score on a barrier question or below a cut-score on a benefit question received tailored education to directly address that behaviour.

Overall, it would appear that most of the studies reviewed had delivered the information in a format that was more "didactic" than acknowledging an individual's learning needs. For example, Serxner, Miyaji and Jeffords (1998) sequentially mailed to the patient over a 16 week period, information regarding CHF, healthy eating and lifestyle behaviours. Although the results demonstrated improved self-care practices, it was sometimes the spouse who completed the outcome questionnaires. It was therefore, difficult to know whether patients had read the information and consequently made lifestyle adjustments. A drawback with didactic strategies is that they are predominantly used to teach technical skills and do not necessarily acknowledge the recipients current level of understanding, nor their readiness to learn or move towards health behaviour change (Bodenheimer, Lorig, Holman, & Grumbach, 2002).

Who Provided the Education?

In all ten studies education was primarily delivered by a nurse although two studies (Bjorck Linne et al., 1999; DeWalt et al., 2006) also involved a pharmacist. Nonetheless, it would appear that the expertise of the nurses varied across the studies. Although Caldwell et al. (2005) demonstrated that registered nurses with no prior specialised cardiovascular training can deliver a simplified education program. Rollnick, et al. (2002) argue that counselling patients requires a degree of expertise, not only on the principles of adult education and health behaviour change but also the course of the disease itself. Without these skills, patient education tends to be an advice-giving strategy; whilst this may increase patients' knowledge it is not necessarily a sufficient strategy for health behaviour changes and self-care management (Stromberg, 2002). Therefore, differences in the expertise of the nurses to educate patients may have some influence on health outcomes that were reported.

Timing of the Interventions

Patient education occurred during the hospital admission in three of the studies reviewed (Harrison et al., 2002; Jaarsma et al., 1999; Koelling et al., 2005). The other studies provided patient education post discharge. The length of time spent delivering the education varied from forty-five minutes (Stromberg et al., 2006) to ongoing counselling over twelve months (Krumholz et al., 2002). Despite using a sound nursing theory from which to identify patient self-care deficits and develop individual educational strategies, Jaarsma et al. (1999) identified the short duration of the intervention may have been a limitation to their study. For this reason it may help to explain why self-care behaviours were not maintained in the longer-term. This suggests that in order to adequately teach CHF self-care behaviours it requires ongoing counselling, as was evident in the study by Krumholz et al. (2002).

As previously alluded to, self-care is a major strategy in the long-term management of CHF. The purpose of this review was to examine education strategies directed at improving self-care skills. Only three studies directly assessed improved self-care with a validated measure as an outcome of the intervention. Other health outcomes that appeared to improve as a result of the education intervention applied included hospital readmissions and quality of life.

It has been recommended that measuring improvements in self-care skills and behaviours can be used as an evaluation of patient education and counselling (Jaarsma et al., 2003). In this manner it will become evident as to both successful and less successful strategies where changes may be required in the application of educational and support strategies. Furthermore, assessing individuals' knowledge and understanding of self-care on enrolment in a CHF-MP can help in the formulation of an individualised education and counselling care plan (Stromberg, 2005).

Determining the Optimum Time and Intensity for Patient Education

Patient education and counselling is crucial for patients with CHF to acquire the skills and knowledge necessary to master self-care (Edwardson, 2007). Self-care has been

described as a non-pharmacological strategy in the management of CHF (Heart Failure Society of America, 2006). It has been recommended that patient education should begin during the hospital admission but needs to continue on an ongoing basis post discharge (Hunt et al., 2005; Krum et al., 2006; Swedberg et al., 2005). Furthermore, counselling should be directed at helping patients to develop the necessary “know how” skills, such as being able to select low sodium foods, to recognise symptoms that require either making contact with their health professional for advice or self-medicating an increase in their diuretic (Riegel, Dickson et al., 2006). Despite these recommendations it is unclear from the literature as to the most suitable environment, length of time and level of intensity required to teach patients. From the ten RCTs reviewed the application of patient education interventions were diverse, ranging from short-term inpatient education only (Jaarsma et al., 1999) to ongoing counselling over a 12-month period (Krumholz et al., 2002).

Several studies have shown that patients find it difficult to retain information which has been provided during their hospital admission (Ni et al., 1999; S. Stewart & Pearson, 1999). Other studies (including a meta-analysis) have demonstrated that inpatient education as a standalone intervention is inferior to that subsequently provided in the community setting (McAlister et al., 2004; Naylor et al., 1994; Naylor & McCauley, 1999; S. Stewart, Pearson, Luke, & Horowitz, 1998). Propositions for such findings indicate that patient education undertaken during the in-patient phase can be quite overwhelming because: patients may be physiologically compromised; have reduced concentration because of sleep deprivation and emotional distress. All of these factors make learning difficult (Rankin & Stallings, 2001; S. Stewart & Pearson, 1999). Consequently, the potential impact of home-based strategies in chronic disease states such as CHF, is built on the premise that a more appropriate time to deliver extensive patient education and counselling is when patients are clinically more stable and adjusting physically and emotionally to living with the syndrome (Stromberg, 2005). It is at this time that patients perceive self-management to have greater relevance in their lives (Toman, Harrison, & Logan, 2001).

More recently, Jaarsma et al (2008) compared the effect of moderate or intensive disease management strategies on health outcomes in a multi-centre study involving

1023 patients with CHF. Moderate disease management strategies consisted of four visits to the cardiologist and nine telephone contacts with the heart failure nurse. In addition to moderate disease management strategies patients' receiving intensive interventions had an increased number of phone contacts with the nurse, two home visits and two education sessions provided by a multidisciplinary team. The results demonstrated that neither intervention reduced the combined endpoint of death or heart failure. However, a small non-significant decrease in all-cause mortality which was potentially clinically relevant was found with both interventions. These results demonstrate that more evidence is required to determine the most appropriate level of intensity and follow-up required to improve self-care and health outcomes.

In Chapter 5 there will be an examination of differences in self-care skills between patients newly diagnosed and those with more than two months experience of living with CHF symptoms and exposure to a CHF-MP. The results may provide further information as to the time and resource investment required to support patients achieve an adequate level of self-care.

Development of a Conceptual Model of Self-care

As discussed previously, the aim of the research program was to develop a conceptual model of self-care. In conducting the above literature review it became evident that despite universal attention to developing educational and support strategies, self-care is often inadequate (Riegel, Driscoll et al., 2009). Many factors are construed to account for why optimal self-care skills and behaviours are not easy for most patients with CHF to acquire (Jovicic & Straus, 2007; Moser, 2008; Moser et al., 2005; Riegel, Dickson, Goldberg, & Deatrck, 2007; van der Wal et al., 2006). The following section provides an overview of factors that are perceived to be barriers in developing effective self-care skills and behaviours. This evidence will provide the rationale for determining the variables that will be included and tested in the conceptual model of factors that predict self-care. Of particular concern it will become evident from the following section that cognitive impairment is a particular problem in patients with CHF. This evidence helps to support the rationale for conducting this research program.

Barriers and Stimuli to Developing Adequate Self-care

Regardless of the important role that self-care plays in the management of CHF, adequate achievement of this therapeutic goal is difficult for many. In a study involving 2,082 patients from both developed and developing countries self-care maintenance, management and confidence levels were poor across the whole sample (Riegel, Driscoll et al., 2009). Chronic heart failure is a complex syndrome that predominantly occurs in older people. It has been proposed that a combination of age-related and causal factors can impact on patients' ability to develop the necessary health skills required for proficient and independent practice of self-care behaviours. One other conceptual model has recently been developed which identifies five causal factors that affect decision making and ultimately CHF self-care (Moser & Watkins, 2008). The Life Course Model (Moser & Watkins, 2008) was developed from a comprehensive review of the literature but has not been tested in clinical practice nor have clinical parameters been applied to the factors included. It provides support for the factors tested in the 'InCOGNITO' conceptual models which are discussed below.

Psychological Status

In selected CHF populations up to 69% (Freedland et al., 2003; Lesman-Leegte, Jaarsma, Sanderman, Linssen, & van Veldhuisen, 2006; Moser et al., 2005) of patients have some form of depression which is evident from a variety of valid screening measures. Patients with anxiety and depression are at increased risk of death and cardiac events (Moser & Worster, 2000). Furthermore, depression appears to worsen heart failure symptoms such as dyspnoea and fatigue (Evangelista et al., 2008; Heo, Doering et al., 2008; Ramasamy et al., 2006) which may help to explain why hospital utilisations are greater in CHF patients with co-morbid mental health disorders such as anxiety or depression (Sayers et al., 2007). In addition, depressive symptoms appear to impede the practice of proficient self-care (Riegel et al., 2007; Schnell et al., 2006).

There are many reasons given to explain why self-care may be inadequate in depressed patients with CHF. First, depression appears to be correlated to the presence of cognitive impairment (Gunstad et al., 2006; Lopez et al., 2003). Depressive symptoms

appear to indirectly affect all areas of cognitive function but in particular it can result in slowing or delayed information processing (Butters et al., 2004). This may affect the ability of patients to make decisions at unscheduled and inopportune times, which as discussed previously is an essential element of self-care (Riegel & Dickson, 2008). Second, depression may also have a negative impact on self-efficacy, resulting in worse health outcomes (Jerant, Kravitz, Moore-Hill, & Franks, 2008).

The model of Self-care in Chronic Illness (Connelly, 1993) recognises the important influence that psychological status can have on general self-care behaviours to promote health and prevent illness. Dickson, Deatrik & Riegel (2008) in developing a typology of self-care in patients with CHF found that those without depression and who reported adequate self-confidence, tended to perform CHF self-care more consistently. Others (Tsay & Chao, 2002) have also found that self-efficacy is an important factor in patients' motivation to maintain physical function and has an indirect influence on depression. In a study that sought to investigate whether depression, anxiety or self-efficacy were independent predictors of adherence, it was self-efficacy that strongly predicted adherence with self-care behaviours such as daily weighing and following the medication regimen (Schweitzer, Head, & Dwyer, 2007). Riegel & Dickson (2008) in the Situation Specific Theory of Heart Failure Self-care also recognise that higher self-confidence appears to have a moderating effect on self-care management, resulting in better self-care and health outcomes.

Depression has also been proposed to be a major factor for non-adherence to prescribed medication, dietary regimens and exercise programs (Moser, 2008). Moreover, it is the non-adherence to their management plan that has been identified as a proximate cause for exacerbations of CHF (Bennett et al., 1998; Michalsen, Konig, & Thimme, 1998; Schiff, Fung, Speroff, & McNutt, 2003; S. Stewart & Horowitz, 2002a). These exacerbations result in frequent readmissions and increased mortality (Bennett et al., 1998; Ghali, Kadakia, Cooper, & Ferlinz, 1988; Happ, Naylor, & Roe-Prior, 1997; Opasich et al., 2001). The poor health outcomes associated with depression are therefore attributed to both physiological responses and behavioural effects to anxiety and depression (Konstam, Moser, & De Jong, 2005). In contrast, patients who are not depressed adhere more frequently with self-care resulting in better health outcomes

(Evangelista, Berg, & Dracup, 2001; van der Wal et al., 2006). This evidence suggests that patients with depression and CHF have more to gain from self-management interventions than their counterparts without depression (Jerant et al., 2008).

Social Support

The absence or presence of social supports appears to be a key factor in adherence with self-care. One of the most common factors associated with medication non-adherence appears to be a lack of social support (Happ et al., 1997; Wu, Moser, Lennie, & Burkhart, 2008). In most studies involving patients with chronic diseases (DiMatteo, 2004) and CHF (Happ et al., 1997; Wu, Moser, Lennie, & Burkhart, 2008), living alone is associated with a greater risk of medication non-adherence. In contrast, the presence of adequate social support appears to positively influence adherence with self-care maintenance behaviours such as daily weighing and following a low sodium diet (Sayers et al., 2008). This may reflect the active role of family members in managing diet and medication regimens and making self-care decisions such as, assessing the need to contact a doctor when symptoms change (Horowitz, Rein, & Leventhal, 2004; Molloy, Johnston, & Witham, 2005).

Sebern & Riegel (2008) corroborate the proposition that supportive interpersonal relationships influence adherence to health behaviours and enhance self-confidence. In the 75 patients who were able to share self-care decisions with their partner there was a strong correlation with higher self-care maintenance and confidence (Sebern & Riegel, 2008). Conversely, social supports can negatively influence self-care if the self-care activities conflict with the actions of other family members (Schnell et al., 2006). These studies indicate that a comprehensive psycho-social assessment is a requisite when developing and applying patient education and support strategies. For this reason, social support, self-efficacy and screening for depression were factors included in the conceptual model being tested as part of this study.

Health Literacy

Compounding the problem of teaching and supporting patients with CHF self-care, is the issue that the syndrome is associated with elders who often have poor literacy levels (Laramée et al., 2007; Morrow et al., 2006). In the US it has been estimated that 47% of adults have limited literacy skills (DeWalt, 2007; Gazmararian, Williams, Peel, & Baker, 2003) which contributes to poor health outcomes including knowledge, morbidity, poor health status and increased health care utilisation (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Pignone, DeWalt, Sheridan, Berkman, & Lohr, 2005). It is perceived that one of the mechanisms by which limited literacy leads to poor health outcomes is by its impact on the capacity for self-care (Pignone & DeWalt, 2006).

As previously discussed, optimal self-care requires health skills to process complex information and utilise past experiences to make decisions that are compatible with personal values (Lipshitz et al., 2001). Health literacy is central to self-care and refers to the capacity of individual's to know when to seek medical help, to communicate effectively with health professionals and to adhere to treatment regimens (Jordan, Briggs, Brand, & Osborne, 2008). Although it is recognised that education level is independently associated with health literacy, it appears that cognitive function is likewise correlated (Morrow et al., 2006). As impaired cognitive function occurs frequently in patients with CHF (Vogels, Scheltens, Schroeder-Tanka, & Weinstein, 2007), it could be construed that the interplay between health literacy and cognitive function may also contribute to poor self care.

Two studies (DeWalt et al., 2006; Sisk et al., 2006) have recently suggested that vulnerable CHF patients with low literacy stand to have substantial gain in health outcomes by the application of educational interventions. In both studies the interventions of supportive education and counselling significantly improved physical functioning and reduced the risk of hospitalisations and death in CHF groups who had been identified as having low health literacy (DeWalt et al., 2006; Sisk et al., 2006). In view of the apparent relationship between health literacy and self-care, education level was included in the conceptual model tested in phase 2.

Symptoms

Early identification of symptom changes and distinguishing symptoms of CHF from other potential causes is a key concept in CHF self-care management. Recognition of early clinical deterioration should be a prompt to initiate self-care actions and can result in proactive rather than reactive health care utilisation (Lorig & Holman, 2003). Yet many patients fail to recognise early or even acknowledge the symptoms of CHF (Carlson et al., 2001; Patel, Shafazand, Schaufelberger, & Ekman, 2007). Patients describe a gradual change in symptoms over a period of around seven days until they experience significant distress from symptoms, requiring urgent medical assistance (Friedman & Quinn, 2008; Patel et al., 2007). In the perspective of early clinical deterioration, the delay in seeking early medical help contributes to poorer health outcomes (Evangelista, Dracup, & Doering, 2000; Friedman, 1997). Consequently, surveillance to identify early clinical deterioration and promotion of self-care actions are the cornerstone of nurse-led home based interventions (S. Stewart & Horowitz, 2002a; Thompson, Roebuck, & Stewart, 2005). Reasons to explain why patients do not seek assistance in the early stages of symptom changes appear to be multi-factorial.

As previously alluded to, CHF is considered a syndrome because of the constellation of symptoms associated with it. Although patients express dyspnoea as the most distressing symptom they often report experiencing at least seven heart failure related symptoms (Friedman & Griffin, 2001; Friedman & Quinn, 2008; Jurgens, 2006; Parshall et al., 2001). This suggests that patients with CHF often lack the ability to detect and interpret symptoms. Jurgens (2006) describes the phenomenon of symptom detection and interpretation as somatic awareness which may be influenced by various physical and psychological factors. For patients with CHF, physical changes may be confusing to interpret because of the sheer number of potential symptoms and the insidious nature in which symptoms change. Furthermore, some of the symptoms experienced may be secondary to pharmacologic therapy and other co-morbid illnesses. Difficulty in determining the meaning of symptoms leads to uncertainty (Miller, 2000; Winters, 1999) and failed self-care (Jurgens, 2006).

Due to the underlying pathophysiology of CHF and its association with ageing, these vulnerable patients often have multiple co-existing co-morbidities (Krum & Gilbert, 2003). In selected CHF samples (Moser et al., 2005; J. X. Zhang, Rathouz, & Chin, 2003), 90% of patients report having more than one co-morbidity and of those, almost half have more than two co-morbidities. Furthermore, independent correlates of early clinical deterioration appear to be older age and higher co-morbidity (S. Stewart & Horowitz, 2002a). Needless to say living with both CHF and other co-morbid conditions can make performance of self-care quite challenging (Carlson et al., 2001). Plausible explanations for such findings are: patients find it difficult to distinguish between symptoms related to CHF and other co-morbid illnesses (Carlson et al., 2001); they lack confidence to manage overlapping symptoms (Chriss, Sheposh, Carlson, & Riegel, 2004); they are physically and emotionally overwhelmed with the complexities of managing their health (Kerr et al., 2007; Nagy & Wolfe, 1984); depression and anxiety which occurs frequently in these patients may impact on their motivation to care for themselves (Konstam et al., 2005). Conversely, others (Artinian, Magnan, Sloan, & Lange, 2002; Riegel et al., 2007) have found that higher co-morbidity correlated with better CHF self care. This discrepancy indicates the need for further research to determine how co-morbidity influences self-care, providing a strong argument for including both co-morbidity and NYHA class in the conceptual model being tested.

Prior Experience

It is possible that patients with other chronic conditions have already acquired proficient self-care skills and practices from their experience of living with that chronic condition. As described earlier in this chapter, experience plays a vital role in effective self-care decision making (Riegel & Dickson, 2008). Naturalistic Decision Making Theory contends that proficient decision makers rely on their knowledge and experience to make context-specific choices. Decisions are influenced by knowledge about the situation, experience with decision-making in the particular context, skill to act on the decision made and the decision and action need to be compatible with their own values (Lipshitz et al., 2001). In Chapter 5 the logical assumption that level of experience with CHF will impact on performance of self-care will be further examined.

To compound matters further, it is evident that despite experience with CHF, patients often have a misconception about the chronicity of their symptoms and perceive it more as an acute and episodic event (Horowitz et al., 2004; Stull, Starling, Haas, & Young, 1999). This lends support for patient education and counselling to be framed from within a developed and coherent chronic care model that offers a holistic approach in supporting patients with self-care (Harvey et al., 2008; Holland et al., 2005; Horowitz et al., 2004). Such a model of care needs to also consider patients' preference for involvement in self-care and medical decisions; a factor that may be influenced by age (Rodriguez, Appelt, Switzer, Sonel, & Arnold, 2008).

Ageing

Not only is the prevalence and incidence of CHF greater in patients over the age of 65 years but it is also predicted that in this group of the population the incidence of CHF will dramatically increase over the next decade (S. Thomas & Rich, 2007). Furthermore, CHF in the elderly appears to be more a feature of diastolic dysfunction, particularly amongst females (Kitzman & Daniel, 2007). Programs of CHF care need to clearly understand how the ageing process impacts on the pathophysiology of this syndrome, the response to treatment and the multiple barriers to implementing current recommended non-pharmacotherapy best-practice guidelines (Petrie, Berry, Stewart, & McMurray, 2001). In particular there are many factors associated with ageing that can impact on the self-care decision making process.

Older persons often expect a paternalistic type of relationship with health professionals, typical of the cultural norms from the 1950s (Benbassat, Pilpel, & Tidhar, 1998). This is in opposition to self-care which supports patient empowerment in medical decisions, a cultural norm pertaining to younger people (Arora & McHorney, 2000). In a study of 90 older patients with CHF (Rodriguez et al., 2008), half the patients preferred a passive role in medical decisions. This makes it a challenge to support patients in self-care. Others (Berg, Sarvimaki, & Hedelin, 2006; Heidrich, 1998; Leenerts, Teel, & Pendleton, 2002) contend that elderly people prefer to be independent and self-reliant. This indicates that patients have differing motivations and preferences for their level of

involvement in management-decisions. It also supports the need to include family members in patient education activities. Family members may be willing to be actively involved in making self-care decisions on behalf of the patient; a role they may feel more comfortable with.

Other factors associated with ageing not only make the optimal management of CHF difficult to achieve but may also help to explain why it is difficult for many elderly patients to develop adequate self-care skills and behaviours (Petrie et al., 2001). Older people have a disproportional high occurrence of co-morbid illnesses (Australian Institute of Health and Welfare, 2004) which can add to the burden of living with CHF. Furthermore, associated with ageing are physical changes such as hearing loss, reduced visual acuity, reduced cognition, gait disturbances and psycho-social factors that can both impair learning and performance of simple self-care activities. In one study 62% of patients reported their vision impairment prevented them from being able to read medication labels (Moser et al., 2005), while others may have had significant hearing loss to the point that they are unable to hold telephone conversations (Carlson et al., 2001). Moreover, as people age their reading ability regresses from their last level of achievement (Toman et al., 2001). Education level, has been identified as a strong predictor of CHF self-care (Chriss et al., 2004) which as previously discussed may also influence health literacy. Age-related barriers may contribute considerably to confusion, uncertainty and non-adherence with self-care.

Ageing is also associated with diminished sensory perception (Battaglia et al., 2005). Interoception is the process by which sensory nerve receptors receive and process stimuli that originate inside the body. Poor interoception is another possible cause of failure to detect and interpret CHF symptoms. Visceral sensory receptors or interoceptors include physiological receptors that monitor ongoing function of visceral organs and mediate visceral reflexes for this reason, older people may simply be unaware of bodily symptom changes (Riegel, Dickson et al., In Press). In a study investigating whether ageing was associated with less ability to detect afferent physiological information, age-related differences in symptom detection and interpretation became apparent (Riegel, Dickson et al., In Press). Older patients were twice as likely as the younger ones to report either more or less shortness of breath than that noted by the researcher. The

discrepancy was most pronounced immediately after shortness of breath was stimulated with the 6MWT. The results supported the hypothesis that poor interoception resulted in an inability to detect heart failure symptoms early. Furthermore, despite experience with CHF and patient education to teach self-care, the older sample was not vigilant about monitoring their symptoms. It appeared that they expected some level of disability at their age, while the younger sample focused on what CHF had taken from them and were consequently more attentive to their symptoms. As a result, they detected early, subtle cues more accurately than older patients (Riegel, Dickson et al., In Press). This knowledge has provided a strong rationale for including age and gender in the conceptual model being tested.

Moreover, as people age they are at increased risk of diminishing cognitive functioning (Anstey & Low, 2004; Howieson et al., 2003). In one large study (Zuccala et al., 2005) involving 1511 patients with CHF, 35% had evidence of cognitive impairment determined by scores <7 on the Hodkinson Abbreviated Mental Test. Patients with cognitive impairment were significantly older by six years but other factors that were independently associated included, co-morbidity, anaemia, hypertension and low serum albumin, sodium and potassium levels. Therefore it appears that patients with CHF appear to be significantly more at risk of cognitive decline than age-matched controls (Cacciatore et al., 1998; Taylor & Stott, 2002). In a review of the literature (Vogels et al., 2007) with a pooled sample of 2937 heart-failure patients and 14,848 control subjects, the odds ratio for cognitive impairment was 1.62 (95% confidence interval:1.48-1.79, $p < 0.0001$) among subjects with CHF. Accordingly there are several reasons to account for this relationship between cognitive impairment and CHF.

Cognitive Impairment and Heart Failure

Not only does cognitive impairment occur frequently in patients with CHF but the deficits are subtle, not meeting the clinical diagnosis of dementia. Therefore unless screening is purposefully undertaken health professionals are unaware of patients diminished cognitive status (Bennett, Sauve, & Shaw, 2005; Riegel, Bennett et al., 2002). The conceptual model of cognitive impairments in patients with CHF was developed from

both empirical and theoretical literature (Bennett, Sauve et al., 2005). The most likely aetiology for cognitive impairments relate to inadequate cerebral perfusion and acute or chronic hypoxic brain damage (Aconfora, Trojano, & Iannuzzi, 1996; Bennett, Sauve et al., 2005; Dickson et al., 2007; Zuccala et al., 2005). However, duration of CHF (McLennan, Pearson, Cameron, & Stewart, 2006; Wolfe, Worrall-Carter, Foister, Keks, & Howe, 2006), reduced oxygen levels (Staniforth, Kinnear, & Cowley, 2001), severity of cardiac dysfunction and presence of arrhythmias (Antonelli et al., 2003; Petrucci et al., 2006; Sabatini, Barbisoni, Rozzini, & Trabucchi, 2002; Vogels et al., 2007; Zuccala et al., 1997) cannot be discounted. Co-variates that also appear to contribute to cognitive impairments include age, co-morbidity, hypertension, depression and medications (Bennett, Sauve et al., 2005). Insufficient cerebral perfusion affects several cognitive domains which may ultimately have a bearing on patients' capacity to make self-care decisions. The findings from Bennett et al. (2005) influenced the choice of variables included and tested in the Conceptual Model.

The impact of cognitive impairment in patients with CHF can have dire consequences on their survival (McLennan et al., 2006; Qiu et al., 2006; Zuccala et al., 2003). McLennan, Pearson, Cameron & Stewart (2006) found over a five year period, that patients with mild cognitive impairment (MCI) had a 1.4-fold increased risk of being admitted or dying ($p=0.002$) relative to cognitively intact patients and after adjusting for potential confounders (See Figure 8).

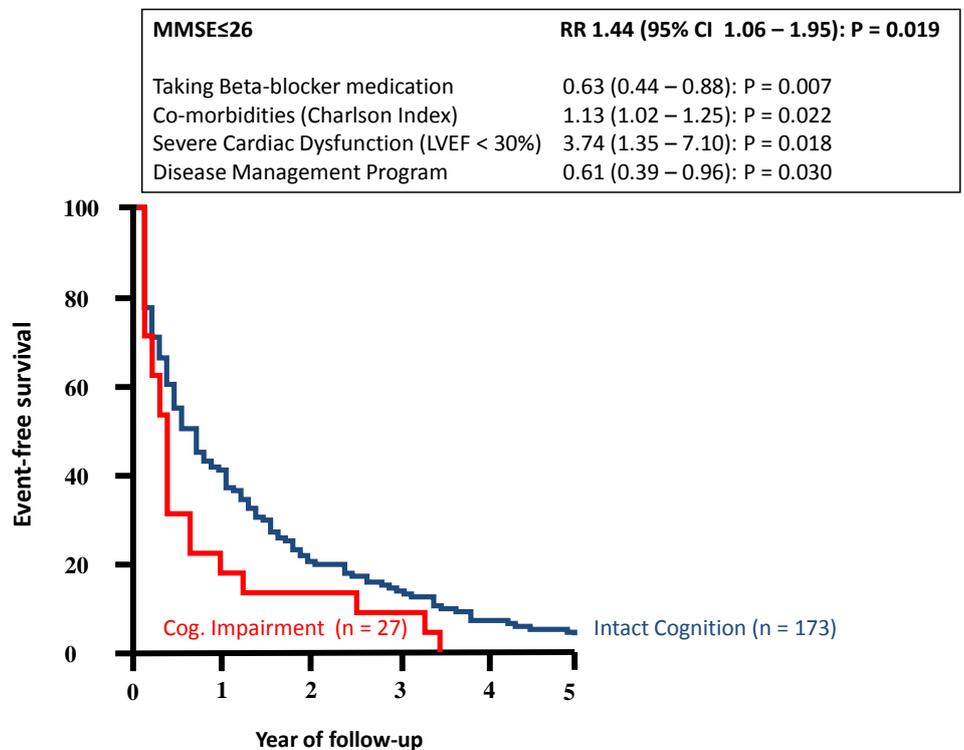


Figure 8: Kaplan Meier survival curves for event-free survival: cognitively impaired versus cognitively intact patients with CHF

(McLennan et al., 2006)

Furthermore, despite receiving gold-standard treatments from a home-based nursing intervention, patients with MCI had a two-fold increased risk of death ($p=0.03$) compared to those with normal cognitive functioning; suggesting that cognitive impairment blocked the beneficial effects of a home-based nursing intervention (see Figure 9: Adjusted all-cause mortality curves for patients assigned to usual care (UC) or the CHF-MP based on cognitive status at baseline).

