EVALUATING A WEB-BASED SELF-MANAGEMENT INTERVENTION IN PATIENTS WITH HEART FAILURE: A PILOT STUDY

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Abstract

Background: Heart failure (HF) has a major impact on quality of life and is a key elevator of health care expenditures. Enhancement of self-management skills can improve health related outcomes in patients with HF. Based on outcomes of previous research, web-based self-management interventions have the potential to improve quality of life and reduce hospitalisations in patients with chronic diseases including HF. The aim of this pilot study was to examine the feasibility of a web-based self-management intervention to improve knowledge, self-management and self-efficacy in patients with HF.

Methods: A web-based HF self-management application was developed based on feedback from clinical experts, IT consultants and HF patients. User friendliness and the appropriateness of the study instruments were examined during preliminary testing. Feasibility of the web-based intervention was then tested using a controlled intervention study design, with a four week follow-up period.

A total of 28 participants were recruited from the HF service of a large tertiary referral hospital and University health clinic. The intervention group (*n* = 14) received online self-management education in addition to usual care. For the purpose of education, the intervention group also entered a number of daily measures such as weight and HF symptoms. The control group (*n* = 14) received usual care. Data were collected through validated instruments including the Dutch HF Knowledge Scale, Self-Care HF Index and Self-Efficacy for Managing Chronic Disease Scale.

Results: Recruitment was slow in part due to HF patients' lack of interest in the intervention, internet access or computer skills. Change scores and effect size estimates showed that the mean differences in HF knowledge (d = .06), self-care (d = .32) and self-efficacy (d = .37) in both intervention and control groups were small to negligible. Despite email reminders only 50% of the sample accessed the site daily and 28% had no record of access.

Conclusion: Although the results of this study are consistent with systematic reviews which have failed to show the benefits of web-based self-management interventions for chronic disease, many existing studies are of poor quality and lack theory. The design and development of web-based interventions therefore must be carefully executed in future research. Strengthening the intervention based on self-efficacy theory is likely to have the potential to improve patient outcomes. Hence, the outcomes of this pilot include recommendations for future intervention research in this area.

Glossary

Heart Failure

HF is a complex clinical syndrome with typical symptoms (e.g. dyspnoea, fatigue) that can occur at rest or on effort and is characterised by objective evidence an underlying structural abnormality or cardiac dysfunction that impairs the ability of the ventricle to fill or eject blood particularly during physical activity. (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011, p. 6)

Self-management

Self-management is a patient's ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes to maintain quality of life (Barlow et al., 2002).

Ejection Fraction

Ejection fraction is a measurement of the blood which leaves the left ventricle with each contraction (American Heart Association, 2013).

Information technology

Information technology is the use of computers and telecommunications equipment to store, retrieve, transmit and manipulate data (Daintith, 2009).

List of Publications

Published Abstracts:

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2. Bashi, N.G.G., Howie, J.S., & Clark, R.A. (2012). Development and testing of an iPad application for teaching self-management to heart failure patient. *Heart and Lung: The Journal of acute and critical care, 41*(4), 421-422.

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List of Abbreviations

ACE	Angiotensin Converting Enzyme
ARB	Angiotensin II Receptor Blockers
CHF	Chronic Heart Failure
EF	Ejection Fraction
LVEF	Left Ventricle Ejection Fraction
HF	Heart Failure
IT	Information technology
LV	Left ventricular
MI	Motivational interviewing
NYHA	New York Heart Association

Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

QUT Verified Signature

Signature:

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Chapter 1: Introduction

1.1. Background

Chronic cardiac diseases such as heart failure (HF) represent complex health problems and feature debilitating symptoms which adversely influence morbidity (Barnason, Zimmerman, Hertzog, & Schulz, 2010). Despite advanced medical, pharmacological and surgical treatment of HF, patient outcomes are poor and hospital readmissions remain high (Dickson, Lee, & Riegel, 2011). Patients often experience symptoms such as dyspnoea, chronic fatigue and oedema (Bisognano, Baker , & Early, 2009). Lack of symptom monitoring and seeking treatment when necessary may result in hospital readmissions in this population. Hence, being diagnosed with HF not only has a major impact on quality of life, but is also a key elevator of healthcare expenditure (Bisognano et al., 2009). In seeking to address these complexities, HF patients are encouraged to modify their lifestyles and constantly monitor symptoms related to their condition. Furthermore and to effectively manage HF, intensive inpatient and community based interventions are required along with a high level of participation by patients and health care professionals (Barnason et al., 2010).

One strategy to improve health related outcomes in patients with HF is to enhance self-management by adopting healthy behaviours such as reducing salt and fat intake, monitoring alcohol consumption, daily weighing, regular exercise, and medication adherence (Tomita et al., 2009). Self-management education is considered a critical strategy to empower HF patients to be informed and actively engaged in self-managing their condition (Barnason et al., 2003). This strategy requires a multidisciplinary approach to develop and tailor self-management interventions for individual patients. Consequently, it is expensive and demands a high level of effort (Boyde, Turner, Thompson, & Stewart, 2011).

The rapid growth of internet use has given rise to considerable interest in this medium as an alternative to educate patients and manage chronic diseases. Internet based interventions can now be delivered by web pages and emails and accessed by multiple devices such as desktop computers, laptops, tablets or smart phones (Bond, Burr, Wolf, & Feldt , 2010; Lorig, Ritter, Laurent, & Plant, 2011). Previous research has suggested that internet based interventions have the potential to improve quality of life and reduce hospitalisations in patients with chronic diseases including HF (Evangelista, Dracup, & Doering, 2000; Lorig et al., 2011; Lorig et al., 2013; Tomita et al., 2009). Utilising a web-based application as a cost effective educational intervention may facilitate patient access to essential information and may improve self-management skills (Evangelista et al., 2006). Patients who have received such an intervention have suggested that it is a suitable method to access up-to-date information and could change the way that they self-manage their conditions (Evangelista et al., 2006).

Although research in this area has resulted in the development of a large number of web-based interventions, evidence regarding their effectiveness remains indecisive (Bond et al., 2007). A growing body of systematic reviews appears to confirm the effectiveness of only a limited number of internet-based interventions and indicates that most evidence has been negative or had small effect sizes (Free et al., 2013; Kuijpers, Groen, Aaronson, & Harten, 2013). However, it is not clear whether limited effects are related to the methodological approaches of the interventions, such as structure or follow-up periods, or patient barriers in using the internet and/or computer (Kuijpers et al., 2013).

A review of literature has concluded that there are very few clearly conceptualised empirical studies that have evaluated the effect of web-based intervention for HF patients (Evangelista et al., 2006; Holst , & Machraoui, 2012; Tomita et al., 2009). The purpose of this pilot study was to investigate the feasibility of a web-based intervention in improving HF patient knowledge and self-management skills.

1.2. Significance of the Study

HF is a debilitating illness and the largest disease contributor to healthcare expenditure (Bisognano et al., 2009). The incidence and prevalence of HF cases are dramatically increasing (Bisognano et al., 2009). One reason is that many more patients who survive myocardial infarction are subsequently diagnosed with HF (Liang & Delehanty, 2009). Given the complex and progressive nature of HF that often results in adverse events and hospital readmission, it is imperative to identify interventions that slow disease progression and assist affected individuals to practice effective self-management (Shively et al., 2013).

The potential role of the proposed web-based intervention is to improve patient HF knowledge and self-management skills and particularly fluid management and symptom monitoring. The web-based application may benefit HF patients as an inexpensive and replicable self-management program. It allows patients to access the latest critical HF and self-management information wherever and when it is needed. Such a program may also be utilised as a tool for patient education by hospital and community healthcare workers caring for HF patients. A web-based application may also provide healthcare professionals a means of generating daily HF symptoms information without patients visiting clinics.

1.3. Scope of the Research

The scope of this pilot research was to develop and investigate the feasibility of an educational web-based intervention for HF patients. The use of web-based applications arguably allows access for more users through laptops, desktops, tablets and smart phones. This approach also has capacity to be upgraded instantly. Furthermore, it allows remote monitoring of patient symptoms and the use of different forms of media such as videos, texts, audios, animations, avatars, and images. In the current research, the web-based application was designed to produce information on fluid management and symptom monitoring. Essential educational materials to fulfil the requirements for this intervention were derived from the National Heart Foundation and The Cardiac Society of Australia and New Zealand HF guidelines (2011).

As a pilot study, this study was not powered to determine the safety, efficacy and effectiveness of the intervention. This study was an initial and essential step in exploring a web-based self-management intervention for HF patients. Results of this study were used to examine the feasibility of the web-based application to inform future studies.

1.4. Research Objectives

The purpose of this pilot project was to design and develop an engaging and interactive web-based application and to utilise it as an educational intervention to improve HF patient knowledge and self-management skills. In this research, the web-based intervention was developed for HF patients whose primary language was English.

1.5. Research Aims

The aims of this pilot study were to:

- Develop an interactive educational web-based application for HF patients to improve self-management skills;
- Examine the feasibility of the web-based self-management intervention to improve knowledge, self-management and self-efficacy of HF patients who had access to the web-based intervention for four weeks;
- Identify the strengths and limitations of the proposed intervention to be tested in future studies with larger sample sizes; and
- Evaluate the feasibility of recruitment, randomisation, retention and assessment procedures, and the implementation of the proposed intervention.

1.6. Research Question

Is using a web-based self-management intervention feasible to improve heart failure knowledge, self-management and self-efficacy compared to usual care for HF patients?

1.7. Research Design

The study consisted of two phases. First, a web-based application was developed based on feedback from three groups including HF experts, an IT team and HF patients. The role of the HF expert panel was to ensure integrity of the content according to evidence based guidelines, applicability of study instruments, appropriate language and images, and appropriate user interfaces. HF patients provided their feedback and recommendations on the content, ease of navigation, and user friendliness.

To increase participant HF knowledge, the application consists of written materials, video clips and images. The web-based application was developed based on the two key elements of Banduras' (1977) self-efficacy theory: role modelling and mastery of experience. For example, female or male avatars were adapted to resemble role models and to help participants follow educational materials. In addition, a section was developed for participants to enter their daily weight and signs and symptoms of fluid overload. It was anticipated that monitoring these factors would help mastery and self-management of the condition. The feasibility of the web-based application and the applicability of instruments were also examined in phase one of the study.

In phase two of this pilot study, the feasibility of the web-based intervention was examined using a controlled intervention study design, with a four week follow-up. The intervention group received the online education in addition to usual care. For the purpose of education, the intervention group also entered a number of daily measures such as weight and belt tightening. The application covered topics such as heart failure definition, instructions to weigh daily, fat and fluid differentiation, tips for healthy eating and reading food labels, and being active. In a face-to-face introductory session, the researcher demonstrated the web-based application and assigned a username and password to each participant in the intervention group. Over the four weeks, members of the intervention group were asked to log on to the web-based application each day, review the content for a minimum of 15 minutes and enter their weight and signs and symptoms of HF such as coughing, belt tightening, shoes and/or socks. Entry of the above factors was designed to encourage participants to monitor their condition at home. The intervention group also received a weekly email from the researcher to encourage continuation with the program.

1.8. Thesis Outline

This thesis consists of eight chapters. The research problem and significance of the study were addressed in Chapter 1. The aims and objectives of the study with an overview of the thesis structure were also described in Chapter 1. In Chapter 2 the literature on chronic disease self-management interventions including HF and the strengths and weaknesses of the current web-based interventions on HF outcomes is reviewed. Chapter 3 provides information on common self-management models for chronic diseases and presents a review of Bandura's self-efficacy theory which underpins the conceptual framework of this study.

Chapter 4 addresses the design and development of the web-based application and also the methodology used to examine the feasibility of the web-based intervention in the current research. Results of the study are presented in Chapter 5 and a discussion of the study results provided in Chapter 6 including the feasibility of the web-based intervention, effect size estimates, study strengths and limitations. Recommendations for future research along with proposed modifications to the web-based self-management intervention are provided in Chapter 7 of the thesis. Chapter 7 also engages with some concluding observations and reflections on the research process.

A review of current literature related to HF self-management with a focus on web-based interventions for patients with chronic diseases is the focus of the following chapter.

Chapter 2: Literature Review

Heart failure (HF) is a complex clinical syndrome caused by cardiac dysfunction and generally results from myocardial muscle dysfunction or loss (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011). The underlying cause for the dysfunction can be structural abnormality which is characterised by either left or right ventricle dilation or hypertrophy (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011). Regardless of the underlying cause, HF generally leads to neurohormonal and circulatory abnormalities, usually resulting in symptoms such as fluid retention, shortness of breath, and fatigue, especially on exertion (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011). Coronary heart disease, previous myocardial dysfunction , long-term hypertension, diabetes and cardiomyopathy have all been identified as common causes of HF (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011). However, the most important risk factors for heart failure are coronary heart disease and hypertension (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011). Less common causes of HF include heart valve disease (such as with chronic rheumatic heart disease) and thyroid problems (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011).

Although there is limited data, the available evidence points to a high prevalence of HF in Australia (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011). Based on cohort studies undertaken in Europe

(Stewart, Capwell, & McMurray, 2003) and Australia (Australian Institute of Health and Welfare, 2011), it has been estimated that the annual prevalence of HF within the Australian population is 300,000 people (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011).

The National Health Survey (NHS) of 2007 and 2008 similarly estimated that 1.3% of the Australian population had HF, equating to approximately 277,800 people (Australian Institute of Health and Welfare, 2011). In terms of gender, the prevalence of HF for women (177,200) was higher than men (100,500) in every age group and especially among females aged 85 years and over. Furthermore, the prevalence of HF, not surprisingly, rises markedly with age among Australians (Australian Institute of Health and Welfare, 2011). For example, it has been estimated that 1% of people aged 50-59 experience HF, 10% aged 65 years or more and over 50% aged 70 and older (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011).

Despite improvement in pharmacological treatment and prevention, chronic HF remains a serious health care burden and carries a poor prognosis (Bisognano et al., 2009). HF is the third leading cause of death from heart, stroke and vascular diseases in Australia (National Centre for Monitoring Cardiovascular Disease, 2004). Disease severity is often categorised according to four stages based on the New York Heart Association (NYHA) functional classification system (Heart Faliure Society of America, 2011). Among patients with class I symptoms, the mortality rate is approximately 5-10% per year and rises to 40-50% per year for those with class IV symptoms (Bisognano et al., 2009).

To reduce hospitalisations and increase quality of life, guidelines recommend that HF patients be supported to successfully self-manage their condition (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011). Involving patients through education is perceived as the most effective means to improve self-management skills (Evangelista et al., 2006). This chapter presents a literature review on HF with a focus on self-management interventions. The use of web-based interventions to improve self-management in patients with chronic diseases and HF is also explored below.

2.1. Self-management in Patients with Chronic Disease

Barlow, Wright, Sheasby, Turner, & Hiansworth (2002) described self-management as the patient’s ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes to maintain quality of life. In other words, it is the gaining of mastery over skills that enable patients to appropriately manage their disease. The core skills are problem solving, decision making, resource utilisation, action planning, and self-tailoring (Lorig & Holman, 2003). Self-management is considered an important contemporary issue for people with chronic diseases because apart from acute episodes and in contrast to acute disease, people who are affected by chronic conditions are required to learn to live with their condition and to manage themselves on a day to day basis (Nolte, Elsworth, Newman, & Osborne, 2012).

Self-management intervention is now widely recognised as part of HF management that aims to improve patient wellness and quality of life (National Heart Foundation Australia & The Cardiac Society of Australia and New Zealand, 2011). To increase self-management in patients with chronic diseases, a broad range of interventions have been implemented such as monitoring symptoms, reducing alcohol consumption, and following a healthy diet (Bahrer-Kohler, 2009). Yet, despite increasing attention to self-management in the literature, current evidence shows mixed results. On the one hand, meta-analyses generally show that people with diabetes and hypertension benefit from self-management programs (Chodosh, Morton, & Mojica, 2005; Warsi, Wang, LaValley, Avorn, & Solomon, 2004). On the other hand, self-management interventions appear to have none to small effect for other chronic conditions such as arthritis, osteoarthritis, rheumatoid and chronic low back pain (Chodosh et al., 2005; May, 2010). A recent systematic review of group-based manualised programs for arthritis and other chronic conditions following the Stanford self-management model found negligible to small effect sizes across a range of patient outcomes including pain, disability, depression, physician visits, general health, fatigue, communication with physician, anxiety and physical functioning (Nolte et al., 2012).

Another review of systematic reviews on self-management programs for chronic obstructive pulmonary disease showed that despite over a decade of research, there is still uncertainty about the effectiveness of these interventions (Jonsdottir, 2013). While healthcare utilisation was reduced and quality of life increased, no significant changes were observed in other health related variables such as days lost from work and lung function (Jonsdottir, 2013). Potential explanations for these findings are the limited number of studies conducted in this area, their variations in methodological approaches and small sample sizes (Jonsdottir, 2013). Furthermore, there was a lack of family participation in the programs although the self-management literature considers that this is important. Notably, there was also an absence of theoretical or conceptual frameworks around self-management. The health professional centred approach was prominent, although in the most recent studies patient centeredness has been emphasised (Jonsdottir, 2013). Jonsdottir (2013) concluded that self-management programs should include appropriate techniques for behavioural change, tailor interventions for individuals as well as assume a holistic approach toward patients and their families in their everyday life, take patient perspectives into account, and reflect the course of condition and its co-morbidities.

A number of meta-analyses and systemic reviews have evaluated the impact of HF self-management programs on different outcomes including mortality, all cause hospital readmission, hospitalisation rate, and patient quality of life (Boyde et al., 2011; Ditewig, Blok, Havers, & van Veenendaal, 2010; Jovicic, Holroyd-Leduc, & Straus, 2006). A meta-analysis performed by Jovicic et al. (2006) examined the effect of self-management intervention in six randomised trials comprising 857 HF patients. Although self-management interventions reduced all cause hospital readmissions, the effect on mortality rate and quality of life was inconclusive (Jovicic et al., 2006). For example, functional capabilities and symptom status did not change (Jovicic et al., 2006). Results did show an improvement in patient adherence to medical advice and importantly studies with intensive education including follow-up and nurse led education showed more benefits than others. However, it was difficult to assess whether or not communication frequency during follow-up affected patient outcomes (Jovicic et al., 2006).

Ditewig et al. (2010) evaluated the self-management interventions on mortality, hospital readmissions, hospitalisation rate and quality of life of HF patients. These authors only reviewed studies that were RCTs and were carried out based on a self-management approach developed by Barlow et al. (2002). Patient education was found to be the main component of self-management interventions across the studies, consisting of early recognition of HF signs and symptoms, the importance of pharmacological treatment adherence, daily weighting and lifestyle change. Among the 19 studies reviewed, nine examined the effect of self-management on mortality rates. However, only one study reported a significant reduction in the intervention group on the rate of death per year (Ditewig et al., 2010). While all cause hospital readmission was considered an outcome in eight studies, only two studies showed a significant reduction. There were four studies that evaluated the effect of self-management on hospitalisation rate and between them two studies described significant reduction in the intervention group (Ditewig et al., 2010). Using a variety of questionnaires, 14 studies evaluated HF patient quality of life. The results showed that eight studies found significant improvement in the quality of life and six no significant change (Ditewig et al., 2010).

It can be concluded that the use of self-management interventions for HF patients appears to be effective and thus is a promising approach. However, this form of intervention is not always significant particularly in the area of reduction of all cause hospital readmissions (Ditewig et al., 2010).

A review of systemic reviews concluded that self-management interventions for HF patients suffer from a lack of appropriate methodology (Ditewig et al., 2010). It was argued that future research needs to address the following areas: (i) improvement of research methodology by designing and performing multicentre RCTs from combined primary and secondary healthcare services, (ii) considering adequate follow-up duration and identifying to what extent intervention must be empowered and supported by health-care professionals and/or technology devices, and (iii) defining the key terms such as self-management and using appropriate conceptual frameworks to achieve consistency in the interpretation of results (Ditewig et al., 2010).

In turning to education and HF, Boyde et al. (2011) evaluated interventions that were specifically designed for HF patients from 19 randomised trials. Although the educational interventions varied between studies, the most common form of education involved one-on-one sessions conducted by a nurse. While the traditional form of patient education has been verbal instruction, it is now considered the least effective strategy unless combined with other media for reinforcement such as videos, interactive CD-Rom and TV channels. In addition, a few studies were supplemented by emails or text messages (Boyde et al., 2011). Despite current attempts to develop patient education based on one or more theories, only seven studies developed a theory based educational intervention. Yet, since each employed a different theory, it was difficult to draw conclusions about any particular methodology (Boyde et al., 2011). Considering that patients may need different levels of education because of factors such as time since diagnosis and previous education, only four studies assessed patients prior to an intervention. Boyde et al. (2011) argued that tailoring education to patient needs and preferences should be a key component of patient-cantered education (Boyde et al., 2011). The authors also pointed out that empowerment had a consistent presence in the studies that evaluated knowledge as an outcome measure and an increase in knowledge did not necessarily result in patient behaviour change. In this review, self-care was reported as an outcome measure in eight studies, seven of which showed a statistically significant improvement. Among 12 studies that measured quality of life only two reported a positive effect. In this review, decreased readmissions and mortality were reported in four studies (Boyde et al., 2011). Finally, Boyde et al. (2011) noted that heterogeneity of the included studies in this review resulted in variable outcomes. Hence, it was difficult to identify the most effective educational strategy as the delivery methods, duration and the outcome measures of educational interventions differed considerably.

From the above systematic reviews it can be concluded that there is no strong evidence supporting the effect of education on patient outcomes. Effects may be shown, however, if the intervention is specifically targeted and the follow-up times are long enough. It is also argued that it is essential to design interventions based on patient-centred approach and to tailor education to the identified needs and preferences of patients (Boyde et al., 2011).

Further studies conducted in this area also confirm uncertainty about the effectiveness of self-management interventions (Shively et al., 2013; Smeulders et al., 2010; Welsh et al., 2013). A randomised, repeated measure experimental design was used to evaluate a low-sodium diet self-management intervention during six weekly sessions among HF patients (Welsh et al., 2013). Both the intervention and control group (*N* = 52) were assessed by completion of a dietary sodium restriction questionnaire consisting of items such as attitudes, subjective norm, and perceived behavioural control. While the total attitudes subscale score was highly significant in the intervention group after six weeks, there were no differences between two groups at baseline and the six month study endpoint (Welsh et al., 2013). Furthermore, no differences were observed between scores of the intervention and usual care group for the subjective norms and perceived behavioural control at baseline, six weeks, or six months. The results also showed that dietary sodium intake of the intervention group did not decrease at six weeks. It was, however, significantly lower after six months (Welsh et al., 2013). The limitations of the study included participant attrition due to a number of reasons including death. Furthermore, the sodium dietary intake was self-report and subjected to bias. Nonetheless, the authors emphasised that using a home–based educational intervention would be cost-effective compared to hospitalisations related to high sodium intake and fluid retention (Welsh et al., 2013).