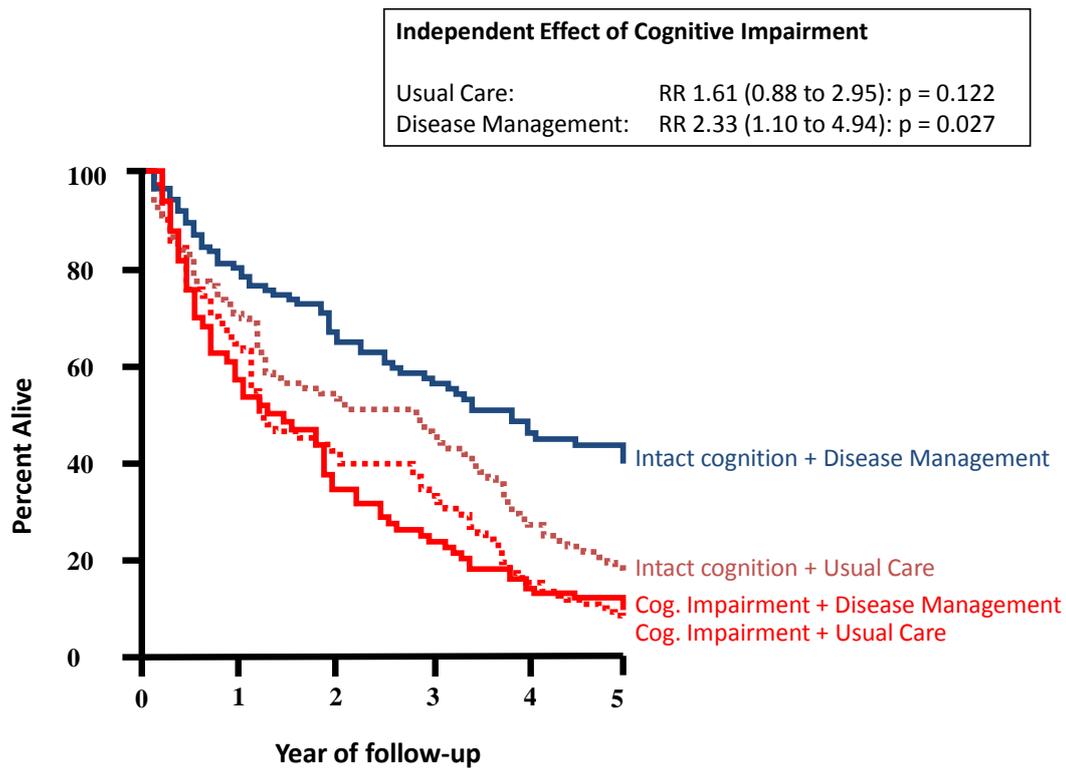


Figure 9: Adjusted all-cause mortality curves for patients assigned to usual care (UC) or the CHF-MP based on cognitive status at baseline

(McLennan et al., 2006)

Reasons to account for the poorer health outcomes observed in this group of patients with CHF are two-fold. Cognitive impairment may be associated with a number of predictors and mediators of adverse health outcomes (Anstey, Mack, & von Sanden, 2006). Secondly, cognitive deficits may impair the ability of patients' to learn and carry out self-care resulting in worse health outcomes. Bennett, Sauv e and Shaw (2005) acknowledge that there are a number of factors that can contribute to the cognitive deficits that occur in almost half the patients diagnosed with CHF. Furthermore, structural changes in the brain resulting in grey matter loss in the insular and cingulate cortex may account for the functional impairments that are often found (Dickson et al., 2007). The common cognitive domains that appear impaired are: attention, memory, concentration, learning, executive functioning and psychomotor speed (Almeida &

Flicker, 2001; Bennett & Sauve, 2003; Wolfe et al., 2006) According to Dickson, Tcaks & Riegel (2007) deficits in memory and attention may result in forgetfulness and poor learning ability, marring treatment adherence. In contrast higher order cognitive functions are used to make decisions and plan actions. Executive dysfunction may therefore result in impairments to make decisions in complex situations, such as interpreting symptom changes and analysing the risks or benefits in implementing, or not, self-care actions (Dickson et al., 2007; Hicks & Holm, 2003).

Despite MCI being acknowledged as a significant health issue in patients with CHF there is evidence that it is potentially modifiable by: Addressing cardiovascular risk factors (Kilander, Nyman, Boberg, Hansson, & Lithell, 1998; Popovic, Seric, & Demarin, 2007); Through rehabilitation strategies (Kurz, Pohl, Ramsenthaler, & Sorg, 2009; Lautenschlager et al., 2008; Londos et al., 2008); By use of cognitive enhancing medications and antioxidants (Weinstein, Barton, Ross, Kramer, & Yaffe, 2009). This evidence supports the need for multi-disciplinary strategies to address the health needs of patients with CHF who are found to have MCI.

As discussed previously, the aims of teaching patients self-care is to encourage them to monitor their symptoms and link symptom changes (daily weight gain) to an interpretation (fluid retention). Ideally the recognition of symptom changes should stimulate the use of self-care treatments (Riegel & Dickson, 2008). However, it is deficits in the prefrontal and cortex regions of the brain that may interfere with their ability to make these links and master these skills. The delay in responding to symptoms may signal neural processing problems which are manifested by increased time in making self-care decisions and difficulty in foreseeing the consequences of their actions (Dickson et al., 2007).

Research Issues Considered in Testing the ‘InCOGNITO’ Model

Although others (Dickson et al., 2007; Moser & Watkins, 2008) have hypothesised that cognitive impairment may help to explain some of the self-care deficits seen in

persons with CHF, few researchers have set out to establish this link. It was the intention of this research program to further explore self-care practices in patients with CHF and in particular establish the impact that cognitive impairment has on self-care practices. Phase 1 of the 'InCOGNITO' research program (Chapter 3) will test a conceptual model of factors, including cognitive function, that predict CHF self-care. Phase 2 of the research program (Chapter 4) will further validate the conceptual model and specifically examine if differences in self-care practices exist between CHF patients with and without cognitive impairment. Furthermore it has previously been identified (Pressler et al., 2008) that currently there is a need to identify how best to screen patients for cognitive impairment in the clinical setting. A secondary aim of Phase 2 was to compare the utility of the Montreal Cognitive Assessment against the Mini Mental State Exam in screening for mild cognitive impairment.

In order to test the conceptual model a decision needed to be reached as to the most appropriate manner to measure self-care for the purpose of the 'InCOGNITO Heart Failure research program'. The first literature review discussed above, demonstrated there was little attention given to the use of reliable and validated instruments to measure changes in self-care as a performance indicator of patient education. It is this second contemporary issue that required further exploration before the methodology for the research program could be decided upon. With this in mind a second literature review was conducted.

Aim of the Second Literature Review

The aim of the second literature review was to identify instruments that measure Chronic Heart Failure (CHF) self-care and demonstrate their psychometric properties. The knowledge gathered from this second literature review informed the methodology for measuring CHF self-care in the 'InCOGNITO Heart Failure study'. An outcome from the second literature review has been the publication of a peer reviewed publication (Cameron, Worrall-Carter, Driscoll et al., 2009) (See Appendix A).

Methods for Identifying Clinical Instruments Developed to Measure Self-care Behaviours and Skills

The following databases were searched Medline, CINAHL, Medline, PsycArticles, Psychology and Behavioural Sciences Collection and PsycINFO between the dates of January 1980 and February 2009. Search terms used were: patient compliance/*statistics and numerical data/CHF/heart disease/heart failure, congestive/self-care/health surveys/self-management. Clinical instruments selected were disease specific measures of CHF self-care behaviours. As discussed in Chapter 1, these behaviours are promoted in Best Practice Guidelines (Dickstein et al., 2008; Hunt et al., 2001; Krum et al., 2006). As a valid instrument was required for the 'InCOGNITO' Heart Failure study, only instruments that reported estimates of reliability and validity were included in this review.

Evaluation of psychometric properties of the self-care instruments reviewed was based upon the criteria developed by Elliott (2007) who recommends the following: Appropriate methods have been used to test reliability and validity; Reliability and validity estimates are re-assessed in contrasted samples; Strengths and weaknesses of an instruments reliability and validity are appropriately discussed; Responsiveness is reported in relation to clinically important differences.

Clinical Instruments Identified that Measure Heart Failure Self-care

Despite the extensive literature search, only two instruments were found that measured CHF self-care with published estimated of reliability and validity (Jaarsma et al., 2003; Riegel et al., 2004). All together, 21 instruments were identified in published in peer reviewed journals that measured aspects of self-care. One instrument measured compliance with CHF self-care behaviours (Evangelista et al., 2001), one measured factors that influence self-care decisions (Hicks & Holm, 2003), three assessed factors thought to influence beliefs and attitudes with following a low salt diet and taking medications (Bennett, Milgrom, Champion, & Huster, 1997; Bentley, Lennie, Biddle, Chung, & Moser, 2009; Wu, Chung, Lennie, Hall, & Moser, 2008), six assessed self-care knowledge (Artinian et al., 2002; Baker, Brown, Chang, Dracup, & Keeler, 2005; Gwady-Sridhar et al., 2003; Karlsson et al., 2005; Lainscak & Keber, 2005; van der Wal, Jaarsma, Moser, & van

Veldhuisen, 2005) and three measured self-efficacy to undertake self-care (Flynn et al., 2005; LaFramboise, Toderro, Zimmerman, & Agrawal, 2003; Schreurs, Colland, Kuijter, de Ridder, & van Elderen, 2003). These fourteen instruments were determined to measure constructs that predict or correlate to self-care rather than specific self-care behaviours and on this basis it was judged they would not be included in this review. Three other instruments were excluded on the basis that their reliability and validity had not been established (DeWalt, Pignone et al., 2004; Gonzalez et al., 2004; Stromberg et al., 2006). Two instruments were found that measured self-care in chronic conditions (Battersby, Ask, Reece, Markwick, & Collins, 2003; Osborne, Elsworth, & Whitfield, 2007); as they had not necessarily been validated in CHF patients they were not included in this review.

Comparison of the European Heart Failure Self-care Behaviour Scale and the Self-care Heart Failure Index

Psychometric evaluation of the two instruments (SCHFI & EHFSBS) was initially conducted in 1202 patients with CHF. The mean ages of the two samples ranged from 70 to 73 years and 55% were male. Essentially, patients from these samples were NYHA classification II or III in whom disease management strategies appear to have the greatest benefit (Riegel, Carlson, Glaser, & Hoagland, 2000). The ethnicity of the samples where the instruments were initially evaluated was American (Caucasian and African-American) and European (Sweden, Netherlands, Italy); populations that are considered to be representative of CHF-MPs within westernised countries. Subsequently both instruments have undergone further psychometric evaluation in other CHF samples. The EHFSBS has been re-evaluated in 2592 patients from Sweden, Netherlands, UK, Italy, Germany and Spain. The mean age of the sample was 73 and 63% were males (Jaarsma, Arestedt, Martensson, Dracup, & Stromberg, 2009). The psychometric properties of SCHFI v6 has been re-evaluated in 273 patients who were predominately male and either African-American or Caucasian ethnicity (Riegel, Lee, Dickson, & Carlson, 2009).

The SCHFI measures three domains of self-care (see Table 6: p.60) self-care maintenance (behaviours undertaken to maintain health), self-care management (the decision-making process in regards to symptom changes) and self-care confidence (confidence to manage symptoms and evaluate any actions implemented). In initial

psychometric evaluation of SCHFI it was recommended that self-care management only be measured if patients have been symptomatic in the previous three months (Riegel et al., 2004). However in SCHFI v6 it is recommended that self-care management scores are only computed if patients acknowledge shortness of breath or ankle swelling in the past month (Riegel, Lee et al., 2009). Summary scores for each domain are transformed into a sub-scale ranging from 0-100; higher scores reflect superior self-care (Riegel et al., 2004) and adequate self-care is considered with scores >70 on any sub-scale (Riegel & Dickson, 2008). The EHFScBS (Jaarsma et al., 2003) measures three aspects of health maintenance behaviours: compliance with the management regimen, asking for help and adapting daily activities (see Table 10 p.96). A total score is calculated by summing responses from each item and lower scores indicate better self-care (Jaarsma et al., 2003). The 12-item instrument has recently been revised to a nine-item scale (EHFScB-9) and its reliability and validity reassessed (Jaarsma et al., 2009). The psychometric properties of the instruments will now be examined.

Reliability

The aim of assessing reliability is to demonstrate the degree of consistency with which the instrument measures the attribute under study. According to Elliott, (2007) three attributes can be assessed: stability, homogeneity and equivalence. Reliability is an absolute pre-condition to validity because an instrument can be found to be reliable without being valid; however, an unreliable instrument cannot be valid (Elliott, 2007). This pre-condition was met with both instruments reviewed by assessment of internal reliability (see Table 11: p. 97).

Table 10: Summary of instruments that measure heart failure self-care

Measures of HF self-care	Theoretical framework used to developed instrument	Summary of Instrument's Scale
European Heart Failure self-care Behaviour Scale (Jaarsma et al., 2003)	Orem's theory and definition of self-care	<p>The EHFSBS is a 12-item questionnaire that measures three aspects of health maintenance behaviours: 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 behaviour is performed, ranging from "I completely agree" to "I don't agree at all". Scores are summed. Lower scores indicate better self-care.</p> <p>The instrument has subsequently been revised into a 9-item instrument [53]</p>
Self-care Heart Failure Index (Riegel et al., 2004)	Developed from a naturalistic decision-making framework	<p>The SCHFI consists of 15 items that measure three subscales: behaviours undertaken to maintain clinical stability (self-care maintenance), the decision-making process in regards 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 3 months. Summary scores for the 3 sub-scales are used by transforming each sub-scale to scale from 0-100. Adequate scores are >70 on any sub-scale.</p>

Legend: HF – heart failure; EHFSBS - European Heart Failure Self-care Behaviour Scale;

SCHFI - Self-Care of Heart Failure Index

Table 11: Comparison of reliability estimates for instruments that measure CHF self-care

Study	Instrument	Stability	Reliability Homogeneity			Equivalence
			Test-retest	Internal consistency (Cronbach's alpha)	Item-Score analysis	Item-item analysis
Jaarsma et al (2003)	European Heart Failure self-care Behaviour Scale	n/a	Good (.81)	Good correlation ($r < .4$) on all items. Strongest correlation on weight gain item ($r = .74$)	Some items correlated strongly with other: Daily weighing and weight gain ($r = .52$), Contacting someone and symptom recognition ($r = .67$), Contacting someone and taking action ($r = .57$)	n/a
Shulldham et al (2007)		When administered 2 weeks apart, test-retest reliability was good with average difference between scores of -0.5.				
Riegel et al (2004; 2008)	Self-care Heart Failure Index	n/a	Low for Self-care maintenance (.56) Good on Self-care management (.70); Self-care confidence (.82); Index score (.76)	Good correlation on all Self-care management items ($r = .25$ to $.55$) and Self-care confidence items ($r = .58$ to $.67$). Adequate correlations on Self-care maintenance items ($r > .2$ on most items). Flu shot item correlation low ($r = .15$) but this item contributed positively to criterion group difference indices	n/a	n/a

Legend: EHfScBS - European HF Self-care Behaviour Scale; SCHFI - Self-Care of Heart Failure Index

Stability

Stability is an assessment of the consistency of a measure from one time to another and quantifies the instrument's susceptibility to extraneous factors (Elliott, 2007). In a sample of 183 patients from the UK, the stability of the EHFScBS was demonstrated with no statistical difference in item scores when the instrument was administered two weeks apart (Shuldham et al., 2007). However, when the EHFScBS was administered to a Japanese sample over a similar time frame, only seven out of the 12 items demonstrated stability with a weighted kappa greater than 0.40 (Kato, Ito, Kinugawa, & Kazuma, 2008). Although test-retest reliability has not been directly assessed with SCHFI there have been efforts to test whether multiple administrations of the instrument is associated with a learning effect (B. Riegel, personal communication, April, 2009). Accordingly, changes in self-care scores did not differ significantly when SCHFI has been administered repeatedly at monthly intervals. The small changes in self-care scores most likely reflected altered health skills rather than a learning effect from familiarity with the instrument which would have resulted in much larger differences over time.

Homogeneity

Good internal consistency (Cronbach's alpha >0.70)(Elliott, 2007) was demonstrated for total scale scores on the original version of the EHFScBS (Jaarsma et al., 2003) (See Table 12: Comparison of re-assessment of reliability and validity estimates in contrasted groups). When the homogeneity of EHFSCB-9 (Jaarsma et al., 2009) was examined in samples from different countries the reliability estimates ranged from 0.68 in British patients to 0.87 in patients from Netherlands. In the pooled sample the internal consistency of the adherence to regimen sub-scale had a Cronbach's alpha <0.70. However, in separate samples Cronbach's alpha ranged from 0.17 to 0.78 in (Jaarsma et al., 2009).

In the psychometric testing of SCHFI the authors reported an adequate internal reliability (Cronbach's alpha 0.76) for an overall index score (sum of each self-care domain) (Riegel et al., 2004). However with greater use of the instrument and

progression in the conceptualisation of CHF self-care, self-confidence is understood to influence the relationship between self-care and outcomes; for this reason it is no longer appropriate to use an index score. Riegel & Dickson (2008), advocate that each domain is examined separately. In the psychometric evaluation of both SCHFI v4 and v6 the internal consistency was satisfactory to good for self-care management (Cronbach's alpha 0.70 and 0.60 respectively) and self-care confidence subscales (Cronbach's alpha 0.82 and 0.83 respectively) (Riegel et al., 2004; Riegel, Lee et al., 2009). The internal consistency on the self-care maintenance sub-scale was low in the psychometric evaluation of both SCHF v4 and v6 (Cronbach's alpha 0.56 and 0.55). This is however, not unexpected as the scale assesses behaviours that are relatively heterogeneous and can be greatly influenced by many factors other than CHF moderate internal reliability (Riegel et al., 2004).

Equivalence

Inter-rater reliability analysis, otherwise known as equivalence, is concerned with the degree to which different raters give consistent estimates of the same phenomenon (Elliott, 2007). This type of reliability has not been reported for either SCHFI or EHFScBS.

Validity

Validity examines the accuracy of an instrument to measure what it was designed to measure. Evidence is established about the content of a measure and the relationships between the measure of interest and other similar measures or variables. There are seven aspects in assessing the validity of instruments; content experts approach, factor analysis, concurrent approach, predictive, convergent/divergent, contrasted groups and hypothesis testing (Elliott, 2007). Five aspects of validity had been demonstrated with EHFScBS and six aspects of validity had been demonstrated with SCHFI (See Table: Comparison of validity estimates for instruments that measure heart failure self-care in Appendix A).

Content validity

Content validity was established for both instruments by panels of experts from within the clinical field. The experts often consisted of nurses and cardiologists.

Factor analysis

Factor analysis had been used with both instruments to validate the concept being measured. In developing the EHFScBS, Jaarsma and colleagues (2003) had speculated that the scale would assess three dimensions of self-care: complying with regimen, asking for help and adapting activities. However, factor analysis revealed that several items loaded on more than one factor and the reliability of subscales was low leading to a decision to use only a total score. Subsequently, removing three items associated with adapting behaviours demonstrated an improvement in the scale's validity (Jaarsma et al., 2009). In developing the SCHFI, exploratory factor analysis of the five self-care maintenance items revealed that four items loaded substantively but the flu shot item failed to load with the others (Riegel et al., 2004). Exploratory factor analysis on ten items which address self-care management and confidence revealed that all items loaded substantively. Confirmatory factor analysis of the SCHFI validated the model of self-care maintenance, self-care management, and self-confidence and the comparative fit index was adequate (0.73) (Riegel et al., 2004).

Concurrent Approach

Concurrent validity examines the degree of correlation between two measures of the same concept. It is often used to compare a new instrument to an established instrument (Elliott, 2007). These instruments have been compared against each other as there is not an established 'gold standard' measure of CHF self-care (Shuldham et al., 2007). There were weak and non significant correlations between global scores on EHFScBS and SCHFI ($R=0.09$, $p=0.25$) indicating that these two instruments measure differing aspects of CHF self-care. This has been further supported in a small study of 34 patients (personal communications with Prof Riegel, 2009) in which only the self-care maintenance scale on SCHFI was moderately correlated to the EHFScBS ($r=-0.65$,

$p < 0.001$) In contrast the EHFScBS did not correlate with self-care management or confidence domains on SCHFI.

Predictive validity

Predictive validity explores whether scores are able to predict a future behaviour (Elliott, 2007). No studies have been constructed to test predictive validity using either SCHFI or EHFScBS.

Convergent Validity

Convergent validity assesses whether instruments that theoretically measure the same construct are correlated (Elliott, 2007). This aspect of validity has been further investigated by analysing the relationship of the EHFScBS with a validated compliance and quality of life questionnaire (Jaarsma et al., 2009). There was a moderate correlation between the revised heart failure compliance questionnaire and the 12 or nine-item EHFScBS ($r = 0.32$ and 0.37 , $p < 0.001$ respectively). The correlation between the Minnesota living with heart failure questionnaire and the 12 or nine-item EHFScBS was low ($r = 0.01$ and 0.18 , $p = ns$ respectively). This was as hypothesized and provides evidence that the EHFScBS is not a measure of quality of life and although the correlation with an adherence instrument was moderate the authors suggest a different concept is measured (Jaarsma et al., 2009).

Convergent validity has also been assessed in the SCHFI using data triangulation methods with quantitative and qualitative data collected from three studies. In 71% of the sample improvements in self-care scores also matched verbalized behaviour change (Riegel, Dickson et al., 2006). In a study investigating factors related to expertise in self-care (Riegel et al., 2007), experts were able to describe their symptoms, linking them to both the physiology of CHF and self-care behaviours and were able to verbalise an understanding of their treatments. This was matched with scores above 80 on self-care maintenance and management. In contrast, patients categorized as poor self-managers had scores ≤ 60 on each self-care domain and the qualitative data demonstrated they did not routinely perform self care maintenance and were unable to manage symptoms. In a

study involving 41 younger patients with CHF (Dickson et al., 2008), once again the qualitative data investigating self-care behaviours corresponded to the quantitative data in 90% of cases.

Contrasted Groups

Contrasted validity assesses differences in the trait under examination between two groups where score are expected to contrast (Elliott, 2007). Differences in scores on each sub-scale of SCHFI were examined between patients newly diagnosed and patients experienced (≥ 2 months) with symptoms (Riegel et al., 2004). Statistically significant differences were evident based on experience for each subscale which further supported construct validity of the instrument. Likewise the validity of the EHFSBS was examined to determine if it was able to discriminate between patients who had or had not received education. Patients who received education had a 3.7 point lower self-care score than patients receiving standard care (29.6 ± 9.0 vs 33.3 ± 7.8 , $t=2.6$, $p=0.09$); indicating a trend in improved self-care with education and support strategies (Jaarsma et al., 2003). Subsequently in a study with 99 Italian patients diagnosed with CHF, there were statistically significant differences in self-care scores between patients who had or had not received intensive educational strategies (20.9 ± 4 vs 28.9 ± 6 , $p<0.001$) (Pulignano et al., 2004). In addition, global scores on EHFSBS improved over a 15-month period of follow-up in a CHF outpatient clinic ($p<0.001$) (Gonzalez et al., 2006). This indicates the EHFSBS is able to discriminate between patients who have or have not received patient education and support strategies.

Hypothesis-testing

Hypothesis-testing approach uses the underlying theory of an instrument's design to develop and test hypotheses regarding varying scores on the measure. Data collected is used to test hypotheses and allow inferences about the adequacy of the instrument's construction to explain the findings (Elliott, 2007). Both instruments were underpinned by a theory, however inferences made about the instrument's construction and the underlying hypothesis appears to have only been explored with SCHFI. Evidence from other studies that had utilized the SCHFI was gathered to test the situation-specific

theory of heart failure self-care (Riegel & Dickson, 2008). From this theoretical framework three propositions were tested: 1) symptom recognition is the key to successful self-care management, 2) knowledge, experience, skill and personal value all influence self-care practices, 3) confidence mediates and/or moderates the influence of self-care on outcomes (Riegel & Dickson, 2008). Each of these propositions substantiated the situation-specific theory of CHF self-care and demonstrated how it was possible for theory to guide research methodology that ultimately translates into clinical practice.

Re-assessment of Reliability/Validity in Contrasted Samples

Reliability and validity is not a static concept and can vary with each sample over time. Therefore, reliability and validity should be computed with each cohort where the instrument is administered to determine if the tool remains adequate. With extended clinical testing the evidence of an instrument's reliability and validity should be strengthened as this concept is re-examined (Elliott, 2007). Reliability has been re-established in both instruments when administered to different samples (see Table 12: Comparison of re-assessment of reliability and validity estimated in contrasted groups). The SCHFI has been administered to 2,082 patients from America, Australia, and Thailand where the internal reliability was moderate to good; Cronbach's alpha 0.61 (maintenance), 0.67 (management) and 0.88 (confidence) (Riegel, Driscoll et al., 2009). The administration of SCHFI in other CHF populations has resulted in the instrument being translated into Spanish and Thai using standardised methods. Likewise, the EHFScBS has been translated using standardised methods into 14 languages, allowing extensive testing across European populations. Internal reliability for total scales scores on EHFScBS was good (Cronbach's alpha 0.77) however, the internal reliability for the subscale 'adherence to regimen' was low (Cronbach's alpha 0.56) (Jaarsma et al., 2009).

Table 12: Comparison of re-assessment of reliability and validity estimates in contrasted groups

Study	Instrument	Populations	Reliability calculated in contrasted groups	Comments
Jaarsma et al (2009)	European Heart Failure self-care Behaviour Scale	Swedish (161), Netherlands (1243) UK (177) Italian (173) German (285) Spanish (553)	Overall internal consistency higher in 9 vs 12 item scale (0.80 vs 0.77, respectively). With the exception of UK internal consistency of the EHFSsB-9 was high (>0.70). Less internal consistency on subscale 'adherence with regimen' (0.56) but high on subscale 'asking for help' (>0.70)	Translated into 14 languages
Riegel et al (2009)	Self-care Heart Failure Index	USA (453) Australian (1095) Thai (400) Mexican (134)	Internal consistency moderate to high; 0.61 (maintenance), 0.67 (management), 0.88 (confidence)	Officially translated into Spanish and Thai languages and requests to use it in 24 other countries.

Legend: EHFSsBS - European HF Self-care Behaviour Scale; EHFSsB-9 – revised version of EHFSsBS to 9 items; SCHFI - Self-Care of Heart Failure Index

Strengths and weaknesses appropriately addressed

The authors of each instrument appropriately acknowledged the strengths and weaknesses of their instruments. For example, Riegel et al (2004) acknowledge that the SCHFI only measures an individual's self-care response to two symptoms associated with CHF which may limit its use. However, it is acknowledged that shortness of breath and peripheral oedema are two of the most common symptoms associated with fluid management and are primary causes for hospital readmissions. Furthermore Riegel et al., (2004) suggest the use of an objective measure to assess treatment adherence may help to establish an acceptable level of internal consistency for the self-care maintenance subscale. Three items on the EHFSsBS were found to have poor reliability with the total score and were perceived to be activities forced upon patients by clinical deterioration rather

than a deliberate self-care action. This provided the rationale to re-examine the psychometrics of the scale by removing the three items that assessed 'adapting activities', resulting in superior construct validity and reliability than the 12-item scale. However, two items continue to show skewed responses affecting homogeneity of the scale. These two items (taking medications as prescribed and exercising regularly) have been retained in the scale as they are important aspects to CHF self-care (Jaarsma et al., 2009).

Precision of the Instruments to Measure Clinically Important Differences

Responsiveness reflects the magnitude of change in a participant's score that is clinically relevant (Elliott, 2007). This psychometric aspect has only been reported with SCHFI. An improvement of one half of a standard deviation from pre-test to post-test on at least one of the subscales indicates that there has been a clinically significant improvement in self-care practices (Riegel & Carlson, 2004). Furthermore scores above 70 on any of the self-care domains are able to discriminate between patients with poor self-care and patients deemed to have good expertise in practicing self-care (Riegel et al., 2007).

Determining How Best to Measure Self-care Behaviours

Improving self-care is an important outcome of patient education and counselling. However, in order to advance our understanding of clinical practice directed towards improving this outcome, measuring changes in self-care is required. Instruments that are consistent and accurate need to be utilised in order to draw firm conclusions about the effectiveness of educational strategies. A rationale for undertaking this second literature review was to identify the most appropriate instrument that measures changes in self-care skills and behaviours, for the purpose of the 'InCOGNITO' research program. Only two reliable and valid disease specific instruments were identified. Both instruments have either good internal reliability or valid reasons have been offered to explain factors influencing the homogeneity of particular items. The SCHFI has undergone more

extensive validity testing than EHFSBS. Likewise, responsiveness of the instruments to detect clinically important changes has only been reported with the SCHFI. A minor shortcoming in the psychometric testing of both instruments was the lack of discussion on procedures used for selecting experts to examine content validity. It has been recommended the selection process of expert panels, their qualifications and experience should be included when discussing content validity (American Educational Research Association (AERA), American Psychological Association (APA), & National Council on Measurement in Education (NCME), 2004). Despite this, it is apparent that both instruments have undergone extensive psychometric testing and subsequently have been used in more diverse populations to further our understanding of self-care in patients with CHF.