A similar study conducted by Smeulders et al. (2010) found that a chronic disease self-management program in HF patients (*N* = 317) improved the cognitive symptom management, self-care behaviour and cardiac specific quality of life in the short term. However, no effects were found at six and 12 month follow-ups (Smeulders et al., 2010).

The randomised behavioural trial conducted by Powell et al. (2010) evaluated self-management counselling in patients with HF. A total of 902 HF patients received 18 contacts and 18 HF educational tip sheets during the course of one year. While patients in the education group received tip sheets by email or phone call, the self-management group received self-management education plus counselling in a group-based sessions (Powell et al., 2010). A number of variables were measured in both groups including annual event rate, all cause hospitalisations, change in NYHA class, heart rate, and self-efficacy. Study results indicated that adding self-management counselling to an enhanced educational intervention did not reduce death or hospitalisations in the study population. However, 28% of the participants in the self-management group restricted their sodium intake compared to 20% of the education group (Powell et al., 2010). Interestingly, self-efficacy and depressive symptoms improved in both groups. While the effect of using the technologies on patient self-management was not evaluated in this trial the results suggest that the use of technology such as email may be an effective way to enhance patients' self-management skills (Powell et al., 2010).

In a further study, Shively et al. (2013) examined the effect of patient activation on HF self-management. The concept of activation refers to having the information, motivation, and behavioural skills necessary to self-manage chronic illness, collaborate with health-care providers, maintain functioning, and access appropriate care (Shively et al., 2013). To measure patient activation, the investigators used a randomised, two group, repeated measures design in 84 HF patients over a six month period. The patient activation program was individually tailored for the intervention group (N = 43) and meetings or telephone calls were used for each patient in the intervention group (Shively et al., 2013). The investigators used several measurement instruments including patient activation measure, self-care HF index, medical outcomes study specific adherence scale and hospitalisation and emergency department (ED) visits (Shively et al., 2013). There were statistically significant improvements in activation scores from baseline to six months in the intervention group. Self-management measured by a self-care HF index did not, however, improve significantly. The intervention group experienced fewer hospitalisations but no difference was observed for ED visits (Shively et al., 2013). The limitations of the Shively et al. study (2013) extended to sample size, age and gender demographics, attrition, missing data and instrumentation issues. The mean age of participants was 68.9 in the intervention group and comprised 97.6% male and, 63.9 and 100% respectively for the usual care group. The figures reflect the single site study which was conducted in New York in a Veteran Affairs institution (Shively et al., 2013). A further limitation was instrumentation and measurement. Because the patient activation on self-management measure was quite new, findings related to the impact of increased activation on self-management were not conclusive (Shively et al., 2013). Furthermore, the authors emphasised that although the SCHFI was said to reflect self-management and healthy behaviour, it was not sensitive to the intervention in this study.

Conversely, Tung et al. (2010) found that self-management intervention for a period of two months improved quality of life and self-care ability in Taiwanese HF patients (*N* = 88). To determine the effect of self-management intervention, SCHFI and the Minnesota Living with HF questionnaires were examined at baseline, four and eight weeks (Tung et al., 2010). Self-management intervention included a patient book, self-management training and telephone follow-up for a period of two months (Tung et al., 2010). Education included the nature of home care for HF, self-management skills, appropriate attitudes and confidence in managing the disease, how to become active self-manager, forming action plan based on self-management theory, the behaviour needed to manage symptoms and illness, and how to improve compliance to treatment and promote a healthy lifestyle. The book also contained a medication log, symptoms management sheet, biological data sheet, and diet and exercise sheet. Fewer hospitalisation rates or deaths were also reported for HF patients with low literacy levels who received self-management intervention in a randomised control trial conducted by Dewalt et al. (2006) and Otsu and Moriyama (2011).

Mead, Anders, Ramos, Siegel and Regenstein (2010) investigated the barriers associated with self-management in patients with cardiac diseases. The sample constituted 33 focus group discussions with patients recruited from US communities. Participants identified a number of issues as significant challenges in managing their condition on a daily basis. These included, but were not limited to, inadequate information on how to manage their disease, lack of provider support and supports to improve self-management. Inadequate information, such as adjusting daily activities, was considered by participants to be a primary barrier to self-management (Mead et al., 2010). Lack of patient-provider support was another barrier that was significantly explicated by participants. This form of support included efficient communication, accessibility and active partnership with patients (Mead et al., 2010). Participants pointed to a lack of communication and time spent with their physicians as a serious problem in patient-provider relationship (Mead et al., 2010). Furthermore, patients who received self-management programs were highly positive about the support provided by these programs (Mead et al., 2010). Mead et al. (2010) argued that these programs can reduce barriers that interfere with self-management.

2.2. Summary

The review of existing research indicates that some chronic diseases benefit more from self-management programs than others. Results of the review showed that education and promotion of effective self-management combined with optimal medical management has the potential to improve health related outcomes for HF patients. To do this, different self-management interventions have been designed and developed. The studies indicate, however, that many factors impact the effectiveness of the interventions such as sample size and follow-up duration; methodological approach; and intervention strategies. Furthermore, some researchers did not define terms such as self-management or address the conceptual framework underlying an intervention. This caused inconsistency in the interpretation of the results of self-management interventions. The results of systemic reviews also show that the extension of many interventions regarding the support of health care providers is not clear. Future self-management programs should also be tailored for individuals with HF and consider patients and their family members as a whole. As a result, developing optimal self-management intervention that could benefit HF patients is still controversial. Furthermore, such research demands a multidisciplinary approach and substantial budget.

2.3. Web-based Interventions for Self-management in Chronic Disease

As noted above, increasing use of the internet by consumers of health information and ongoing technological development has led to the design and institution of many internet based interventions. These interventions are designed to improve self-management in patients with chronic diseases such as heart disease, diabetes, and arthritis. A number of studies have been conducted to evaluate internet based interventions (Bond et al., 2010; Lorig et al., 2011; Lorig et al., 2013)

A recent systematic review of mobile-health technology that covered health behaviour change and disease management interventions found mixed results regarding the effectiveness of interventions (Free et al., 2013). While the results showed no or small effect in diet and physical activity interventions on weight control, there was some evidence of benefit for short term management of diabetes and asthma and for reminders for vaccine appointment attendance and cardiopulmonary resuscitation training. As a result, mobile technology based interventions are not yet optimal and need to incorporate additional components found in effective self-management interventions. High quality trials with optimised interventions are also required in areas of health behaviour change and disease self-management programs involving mobile technology (Free et al., 2013).

A meta-analysis of mobile health technologies in patients with diabetes mellitus also found significant improvement across a range of patient outcomes including blood glucose reduction, medication adherence, healthy lifestyle and self-efficacy (Liu & Ogwu, 2012). Findings from the meta-analysis suggest that health reminders, disease monitoring and management, and education through mobile technologies, may significantly improve patient outcomes (Liu & Ogwu, 2012).

Lorig et al. (2011) evaluated an internet based chronic disease self-management program including measurement of perceived self-efficacy. The 958 participants were randomised to intervention and usual care groups and were assessed at six and 12 months after enrolment. The program provided small group online workshops for the intervention group (approximately 25 patients per workshop). Patients with different chronic disease such as heart disease, chronic lung disease and type 2 diabetes attended the online workshops (Lorig et al., 2011). There was statistically significant improvement in a variety of health outcomes including health distress, fatigue, pain, and shortness of breath in the intervention group. Self-efficacy which reflected participants' confidence to manage their disease in general also improved significantly in the intervention group (Lorig et al., 2011). However, none of the healthcare utilisation variables were significant in the hypothesised direction. The study was limited in areas such as differences in recruitment methods, disease frequencies and participants' computer literacy (Lorig et al., 2011).

In a subsequent study, Lorig et al. (2013) examined a six week peer led online chronic disease self-management program in South Australia based on Bandura's self-efficacy theory. A total of 254 patients with one or more chronic conditions answered two online questionnaires at baseline, six and 12 months and 194 continued the program for 12 months (Lorig et al., 2013). Health outcomes measures included health care utilisation and self-efficacy. Outcomes at the six months point were compared with baseline. This process was also repeated for outcomes at one year. The results of the study were slightly different for the six and 12 months follow-up (Lorig et al., 2013). The study outcomes were statistically significant for all measured variables and showed that the online program was acceptable and useful for the proposed population (Lorig et al., 2013).

Results also indicated that while health behaviours and the self-efficacy of participants were improved, symptoms and health-care utilisation were reduced (Lorig et al., 2013). There were some limitations that need to be considered in future studies. First, the study was not randomised. Second, due to a programming error, the number of cases and some statistical power were reduced. Since there was no control group it was not possible to identify whether or not the reduction in participants' number affected the outcomes. Conducting an RCT was considered highly desirable (Lorig et al., 2013).

Bond et al. (2010) examined the impact of a web-based intervention on psychosocial well-being with a focus on self-management among adults aged 60 and older with diabetes. The intervention group participants (*n* = 31) were encouraged to maintain their health, set goals and use problem solving skills to overcome barriers through a web-based program that was accessed for six months. Furthermore, interaction between nurses and the intervention group was performed via two methods either simultaneously (instant messaging and chat) or by e-mail and bulletin board (Bond et al., 2010). Participants in the control group received standard care from their health-care providers without further educational or training materials. Study participants were assessed at baseline and six months. Findings from this study and one conducted by Bromberg et al. (2012) showed that depression, quality of life, self-efficacy and social support were significantly improved for participants who received a web-based intervention.

In a similar study, web-based usability was evaluated by 30 breast cancer survivors. Education, action planning, and automatic feedback were tailored for individual participants through an assessment process over the period of 12 weeks (Lee, Park, Yun, & Chang, 2013). Patients rated the program as easy to understand and use and 90% of patients were found to consistently use the program during the study (Lee et al., 2013). The authors concluded that the internet provided immediate access to the intervention, monitoring of progress, tailored action plans and short message services (SMS) using mobile phones (Lee et al., 2013). However, patient knowledge and self-management skills related to exercise and diet were not evaluated

Some studies found less improvement in the performance and maintenance of self-management. A mixed methods investigation conducted by Kerr et al. (2010) examined the potential of a web-based intervention for heart disease self-management over a period of nine months. The comprehensive health enhancement and social support (CHESS) living with heart disease web-based intervention was used to provide interactive information, behaviour change support, peer support, and expert support. First, participants were individually trained to use the web-based intervention and were informed on local, free, or low cost public internet services. The authors then examined the frequency of use of the web-based intervention and the factors influencing participants to do so (Kerr et al., 2010). The program automatically recorded frequency of logins and pages viewed by the 168 participants. Individual semi-structured interviews were performed as an additional qualitative component with a subsample of participants (*n* = 19) (Kerr et al., 2010). The quantitative results indicated that factors such as time since the most recent chronic heart disease (CHD) or cardiac event, access to home internet, and prior internet experience influenced participants to use the intervention. How and why these factors influenced use or lack of use of the intervention was explored through the qualitative data. Statistical results indicated that median use of intervention over nine months among participants was four logins or viewing 148 pages of the intervention (Kerr et al., 2010). The study outcomes showed that the availability of a web-based intervention, with support for use at home or via public internet services, did not increase the use of the intervention by the majority of participants (Kerr et al., 2010). This may have occurred because participants had a higher level of education, better access to internet and fewer problems with their condition compared with the general CHD population. As a result, the effectiveness of web-based interventions for patients with chronic diseases remains a significant challenge and further studies need to be conducted in this area (Kerr et al., 2010).

On the other hand, an online self-help chronic back pain intervention was found to improve participant outcomes such as ability to conceptualise, self-manage and react to pain over the period of six months (Carpenter, Stoner, Mundt, & Stoelb, 2012). A similar study determined that the use of a web-based diabetes case-management program significantly improved participant self-efficacy in the intervention group measured after 12 months (Goldberg et al., 2009).

For assessing the effectiveness of web-based interventions for improving empowerment and physical activity in patients with chronic diseases, Kuijpers et al., (2013) performed a systemic review. Primary English language studies, with RCT designs and participants with at least one chronic disease, were selected (Kuijpers et al., 2013). At least one outcome variable including physical activity and /or patient empowerment had been evaluated within the reviewed study. All relevant and related outcomes such as self-efficacy, self-management and self-care were considered as patient empowerment.

In this review, the mean age of the participants involved in the interventions was 60 years and ages ranged from 40-76 years. Of the 19 studies only six collected information on participants' prior experience with computers and/or internet use (Kuijpers et al., 2013). Results indicated that four studies reported significant positive effects on patient empowerment and two studies demonstrated positive effects on physical activity. The remaining studies showed mixed results or no significant group differences in the above mentioned outcomes (Kuijpers et al., 2013). In other words, the results of several studies were significant and positive for both intervention and control group. Nonetheless, in many studies the comparison group also received the intervention and it was not possible to appropriately detect the effect of the web-based intervention. This is because the usual care situation is rapidly evolving and establishing appropriate control groups have become increasingly difficult (Kuijpers et al., 2013). The authors indicated that interventions significantly varied in duration, frequency and the content. The variety of elements frequently observed in the reviewed interventions included education, self-management training, personal exercise program, and communication with either healthcare providers or fellow patients (Kuijpers et al., 2013). There is some debate over whether or not web-based intervention should have structured programs. Certainly for systematic reviews this would be useful. But any move towards homogeneity in web-based program design would be interesting challenge to the concept of patient tailored interventions.

Finally, Kuijpers et al. (2013) concluded that web-based interactive interventions have the potential to be beneficial for patients with various chronic diseases as empowered individuals who are physically active are likely to have better health status and quality of life. Further research is needed to establish optimal interventions with a focus on specific disease characteristics (Kuijpers et al., 2013). It was noted that only five studies reported on perceived barriers such as problems with internet connection, security concerns and discomfort with using the computer or internet. Hence, greater focus on participant perceived barriers and methods to eliminate those barriers is recommended for future studies (Kuijpers et al., 2013). There were also a number of methodological issues. Future RCTs involving web-based interventions need to clearly explain the methods of randomisation, concealment of treatment allocation, and sample size calculation (Kuijpers et al., 2013).Greater clarification is also needed around frequency and duration (Kuijpers et al., 2013).

2.4. Summary

Overall the literature indicates that effectiveness of internet-based self-management programs for people with chronic disease remains inconclusive as current available published studies have methodological shortcomings. Such shortcomings need to be considered in future research. These include the development of web-based interventions focused on specific diseases such as HF, clarifying intervention strategies, and identifying patient barriers related to the use of internet and/or computer. The following section presents a discussion on studies focused on developing and testing web-based interventions for HF patients.

2.5. Web-based Interventions for Heart Failure Patients

Web-based interventions appear to be an efficient method to improve self-management among patients with HF (Evangelista et al., 2006). A multidisciplinary internet-based self-management program for patients with heart failure (HF) was developed and tested by Tomita et al. (2009). The study design was an RCT ($N = 40$) conducted in USA over one year. The intervention group received e-health intervention in addition to usual care. Participants were assessed with a number of questionnaires including adherence to program, HF knowledge, HF-specific symptoms and general indicators, quality of life and health care utilisation (Tomita et al., 2009).

The results of the study indicated that HF knowledge in the intervention group improved significantly while it was lower than the control group at baseline. The intervention group also showed significant improvement in recognising HF specific symptoms such as dyspnoea and fatigue (Tomita et al., 2009). The quality of life scores increased significantly for both groups during the first six months and remained the same for another six months. However, the intervention group gained significantly higher scores during follow-up. While health care utilisation did not change for the control group, the number of visits to emergency rooms and the length of hospital stays decreased significantly for the intervention group and this was maintained for 12 months (Tomita et al., 2009).

In a further study, a web-based program to educate HF patients (N = 12) was developed by Evangelista et al. (2006). The program was developed in two phases involving both health care providers and patients (Evangelista et al., 2006). Website educational materials were provided in three modules including general information about HF with an emphasis on medications and symptom recognition; promoting healthy lifestyle habits; and psychosocial and spiritual issues. Furthermore, the web-based program was designed to provide security for patients and providers, online support forum for group discussion, and interactive disease management tools (Evangelista et al., 2006). Patients in that study were asked to evaluate the user-friendliness of the program (Evangelista et al., 2006). Evangelista et al. (2006) found that a high percentage of participants was very satisfied with the web-based eduation. However, the impact of the web-based program on HF patients' health related outcomes such as self-management, quality of life or hospital readmissions were not evaluated.

A similar study conducted by Delgado, Costigan, Wu and Ross (2003) examined the impact of an interactive website on quality of life of HF patients. The website was designed to be a source of information and a daily communication between HF patients and clinic. It also allowed patients to perform online monitoring of weight and blood pressure, checking of medications and communicating with their health care providers. The sample consisted of 16 HF patients and their quality of life was measured through the completion of the Minnesota Living with HF questionnaire.

One group pre-test/post-test results showed that patient quality of life was improved after using the website for three months (Delgado et al., 2003).

A recent study, known as The Baltic Heart Trial, evaluated the impact of e-health and e-learning on patients living with HF. The study was multi-centred across seven Europeans countries (Holst & Machraoui, 2012, para. 3). It was a non-randomised prospective study which examined the impact of web-based education and telemedicine (web-based program for monitoring) on patient quality of life and rehospitalisation. Although there is, as yet, no further information available on the results of this study, the preliminary results showed that after six months of education of HF patients, rehospitalisation and emergency visits were significantly reduced (Holst & Machraoui, 2012, para. 3). Holst and Machraoui (2012, para. 3) found that HF patients were more satisfied with the use of web-based education than telemedicine.

2.6. Conclusion

A comprehensive literature review has been carried out and reported upon in this chapter to demonstrate the strengths and weaknesses of existing self-management intervention research. It is clear that self-management assumes a significant role in modern healthcare. Thus, to optimise healthcare delivery and patient satisfaction, many self-management interventions have been developed for people who are affected by chronic disease. Despite improvements in knowledge, the results are variable for other outcomes such as self-care, hospital readmissions, quality of life and mortality. Results indicate that research in the area is limited by methodological shortcomings. These include small sample sizes, lack of family participation, lack of appropriate conceptual framework, inappropriate methodology, inadequate follow-up and issues around the choice of instruments. According to the systemic reviews noted above, identifying the most effective self-management intervention is difficult as interventions varied considerably in delivery methods, follow-up duration, type of questionnaires, and outcome measures. Furthermore, some studies developed instrument/s for their intervention and since the instruments were newly developed, it was not possible to measure the impact of such a tool on self-management. Results of the literature review also indicate that future research should be committed to patient tailored education, consider patient preferences and be patient-centred rather than healthcare-centred. This means that self-management must not involve only those with a chronic disease but also their family members who are integral to the everyday lives of those who are chronically ill. Hence, improving self-management, quality of life and reducing hospitalisation for patients with chronic disease remain challenge for health-care providers.

Self-management is considered an important intervention for HF patients. Improving health related outcomes in patients with HF might be achieved through enhanced self-management by adopting healthy behaviours such as reducing salt and fat intake; monitoring alcohol consumption; daily weighing; committing to regular exercise; and medication adherence. This strategy requires a multidisciplinary approach and tailored self-management interventions for individual patients. Yet the time and cost of effective interventions is likely to be considerable.

In conclusion, the above review of existing research showed that web-based interventions have the potential to improve self-management and quality of life in patients with chronic diseases including HF and therefore reduce hospitalisations. Such a program may facilitate patient access to information and health care professionals and be supportive and sustainable rather than merely directing, guiding or training. Furthermore, web-based programs are cost effective and satisfy patients.

Future research that will evaluate web-based programs must provide comprehensive information related to an intervention including elements, frequency and duration. Furthermore, a broader perspective that extends to participants' perceived barriers related to internet connection, security and usability will give greater insight into the complexities of this area of research. Regarding the methodological approach, randomised trials are highly desirable. But researchers conducting randomised trials must clearly identify the method of randomisation and the sample size calculation. It also appears that greater success in the area of research will be achieved through the development of web-based self-management programs specifically for one condition rather than focusing on group of diseases or illnesses.

Finally, there are very few clearly conceptualised empirical studies related to web-based self-management intervention for HF patients. Furthermore, there is a lack of randomised trials in this area. As a result, it is still unclear whether a web-based intervention with appropriate methodology and follow-up duration will improve HF patient self-management and/or other health related outcomes. The conceptual framework underpinning the current study is argued in the following chapter.

Chapter 3: Conceptual Framework

3.1. Self-management History and Definition

Thomas Creer used the term “self-management” for the first time in 1976 in his work on the rehabilitation of chronically ill children. Creer and his colleagues used the term in conjunction with their paediatric asthma program and acknowledged that their work was based on Bandura’s self-efficacy theory (Lorig & Holman, 2003). These authors argued that underpinning self-management was the belief that patients should be active participants in their own care. In 1988, Corbin and Strauss expanded upon the concept of self-management based on three essential processes including the medical, behavioural (role), and emotional management of chronic illness (Novak, Costantini, Schneider, & Beanlands, 2013). While medical management encompasses patient adherence to prescribed medications, role and emotional aspects address the lifestyle modifications and psychosocial barriers that often surround patients. Yet as Lorig and Holman (2003) have since pointed out, despite the fact that all three dimensions concurrently inform patient education and self-management programs, the predominant approach remains focused on medical and behavioural management.

Lorig and Holman (2003) expanded the self-management principles based on the work of Corbin and Strauss in defining five core skills for self-management including problem solving, decision-making, resource utilisation, patient /healthcare provider partnership, and taking action. Problem solving skills include identifying a problem, providing possible solutions and then implementing and evaluating those solutions (Lorig & Holman 2003). Decision-making is the second skill of self-management. For the patient with chronic disease it is considered essential to make day-to-day decisions in response to physical and psychosocial changes that occur during the course of disease. In order to make these changes an effective level of knowledge is necessary. Hence, a third skill of self-management is how to find and use resources (Lorig & Fries, 2006). Lorig and Holman (2003) stated that many self-management programs introduce varied resources such as a phone book, internet, library and community resources to participants. However, they do not teach participants how to use the resources when they are required. Helping patients to form partnerships with their health care providers is a further self-management skill. The final skill, taking action, is grounded in the D' Zurila model and the concept of skill mastery from the Bandura's theory of self-efficacy (Lorig & Holman, 2003). Lorig acknowledged that Banduras' conceptualisation of self-efficacy was a major theoretical influence in her work (Ryan & Sawin, 2009). This is evident in the ongoing work of Lorig and colleagues that has contributed to knowledge related to self-management through the development of a program known as the Lorig course. Many other self-management programs have been based on this course and have been developed and evaluated for a variety of conditions such as lung disease, heart disease, diabetes and arthritis (Dongbo et al., 2003; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001; Lorig, Ritter, & Gonzalez, 2003). The results of this body of research taken as a whole indicate that self-management is a critical issue across chronic conditions (Ryan, & Sawin, 2009).

Ryan and Sawin (2009) posed a different perspective on self-management. Traditionally, self-management has been focused on individuals or families. However, a new framework from these authors combined and integrated the two parallel components known as individual and family self-management (Ryan & Sawin, 2009). The assumption was that a change in one component of a system (i.e., family member) would lead to changes in the system (family). Grey, Knafi and McCorkle (2006) also proposed a framework that incorporates the family structure and interactions in self-management. In the context of self and family management (Grey et al., 2006), self-management occurs within families, communities and environment. Within this framework, a number of factors, referred to as risk and protective factors, mediate self-management. The contextual risk and protective factors include condition, individual, family and environment. Although acknowledging conceptual differences to the Grey, Boland, Davidson and Tamborlane (2001) framework, Ryan and Sawin (2009) argued that the new broad approach clarifies self- and family management through a much clearer delineation of risk and protective factors. These categories of factors are addressed, in turn, below.

3.1.1. Condition Factors

Condition factors that influence self and family management include severity of the condition, treatment regimen, and condition trajectory (Rayan & Sawin, 2009). Health care providers and patients or family members, however, may have differing views on the severity of a condition (Grey et al., 2006). While health care providers may view it as a disease prognosis, patients and their family members might consider it a disease burden. The treatment regimens also vary across different conditions. It may be as simple as taking a daily dose of hormone for hypothyroidism or a complex regime for diabetes involving multiple medications and significant lifestyle changes (Grey, et al., 2006). Trajectory is defined as the various stages experienced by people over the course of a condition or disease. The course of a condition presents as the cumulative disease effects and consists of physical symptoms and the impact of the illness on an individual's quality of life. Depending on the stage of a condition or individual current trajectory, the focus of intervention must be specific to promote the coping and stability skills of patients and their family members (Grey et al., 2006). Moreover, there is considerable variability across conditions with complex interactions between severity, trajectory and regimen. The resultant complexities impose greater demands on self and family management (Grey et al., 2006).

3.1.2. Individual Factors

Individual factors including age, gender, ethnicity and culture play an integral role in determining how patients and their families self-manage a chronic condition (Grey et al., 2006). While individuals at a young age with a chronic condition are completely dependent on their families for care, the degree of dependency changes and individual responsibility increases with maturity. Conversely, elders may become more dependent as they get older (Grey et al. 2001).

Gender may also affect the nature of individual self-management. Previous research has indicated that women with diabetes assist their spouses in self- management quite differently to the way they manage themselves (Fisher et al., 2000). Factors related to ethnicity, culture, educational level and language also have an effect on self-management. Grey et al. (2001) point to mortality and morbidity rates in minority ethnic groups, regardless of socioeconomic status, and suggest that this indicates the importance of understanding the self and family self-management practices across contexts.

3.1.3. Family Factors

As self-management takes place in the context of family and community, much research has been undertaken to identify factors associated with the impact of family functioning on self-management. It has been found that regardless of the age of an ill person, better family functioning results in more effective social support, adequate resources, the ability to find positive meaning in the experience, and fewer stressors (Grey et al., 2006). Weihs, Fisher and Baird (2003) performed a comprehensive literature review on the contribution of family variables to the self-management of ill members with chronic conditions. Their review indicated that variables including caregiver coping skills, family closeness, mutually supportive family relationship, clear family organisation and direct communication about a condition resulted in better individual and family outcomes.

Lastly, different patterns or typologies of family responses have been identified (Weihs et al., 2003). Family typologies integrate different aspects of family life and this approach is able to generate an understanding of how a family, as a system, engages with and responds to an illness (Knafi & Deatrick, 2003).

3.1.4. Environmental Factors

The influences of environmental factors such as social networking, community and healthcare system on self-management have been well documented (King et al., 2007; Grey et al., 2006). The body of research supports the importance of developing interventions that take into account different environmental factors and their contexts such as health care access, utilisation and provider relationship (Grey et al., 2006). Xu, Toobert, Savage, Pen and Whitmer (2008) found that provider relationships may have positive effects on patient self-management and may lead to better adoption of disease management programs. The authors also concluded that communication between provider and patients may influence patients in building their knowledge and beliefs about treatment and confidence in the management of their diabetes (Xu et al., 2008).

A range of community- and peer-based strategies have been recognised as important environmental mechanisms that influence patient self-management. Examples are the use of coaches to help individuals identify available resources and community based groups or local government representatives to develop resources such as walking paths and advocacy campaigns (Fisher et al., 2005).

3.2. Approaches to Chronic Disease Self-management

A broad range of self-management models has been developed and implemented nationally and internationally (Department of Health Victoria, 2008). The Stanford chronic disease self-management program, also known as the Lorig course as noted above, was developed in the 1990s at Stanford University. The program was initially developed for arthritis self-management and extended across different chronic diseases. The program has a structured content and includes a six week group based course for 10-15 patients (Department of Health Victoria, 2008). Since the program is based on group intervention, it is considered effective in reducing isolation and therefore facilitating self-efficacy. It was also proposed that self-efficacy of participants would improve thorough peer learning and sharing. The program offers strong goal setting and problem solving skills.

There are, however, limitations associated with this model of self-management (The Australasian Society for HIV Medicine, 2009). Since the capacity of a group environment is limited, it is not possible to address individual barriers. The program content is pre-structured and has restricted flexibility for participants who have different learning needs, styles and speeds. Furthermore, the program is very time limited and participants often seek further support after completing the course (Department of Health Victoria, 2008). The Stanford model has also been found to have no to a small effect on outcomes such as pain, depression and disability (Nolte et al., 2012). Indeed, the Stanford model is not applicable to the current research because in this study participants will use the web-based application individually, at home, or in a workplace. This will allow participants to review the educational materials based on their learning needs which suggests greater flexibility than evident in the Lorig course. In addition and while this may not reduce the sense of isolation among participants, it could encourage family members to be involved in the self-management process.

A further approach to augment self-management for patients with chronic disease is the 1990s Flinders University model developed by Battersby and colleagues (Department of Health Victoria, 2008). This model provides a set of tools and processes that enables clinicians to undertake a structured process for specific disease management. The assessment tools are based on self-managing behaviours, collaborative identification of problems and goal setting and can be applied for any chronic disease to develop individualised care plans (Flinders University, 2014, Para. 2).

The model is based on six internationally recognised principles for effective self-management. These principles are (i) knowledge of one’s condition; (ii) following a treatment plan agreed with health professionals; (iii) actively sharing decision making with health professionals; (iv) monitoring and managing signs and symptoms of ones’ condition, (v) managing the impact of the condition on ones’ physical, emotional, and social life, and (vi) adopting a healthy lifestyle (Smith, Hirschmann, Iobst, & Battersby, 2006).

The Flinders model seeks to improve relationships between clients and health professionals through collaboration in identifying problems, targeting interventions, becoming motivational, and allowing for measurements over time. This model in the original format, however, may not be appropriate for all people with chronic diseases as some patients may not be ready for change and may find the program confronting. In addition, the Flinders model is time intensive when implemented as originally conceived. A further characteristic of the model is that, while placing emphasis on collaboration, it is driven by health care professionals and not patients (The Australasian Society for HIV Medicine, 2009).

The Flinders model was applied by Lawn, Battersby, Harvey, Pols, and Ackland (2009) in research that sought to improve self-management in Aboriginal patients with type 2 diabetes. The result was a significant reduction in average HbA_{1c} over 12 months and an overall reduction of complications. The program consisted of a comprehensive patient self-management assessment, development of an agreed upon 12 month care plan including monitoring (blood glucose, blood pressure and lipids), self-management education and goal setting with follow-up appointments. A similar study by Smith et al. (2006) resulted in an improvement of patients’ sense of well-being and health status. In turning to the current research question and aims, some principles underpinning the Flinders model do fit including the provision of educational materials to HF patients; assessment of patient knowledge and self-management skills; following a treatment plan and daily monitoring of HF sign and symptoms; and adopting the healthy lifestyle.

Motivational interviewing (MI) is a third model which may be applied in chronic disease self-management. It was developed by William R. Miller in the early 1980s as a result of his experience in the treatment of people addicted to alcohol (Konkle-Parker, 2001). MI is a collaborative, person- centred motivational process, which seeks to explore and resolve an ambivalence to facilitate change (Konkle-Parker, 2001). In MI, health care providers utilise five basic principles including expressing empathy, eliciting personal goals, avoiding confrontation with non-adherence behaviour, allowing a person to take responsibility, and supporting self-efficacy (Konkle-Parker, 2001). The MI differs from the aforementioned models in terms of flexibility and can be applied to many fields of work and modes of health care intervention. Furthermore, it appears to be an appropriate model for patients who are at different stages of readiness and is argued to be more effective than advice or skills training in facilitating change (Rollnick, Heather, & Bell, 1992). The limitation of this model is that it does not provide a formal structure and therefore clinicians without a counselling background may struggle to develop confidence in their ability to motivate patients (Department of Health Victoria, 2008). MI is not the self-management model selected for this research as it is based on in-depth interviewing which sits outside the research design.

Health Coaching Australia (HCA), as an emerging self-management model, is a method by which health care practitioners work with patients and assist them to make and maintain behavioural changes that lead to improved health outcomes (Gale, 2008). The model utilises a number of principles and techniques from different fields such as psychology and counselling (Rollnick, Mason, & Butler, 1999). According to Gale (2008), it is required that health care professionals gain a number of skills to work effectively with their clients. These are (i) medical conditions and adherence knowledge; (ii) behaviour change interviewing techniques; (iii) knowledge on psychological theory of health behaviour change; and (iv) behaviour modification, cognitive change and emotion management techniques (Gale, 2008). The HCA model is an evidenced-based model underpinned by MI and cognitive behavioural approaches. The model is highly flexible and is appropriate for patients with different stages of readiness. Yet, as is the case with MI, here health-care professionals may struggle to gain confidence in engaging with the complexities of this model (Department of Health Victoria, 2008). Again, emphasis on interviewing techniques and performing interviews situates this model outside the scope of the current research.

Following the above review of the most frequently applied models around the broad area of patient self-management, the next section will focus on reviewing self-efficacy theory and its application in research.

3.3. Theory of Self-efficacy

It is evident from literature review that a great deal of emphasis is placed on self-efficacy (SE) in both self-management interventions as well as developing models. Hence, to develop an appropriate model for this study, it is imperative to understand SE theory. The concept of SE lies at the centre of Bandura’s social cognitive theory (SCT) and was first employed with the objective of altering fearful and avoidance behaviour of people with snake phobia (Bandura, 1997).

More broadly, there is a robust presence in the literature that supports the concept of self-efficacy. Studies in fields and settings cover an expansive area including clinical and psychosocial problems (depression, phobias, stress related concerns and addictions), coping with haemodialysis, eating behaviours, and recovery from heart disease (Akpanudo, Price, Jordan, Khuder, & Price, 2009; Lau-Walker, 2004; Zrinyi et al., 2003). It has been determined that the effective use of SE theory enhances personal adjustment and adoption to situations (Shell, Newman, & Fang, 2010; Shi, Ostwald, & Wang, 2010). Furthermore, research findings suggest that SE can be measured both generally and specifically for behaviours such as alcohol consumption and glycaemic control (Shell et al., 2010).

Bandura initially defined self-efficacy as “the conviction that one can successfully execute the behaviour required to produce the outcome” (Bandura, Adams, & Beyer, 1977). This definition has been further expanded to individuals’ “beliefs about their abilities to exercise control over events that affect their lives” (Bandura, 1989) and “beliefs in their capabilities to mobilize the motivation, cognitive resources, and courses of action needed to exercise control over task demands” (Bandura, 1990). Because SE is related to the attitudes, abilities, and cognitive skills of a person it therefore varies from person to person (Bandura, 1977).

One’s level of SE has a great effect on how one perceives situations and responds to different circumstances. More specifically, it is proposed that an increase in SE improves skills for understanding tasks, constructing and evaluating the course of actions, setting proximal goals, and motivating to be engaged in activities (Bandura, 2006). There are two cognitive components that characterise SE; efficacy expectations and outcome expectations (Bandura et al., 1977; 1982). The influence of the combination of these components on behaviour is integral to successful outcomes. In other words, both confidence in ability (efficacy expectation) and the belief that behaviour results in success (outcome expectation) are required for achieving outcomes (Bandura, 1982).

Efficacy expectation is defined as an individual's judgment of their capabilities to perform a task that requires a course of action (Bandura, 1986, p. 391). Individual efficacy expectations also vary depending on situations. For instance, a person may judge him/herself quite competent in one area and less competent in another (Bandura, 1986). For Bandura (1986), this reflected the judgement of people as opposed to their skills. People's judgment, in turn, is related to experience and affected by three factors including level (magnitude), strength and generality of efficacy belief. Magnitude relates to task difficulty. Strength is described as a person's faith to complete a task and generality defines how experience of SE can be generalised from a previous task to new challenges (Bandura, 1977; Bandura 1986). Thus, Bandura (1989) defined outcome expectation as a personal judgement about the results of enacting behaviour and whether the behaviour would produce the desired outcome. Yet, while efficacy and outcome expectation are two significant factors that predict behaviour, efficacy expectation has a higher force in the process than outcome expectation (Bandura, 1986).

In some circumstances, there is no association between efficacy and outcome expectations. This occurs when it is anticipated that an action will not result in a specific outcome or where the outcome is loosely linked to the level or quality of the performance (Bandura, 1986). Nonetheless, both efficacy and outcome expectations have been implemented in attempts to change behaviours including the performance of functional activities (Galic, Pretzer-Aboff, & Resnick, 2011; Resnick & D`ADamo, 2011; Resnick, 2002), adoption and maintenance of exercise behaviour (Chase, 2011; Grim, Hortz, & Petosa, 2011), and hip fracture prevention behaviour (Nahm et al., 2010). Bandura (1977) also argued the multifaceted nature of SE in proposing four influencing factors: mastery experience, role modelling, social (verbal) persuasion, and emotional states in judging one’s capabilities.

The first is mastery experience (performance accomplishments) which refers to the successful experience of performing a task. Mastery develops and is achievable by learning through personal experience (Bandura, 1977). When a person becomes successful in performing a difficult or previously feared task, SE will increase. Mastery experience is considered the most effective factor influencing SE (Bandura, 2006) and is also the most common intervention designed to strengthen efficacy expectations in older adults (Smith & Liehr, 2013, p. 201). To increase SE through mastery experience, one is engaged with a behaviour or task and through such engagement one will develop and refine skills. In addition, it enhances the coping mechanisms to deal with problems encountered (Bandura, 2006). If mastery is to be achieved it means that the learner will have been educated adequately and in-depth about the content of that which is to be mastered (Bandura, 1977).Other factors may also influence the cognitive appraisal of SE including perceived difficulty of the task, the amount of effort expanded, the external aid received, the situational circumstances and the past successes and failures (Smith & Liehr, 2013, p. 202).

Second is role modelling (vicarious experience) where a learning experience occurs through modelling and/or observation of events (Strecher, DeVellis, Becker, & Rosenstock, 1986). The models display a set of behaviours that illustrate a certain principle, rule or response. For example, if a character in a TV drama has a myocardial infarction during or immediately after physical exercise, this may affect a person who feels vulnerable to a heart attack (Strecher et al., 1986). As a result he/she may be afraid to exercise as a direct result of watching the TV program. Another example is a person who wants to lose weight but observes a friend’s difficulty in controlling food intake. This person may then come to the conclusion that he/she will not be able to adhere to any form of weight control.

Conversely, observing a successful model who has overcome a difficult task can enhance a person’s expectations of mastery (Bandura, 1977). An effective model in this context must be viewed as a person who overcame barriers through a determined effort rather than with ease (Bandura, 1977). The role modelling is influenced by a number of conditions. For instance, if a person has not been exposed to the behaviour or has had minor exposure with it, role modelling is likely to have a greater impact. This also occurs when clear guidelines for performance have not been elucidated (Smith & Liehr, 2013, p. 202).

The third factor is verbal persuasion which is an easy and available method and has been widely used in education and also by health care providers (Strecher et al., 1986). Furthermore, there is evidence that verbal persuasion is effective in supporting recovery from chronic illness (Smith & Liehr, 2013, p. 203). Persuading people through verbal suggestion helps them to believe they can cope successfully with a specific task that has overwhelmed them in the past (Bandura, 2006). It is argued that verbal persuasion will increase SE through effective communication and feedback to guide a person through the task or to motivate them to make their best effort (Strecher et al., 1986). This factor is likely to be weaker than other SE sources (Bandura, 1977).

Emotional state (physiological feedback) is the fourth factor that shapes judgement of one’s abilities. It is considered that people are more likely to experience failure when they are very tense and agitated. For example, those who experience severe anxiety prior to talking publically find that their SE decreases (Bandura, 2006). Similarly, if a HF patient has a fear of a cardiac event when walking, a highly emotional state associated with that fear may affect performance and decrease confidence in the ability to perform the activity. Physiological indicators play a significant role in coping with stressors, physical accomplishments and health functioning. Thus interventions can be implemented to adjust individual physiological feedback to help people cope with physical sensations and in turn SE will be enhanced and performance improved. The proposed interventions are visualised mastery to eliminate emotional reaction to a given situation (Bandura et al., 1977), enhancement of physical status (Smith & Liehr, 2013, p. 202), and altering the interpretation of bodily states (Li, Fisher, Harmer, & McAuley, 2005; Schnoll et al., 2011).

Helping adults to improve their SE is a powerful and persistence factor in increasing competence (Strecher et al., 1986). Patients with more SE are more willing to learn and commit to achieving goals. People with low SE are more likely to avoid performing a task (Bandura, 2006).

Nonetheless, there has been some criticism of SE theory. Lee (1989), early on, argued that SE suffered from lack of a scientific basis and clarity. Furthermore, Lee claimed that the only reason for using SE was that it was simple and well known. The author proposed that, as in a range of cognitive models of behaviour, SE theory was based on undefined and unobservable variables that could not be measured (Lee, 1989). Yet, Bandura has consistently responded to criticism by arguing that the theory identifies a casual mechanism (self-efficacy) which is the proximal determinant of both the initiation of and persistence with behaviour (Bandura, 1984; Bandura, 1986). There are also perceived problems with variables that interact with SE. For instance, Bandura argued that efficacy expectations are influenced by skills and incentives (Lee, 1989). However, there is no framework to specify how efficacy expectations interact with these variables (Lee, 1989).

Although SE allows for the prediction of behaviour with a fair degree of accuracy, at the level of analysis it simply provides a description, rather than an explanation, of behaviour change (Lee, 1989). Finally, although the SE model has advantages compared with other less complex models of behaviour it is necessary and legitimate to infer the existence of unobservable processes that produce human behaviours (Mahoney, 1974).

In addressing the point above, Tryon (1981) criticised Bandura for being unaware or ignorant about the susceptibility of behavioural approach tests to social contexts. Although Bandura allowed for the possibility that other mediators may affect the result of SE theory, he omitted any possible effects of alternative factors, such as social reinforcement contingencies (Tryon, 1981). This issue has been reported by Bernstein and Nietzel (1973) who found that subjects avoided phobic objects much more in a clinical situation than in an experimental context unrelated to fear assessment. Tryon (1981) thus argued that to accept SE theory, it was crucial to address this methodological problem. To solve this issue and to control the impact of social context on SE, it was asserted that the effects of social demand on theoretical predictors must be minimised by experimental conditions and by separating the assessment of efficacy expectations from the evaluation of performance (Tryon, 1981).

Further to the above criticisms, Eastman and Marzillier (1984) argued that SE theory did not provide a clear conceptual distinction between the two expectancies. In addition, these authors disputed that the SE is influenced by definition and elements of outcome rather than efficacy expectancies. Bandura (1984) responded by insisting that efficacy expectations and outcome expectations are conceptually distinct and that the types of outcomes people anticipate are influenced strongly by self-efficacy expectancies. Maddux and Stanley (1986) agreed that efficacy and outcome expectancies are distinguishable and may have a significant effect on behaviour. Eastman and Marzillier (1984), however, countered this point in suggesting that although SE oversimplifies the variables involved in behaviour change, Bandura had failed to credit the importance of outcome expectancies in his analysis. Bandura treated his patients by assessing their behavioural and cognitive measures tied to discrete and circumscribed tasks (Eastman & Marzillier, 1984).

Yeo and Neal (2013) argued that Bandura identified a number of requirements for the test of social cognitive theory (SCT). Nonetheless, he omitted one important condition that any empirical test of a theory must be conducted at the appropriate level of analysis. Meta-analyses and the majority of primary studies that were performed to test the SCT were at the between-person level and did not provide a complete picture of self-efficacy’s role in self-regulation (Yeo & Neal, 2013). Although between-person research consistently showed a positive association between SE and performance, research focused on within- person found that SE can be negatively associated with performance (Lord, Diefendorff, Schmidt, & Hall, 2010). Yeo and Neal (2013) proposed that aggregating within-person to between-person level during analysis may mask the true effects of within-person. Analysing the between person is appropriate to address research questions that relate to statistic differences between individuals. For instance, the concept of between-person has been used by Bandura to examine whether individuals with higher self-efficacy were more likely to overcome phobias than those with low self-efficacy (Yeo & Neal, 2013). The authors also argued that the between-person level cannot relate changes in SE within an individual to subsequent changes in performance (Yeo & Neal, 2013).