The strength of both instruments is that although initially tested in a homogenous western population they have since been translated into other languages and used to examine CHF self-care in other populations. Published data on the EHFSBS demonstrates it has been administered to over 2590 patients with CHF across Europe (Sweden, Netherlands, UK, Italy, Spain and Germany). Likewise, published data on the SCHFI demonstrates it has been administered to over 2000 patients from both developing populations (Thai and Mexican) and developed populations (American and Australian), has formerly been translated into several other languages. Furthermore the primary author of SCHFI (B. Riegel, personal communications, May 2009) has had requests to use the instrument from health professionals from 24 countries around the world.

Notwithstanding the need for reliable and valid measures of self-care, few published reports evaluating the psychometrics of available measures were found. Only one other study was found that investigated the similarities and discrepancies between instruments developed to measure CHF self-care. Shuldham, Theaker, Jaarsma and Cowie (2007) evaluated the reliability and validity of the EHFSBS in a British sample of patients with CHF. It was concluded from this study that the weak and non-significant correlation between scores on both the EHFSBS and SCHFI indicated that the instruments do not measure the same self-care constructs. A limitation to their study was the use of the index score on the SCHFI for correlation analysis. Although in the development of SCHFI it was originally conceived that an index score could be computed

from the sum of each self-care sub-scale, this practice is no longer recommended because the sub-scale 'self-confidence' is now known to moderate and mediate the relationship between self-care and outcomes (Riegel & Dickson, 2008).

Research Implications

An aim of the 'InCOGNITO' Heart failure study is to investigate whether cognitive problems impact on self-care which is acknowledged to be a decision-making process. On this basis it was concluded that SCHFI was a more appropriate measure of self-care because it examines three aspects of the self-care process: maintenance behaviours, management decisions and actions and confidence to undertake such behaviours. Overall, this research program will determine the link between the three self-care domains and mild cognitive impairment.

Chapter Summary

Patient education and counselling directed at supporting patients and their families in self-care, is the cornerstone in the long-term management of patients with CHF. In this review of the current literature the potential impact of education on improving self-care behaviours in patients with CHF was examined. Despite an extensive search only six randomised controlled studies (Caldwell et al., 2005; DeWalt et al., 2006; Jaarsma et al., 1999; Koelling et al., 2005; Serxner et al., 1998; Sethares & Elliott, 2004) were identified that specifically examined this outcome. One reason to account for this may be the limited number of reliable and valid instruments available that measure CHF self-care. A fact that became apparent in the second literature review where only two clinical instruments were found that measure self-care behaviours (SCHFI and EHFScBS) and have undergone rigorous psychometric testing in CHF populations.

Adequate self-care is difficult for most patients with CHF to achieve and there are a multitude of factors to account for this. It has been implied that cognitive impairments, which occurs frequently in patients with CHF, may be one of the factors associated with inadequate self-care. Clearly, more research is required to expand our understanding of

barriers in achieving optimal self-care skills and in time this knowledge may help determine how best to tailor strategies to individual need. The literature review presented in this Chapter has provided the rationale for including specific factors to develop a conceptual model that may help predict self-care. The following Chapter will demonstrate the initial testing of this model. The translation into clinical practice of the knowledge gained from each Phase of the 'InCOGNITO research program' will be discussed in Chapter 6.

Chapter 3: Phase 1 of The InCOGNITO Heart Failure Study

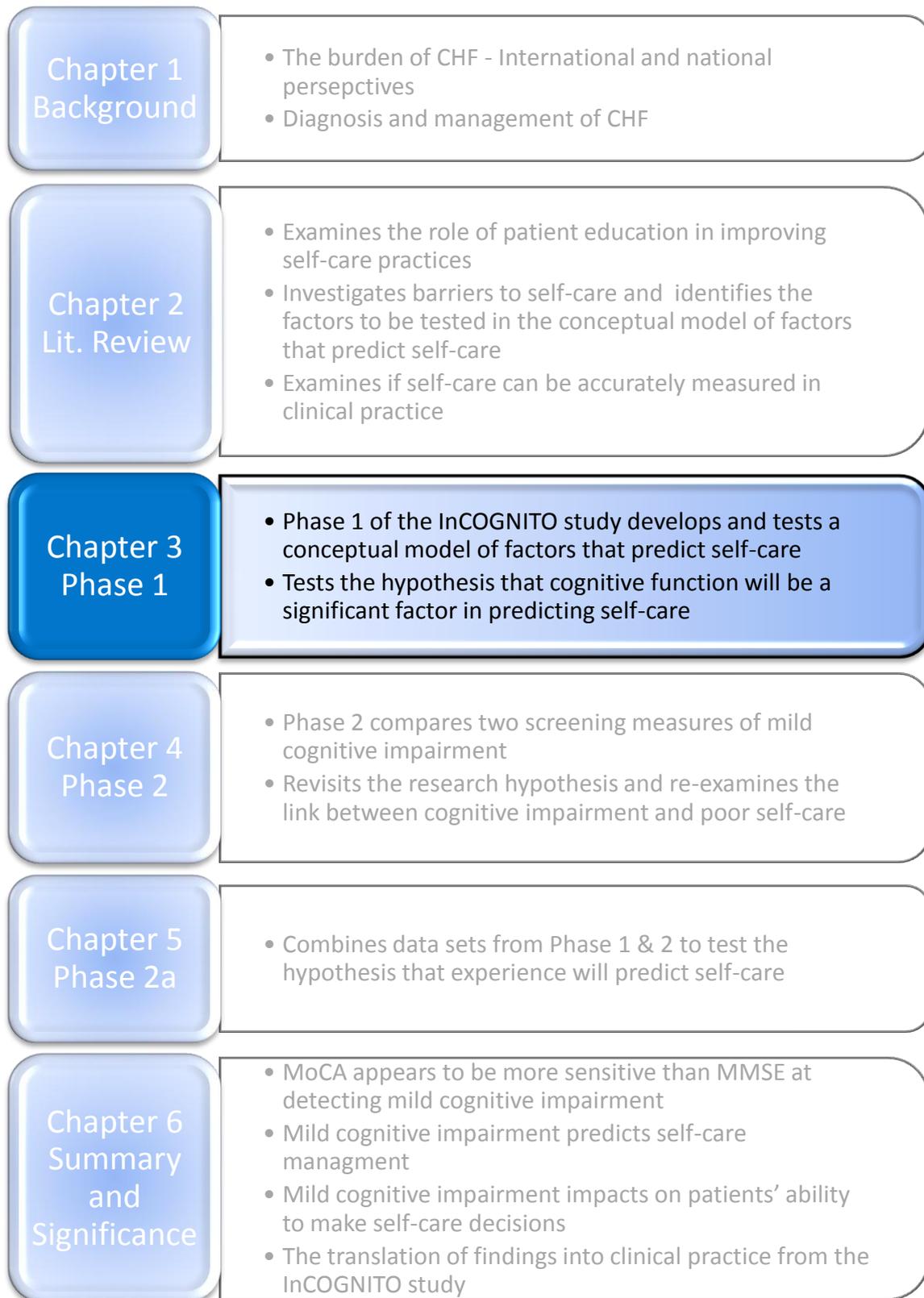


Figure 10: Overview of Chapter 3

Chapter 3 Introduction

In Chapter 2 it was established that teaching patient self-care skills and behaviours is an important consideration in the long-term management of patients with CHF. Nonetheless, achievement of optimal self-care such as recognition symptom changes early and initiating decisions and actions to reduce symptoms, is difficult for many patients to accomplish. The literature review identified a number of modifiable and non-modifiable correlates that help to explain this (pg. 80-92). Potential modifiable factors or symptoms identified were: depression, social support, cognitive impairment and NYHA class. The non-modifiable factors identified were: age, gender, educational attainment, co-morbidity and level of experience. This Chapter represents Phase 1 of the 'InCOGNITO Heart Failure study' which describes the testing of the conceptual model.

To highlight this Phase of the research program, the background presented below pertains to the rationale for developing and testing the conceptual model. Specifically arising from the literature and my own clinical experience, it was hypothesised that cognitive function and depressive symptoms would play a major role in predicting CHF self-care in patients without a history of neurocognitive problems. Results from this Phase of the research program have been published in a peer reviewed journal (Cameron, Worrall-Carter, Riegel et al., 2009)(see Appendix A).

Background to Chapter 3

The prevalence of CHF within ageing populations in the Western World remains high (Bleumink et al., 2004; Rosamond et al., 2007). The clinical trajectory of CHF is characterised by chronic symptoms and often interspersed with acute symptoms requiring hospitalisations for treatment (Krumholz et al., 2000). It has been estimated that 50% of these re-hospitalisations are potentially preventable (Braunstein et al., 2003; Cline, Israelsson, Willenheimer, Broms, & Erhardt, 1998) through better adherence with self-care practices (Artinian et al., 2002; C. S. Lee, Tkacs, & Riegel, 2009; Moser et al., 2005).

Given the importance in preventing potential fatal health crises, teaching patients self-care behaviours is a key non-pharmacological component in the management of CHF (C. S. Lee, Tkacs et al., 2009; Rich, 2002). Patients are taught self care strategies that enable them to engage in healthy behaviours such as following a low sodium diet and taking appropriate actions for symptoms (Riegel & Carlson, 2002). This approach to patient education has been shown to substantially reduce hospitalisations (McAlister et al., 2004).

Despite a strong focus on patient education, the process of self-care is not readily learnt or understood by most patients (Horowitz et al., 2004; Riegel, Driscoll et al., 2009). As discussed in Chapter 2 (p.61), self-care decisions are often based upon the interaction between the person, the problem and their environment (Riegel & Dickson, 2008) and factors known to enable self-care include patient characteristics, environmental factors and social support (Connelly, 1993). Barriers that can interfere with effective self-care and achievement of therapeutic goals include physical factors, increasing age (Chriss et al., 2004; Michalsen et al., 1998; Moser & Watkins, 2008), co-morbidity (Artinian et al., 2002; Riegel et al., 2007), gender (Chriss et al., 2004; Karlsson et al., 2005), psycho-social factors (social support) (Sayers et al., 2008), depressive symptoms (Connelly, 1993; Schnell et al., 2006), and self-efficacy (Jerant et al., 2008; Tsay & Chao, 2002). Furthermore, the complexity and collection of symptoms associated with CHF cause functional and cognitive impairments that contribute to the challenge of living with this chronic illness (Bennett, Sauve et al., 2005; Stromberg, 2005; Wolfe et al., 2006).

Patients with CHF appear to have a 1.6-fold increase in risk for developing cognitive impairment than normal controls (Vogels et al., 2007). Patients with impaired cognition have poor health outcomes, even when enrolled in a CHF -MP (McLennan et al., 2006). One suggested explanation for this is that cognitive impairment decreases patients' abilities to assimilate self-care instruction and implement appropriate actions (Dickson et al., 2007) and appears to be associated with relatively poorer health outcomes in those with CHF (McLennan et al., 2006). Despite acknowledging the impact of cognitive impairment on the decision-making process there remains a lack of evidence as to the specific reasons why most CHF patients fail to master self-care.

Objectives

The primary aim of this study was to test a conceptual model of factors drawn from the literature as potential determinants of CHF self-care (see figure 11 below). Potentially important factors identified from the literature review in Chapter 2, were examined as determinants of CHF self-care in an elderly cohort of patients with the syndrome. As cognitive impairment occurs frequently in patients with CHF, we hypothesised that impaired cognitive function is often unrecognised and would be associated with poor CHF self-care practices. Due to its association between cognitive function and self-efficacy, as discussed in Chapter 2, depression was an important factor that also needed to be tested in the conceptual model. To date the association between cognitive impairment, depression and self-care is under explored and there is limited causal evidence that these two variables are barriers to self-care decisions.

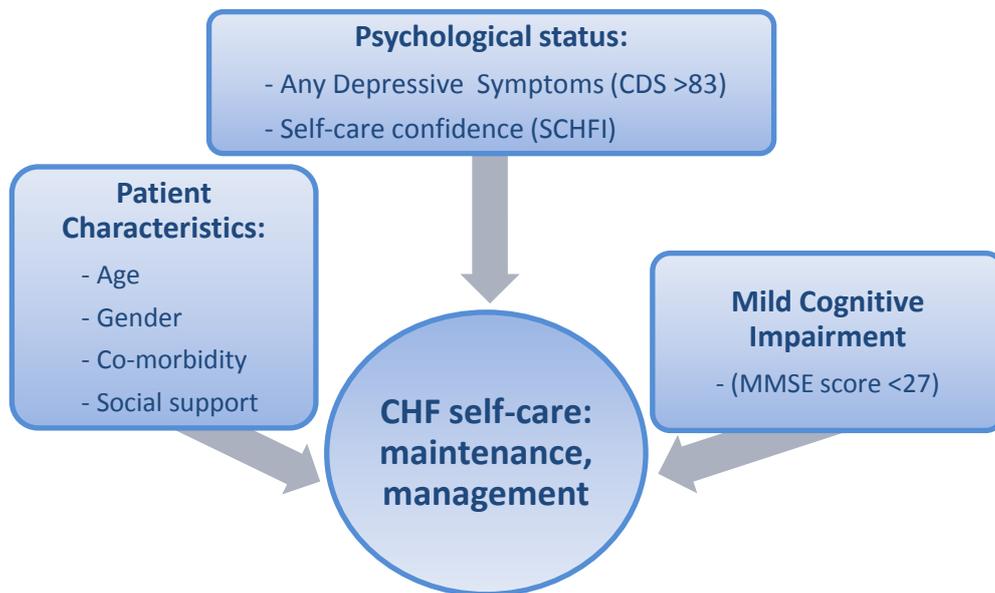


Figure 11: Phase 1 Initial conceptual model of factors that help predict heart failure self-care

Methodology

A convenience sample of consecutive patients hospitalised with CHF were screened for cognitive impairment, depressive symptoms, and self-care was assessed through the administration of questionnaires during the index hospital admission. It was calculated that to detect a moderate effect size ($R^2 = 0.3$), with a significance level of 0.05 and allowing for seven predictor variables, a sample size of 50 would achieve 0.9 power. The study was approved by both the Health Network Research Committee and the University Human Research Ethics Committee and conforms to the principles outlined in the Declaration of Helsinki. As the research was conducted in patients with cognitive impairment some of the ethical considerations will be briefly elaborated on.

Ethical Considerations

Due to the inclusion and exclusion criteria of the study the following ethical issues were given careful consideration. Patients who were non-English speaking could not be included due to the cost of translation services. This limitation is addressed in Chapter 6 in discussing the implications of the findings from the InCOGNITO study. Patients were not approached if they were deemed to be unable to provide informed consent. This included patients who had documented dementia. Mild cognitive impairment in patients with CHF is often not apparent to nurses caring for them, therefore at the time of asking for informed consent the patient's capacity for consent was unknown. There is evidence to indicate that patients with MCI are able to understand information of a minimal risk protocol and have capacity to make an informed decision (Buckles et al., 2003). Therefore, it was determined that if an individual was able to understand the cover letter, plain language statement and consent form they would be competent to provide consent to participate in this project even if they potentially were screened as having MCI by scores <27 but greater >18 on the MMSE. In the event that any participant was found to be significantly cognitively compromised after administration of the MMSE (score <18) then it was decided that they would be withdrawn from the study and no further questionnaires would be administered.

Through the administration of the Cardiac Depression Scale (Hare & Davis, 1996), participants who were at risk of depression were screened. Though it could be viewed as a potential risk of the project, it is actually an opportunity to prompt individuals to seek treatment and potentially improve their health outcomes. When individuals were identified as being at risk of depression the findings were discussed with them and permission was sought for their heart failure nurse to be contacted so that further support and management could be offered.

Sample

Between June and December 2005, patients referred to the Chronic Heart Failure Management Program (CHF-MP) across one Victorian healthcare network, Australia were screened for study eligibility. As most patients are referred to the program during their in-patient episode, routine assessment of self-care was investigated at this time point so that recommendations could be made for applying and tailoring components of the CHF-MP to individual need.

The inclusion criteria for the study were a diagnosis of CHF using the clinical criteria from the Framingham study (Ho, Anderson, Kannel, Grossman, & Levy, 1993) and moderate systolic dysfunction (ejection fraction <45) recorded on an echocardiogram report. As CHF affects mainly elderly persons, patients under 45 years of age were not included so that the results could be applicable to the wider CHF population. Patients were excluded from the study on the following basis: Neurocognitive problems documented in the medical history (cerebral vascular accident, transitional ischemic attack, short-term memory loss or dementia); residing in a residential nursing home; and inability to answer questionnaires independently due to language barriers. Patients who met the inclusion criteria were approached by a hospital CHF case manager to participate in the study and then referred to the researcher.

Of the 96 patients with CHF screened, 7 patients (4%) were excluded because English was not their primary language, 24 (14%) were excluded because they had a history of a cerebral vascular disease or a transient ischemic attack (TIA), eight (5%) were excluded for dementia, and 7 (4%) declined to participate in the study. These 46 patients

could not be compared to the 50 who were included because no further data were gathered on patients if they were excluded or had refused to participate. Fifty (52%) patients met the inclusion criteria and agreed to participate in the study.

Procedure

The primary investigator obtained informed consent from each patient. Overall, patient interviews were conducted 6 days (SD \pm 5) from admission date, usually while patients were still hospitalised. Administered at the time of the interview were instruments used to measure: CHF self-care index (SCHFI); Cognitive function (Mini Mental State Exam); Depressive symptoms (Cardiac Depression Scale). Descriptive data collected from the medical history were physical and social factors thought to influence self-care including: age, gender, social situation, Charlson co-morbidity index (Charlson, Pompei, Ales, & MacKenzie, 1987), NYHA functional class (The Criteria Committee of the New York Heart Association, 1964), experience with CHF diagnosis (>2 months)(Riegel & Dickson, 2008), level of education, medications, blood pressure and blood pathology.

Instruments Administered

Self-care Heart Failure Index

The Self-Care of Failure Heart Index (SCHFI) (Riegel et al., 2004) was developed to measure adherence to recommended CHF self-care behaviours, patient's decision making ability, and self-care confidence. The tool provides scores reflecting self-care maintenance (behaviours such as adhering to a low sodium diet), self-care management (the ability to recognise symptom changes, implement remedies and evaluate their effectiveness), and confidence with self-care (confidence to engage in each phase of the self-care process). The instrument's reliability and validity has been presented in Chapter 2 (p. 93). According to Riegel & Dickson (2008), maintenance and management reflect self-care, and confidence scores should be used to explain why some patients master self-care and others do not. Responses from each of the three self-care scales are transformed to 100 points each; higher scores reflect superior self-care. Scale scores \geq 70

are considered adequate self-care scores (Riegel et al., 2007). The SCHFI takes approximately ten minutes to complete.

Cardiac Depression Scale

The Cardiac Depression Scale (CDS) (Hare & Davis, 1996), developed in Australia, is a psychometrically sound disease specific measure of depressed mood within cardiac populations. The instrument is made up of 26 items with 7 subscales (sleep, anhedonia, uncertainty, mood, cognition, hopelessness, inactivity). A seven-point response scale is used for each item, with positive items reverse scored. During instrument testing 37% of patients with CHF scored >100, a cut-off thought to indicate severe depressive symptoms. Psychometric analysis of the instrument demonstrated it had good internal consistency (Cronbach's α 0.9). and that it correlates well with the Beck depression inventory (BDI), demonstrating its construct validity (Birks, Roebuck, & Thompson, 2004; Hare & Davis, 1996). Testing in a sample of 141 cardiac patients (Shi, Stewart, & Hare, 2008) demonstrated that a cut-off score ≥ 84 had the same specificity as Beck's Depression Inventory cut-score of ≥ 9 but had statistically superior sensitivity (97% vs 84% $p=0.004$). The ≥ 84 cut-off score was used in this study. More recently a shortened version of the CDS has been validated (Shi, Wu, Stewart, Toia, & Hare, 2008). The 5-item version is internally consistent and was strongly correlated to both the CDS and BDI. A score ≥ 14 has 92% sensitivity and 71% specificity for detecting depression (Shi, Stewart et al., 2008).

Mini Mental State Exam

The Mini Mental State Examination (MMSE), (Folstein et al., 1975) one of the most widely used screening measures for dementia, was developed to estimate the severity of cognitive impairment. The MMSE consists of 30 questions that screen for orientation, short-term memory, concentration and visual spatial skills. The MMSE has satisfactory reliability, internal consistency and test-retest reliability, as well as high levels of sensitivity for moderate-to-severe cognitive impairment (Tombaugh & McIntyre, 1992). Although cut-points are usually reported at 23/24 there is also evidence that using higher-cut scores of 26/27, indicating less severe cognitive impairment, is of prognostic

importance (Gussekloo et al., 1997; McLennan et al., 2006). As discussed in Chapter 2, in a study comparing the long-term outcomes from a CHF-MP (McLennan et al., 2006) patients with mild cognitive impairment were more likely to be re-admitted and less likely to survive the five year follow-up in comparison to patients with normal cognitive function and randomised to usual care. Guidelines for the clinical administration of MMSE suggest using scores 21-26 to indicate MCI, which led to a decision to use 26/27 in this study to ensure capturing of less severe cognitive impairment. A significant advantage of this tool is that it can readily be used in the clinical setting by nurses or allied health professionals, taking only five to ten minutes to complete (Lezak, Howieson, & Loring, 2004).

Charlson Co-morbidity Index

The severity of co-morbid conditions was assessed using the Charlson Co-morbidity Index, which classifies co-morbidity based on the number and seriousness of co-morbid diseases. The weighted index of co-morbidity has proven to be a significant predictor of 1-year survival with higher scores indicating greater risk of death (Charlson, Pompei et al., 1987). Most diseases are assigned an index of 1 but more severe conditions are given a weighted score of 2, 3 or 6. Overall index scores can be categorized as mild, moderate or severe co-morbidity.

Analysis

Data analysis included descriptive statistics and univariate analysis. Normally distributed continuous data are presented as the mean \pm standard deviation. Percentages are presented with 95% confidence intervals (CI) where appropriate. In this sample, all patients reported symptoms of breathlessness or oedema in the previous month, allowing for computation of scores of all three components of the SCHFI: self-care management, self-care maintenance and self-care confidence.

Univariate analysis (ANOVA) was computed to determine which factors were associated with statistically significant differences in mean self-care maintenance, management or confidence scores. Statistical significance was accepted at the adjusted

Bonferroni level $p < 0.017$. Multiple regression analysis was used to assess the model of hypothesised factors and to determine the degree of variance in self-care maintenance and management scores that was explained by cognitive function, depression, co-morbidity (collapsed into two categories: low = weighted index score 1-3 and moderate-to-severe = weighted index scores ≥ 4), gender, social situation and age. In the regression models, self-care confidence was used as a covariate rather than an outcome based on Riegel and Dickson's theory (2008) that confidence influences the ability to perform self-care. For the purpose of testing the theory driven conceptual model independent variables were entered into the regression models using an 'enter' method. SPSS (version 12.0.1 for Windows, Chicago, IL) was used for all analyses.

Results

The socio-demographic and clinical characteristics of the group are presented in Table 13 (p.119). Despite being elderly (mean age 73 years) most patients (60%) were still married and only 28% lived alone. Females represented only 24% of the cohort. Half the group had been diagnosed with CHF more than two months previously and half were functionally compromised (NYHA class III-IV). Twenty-seven (53%) reported depressive symptoms with scores on CDS ≥ 8 . Eighteen (36%) patients had a significant Charlson co-morbidity Index score ≥ 4 . Using the cut-point (26/27) on the MMSE, 18 patients (36%) had evidence of potentially important cognitive impairment.

Table 13: Socio-demographic and clinical characteristics of cohort

Socio demographic characteristics	n=50
Age (years)	73 (\pm 11)
Women (%)	12 (24%)
Married (%)	30 (60%)
Social situation - Lived alone (%)	14 (28%)
Education level <10 years (%)	15 (30%)
When interview conducted (mean days from hospital admission)	6 (\pm 5)
Clinical characteristics	
New Diagnosis of CHF (%) (< 2 months)	25 (50%)
Mild co-morbidity, (%) (Index score 1-3)	32 (64%)
Cognitive Impairment, MMSE <27 (%)	18 (36%)
NYHA classification moderate-to-severe, (class III or IV) (%)	25 (50%)
Hypotension, BP <100mmhg (%)	8 (16%)
Renal impairment, serum creatinine >110umol/l (%)	24 (48%)
Anaemic, serum Hb <10 g/L (%)	19 (38%)
Any depression (scores <83 on CDS) (%)	27 (53%)

Level of CHF Self-care

The mean self-care scores for the group were: 67.8 \pm 17.3 (range 25-100) for self-care maintenance; 50.04 \pm 16.64 (range 17-92) for self-care management; and 62.00 \pm 19.98 (range 25-100) for self-care confidence. In this sample, adequacy in self-care (defined as scores \geq 70% on each component of SCHFI) was evident in only 52% of the

sample in the performance of self-care maintenance. Only 12% were adequate in self-care management and 36% in self-care confidence.

In univariate analysis there were statistically significant differences in mean self-care scores using a Bonferroni adjusted level ($p < 0.017$) amongst four variables. Patients younger than 76 years of age had a 13-point lower self-care maintenance score than patients older than 76 years (61 ± 18 vs 74 ± 14 , $F(1, 48) = 8.4$, $p = 0.006$). Females had a 13-point lower self-care management score than males (39 ± 18 vs 53 ± 15 , $F(1, 48) = 7.5$, $p = 0.009$). Patients with low to moderate co-morbid index had a 13-point lower self-care maintenance score than patients with moderate to high co-morbid index (63 ± 17 vs 76 ± 15 , $F(1, 48) = 6.78$, $p = 0.012$). Patients with depression had a 17-point lower self-care confidence score than patients not depressed (54 ± 18 vs 71 ± 1 , $F(1, 48) = 1.3$, $p = 0.001$).

Two multiple regression models were generated to determine the relationship between hypothesised predictors (age, gender, co-morbidity, cognitive function, depression, social situation and self-confidence) and the criterion variables: self-care maintenance and management scores. There were no issues of multicollinearity amongst the variables (Tolerance values were > 0.1) indicating that the variables in the model were not highly correlated with each other.

When self-care maintenance was regressed on the seven variables, they explained 39% ($F(7, 42) = 3.80$, $p = 0.003$) of the variance in self-care maintenance scores (see Table 14 p. 121). Older age made the largest contribution to self-care maintenance scores ($\beta = 0.51$, $p = 0.001$). To investigate the impact of cognitive function on self-care maintenance a second regression model was analysed removing MMSE score as a factor. The six variables explained 4% less of the variance in self-care maintenance (35% ($F(6, 43) = 3.91$, $p = 0.003$) suggesting that cognitive function added to the model in predicting self-care maintenance.

Table 14: Multiple Regression analysis predicting Self-care Maintenance (n=50)

Predictor variables	Standardized Coefficients Beta	Partial R	F Value	P	R Square
Age	0.51	0.49		<0.01	
Male gender	-0.01	-0.02	3.80	0.92	0.39
Co-morbid index >4	0.34	0.34		0.02	
Cognitive function	0.23	0.23		0.13	
Depression	-0.16	-0.17		0.28	
Social situation – living with support	0.15	0.18		0.25	
Self-care confidence	0.07	0.07		0.64	

When self-care management was regressed on the seven independent variables they explained 38% (F (7, 42) 3.73 p=0.003) of the variance in self-care management scores (see Table 15). Higher self-care confidence made the largest contribution to self-care management scores ($\beta=0.39$, $p<0.01$). For every point increase in self-care confidence, there was a 0.39 point increase in self-care management. Three other variables contributed significantly to the variance: Male gender ($p<0.05$), moderate-to-severe comorbidity ($p<0.05$), depressive symptoms ($p<0.05$). When MMSE score was removed in the second regression model the six variables explained 4% less of the variance in self-care management (34% (F(6, 43) 3.71 p=0.005) suggesting that cognitive function added to the model in predicting self-care management.