Previous research criticised SE theory for a number of reasons including lack of scientific basis and clarity, not providing a clear conceptual distinction between the two expectancies, and being based on undefined and unobservable variables that could not be measured. Nonetheless, it is considered a legitimate approach to the enhancement of patient outcomes. This has been evidenced in the breadth of research undertaken over a number of decades (Clark & Dodge, 1999; Flynn et al., 2005; Holman & Lorig 1992; Lorig et al., 2010; Markes, Allegrante, & Lorig, 2005; Oberg, Bradley, Allen, & McCrory, 2011; Rosal et al., 2011; Schweitzer, Head, & Dwyer, 2007; Tsay & Chao, 2002).

3.4. The Significance of Self-efficacy in Patients with Heart Failure

Like other clinical and psychosocial problems, behaviour of patients with heart disease can be predicted using SE theory (Borsody, Courtney, Taylor, & Jairath, 1999). The evidence has indicated that SE provides an optimistic view that helps improve people’s behaviour. Furthermore, it has been shown that SE has a strong influence on HF patient behaviour in developing self-management skills and overcoming obstacles (Borsody et al., 1999; Carlson, Riegel, & Moser, 2001; Du, Everett, Newton, Salmonson, & Davidson, 2011; Ni et al., 1999). Borsody et al. (1999) found that nurses could enhance HF patients' physical activity through four major sources of SE including mastery experience, social modelling, verbal persuasion and physical and emotional status. It has also been demonstrated that patient health related outcomes are affected by their perceived SE as observed even in patients with the same level of physical and pathological issues (Allen, Becker, & Swank, 1990; Holman & Lorig, 1992; Schweitzer et al., 2007). Rohrbaugh et al. (2004) showed that HF patients who had a higher level of SE managed their condition better in performing daily tasks such as weighing themselves, doing physical activity and avoiding salt. In other words, patients who had little or no self-efficacy performed poorly because they did not believe they could make a difference. Thus a considerable body of research has confirmed a significant correlation between self-efficacy and patient related outcomes (Clark & Dodge, 1999; Flynn et al., 2005; Holman & Lorig, 1992; Markes et al., 2005; Schweitzer et al., 2007; Tsay & Chao 2002).

3.5. The Study Conceptual Framework

The following discussion addresses the rationale and assumptions of the model applied in this study and specifically, the Flinders self-management model and Bandura's self-efficacy theory as it underpins the model. Bandura's work has been chosen for a number of reasons. One is that SE has been applied as the underpinning theoretical framework in many studies that have sought to promote self-management in patients with chronic disease. A further reason is that it provides the basis for the majority of self-management models that have been developed to this point. Finally, SE appears to be good fit with the aims of this study. In this research, three principles of SE including mastery experience, role modelling and verbal persuasion were employed.

Role modelling through education is particularly effective for increasing self-efficacy. It involves observing the effects of the actions of others in situations and may come from many sources such as peers, family and professional (Williams & Bond, 2002). In this research, it is proposed that by providing education using a web-based application, patients will be exposed to an audio-visual model. This model will help those participating to use the web-based materials as a role model for response situations that they may experience as a result of the HF condition.

Mastery experience is the most important source of information for self-efficacy. Lorig and Holman (2003) stated that achieving personal mastery through experience requires individual awareness of health problems. Hence, assisting patients to become more aware of their conditions is essential. Self-monitoring is another factor that influences mastery experience. Self-monitoring helps people to achieve self-awareness and can act as a positive reinforcement for behaviour. Because of this reinforcement, performance will improve (Bandura, 1986). Hence, it was anticipated that daily monitoring of HF signs and symptoms via the web-based application would help patients to recognise changes in their conditions, increase their awareness and become masters.

Social persuasion is a method to increase personal self-efficacy (Bandura, 2006). Social or verbal persuasion can be achieved by face-to-face visits, phone calls or discussion forum (Lorig & Fries, 2006). For instance, it was found that verbal encouragement through telephone calls resulted in increased physical activity among older adults (King et al., 2007; Skinner et al., 2011). Furthermore, encouragement through computer programs was effective in improving participant health behaviours related to unintended pregnancy and infectious diseases (Swartz et al., 2011). In the current study, the intent was to motivate patients to review the web-based materials and monitor their daily symptoms behaviours related to self-management through verbal persuasion.

The conceptual framework of this study has been informed by the Flinders model in four dimensions. The approach was individualised, it promoted a person centre focus, it utilised a number of self-management assessment tools, and it provided health-care providers a scripted process for delivering patient-centre care. The self-management model of the study consisted of five steps; holding a face to face educational session with HF patients; assessing patient HF knowledge, self-management skills and self-efficacy; making an agreement with patients to review the web-based materials and perform daily monitoring for the period of four weeks; repeating the assessment phase following the intervention (after four weeks); and encouraging patients to use the web-based application and reduce possible barriers associated with the use of application through email communication.

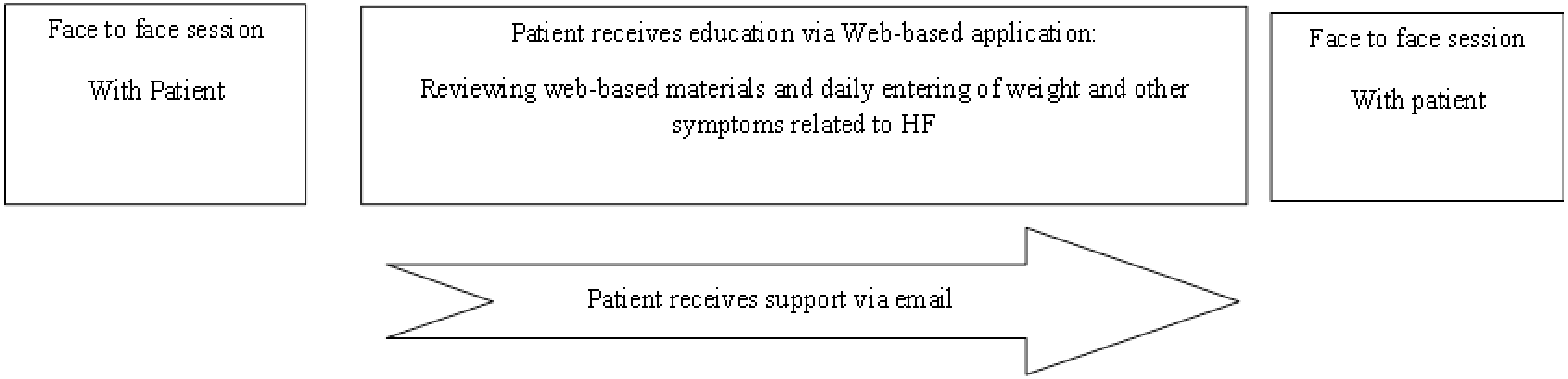

Figure 3.1 Study Procedure

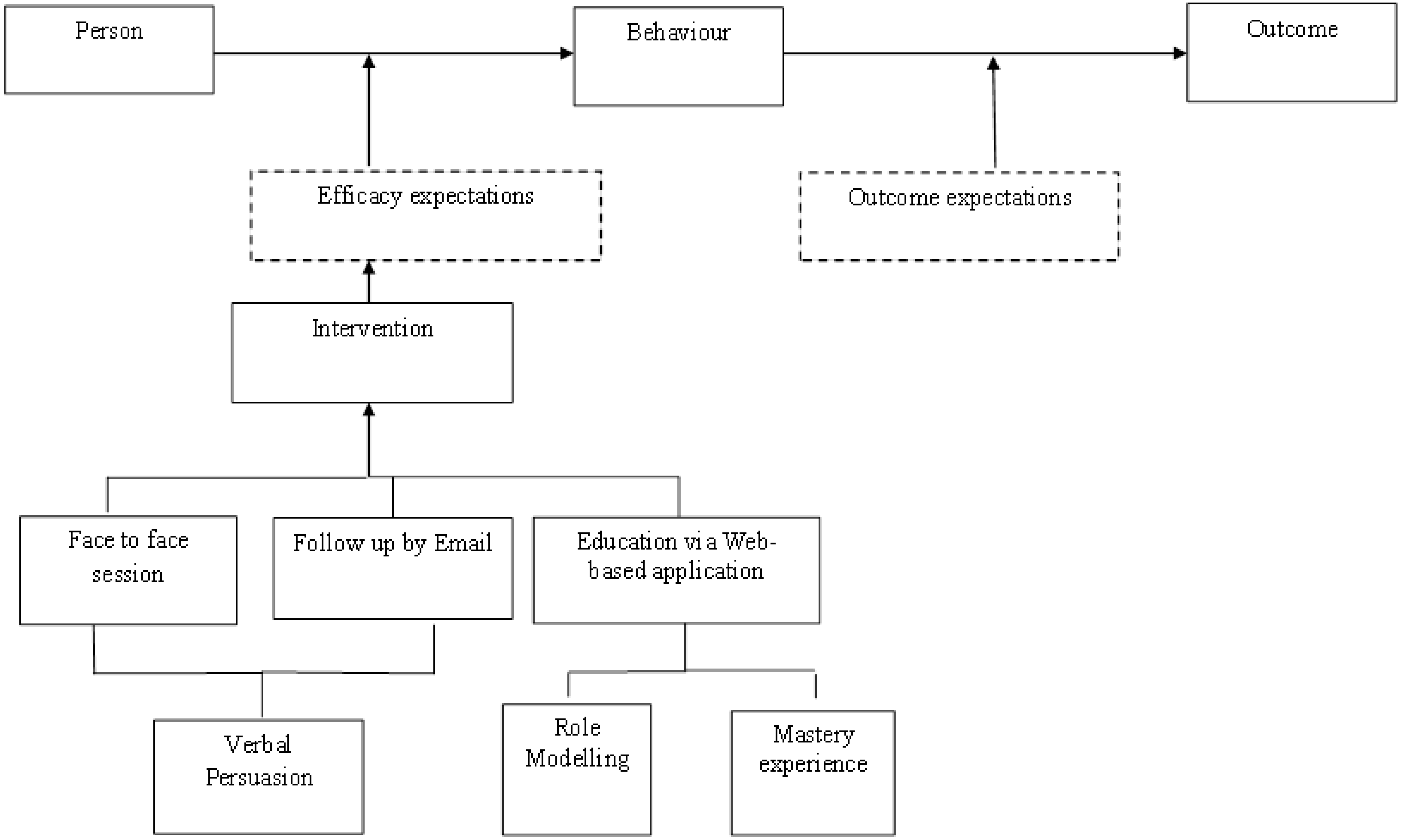

Figure 3.2 Study Model

3.6. Conclusion

In this chapter and in developing the conceptual framework for this pilot study the concept of self-management and its constituent factors were explored. Common self-management models including the Stanford model, the Flinders model, motivational interviewing and health coaching were reviewed and assessed in terms of the scope of the current study. The Flinders self-management model was considered to be the most appropriate for addressing the research aims and objectives. In particular, the study framework was informed by the Flinders approach because the model was individualised and provided the opportunity to utilise multiple self-management tools. While the Flinders model provided key concepts, the underpinning theoretical tools were drawn from the self-efficacy work of Bandura. In justifying Bandura’s self-efficacy theory as the guiding principle the chapter addressed the three constituent components of role modelling, mastery experience and verbal persuasion. Each component was explained as it informed the web based self-management intervention. The following chapter builds on the methodology in describing and justifying in detail the process and the methods that were applied in this study.

Chapter 4: Methodology

4.1. Introduction

The review of the literature identified a lack of educational web-based self-management interventions for HF patients (Evangelista et al., 2006; Tomita et al., 2009). This chapter consists of two phases. The first phase provides information on the development of an educational web-based application and includes assessment of heart failure knowledge and self-management skills using pre and post-test analysis. The second phase presents the methodology used to examine feasibility of the proposed web-based self-management intervention in improving knowledge, self-management and self-efficacy of HF patients.

4.2. Phase one: Developing a Web-based Application

The web-based application pedagogical principals were based on two key elements of the self-efficacy theory; role modelling and mastery experience. Role modelling through observing others actions is considered effective in increasing self-efficacy (Bandura, 2006). Female or male avatars were created to resemble role models and to help users engage with educational materials. Mastery experience was implemented by asking participants to monitor and record their signs and symptoms related to HF fluid overload. A further source of self-efficacy, verbal persuasion, was applied in the self-management intervention through weekly email reminders.

In this study, the Flinders model of self-management was used to implement the web-based self-management intervention. The model was chosen because it is individualised and patient centred. In addition, a number of self-management assessment tools can be applied in conjunction with the Flinders model and the model guides health-care providers in delivering patient-centre care.

The web-based intervention was developed based on feedback from three groups including HF experts, an IT team and HF patients. The HF expert panel consisted of two cardiologists, four cardiac nurse researchers and one HF nurse practitioner. The role of this panel was to ensure the integrity of the educational content according to evidence based guidelines, applicability of psychometric tools, and the use of appropriate language and images. The web-based application software was developed by an IT team. The IT team also provided feedback on how to store and retrieve data from databases and the web-based application security. A sample of five HF patients provided their feedback and recommendations on the application content, ease of navigation, and user friendliness.

The web-based educational materials were drawn from the National Heart Foundation and The Cardiac Society of Australia and New Zealand's (2011) guidelines on the detection, prevention and management of heart failure in Australia. HF experts provided their feedback by email to the open-ended question: *Overall what did you think about the web-based application? Please provide your comments*. Similarly, to gain feedback and recommendations, a group of five HF patients were asked to answer the same question, following review of the web-based application. After receiving feedback and recommendations from the stakeholders on the first draft of the web-based application, instructions were prepared for the IT team to develop the second draft of the web-based application. The aforementioned procedures were repeated for the second draft of the web-based application. Feedback on the first and the second drafts was received in April and October 2012, respectively. Other than feedback from HF panel and patients there were no other face and content validity measures.

The aim of this web-based intervention was to improve participant knowledge and self-management. To increase participant HF knowledge, the application consists of written materials, video clips and images.

Due to scope of the pilot project and the limited budget, it was not possible to address all key materials and tools within the proposed web-based self-management intervention. Hence, it was decided to prioritise items and include only essential tools and materials. This was also compatible with the nature of the pilot study and it was understood that the study findings might indicate a need for modification and extension of the existing elements and tools.

For mastery, self-monitoring is argued to be an effective method and helps people to achieve self-awareness (Bandura, 1986). Hence, a section was developed for patients to enter their daily weight and signs and symptoms of fluid overload. It was assumed that the monitoring of these factors may enhance mastery and self-management of the HF condition.

The web-based application was password protected and both health care professionals and HF patients could register to use the web-based materials. The content included interactive HF teaching tools, self-mangement tools, a chart for recording daily measures and self-management questionnaires.

Teaching tools*:* This section consisted of educational topics including an HF definition (with animations), HF signs and symptoms, instructions for daily weighing, fat and fluid differentiation, suggestions for healthy eating and being active, methods to avoid salty foods and tips for reading food lables, and taking appropriate action when symptoms were exacerbated.

Self-management tools: In this section HF patients could enter daily symptoms related to their condition including daily weight and any indications of fluid retention which may be observed through tightness of belt, shoes, or socks.

My chart: This tool allowed patient to visually monitor their daily weight and severity of other HF symptoms through a simple graph. In addition, health care professionals were able to monitor their patients' daily symptoms by accessing their charts.

Self-management questionnaires: The final section was designed to help healthcare providers to perform multiple assessments of patients' knowledge and self-management skills over time. It included questionnaires such as the self-care HF index and HF knowledge.

4.2.1. Feedback from Heart Failure Expert panel

The heart failure expert panel provided a number of feedback comments and recommendations. Some examples are as follows.

Background colours of the web-pages

It was suggested that soft colours be used, a preferably white background and gender preferences in background colours be avoided. Comments received from HF panel were:

- *Change pink background (which traditionally is used more for females) to be more non-gender specific.*

- *Use white background*

- *Soften background colours to pastel.*

Health literacy

Health literacy of the educational materials was the next code that was addressed. Many words appearing within the educational materials were not considered appropriate for patients with low literacy. The following comments were received from the HF panel:

- *I would prefer "Systolic blood pressure" to "Blood Pressure Upper Limit" and "Diastolic blood pressure" to "Blood Pressure Lower Limit.*

- *Should you say tight belt or need to increase belt size?*

Measuring Units

Another issue that was identified by the HF panel was incompatibility of the measuring units used in the web-based application with Australian standards. For instance it was suggested that:

> *I would put the weight in kg (rather than grams) and put pounds in brackets. It would be nice to be consistent with our current guidelines. We said more than 2 kg in 2 days, but not sure if that helps.*

Medical Terms

A further point raised by the HF panel was to avoid medical terms6 in educational materials. For example:

- *Do you actually need to say dyspnoea, etc? Also, should say, breathless when lying down when you describe orthopnoea.*

- *It is recommended that you not use words such as dyspnea and Orthopnea as these are medical terms.*

Font size

Using a larger font size was recommended by the HF panel as stated in the following sentence:

- *Larger font for all questions and fill entire page with max 4 questions per page*.

Images and video clips

The HF panel recommended incorporating more pictures in the educational materials: *Use an Avatar or picture on every page*

- *Use more pictures to clearly visualise the intended messages.*

The other issue related to images was lack of cultural diversity. As an example, it was noted:

- *Recommend change to reflect a variety of ethnic/cultural backgrounds to reflect the project.*

Since the application restarted after watching a video link, many comments were directed to this issue:

- *Fix all video links to return to page after completion.*

- *It seems frustrating to start from beginning following watching video clips.*

4.2.2. Feedback from IT Team

The comments from the IT team have been categorised and outlined under the following topics:

Organising information

- *A plan is needed for the order in which the educational materials should be presented.*
- *How sections should be navigated?*

Information was not categorised and there were no connections between elements of the educational content. Hence, the navigation process was difficult to build. For ease of access, it was important to identify how, when and under which circumstances a particular piece of information or topics needed to be displayed.

Data security

- *Which level of data security is required for the web application?*
- *Do users need to have username and password?*
- *Who will access the data?*

To ensure security of the web-based application and to separate data entry among patients and health care providers it was essential to build a secure gateway. These demanded the use of a user name and password interface. Since the majority of HF patients are elderly and may not be able to remember the username and password and traditional password retrieval was difficult for them to proceed, it was decided to give permission to healthcare providers to reset passwords of their own patients. In other words, a nurse could only change password or review data related to his/her patients. As a result, data could only be accessed by the researcher, authorised health care provider and the patient. Authorisation was only granted by the web-based administration.

Data storage

How the data needs to be stored and retrieved from the website?

Another important issue was to ensure that the data cannot be accessed by unauthorised person. Hence, patient information was encrypted. There were two types of data stored in the web-based application including questionnaires and patient date entry related to HF signs and symptoms. Data related to questionnaires only could be retrieved by researcher and data entered by patients could be reviewed by the nurse or researcher who assigned the user name and password.

4.2.3. Feedback from Patients

Patients commented that animations are an appropriate tool for learning new materials. Furthermore, using buttons for answering questions and navigating through the web pages was an attractive feature. In general, their comments were:

- *Heart failure animation clearly explains heart in failure.*
- *I can now understand heart failure better.*
- *Touch screen buttons are interesting.*
- *I had fun to touch the answers in iPad.*

Two patients expressed that some sections in the educational materials did not present enough information. Their comments are as follows:

- *Adhere to low salt diet", is not giving enough information how to adhere to law salt diet and how many grams is sodium intake for heart failure patients.*

- *The following message "exercise as prescribed", is not giving enough information how to exercise or which type of physical activity is appropriate for HF Patients. Do we need to do specific exercise or attend gym?*

The addition of sections

HF patients requested that new sections be added to the web-based application with a focus on food recipes and online chat. They stated that:

- *Can you provide food recipes for us?*

- *Is it possible to have an online chat to ask our questions?*

4.3. Participants

Patients with a clinical diagnosis of HF were invited to participate in this first research phase at the time of their scheduled clinic appointment by their nurse practitioner. If patients agreed to participate, they were asked to sign an informed consent. For this step of the study, purposive sampling was used to identify patients with a range of patient characteristics including sex, age, and years with HF. Thus purposeful sampling allowed for the selection of the participants who had the capacity to provide relevant information required for the study.

4.3.1. Inclusion and Exclusion Criteria

For participation in the preliminary phase of the study the inclusion criteria were having been diagnosed with HF by cardiologists as Class I-III according to the New York Heart Association, greater than or equal to18 years old, interested in IT, and able to give time to participate in research. Exclusion criteria for this phase were living in a nursing home or institution (as these groups of patients generally do not self-care), aged less than 18 years, severe cognitive deficits; serious life-limiting co-morbidity, and/or limited or no English language skills.

4.3.2. Study Setting and Procedure

The web-based application pre-testing was conducted at an outpatient heart failure service at Ipswich Community Health, Queensland, Australia. Prior to recruitment, information sheets (***Appendix H***) were distributed to HF patients by a nurse practitioner. Eligible patients were then introduced to the researcher. Ten primarily English speaking HF patients were recruited. The first group of five patients provided their feedback and recommendations on the design and development of the web-based application by answering the open ended question and a satisfaction survey. The second group of patients was recruited to test the web-based application and to complete questionnaires for measuring HF knowledge and self-management skills. The researcher explained the purpose of the research, the procedures and the time required for reviewing the web-based application and obtained consent prior to commencing data collection. The time required for reviewing the web-based application, completion of surveys and providing feedback was approximately one hour. When patients were accompanied by family members, the latter were also invited to provide their opinions on the web-based application educational contents.

4.4. Instruments

Heart Failure Knowledge

The heart failure knowledge questionnaire (Caldwell, Peters, & Dracup, 2005) was developed based on the previous questionnaire used in the Rapid Early Action for Coronary Treatment (REACT) study in acute MI patients (Simons-Morton et al., 1998). The scale was then modified by Caldwell et al. (2005) and consisted of 20 items that examined HF knowledge, HF sign and symptoms, and reasons for not seeking care. The scale had a minimum score of 0 and a maximum of 20. The internal consistency of this modified questionnaire was reported as 0.83 (Caldwell et al., 2005).

Self-care Heart Failure Index

Self-management skills of participants after receiving education via the web-based application were assessed using the Self-care Heart Failure Index (SCHFI) version six (Riegel, Carlson, & Glaser, 2000). The SCHFI evaluated patient self-management skills through three subscales of self-care including: maintenance, management and confidence. Each subscale had a score of minimum 0 and maximum 100. A score of 70 or more determined adequate self-care. The SCHFI was a valid and reliable tool with internal consistency of 0.76 (Riegel, Moser, Sebern, Hicks, & Roland, 2004).