Table 15: Multiple Regression analysis predicting Self-care Management (n=50)

Predictor variables	Standardized Coefficients Beta	Partial R	F value	P	R Square
Age	0.02	0.02		0.91	
Male gender	-0.33	-0.36		0.02	
Co-morbid index >4	0.33	0.33	3.73	0.03	0.38
Cognitive function	0.25	0.25		0.09	
Depression	0.32	0.34		0.04	
Social situation – living with support	-0.006	-0.007		0.97	
Self-care confidence	0.39	0.39		<0.01	

Discussion

In the current study the hypothesised model of seven variables explained a significant amount of the variance in self-care maintenance and management. Cognitive function, the variable of particular interest, was not a statistically significant predictor but when this variable was removed from the model, less of the variance in self-care was explained by the remaining variables. Unique factors explained self-care maintenance and management. Older age and moderate-to-severe co-morbidity were significant determinants of self-care maintenance (β 0.51 and 0.34, respectively). In contrast male gender (β -0.33), moderate-to-severe co-morbidity (β 0.33), presence of depressive symptoms (β 0.32), and greater self-care confidence (β -0.39) were significant predictors of self-care management. These models illustrate the influence of both modifiable and non-modifiable factors on self-care. Screening for these factors may help identify patients at greater risk of poor health outcomes so that follow-up strategies can be directed to those at greater risk of hospitalisations.

The strongest predictor of self-care was a moderate-to-severe co-morbidity index, which was associated with higher self-care scores for both management and maintenance behaviours. These results are consistent with those of others (Artinian et al., 2002; Riegel et al., 2007) who found that patients with more co-morbid illness and poorer functional class were better at practising self-care. Two possible explanations for this are that people with multiple co-morbid illnesses have had time to adapt to living with a chronic illness and are already conversant with self-care practices. Another possible explanation is that increasing symptoms and reduced functional capacity may motivate patients to be diligent with self-care. Arguably the increasing number of co-morbidities associated with ageing can compete with patient's self-care management resources making the process of self-care overwhelming (Kerr et al., 2007). However, in this small sample we found better self-care in patients with more co-morbid illness and older age.

The finding that older age predicted self-care maintenance is similar to that of other researchers studying chronic diseases (Schreurs et al., 2003) and CHF (Chriss et al., 2004; Michalsen et al., 1998). Qualitative study researchers (Berg et al., 2006) have found similar results and have challenged the stereotype that elderly people are not interested in undertaking health promoting activities suggesting instead, that older patients are often keen to be actively involved in health promoting activities and self-care behaviours because they prefer to be independent and self-reliant. This perspective may help to explain some of our findings.

The correlation between gender and self-care management was surprising, albeit consistent with the results of other investigators. Chriss et al (2004) found that increased age and male gender were significant predictors of CHF self-care, although these variables explained little of the variance in self-care. Karlsson et al. (2005) also found significant differences in self-care between men and women using a researcher developed questionnaire to assess knowledge about CHF management. However, their nurse-based intervention increased knowledge scores in the women over a six month period, so that over time, gender differences were not statistically different (13.5 ± 3.0 vs 12.2 ± 3.7 , $p=ns$). This suggests that women may have more to gain from CHF-MP interventions that focus on teaching self-care management than men.

These results also lend support that depression is associated with poor self-care, which may be linked to the interplay between self-efficacy and depression (Jerant et al., 2008). Tsay and Chao (2002) studied the effects of self-efficacy on depression in patients with CHF and found that self-efficacy was an important factor in patients' motivation to maintain physical function and an indirect influence on their depression. The model of Self-care in Chronic Illness (Connelly, 1993) also recognises the important influence that psychological status can have on general self-care behaviours to promote health and prevent illness. Using this model in a qualitative study investigating factors that influenced self-care, Schnell et al (2006) found that participants who described themselves as being upbeat were able to cope more effectively and practice self-care proficiently. Furthermore depression can result in neurocognitive dysfunction with impairments in memory and executive functions—effects that may indirectly influence self-care (Butters et al., 2004).

It was hypothesised that cognitive function would have a meaningful influence on self-care therefore it was surprising to find that impaired cognitive function contributed to the model but individually did not significantly correlate with self-care maintenance or management. These results are consistent with early results from Pressler and colleagues (S. Pressler, personal communication, November, 2007) who has suggested that CHF patients with impaired cognition are still able to perform self-care maintenance. In Phase 1 it was hypothesised that patients who were cognitively intact would perform superior self-care management on the premise that this behaviour requires the cognitive ability to learn, perceive, interpret and respond to symptom changes (Dickson et al., 2007).

Cognitive deficits can impair patients' ability to learn and carry out self-care. Structural changes of the brain resulting in grey matter loss within the insular and cingulate cortex can cause functional impairments relating to attention, memory, concentration, learning, executive functioning and psychomotor speed (Dickson et al., 2007; Wolfe et al., 2006). Deficits in memory and attention result in forgetfulness and poor learning ability which may impair treatment adherence (Bennett, Sauve et al., 2005; Wu, Moser, Lennie, Peden et al., 2008). Furthermore, executive dysfunctions impair patients' ability to make decisions in complex situations, such as early recognition and interpretation of symptoms (Dickson et al., 2007).

Executive functions or problem solving skills are higher order cognitive functions that originate from the pre-frontal cortex of the brain (Naugle & Kawczak, 1989; Xu et al., 2002). These cognitive functions are needed to construct and execute effective plans of action (Fellows, 2004; Royall et al., 2002). Executive functions are not measured by the MMSE and this limitation may help to explain why cognitive impairment was not a strong predictor of CHF self-care. Future studies investigating the relationship between self-care and cognitive function should use tools that are more sensitive in detecting mild impairment in higher order cognitive functions rather than screening measures for dementia.

Overall, self-care was low in this sample which may reflect that most of the sample had been newly diagnosed and lacked experience with their symptoms. Only half the patients followed self-care maintenance instructions such as daily weighing; most did not understand the significance of their symptoms. Despite being able to evaluate their symptoms, they were not proactive in implementing any self-care actions. Other researchers (Evangelista et al., 2003; Moser et al., 2005; Ni et al., 1999) also have found that despite being given appropriate instructions, adherence with self-care maintenance behaviours is particularly poor, even following a hospitalisation for heart failure. This suggests that patient education alone does not improve self-care practices and the results lend further evidence to the growing body of knowledge surrounding the number of non-modifiable factors that influence self-care practices. These factors must be considered when developing appropriate follow-up strategies and education programs for patients with CHF.

Implications for Research and Practice

The results of this study add to the body of evidence that patients with heart failure overall have poor self-care maintenance and management behaviours in spite of the recent attention to improving this outcome. It remains problematic in developing a systematic approach to applying educational strategies to individual need. There are a few limitations from this Phase of the research program study which impact on the generalisability of the findings but they will be discussed in Chapter 6. The conceptual

model of variables explained a significant amount of the variance in both self-care maintenance and management highlighting that there are a number of non-modifiable variables that are likely to impact on patients' ability to learn, recall and assimilate information. These factors are important potential barriers to self-care and should be considered when planning the level and intensity of follow-up strategies according to individual need. As discussed in the previous two Chapters, strategies directed at preventing hospital readmissions and improving health outcomes include a multi-disciplinary team to consider holistically the ongoing needs of patients and their carers and the delivery of extensive patient education and counselling.

Although it was hypothesised that cognitive function would be a significant factor in predicting self-care it was not apparent in this study which may be due to the chosen instrument to assess cognitive function. Self-care decisions are higher order cognitive functions which are often termed executive functioning. Executive functions are required for insight, will, abstraction and judgment—characteristics used to construct and execute effective plans of action (Fellows, 2004; Royall et al., 2002) and these cognitive domains are not necessarily assessed by the MMSE. Furthermore, only recently has the criteria for MCI been established. According to Portet et al (2006) MCI is characterised by the following features: cognitive complaints or a decline in cognitive function over a 12month period as reported by a patient or their family; impairment in memory or other cognitive domains evidenced by clinical evaluation; Absence of dementia and cognitive impairments having major repercussions on daily life. Subsequent to conducting Phase 1, the Montreal Cognitive Assessment (MoCA) emerged as a reliable and validated screening measure of MCI (Nasreddine et al., 2005). Together, this evidence led to the decision to revise the conceptual model of factors that predict self-care and utilise two screening measures to identifying patients at risk of MCI; the MMSE and MoCA. The following Chapter will present the findings from Phase 2 of the research program and discuss the implications for clinical practice.

Chapter Summary

Patients with CHF are encouraged to become active participants in their care which requires them to be able to interpret the importance of symptom changes, implement appropriate remedies and evaluate their effectiveness. To compound the self-care decision making process, patients with CHF are elderly, suffer concomitant co-morbid illnesses and often have changes in cognition, which may influence their capacity to become effective self-care managers. The results of this study illustrate factors associated with low levels of CHF self care in an Australian population. Clinical and demographic variables explained moderately large proportions of the variance in self-care maintenance and management scores. Although it was hypothesised that cognitive function would be a significant factor in predicting self-care it was not apparent in this study. Self-care decisions are higher order cognitive functions that are not necessarily assessed by the MMSE. Future studies are required that utilise more sensitive screening instruments for identifying mild cognitive impairments affecting executive functions. With this in mind the aim of Phase 2 of the InCOGNITO Heart Failure study was to further examine the correlation between self-care and cognitive function in a larger sample using two instruments to screen for MCI. This Phase of the research program is presented in the following Chapter.

Chapter 4: Phase 2 of the InCOGNITO Study

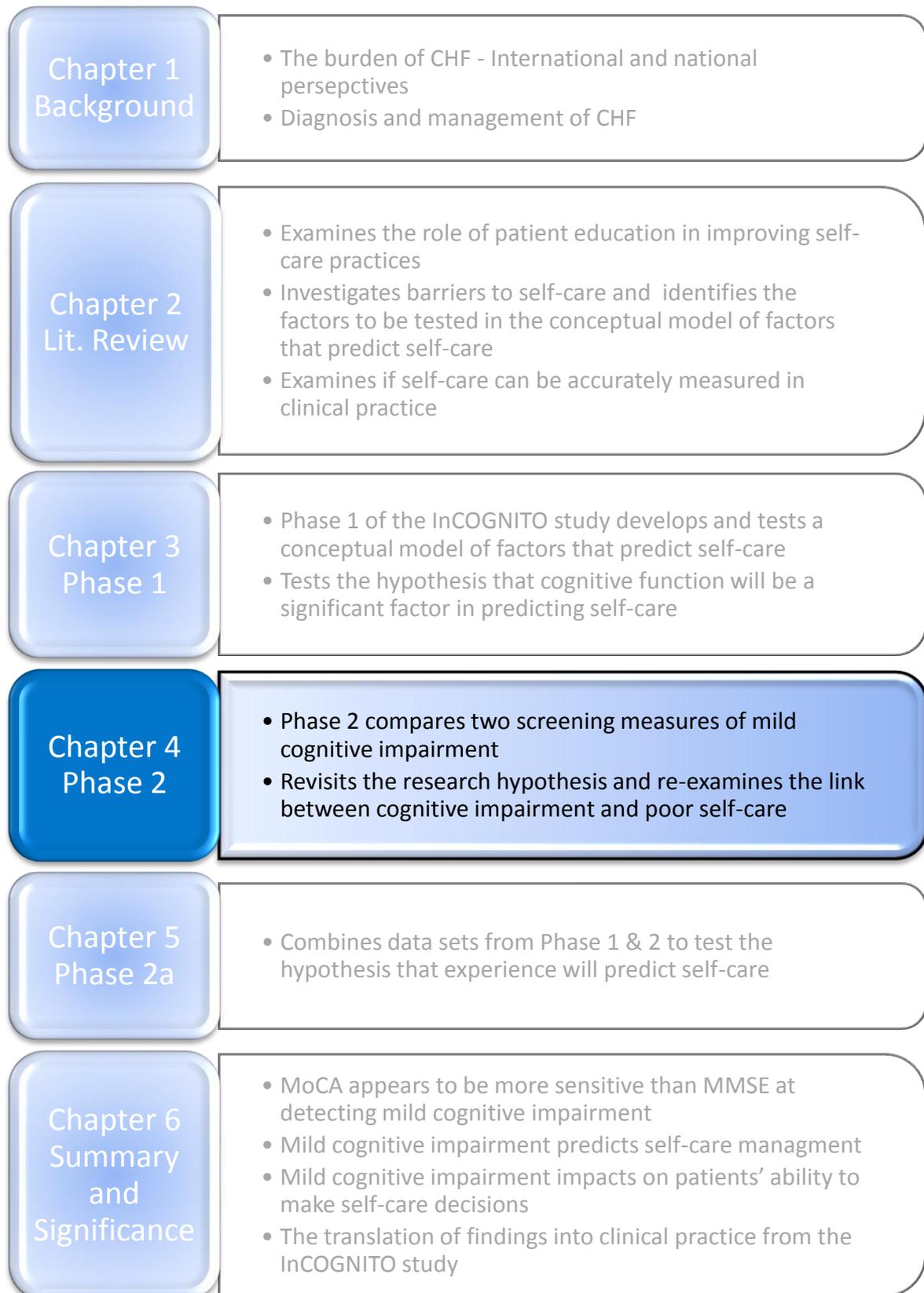


Figure 12: Overview of Chapter 4

Chapter 4 Introduction

It has been established in the previous chapters, the significant role that self-care plays in improving health outcomes in patients with CHF. Despite the significant attention given teaching and supporting patients, self-care is often sub-optimal (Riegel, Driscoll et al., 2009) and there are a number of causal factors and other co-morbid conditions to account for this (Moser & Watkins, 2008). Despite it being hypothesised that cognitive impairment may help to explain some of the self-care decision-making problems seen in persons with CHF (Dickson et al., 2007), few researchers have specifically set out to examine this. Phase 1 of this research program (Chapter 3), specifically developed and tested the conceptual model to determine whether cognitive impairment would impact on the ability of patients to develop adequate self-care skills. Although the hypothesis was not supported, the regression models demonstrated that cognitive function added to the conceptual model in predicting self-care. It was acknowledged that some of the limitations with the MMSE, the screening measure used to assess cognitive function, which may account for the lack of evidence in supporting the hypothesis. The aim of Phase 2 of the 'InCOGNITO Heart Failure study' was to further develop and progress the conceptual model.

In Phase 1 of the study, self-confidence was controlled for on the premise that maintenance and management reflect self-care, and confidence scores should be used to explain why some patients master self-care and others do not (Riegel & Dickson, 2008). In this Phase of the 'InCOGNITO study' factors considered to impact on self-confidence will be tested in the conceptual model. The findings from Phase 2 will be presented in this Chapter. Through using a more sensitive screening instrument than the MMSE, Phase 2 further explores the potential impact of MCI on self-care practices. The following background pertains specifically to this Phase of the research program.

Background

Chronic Heart Failure (CHF) is a significant problem affecting between 2.0% (R. A. Clark et al., 2004) and 4% (Dickstein et al., 2008) of the population in developed Nations. Older CHF patients have a 1.62-fold (95% confidence interval: 1.48-1.79, $p < 0.0001$)

increased risk of diminishing cognitive functioning compared with age-matched controls (Vogels et al., 2007). The most likely aetiology for cognitive impairments in patients with CHF is inadequate cerebral perfusion and acute or chronic hypoxic brain damage (Bennett, Sauve et al., 2005). Cognitive impairment is of concern as it is associated with relatively poorer health outcomes in patients with CHF (McLennan et al., 2006).

In Chapter 3 it was discussed as to how cognitive impairment may impair patients' ability to learn and carry out self-care (see Cognitive Impairment and Heart Failure p. 88). CHF self-care is a process of learning to maintain physiological stability by responding in a timely manner to symptom changes and implementing appropriate actions (Riegel & Dickson, 2008). As presented in Chapter 2 (See The Construct of Self-care p.59), the construct of CHF self-care is described as a naturalistic-decision-making process that distinguishes different skills relating to three self-care domains: self-care maintenance, self-care management and self-care self-confidence (Riegel et al., 2004). Each domain is associated with different behaviours and skill sets (Table 6: Behaviours, decisions and scoring for SCHFI) that require differing cognitive functions. Therefore even subtle cognitive impairments may impact on patients' ability to adequately learn, assimilate information and make apt self-care decisions.

In Chapter 3 (see Implications for Research and Practice p. 125) it was established that the criteria for MCI had only recently been quantified. Mild cognitive impairment refers to a clinical condition in which persons experience loss in memory greater than that expected for their chronological age, yet its severity does not meet the classification of Alzheimer's disease (Petersen et al., 2001). The accepted diagnostic criteria of MCI are cognitive complaints: decline in cognitive functioning over a 12-month period; cognitive dysfunction demonstrated by clinical evaluation; the absence of dementia; the cognitive impairment has limited impact on activities of daily living (Portet et al., 2006). It is recognised that MCI affects higher order cognitive domains. These cognitive domains are often referred to as 'executive functions'. Executive functions are used for managing complex financial affairs, maintaining hobbies and problem solving tasks such as learning to use new equipment (Chertkow et al., 2008; Pernecky et al., 2006; Y. Zhang, Han, Verhaeghen, & Nilsson, 2007). Assessing these cognitive domains requires tests pertaining to executive functioning which is beyond the capacity of the MMSE.

In studies investigating the operational definition of MCI (Luis, Keegan, & Mullan, 2009; Popovic et al., 2007; Smith, Gildeh, & Holmes, 2007) it would appear that patients screened as potentially having MCI often score above the MMSE cut-score of 26 (Nordlund et al., 2007; Petersen et al., 1999). Reasons suggested to account for such findings is that the MMSE has a large component of memory and language items (Naugle & Kawczak, 1989) and may not be sensitive to detect many cases of MCI (Wind et al., 1997; Zadikoff et al., 2008). Despite these limitations the MMSE was chosen as the screening measure in Phase 1 as no other valid alternatives could be found that nurses were able to readily access and use. However, the Montreal Cognitive Assessment (MoCA) has recently emerged as an alternative tool that may potentially be a more appropriate and sensitive screening instrument that specifically screens for MCI and is suitable for use in clinical practice (Nasreddine et al., 2005). The MoCA which is described below (see p. 134) was published after commencement of Phase 1 of this research program, hence it was only included in Phase 2.

An aim of Phase 2 was to further develop and progress the conceptual model of self-care (see Figure 13 p.132). In Phase 1 some of the variables included in the conceptual model were not significant at the univariate level and as the study has been conducted in a smaller sample, they had not been included in the regression models. In Phase 2, it will become evident from the univariate analysis (see Results p. 138) that NYHA class and new diagnosis were significant variables that needed to be include in the regression analyses. Limitations from this Phase of the research program will be discussed in Chapter 6. An outcome from this Phase of the research program has been the development of the manuscript 'Does Cognitive Impairment predict poor self-care in patients with chronic heart failure' that has been submitted for peer review to the Journal of Heart Failure (See Appendix A).

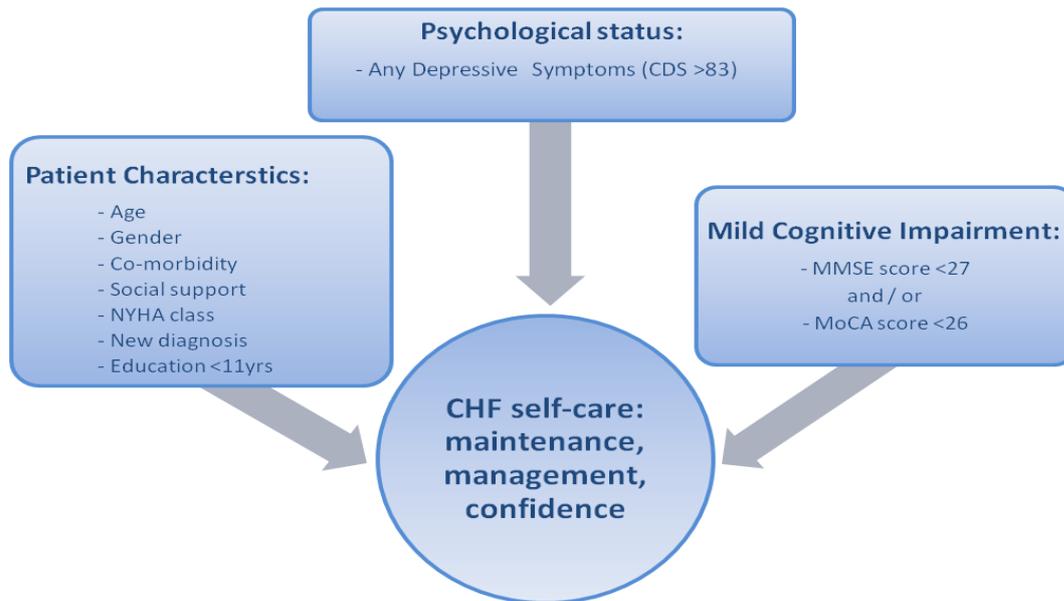


Figure 13: The refined conceptual model (Phase 2) of factors that help predict self-care in persons with heart failure

Legend: NYHA class- New York Heart Association classification; CDS- Cardiac Depression Scale; MoCA – Montreal Cognitive Assessment; MMSE – Mini Mental State Exam

Aims of Phase 2

This Phase of the research program expands on the conceptual model through determining if there was improved predictability of self-care behaviours. A secondary aim was to determine if the MoCA was a suitable screening measure in clinical practice to identify CHF patients at risk of MCI.

Methods

Study setting

The participants included 101 patients referred to a Chronic Heart Failure Management Program (CHF-MP) at two metropolitan health networks in Victoria,

Australia. Assessment of cognitive function, depressive symptoms, and self-care behaviours was undertaken by the primary researcher (JC) through administration of questionnaires during patients' hospital admission.

Study Sample

Between April 2007 and September 2008, 467 patients referred to the hospital CHF case manager were screened for study eligibility. The inclusion and exclusion criteria for the study were essentially the same as for Phase 1 (see Procedure p. 115). The only difference was that patients with diastolic dysfunction were included (Krum et al., 2006). Patients who met the inclusion criteria were approached by the CHF case manager to participate in the study and then referred to the researcher.

Four hundred and seventy-six patients were screened but 206 (43%) did not meet the study criteria. Of the 270 patients who were eligible 169 (63%) were excluded. Reasons for exclusion were: 52 (19%) did not have English as their primary language, 56 (21%) were excluded because they had a history of neurological events, 14 (5%) had poor visual/hearing acuity that was a barrier from completing questionnaires independently, 7 (3%) were deemed to be in the terminal phase of CHF, 6 (2%) were <45 years of age, 4 were residing in a high level supported accommodation. Thirty patients (11%) met the study eligibility but declined to participate. The primary reason for declining was they felt too unwell and participating in the study would be too burdensome. One hundred and one patients met the inclusion criteria and agreed to participate in the study; however eight later requested to withdraw. Participants enrolled in the study were significantly younger than those excluded (73 ± 11 vs 76 ± 13 yrs, $Z=-3.5$, $p<0.001$) but there were no significant gender differences between the two groups ($p=0.08$).

Procedure

The procedure was essentially the same as for Phase 1 (see p.115). The only difference was the administration of the MoCA as an additional screening for MCI. Patient interviews were conducted 6 days (SD ± 5) after hospital admission, usually while they were still hospitalised.

Clinical Instruments Administered

Self-care Heart Failure Index

The Self-Care of Failure Heart Index (SCHFI) has previously been described in Chapters 2 and 3 (see Table 6 p.94). Specifically three scales on the SCHFI reflect self-care maintenance, self-care management and self-care self-confidence (Riegel et al., 2004). Responses from each of these self-care scales are transformed to a score ranging from 0 to 100. Scale scores ≥ 70 are considered to reflect adequate self-care (Riegel et al., 2007).

Mini Mental State Examination

The MMSE (Folstein et al., 1975) is a widely used dementia screening measures that estimates the severity of cognitive impairment. The psychometrics of the MMSE have previously been described (see p.116). The MMSE consists of 30 questions that screen for orientation, short-term memory, concentration and visual spatial skills (Table 16: Cognitive domains covered by MMSE and MoCA p.136).

Montreal Cognitive Assessment

The Montreal Cognitive Assessment (MoCA) was developed in 2005 as a brief screening measure to detect MCI (Nasreddine et al., 2005). The MoCA assesses the cognitive domains of: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations and orientation (Nasreddine et al., 2005) (See Table 16 p.136). In comparison to the MMSE, the MoCA uses more words in assessing memory, has fewer learning trials and a longer delay before testing memory recall. Three tasks assess differing aspects of executive functions: an alternation task adapted from the trail making B task, a phonemic fluency task and a verbal abstraction task (See Table 16). Total possible score is 30 and MCI is indicated by cut-off < 26 . Low educational attainment is corrected by adding 1 point to final score for < 12 years of education. In the instrument development study (Nasreddine et al., 2005) the MoCA had higher sensitivity compared with MMSE at detecting MCI (90% vs 18%,

respectively). Subsequently, this tool has been shown to be a sensitive screening measure for MCI in patients with cardiovascular disease (Brennan, McLennan, Eckert, May, & Stewart, 2007; Popovic et al., 2007), in patients with CHF (Anthilingam, 2008) and cohorts with neurocognitive problems (Luis et al., 2009; Smith et al., 2007; Zadikoff et al., 2008).

Cardiac Depression Scale

The Cardiac Depression Scale (CDS) (Hare & Davis, 1996) was administered as a screening of depressive symptoms. The psychometrics of the instrument has been described in Chapter 3 (see p. 116).

Charlson co-morbidity index

The severity of co-morbid conditions was assessed using the Charlson Co-morbidity Index (Charlson, Pompei et al., 1987). The instrument has been described in Chapter 3 (see p.117).

Table 16: Cognitive domains covered by MMSE and MoCA

MMSE			MoCA		
Cognitive Functions	Task	Points	Cognitive Functions	Task	Points
Visuospatial abilities	Copy intersecting pentagons	1	Visuospatial abilities	Clock drawing	3
				3-dimensional cube copy	1
				Alteration task (adapted from Trail Making B Task)	1
			Phonemic fluency task	1	
			Two-item verbal abstraction task	2	
Language	Repetition (1 syntactically complex sentence)	1	Language	Repetition (2 syntactically complex sentences)	2
	Comprehend instructions	2			
	Read sentence and do as it says	1		Confrontation naming task	3
	Write a short sentence	1			
	Recognise and name 2 common objects	3			
			Attention	Sustained attention task using tapping	1
Concentration	Serial subtraction task or spell 'WORLD' backwards	5	Concentration	Serial subtraction task	3
Working memory	Registration –repeat 3 words	3	Working memory	Digits forward and backward	2
Memory	Short-term memory recall task	3	Memory	Short-term memory recall task	5
Orientation	Orientation to time and place	10	Orientation	Orientation to time and place	6
Normal Cognitive Function = 27-30			Add 1 point if ≤12 yrs education		
Mild cognitive impairment = 21-26			Normal cognitive function = 26-30		
Moderate cognitive impairment = 11-20					

Ethical considerations

The study was approved by both the relevant area Health Network Research Committee and the University Human Research Ethics Committee and conforms to the principles outlined in the Declaration of Helsinki. Other ethical considerations surrounding the issue of recruiting participants with MCI were discussed in the previous Chapter (see Ethical Considerations p.113).

Data management and statistical analyses

Post-hoc power calculations revealed that a sample size of 93 achieved sufficient power. Allowing for nine predictor variables and an effect size of $R^2 = 0.20$ we had a sufficient sample to achieve 83% power ($p=0.05$). Continuous data will be presented as the mean \pm standard deviation. Categorical data will be presented as percentages with 95% confidence intervals (CI) where appropriate. To compare patient groups according to demographic and clinical profile, Chi Square (χ^2) analysis and Likelihood Ratio (LR) was used in calculating the odds ratios (OR) and 95% CI for discrete variables. Student's t-test and analysis of variance were used for continuous variables.

Cognitive function was examined according to cut-points <26 on MoCA and <27 on MMSE. Differences in correct/incorrect responses on each cognitive domain were examined among the group overall and those assessed as having MCI. Significance was defined at the two-sided 0.05. Receiver Operator Characteristics (ROC) was examined to determine the sensitivity of MoCA in classifying patients with MCI. Three multiple regression analyses were performed using a backward stepwise method to determine which independent variables (age, gender, MCI on either screening measure, absence of depressed mood, living with support, co-morbid index, Functional symptoms NYHA class III or IV, completed >11 yrs education, and new diagnosis) were predictors of self-care maintenance, management and self confidence scores. SPSS (version 12.0.1 for Windows, Chicago, IL) was used for analyses and an online Power/sample size calculator used for power calculations (<http://www.danielsoper.com/statcalc/calc17.aspx>).