4.5. Results

The web-based application was developed based on feedback from the HF expert panel and patients. Participants and panel members perceived appropriate the educational content. In this phase of the study, ten HF patients (eight male and two female patients) were involved. The first group of five patients provided feedback on the design and development of the web-based application and the second group was asked to answer a set of questionnaires before and after reviewing the web-based materials. The time required for entering participant data to the SPSS version 19.0 was one day and there were no missing data in this phase of the study.

Patients involved in this study were between 45 and 70 years old with an average age of 60.4 years. Seven were born in Australia and the rest were born in other countries. Five patients were married, two were widowed, one was divorced, and the remainder did not provide information on marital status. While eight patients stated that they were non-smokers or had previously quitted smoking, one patient was smoking 25 cigarettes per day and one patient did not state his/her smoking status. Among the participants for this study, four were non-alcohol consumers and three had previously ceased consuming alcohol. Only one patient was an alcohol consumer (one or two glasses a week) at the time of recruitment. Information on patients' health status was derived from patient records. Based on the available records, only two patients involved in this research phase were diagnosed with HF during 2011-12. The weights of patients involved in this study varied between 51.7 Kg and 146 Kg. The ejection fraction (EF) of patients was between 20% and 63.9% with an average of 37.3%.

The HF knowledge mean score pre intervention was 14.00 ± 3.08 and post intervention score was 15.40 ± 0.89. The mean score for all subscales of SCHFI showed a positive improvement from pre to post intervention. The results indicated that the mean score for section A (self-care maintenance) of HF self-care index was 62.66 ± 16.78 pre and 67.99 ± 19.16 post intervention. The mean score for section B (management) of HF self-care index was 62.50 ± 17.50 pre and 70.00 ± 10.00 post intervention. The mean score for section C (confidence) of HF self-care index was 52.00 ± 7.67 pre and 70.00 ± 21.12 post intervention.

4.6. Discussion

During the phase one of the study, the key components for developing the web-based application for educating HF patients were identified. The application user-friendliness and the appropriateness of study instruments were also evaluated in the phase one. The web-based application provides basic information that may help HF patient to self-manage their condition. The application covers topics such as weight management, fluid management and monitoring HF signs and symptoms. The aim of the application was to provide self-management information in an interactive and engaging form and to improve patient knowledge and self-management related to HF.

The objective of phase one was also to prepare the newly developed web-based application for the pilot feasibility study. The results showed changes in mean scores and provided baseline data to calculate a required sample size for the next phase. In this study, patients demonstrated 10% improvement in knowledge scores after reviewing the web-based application. The scores of participants were also improved for each scale of the self-care HF index including maintenance (8.5%), management (12%) and confidence (34.6%).

Due to difficulties associated with the recruitment of HF patients, a limited number of patients were recruited for preliminary testing of the capacity of the web-based application to improve HF knowledge and self-management skills. Time constraints have been identified as a main barrier in this phase. A further limitation of this phase was that patients' HF knowledge and self-management skills were examined immediately following the review of the application without a follow up period. Hence, to determine whether or not the use of the web-based intervention was feasible for HF patients, a controlled intervention study with an appropriate sample size and sufficient follow up time was needed.

The HF knowledge questionnaire was replaced because participants had to spend time answering a number of questions that were irrelevant and hence were not going to be scored. Despite problems with the structure of the HF knowledge questionnaire that led to its replacement, this phase provided base knowledge for testing the feasibility of web-based self-management intervention.

4.7. Phase two: Feasibility of Web-based Self-management Intervention

This section provides an overview of the research design and methods used to investigate the feasibility of the web-based self-management intervention. The study participants, data collection and recruitment procedure are discussed and the measures and instruments used in the study explained. Ethical considerations related to the study are also presented. Finally, the strategies for data management and analysis are addressed.

4.7.1. Research Aims

The aims of this phase of pilot study were to:

- Examine the feasibility of the web-based self-management intervention to improve knowledge, self-management and self-efficacy of HF patients who had access to the web-based intervention for four weeks;

- Identify the strengths and limitations of the proposed intervention to be tested in future studies with larger sample sizes; and

- Evaluate the feasibility of recruitment, randomisation, retention and assessment procedures, and the implementation of the proposed intervention.

4.7.2. Research Question

Is using a web-based self-management intervention feasible to improve heart failure knowledge, self-management and self-efficacy compared to usual care for HF patients?

4.7.3. Research Design

Using a controlled intervention study design, this research investigated the web-based intervention feasibility focussing on HF knowledge, self-management and self-efficacy, versus usual care with four weeks follow-up. A controlled intervention study design was used to draw conclusions about cause and effect relationships between intervention (using web-based application as an educational tool) and outcome measures such as self-management in this research. An intervention study design, also known as experimental research, is used when an investigator seeks to establish causality (Fisher & Foreit, 2002). To establish cause and effect relationships between an intervention and outcome; (i) the independent variable (intervention) must precede the dependent variable (outcome), (ii) a strong relationship between intervention and outcome must exist, and (iii) this relationship cannot be due to the effects of other variables. A true experiment or intervention requires three components including an intervention, a comparison or control group, and random assignment of participants to intervention or control groups (Melnyk & Morrison-Beedy, 2012). In other words, experiments are characterised by the three key factors of manipulation, control and randomisation. The first element is manipulation where the researcher actively initiates, implements and terminates study procedures. For manipulation, it is essential that the researcher completely control the process of experiment (Ivo & Lynn, 2006). This eliminates threats to valid inference. Furthermore, the researcher is responsible for ensuring control over extraneous forces wherever possible. The third element, randomisation, entails two separate processes: (a) random selection of participants from the target population and (b) assigning participants to intervention or control group randomly (Ivo & Lynn, 2006). In this study, to minimise confounding factors and to enhance the estimated effect of the intervention, random allocation was used (Kirkwood & Sterne, 2007).

The difference between experimental and observational research is the amount of control that the investigator has over the factors in the study. In observational studies, the role of investigator is passive and there is no control over naturally or occurring risk factors. In contrast, in experimental research, the investigator manipulates events by arranging intervention to occur and/or random allocation of subjects to alternative treatment or control groups (Supino & Borer, 2012). The intervention study design was chosen for this study as this method minimises most of the inherent differences that exist between comparison groups and increases the capacity to determine cause and effect relationships between intervention and outcome/s (Supino & Borer, 2012).

4.7.4. Population and Sample

The target population of the research consisted of patients with HF. The accessible sample included HF outpatients at the Royal Brisbane and Women’s Hospital (RBWH) and QUT health clinic located in Brisbane, Australia. A consecutive sampling method was employed to recruit 54 HF patients. Initially, potential participants were invited to participate through research advertisements and information sheets distributed by the clinic staff.

4.7.5. Sample Size

To determine if the proposed sample size was sufficient to answer the research questions, a prospective sample size calculation was performed. The primary outcome variable in this study was self-management (as measured by self-care HF index scale) and the main hypothesis was that there would be an increase in self-management score of participants who received four weeks intervention via the web-based application compared to those who received standard care with no intervention. Based on the means and standard deviations (70.00 ± 10.00) of participants' self-management in the pre-test sample and considering a two sided 5% significance level and a power of 80%, a sample size of 26 patients per group was required. A dropout rate of 10% was also considered. Total sample of 54 HF patients was required to examine the web-based intervention.

4.7.6. Inclusion Criteria

Eligible participants were recruited if they had a definitive diagnosis of HF as defined by cardiologists at RBWH heart failure service or QUT clinic and New York Heart Association Class I-III , echocardiography (LVEF < 40%), greater than or equal 18 years old, interested in IT and had access to the internet, and were able to consent to participate in research.

4.7.7. Exclusion Criteria

Potential participants were excluded if they resided in a nursing home or institution (as these patients are looked after by nurses), were aged less than 18 (it is very rare to have HF at this age), did not read or speak English (the application materials and tools were developed in English), and/or had severe cognitive deficits or serious life-limiting co-morbidity (these patients could not use the web-based application).

4.8. Intervention

The study intervention involved engaging with the web-based application materials for the period of four weeks. In a face-to-face introductory session, the principal researcher demonstrated the web-based application and assigned a username and password to each participant in the intervention group. This session lasted approximately 45 minutes. Over the four weeks, the intervention group were asked to log on to the web-based application each day, review the content for a minimum of 15 minutes and enter their weight and signs and symptoms of HF such as coughing and tightening of belt, shoes or socks. Entering the above mentioned factors was to encourage participants to monitor their condition at home. The intervention group also received weekly email from the principal investigator to encourage them to continue with the program. The usual care group received routine clinical advice from HF health professionals.

4.9. Study Setting

This study received support from the director of cardiology at Royal Brisbane and Women's Hospital (RBWH) and manager of QUT health clinics. Participants were recruited from RBWH HF services and QUT health clinic. RBWH HF services provided comprehensive outpatients programs including physical activity, clinical observations and educational sessions. Individual patients were referred to the programs for a duration of 12 weeks. QUT health clinic provides services for patients with a range of chronic diseases including HF.

4.10. Data Collection

Potential participants were identified by the staff at RBWH HF service and the QUT clinic. Following distribution of information sheets the principal researcher approached interested patients and discussed further the study purpose and procedures. Upon agreeing to participate, each patient was asked to sign a consent form. Following written consent randomisation was undertaken. Participants were then asked to complete baseline questionnaires. Subsequently, the principal researcher assigned a username and password to each participant who was randomised to the intervention group. The intervention group participants were also asked to view the web-based application for the period of four weeks and enter their daily signs and symptoms. The control group received usual care. Throughout the four week period, weekly reminding emails were sent to participants in the intervention group. At one month, all participants completed the same questionnaires. The follow up period for this phase of the study was four weeks. It is acknowledged that a four week follow-up was relatively short to assess the feasibility of the web-based intervention on HF knowledge, self-management and self-efficacy.

4.10.1. Randomisation

A sample of eligible patients was recruited and randomised to the intervention or control groups. Randomisation is the process that gives every participant an equal chance to be in either group. Randomisation eliminates the systemic bias in groups that may affect the dependent variable (Polit & Beck, 2010). To achieve equal numbers of patients in both groups the most common type of simple randomisation, known as one-one randomisation, was used. Simple randomisation does not necessarily result in the groups being equally distributed in terms of significant characteristics such as age and gender between groups. Nonetheless, it will minimise any differences that are not due to chance and systemic allocation of patients to different groups (Laak, Haakon, & Olsen, 2007).

4.10.1.1. Allocation Concealment and Binding

The allocation sequence was concealed from the research candidate (who enrolled and assessed participants) and undertaken by her principal supervisor through the use of randomly mixed envelopes. The envelopes were sequentially numbered, opaque, sealed and stapled. Dark envelopes were used to conceal contents. The scope of the study deemed blinding not feasible.

4.10.2. Participant Consent

The principal researcher explained to interested patients the purpose of the study, the procedures for data collection, potential risks and benefits, time commitment, participants’ rights, and the strategies to protect their privacy and confidentiality before they accept to participate in this study. Participants were advised that (i) participation in this study would be voluntary, (ii) they could withdraw at any time and (iii) the web-based application would be available for all participants to view at the completion of study. They were also given the opportunity to ask questions after reading the information sheet (***Appendix I***). If they agreed to participate in the study, they were asked to sign a written consent prior to randomisation. All signed consent forms were kept securely in a locked filing cabinet in the office of the principal researcher. . The consent forms were accessible only by the principal researcher and supervisors.

4.11. Instruments

Three questionnaires were used in this study to evaluate patient knowledge, self-management, and self-efficacy at baseline and after four weeks. These included an HF knowledge questionnaire (van der Wal, Jaarsma, Moser, & van Veldhuisen, 2005), a self-care HF index (Riegel et al., 2000), and self-efficacy for managing chronic disease (Lorig et al., 2001).

4.11.1. Dutch Heart Failure Knowledge

The Dutch HF knowledge scale (***Appendix C***) was used to measure patients' knowledge related to their condition. This scale was used because it is a validated questionnaire that has been frequently used for measuring knowledge of patients with HF and it was found to be reliable and valid instrument (Boyde et al., 2011; Boyne, Vrijhoef, de Wit, & Gorgels, 2011; Dennion et al., 2012; van der Wal et al., 2006; van der Wal et al., 2005).

The scale was developed by van der Wal et al. (2005) and consists of 15 multiple-choice items concerning HF in general (four items), HF treatment (six items on diet, fluid restriction and activity) and symptoms and symptom recognition (five items). The scale was developed based on an existing knowledge scale (Jaarsma, Stromberg, Martensson, & Dracup, 2003), on the content of the CD-ROM program that was used in HF clinics in Sweden and on a knowledge test of the Netherlands Heart Foundation (Stromberg, Ahlen, Fridlund, & Dahlstrom, 2002). The items were also derived from important self-care concepts covered by the European Heart Failure Self-care Behaviour Scale (Jaarsma et al., 2003). The Dutch HF Knowledge scale is a self-administered questionnaire. For each item, participants could choose from three options, with one option being the correct answer. The scale has a minimum score of 0 (no knowledge) and a maximum score of 15 points (optimal knowledge) (Jaarsma et al., 2003).

4.11.2. Self-care Heart Failure Index (SCHFI) V6.2

In the current study, self-management skills of participants before and after intervention were measured using the self-care heart failure index (SCHFI) questionnaire (***Appendix D***). The SCHFI was chosen for this study because it evaluates patient self-management by assessing skills including ability to confidently manage heart failure and to evaluate the importance of symptoms, ability to recognise changes in health status, ability to take required actions to relieve symptoms, and ability to evaluate the effectiveness of self-management and treatment (Dansky, Vasey, & Bowles, 2008). A further reason to choose SCHFI was the possibility of adjusting time intervals appropriate for study follow-up. For example, if the study follow-up was 3 months, patients can be asked to "think about how you have been feeling in the last 3 months". It has been recommended that no longer than 3 months be used, as there may be issues with recall (Riegel, 2013, para. 1). By scoring three scales of self-care maintenance, management, and confidence separately, even asymptomatic patients will have self-care maintenance and confidence scores. Self-care management scores only benefit persons who have been symptomatic (Riegel, 2013, para. 2).

Patients with higher scores have greater self-management skills (Riegel, 2008). The SCHFI developed by Riegel et al. (2004) measured self-care management through an active and deliberated process. In general, The SCHFI was based on the naturalistic decision making model that addresses how people make decisions in real-world settings (Riegel et al., 2004). Riegel et al. (2004) stated that the SCHFI was developed to measure self-management skills with a focus on treatment adherence and processes for making decisions around management of HF symptoms. It was shown that the scale was reliable and valid with internal consistency of 0.76 (Riegel, 2008).

4.11.3. Self-efficacy for Managing Chronic Disease

An overview of systematic reviews of self-efficacy instruments for patients with chronic disease showed that no self-efficacy instrument had been specifically developed for HF (Frei, Svarin, Steurer-Stey, & Puhan, 2009). Hence, to measure self-efficacy of HF patients, the Self-efficacy for Managing Chronic Disease Scale ***(Appendix E)*** was used in this study. The scale had been examined previously and had been attributed appropriate external validity and high internal consistency (Hu, Li, & Arao, 2013).

The Self-efficacy for Managing Chronic Disease Scale (SEMCD) was developed by Lorig et al. (2001).The items derived from several self-efficacy studies and the scale was tested on 605 patients with chronic disease. The internal consistency was 0.91 with moderate correlation ($r = 0.58$) with general self-efficacy scale indicating that its validity and reliability were acceptable (Lorig et al., 2001). This 6-item scale covered several domains common across chronic diseases including symptom control, role-function, emotional functioning and communicating with physicians. Each item of the questionnaire was rated on a 10-point scale ranging from “not at all confident” (1) to “totally confident” (10) (Hu et al., 2013; Lorig et al., 2001). The scale was interpreted by calculating a mean score over at least four of the six items thus allowing a maximum of two missing item responses. A higher score indicates higher self-efficacy (Lorig et al., 2001).

4.12. Data Cleaning

To perform data cleaning a data coding manual was developed before collecting data. Prior to analysing the data, a cleaning process was performed to check outliers, missing values, duplicates and consistency of variables. Any questionable data items were checked with original data sources. If the entered item was correct, it was considered for data analysis and otherwise missing value codes were inserted (Kirkwood & Sterne, 2007).

According to the tool developers' guidelines, all missing values needed to be assessed separately to determine the effect of missing items on results. In this study, particular care was taken during data collection to ensure no data were missing.

4.13. Data Analyses

4.13.1. Descriptive Analysis

Data were analysed using Microsoft EXCEL 2008 and IBM SPSS Statistics version 19.0 software. Baseline data and sample characteristics for both the intervention and comparison groups were compared using Chi-square, Fishers exact tests and *t*-tests. Univariate statistical techniques were used to investigate distributions (frequencies), central tendencies (mean, mode or median) and dispersion (standard deviation and range). To examine the categorical variables, count and percentage were employed (Kirkwood & Sterne, 2007).

4.13.2. Main Analysis

Prior to the conduct of statistical tests, empirical distribution of continuous variables was evaluated for normality. To do this, histograms, skewness and kurtosis indices and Shapiro-Wilk tests were used. Furthermore, boxplot was used to identify any outliers. ANCOVA assumptions were tested including homogeneity of variances and homogeneity of regression slopes. Homogeneity of variances were tested for outcome variables using Levene's test. If variables did not violate normality, hypothesises were tested using the analysis of co-variance (ANCOVA). If variables did violate normality, change score analyses were applied as an alternative to analyse results. Although participants were randomly assigned to either intervention or control groups in reality groups may not be perfectly equal (Polit, 2009, p. 270). Using ANCOVA maximises group equivalence prior to assessing the effect of independent variables on dependent variables. Potential covariates should be variables that significantly correlate with the dependent variable. For instance, pre-intervention scores would likely be highly correlated with post intervention scores. Regardless of the intervention some participants may have better scores than others (Polit, 2009, p. 265). The effects of confounding variables like pre-intervention scores are removed in the context of ANCOVA. As a result, ANCOVA has greater statistical power to detect the treatment effect and allows a more sensitive test for real group differences. It also can increase the power of analysis and reduce the risk of type II error (Polit, 2009, p. 265).

Within-group analyses were also performed to investigate changes for HF patient knowledge, self-management and self-efficacy in the intervention and control groups.

4.14. Ethical Considerations

Ethical approval for developing the web-based application and for preliminary testing was obtained from Queensland Health (***Appendix A***); and Queensland University of Technology Human Research Committee (***Appendix B***). The research was considered to be of low-risk and as participants provided their feedback during face-to face session with the researcher at Ipswich Heart Failure services.

To examine the feasibility of the proposed web-based intervention ethical approval was sought from Queensland Health (***Appendix F***); and Queensland University of Technology Human Research Committee (***Appendix G***). There were two specific ethical considerations for this study including participant possible discomfort to spend time on the web-based application which clearly addressed in participant information sheet and access of the control group to the web-based application. Upon completion of four weeks, a user name and password were assigned to individual participants in the control group who was interested to access to the web-based application. Ethical approval (with low and negligible risk application) for the duration of three years was received from Queensland Health and QUT Human Research Ethic Committee on 4/11 /2013 and 27/11/2013 respectively.

4.15. Data Management and Confidentiality

Data was managed according to the principles outlined in the Australian National Health and Medical Research Council (NHMRC) code for the responsible conduct of research (http://www.nhmrc.gov.au/guidelines/publications/r39).

Participants' privacy and confidentiality was ensured by de-identifying data. De-identification was achieved by not collecting names, addresses, or phone numbers within the web-based application. Within the application, participants were identified by pseudonyms. For the purpose of follow-up, identifiable information was required. Participant personal information was matched with an associated code. Hard copy of participant identifiable information and associated code was stored separately in a locked cabinet in School of Nursing at QUT. Only the principal researcher and her supervisors had the authority to access the data stored at QUT. Data collected through the web-based application were stored digitally in the Fluid Watchers web-based data base. Fluid Watchers is a secure web-based application, developed by a group of HF researchers.

4.16. Conclusion

A web-based application was developed based on feedback from an HF panel, an IT team and HF patients. Its framework was based on two key elements of SE theory including role modelling and mastery experience and consisted of educational materials, self-management chart and questionnaires. The appropriateness of application and study instruments was tested with a group of HF patients. The preliminary results determined that to examine the feasibility of web-based intervention, a sample size of 54 HF patients was required. Consequently the web-based intervention feasibility was tested over a four week follow-up period with a sample of 28 HF patients. Characteristics of the study population and results are presented in the following chapter.

Chapter 5: Results

This chapter presents the results of the statistical analysis conducted to investigate the feasibility of a web-based self-management intervention in patients with HF. Participants were recruited from the RBWH HF service and a QUT health clinic. The recruitment was conducted between December 2013 and May 2014. Of 75 HF patients who were assessed for eligibility, 29 were eligible for recruitment. There were 24 patients who were not eligible to participate based on the study inclusion and exclusion criteria. Reasons for ineligibility included (i) ejection fraction (EF) over 40% (*n* = 13), (ii) pregnancy (*n* = 1), (iii) mental illness (*n* = 2), (iv) brain injury (*n* = 1), (v) primary language other than English (*n* = 2), (vi) were leaving Brisbane for more than a month (*n* = 2), and (vii) resided in nursing homes (*n* = 3). Furthermore, six patients indicated that they did not want to participate in the research. To participate in the study, HF patients required internet access at home, workplace or via their mobile phones. Among patients who were invited to participate in the study, 16 had no access to internet.

Participants were randomly assigned to an intervention or control group and completed baseline measures. The intervention group had access to a web-based self-management intervention for four weeks and received weekly email reminders from the researcher. The control group received usual care. Of the total 29 participants one withdrew from the study before follow-up measures were completed. The study flow diagram is presented in Figure 5.1.

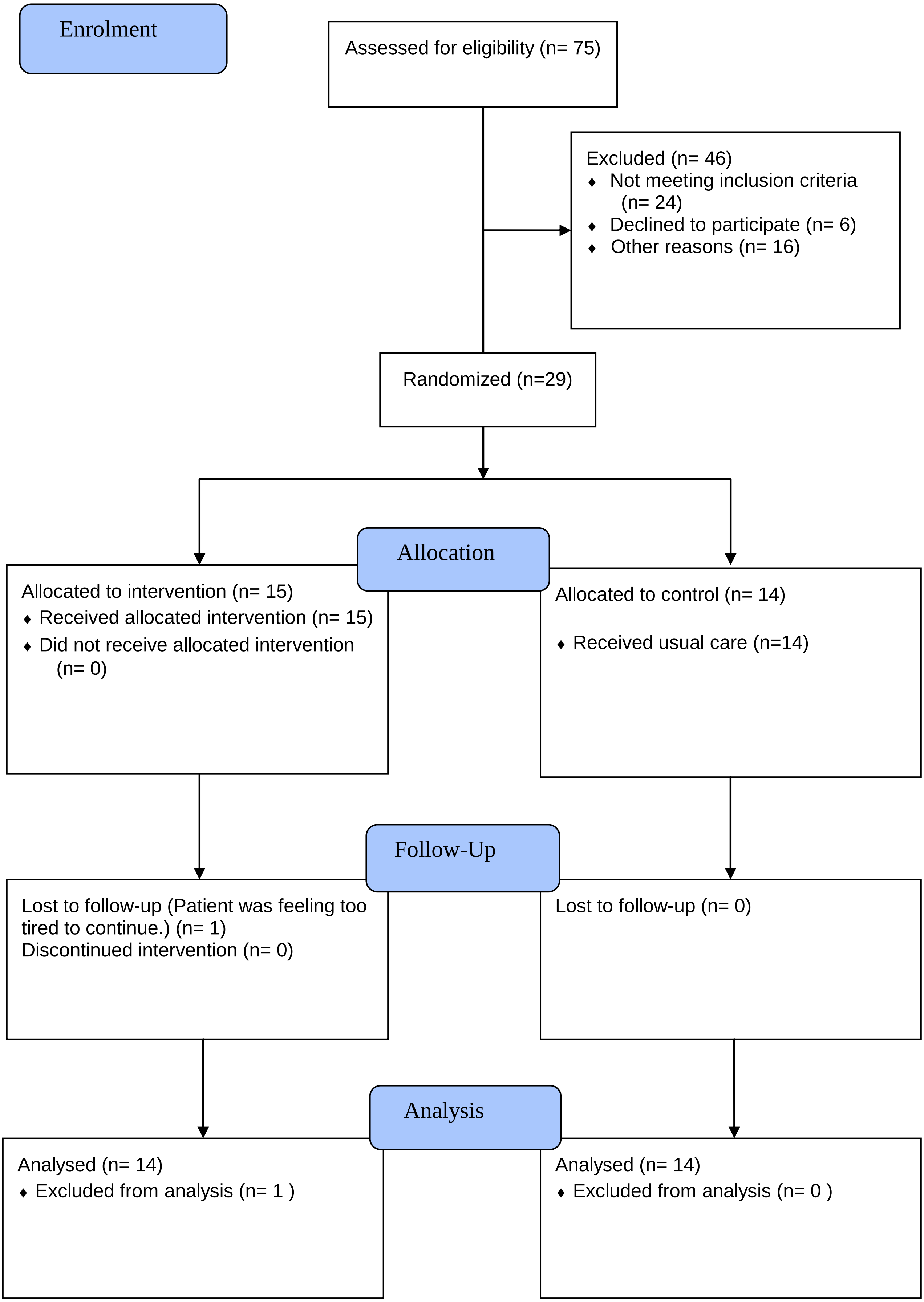

Figure 5.1 Consort Flow Diagram

5.1. Sample Characteristics

Participant demographic information is presented in Table 5.1. Of the total sample (*N* = 28), the majority were men (*n* = 22, 79%) and the mean age was 60.8 ± 11.9, ranging from 34 to 85 years old. Among participants 16 (57%) were married and 16 (57%) lived with other people. Eight (29%) participants had an education level less than 12 years and six (21%) participants had completed high school. The rest of participants (*n* = 14, 50%) had completed a university degree such as bachelor or postgraduate. While seven (25%) participants had a gross annual household income of less than AU $40,000, 15 (54%), participants reported their annual income between AU $40,000 and AU $ 70,000. Half the participants (*n* = 14, 50%) reported their overall health was fair and two (7%) reported poor overall health (Table 5.1).

The mean self-reported disease duration was 4.0 ± 6.9 years. While 14 (50%) participants had class I HF based on New York HF association functional classification, the number of participants with class II was 12 (49 %). The majority of participants were prescribed beta blockers (*n* = 25, 90%) or ACE inhibitor (*n* = 20, 71%). Only 6 (21%) participants reported that they use angiotensin receptor blockers (Table 5.1).

Table 5.1 ***Sample Characteristics***

Characteristics	*n* (%)
Gender	
Male	22 (78.6)
Female	6 (21.4)
Marital status	
Married	16 (57.1)
Widowed	4 (14.3)
Divorced	5 (17.9)
Never married	2 (7.1)
Living arrangements	
Lives alone	11(39.3)
Lives with others	16 (57.1)
Highest level of education	
Less than 12 years	8 (28.6)
High school	6 (21.4)
College degree	5 (17.9)
Bachelor degree	1 (3.6)
Postgraduate degree	7 (25)
Total household Income	
Less than AU $ 40,000/year	7 (25)
AU$ 40,000-69,000/year	6 (21.4)
Au$ 70,000 or more/year	9 (32.1)
Do not know or refused	6 (21.4)
Overall perceived health	
Excellent or very g Good	3 (10.7)
Good	11 (39.3)
Fair	12 (49.2)
Poor	2 (7.1)
Taking an ACE inhibitor	20 (71%)
Taking an ARB	6 (21%)
Taking Beta blocker	25 (90%)
New York HF Classification	
Class I	14 (50%)
Class II	12(42.9%)
Class III	2 (7.0%)
Ejection Fraction	
Mean ± SD	33.7 ± 8.9
Years with HF	
Mean ± SD	3.0 ± 4.8

5.2. Baseline Comparison

Differences in background characteristics and outcomes at baseline between the intervention and control groups were compared by means of Chi-square, Fisher's exact tests and *t*-tests for independent samples. As shown in Table 5.2 the baseline comparison between participants in the intervention and the control group indicated that they were not significantly different in terms of age, gender, years with heart failure, EF and other demographic measures.

Table 5.2 ***Baseline Comparison***

Characteristic	Control	Intervention	Significance
	(*n* = 14)	(*n* = 14)	
Age			
Mean ± SD	60.0 ± 14.0	61.7 ± 9.9	t = - 0.35 p = 0.72
Gender			
Male	11 (78.6%)	11 (78.6%)	x^2= 0.00
Female	3 (21.4%)	3 (21.4%)	p= 1.00
Marital status			
Married	8 (57.1%)	9 (64.3%)	x^2= 0.15
Widowed, divorced or never married	6 (42.9%)	5 (35.7%)	p= 1.00
Living arrangement			
Live alone	6 (46.2%)	5 (35.7%)	x^2= 0.30
Live with others	7 (53.8%)	9 (64.3%)	p= 0.58
Highest level of education			
Less than 12 years or high school diploma	7 (50%)	8 (57.1%)	x^2= 0.14
Some college/associate degree, Bachelor degree or Post graduate degree	7 (50%)	6 (42.9%)	p= 1.00
Total household income			
Less or equal to AU $40,000/year	4 (28.6%)	9 (64.3%)	x^2= 3.5
AU $70,000 or more/year or do not know or refused	10 (71.4%)	5 (35.7%)	p= 0.12
Overall perceived health			
Excellent or very good or good	7 (50%)	7 (50%)	x^2= 0.00
Fair or poor	7 (50%)	7 (50%)	p= 0.64
Taking an ACE inhibitor	10 (71.45%)	10 (71.4%)	x^2= 0.00 p= 1.00
Taking an ARB	4 (28.6%)	2 (14.3%)	x^2= 0.84 p= 0.36
Taking Beta blocker	14 (100%)	11(78.6%)	x^2= 3.36 p= 0.67
New York HF Classification			
Class I	8 (57.1%)	6 (42.9%)	
Class II	6 (42.9%)	6 (42.9%)	x^2= 2.28
Class III	0 (0.0%)	2 (14.3%)	p= 0.31
Ejection Fraction			
Mean ± SD	33.7 ± 8.9	33.4 ± 8.51	t = - 0.87 p = 0.93
Years with HF			
Mean ± SD	3.0 ± 4.8	4.9 ± 8.5	t = - 0.70 p = 0.48

5.3. Testing Underlying Assumptions of Planned Analysis

The normality of pre and post-intervention scores for questionnaires including DHFK, SCHFI (Maintenance, Management and Confidence subscales) and SEMCD was tested using histograms, skewness and kurtosis indices and Shapiro-Wilk tests (Table 5.3). Furthermore, boxplot was used to identify any outliers as they can have a negative effect on the ANCOVA reducing the accuracy of results. Other assumptions also were tested such as homogeneity of variances and homogeneity of regression slopes. Homogeneity of variances tested for outcome variables using Levene’s test. Homogeneity of regression slopes was tested to show that there is no interaction between the covariate and the independent variable.

Results of Shapiro-Wilk tests showed that the DHFK score of both intervention (mean = 12.5 ± 1.1) and control (mean = 12.2 ± 2.4) groups were normally distributed at baseline. However, scores for the intervention group (mean = 12.8 ± 1.7) were not normally distributed following intervention. While scores of intervention (mean = 61.9 ± 20.9) and control groups (mean = 70.2 ± 17.4) were normally distributed for the SCHFI, maintenance subscale at baseline, post-intervention scores of the intervention group (mean = 71.9 ± 15.1) were not normally distributed. Results also indicated that post scores of SEMCD for the intervention group (mean = 7.3 ± 1.6) were not normally distributed (Table 5.3).

Table 5.3 ***Testing Normal Distribution of Outcomes Variables***

Scale	*n*	Pre-intervention score Mean ± SD	Shapiro-Wilk test values	Post-intervention score Mean ± SD	Shapiro-Wilk test *p* values
DHFKQ					
Intervention	14	12.5 ± 1.1	.12	12.9 ± 1.3	.00
Control	14	12.2 ± 2.4	.07	12.8 ± 1.7	.05
SCHFI, Maintenance					
Intervention	14	61.9 ± 20.9	.58	71.9 ± 15.1	.04
Control	14	70.2 ± 17.4	.66	66.6 ± 17.7	.24
SCHFI, Management					
Intervention	3	56.6 ± 22.5	.87	50 ± 14.1	.15
Control	2			50 ± 30.4	
SCHFI, Confidence					
Intervention	14	67.1 ± 20.3	.86	71 ± 17.0	.22
Control	14	65.5 ± 21.4	.74	69.9 ± 19.2	.19
SECDM					
Intervention	14	7.3 ± 1.6	.11	8.0 ± 1.7	.03
Control	14	7.1 ± 1.4	.78	7.4 ± 1.5	.74

There are two standard methods to analyse pre-test–post-test data including analysis of covariance with the post-test as outcome and the pre-test as covariate (ANCOVA) and computing change scores from baseline, using the difference between post and pre-test score as outcome (van Breukelen, 2013). Given the small sample size and non-normal distribution of outcome variables, change score analysis with non-parametric statistics was used instead of ANCOVA (Tabachnick & Fidell, 2007, p. 222). This was to detect whether or not the use of web-based self-management intervention can significantly improve participant outcomes in the intervention group. The only assumption of change score analysis is that pre and post-test scores should be on the same numerical scale (Salkind, 2010).

Aanalysis of covariance (ANCOVA) tests differences in covariate-adjusted scores. Therefore, ANCOVA addresses the question of whether an individual score belonging to one group is expected to change more (or less) than an individual belonging to the other group, “given that they have the same baseline response" (Fitzmaurice, Laird, & Ware, 2004). In contrast, the change-score analysis concerns changes in group means.

5.4. Between Group Analyses

In the current study the mean difference between participant pre and post intervention score was computed for each group. Then change scores were compared using Mann-Whitney U tests. The results are presented in the Table 5.4.

5.4.1. Dutch Heart Failure Knowledge Questionnaire (DHFKQ)

The mean pre-intervention scores of DHFKQ were 12.5 ±1.1 for intervention and 12.2 ± 2.4 for control group. This means that HF knowledge of the intervention group was slightly higher than the control group at baseline. Analysis of post-intervention data indicated that the mean score of participants in the intervention (mean = 12.9 ± 1.3) and control groups (mean = 12.8 ± 1.7) increased after four weeks. However, HF knowledge of the control group improved more than the intervention group. Change scores showed that the mean improvement in HF knowledge was .35 (95% CI -.67 to 1.3) for the intervention group and .57 (95% CI -.05 to 1.2) for control group. The results of a Mann-Whitney test revealed that there was no significant difference between groups (*U* = 91.5, *p* = 0.75) (Table 5.4).Consequently the influence of web-based application on HF knowledge is inconclusive.

5.4.2. Self-care Heart Failure Index (SCHFI)

At baseline, the mean score of the SCHFI maintenance subscale for the control group (mean = 70.2 ± 17.4) was higher than the intervention group (mean = 61.9 ± 20.9). However, the mean score of control group reduced after four weeks (mean = 66.6 ± 17.7). Analysis of post-intervention data indicates that the SCHFI maintenance score of participants in the intervention group (mean = 71.9 ± 15.1) improved following using web-based application. Calculating pre-post change scores, the mean difference for SCHFI maintenance subscale was 9.9 (95% CI -3.6 to -23.6) for the intervention and -3.5 (95% CI -10.3 to 1.3) for the control group. However, by comparing two groups, the results of Mann-Whitney test showed there was no significant difference between participants who received four weeks web-based self-management intervention and those who did not (*U* = 59.9 , *p* = .07) (Table 5.4).

As shown in table 5.4, only five participants reported that they had symptoms during the previous month and therefore responded to the management subscale. The mean scores of SCHFI management were 52.2 ± 23.4 for the intervention group and 56.2 ±

21.3 for control group at baseline. Follow-up results showed that scores of the SCHFI management subscale for participants in both intervention (mean = 50 ± 30.4) and control (mean= 50.0 ± 14.1) groups were reduced after four weeks. Results of change scores showed that the mean difference for management subscale was -6.6 (95% CI -46.5 to 33.2) for the intervention group and -20.0 (95% CI -.14 to .10) for the control group. Results of the Mann-Whitney test showed that there was no significant difference in the management skills of participants who received web-based self-management intervention compared with those who did not (*U* = 1.00, *p* = .24).

The score of the SCHIFI confidence subscale for participants in the intervention group (mean = 67.1 ± 20.3) was higher than the control group (mean = 65.5 ± 21.4) at baseline. Results showed that mean scores of the SCHFI confidence subscale of participants in the control group (mean = 69.9 ± 19.2) improved more than the intervention group (mean = 73.0 ± 18.0) after four weeks. Furthermore, pre-post mean differences for the intervention group was 3.8 (95% CI -4.3 to 12.0) and for the control group was 4.3 (95% CI -3.3 to 12.0). The value of Mann-Whitney test was 89.5 with a *p* value of .94 (Table 5.4).

5.4.3. Self-efficacy for Managing Chronic Disease

The mean score of self-efficacy for the intervention group at 7.3 ± 1.6 was similar to control group at 7.1 ± 1.4 at baseline. Results of post-intervention analysis showed that the mean score of self-efficacy for both intervention (mean = 8.0 ± 1.7) and control (mean = 7.4 ± 1.5) groups was improved following four weeks. Results of this study also showed that the mean differences of pre-post scores for the intervention group was .70 (95% CI -.54 to 1.9) and the control group was .35 (95% CI -.21 to .92). However, results of the Mann-Whitney test showed no significant difference in scores of SEMCD for participants who received the four week intervention compared with those who did not receive the intervention (*U* = 87.0, *p* = .61; see Table 5.4).

5.5. Cohen's *d* Effect Size

The magnitude of the effect of the intervention was calculated by Cohen's *d*. Values of *d* from 0.56 to 1.2 are considered large, 0.33 to 0.55 moderate, and 0 to 0.32 small (van Straten, Cuijipers, & Smith, 2008; Morris, 2008). The results indicated the effect of intervention on participants' HF knowledge (*d* = .06) was negligible. Likewise, the effect sizes of the intervention on participants' self-management subscales were maintenance (*d* = .32), management (*d* = 0.0) and confidence (*d* = .16). The effect of the intervention on participants' self-efficacy scores was moderate (*d* = .37) (Table 5.4).

Table 5.4 ***Change-scores Analyses***

Scale	*n*	Pre-intervention Total score Mean ± *SD*	*n*	Post-intervention Total score Mean ± *SD*	Pre-post differences Mean (95% CI)	Mann-Whitney *U* test Value	*p* value	Effect size (*d*)
DHFKQ								
Intervention	14	12.5 ± 1.1	14	12.9 ± 1.3	.35 (-.67 to 1.3)	91.5	.75	.06
Control	14	12.2 ± 2.4	14	12.8 ± 1.7	.57 (-.05 to 1.2)			
SCHFI, Maintenance								
Intervention	14	61.9 ± 20.9	14	71.9 ± 15.1	9.9 (-3.6 to -23.6)	59.5	.07	.32
Control	14	70.2 ± 17.4	14	66.6 ± 17.7	-3.5 (-10.3 to 1.3)			
SCHFI, Management								
Intervention	4	52.2 ± 23.4	2	50.0 ± 30.4	-6.6 (-46.5 to 33.2)	1.00	.24	.00
Control	9	56.2 ± 21.3	3	50.0 ± 14.1	-20.0 (-.14 to .10)			
SCHFI, Confidence								
Intervention	14	67.1 ± 20.3	14	73.0 ± 18.0	3.8 (-4.3 to 12.0)	89.5	.94	.16
Control	14	65.5 ± 21.4	14	69.9 ± 19.2	4.3 (-3.3 to 12.0)			
SECDM								
Intervention	14	7.3 ± 1.6	14	8.0 ± 1.7	.70 (-.54 to 1.9)	87.0	.61	.37
Control	14	7.1 ± 1.4	14	7.4 ± 1.5	.35 (-.21 to .92)			

5.6. Within Group Analyses

Considering non-normal distribution of outcomes variables, Wilcoxon tests were conducted to evaluate within group changes for HF patient knowledge, self-management and self-efficacy in the intervention and control groups. The results are presented in the Table 5.6.

5.6.1. Dutch Heart Failure Knowledge Questionnaire (DHFKQ)

The DHFKQ mean pre and post-intervention scores for the intervention group were 12.5 ± 1.15 and 12.9 ± 1.3 respectively. The mean scores of participants in the control group at baseline were 12.2 ± 2.4 and follow-up were 12.8 ± 1.7. Results of Wilcoxon test showed that the HF knowledge of participants in the intervention group was not significantly improved in the four weeks follow-up (z = -.90, p = .36). Results were similar for the control group (z = -1.81, p = .07) (Table 5.6).

5.6.2. Self-care Heart Failure Index (SCHFI)

The mean of pre and post-intervention scores of SCHFI maintenance subscale for the intervention group was 61.9 ± 20.9 and 71.9 ± 15.1. Results of the Wilcoxon test showed no statistically significant improvement within the intervention group (z = -1.54, p = .12). Furthermore, there was no statistical significant improvement within the control group (z = -1.02, p =.30) (Table 5.6).

As shown in Table 5.5, mean scores of the SCHFI management subscale for the intervention group were pre-intervention 52.2 ± 23.4 and post-intervention 50 ± 30.4. Results of the study showed that there was no statistically significant improvement within the participants of the intervention group (z = -.44, p = .65). The score of participants in the control also decreased from baseline (mean = 56.2 ± 21.3) to follow-up (mean = 50 ± 14.1) and results of the Wilcoxon test were z = -1.34, p = .18 (Table 5.6).

The pre and post mean scores of SCHFI confidence for the intervention group were 67.1 ± 20.3 and 73.0 ± 18.0 respectively which improved following intervention. However, results of the Wilcoxon test showed no significant improvement within the group (z = -1.10, p = .26).The score of participants in the control group were improved slightly from baseline (mean= 65.5 ± 21.4) to follow-up (mean= 69.9 ± 19.2). However, the improvement was not statistically significant (z = -1.01, p = .31) (Table 5.6).

5.6.3. Self-efficacy for Managing Chronic Disease

Pre and post mean scores of SEMCD for the intervention group were 7.3 ± 1.7 and 8.0 ± 1.6 respectively. Although the score of the intervention group improved after using the web-based application, results of Wilcoxon test were not statistically significant (z = -1.53, p =.12). As shown in Table 5.5, the mean score of participants in the control group were 7.13 ± 1.4 at baseline and 7.4 ± 1.5 at follow-up and results of Wilcoxon test were z = -1.65, p =.09 (Table 5.6).

Table 5.5 ***Within Group Analyses***

Scale	*n*	Pre-intervention Total score Mean ± SD	*n*	Post-intervention Total score Mean ± SD	Wilcoxon Test value	*P* Value
DHFKQ						
Intervention	14	12.5 ± 1.1	14	12.9 ± 1.3	-.90	.36
Control	14	12.2 ± 2.4	14	12.8 ± 1.7	-1.81	.07
SCHFI, Maintenance						
Intervention	14	61.9 ± 20.9	14	71.9 ± 15.1	-1.54	.12
Control	14	70.2 ± 17.4	14	66.6 ± 17.7	-1.02	.30
SCHFI, Management						
Intervention	4	56.2 ± 23.4	2	50.0 ± 15.1	-.44	.65
Control	9	52.2 ± 21.3	3	50.0 ± 14.1	-1.34	.18
SCHFI, Confidence						
Intervention	14	67.1 ± 20.3	14	73.0 ± 18.0	-1.10	.26
Control	14	65.5 ± 21.4	14	63.9 ± 19.2	-1.01	.31
SECDM						
Intervention	14	7.3 ± 1.6	14	8.0 ± 1.7	-1.53	.12
Control	14	7.1 ± 1.4	14	7.4 ± 1.5	-1.65	.09

5.7. Use of the Web-based Self-management Intervention

The usage and engagement of the website within the intervention group was examined based on records of participants' data in the application database. It should be noted that the percentage of participants viewing elements of the web-based application could not be determined through the application database. Hence, other means of measurement such as face-to-face and email communications were adopted to determine the statics of the self-management tools used by participants.

Through the four weeks follow-up, it was found that 50% of participants accessed the web-based application every day and 28% of participants had no record of access. No reasons were provided by the participants for the latter issue. To avoid missing data, participants were asked to answer surveys in a face-to-face meeting with the researcher.

In general, all study participants from the intervention group accessed the web-based application with an average of 16.8 times within the one month intervention period. Based on the researcher's communications with participants, 78% of participants accessed the web-based application from home and 22% had access through their mobile phones. There were no negative comments from participants in relation to ease of use of the web-based application materials and tools such as individual data entry section. Furthermore, the most reviewed sections of the web-based application were "how do I learn to read food labels" followed by "how do I reduce salt in my daily meal", "what is the difference between fat and fluid weight gain", and "how do I become more physically active".