Results

Overall the group were elderly (mean age 70 \pm 11years), predominantly male (71%), and a less than one-third (30%) were newly diagnosed with CHF (See Table 17). Thirty-nine (42%) were living alone, most were retired (81%) and had completed <12years of education (77%). Half the group were functionally compromised (NYHA III or IV), fifty eight (62%) had a medium to high com-morbid index and only 25 (27%) were not depressed. The majority of patients had been prescribed pharmacotherapy considered gold standard in the treatment of CHF (Krum et al., 2006). Seventy-eight (84%) had been prescribed an ACE-I or ARB and seventy-nine (85%) had been prescribed a beta-blocker.

Table 17: Socio demographics and clinical characteristics of the group (n=93)

Socio Demographics	N (%)
Female	27 (29%)
Living Alone	39 (42%)
Did not complete 12yrs education	72 (77%)
Retired	75 (81%)
Clinical Data	
New Diagnosis	28 (30%)
NYHA III	42 (45%)
NYHA IV	5 (5%)
Hypotensive, systolic BP <100 mmHg	13 (14%)
Renal Impairment, serum creatinine >120umol/l	50 (54%)
Anaemic, serum Hb <100g/l	18 (19%)
History of ischaemic heart disease	55 (59%)
Not diabetic	52 (56%)
Smoking history	78 (84%)
Co-morbid index low	35 (38%)
Co-morbid index medium	40 (43%)
Co-morbid index high	18 (19%)
Either on ACEI or ARB	78 (84%)
Prescribed diuretic	90 (97%)
Prescribed aldosterone antagonist	31 (33%)
Prescribed Beta Blocker	79 (85%)
Depressive symptoms	68 (73%)

Key: NYHA - New York Heart Association classification; ACEI- Angiotensin Converting Enzyme Inhibitor; ARB - Angiotensin II Receptor Antagonists

Cognitive function amongst the group

Twenty-five (27%) patients had normal cognitive function on both MMSE and MoCA (See Figure 14). Sixty eight (73%) were coded as having mild but potentially significant cognitive impairments (MCI) on both screening measures. Only 1 person scored <27 solely on the MMSE. Thirty-six (39%) had scores <26 only on the MoCA and 31 (33%) had scores below the threshold for MCI on both MoCA and MMSE (See Figure 14 below).

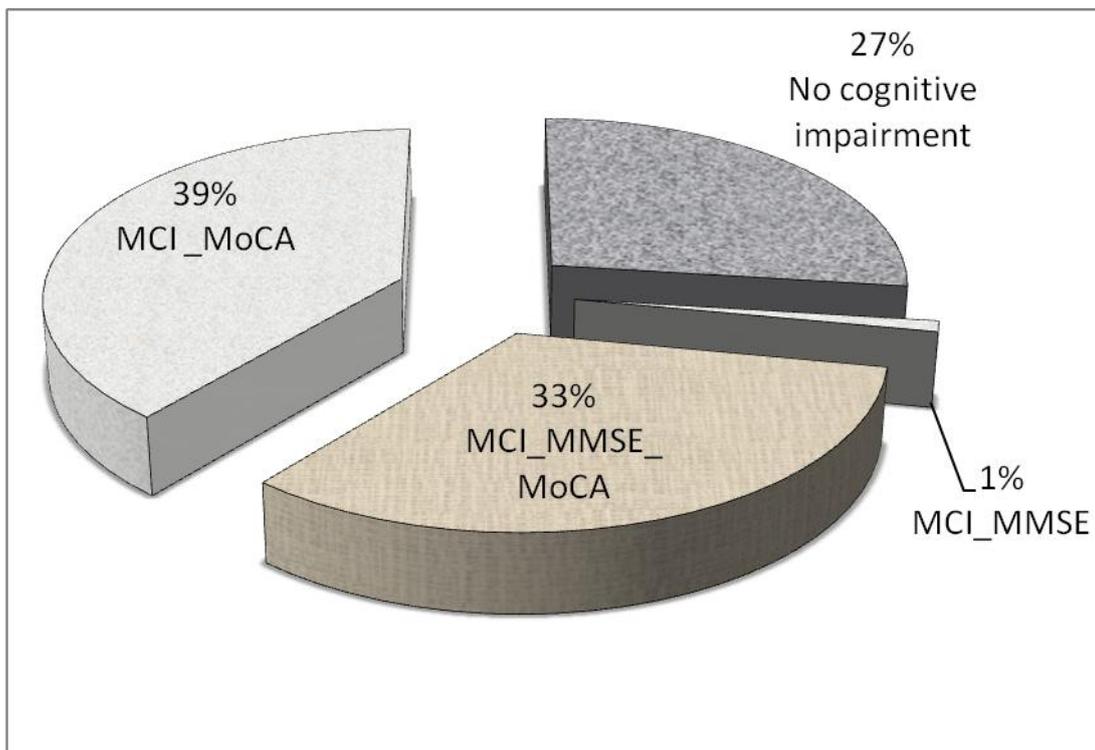


Figure 14: Occurrence of cognitive impairment amongst the group

Legend: No cognitive impairment – scores ≥ 27 on MMSE and ≥ 26 on MoCA; MCI_MoCA – patients scored <26 on MoCA only; MCI_MMSE_MoCA - patients scored <27 on MMSE **and** <26 on MoCA; MCI_MMSE – patients scored <27 on MMSE only

An examination of incorrect responses on the screening measures of cognitive function demonstrated that patients screened as MCI had errors on all tasks with the exception of the MMSE registration task (see Table 18 p.142). In contrast the digit

forward and backward test of MOCA is an equivalent measure of working memory and 19 patients with MCI had errors on this task. Patients screened as MCI were more likely than their cognitive intact counterparts to have errors on 3 cognitive domains assessed by both MoCA and MMSE: language, memory recall, and orientation to time and place. Patients with MCI had a 72% increase in the likelihood of executive function errors (OR 1.72, 95% CI 1.12 to 2.62, LR <0.01), a 52% increase in visuospatial errors (OR 1.52, 95% CI 1.21 to 2.07, LR <0.01) and 42% increase in concentration task errors (OR 1.42, 95% CI 1.17 to 1.71, LR <0.01) assessed by MoCA only. Patients screened as MCI had a similar risk as patients cognitively intact in having errors with the tapping command from MoCA which assesses attention (OR 0.97, 95% CI, 0.63 to 1.48, LR =0.88).

Table 18: Incorrect responses to each cognitive domain assessed

Cognitive domain	Screening measure	Overall (n=93)	Cognitively intact (n=25)	MCI (n=68)	OR (95% CI)
Visuospatial	MMSE	78 (84%)	0 (0%)	15 (100%)	—
	MoCA	57 (61%)	9 (16%)	48 (84%)	1.52 (1.21 to 2.07)**
Executive Functions	MoCA	68 (73%)	12 (48%)	56 (82%)	1.72 (1.12 to 2.62)**
Language	MMSE	57 (61%)	11 (19%)	46 (81%)	1.32 (1.00 to 1.76)*
	MoCA	65 (70%)	10 (15%)	55 (85%)	1.82 (1.21 to 2.75)**
Attention	MoCA	10 (11%)	3 (30%)	7 (70%)	0.96 (0.62 to 1.56)
Concentration	MMSE	17 (18%)	0(0%)	17 (100%)	—
	MoCA	20 (21%)	1 (5%)	19 (95%)	1.42 (1.17 to 1.71)**
Working memory	MMSE	1 (1%)	1 (100%)	0 (0%)	—
	MoCA	19(20%)	0 (0%)	19 (100%)	—
Memory recall	MMSE	60 (65%)	9 (15%)	51 (85%)	1.65 (1.17 to 2.34)**
	MoCA	87 (94%)	21 (24%)	66 (76%)	2.38 (0.73 to 7.1)*
Orientation	MMSE	36 (39%)	3 (8%)	33 (92%)	1.49 (1.19 to 1.88)**
	MoCA	31 (33%)	2 (6%)	29 (94%)	1.49 (1.2 to 1.84)**

Key – some cells have no cases so OR not computed, * = LR < 0.05, ** = LR < 0.01

Patients coded as MCI more frequently had errors on cognitive domains tested by MoCA than the MMSE (See Figure 15 below). Sixty-five (97%) patients with MCI did not respond correctly to the memory recall task on MoCA compared with 50 (75%) on the MMSE. Forty-eight patients (72%) had errors on the visuospatial tasks on MoCA compared with 15 (22%) on the copying task on the MMSE. No patients coded as MCI had errors on the MMSE working memory task where as 19 (28%) had errors for digit forward and backward, the equivalent working memory task on the MoCA. Executive function is cognitive domain measured only on MoCA by three tasks and in this area 55 (82%) patients had errors. This suggested the MoCA identified cognitive dysfunctions more frequently than MMSE.

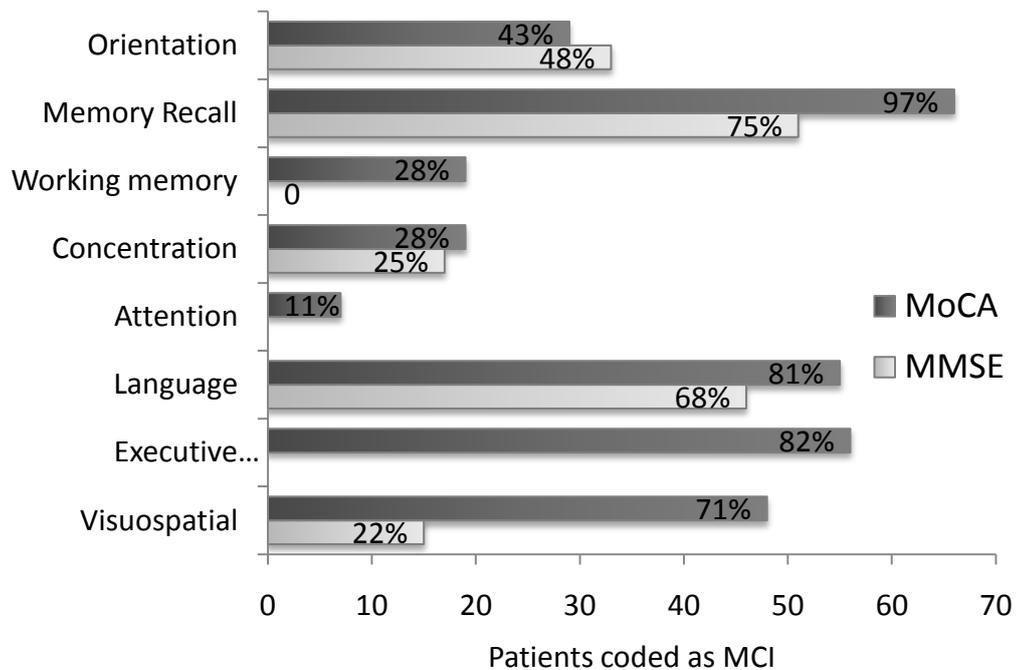


Figure 15: Differences between MMSE and MoCA in screening for cognitive problems

To assess the ability of MoCA as a screening measure to correctly screen patients with and without MCI, a Receiver Operating Characteristics (ROC) curve was analysed. The MMSE was used as the comparator with threshold for MCI as 26/27. Areas under the

curve are a measure for the diagnostic accuracy of an instrument. Using the ROC analysis, the area under the curve for MoCA was 81% (See Table 19 below).

Table 19: Area under the curve for MoCA

Area under the curve	Std. error	Asymptomatic significance	95% Confidence Interval	
			Lower bound	Upper bound
.817	.045	.000	.728	.906

The ROC analysis also provided the sensitivity and specificity of the MoCA at various cut-off scores (See Table 20 below).

Table 20: Coordinates of the ROC curve showing sensitivity and specificity of MoCA

Score positive if less than or equal to	Sensitivity	1 - Specificity
17.50	.188	.000
18.50	.219	.049
19.50	.313	.049
20.50	.500	.082
21.50	.531	.098
22.50	.656	.115
23.50	.688	.262
24.50	.813	.410
25.50	.969	.590
26.50	.969	.705
27.50	1.000	.803
28.50	1.000	.885
29.50	1.000	.951
31.00	1.000	1.000

The cut-score of <26 on MoCA had excellent sensitivity of 97% to screen for MCI. However, the threshold score < 26 may have coded cognitively normal patients as MCI (false-positive) 29% of the time. For screening purposes it is recommend that tests have higher sensitivity than specificity (Strik, Honig, Lousberg, & Denollet, 2001) and both

levels should be at least 75% (Lowe et al., 2004). With this in mind a more appropriate threshold would have been a score <24 which would have given a sensitivity of 81% in detecting MCI and a specificity of 59%.

Self-care behaviours for the group

In this sample, all patients reported symptoms of breathlessness or oedema in the previous month, allowing for computation of scores for all three self-care domains. Over all self-care scores were low for the group (Figure 16 p. 146). The mean self-care maintenance score was 69 ± 14 and half (53%) had adequate scores. The mean self-care management score 57 ± 20 and less than a third (27%) had adequate scores. There was no significant difference in mean self-care maintenance scores between patients coded with and without cognitive impairment (68.5 ± 14.7 vs 68.9 ± 11.4 ; $t(91) = 0.09$, $p=0.93$). In contrast patients coded as MCI on average had lower scores on self-care management (53.3 ± 19.5 vs 65.4 ± 18.0 ; $t(91) = 2.7$, $p \leq 0.01$) and self-care confidence (64.7 ± 15.4 vs 72.1 ± 14.8 ; $t(91) = 2.4$, $p < 0.02$) and the magnitude in the differences in mean scores was moderate ($\eta^2 0.07$ and $\eta^2 0.06$, respectively). Fifty-one (76%) patients with inadequate self-care management were coded as MCI (OR 1.27, 95% CI 0.9 to 1.8, LR =0.13). Patients coded with MCI were more likely to have inadequate self-care confidence (OR 1.33, 95% CI 1.1 to 1.75, LR=0.04).

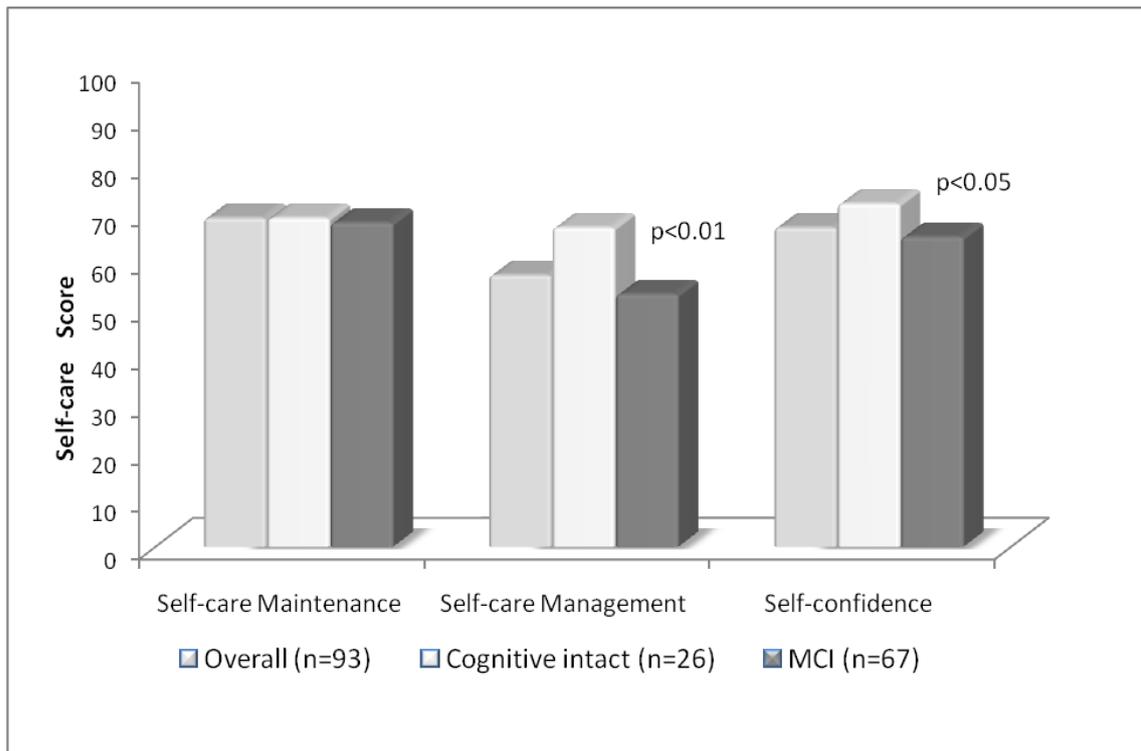


Figure 16: Mean self-care scores among the group of patients with CHF

Testing the Conceptual Model to Determine Which Factors Predicted Self-care

Univariate analysis (ANOVA) was computed to determine which factors were associated with statistically significant differences in mean self-care maintenance, management or confidence scores. Statistical significance was accepted at the adjusted Bonferroni level $p < 0.017$. Experience with CHF correlated with self-care maintenance ($r=0.31$, $p=0.003$); patients newly diagnosed with CHF (< 2months) had 9-point lower self-care maintenance (62 ± 15 vs 71 ± 14 ; $F(1, 91) = 9.6$, $p=0.003$) than patients experienced with CHF (diagnosis >2 months).

Four variables correlated with the self-care management score: MCI ($r=-0.27$, $p=0.008$), functional symptoms ($r=0.26$, $p=0.01$), co-morbid index ($r=0.28$, $p=0.007$), Age ($r=-0.21$, $p=0.05$). Patients coded with MCI had a 12-point lower self-care management scores (53 ± 20 vs 65 ± 18 ; $F(1, 91) = 7.3$, $p=0.008$) than those cognitively intact. Patients with NYHA class III or IV had a 10-point higher self-care management scores (62 ± 19 vs 52

± 20 ; $F(1, 91) = 6.7, p=0.011$) than patients with NYHA class I or II. Patients with co-morbid index 1-3 had a 14-point lower self-care management score (54 ± 19 vs 68 ± 20 ; $F(1, 91) = 7.6, p=0.007$) than those with moderate to high co-morbid index (≥ 4). When age was dichotomised at the mean, the six-point difference in self-care management between patients younger or older than 71 years of age was not statistically significant.

Three variables correlated with self-confidence: MCI ($r=-0.21, p=0.04$) depression ($r=0.03, p=0.003$) and age ($r=-0.25, p=0.02$). Patients with depressive symptoms had a 10-point lower self-care confidence scores (64 ± 15 vs 74 ± 13 ; $F(1, 91) = 9.2, p=0.003$) than those without depressive symptoms. Although patients with MCI had a 7-point lower self-care confidence than patients cognitively intact (65 ± 15 vs 72 ± 17 ; $F(1, 91) = 4.3, p=0.04$) but using the adjusted Bonferroni level this was not statistically significant. When age was dichotomised at the mean, the five-point difference in self-care confidence scores between patients younger or older than 71 years of age was not statistically significant.

On the basis of the results from the univariate analyses conducted in Phase 1 and Phase 2 of the research program, together with the evidence from the literature review (see Barriers and Stimuli to Developing Adequate Self-care p.79), the following modifiable and non-modifiable factors were tested. Age, gender, co-morbidity, new diagnosis and educational attainment were considered non-modifiable factors. Depressive symptoms, NYHA class, social support and MCI were considered modifiable factors. Direct multivariate regression was performed to assess the impact of these factors on self-care maintenance, management and confidence scores (Table 21 p.148).

When self-care maintenance was regressed on the nine factors, experience with CHF (diagnosis >2 months) was the most significant factor, explaining 10% of the variance in self-care maintenance scores ($p<0.01$). Self-care management was similarly regressed. Overall NYHA class III or IV, co-morbid Index and MCI explained 20% of the variance in this score ($p<0.01$). It was MCI that made the largest contribution to the model explaining 9% of the variance in self-care management. Only younger age and absence of depressive symptoms were significant factors when self-care confidence was regressed. These two factors explained 13% of the variance in self-care confidence scores ($p<0.01$).

Table 21: Regression models for self-care

Model	Predictor Variables	Standardized Coefficients Beta	Sig.	Part Correlations	F	p	R ²
Self-care maintenance	Experience with CHF	.31	<0.01	.31	9.6	<0.01	0.10
Self-care management	NYHA class III or IV	.21	0.04	0.20	7.3	<0.01	0.20
	Charlson co-morbid index	.20	0.05	0.19			
	MCI	-.30	<0.01	-0.30			
Self-care confidence	Age	-.28	<0.01	-0.28	6.9	<0.01	0.13
	Depression	-.27	<0.01	-0.26			

Discussion

In this Phase of the research program three-quarters (73%) of a sample of CHF patients chosen because they were without a history of neurocognitive problems were screened as potentially having significant and unrecognised cognitive impairments. The results indicate that CHF patients who were screened as potentially having MCI were as likely as cognitively intact patients to follow recommended self-care maintenance behaviours such as daily weighing. Conversely, patients coded as MCI were 30% more likely than patients cognitively intact to have inadequate self-care confidence. In the univariate analysis it was MCI that made the strongest contribution to predicting self-care management. The evidence from this study suggests that mild cognitive dysfunction potentially impacts significantly on the ability of patients to independently recognise symptom changes and make appropriate self-care decisions. These cognitive deficits appear to correlate to the acquisition of self-care skills which potentially has notable clinical ramifications.

Other researchers (Friedman & Quinn, 2008; Patel et al., 2007) have found that a delay in symptom recognition and initiation of self-care actions potentially increases the risk of hospital admission or premature death. Furthermore, optimal self-care practices are hypothesized to contribute to physiological stabilization, retard the progression of cardiac dysfunction resulting in improved health outcomes (C. S. Lee, Tkacs et al., 2009). As previously discussed in Chapter 2, McLennan et al (2006) found over a five year period, that patients that patients with MCI had a 1.4-fold increased risk of being admitted or dying ($p=0.002$) relative to cognitively intact patients and after adjusting for potential confounders. Despite receiving gold-standard treatments from a home-based nursing intervention, patients with MCI had a two-fold increased risk of death ($p=0.03$) compared with those with normal cognitive functioning. Potentially cognitive impairments resulted in neural processing problems, impacting on the ability of patients to remember and learn self-care skills, ultimately blocking the beneficial effects of a home-based nursing intervention (McLennan et al., 2006).

It has been recognised that patients with CHF are at an increased risk of developing cognitive issues that potentially will progress to dementia including Alzheimer's disease (Qiu et al., 2006). The most likely reason for the development of cognitive impairment in this group of patients is the result of inadequate cerebral perfusion and acute or chronic hypoxic brain damage (Aconfora et al., 1996; Bennett, Sauve et al., 2005; Dickson et al., 2007; Zuccala et al., 2005). Other variables that also appear to contribute to the development of cognitive impairment in this group of patients include age, co-morbidity, hypertension, depression and medications (Bennett, Sauve et al., 2005). Structural changes in the brain (Dickson et al., 2007) may explain attention, memory, concentration, learning, executive functioning and psychomotor speed are the most common cognitive domains impaired in patients with CHF (Almeida & Flicker, 2001; Bennett & Sauve, 2003; Wolfe et al., 2006). According to Dickson, Tkacs & Riegel (2007) deficits in memory and attention may result in forgetfulness and poor learning ability, marring treatment adherence. In contrast neural processing deficits may be the consequence of executive dysfunction, resulting in prolonged time to construct self-care decisions and difficulty in foreseeing the consequences of actions taken, or not

taken (Dickson et al., 2007; Hicks & Holm, 2003). This perspective may help explain why we found that MCI was the most significant predictor of self-care management.

Other factors that appear to predict better self-care were non-modifiable: experience with CHF, being symptomatic (NYHA class III or IV), higher co-morbidity, younger age and absence of depressive symptoms. Although these factors were significant in our models there remains a large unexplained variance still exists. This lends support to other researchers who have proposed that there are a multitude of factors that impede patients' ability to independently and adequately undertake self-care behaviours (Moser & Watkins, 2008; van der Wal, Jaarsma, & van Veldhuisen, 2005). This was previously discussed in Chapter 2. These factors should be considered when applying educational strategies to individual need.

Not only does depression occur frequently in patients with CHF but may worsen heart failure symptoms such as dyspnoea and fatigue (Ramasamy et al., 2006), resulting in greater hospital utilisations (Sayers et al., 2007). In addition, depressive symptoms appear to impede the practice of proficient self-care (Schnell et al., 2006) and may be linked to the interplay between self-efficacy and depression (Jerant et al., 2008). Patients who are not depressed have greater self-confidence and appear to adhere more frequently with self-care, resulting in better health outcomes (Dickson et al., 2008; Evangelista et al., 2001). This suggests that patients who lack self-confidence and suffer depression may require greater attention to support them in self-care (Jerant et al., 2008).

Age related differences in self-care confidence found in our study may relate to differences in cultural norms (Rodriguez et al., 2008) and the ageing process itself impacting on somatic awareness (Jurgens, 2006). The inability to detect and recognise symptoms may lead to uncertainty and reduced self-confidence to manage and control symptoms (Winters, 1999), ultimately contributing to failed self-care. Furthermore, it is not uncommon for older patients to have several co-existing co-morbidities (Krum & Gilbert, 2003). Needless to say living with both CHF and other co-morbid conditions can make performance of self-care quite challenging (Carlson et al., 2001).

In contrast, other studies (Artinian et al., 2002; Cameron, Worrall-Carter, Riegel et al., 2009; Riegel et al., 2007) have demonstrated that patients with increasing co-morbidity are better self-managers. It is possible that patients who have had experience with a chronic condition may already have acquired proficient self-care skills and practices. Furthermore, the level of functional disability may also be a motivating factor with self-care. Indeed, a self-management intervention resulted in higher hospitalisations in patients who were asymptomatic (Riegel, Carlson, Glaser et al., 2000), indicating the need to selectively target education and support strategies to those patients with symptoms, who are at greater risk of hospitalisations.

In Phase 2 of the 'InCOGNITO Heart Failure study' level of experience with CHF was an important determinant of self-care maintenance. Experience plays a vital role in effective self-care decision making (Riegel & Dickson, 2008). Naturalistic Decision Making Theory (Lipshitz et al., 2001) contends that proficient decision makers rely on their knowledge and experience to make context-specific choices. These decisions are influenced by knowledge about the situation, experience with decision-making in the particular context, skill to act on the decision made and the decision and action need to be compatible with their own values (Lipshitz et al., 2001). With this in mind, the following chapter will examine whether the logical assumption holds true in a contemporary sample where awareness is greater, that level of experience with CHF will impact on self-care. If the hypotheses are supported it will provide some evidence as to the length of time required for patients to develop adequate self-care skills. This may help in determining the intensity of educational efforts required in the initial phase of diagnosis and over the longer term. In this manner, the allocation of resources may have a greater cost-benefit effect.

One of the problems in tailoring educational strategies to individual need, is knowing how to systematically screen for the multitude of variables that impede the acquisition of self-care skills. The conceptual model that was tested in the 'InCOGNITO Heart Failure study' demonstrates the application of suitable screening measures in clinical practice that may help predict patients at greater risk of sub-optimal self-care. The use of the MoCA as a screening measure of cognitive function detected more cognitive impairment than the MMSE. For screening purposes it is important to have an instrument

with high sensitivity (Strik et al., 2001) indicating few false-negatives (i.e., undetected cognitive impairment), to have higher sensitivity than specificity (Strik et al., 2001) and both levels should be at least 75% (Lowe et al., 2004). Specificity is concerned with how a test can correctly identify the subjects as having the problem under investigation (Loong, 2003). Higher specificity means fewer false-positives (i.e. cases erroneously coded as having cognitive impairment) (Lowe et al., 2004). In this study the cut-off scores <26 on MoCA had excellent sensitivity but low specificity. The threshold score < 26 on MoCA may have coded cognitively normal patients as MCI 29% of the time. In clinical use, positive results would normally be followed up with further evaluation, thereby minimising false-negative results. In order to minimise the number of false-positive results a more appropriate threshold in clinical practice may be to use a score <24 on MoCA which would have given adequate sensitivity and improved the specificity (see

Table 20: Coordinates of the ROC curve showing sensitivity and specificity of MoCA).

Further testing of the predictive ability of MoCA to correctly screen for MCI in patients with CHF requires greater analysis against gold standard neuropsychological assessments; this was beyond the scope of the 'InCOGNITO' study. Disadvantages from using a battery of neuropsychological tests in clinical practice is the length of time required administering them and the financial costs in employing a qualified psychologist to administer the tests. Both these constraints preclude the routine adoption of such practices within CHF-MPs. Hence the need to find a sensitive screening measure that can be readily used by nurses and other health professionals. Additional research is required to determine the most appropriate cut-off scores on the MoCA in correctly screening for MCI amongst patients with CHF.

Chapter Summary

This program of research builds on and contributes to work in understanding barriers to achieving optimal self-care. Phase 2 describes some of the factors that impact on patients' ability to competently make self-care decisions and develop adequate self-care skills. Furthermore, this Phase has demonstrated that MCI is a hidden co-morbidity and potentially occurs more frequently than realised, suggesting the need to purposively screen for it. The 'InCOGNITO Heart failure study' provides insight into the clinical application of a conceptual model that may be used in the future to help systematically screen for known barriers in the acquisition of self-care skills. Acknowledging these barriers may help in tailoring the application of patient education and support strategies to individual need. The findings from this research program suggest that patients with subtle cognitive impairments require longer term support in making appropriate self-care decisions. When patients do not have the social support to help in these self-care decisions then additional community supports may be required. Examples of social supports that are often applied in CHF-MPs include tele-monitoring (R. A. Clark, Inglis et al., 2007; Dar et al., 2009) and community home visits (Pearson et al., 2006; Yu et al., 2006). Improving self-care practices amongst the many patients diagnosed with CHF may help to reduce the physical, functional and cognitive limitations often experienced. Furthermore, improved self-care practices may also lessen the burden of the syndrome on the healthcare system by improving the long-term health outcomes. The following chapter will examine the role that experience plays in an attempt to further develop our understanding in the achievement of optimal self-care.

Chapter 5: Phase 2a: Does experience with heart failure symptoms really makes a difference in self-care practices?

<p>Chapter 1 Background</p>	<ul style="list-style-type: none"> • The burden of CHF - International and national perspectives • Diagnosis and management of CHF
<p>Chapter 2 Lit. Review</p>	<ul style="list-style-type: none"> • Examines the role of patient education in improving self-care practices • Investigates barriers to self-care and identifies the factors to be tested in the conceptual model of factors that predict self-care • Examines if self-care can be accurately measured in clinical practice
<p>Chapter 3 Phase 1</p>	<ul style="list-style-type: none"> • Phase 1 of the InCOGNITO study develops and tests a conceptual model of factors that predict self-care • Tests the hypothesis that cognitive function will be a significant factor in predicting self-care
<p>Chapter 4 Phase 2</p>	<ul style="list-style-type: none"> • Phase 2 compares two screening measures of mild cognitive impairment • Revisits the research hypothesis and re-examines the link between cognitive impairment and poor self-care
<p>Chapter 5 Phase 2a</p>	<ul style="list-style-type: none"> • Combines data sets from Phase 1 & 2 to test the hypothesis that experience will predict self-care
<p>Chapter 6 Summary and Significance</p>	<ul style="list-style-type: none"> • MoCA appears to be more sensitive than MMSE at detecting mild cognitive impairment • Mild cognitive impairment predicts self-care management • Mild cognitive impairment impacts on patients' ability to make self-care decisions • The translation of findings into clinical practice from the InCOGNITO study

Figure 17: Overview of Chapter 5

Chapter 5 Background

There are many reasons to explain why achievement of optimal self-care can be difficult for many patients with chronic heart failure (CHF). In the previous two Phases of the InCOGNITO Heart Failure research program a conceptual model was tested to determine which variables were significant predictors of self-care. Experience with CHF was the most significant factor ($\beta = 0.31$, $p < 0.01$) explaining 10% of the variance in self-care maintenance. Self-care theory contends that experience is a prominent factor in developing expertise in self-care decisions.

To further explore and test the hypothesis that experience will influence self-care, Phase 2a combines data from the previous two Phases and investigates in 143 patients, whether differences existed in self-care skills between patients with and without experience of CHF symptoms. This Chapter will present the findings from testing the hypothesis using hierarchical regression modelling which was chosen so that the variance of demographic and clinical variables could be controlled for. In this manner testing for experience was not confounded by all the other potential influences. An Introduction is given below that pertains specifically to this Chapter.

Introduction

As discussed in Chapter 2, self-care has a role in empowering patients to have more control over their daily lives through active participation in their management (Lorig & Holman, 2003). Self-care is characterised by individuals taking extensive responsibility to monitor their chronic condition and to effect cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). With respect to CHF, self-care is a means of engaging patients to adopt an array of health maintenance principles such as fluid, diet and medication management and implementing remedies when symptoms become more evident (Albert, 2008). Despite universal attention to educational strategies directed at improving self-care, overall it is still poorly understood and mastering these skills is not easy for many patients with CHF. There are many potential explanations for this (Moser & Watkins, 2008; Riegel et al., 2007; van der Wal et al., 2006). Given the ageing population

and escalating burden of CHF on the health care system, patients, and their families (S. Thomas & Rich, 2007), it is even more imperative that patient education and counselling strategies are effective at helping patients successfully self-manage their condition.

In Phase 1 and 2 of the InCOGNITO research program it became evident that there were a number of factors that predict self-care. In Phase 2, level of experience was the most significant factor in predicting self-care maintenance. Self-care theory contends that experience plays a vital role in effective self-care decision making (Riegel & Dickson, 2008). Naturalistic Decision Making Theory maintains that proficient decision makers have developed a level of expertise to make context-specific choices. Experience is a prominent factor in the development of this expertise. Other factors that influence the choices that are made include: knowledge about the situation, skill to act on decisions made, decisions and actions need to be compatible with personal values (Lipshitz et al., 2001).

As discussed in Chapter 3, Riegel et al. (2004) framed the development of the Self-care Heart Failure Index (SCHFI) using Naturalistic Decision Making to explain the process of CHF self-care. This instrument is extremely useful in that it measures three domains of self-care: self-care maintenance, self-care management and self-care self-confidence. Each domain is associated with different behaviours and skill sets (See Table 6 pg.61). These behaviours include recognition of symptom changes and a cognitive health behavioural response (i.e. restrict fluid and sodium intake, apply flexible diuretic dosing, contacting health professional) to moderate symptoms (Riegel & Dickson, 2008). In psychometric testing of the SCHFI (Riegel et al., 2004), construct validity was supported by demonstrating the instrument was able to distinguish significant differences in each self-care domain based upon <2 or >2 months experience with CHF symptoms.

Using the same time frame to qualify patients as either experienced or novices, Francque-Frontiero et al. (2002) demonstrated in a sample of 94 North American patients with CHF that experience is essential in the CHF self-care process. Not surprisingly, novices were poor at recognizing symptoms ($F=6.62$, $df=1$, $p=0001$) and had significantly lower self-care management scores ($F=27.53$, $df=1$, $p<0.001$) than their experienced counterpart. Overall, self-care in this sample was poor despite experience with CHF.

Findings from this study indicated that novices had differing and more pressing learning needs and secondly, educational methods implemented at that time were not very effective for many patients with CHF. A limitation to the study was the use of an earlier version of the SCHFI that had not undergone as rigorous psychometric testing (Riegel, Carlson, & Glaser, 2000) as the later version (Riegel et al., 2004).

With the increasing important role of patient education and counselling, Phase 2a examines whether the logical assumption holds true in a contemporary sample where awareness is greater, that level of experience with CHF will impact on self-care. If the hypotheses are supported it will confirm the need for an individualised approach to patient education that considers at least, level of experience with symptoms, in determining the intensity of educational efforts required.

Aims

The aim of this secondary analysis was to test in patients enrolled in Phases 1 and 2, the following null hypotheses:

1. There is no difference in self-care maintenance behaviours between patients newly diagnosed (novices) and those experienced with CHF symptoms.
2. There is no difference in self-care management decisions and actions between patients newly diagnosed (novices) and those experienced with CHF symptoms.
3. There is no difference in self-confidence with self-care management decisions and actions between patients newly diagnosed (novices) and those experienced with CHF symptoms.

Methods

Study setting

The study was conducted across two health networks in Victoria, Australia and data was collected at two time points. Phase 1 was conducted from June to December 2005 and Phase 2 was conducted from April 2007 to September 2008. Patients referred to the hospital CHF case manager, were screened for study eligibility which is described below. Patients who met the inclusion criteria were approached by the CHF case manager to participate in the study and then referred to the researcher. Interviews were conducted during patients' hospital admission by the primary researcher (JC), who was aware of their clinical status.

Study sample

The inclusion criteria for the study were a diagnosis of CHF using the clinical criteria from Australian Best Practice Guidelines (Krum et al., 2006) and evidence of cardiac dysfunction recorded on an echocardiogram report. Aged 45 years and over. Patients were excluded from the study on the following basis: neurological problems documented in the medical history (cerebral vascular accident, transient ischemic attack, short-term memory loss or dementia); residing in a residential nursing home; and inability to answer questionnaires independently due to language barriers or visual/hearing deficits.

Of the 572 patients screened, 216 did not meet the study criteria and 205 were excluded for the following reasons: Non English Speaking Background (59); Documented history of neuro-cognitive problems (88); Poor visual or hearing acuity (14); Terminal Phase (7); Declined to participate (37). Patients who met the inclusion criteria were approached initially by a hospital CHF case manager to participate in the study and then referred to the researcher who obtained informed consent. This occurred with 151 participants; however eight withdrew their consent and were withdrawn from the study leaving a total of 143 patients enrolled. Patient interviews were conducted a mean of six days (SD \pm 5) post hospital admission at their respective homes.

Study data

Patients were prospectively designated as “novices” or “experienced” based upon a confirmed diagnosis and treatment for CHF < 2 months or > 2 months. This designation had been established in previous studies (Francque-Frontiero et al., 2002; Riegel et al., 2004). Assessment of self-care behaviours was undertaken by the principle researcher through administration of the Self-care Heart Failure Index (SCHFI) questionnaire. The SCHFI has been used in diverse populations throughout the world (Riegel, Driscoll et al., 2009) to measure three aspect of CHF self-care: self-care maintenance, self-care management and self-care confidence. Its validity and reliability is described below. In addition to assessment of self-care, the principle researcher also collected clinical data on cognitive function, depressive symptoms (Cardiac Depression Scale (Hare & Davis, 1996)) and descriptive data from the medical history included: age, gender, social situation, Charlson co-morbidity index (Charlson, Sax et al., 1987), NYHA functional class, medications, blood pressure and blood pathology results. For the purpose of Phase 2a patients could only be coded as MCI using a score <26 on the Mini Mental State Exam (MMSE) (Folstein et al., 1975) because the Montreal Cognitive Assessment had not been administered to patients in Phase 1.

Instrument used to measure self-care

The SCHFI was used to measure self-care practices. The psychometrics of the instrument has been described in Chapter 3 (see p. 94). In brief, the instrument measures three self-care domains: Maintenance and management reflect self-care skills; Confidence helps to explain why some patients master self-care and others do not (Riegel & Dickson, 2008). Responses from each of the three self-care scales are transformed to 100 points each; higher scores reflect superior self-care. Scale scores >70 are considered adequate self-care (Riegel et al., 2007). The SCHFI has been extensively used across diverse populations which has established its place as one of the most reliable and valid measures of CHF self-care (Cameron et al., 2007). The internal reliability in this study of both, self-care maintenance and self-care management scales

was low (Cronbach's α .59 and α .52 respectively), however the internal consistency for self-care self-confidence was high (Cronbach's α .80).

Ethical considerations

The study was approved by both the relevant area Health Network Research Committee and the University Human Research Ethics Committee and conforms to the principles outlined in the Declaration of Helsinki.

Data management and statistical analyses

This study involved a prospectively planned secondary analysis of data from a descriptive study that examined the link between cognitive impairment and CHF self-care. Based on previous research (Francque-Frontiero et al., 2002) we tested the two-sided hypothesis that an eight point difference in mean self-care scores on each domain would exist between novices and patients experienced with CHF. With a minimum sample size of 36 in each group, the study had 80% power to detect a significantly significant ($p=0.05$) eight point difference in mean self-care scores with a standard deviation of 16. SPSS (version 12.0.1 for Windows, Chicago, IL) was used for analyses and an online Power/sample size calculator used for post-hoc power calculations (<http://www.stat.ubc.ca/~rollin/stats/ssize/n2.html>). Normally distributed continuous data are presented as the mean \pm standard deviation and non-Gaussian distributed variables as the median plus interquartile range (IQR). Categorical data are presented as percentages with 95% confidence intervals (CI) presented where appropriate. To compare patient groups according to demographic and clinical profile, we used Chi Square (χ^2) analysis with calculation of odds ratios (OR) and 95% CI (where appropriate) for discrete variables, Student's t-test and analysis of variance for normally distributed continuous variables. Three hierarchal regression analyses were performed controlling the variance of demographic and clinical variables (age, gender, cognitive function, absence of depressed mood, living with support, retired, co-morbid index >4 , NYHA class I-II, completed >11 yrs education) and testing if level of experience was able to predict a

significant amount of the variance in self-care maintenance, self-care management and self-care confidence. Significance was accepted at the two-sided level of 0.05.

Results

The mean age of the group (n=143) was 72 ±11yrs, 90 (63%) lived with support and 39 (27%) were females (See Table 22 p.162). Seventy (49%) were symptomatic on minimal exertion or at rest (NYHA class III-IV) and 26 (18%) had more than four co-morbidities. One hundred and nineteen (83%) had been prescribed an angiotensin-converting enzyme inhibitor (ACEI) or angiotensin II receptor antagonists (ARB), 138 (97%) were on a diuretic and 114 (79%) had been prescribed a beta blocker.

Table 22: Clinical and demographic profile the sample

<i>Socio-demographic profile</i>	<i>All 143 (%)</i>	<i>New 53 (%)</i>	<i>Experienced 90 (%)</i>	<i>Odds Ratio (95% CI)</i>	<i>P value</i>
Mean age (years) ±SD	72 ±11	70 ±12	73 ±12		0.23
Females	39 (27%)	13 (25%)	26 (29%)	1.2 (0.7 – 1.9)	0.57
Married	76 (53%)	29 (38%)	47(62%)	1.1 (0.8 – 1.4)	0.77
Lived alone	53 (37%)	15 (28%)	38 (72%)	0.7 (0.4 – 1.1)	0.09
Currently employed	17 (12%)	12 (71%)	5 (29%)	4.1 (1.5 – 10.9)	<0.01
Did not complete year 12 education	74 (52%)	25 (34%)	49 (66%)	1.2 (0.8 – 1.6)	0.40
Clinical characteristics					
Systolic CHF	125 (87%)	47 (38%)	78 (62%)	1.0 (0.9 – 1.2)	0.72
Low-moderate Comorbidity Index (1-4)	117 (82%)	49 (42%)	68 (58%)	1.6 (1.1 – 1.4)	<0.01
NYHA class I or II	73 (51%)	35 (48%)	38 (52%)	1.6 (1.2 – 2.1)	<0.01
Prescribed ACEI/ARB	119 (83%)	49 (42%)	70 (58%)	1.2 (1.1 – 1.4)	0.02
Prescribed Diuretic	138 (97%)	50 (36%)	88 (64%)	1.0 (0.9 – 1.0)	0.30
Prescribed Beta Blocker	114 (79%)	39 (34%)	75 (66%)	0.9 (0.7 – 1.1)	0.17
Hypotensive, Systolic Blood Pressure < 100mmhg	21 (15%)	9 (43%)	12 (57%)	1.3 (0.6 – 2.9)	0.50
Renal impairment, Serum creatinine >110	73 (51%)	19 (26%)	54 (74%)	0.6 (0.4 – 0.9)	<0.01
Anemic, Serum Heamaglobin <100	23 (18%)	5 (22%)	18 (78%)	0.7 (0.2 – 1.2)	0.09
Mild cognitive impairment, Mini Mental score <27	48 (34%)	14 (29%)	34 (71%)	0.7 (0.4 – 1.2)	0.16
Depressed, Cardiac Depression Score >84	89 (62%)	27 (30%)	62 (70%)	0.7 (0.6 – 0.9)	0.03

Clinical characteristics

Fifty-three (37%) subjects were classified as a novice and the remaining 90 (63%) were experienced with CHF. Novices differed from experienced patients in several clinically important areas (See Table 22 above). It was evident that novices had fewer health problems than patients experienced with CHF; they were four times more likely to be employed (OR 4.08; 95% CI, 1.5 to 10.9, LR<0.01) than their experienced counterparts; had a 60% increased likelihood to be in NYHA class I or II (OR, 1.6; 95% CI 1.2 to 2.1, LR<0.01); and were 20% more likely to have a Charlson co-morbid Index 1-4 (OR, 1.2; 95% CI 1.1 to 1.4, LR<0.01). Conversely they were less likely to be depressed (OR, 0.74; 95%CI 0.5 to 0.9, LR=0.03), were less likely to have renal impairment (OR, 0.6; 95% CI 0.4 to 0.9, LR<0.01) and they were more likely to be prescribed either an ACEI or ARB (OR, 1.19; 95%CI 1.1 to 1.4; LR=0.02).

Self-care behaviours for the group

Mean scores for self-care maintenance and self-care confidence were examined in all 143 subjects. One subject had reported no symptoms of breathlessness or oedema in the previous month so mean self-care management scores were computed in 142 subjects. The mean self-care scores for the group as whole, were low (see Table 23 p. 164). Only half the group (53%) had adequate self-care maintenance scores (mean 68 ±15), less than a third (23%) had adequate self-care management scores (mean 54 ±19) and less than half (43%) had adequate self-care self-confidence scores (mean 65 ±17).

Table 23: Comparison of self-care scores across the group of 143 patients with heart failure

	All 143 (%)	New 53 (%)	Experienced 90 (%)	Odds Ratio (95% CI)	P value
Mean Self-care Maintenance	68 ±15	63 ±16	71 ±14		<0.01
Adequate scores	76 (53%)	21 (27%)	55 (63%)	0.7 (0.5 – 0.9)	0.02
Mean Self-care management	54 ±19	48 ±17	58 ±19		<0.01
Adequate scores	33 (23%)	5 (15%)	28 (85%)	0.3 (0.1 – 0.7)	<0.01
Mean Self-care Confidence scores	65 ±17	64 ±17	66 ±17		0.40
Adequate scores	61 (43%)	20 (33%)	41 (67%)	0.9 (0.6 – 1.3)	0.6

Comparison of self-care based on experience with symptoms

In univariate analysis, level of experience explained 9% of the variance in self maintenance scores with novices having an eight point lower mean score (63 ±16 vs 71 ±14, $\eta^2 = 0.09$, $p=0.05$). Novices were less likely than experienced patients to have adequate self-care maintenance (OR, 0.7; 95% CI 0.5 to 0.9; LR=0.01) (see Table 25 above). Level of experience explained 6% of the variance in self-care management scores with novices having a 10 point lower mean self-care management score (48 ±17 vs 58 ±19, $\eta^2 = 0.06$, $p=0.003$). Novices were a third less likely to have adequate self-care management than experienced patients (OR, 0.3; 95% CI 0.1 to 0.8, LR <0.01). However, the difference in mean self-care confidence scores between the two groups was not statistically significant (64 ±17 vs 66 ±17, $p=0.40$; OR, 0.9; 95% CI 0.6 to 1.4, LR=0.57).

Hierarchical regression was performed to assess if level of experience predicted a significant amount of the variance in self-care whilst controlling for age, gender, co-morbidity, cognitive function, NYHA class, living with support, level of education, renal impairment, employed. The model overall explained 20% of the variance in self-care maintenance ($F(11, 131) = 2.98, p < 0.001$). Level of experience explained an additional 7% of the variance and made the largest contribution in explaining self-care maintenance (See Table 24 below). The first null hypothesis that there was no difference in self-care maintenance behaviours between novices and those experienced with CHF symptoms was rejected.

Table 24: Hierarchical regression model of self-care maintenance

Variable	Beta	Sig.	Partial Correlations	F Value	sig	R2	R2 change	Sig F change
Age	0.19	0.03	0.18					
Gender	0.06	0.50	0.06					
lives with support	0.09	0.29	0.09					
<11yrs education	-0.05	0.54	-0.05	2.98	0.001	0.2	0.07	0.001
Employed	0.00	0.99	0.00					
NYHA class III to IV	-0.01	0.90	-0.01					
Co-morbid Index 1-4	-0.10	0.24	-0.10					
Cognitive impairment	0.12	0.14	0.13					
Depression	-0.17	0.04	-0.18					
Renal impairment	-0.01	0.91	-0.01					
Diagnosis >2 months	0.29	0.00	0.28					

Adequate self-care management was similarly regressed and the model overall explained 24% of the variance in self-care management ($F(11, 131) = 3.77, p < 0.001$). Level of experience explained an additional and statistically significant 3% ($p = 0.02$) of the variance. As shown in Table 25, gender, NYHA class, co-morbidity and level of experience were the four variables that made significant contributions to the model. The second null hypothesis that there was no difference in self-care management decisions and actions between novices and those experienced with CHF symptoms was also rejected.

Table 25: Hierarchical regression model of self-care management

Variable	Beta	Sig.	Partial Correlations	F Value	sig	R2	R2 change	Sig F change
Age	-0.13	0.15	-0.13					
Gender	-0.19	0.02	-0.20					
lives with support	0.07	0.39	0.07					
<11yrs education	0.09	0.29	0.09	3.77	0.00	0.24	0.03	0.02
Employed	0.01	0.92	0.01					
NYHA class III to IV	0.25	0.00	0.25					
Co-morbid Index 1-4	-0.24	0.01	-0.24					
Cognitive impairment	-0.05	0.55	-0.05					
Depression	-0.11	0.19	-0.11					
Renal impairment	-0.01	0.92	-0.01					
Diagnosis > 2 months	0.20	0.02	0.20					

On multivariate analysis the covariates explained between 22% of the variance in self-care self-confidence. The model was significant ($F(11, 131) = 3.44, p < 0.001$). As shown in Table 26, two variables made significant contributions to the model: depression ($p = 0.01$) and male gender ($p = 0.02$). On the basis of these results the third null hypothesis was accepted that there was no difference in self-care self-confidence between novices and those experienced with CHF symptoms.

Table 26: Hierarchical regression model of self-care confidence

Variable	Beta	Sig.	Partial	F Value	sig	R ²	R ² change	Sig F change
Age	-0.16	0.08	-0.15					
Gender	-0.19	0.02	-0.20					
lives with support	-0.07	0.40	-0.07	3.44	0.00	0.22	0.02	0.06
<11yrs education	0.15	0.06	0.16					
Employed	0.04	0.63	0.04					
NYHA class III to IV	-0.13	0.12	-0.14					
Co-morbid Index 1-4	-0.01	0.91	-0.01					
Cognitive impairment	-0.03	0.72	-0.03					
Depression	-0.22	0.01	-0.23					
Renal impairment	-0.11	0.20	-0.11					
Diagnosis >2 months	0.17	0.06	0.17					

Discussion

The secondary analysis of the combined data from Phases 1 & 2 has several important findings with implications for nursing practice. Level of experience not unexpectedly, helped to predict self-care maintenance and management skills. Patients experienced with CHF symptoms were more likely than their novice counterparts to: monitor their CHF symptoms, adhere to behaviours that help maintain physiological stability and make appropriate decisions when their symptoms changed. Yet despite experience and exposure to a CHF-MP, the majority of patients classified as experienced lacked adequate skills in making appropriate self-care decisions. Less than one third of experienced patients adequately recognised symptoms and implemented an appropriate course of actions and more than half lacked confidence in managing their symptoms. Translating this into practice, it suggests that supporting patients to develop adequate self-care skills is a long-term investment and ongoing research efforts are required to determine the optimal length of time required to comprehensively teach and support patients in developing these skills. Conversely, the implications of poor self-care are significant, potentially contributing to worsening symptoms and poorer health outcomes (C. S. Lee, Tkacs et al., 2009).

The findings from this Phase of InCOGNITO research program are in keeping with other studies that have also used a two month time frame to delineate novices from experienced patients (Francque-Frontiero et al., 2002; Riegel, Carlson, Glaser, & Romero, 2006; Riegel et al., 2004). In testing the psychometric properties of the SCHFI, Riegel et al (2004) found in a sample of 760 patients that patients with experience in living with CHF reported significantly higher self-care scores on each domain of the instrument. Furthermore in a sample of 134 Hispanic patients with CHF, experienced patients had on average eight point higher ($p=0.04$) self-care management scores (Riegel, Carlson et al., 2006). Ni et al (1999) found that previous CHF hospitalisations predicted knowledge scores and adherence with self-care behaviours, suggesting the role that experience played on increasing patient's understanding of self-care. Such findings are consistent with self-care theory.

One of the underlying principles of self-care is that early recognition of symptom changes and initiation of appropriate self-care actions will result in pro-active utilisation of health services and long-term will reduce progression of cardiac failure (Lorig & Holman, 2003). In contrast, poor self-care may result in more physical limitations and a poorer quality of life (Grady, 2008), culminating in an increased use of acute services for aggressive management, including the need of hospitalisation (Bourbeau et al., 2006; Happ et al., 1997; C. S. Lee, Tkacs et al., 2009). As discussed earlier, Naturalistic Decision Making Theory contends that proficient decision makers rely on their knowledge and experience to make context-specific choices which are influenced not only by their previous experience in that situation but previous actions (Lipshitz et al., 2001). Thorne, Paterson & Russell (2003) contend that self-care is not simply a matter of learning to comply with recommend therapeutic behaviours. Instead it is the development of knowledge and skills that are founded on personal experience with the chronic condition, listening for body cues, interpreting patterns of symptoms and then fine tuning self-care decisions based on trial and error in adjusting routines and treatment recommendations. In familiar circumstances, self-care decisions are made rapidly and subconsciously. However, in unfamiliar contexts, self-care decisions tend to be much more calculated (Thorne et al., 2003).

Intuitively, one would expect that patients experienced with CHF to have an increased understanding of their daily responsibility in managing their condition due to having had both greater exposure to patient education and experience with symptom recognition. The surprising finding was that the level of experience did not result in greater confidence to self-manage CHF symptoms. Francque-Frontiero et al. (2002) also found that level of experience did not result in greater self-care self-confidence. Riegel & Dickson (2008) acknowledge that self-care confidence appears to have a moderating effect on health outcomes. It was found in a randomised study of telephone case management involving 143 Hispanics, that superior self-care correlated with better economic outcomes but only when confidence skills were high (Riegel, Carlson et al., 2006). Furthermore, Riegel & Dickson (2008) have also demonstrated that patients with good social support have increased self-confidence and self-care abilities, indicating that confidence has a mediating effect between social supports and self-care. Others have

shown that self-efficacy appears to be an important factor in patients' motivation to maintain physical function and an indirect influence on their depression (Jerant et al., 2008; Tsay & Chao, 2002).

Similar to other studies (Moser et al., 2005), two-thirds of our sample reported depressive symptoms and this variable was associated with self-care maintenance and confidence. Not only can depression occur frequently in patients with CHF but it may be linked with increased readmissions and morbidity, resulting in a greater burden to the health care system (Friedmann et al., 2006; Sayers et al., 2007). This highlights the need for on-going assessment of CHF self-care skills and suggests that that even with experience in living and adjusting to CHF, patients require ongoing patient education counselling directed at improving their level of confidence and competency in self-managing their symptoms. Furthermore, it is evident that depression is associated with some neurocognitive changes which can result in mild cognitive changes affecting the ability to process information, make decisions and solve problems (A. J. Thomas & O'Brien, 2008); suggesting that depression may have both a direct and indirect effect on self-care performance.

In Phase 2a of the research program, MCI was not a significant variable in explaining self-care. This Phase was secondary data analysis combining the data from the previous 2 Phases of the InCOGNITO research program. In Phase 2a it was only possible to examine MCI according to the cut-score on MMSE. In Chapter 3, it was also acknowledged that the hypothesis tested in Phase 1 was not supported and this may have been due to the use of MMSE as the only instrument to detect MCI. In Phase 2 (Chapter 4), when the frequency of errors on items from the MoCA was compared with items from the MMSE, discrete variances between the two screening measures became apparent. Patients with MCI more frequently had errors on items from the MoCA that assessed memory recall, visuo-spatial and executive functions in comparison to similar items of the MMSE. This suggests that the MoCA was a more sensitive screening measure of MCI than the MMSE. Therefore, a reason that may explain why MCI did not appear to be a significant factor in predicting self-care in Phase 2a was due to the MoCA not being administered across the whole sample.

Two other variables found to predict self-care in this study warrant further discussion. Younger age was significantly correlated with self-care confidence, a finding also reported by Riegel, Dickson et al. (In Press). In contrast, older patients were more vigilant with self-care maintenance behaviours. As previously discussed in Chapter 2, it is plausible that elderly patients prefer to be independent and self-reliant (Berg et al., 2006; Heidrich, 1998; Leenerts et al., 2002), and therefore comply more so than younger patients, with symptom monitoring behaviours such as daily weighing. Nonetheless, age-related changes can result in reduced ability to recognise and interpret symptom changes and an increasing number of co-morbid health problems, whereby symptom changes are discounted as being related to CHF (Riegel, Dickson et al., In Press). Such uncertainty may account for the relationship between self-care confidence and younger age found in this study.