During the four weeks intervention, participants were asked to read information on self-management skills and then enter their daily weight, number of pillows and possible HF signs and symptoms in a specific web form designed for this purpose on the web-based application. Based on data recorded on the web-based application, seven participants entered their data every day, one participant 25 days, one participant 12 days, one participant four days and four participants did not enter any data.

5.8. Spearman's correlation between Participants Change scores and Frequency Usage of the Web-based Application

To further investigate the effectiveness of the web-based application, correlation between participants' change scores in the intervention group and frequency of usage of the web-based intervention were examined using Spearman's correlation. The results showed that the correlation between participants' HF knowledge and frequency of usage of the web-based application was weak (r_s = .34) (Chan, 2003).

The r values of the maintenance (r_s = -.43) and confidence (r_s = -.40) showed a negative relationship between participants' change scores of self-management and frequency usage of the web-based application. The correlation between participants' change scores related to self-efficacy and frequency of usage of the web-based application was negative (r_s = -.45) (Table 5.5).

Table 6.5 ***Correlation between participants' change scores and frequency of usage of the web-based application***

Change scores	*n*	Spearman's rho	*p value*
HF knowledge	14	.34	.91
SCHFI, Maintenance	14	-.43	.13
SCHFI, Confidence	14	-.40	.19
Self-efficacy	14	-.45	.12

5.9. Conclusion

There was no difference in background characteristics and demographic information between the intervention and control group at baseline. Due to the small sample size and non-normally distributed outcomes, change score analysis together with Mann-Whitney U tests were used to examine the effect of intervention on participants' HF knowledge, self-management and self-efficacy. Although HF knowledge of participants improved in the intervention group, results of this pilot study showed no significant difference between the intervention and control group.

Outcomes of maintenance, management and confidence of SCHFI survey were separately analysed. Results indicate that self-care maintenance in the intervention group was considerably higher than the control group. Nevertheless, it did not show any statistically significant improvement. Whilst management scores reduced in both intervention and control groups after four weeks follow-up, the score of confidence in the control group was higher than that in the intervention group. As a result, the web-based intervention did not significantly changed the self-care skills of participants.

The SEMCD scores of participants in the intervention group were improved following the use of web-based self-management intervention. However, there was not a statistically significant difference between participants who received the intervention compared with those who did not. Furthermore, to evaluate the effect of web-based self-management intervention on participants' HF knowledge, self-management skills and self-efficacy, Cohen's *d* effect sizes were calculated. Results of the study indicated that the intervention had a minimum effect on HF knowledge and self-management skills. The effect of intervention on self-efficacy was moderate. Furthermore, ccorrelations between participants' change scores in the intervention group and frequency of usage of the web-based interventions were examined using Spearman's correlation. The results showed that the correlation between participants' HF knowledge, self-management and self-efficacy and frequency of usage of the web-based application were not significant.

Chapter 6: Discussion

This pilot study examined the feasibility of a web-based self-management intervention on the knowledge, self-management and self-efficacy of patients with HF. The feasibility of the intervention was determined through comparisons between the intervention and control group. This chapter presents the main findings of the pilot study, the feasibility of the intervention and its effect size on patients' HF knowledge, self-management and self-efficacy. The chapter then turns to a broader critical discussion of research on web-based interventions in relation to chronic diseases.

6.1. Main Findings

Based on the outcomes of this pilot study, it appears that the HF knowledge of patients who received four weeks web-based self-management intervention did not improve compared with those in control group. Change scores showed that the mean difference of HF knowledge was .35 (95% CI -.67 to 1.3) for the intervention group and .57 (95% CI -.05 to 1.2) for control group. The intervention effect size was negligible at $d = .06$.

In the current study, the Dutch HF knowledge questionnaire was used and the maximum score for this scale is 15 (van der Wal et al., 2005). A score above 10 indicates adequate knowledge (van der Wal et al., 2005). Another reason that participant HF knowledge was not improved may be high pre-intervention scores of participants (ceiling effect). The mean scores of participants in the intervention group were 12.5±1.1 at baseline.

A review of previous studies concluded that self-management educational interventions influence the enhancement of knowledge in HF patients (Balk et al., 2008; Boyde et al., 2012; Tomita et al., 2009). For example, a multidisciplinary internet-based self-management program for patients with HF developed and tested by Tomita et al. (2009) found that the HF knowledge of the intervention group improved significantly after one year while it was lower than control group at baseline. It should be noted that the intervention group received individual personal computers with internet access and computer training. The educational information was comprehensive and covered topics such as HF medications, effects of alcohol and smoking, depression, prescribed home exercise, nutrition, weight management, and exercise. By contrast, educational tools provided via the web-based intervention in the current study were basic and covered only part of educational information for HF patients.

Participant HF knowledge was improved following a nine month educational intervention via a TV channel which provided educational materials, reminders of medication, health related surveys and motivational messages to encourage the prescribed lifestyle regimen (Balk et al., 2008). Utilising a self-care educational manual combined with a DVD also improved patient HF knowledge (Boyde et al., 2012). The manual was divided into five sections and each section contained written materials, pictures, stories from heart failure patients and concluded with multiple questions to stimulate knowledge. The focus of the DVD was on role-modelling of self-care activities and a follow-up time of eight weeks was selected to allow participant enough time to spend on each topic provided via DVD. A comparison between this current study and that of Boyde et al. (2012) indicates that the educational intervention in that study was more comprehensive. Furthermore, the sample size was larger and the follow-up period was twice as long.

The effects of the web-based self-management intervention on HF self-management skills were examined by the SCHFI which consisted of three subscales including maintenance, management and confidence. The raw scores for each subscale are standardised to a 0 to 100 point range, with score of 70 or more required to determine adequate self-care skills (Riegel et al., 2009). In the current study results of the SCHFI maintenance subscale showed that the mean improvement of scores for the intervention group was 9.9 (95% CI -3.6 to -23.6), whereas the control group mean maintenance scores decreased by -3.5 (95% CI -10.3 to 1.3) units. The effect size of the intervention on HF self-care maintenance was small at *d* = .32.

Scores for the subset of participants who completed the SCHFI management subscale were reduced in both intervention and control groups after four weeks. Results of change scores showed that mean differences for the symptom management subscale was -6.6 (95% CI -46.5 to 33.2) for the intervention group and -20.0 (95% CI -.14 to .10) for the control group.

SCHFI confidence scores of participants in the intervention group did not improve following intervention compared with the control group. Pre-post mean differences for the intervention group was 3.8 (95% CI -4.3 to 12.0) and 4.3 (95% CI -3.3 to 12.0) for the controls. Again, this results demonstrates a negligible effect size of *d* = .16.

While the results of this study indicate no improvement in self-management skills of HF patients, previous research conducted by Tomita et al. (2009) showed that the use of a web-based intervention significantly increased patient’s knowledge in recognising HF symptoms such as dyspnoea and fatigue. The finding in the current study may be due to the small sample size and limitations of the proposed web-based application.

In relation to the latter point above, Tomita et al. (2009) used instrumental supports in their web-based intervention that consisted of recording daily data including blood pressure, pulse, weight, medication use, type and amount of exercise, levels of fatigue, intake of salt, sugar, alcohol, and tobacco, health changes, and HF-specific questions regarding swelling (Tomita et al., 2009). However, in the current study, participants were asked to enter a few items such as weight, tight belt, and the number of pillows used for sleeping.

A sample of 88 Taiwanese HF patients demonstrated improvement in quality of life and self-care ability following a self-management intervention that included a patient book, self-management training and telephone follow-up for a period of two months (Tung et al., 2010). The intervention used by Tung et al. (2010) was more comprehensive than that used in this study. A significant effect on primary outcome of self-care behaviours was also found in a study that provided nurse led educational intervention with multiple telephone follow-ups in HF patients (Zamanzadeh, Vahidzadeh, Howard, & Jamshidi, 2013). A comparison with the Zamanzadeh et al. (2013) study indicates that their follow-up period was longer and the sample size was larger than the current study. Self-care behaviours in HF patients were also improved using the educational manual and DVD (Boyde et al., 2012). The authors stated that this may be due to the strong focus of the educational materials on self-care behaviours such as constant reminders throughout the manual and real life stories from people with HF (Boyde et al., 2012).

In contrast to above mentioned studies, Shively et al. (2013) did not find improvement in HF patients' self-management following a patient activation intervention (Shively et al., 2013). The authors described patient activation as having information, motivation, and behavioural skills necessary to self-manage chronic illness, collaborate with health-care providers, maintain functioning, and access appropriate care (Shively et al., 2013).

This current study also explored whether using a four week web-based intervention could improve patient self-efficacy measured by SEMCD scale. The scale was interpreted by calculating a mean score over at least four of the six items thus allowing a maximum of two missing item responses. A higher number indicates higher self-efficacy (Lorig et al., 2001). The mean differences of pre-post scores for the intervention group was .70 (95% CI -.54 to 1.9) and the control group was .35 (95% CI -.21 to .92). Based on the results of this pilot study it appears that self-efficacy of patients who received the web-based self-management intervention did not improve compared to the control. The intervention effect size was also nil (d = .37).

When comparing the results of the study reported upon here with the literature, there are number of studies that found improvement in self-efficacy for HF patients using a variety of educational interventions such as web-based, group based and face-to-face (Barnason et al., 2010; Lorig et al., 2011; Lorig et al., 2013; Powell et al., 2010). Self-efficacy and depressive symptoms improved in both intervention and control groups in a randomised trial of self-management education and group based counselling in 902 HF patients (Powell et al., 2010). Self-efficacy was also evaluated in a group of HF patients by providing hospital transition modules and counselling including health literacy–adapted educational materials and delivering subsequent education and counselling sessions via telephone within the first two to three weeks after hospitalization (Barnason et al., 2010).

The follow-up period may also have had influence on the results of the current study as online chronic disease self-management programs with 12 months follow-up found significant effects on self-efficacy (Lorig et al., 2011; Lorig et al., 2013). Lorig et al. (2011) found that online workshops for a group of 25 patients with a range of chronic diseases improved self-efficacy after 12 months. In a subsequent study, a six week peer led online chronic disease self-management program in South Australia based on Bandura’s self-efficacy theory improved self-efficacy of patients with chronic disease (*N* = 254) at six and 12 months (Lorig et al., 2013).

As discussed in the literature review, factors such as sample size and follow-up impact the effectiveness of educational interventions (Ditewig et al., 2010; Jovicic et al., 2006). Lack of power and limited time for follow-up in this pilot study may be reasons why the proposed web-based self-management intervention did not show improvement in knowledge, self-care and self-efficacy of HF patients.

A further factor that may have adversely influenced the results of this study is the limited educational materials provided in the proposed web-based intervention. In comparison with educational tools used in usual care, the intervention material was basic and covered a relatively small range of relevant issues. The reviewed literature suggests that the type and scope of educational materials incorporated in web-based applications may influence the feasibility of these types of interventions (Tomita et al., 2009; Boyde et al., 2012).

A comparison between the proposed web-based intervention and those developed by others (Balk et al., 2008; Boyde et al., 2012; Tomita et al., 2009; Tung et al. 2010) indicates a requirement for modification of the proposed web-based self-management intervention to enhance monitoring, follow-up, and educational tools. This needs to be addressed before using the proposed web-based intervention in future studies with larger sample sizes.

It should be noted at this stage that the effect size of the proposed web-based intervention was indicative due to small sample size used in this study. Questions about the efficacy of the intervention might be further explored by examining a Spearman’s correlation between participants’ change scores and frequency of usage of the website. However, in this study, correlation between participants’ HF change scores and usage of the web-based intervention was weak and in an unexpected direction. The negative correlation may be related to the small sample size (Taylor, 1990) and the fact that it was not possible to identify whether or not participants reviewed educational materials within the proposed intervention. Hence, more effective monitoring facilities such as short quizzes would strengthen the educational tools. This will enable healthcare providers to assess participant understating about the specific topic.

Access to the internet is considered a challenge for the feasibility of the web-based interventions. Although a majority of people in developed countries have access to the internet there is still a significant minority that has not (Tomita et al., 2009). This issue is particularly relevant to older people. Entering a user name and password to log in and using a web-based intervention can be highly challenging for older patients as they may not be familiar with this type of technology. This may be another factor that influenced the feasibility of the web-based intervention. The data recorded by patients on the web-based application in the current study indicated that 28% did not access the web-based tool during the four weeks intervention. It should be noted that half of these patients were 70 years of age and over, which may have influenced their ability to work with computers. For example, there were two participants who did not have enough knowledge to use the internet and particularly a web-based application. Despite the researcher's effort to help them through several phone conversations they could not enter any data into the web-based application during the four week follow-up. This indicates the need for basic computer training to educate patients how to use a computer and particularly a web-based application. Previous studies conducted by Evanglista et al. (2006) and Tomita et al. (2009) provided face-to-face educational sessions to teach participants basic computer and internet skills.

An adequately powered randomised control trial (RCT) is needed to examine the effectiveness of the web-based intervention on HF patients' outcomes. Based on the effect size of the intervention on the self-management maintenance subscale (d = .32) captured in this pilot study together with power calculations (power =. 80; p = .05) to investigate mean difference between two independent groups, a sample of 153 HF patients in each group is required for future study. Considering a dropout rate of 10%, a total sample size will be 338 or 169 patients in each group. The sample size calculated for future studies based on the results of this study is an estimation as this was a small pilot study and we acknowledge this limitation.

Although there are single studies that found that self-management interventions were effective in improving HF patient outcomes, systematic reviews and meta-analyses confirms that the current evidence is indecisive (Boyde et al., 2011; Ditewig et al., 2010; Jovicic et al., 2006). It is difficult to translate current self-management interventions to practice as they vary considerably in delivery methods and duration as well as outcomes measures (Boyde et al., 2011; Ditewig et al., 2010; Jovicic et al., 2006).

6.2. Web-based interventions and chronic disease

Although some studies, as noted above, have found that web-based interventions are effective to improve outcomes of patients with chronic disease (Tomita et al., 2009; Lorig et al., 2011; Lorig et al., 2013), the current study findings are consistent with a body of literature confirming the limited evidence of the effectiveness of web-based self-management interventions for chronic disease (Kuijpers et al., 2013; Macea, Gajos, Armynd, Calil, & Fregni, 2010). Despite development of a plethora of internet-based interventions, there is limited evidence that indicates their effectiveness (Samoocha, Bruinvels, Elbers, Anema, & van der Beek, 2010; Stellefson et al., 2013). This is attributed, in the first instance, to issues of methodology where most evidence has been negative or had small effect size (Bewick, Trusler, Barkham, Hill, & Mulhern, 2008; Bond et al., 2007; Kerr et al., 2010; Kuijpers et al., 2013). For example, a meta-analysis of the web-based interventions for chronic pain concluded that pain reduction was minimal in intervention groups compared with controls (Mecea et al., 2010). A systematic review of web-based interventions and patient empowerment in diabetes self-efficacy research also showed no effect (Samoocha, et al., 2010). Moreover, studies conducted on web-based interventions in improving health outcomes of patients with chronic disease confirm the uncertainty of the effectiveness of this type of intervention (Bossen, Veenhof, Dekker, & Bakker, 2014; Garcia-Lizana & Saria-Santamera, 2007; Stellefson et al., 2013). Generally, the quality of the research has been poor and much exists as pilot studies (Murray, 2012).

Thus, it is interesting to note that after decades of internet based interventions development, methodological shortcomings still prevail. The most common is their variability in research design. There are significant variations in configuration (educational materials, asynchronous discussion, live conferencing), instructional methods (e.g. practice exercise, cognitive interactivity) and presentation (Kuijpers et al., 2013). These extend to types of assessments, study populations, the aetiology of symptoms, and times of intervention (Garcia-Lizana & Saria- Santamera, 2007; Macea et al., 2010). What is thus absent is a standard structure. There is, however, some debate on whether or not web-based intervention research should conform to a structured program (Kuijpers et al., 2013).

A further and related issue is the sustainability and generalisability of the internet based interventions. In most studies, web-based interventions have been tested over short periods of time and therefore, the possibility of any enduring effect is unknown (Neville, O’Hara, & Milat, 2009). This is evident in systematic reviews where majority of studies had follow-up of less than six months (Beatty & Lambert, 2013; Cotter, Durant, Agne, & Cherrington, 2014; Kuijpers et al., 2013)

Web-based interventions not only suffer from methodological shortcomings but also a lack of appropriate theoretical underpinnings (Cotter et al., 2014; Liu et al., 2013). In many studies, the theoretical rational for multiple assessments and how these informed the development of the web-based interventions is missing. Hutton et al. (2011) performed a systematic review of web-based interventions on smoking cessation among adults, student colleges and adolescents and pointed out that although theory driven interventions appeared to be more effective than a theoretical interventions. Only 50 percent of the reviewed studies on adults applied a specific theory and across all studies behaviour change method varied wildly (Hutton et al., 2011). Overall, published studies of internet based interventions have not specifically addressed theory in their designs. More recently, the results of a systematic review on the effects of the web-based interventions to support lifestyle modification of patients with diabetes indicated that a limited number of interventions applied evidence based theory (Cotter et al., 2014).

From the above systematic reviews it can be concluded that the role of theory in developing internet based interventions has been largely disregarded. Although precise measures of key constructs and outcomes, along with well-defined associations, improve research precision, strong theory is needed to inform the choice of study design and to enhance an understanding of causal relationships (Campbell-Voytal, 2010). Robust theory is also critical in identifying the effectiveness of the specific components of the interventions and optimising their intensity (Campbell-Voytal, 2010; Neville et al., 2009; Philips, Kennedy, & McNaught, 2012). Key theoretical constructs and associations should therefore be applied in efficacy trials, tests of effectiveness, and adoption and sustainability studies. Hence, it is needed to develop internet based interventions based on existing theories and models developed for disease management such as self-efficacy theory.

A further issue relates to context. Context is rarely addressed in internet based interventions. Evidence on cultural differences, for example, and how they shape tailored web-based interventions is limited (Lustria, Noar, Cortese, Van Stee, & Glueckauf, 2013). Previous research has found that cultural related constructs such as beliefs about health, disease and treatment are diverse across racial and ethnic minority groups and construct the ways in which individuals make decisions about their health conditions. This was also found to influence preferences for health messaging (Lustria et al., 2013). It can be concluded that lack of cultural awareness affects the effectiveness of the internet based interventions.

Gaps in the evidence and lack of effectiveness raise a number of questions. The first is whether an explanation for the limited effectiveness of internet based interventions sits solely in the realm of methodological issues or extends to broader underpinning factor. It is assumed that because the internet is available 24 hours a day and allows patients to access information regardless of time and geographic limitation (Evanglista et al., 2006) the potential exists for a web-based intervention to reach a large number of users simultaneously (Im & Chang, 2013). Griffiths, Lindermeyer, Powell, Lowe, and Thorogood (2006) conducted a systematic review to identify the reasons for using the internet to deliver health interventions. The included the unique advantages of the internet technology, reduced cost and increased convenience for users, reduced health service costs, access for isolated or stigmatized groups, timeliness of access to the internet, need for user or supplier control of the intervention, and research-related reasons.

Cost-effectiveness and user convenience is the most often cited reason internet-based interventions. Some have argued that such interventions can increase access to underserved communities (Murray, 2012). Yet while internet based interventions may reduce the cost of travelling and time users from low socioeconomic backgrounds may not have access to the internet. There is evidence to suggest that reliance on web-based interventions may, in fact, exacerbate health inequalities by excluding those on the “wrong” side of the digital divide (Murray, 2012). As Griffith et al. (2006) pointed out an often used justification for internet based interventions is that they may reach patients who are either geographically isolated or unable to leave home. An example of this approach would be a study conducted by Andersson et al. (2006) who examined internet-based, self-help intervention plus minimal therapist contact via e-mail in conjunction with brief group exposure. The results of the study showed positive effects on reducing isolation of people suffering from social phobia. However, results of a recent meta-analysis of the effectiveness of internet-based psychotherapeutic interventions including the interventions that aimed to reduce isolation in people with diabetes and social phobia showed that the overall effect size of web-based interventions was similar to traditional mode of face to face interventions (Barak, Hen, Boniel-Nissim, & Shapira, 2008).

In a further study, Stinson, Wilson, Gill, Yamada, and Holt (2008) conducted a systematic review of internet based self-management interventions for youth health conditions. The authors pointed that although it is essential to conduct more high quality studies with adequate samples sizes, but also it is important to perform cost-benefit analyses that compare internet based interventions to standard approaches (e.g., face-to-face, group formats). The point here is that cost and cost-effectiveness analysis of health information technology interventions is negligible. This no doubt reflects both the difficulty of conducting such analyses and the incremental nature of health IT adoption (Goldzweig, Towfigh, Maglione, & Shekelle , 2009).

Health care system costs rise as a population ages and due to the related prevalence of long-term conditions, and improved survival rates because of new health technologies. Internet-based interventions seem to offer a promising approach to overcome health care costs and many studies claim to objective of reducing costs of health care services. However, a limited number of studies have successfully demonstrated this economic outcome (Griffith et al., 2006). Indeed, there is a lack of published data on the cost effectiveness of internet based interventions as economic analysis of this type of intervention is in the early stages (Tate, Finkelstein, Khavjou, & Gustafson, 2009).

Several interventions hypothesised that use of the internet facilitates information and advice at a time of crisis to support Alzheimer’s care givers, young mothers with breast cancers, and people with AIDS (Griffith et al., 2006). Recent investigation on the impact of two internet based support programs including chat and video on Alzheimer’s care givers showed improvement for the video group in mental health compared to the chat group (Marziali & Garcia, 2011). The video group also demonstrated improvement in self-efficacy, neuroticism, and social support. Although internet interventions for dementia caregivers had some positive effects on caregiver well-being, the available evidence lacks methodological quality (Boots, de Vugt, van Knippenberg, Kempen, & Verhey, 2014) and therefore, the current evidence in this area remains indecisive.

Griffiths et al. (2006) pointed that the reason for some internet based interventions was reducing stigma among the specific population. In a study conducted by Finkelstein and Lapshin (2007), a web-based program was effective in reducing depression stigma. In a further study, Adam et al. (2011) found that an internet based intervention was effective to reduce stigma among gay and bisexual men. However, there is a lack of published evidence regarding the effectiveness of internet based interventions on reducing stigma.