Another interesting finding was the finding that male gender was a subjective determinant of self-care maintenance, a finding also reported by others (Chriss et al., 2004; Heo, Moser, Lennie, Riegel, & Chung, 2008). Likewise, in a cross-sectional study data collected on 2,082 adults with CHF (C. S. Lee, Riegel et al., 2009), males reported having an overall higher level of self-care maintenance than women but there were no gender differences in self-care management and confidence. However, in multivariate models gender was not a significant determinant of any aspect of self-care or increased the likelihood of reporting adequate self-care. The researchers (C. S. Lee, Riegel et al., 2009) concluded that there were no clinically relevant gender differences in any aspect of subjective CHF self-care however, significant factors related to self-care included age, having equal or greater than high school education, Charlson co-morbidity category, new diagnosis (<2 months), NYHA functional class, and CHF aetiology. These findings lend further weight to support the conceptual model of factors tested in this research program to predict self-care.

Limitations

Limitations of this Phase of the research program are acknowledged and discussed in Chapter 6 (p.180).

Chapter Summary

The findings from Phase 2a of the InCOGNITO study found that self-care maintenance, management and confidence skills and behaviours were less than adequate. There were significant differences in self-care maintenance and management skills between novices and experienced patients. Nonetheless, experienced patients were as likely as novices to lack adequate self-care confidence skills. These findings suggest that tailoring educational and support strategies to individual need, should consider level of experience with the syndrome. However, further research efforts are required to determine the optimal time required for patients with CHF to develop and practice adequate self-care skills and behaviours. Extending testing of the conceptual model developed in this research program may help to inform the application of patient education, counselling and support strategies directed to individual need. In this manner it may become evident as to the expected period of time required to teach patients and the intensity of counselling strategies required for patients to become competent self-managers. This knowledge may have important ramifications for the application of more effective educational and counselling interventions, whereby the allocation of support resources are more equitably distributed with a greater cost-benefit effect.

Chapter 6 – Summary of Findings from the InCOGNITO Heart Failure Study

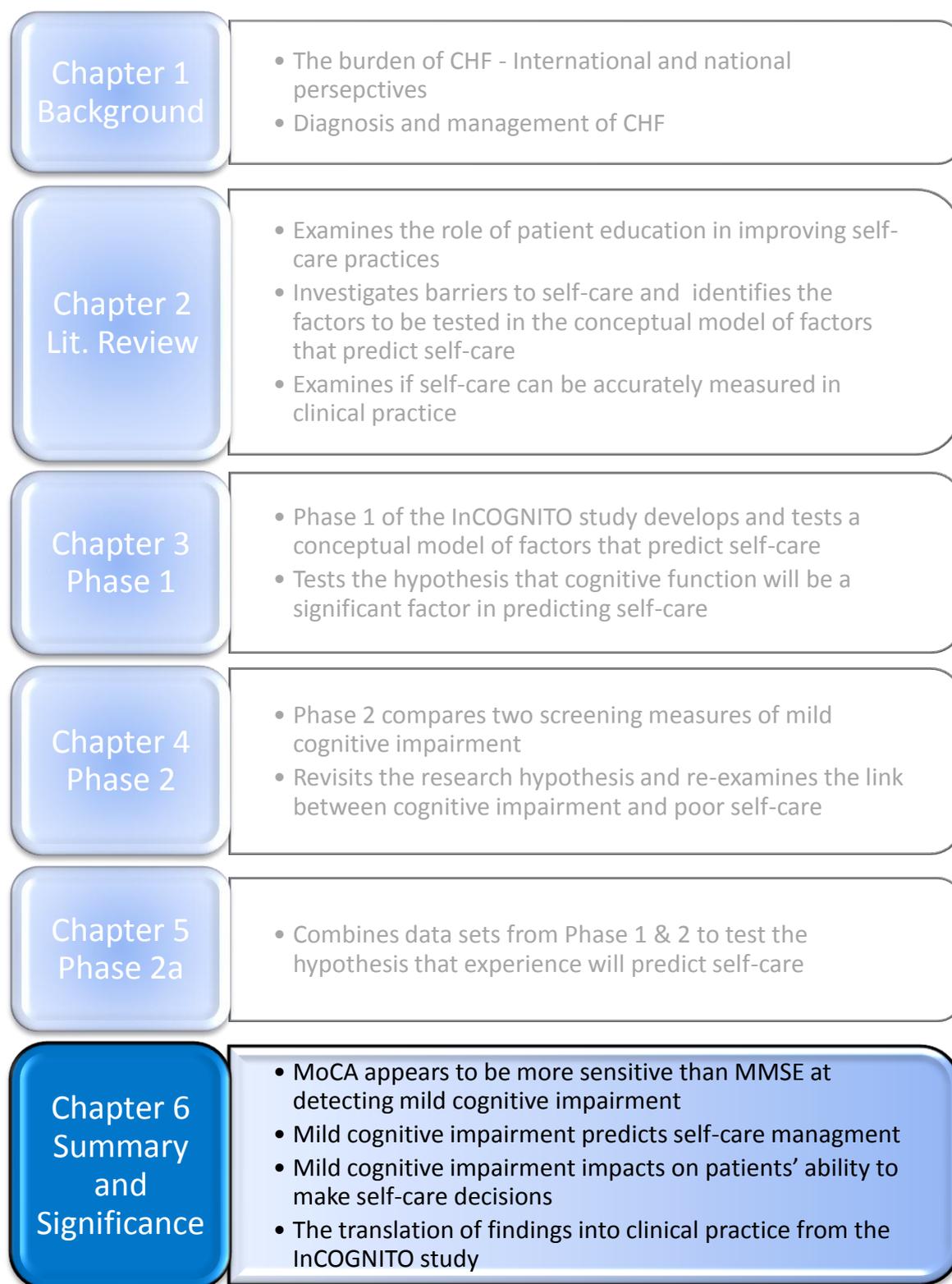


Figure 18: Overview of Chapter 6

Summary of the Research Program

The aims of the 'InCOGNITO Heart Failure study' were to develop and test a conceptual model known as the InCOGNITO model that predicts CHF self-care maintenance, management and confidence. The research program evolved from concerns regarding the difficulties many patients experienced in learning and accomplishing an adequate level of CHF self-care skills and behaviours. Throughout the research journey the evidence surrounding barriers to self-care has been unpacked in a variety of systematic phases. These included intensive and comprehensive reviews of the literature which resulted in the extrapolation of factors examined and tested in a conceptual model predicting self-care. Through detailed experimentation of the 'InCOGNITO' conceptual model there has been an analysis of clinically reliable and valid tools that measure self-care and cognitive function. A greater understanding has emerged of the phenomenon of CHF self-care and individual factors that appear to be barriers in the practice of adequate self-care. This Chapter presents summary findings from each Phase of the research program, reviews the potential limitations of each Phase and discusses how the findings may translate into clinical practice.

Findings of the Literature Reviews

Chapter 1 provided the background as to the burden of CHF. In particular the pathophysiology of CHF was described to help explain why patients often have chronic physical and functional limitations from the constellation of symptoms associated with this syndrome. In Chapter 1 it was identified that teaching patients how to maintain their health and master self-care management skills and decisions was a fundamental strategy in the long-term management of patients with CHF (Dickstein et al., 2008; Krum et al., 2006).

The chronic activation of the neurohormonal system was described as part of the underlying pathophysiology in CHF (See figure 6 p.37). In order to protect and preserve myocardial functioning, reduce symptoms and improve mortality, pharmacological agents such as ACE-I and beta blockers are prescribed to those diagnosed with CHF (McMurray et al., 2005). Encouraging compliance with the prescribed medication

regimen therefore, is perceived to be a cardio-protective strategy (C. S. Lee, Tkacs et al., 2009). Additionally, patients who engage in effective self-care are more likely to maintain an optimal fluid balance and recognise early symptom changes. These symptom changes can be managed by restricting fluid or sodium intake and in some circumstances patients may take an extra diuretic. These strategies can avoid clinical congestion and lessen the need for acute management of cardiac decompensation (C. S. Lee, Tkacs et al., 2009). Effective health maintenance behaviours may also reduce active inflammatory processes and cytokine elevations linked to acute illnesses such as pneumonia (C. S. Lee, Tkacs et al., 2009). Hence, recommended self-care maintenance strategies include advice about protection of oneself and therefore avoiding people who are sick and having an annual vaccination (Dickstein et al., 2008; Krum et al., 2006).

Effective self-care practices are therefore perceived to be complimentary to optimal medical management in delaying heart failure progression and improving health outcomes (Adams et al., 2006c; C. S. Lee, Tkacs et al., 2009). Furthermore, it has been hypothesised that practising self-care improves clinical stability and reduces the likelihood of acute decompensation (C. S. Lee, Tkacs et al., 2009). The literature review investigating the phenomena of self-care that identified efficacious teaching strategies (Chapter 2) highlighted that patient education directed at promoting self-care improved a number of health outcomes. However, improvements in self-care had been infrequently measured in the randomised controlled studies that were reviewed for this thesis. Furthermore, despite significant attention directed at teaching patients self-care, it largely remains sub-optimal (Riegel, Driscoll et al., 2009). A number of factors were identified that appear to be barriers in the accomplishment of an adequate skill level in self-care (Moser & Watkins, 2008).

In order to both advance and develop evidence-based nursing practice (Walker & Avant, 2005) it is important that nursing research is conducted to expand the current knowledge base as to the phenomenon of CHF self-care. Subsequently, a conceptual model of factors considered to be barriers in self-care was developed. However, in order to truly test the veracity and robustness of this model a decision needed to be made as to how self-care would be measured. A second review of the literature was conducted for this purpose.

The review of clinical tools that assess self-care found that only two reliable and valid instruments measured CHF self-care (SCHFI and EHFScBS) had been developed to date. This finding may account for the infrequent reporting of improvements in self-care care as a direct consequence of patient education and counselling; an issue that was raised in the first literature review. The second review demonstrated that the SCHFI examines three aspects of the self-care process (maintenance behaviours, management decisions and actions and confidence to undertake such behaviours). On this basis, it was concluded that the SCHFI was the most appropriate tool in measuring self-care for the purpose of this research program. Findings from the high level reviews of the literature allowed for extrapolation of evidence surrounding the phenomena of self-care in patients with CHF. The translation of this knowledge into the clinical interface has led to elucidation of conceptual underpinnings resulting in two peer-reviewed manuscripts accepted or publication (Cameron et al., 2007; Cameron, Worrall-Carter, Driscoll et al., 2009). They are included in Appendix A.

Summary of Findings from Phase 1

As discussed earlier, an aim of the 'InCOGNITO Heart Failure study' was to develop (Phase 1) and test (Phase 2) a conceptual model predicting CHF self-care. It was hypothesised that due to structural and functional changes in the brain, cognitive impairment would play a major role in predicting CHF self-care in those patients without a history of neurocognitive problems. Chapter 3 presents the findings from Phase 1. A number of factors explained self-care maintenance and management. Older age and moderate-to-severe co-morbidity were significant determinants of self-care maintenance (β 0.51 and 0.34, respectively). In contrast male gender (β -0.33), moderate-to-severe co-morbidity (β 0.33), presence of depressive symptoms (β 0.32), and greater self-care confidence (β -0.39) were significant predictors of self-care management. Although the hypothesis was not supported that cognitive function would be a significant factor in predicting self-care, the regression models demonstrated that cognitive function added to the conceptual model in predicting self-care. Moreover, the conceptual model illustrated the influence of both modifiable and non-modifiable factors on self-care. It was suggested that the clinical application of the conceptual model in nursing practice

may be useful in identifying patients at greater risk of sub-optimal self-care. In this manner directing evidenced-based nursing practice specifically to patients at greater risk of hospitalisations could further improve their health outcomes. The findings from Phase 1 have been published in a peer reviewed nursing journal (Cameron, Worrall-Carter, Riegel et al., 2009) (See Appendix A).

In Phase 1, cognitive impairment (the variable of particular interest) was not a statistically significant predictor in the self-care models. However, when this factor was removed from the models, less of the variance in self-care was explained by the remaining six factors, suggesting it does have a role to play. Self-care decisions are higher order cognitive functions which are not necessarily assessed by the MMSE, which was the only tool used to assess cognition in Phase 1. Subsequently to conducting Phase 1 not only was the criteria for MCI established (Portet et al., 2006) but the MoCA emerged as a reliable and valid instrument to identify this feature (Nasreddine et al., 2005). This evidence led to the decision to revisit the study hypothesis and re-examine the conceptual model of factors that predict self-care by utilising two screening measures to detect MCI; the MMSE and MoCA. The aim of Phase 2 of the 'InCOGNITO Heart Failure study' was to further develop and progress the conceptual model and to compare the MoCA with MMSE in identifying patients with MCI.

Summary of Findings from Phase 2

The same methodology as Phase 1 was applied in Phase 2 with the exception that the MoCA was now added as a screening measure of MCI. In this Phase, three-quarters (73%) of a sample of CHF patients chosen because they were without a history of neurocognitive problems actually had cognitive impairments that were unrecognised because of their subtle nature. These important findings indicate that MCI is largely a hidden co-morbidity suggesting the need to purposively screen for it. Sub-analysis unpacked the cognitive domains that were identified by the MoCA as being impaired. This evidence suggests the MoCA is more sensitive than MMSE at screening and identifying MCI. However, extended testing is required comparing the MoCA against a 'gold

standard' neuropsychological battery before confirmation of such a statement can be made.

Results from Phase 2 also demonstrated that patients identified as having MCI can still learn self-care maintenance behaviours such as daily weighing, and do so as equally well as cognitively intact patients. Nonetheless, subtle cognitive impairments appear to impact significantly on patients' ability to make appropriate self-care management decisions and their confidence in being able to self-manage symptoms. Potentially such deficits in self-care skills have notable clinical ramifications.

The findings from Phase 2 suggest that patients identified as potentially having MCI require continued support in making appropriate self-care decisions. Partners or family members are often given an increased role in the ongoing management of the individual with CHF (Aldred, Gott, & Gariballa, 2005; S. Stewart, 2005b). This highlights the need to include carers in educational and counselling strategies, if they are to have a positive influence and an active role in self-care decisions and behaviours (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Luttik, Jaarsma, Moser, Sanderma, & van Veldhuisen, 2005; Sayers et al., 2008). However, having such an active role in the ongoing management increases the burden placed upon carers, potentially influencing their own health status and putting the family unit at greater risk of worse health outcomes (Luttik, Jaarsma et al., 2007).

As the CHF population is affecting an increasingly elderly population (S. Stewart, MacIntyre, Capewell, & McMurray, 2003), these patients are as equally likely to have either an old and frail partner (S. Stewart, 2005b); or potentially their children are also heading into twilight years with their own health problems to consider. It is therefore important that the "other half" of the heart failure equation are not ignored but also offered support strategies within the holistic approach provided in CHF-MPs (S. Stewart, 2005b).

As discussed in Ch 1, CHF-MPs were developed on the premise of addressing patient-centred care by providing ongoing support strategies in the long-term management of CHF. However, one of the issues in clinical practice is knowing just how

to tailor educational and support strategies to individual need (Jaarsma et al., 2008). The conceptual model that has been developed in this research program may be useful to nurses in identifying patients at 'high risk' of sub-optimal care so that follow-up strategies can be applied to individual need. The next phase in terms of post-doctoral study could be to translate the use of the conceptual model into clinical practice and develop an algorithm of follow-up strategies according to individual risk of sub-optimal self-care.

The conceptual model tested demonstrates the application of suitable screening measures in clinical practice that may help predict patients at greater risk of 'failed' self-care. However, it is important to note that a large variance in self-care remains unexplained. This indicates that greater research efforts are required to further understand the phenomenon of CHF self-care and identify other factors that may influence patients' ability to achieve an optimal skill level. A further finding from Phase 2 was that experience with CHF (>2 months) was the most significant factor in predicting self-care maintenance ($p < 0.01$). Consequently, a decision was made to further examine how level of experience with CHF symptoms impacted on self-care practices.

Summary of Findings from Phase 2a

Chapter 5 presents the findings from secondary analyses of the combined data sets from Phases 1 and 2. The aim was to test the null hypothesis that level of experience would not impact on self-care maintenance, management or confidence. The findings demonstrate that level of experience was indeed a significant factor in predicting only two self-care domains; maintenance and management. Nonetheless, patients experienced with CHF demonstrated difficulties in achieving an adequate skill level in self-care management decisions. Compared to novices, patients experienced with CHF had similarly low levels of self-confidence. This is of concern as confidence has a negative impact on an individual's motivation to practice self-care (Jerant et al., 2008), can indirectly influence depression (Tsay & Chao, 2002) and may have a moderating effect on other health outcomes (Riegel, Carlson et al., 2006; Riegel & Dickson, 2008) including exercise adherence and risk factor modification (Barnason et al., 2003).

These findings suggests that it takes time for patients to acquire self-care skills, requiring a long-term investment in educational and counselling strategies directed at improving this health outcome. To date, there is limited evidence as to the optimal time required to teach and support patients to a level where they are competent self-managers. As described in Chapter 2, randomised controlled studies that have investigated the application of educational strategies have applied differing time frames in which to teach patients (see pg.76). Further research efforts are needed to determine the intensity and model of educational and counselling efforts required in the initial phase of diagnosis and over the longer term. Lessons could be learnt from the experience of cardiac rehabilitation programs which have been developing and improving models of care for a much longer period than CHF-MPs. Despite cardiac rehabilitation programs consistently demonstrating improved health outcomes, patients most likely to have the greatest benefit are the least likely to attend (Witt et al., 2004). Consequently, these programs have tried to be less prescriptive in their application of educational approaches by developing more flexible models that take into account patients' choices and their preferred learning styles (Dalal et al., 2007; Redfern, Briffa, Ellis, & Freedman, 2008, 2009). In a similar fashion, CHF-MPs may also need to be less prescriptive in their approach to patient education by acknowledging patients' current skill level and physical, psychosocial and cognitive functional limitations that are barriers in the acquisition of self-care skills. In this manner patient centred approaches to counselling and follow-up strategies would be developed, potentially enabling the allocation of resources to have a greater cost-benefit effect.

Limitations from Each Phase of the Research Program

The above section has illustrated the findings from the 'InCOGNITO Heart Failure study' and the ramifications for clinical practice. However, the findings need to be put into context among the limitations to each Phase of the research program, which are discussed below. Limitations with the research program relate to: selection criteria used in the literature reviews, sample selection criteria used in Phase 1 and 2, methodology applied in each Phase of the research program.

Limitations Due to Selection Criteria Used in the Literature Reviews

A limitation of the first literature review was that outcomes from only randomised controlled studies were reported. Observational studies have also reported favourable outcomes from educational interventions employed (Lupon et al., 2008; Riegel, Dickson et al., 2006; Shearer, Cisar, & Greenberg, 2007). Nevertheless, the intention was to present only evidence from studies that, due to their inherently stronger methodological approach guarded against possible bias.

The second literature review used the criteria for evaluating psychometric properties of instruments derived from recent guidelines (Elliott, 2007). Only data from the published psychometric evaluation of instruments were reviewed. It is possible that in the development stages of the instruments being reviewed, that their psychometric properties had been more rigorously tested but such information may have been omitted from published papers. To overcome this limitation author's of the EHFSBS and SCHFI were personally contacted for further information regarding the psychometrics of these two instruments. It is acknowledged that there are many other instruments that have been developed to measure constructs such as beliefs, attitudes, knowledge, symptom influence and perceived behavioural control which are important to the process of self-care. However, due to time factors it was not possible to complete a high-level critique of all these constructs and include them in the literature review.

Limitations due to Sample Selection Criteria

In Phase 1 it was acknowledged that females were not well represented in the study. This may have been due to the screening criteria to include only those with systolic dysfunction on echocardiography. Women often have a different aetiology for CHF than males as they suffer more from hypertension than ischemic heart disease resulting in more diastolic dysfunction/preserved systolic function (Ho et al., 1993). At the time of writing the study protocol there was no specific diagnosis for diastolic heart failure (Mottram, Short, Baglin, & Marwick, 2003) and practice guidelines were directed at patients with systolic dysfunction (Krum, 2001). In Phase 2 the inclusion criteria was

modified to include patients with diastolic heart failure based upon the up-dated criteria used to diagnosis CHF (Krum et al., 2006).

In Phase 1 it was not possible to assess for a potential sampling bias because demographic data had not been collected on patients who qualified for the study but were excluded. This issue was amended in Phase 2 but due to the exclusion criteria it was only possible to make comparisons based upon age and gender. In this large sample, participants enrolled in the study were significantly younger than those excluded ($p < 0.001$) but there were no significant gender differences between the two groups ($p = 0.08$).

Both Phases of the 'InCOGNITO Heart Failure Study' were conducted in a selective sample of patients with CHF. Patients who were unable to independently answer questionnaires could not be recruited, so the results may not truly represent self-care practices in more diverse CHF populations. However it is likely that the sample represents the 'best' of the CHF population. In Phase 2 patients recruited were significantly younger than those excluded yet their self-care management was on the whole sub-optimal. This would suggest that those excluded were even less competent with self-care and potentially at a higher risk of poor health outcomes due to this.

Limitations in the Research Methodology

In both Phases, social support was not formally assessed. Patients were asked whether or not they were living alone. This short-coming may explain why a correlation was not found between social support and self-care, as others have found (DiMatteo, 2004; Sayers et al., 2008). The internal reliability of self-care maintenance and management sub-scales was particularly low in Phase 2 which contrasted to the findings reported in the construction and psychometric testing of the SCHFI (Riegel et al., 2004). At that time it was acknowledged by the authors (Riegel et al., 2004) that a low Cronbach's alpha for the self-care maintenance scale was not unexpected because the sub-scale measures a diverse range of therapeutic and lifestyle behaviours, many of which are influenced by factors other than CHF. In other studies (Riegel et al., 2004; Riegel, Driscoll et al., 2009) involving close to 3000 subjects, the internal consistency of

self-care management subscale has been adequate ($\alpha=0.7$). This led to an examination of the item-total analysis for the self-care management scale which in Phase 2 demonstrated that despite reporting problems in recognising symptoms quickly, patients responded that they were very likely to implement self-care actions such as “take an extra water pill”. This suggests there was a socially desirable response for self-care management behaviours.

There is always the potential risk of socially desirable responses with self-reports. If this were the case in this research program, then genuine self-care practices were masked and may potentially have been worse than that reported. Studies using both self-report and qualitative data provide more comprehensive evidence that guard against potentially social desirable responses. In re-evaluating the convergent validity of the SCHFI (Riegel, Lee et al., 2009), qualitative and quantitative data were analysed. There was congruence 71-90% of the time between the qualitative data reflecting responses on each self-care domain of the SCHFI. Furthermore, qualitative data analysis has demonstrated that patients classified as experts have significantly higher scores across all three self-care domains in comparison to patients classified as poor or good self-managers (Riegel, Lee et al., 2009). This data supports the validity of the SCHFI in assessing self-care and helps to qualify findings in this research program.

Self-care and cognitive function were measured during the acute in-patient admission when patients were potentially sleep deprived, cognitively worse than normal and most vulnerable. Other studies (Lainscak et al., 2007) have acknowledged that these factors can overwhelm patients and render in-patient education ineffective. This time point however, was purposefully chosen because it is often during the in-patient phase that individuals are recruited to heart failure management programs. At this time point it is often problematic in terms of deciding who would most benefit from patient education and support unless specifically screening for factors that increase the risk of a readmission. It is acknowledged that further research is required to describe the trajectory of cognitive impairment over a longer time frame (Pressler, 2008) and determine if it continues to impede self-care decision-making.

Issues with Phase 2a were that it was secondary analysis of data which had been collected across two differing time points. Therefore, it cannot be ruled out that patient management practices had changed and influenced some of the findings. Furthermore, as the researcher conducting the testing was not blinded to the clinical status of patients, it is possible that investigator bias had been introduced in the recording of patient responses. This could have been overcome by administering questionnaires before collecting demographic or clinical characteristics.

Future Recommendations

The research program has provided an in-depth analysis as to the phenomena of CHF self-care and developed a mid-range theory (Walker & Avant, 2005, p. 13) of a number of critical factors that help to predict CHF self-care. In particular, it has been shown that MCI is potentially a very common co-morbidity and is not readily recognised unless specifically screened. Furthermore, the cognitive deficits experienced had a significant impact on the ability of patients to confidently make adequate self-care management decisions in regards to symptom changes. This deficit potentially increases not only the risk of acute decompensation requiring aggressive management in hospital but also premature death. Several issues have emerged from the overall findings in this research program that warrant further investigation.

Although the MoCA appears to be more sensitive than MMSE in screening for MCI, further research is required to examine the predictive validity of the MoCA against another 'gold-standard' measure. The course of cognitive impairments need to be examined over a longer time period to establish if it is only during acute periods of cardiac decompensation that it is apparent and whether treatment of depression may improve cognitive function (A. J. Thomas & O'Brien, 2008). The conceptual model needs to be used in clinical practice to identify patients at high risk of sub-optimal self-care. With use in larger numbers it may also be possible to identify other factors that influence patients' ability to achieve optimal self-care skills. Ultimately, funding will be sought to enable further research that considers developing an algorithm of educational and follow-up strategies, according to individual risk of sub-optimal self-care. In this manner

it can be determined if acceptable health outcomes are being achieved by the application of evidence-based nursing practice (Walker & Avant, 2005). This evidence will contribute to further advancing nursing practice and potentially shaping patient-centric models of CHF care.

Future Directions

In acknowledging my research training and development during my PhD, the next phase will be to apply for post-doctoral fellowships. The next Phase of testing the 'InCOGNITO' conceptual model is to develop a model of care by devising an algorithm of education and follow-up strategies according to individual risk of sub-optimal self-care. The application of such a model of care in clinical practice may help tailor nursing strategies according to individual need. It is anticipated that such a model may result in improvements in health outcomes and resource utilisation.

The next Phase of the InCOGNITO research program is to disseminate the findings so that they reach the interface of clinical practice. It is planned that this will occur at three levels: international, national and local. At an international level one abstract has been accepted for presentation at the American Heart Association scientific conference in November 2009 (Cameron, Worrall-Carter, Page, Riegel, & Stewart, 2009). The program of research has also resulted in 5 manuscripts that have been submitted to peer review journals. Three of these manuscripts have either been published or accepted for publication and two are currently under review (See Table 1 p.5). It is anticipated that at least two other manuscripts will be developed from the findings of the 'InCOGNITO Heart Failure Study' and submitted for consideration to high impact peer reviewed journals.

At a national level, abstracts will be submitted to appropriate scientific meetings. Currently, two abstracts have been accepted to the Cardiac Society of Australia and New Zealand meeting in August 2009. The abstract "Does experience necessarily equal better self-care in patients with chronic heart failure?" has been nominated for presentation in the Affiliates prize session (Cameron, Worrall-Carter, Page, & Stewart, 2009).

At a local level, presentation of the research findings will be offered to nurses who currently practice within CHF-MPs across Melbourne and organisations such as the Heart Research Centre. It is anticipated that that this will result in being asked to present at future seminars or workshops conducted for nurses and allied health professionals' working in this field of chronic disease management. Abstracts will also be submitted to local hospitals in respect to their Research Week activities that are organised on an annual basis. To date, the abstract 'Cognitive Impairment and Heart Failure Self-care: The InCOGNITO study' has been nominated for presentation in the Junior Investigator Award during St Vincent's Hospital Research week (Cameron, Worrall-Carter, Page, Riegel, & Stewart, 2009).

Chapter Summary

This Chapter has reviewed the findings from each Phase of the 'InCOGNITO Heart Failure Study' and discussed the limitations. The cognate area in which I have developed expertise is in the phenomena of self-care in patients with CHF. My contribution to new knowledge is concerned with the interface or nexus between self-care and cognitive impairment. The next Phase of the research journey will be to further build on this important area of research and move from testing the conceptual model to developing a model of care and to disseminate findings into clinical practice.

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Appendix A: Published Manuscripts

Extent of Heart Failure Self-Care as an Endpoint to Patient Education: A Review of the Literature. Published in the British Journal of Cardiac Nursing, 2007:2(4): 188-197.

Measuring Self-care in Chronic Heart Failure: A Review of the Psychometric Properties of Clinical Instruments. Journal of Cardiovascular Nursing, 2009; 24(6): E10-22.

Testing a Model of Patient Characteristics, Psychological Status and Cognitive Function as Predictors of Self-care in Persons with Heart Failure. Heart & Lung the Journal of Acute & Critical Care, 2009; 38(5): 410-418.

Does Cognitive Impairment Predict Poor Self-care in Patients with Chronic Heart Failure? European Journal of Heart Failure, 2010; 12(5): 508-15.

Self-care Behaviours and Heart Failure: Does Experience with Symptoms Really Make a Difference? European Journal of Cardiovascular Nursing, 2010; 9(2):92-100.

Appendix B: Questionnaires used in the InCOGNITO Study

Inclusion criteria:

Screening Date _____

Diagnosis of CHF determined by symptoms at rest or on exercise, such as:

- Exertional Dyspnoea Orthopnoea PND Bilateral oedema
- Fatigue Lung crepitations Cardiomegaly on Chest x-ray 3rd HS
- APO Elevated JVP Hepatomegaly Palpitations
- Elevated BNP level

And objective measurement of ventricular function from an echocardiogram.

Echocardiography findings: date _____

- At least moderate LV dysfunction FS <28% EF <45%
 - Diastolic dysfunction and abnormal filling pressures Left atrial enlargement **BNP**
- Date and level _____

Exclusion Criteria:

- NESB TIA CVA Dementia / Alzheimer's
- Residing in a nursing home Unable to read

And in cases when diagnosis in doubt, response to treatment directed towards

Heart failure

If patient meets the above criteria,

Please ask their permission for me to visit and discuss their participation in the study.

If they agree please contact Jan Cameron with their details (bed, ward, name and expected date of discharge):

92883691 or 98888009 or 0411279621

Jan.CAMERON@svhm.org.au or j.cameron@optusnet.com.au

Many thanks

Clinical and demographic details collected

Date: _____

Demographics

Age: _____ **Gender:** 0 Male 1 Female

Marital Status: 1 Single 2 Married/defacto 3 Divorced/separated
4 Widowed

Social Situation: 1 Lives alone 2 Lives with support

Years of education and highest level of education achieved (please circle one) yrs

1 did not complete yrs 12 2 completed yr 12

1 Some primary School 2 Some secondary 3 some secondary plus trade

4 Completed secondary 5 Begun Tertiary

Employment (please circle one)

1 Employed full time / 2 Employed part time / 3 Employed casually / 4 Retired / 5 On sickness benefits / 6 Unemployed / 7 Home Duties

Admission Diagnosis : _____

Diagnosis for CHF >2months? 1 Yes / 0 No NYHA classification _____

BP _____ **HR** _____ **Creatinine level** _____ **Hb** _____

Sodium Level _____

Cardiac History : PTCS/Stent AMI CAGS PPM AICD

Cardiac Risk Factors :

Hypertension : 0 never 1 past 2 current

Hypercholesteremia : 0 never 1 past 2 current

Diabetes Mellitus : 0 never 1 type 1 2 type 2 Diet 3 type 2 OHA

4 type 2 Insulin

Smoking : 0 never 1 past 2 current

Details _____

Comorbidities :

Weighted Score of 1: AMI CCF PVD COPD Ulcer disease

Type 2 Diabetes requiring meds or insulin Chronic hepatitis

Connective Tissue disease (Rheumatoid Arthritis)

Weighted score of 2: Diabetes with end stage organ damage Moderate or severe renal disease (Cr >3mg%) Tumour without metastasis Leukaemia

Lymphoma

Weighted score of 3: Cirrhosis with portal HTN

Weighted score of 6 Metastatic solid tumour

Weighted Charlson index score : _____ Low 1-2 Moderate 3-4 High >5

Medications :

ACE I Name and dose : _____

A2 inhibitor Name and dose : _____

Diuretic Name and dose : _____

Aldosterone Antagonist Name and dose : _____

Beta Blocker Name and dose : _____

Nitrates Warfarin Digoxin Amioderone

Number of days from hospital admission that measures conducted: _____

LoS _____

NART Error Score _____

MMSE Score : _____

MoCA Score: _____

CDS Score : _____

Folstein Mini Mental Status Examination			
Task	Instructions	Scoring	
Date Orientation*	"Tell me the date?" Ask for omitted items.	<input type="checkbox"/> year <input type="checkbox"/> season <input type="checkbox"/> date <input type="checkbox"/> day of week <input type="checkbox"/> month	5
Place Orientation*	"Where are you?" Ask for omitted items.	<input type="checkbox"/> house number <input type="checkbox"/> residential street <input type="checkbox"/> suburb/ town <input type="checkbox"/> state <input type="checkbox"/> building	5
Register 3 Objects	Name three objects slowly and clearly. Ask the patient to repeat them.	<input type="checkbox"/> Apple <input type="checkbox"/> Penny <input type="checkbox"/> Table	3
Serial Sevens*	Ask the patient to count backwards from 100 by 7. Stop after five answers. (Or ask them to spell "world" backwards.)	<input type="checkbox"/> 93 <input type="checkbox"/> 86 <input type="checkbox"/> 79 <input type="checkbox"/> 72 <input type="checkbox"/> 65 <input type="checkbox"/> D <input type="checkbox"/> L <input type="checkbox"/> R <input type="checkbox"/> O <input type="checkbox"/> W	5
Recall 3 Objects	Ask the patient to recall the objects mentioned above.	<input type="checkbox"/> Apple <input type="checkbox"/> Penny <input type="checkbox"/> Table	3
Naming	Point to your watch and ask the patient "what is this?" Repeat with a pencil.	<input type="checkbox"/> Watch <input type="checkbox"/> Pen/pencil	2
Repeating a Phrase	Ask the patient to say "No ifs, ands, or buts."	One point if successful on first try	1
Verbal Commands	Give the patient a plain piece of paper and say "Take this paper in your right hand, fold it in half, and put it on the floor."	One point for each correct action	3
Written Commands	Show the patient a piece of paper with "CLOSE YOUR EYES" printed on it.	One point if the patient's eyes close	1
Writing	Ask the patient to write a sentence.	One point if sentence has a subject, a verb, and makes sense	1
Drawing	Ask the patient to copy a pair of intersecting pentagons onto a piece of paper. 	One point if the figure has ten corners and two intersecting lines	1
Scoring	A score of 24 or above is considered normal. A score below 24 indicates probable cognitive impairment. A score below 17 indicates definite cognitive impairment.		30
Adapted from Folstein et al, Mini Mental State, J PSYCH RES 12:196-198 (1975)			

MONTREAL COGNITIVE ASSESSMENT (MOCA)

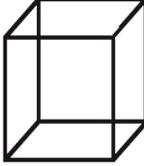
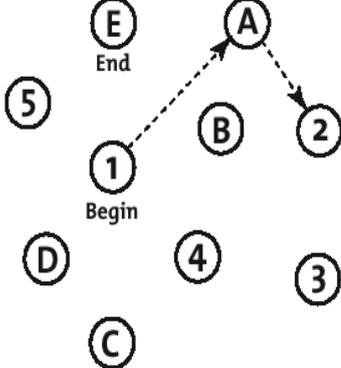
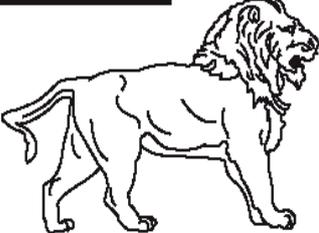
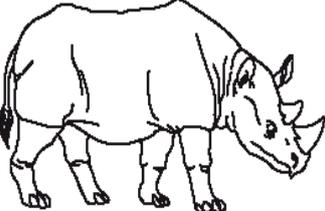
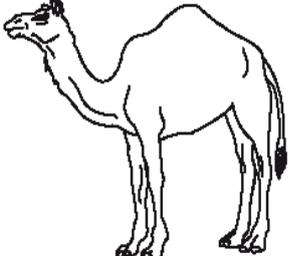
NAME :

Education :

Date of birth :

Sex :

DATE :

VISUOSPATIAL / EXECUTIVE				Copy cube []	Draw CLOCK (Ten past eleven) (3 points) [] [] [] Contour Numbers Hands	POINTS ___/5
						
NAMING						[] [] [] ___/3
MEMORY	Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.	FACE VELVET CHURCH DAISY RED	1st trial 2nd trial			No points
ATTENTION	Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [] 2 1 8 5 4 Subject has to repeat them in the backward order [] 7 4 2					___/2
	Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [] FBACMNAAJKLBAFAKDEAAAJAMOFAB					___/1
	Serial 7 subtraction starting at 100 [] 93 [] 86 [] 79 [] 72 [] 65 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt					___/3
LANGUAGE	Repeat : I only know that John is the one to help today. [] The cat always hid under the couch when dogs were in the room. []					___/2
	Fluency / Name maximum number of words in one minute that begin with the letter F [] ____ (N ≥ 11 words)					___/1
ABSTRACTION	Similarity between e.g. banana - orange = fruit [] train - bicycle [] watch - ruler					___/2
DELAYED RECALL	Has to recall words WITH NO CUE	FACE [] VELVET [] CHURCH [] DAISY [] RED []				___/5 Points for UNCUEDE recall only
Optional	Category cue Multiple choice cue					
ORIENTATION	[] Date [] Month [] Year [] Day [] Place [] City					___/6
© Z.Nasreddine MD Version November 7, 2004		Normal ≥ 26 / 30		TOTAL ___/30 Add 1 point if ≤ 12 yr edu		

Below is a list of words. Please say each word out loud. Speak slowly.

1. Ache	2. Aeon
3. Debt	4. Cellist
5. Psalm	6. Zealot
7. Depot	8. Abstemious
9. Chord	10. Gouge
11. Bouquet	12. Placebo
13. Deny	14. Façade
15. Capon	16. Aver
17. Heir	18. Leviathan
19. Aisle	20. Chagrin
21. Subtle	22. Détente
23. Nausea	24. Gauche
25. Equivocal	26. Drachm
27. Naïve	28. Idyll
29. Thyme	30. Beatify
31. Courteous	32. Banal
33. Caveat	34. Sidereal
35. Procreate	36. Puerperal
37. Quadruped	38. Topiary
39. Catacomb	40. Demesne
41. Superfluous	42. Labile
43. Radix	44. Phlegm
45. Assignat	46. Syncope
47. Gist	48. Prelate
49. Hiatus	50. Simile

DATE / /

ID.....

CDS

This questionnaire consists of a number of statements about the way you feel **at present**.

Next to each statement there is a rating scale from 1 to 7 for you to indicate how much you agree or disagree with the statement.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

Please indicate how strongly you agree or disagree with each statement by circling one of the numbers on the scale.

For example, a score of a 4 would indicate that you neither agree nor disagree with the statement, a score of 1 that you strongly disagree, and a score of 7 that you strongly agree.

EXAMPLE

Strongly disagree 1 (2) 3 4 5 6 7 Strongly agree

This indicates that you quite strongly disagree with the statement.

THERE ARE NO RIGHT OR WRONG ANSWERS

PLEASE ENSURE YOU HAVE COMPLETED ALL 26 ITEMS

© D.L. Hare, 1993

<h1>CDS</h1>								
CHECK TO MAKE SURE YOU HAVE ANSWERED ALL QUESTIONS	Strongly Disagree			Strongly Agree				
1. I have dropped many of my interests and activities...	1	2	3	4	5	6	7	
	None dropped			All dropped				
2. My concentration is as good as it ever was...	1	2	3	4	5	6	7	
	Very poor Concentration			Excellent Concentration				
3. I can't be bothered doing anything much...	1	2	3	4	5	6	7	
	Keen to do things			Can't be bothered				
4. I get pleasure from life at present...	1	2	3	4	5	6	7	
	No pleasure			Great pleasure				
5. I am concerned about the uncertainty of my health...	1	2	3	4	5	6	7	
	Not concerned			Very concerned				
6. I may not recover completely...	1	2	3	4	5	6	7	
	Will recover completely			Will not recover				
7. My sleep is restless and disturbed...	1	2	3	4	5	6	7	
	Not restless			Very restless				
8. I am not the person I used to be...	1	2	3	4	5	6	7	
	Just the same			Completely different				

CHECK TO MAKE SURE YOU HAVE ANSWERED ALL QUESTIONS	Strongly Disagree	Strongly Agree	
9. I wake up in the early hours of the morning and cannot get back to sleep...	1 2 3 4 Never wake	5 6 7 Always wake	
10. I feel like I'm living on borrowed time...	1 2 3 4 Unlimited time	5 6 7 Very much on borrowed time	
11. Dying is the best solution for me...	1 2 3 4 No solution	5 6 7 Best solution	
12. I feel in good spirits...	1 2 3 4 Very poor spirits	5 6 7 Excellent spirits	
13. The possibility of sudden death worries me...	1 2 3 4 Not at all	5 6 7 Very worried	
14. There is only misery in the future for me...	1 2 3 4 No misery	5 6 7 Only misery	
15. My mind is as fast and alert as always...	1 2 3 4 Slow and inattentive	5 6 7 Very fast and alert	
16. I get hardly anything done...	1 2 3 4 Everything done	5 6 7 Nothing done	
17. My problems are not yet over...	1 2 3 4 All problems over	5 6 7 Still major problems	

CHECK TO MAKE SURE YOU HAVE ANSWERED ALL QUESTIONS	Strongly Disagree	Strongly Agree	
18. Things which I regret about my life are bothering me...	1 2 3 4 5 6 7 Absolutely no regrets	Great regrets	
19. I gain just as much pleasure from my leisure activities as I used to...	1 2 3 4 5 6 7 No pleasure at all	Very great pleasure	
20. My memory is as good as it always was...	1 2 3 4 5 6 7 Very poor memory	Excellent memory	
21. I become tearful more easily than before...	1 2 3 4 5 6 7 Not at all tearful	Very easily tearful	
22. I seem to get more easily irritated by others than before...	1 2 3 4 5 6 7 Never irritated	Very easily irritated	
23. I feel independent and in control of my life...	1 2 3 4 5 6 7 No independence	Completely independent	
24. I lose my temper more easily nowadays...	1 2 3 4 5 6 7 Never lose temper	Lose it very easily	
25. I feel frustrated...	1 2 3 4 5 6 7 Not at all frustrated	Extremely frustrated	
26. I am concerned about my capacity for sexual activity...	1 2 3 4 5 6 7 No concern at all	Grave concern	

SELF-CARE OF HEART FAILURE INDEX

Listed below are common recommendations for persons with heart failure. How often do you do the following?

	Never or rarely	Sometimes	Frequently	Always or daily
1. Weigh yourself?	1	2	3	4
2. Check your ankles for swelling?	1	2	3	4
3. Try to avoid getting sick (e.g., flu shot, avoid ill people)?	1	2	3	4
4. Do some physical activity?	1	2	3	4
5. See your doctor or nurse?	1	2	3	4
6. Eat a low salt diet?	1	2	3	4
7. Exercise for 30 minutes?	1	2	3	4
8. Forget to take one of your medicines?	1	2	3	4
9. Ask for low salt items when eating out or visiting others?	1	2	3	4
10. Use a system (pill box, reminders) to help you remember your medicines?	1	2	3	4

Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure.

In the past three months, have you had trouble breathing or ankle swelling? Circle one.

- 1) No 2) Yes

1. The LAST TIME you had trouble breathing or ankle swelling, **(circle one number)**

	Have not had these symptoms	I did not recognise it	Not Quickly	Somewhat Quickly	Quickly	Very Quickly
How quickly did you recognise it as a symptom of heart failure?	N/A	0	1	2	3	4

Listed below are remedies that people with heart failure use. If you have trouble breathing or ankle swelling, how likely are you to try one of these remedies? (Circle **one** number for each remedy)

	Not Likely	Somewhat Likely	Likely	Very Likely
2. Reduce the salt in your diet	1	2	3	4
3. Reduce your fluid intake	1	2	3	4
4. Take an extra water pill	1	2	3	4
5. Call your doctor or nurse for guidance	1	2	3	4

6. Think of a remedy you tried the last time you had trouble breathing or ankle swelling, **(circle one number)**

	I did not try anything	Not Sure	Somewhat Sure	Sure	Very Sure
How <u>sure</u> were you that the remedy helped or not?	N/A	1	2	3	4

In general, how confident are you that you can:

	Not Confident	Somewhat Confident	Very Confident	Extremely Confident
7. Keep yourself <u>free of heart failure symptoms</u> ?	1	2	3	4
8. <u>Follow the treatment advice</u> you have been given?	1	2	3	4
9. <u>Evaluate the importance of your symptoms</u> ?	1	2	3	4
10. <u>Recognise changes</u> in your health if they occur?	1	2	3	4
11. <u>Do something</u> that will relieve your symptoms?	1	2	3	4
12. <u>Evaluate</u> how well a remedy works?	1	2	3	4

Appendix C: Human Research Ethics Approval for the Conduct of the Study across Eastern Health

Eastern Health Research & Ethics Committee

Level 2, Clive Ward Centre

Telephone 9895 3398

Facsimile 9895 3461

Email: ethics@easternhealth.org.au

21 April 2008

Mrs J Cameron
St Vincent's/ ACU National Centre for Nursing Research
Locked Bag 4115
Fitzroy
Victoria 3065

Dear Mrs Cameron

RE: E83/0405 the nexus between cognitive function and self-management ability in patients with chronic heart failure

Thank you for the submission of amended documents. The Committee reviewed the documents at its meeting on 17 April 2008.

The following documents have been approved:

- *Study protocol Amendment 4 dated February 2008 with Appendices A - D*
- *Information letter to participants and Consent Form version dated 05 February 2008*

Yours Sincerely

Lai Wan Reid

Manager

Eastern Health Research and Ethics

Eastern Health Research & Ethics Committee

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Email: ethics@easternhealth.org.au

25 January 2008

Mrs J Cameron
St Vincent's/ ACU National Centre for Nursing Research
Locked Bag 4115
Fitzroy
Victoria 3065

Dear Mrs Cameron

RE: E83/0405 The nexus between cognitive function and self-management ability in patients with chronic heart failure

Thank you for the submission of amended documents. The Committee reviewed the documents at its meeting on 24 January 2008. The following document has been approved:

- *Study Protocol (EH Amendment v3 dated Dec 2007) including Appendices A, B, C and D*

The following documents were approved subject to amendments:

Participant Information Letter and Consent form (EH Amendment v3 Dec 2007)

- The Eastern Health logo should be the prominent logo. ACU National should either be deleted or reduced in size. This is appropriate as potential participants are Eastern Health patients
- Please change and update both version number and version date from the previous approved version; the same version number and date should be inserted in the footer
- Section 14 Ethical Guidelines please replace the "National statement on Ethical Conduct in Research involving humans (June 1999)" with the "National Statement on Ethical Conduct in Human Research (2007)
- Researcher will be reminded to use "strike through" and underline to demonstrate changes otherwise documents are difficult for the Committee to read.

Yours Sincerely

Lai Wan Reid

Manager

Eastern Health Research and Ethics



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21 May 2007

Ms J Cameron
CHF Case Manager
4th Floor
Clive Ward Building
Box Hill Hospital

Dear Ms Cameron

RE: E83/0405 The nexus between cognitive function and self-management ability in patients with chronic heart failure.

At its meeting on 17 May 2007 the Eastern Health Research and Ethics Committee approved correspondence dated 26 April 2007 and the following revised documents:

- Amended Description of Project (undated),
- Revised Consent Form and Plain Language Statement version 3 dated 10 May 2005,
- Montreal Cognitive Assessment (MOCA) version dated 7 November 2004
- MOCA Administration and Scoring Instructions version dated 12 November 2004.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Lorraine Little".

Lorraine Little
Manager
Eastern Health Research and Ethics

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Email: bronwen.williamson@boxhil.org.au

24 October 2005

Mrs J Cameron
[Redacted]
[Redacted]

Dear Mrs Cameron

RE: **E83/0405** The nexus between cognitive function and self-management ability in patients with chronic heart failure

At its meeting on 20 October 2005 the Eastern Health Research and Ethics Committee tabled, reviewed and approved your letter of 12 October 2005 requesting an amendment to the original submission for this study. This amendment was to extend the study to an additional site, the Angliss Hospital.

Please quote our reference number **E83/0405** in all future correspondence.

Yours sincerely

Dr Jacinta Mogg
SENIOR MEDICAL ADVISOR
CLINICAL RISK MANAGEMENT

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26 May 2005

Mrs J Cameron

[Redacted address]

Dear Mrs Cameron

RE: **E83/0405** The nexus between cognitive function and self-management ability in patients with chronic heart failure

At its meeting on 21 April 2005, the Eastern Health Research & Ethics Committee tabled, reviewed and approved the submission for the above study, to be conducted at Box Hill Hospital and Maroondah Hospital, subject to the amendments outlined in our letter of 22 April 2005.

Following receipt of your letter dated 11 May 2005 and the enclosed amended documents I can now give approval for the study to proceed.

I confirm that the following documents have been reviewed and approved:

- Application
- Screening tool and data collection sheet
- Copy of NHMRC/NHF grant
- Patient information and consent form, version 2 dated 10 May 2005

Conditions for approval are outlined on the attached sheet. The Eastern Health Research and Ethics Committee is constituted and functions in accordance with the National Health and Medical Research Council Guidelines (*National Statement on Ethical Conduct in Research Involving Humans 1999*).

Please quote our reference number **E83/0405** in all future correspondence.

Yours sincerely

Dr Jacinta Mogg
 SENIOR MEDICAL ADVISOR CLINICAL RISK MANAGEMENT

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22 April 2005

Mrs J Cameron
[REDACTED]
[REDACTED]

Dear Mrs Cameron

RE: E83/0405 The nexus between cognitive function and self-management ability in patients with chronic heart failure

At its meeting on 21 April 2005, the Eastern Health Research & Ethics Committee tabled, reviewed and approved the submission for the above study, to be conducted at Box Hill Hospital and Maroondah Hospital, subject to the following clarification:

- The Committee noted that the Plain Language Statement and Consent Form were Deakin University documents and that information usually included in them was elsewhere in the submission. Clarification was requested.

Please quote our reference number **E83/0405** in all future correspondence.

Yours sincerely

Dr Jacinta Mogg
SENIOR MEDICAL ADVISER CLINICAL RISK MANAGEMENT

Members of Eastern Health

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Information Letter to Participants

Version 5 Feb 2008

PROTOCOL NO. (**E83/0405**):

NAME OF PARTICIPANT:

UR NO:

TITLE OF PROJECT: The nexus between cognitive function and self-management ability in patients with chronic heart failure.

PRINCIPAL INVESTIGATOR : Jan Cameron

SUPERVISOR : Professor Linda Worrall-Carter

PROGRAMME IN WHICH ENROLLED: PhD Nursing

This Participant Information and Consent Form is **6** pages long.

Dear Participant,

1. Your Consent

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it. Please read this Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project. The Participant Information sheet is for you to keep as a record.

2. The aim or purpose of the research

The purpose of this project is to assess how heart failure may affect people's thinking and memory and whether this impacts on their ability to follow instructions provided by their health care professional. Previous experience has shown that Heart Failure is a common problem experienced by many people worldwide. Treatment is often complicated with patients having to take many medications, make many lifestyle changes and interpret significant symptoms related to their condition. Recent research suggests that patients with heart failure may experience problems with thinking and memory, making it difficult for them to manage the disease themselves. We aim to discover whether problems with thinking and memory are linked to the difficulties in self-managing heart failure. It is expected that this study will make an important contribution to improving the education and follow-up provided in heart failure management programs.

Our study requires 100 participants who have been diagnosed with chronic heart failure and are aged 45 years and over. You are invited to participate in this research project because we believe you fulfil the criteria.

This trial has been initiated by the investigator, Professor Linda Worrall-Carter at the School of Nursing, Australian Catholic University. The results of this research may be used to help Jan Cameron obtain a research degree.

3. Procedures

Participation in this project will involve one interview with you where you will be asked some information about your-self and then asked questions from five short questionnaires. The five questionnaires assess different aspects of your health: knowledge of your heart condition; memory, thinking capacity and reading ability; your emotional well-being. The researcher will also need to access your confidential hospital records to collect information in regards to your past and current health and medications that you are currently taking. The interview should take approximately 45-55 minutes to complete.

4. Possible Benefits

We cannot guarantee or promise that you will receive any benefits from this project but the results may help further develop effective teaching and follow-up strategies for people discharged from hospital with heart failure. On scoring one of the questionnaires, if it becomes apparent that you are experiencing significant depressive symptoms then we will notify your heart failure nurse so that this may be monitored and appropriate strategies can be offered to you to overcome the problem.

5. Possible Risks

We do not anticipate this study to cause any inconvenience or harm to you, however possible risks and discomforts include feeling tired or emotional from answering the questionnaires. During the interview your level of fatigue and willingness to continue will be assessed. You may suspend or even end participation in the study if distress does occur.

If an adverse reaction during the interview was to occur then your heart failure nurse will be contacted who can arrange trained counselling, independent of the research team. There may be additional unforeseen or unknown risks. Continual review and monitoring

of the study will take place, regarding the efficiency and safety of the research project, and this will enable early detection of any problems patients may suffer.

Participation in the study does not involve exposure to radiation.

6. Alternatives to Participation

Standard treatment of heart failure includes providing patients with information about how the condition is managed with medications and actions that individuals can follow to help lessen their symptoms. This study does not interfere with your standard treatment.

7. Privacy, Confidentiality and Disclosure of Information

Any information obtained in connection with this project and that can identify you will remain confidential. To maintain your confidentiality, all questionnaires will be coded. This means that your information will be allocated a code that will be stored separately from any information that could be used to identify you. Information will also be stored in a data base on the researcher's computer that is password protected. Only the researchers will have access to participant information.

Any documents that you sign, where you can be identified by name will be kept in a locked drawer within a locked office at the St Vincent's / ACU National Centre for Nursing Research. These documents will be kept confidential. Your identity will be coded on all documents. The documents will be destroyed after seven years from the end of the study in accordance with the Health Records Act. Your information will be held in a research repository (database). However, information collected in this study will not be re-used or disclosed for a purpose other than this study, unless you have given written permission to do so, or it is required by law.

If you give us your permission by signing the Consent Form, we plan to publish a report arising from this study in a professional journal, however no names will be included in any report, and it will not be possible to identify any participants.

8. Alternatives to Participation

Standard treatment of heart failure includes providing patients with information about how the condition is managed with medications and actions that individuals can follow to help lessen their symptoms. This study does not interfere with your standard treatment.

Any information obtained in connection with this project and that can identify you will remain confidential. To maintain your confidentiality, all questionnaires will be coded. This means that your information will be allocated a code that will be stored separately from any information that could be used to identify you. Information will also be stored in a data base on the researcher's computer that is password protected. Only the researchers will have access to participant information.

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If you give us your permission by signing the Consent Form, we plan to publish a report arising from this study in a professional journal, however no names will be included in any report, and it will not be possible to identify any participants.

9. New Information Arising During the Project

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs and medical condition.

10. Results of Project

If you wish to obtain the results of the testing done during this study, you may do so by requesting your information in writing from the principal researcher's supervisor.

11. Further Information or Any Problems

If you require further information or if you have any problems concerning this project (for example, any side effects), you can contact the principal researcher's supervisor, Professor Linda Worrall-Carter on 03 9953 3644. Other Issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Name: ***Lai Wan Reid***

Position: Manager, Eastern Health Research & Ethics

Telephone: 9895 3398

You will need to tell ***Lai Wan Reid*** the name of one of the researchers given in section 10 above.

Alternatively if you have any query that the Investigator has not been able to satisfy, you may write to the Chair of the Human Ethics Committee at the Australian Catholic University:

Chair, HREC

C/o Research Services,

Australian Catholic University Melbourne Campus

Locked Bag 4115, Fitzroy, Vic 3065

Telephone: 99533158

12. Research Participant Rights

If you have any questions about your rights as a research participant, then you may contact the Executive Officer, Research and Ethics at Eastern Health on Telephone: 9895 3398.

13. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with Eastern Health.

Before you make your decision, a member of the research team will be available so that you can ask any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

14. Ethical Guidelines

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Eastern Health and the Australian Catholic University.

15. Reimbursement for your costs

You will not be paid for your participation in this trial.

Thank You

J CAMERON

Jan Cameron
Principal Investigator



Professor Linda Worrall-Carter
Supervisor



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www.easternhealth.org.au
ABN 68 223 819 017

CONSENT FORM

TITLE OF PROJECT: The nexus between cognitive function and self-management ability in patients with chronic heart failure.

PRINCIPAL INVESTIGATOR: Jan Cameron

SUPERVISOR: Professor Linda Worrall-Carter

PROGRAMME IN WHICH ENROLLED: PhD Nursing

I have read and I understand the Participant Information version **5** dated **Feb 2008**.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep.

I understand that the researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant's Name (printed)

Signature Date

Name of Witness to Participant's Signature (printed)

Signature Date

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's Name (printed)

Signature Date

* A senior member of the research team must provide the explanation and provision of information concerning the research project. *Note:* All parties signing the Consent Form must date their own signature.



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Revocation of Consent

TITLE OF PROJECT: The nexus between cognitive function and self-management ability in patients with chronic heart failure.

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with Eastern Health.

Participant's Name (printed)

Signature

Date