Increased user and supplier control of the intervention was a further reason pointed to by Griffiths et al. (2006) for developing internet based interventions. Many authors have advocated the use of the internet because users can take control of the intervention and tailor it to their own needs. However, there are number of concerns around this issue. Tailoring interventions based on individual needs and reliance on technology may result in adverse effects on user health outcomes. A further concern is the difficulty in communicating accurate messages and feelings while providers and users using internet based communication and also cross-cultural misunderstandings may intensify the problem. Therefore, evaluation of internet based interventions must include both the benefits and potential harms of the mode of delivery for users.

The most significant issue influencing the effectiveness of the internet-based intervention concerns underpinning assumptions. Although internet-based interventions have been developed and implemented for decades, there continue to be methodological and theoretical limitations. It appears that the prevailing rationale for web-based interventions has been the potential of this approach to position patients as autonomous individuals responsible for their own care. Giving a patient a user name and password to self-mange his/her condition, however, would not be adequate to create an effective change. As Liang, Xue, and Berger (2006) argue, while participants may demonstrate a willingness to use online healthcare information they prefer more personal attention from healthcare providers. These authors contend that to decrease participant dropout rate, establishing a therapeutic relationship plays a significant role in encouraging patient to use the intervention. For example, Ritterband, Thorndike, Cox, Kovatchev, and Gonder-Frederick (2009) showed that participants provide feedback on the provided online information when they have been involved for long enough. Lack of a therapeutic relationship with healthcare professionals may be perceived as a burden for an individual and may result in high dropout rates and disengagement. Hence, to increase participant compliance, it is suggested to equip the internet based interventions not only with written, video and photographic materials but also with direct communications with healthcare professionals (Neville et al., 2009). As human supported interventions have been found more effective than self-guided interventions (Cowpertwait & Clarke, 2013), health professionals must carefully consider the needs of their patients and then decide whether to use this medium, other media or a combination of media and human support (Cook, Garside, Levinson, Duprs, & Monotori, 2010). Also problematic is the assumption that a single design of an internet based intervention can be effective in improving health outcomes of patients with diverse chronic diseases. A meta-analysis of web-based interventions on behavioural change across different conditions showed that tailored web-delivered interventions were significantly more effective than non-tailored web-delivered interventions in achieving behavioural outcomes (Lustria et al., 2013). Therefore, it is essential to tailor information within the web-based interventions. To achieve this, different communication methods such as chat, discussion forum and individualised messages can be used.

In summary, the enthusiasm and rapid growth of research in this area has not translated into expected benefits. Although methodological shortcomings are considered the major contributing factor in lack of effectiveness of internet based interventions research, the area is most obviously lacking in theory. As a result, what is required are for effective web-based intervention are studies with an appropriate design and based on theory. Furthermore, such interventions need to cover comprehensive information and have the facility for effective communication with patients. There is also a lack of evidence on the cost effectiveness of web-based interventions and more research is needed to evaluate the cost of this media against the traditional method of education. Furthermore, it is required to evaluate the effect of web-based intervention on patient-provider relationship. A further issue that needs to be investigated is the effect of web-based interventions on patient comfort level.

Finally, existing self-management models provide appropriate methods to facilitate patient provider communication. In Chapter 7 of this thesis a model is proposed to modify the web-based intervention based on self-efficacy theory and self-management models.

6.3. Study strengths

In this pilot study, the web-based application was developed to provide self-management education related to HF knowledge and self-care skills. Expert feedback was utilised to ensure that web-based application information is valid and reliable. The next strength of this study was preliminary testing prior to testing the feasibility of the web-based application. The preliminary testing ensured that any potential difficulties with questionnaires were addressed. As a result, psychometrically validated instruments were used and appropriate research methodology was employed to examine the feasibility of the web-based self-management intervention. Moreover, to prevent bias, participants were randomised to two experimental groups (intervention and control). Comparison of the intervention and control groups indicated that the randomisation procedure had been successful as inferential tests confirmed no difference between two groups at baseline.

6.4. Study limitations

Despite several measures that were taken to engender a proper design and best practice within this study, there were some issues beyond researcher control. This pilot study suffered from several limitations. The first limitation was related to participant recruitment. Since it was required that researcher hold a face to face meeting with participants to demonstrate how to use the web-based application and enter data, it was only possible to recruit participants who were attending a HF management program provided at a QUT health clinic or the RBWH heart failure service. As described in Chapter 5 of this thesis, among HF patients who were invited to participate in the study 26 patients were not eligible to participate based on the study inclusion and exclusion criteria. This is one reason that the sample size of the current study was limited.

Limited access to the internet for potential participants was a further limitation of this study. To participate in the study it was essential that HF patients had access to the internet at home/workplace or via their mobile phones. Although a large proportion of the HF population did have access to internet (about 70%), there was still a significant minority who did not. As a result, the current study was based on a small sample size which limited statistical power.

The study follow-up was relatively short in examining the feasibility of the web-based intervention on patient knowledge, self-care and self-efficacy. Entering weight and possible HF signs and symptoms to the web-based application motivated patients to keep a record of their daily weight and to monitor any changes related to their HF. A four week intervention, therefore, provided an opportunity for patients to practice skills related to HF self-management. However, it is acknowledged that the study follow-up was not sufficient. Based on the reviewed literature, it is recommended that a minimum of six months follow-up be applied to evaluate the effect of this type of intervention on patient outcomes (Ditewig et al., 2010; Tomital et al., 2009). A four week follow-up was considered appropriate given the study scope and because this research was a feasibility study that sought to examine the preliminary effects of the web-based intervention in improving heart failure patient knowledge and self-management skills.

The web-based educational tools were very basic and only covered information on self-management skills. However, educational information provided by health care professionals at the HF service was comprehensive and covered a number of topics such as medication, nutrition, exercise and psychosocial issues. Thus the type of education and the level of information provided by HF services was more expansive than a basic web-based self-management intervention such as the one used in the current study. This may have diminished the contrast between the intervention and control groups in detecting substantial favourable effects of the web-based intervention.

6.5. Conclusion

The aim of this pilot study was to develop a web-based self-management intervention and to examine its feasibility with comparing two randomised groups with four weeks follow-up. While there was no difference between intervention and control groups in terms of baseline characteristics, it appears that results of this study did not find difference in HF patients’ knowledge, self-management and self-efficacy when compared with that gained through usual care.

To effectively evaluate the web-based intervention, what is required is a randomised controlled trial with an adequate sample and follow-up. Furthermore, review of the literature in this area indicated that web-based interventions suffer from methodological shortcomings and lack of theory. Hence, this indicates a need to revise web-based self-management interventions based on existing self-management interventions and the self-efficacy theory.

This study underscores the importance of a well conceptualised and piloted intervention in order to move the research in this field forward. The lessons learned and implications for a larger clinical trial have contributed to knowledge in this area.

The final chapter of this thesis addresses the implications and recommendations that are required to develop a revised web-based self-management intervention for future research.

Chapter 7: A proposed modified web-based self-management intervention

7.1. Introduction

The pilot study represented a fundamental phase of the development of web-based self-management intervention process for patients with HF. It was used to evaluate the feasibility of recruitment, randomisation, retention, assessment procedures, implementation, and modification of the web-based self-management intervention. On the basis of the results of the pilot study and related literature this chapter proposes and justifies a modified and extended approach to web-based intervention for the purposes of future research. Such research would require a larger scale randomised clinical trial (RCT) to examine the effectiveness of the proposed modified web-based intervention.

The proposed RCT needs to include randomised group assignment, double-blinded assessments, and control or comparison groups (Liang et al., 2006) with a primary goal to minimise the bias in the estimation of the treatment effect on patients' outcomes (Leon et al., 2006; Leon & Davis, 2009). It has been established that educational tools (Boyde et al., 2012) and the use of Bandura's self-efficacy (SE) theory (Webb, Joseph, Yardley, & Michie, 2010) are the most important elements in an intervention that influence patient outcomes.

7.2. Educational Tools

In providing effective self-management intervention, outcomes of previous research have indicated that the intervention needs to ensure that educational tools are designed around comprehensive information on HF issues (Boyde et al., 2012). These dimensions include nutrition and diet; physical activity; effects of alcohol and smoking; medication and their side effects (Barnason et al., 2010); and psychosocial and emotional issues (Boyde et al., 2012; Balk et al., 2010; Tung et al., 2009). Furthermore, previous study conducted by Lee, Arthur and Avis (2008) recommended that information be provided within the intervention on how the physiological system responds to different situations.

Based on the Lorig self-management program, the educational tools would include problem solving, decision-making, resource utilisation, patient / healthcare provider partnership, and taking action (Department of Health Victoria, 2008). The tools would be divided into five sections. The first section would comprise an introduction and include an overview of self-management skills and the benefits of self-management for health status. This dimension of the tool should present examples of problem solving skills for HF patients. The focus of the second section is on the decision making process. The emphasis here is directed towards decisions needed to manage symptoms and illness as well as improve compliance to treatment and promotion of a healthy lifestyle. The third section would provide useful resources for HF patients and the methods to use them. The next section covers the importance of patient– health care provider partnership and the final section addresses the importance of becoming an active self-manager, taking actions, and forming an action plan (Lorig et al., 2011; Lorig et al., 2013).

All the above areas can be addressed through the provision of multimedia educational modules as these are known to be effective and have been used in previous studies relevant to HF and diabetes (Balk et al., 2008; Maddison, Prapavessis, & Armstrong, 2008; Yu et al., 2012).

Moreover, Tomita et al. (2009) stated that the intervention needs to provide instruction about types and level of exercises that positively influence patient’s outcomes. These include walking, breathing, stretching, range of motion, and upper and lower extremity strength training. For better outcomes and in order to encourage HF patients to maintain healthy life style, the proposed intervention shall also include information on recommended nutrition and diets (Tomita et al., 2009).

The educational tools used in the pilot study were restricted to general information derived from National Heart Foundation and The Cardiac Society of Australia and New Zealand’s (2011) and consisted of tips and short messages. Hence, this section needs to be extended or modified to cover information on exercises (type, duration, and symptoms) and diets and nutrition such as food recipes for HF patients.

7.3. Interventions based on self-efficacy theory

The aim of the pilot study was to explore the feasibility of the web-based self-management intervention and to reinform an evidence-based theory driven intervention for future research. The modified intervention reflects the conceptual framework used in the pilot study and is based on the results of the current study and existing research and literature.

The framework of the study was underpinned by Bandura’s SE theory. Previous research conducted by Nichols, Schutte, Brown, Dennis, and Price (2009) showed that the use of an interactive workbook developed based on Bandura’s SE is effective and increases patient outcomes. Hence, one may assume that the use of these informational sources within the web-based intervention can improve participant's SE.

The key elements of the Bandura's SE theory were mastery experience, role modelling and verbal persuasion. Researchers can alter these key elements to some extent to obtain maximum benefits. For example, Nichols et al. (2009) used an interactive workbook that contained "exploring aspects of confidence," "mastery", "building confidence", "using encouragement", "exploring how to respond to stress" and "keeping motivated."

The sources and mediators of SE have been used in formatting the self-management interventions and selecting tools in previous research (Yu et al., 2012). Feedback, goal-setting, peer story-telling, monitoring tools, computer-generated responses to user entries, videos of peer testimonials, measuring blood pressure, monitoring weight, physical activities and diaries are some examples for the use of SE sources (Yu et al., 2012).

SE interventions can be rigorous and effective and able to overcome some of the barriers associated with the disease condition to promote the individual's confidence (Bandura, 1997). As a result, a combination of the four primary sources of SE theory is likely to have the potential to promote a higher sense of SE and a greater willingness to undergo behavioural change and therefore produce optimal results (Chao, Scherer, Yow-wu, Lucke, & Montgomery, 2013). Hence, individuals can weigh and integrate information from various sources to form a personal judgment of efficacy (Bandura, 1986).

McAuley, Courneya, Rudolph, & Lox (1994), Lorig et al. (2011), and Lorig et al. (2013) are examples of previous studies that have used a combination of the four primary dimensions of efficacy to enhance self-management in adults with chronic disease. The primary focus of the interventions was the provision of efficacy-based information including the mastery of performance accomplishments, role modelling (vicarious learning), social persuasion (verbal encouragement), and the interpretation of physiological and emotional responses. In the studies noted above, participants who experienced the benefit of these programs adhered better to self-management tasks than those in the control groups who received attention and health information but where efficacy was not enhanced (Lorig et al., 2011; Lorig et al., 2013).

7.3.1. Mastery Experience (performance accomplishments)

Mastery experience (performance accomplishments) has been recognised as a significant factor that influences SE (Bandura, 1977). It invites participants to explore new way of thinking and feelings related to previous experiences in various situations (Nichols et al., 2009).

Mastery experience can be monitored and encouraged by specifying individual goals, rehearsal of desired behaviours, review of activity log and workbook, engaging with a task, and encouragement through body group (Allison & Keller, 2004; Lee et al., 2008). It also encourages patients to incorporate identified skills into anticipated behaviour related to their conditions (Nichols et al., 2009). For a successful outcome, this demands informing patients about their health problems prior to gain mastery through experience (Lorig & Holman, 2003).

Lorig (1996) emphasised that it is much easier to build skill mastery upon a progression of successes rather than failures. According to Lorig and Holman

(2003), one of the best ways for patients to gain skill mastery is to make contracts for specific behaviours. As a result, patients were asked to fill a report or journal in a form of weekly behavioural contract. Using weekly contracts gave patients the opportunity to explore various self-management behaviours during the intervention.

The use of action plan is another method to enhance performance accomplishment. It looks as a homework activity for patients (Lorig, 1996; Lorig & Fries, 2006; Lorig & Holman, 2003) and generally consisted of one week behaviour specific plan created by the patient. This plan is a list of activities that the patient decides to do (instead of getting instructions from a health care professional to undertake activities). It may include one or number of activities that patient with HF desire to do in order to change lifestyle like losing weight, walking for a certain distance and/or consuming fresh fruits and vegetables instead of fast foods. The action planning concept is based on theories of self-efficacy and has proven successful in self-management (Lorig, 1996; Lorig & Fries, 2006; Lorig & Holman, 2003).

Another factor affecting mastery experience is self-monitoring which is a complex concept that involves monitoring, understanding, interpretation and response with appropriate actions to signs and symptoms (Hoffman, 2013). Research conducted in the past on patients with chronic conditions showed that self-monitoring improves body awareness, results in a better communication with health professionals, and improves sense of self-efficacy (Hardman, 2002). To improve health outcomes, it is important to utilise self-monitoring in self-management interventions (Gleeson-Kreig, 2006).

E-diaries are an effective element in self-monitoring (Kritjansdottir et al., 2013; Lee, Lennie, Warden, Jacobs-Lawson, & Moser, 2013) and can be used to increase patient compliance (Nes et al., 2012; Oerlemans, Van Cranenburgh, Herremans, Spreeuwenberg, & Van Dulmen, 2011) by providing patients with manual and trigger alarm to indicate that the diary needs to be filled (Morren, Dulmen, Ouwerkerk, & Bensing, 2009). A systematic review of web-based interventions with e-diaries revealed that adherence to the diary was higher in older patients and when the components of diary (items that need to be completed) were short (Morren et al., 2009).

Multiple choice or Likert scale questions with brief open responses may be used in diaries (Arsand, Tatar, Østengen, & Hartvigsen, 2010). Questions may be related to types of food (low fat, high fat, low salt, high salt, percentages of fresh fruit and vegetables), level of physical activities, severity of symptoms and medication adherence (Arsand et al., 2010). The questions are chosen to support self-monitoring and awareness of feelings, thoughts related to the symptoms and applied self-management strategies. The diaries also may include a comment field giving participants the opportunity to write a short personal message to the therapist (Arsand et al., 2010).

Diaries may be completed in the morning, afternoon, and/or evening. While the morning diary is to assess quality of sleep; current severity of signs and symptoms; and intended activities for the day, the afternoon diary assess the severity of signs and symptoms and inquire patient to explain accomplished activities, cognitions, and feelings (Kritjansdottir et al., 2013). The evening diary may also ask about severity of signs and symptoms as well as satisfaction with activity level and achievements of that day (Nes et al., 2012).

It is also recommended to ask participant to nominate a convenient time for receiving the morning and evening diaries (Nes et al., 2012). To adopt diaries as participant’s daily routine, it is appropriate to make agreement at the first meeting with the participants.

As noted in Chapter 2 of this thesis, fluid retention is the most common reason for rehospitalisation of HF patients (Chaudhry, Wang, Concato, Gill, & Krumhole, 2007). Therefore, participants in this pilot study were only asked to enter their weight together with possible signs and symptoms related to fluid retention. In other words, other means of mastery experience (i.e., the use of journals and diaries) are missing in the proposed web-based application.

As a result and for a better outcome, the author of this thesis recommends adding an online diary (Electronic diaries or e-diaries) and journal to the self-monitoring section of the proposed web-based application based on the work of Kritjansdottir et al. (2013), Oerlemans et al. (2011), Nes et al. (2012), and Lorig and Holman (2003). Participants are asked to complete their own diary and journal with their daily and /or weekly activities.

These will assist patients to more effectively monitor their signs and symptoms and keep records of their behaviours related to their conditions (Nes et al., 2012) and consequently increase their awareness about their disease (Morren et al., 2009). It will also help patients to understand how their conditions are affected by their daily activities, diet, and fluid they take which may motivate them to more frequently monitor their conditions.

7.3.2. Role modelling (vicarious experience)

Bandura (1997) indicated that the individual should play an active role in the management of their condition. Role modelling draws attention of non-physically active patients to relative progress of other physically active HF patients within the same age. Nichols et al. (2009) stated that building confidence can be implemented through learning from other individuals.

For effective outcomes, observers must be able to relate to role models on multiple levels such as health condition, age, gender, ethnic origin, and/or socioeconomic status (Lorig, 1996). The role model may contain verbatim testimonials from other patients' experiences with focus on aspects of mastery, perseverance, and success when encountering common issues related to self-management. These have been frequently used in previous educational interventions (Boyde et al., 2012; Lee et al., 2008; Maddison et al., 2008).

Furthermore, patients must feel a connection between their conditions with patients who successfully managed their disease. Therefore, visualising individuals' stories and written successful stories from HF patients who have managed their condition through self-management skills could be an appropriate method to increase effects of role modelling. Using video clips may be an appropriate method to visualise the successful models (Balk et al., 2008; Boyde et al., 2012).

The selected models must clearly demonstrate patients' confidence on their progress and achievements through self-management skills. Therefore, these may contain a variety of strategies to cope with patients' conditions; to provide an indication of maximal effort required to manage their disease; and to nominate solution on how to overcome the associated discomforts. Emphasis may be placed on strategies (i.e., attention control, breathing regulation, goals, and key words) with a focus on the patients' efforts during subsequent tasks (Maddison et al., 2008).

In the current study, avatars were the only item used as role modelling. It did not cover the aforementioned factors. Hence, a particular attention needs to be given to expand it to bring maximum benefits to HF patients. Modelling can also be implemented through group feedback. It may be provided by facilitators and/or peer fellows in an online discussion forum. In this case, patients are able to post their questions in a common area. Facilitators and/or peer(s) can provide their responses to the questions. This brings up a new opportunity for patients to directly use experience of other patients and be in touch with those who successfully managed their disease (Lee et al., 2008; Maddison et al., 2008).

Viewing questions and answers in the common area allows for further exploration and discussion about the issue by facilitator and/or peers. Such a modelling generally entails task specific feedback and shows the patients that they can be their own models, generate their own solutions, and possess useful information that can benefit others (Lee et al., 2008; Maddison et al., 2008).

7.3.3. Social persuasion (verbal encouragement)

Verbal or social persuasion is a self-efficacy-enhancing mechanism that is widely used by many educators and can take many forms from fear arousal to social support (Lorig, 1996). Verbal persuasion may be used to encourage patients' relative progress, to attribute accomplishments to their own abilities, and to involve their family members in the activity plan to support and reinforce patients’ behaviours (Allison & Keller, 2004). As an example, previous research conducted by Allison and Keller (2004) and Zamanzadeh et al. (2013) on SE interventions through telephone contacts showed that patients’ outcomes can be improved by building confidence in patients through initiating and maintaining behaviour. Nichols et al. (2009) stated that health care professionals can use verbal persuasion to assist patients to write down useful encouraging statements that can be later on used by them to encourage their family members and friends to support them.

Since behaviours of patients with chronic disease are influenced by environment and behaviour of people surrounding them, self-management of chronic illness demands involvement of other parties such as patients’ family members and friends as well as their health care professionals (King et al., 2007; Grey et al., 2006). Among these, relationships between patients and their health care providers play a significant role (Grey et al., 2006). This is the basis of Flinders self-management model (Department of Health Victoria, 2008) to strengthen the partnership and to maintain therapeutic relationship through effective communication.

In a clinical consultation, health care professionals act as a source of information for patients and provide specific information on disease and treatment methods. Furthermore, this is the responsibility of the health care professionals to ensure that the information given to patients is in a way that is compatible to the knowledge, interests, and other characteristics of the patients (Novak et al., 2013).

A systematic review conducted by Webb et al. (2010) stated that the use of communication tools in the web-based interventions can positively influence patients' outcomes. There are two types of the communications within a web-based intervention. The first one that is mostly in regard with user friendliness of the web-based application creates a better connection between users (patients and / or health care providers) and the application. The aim of this concept is to motivate patients to use the web-based application as well as assisting health care providers with real-time monitoring of patients and preparation of reports. This may include shape, size, and colour of the text; graphic-based materials; videos and tips that need to cope with the patients' conditions as well as online monitoring and reporting facilities (Longo et al., 2010).

The second method of communication is to ensure that patients have facilities to communicate with their health care providers to receive real-time assistance. This may include an online forum to communicate with peers, online verbal and non-verbal chat services, telephone follow-up, and email facility (Webb et al., 2010). While email communications would be appropriate to send reminder and motivational messages, telephone follow-up and verbal chat communication may assist health care professionals to maintain therapeutic relationship with patients and to resolve possible issues related to the use of intervention. It has been also recommended to use more than one communication method during the intervention (Webb et al., 2010).

In the pilot study, weekly email was used to encourage participants to engage with the intervention. There was a minority of participants who had no or little experience in using email. In addition, no other means of communication was adopted (except for the case when participants could not remember their username and/or password where telephone communication was used). Hence based on the work of Longo et al.

(2010), what is recommended is the use of communication facilities in a web-based intervention to give healthcare providers an opportunity to encourage patients through verbal persuasion. Online chat and messaging services to achieve this objective would be appropriate methods. It may assist healthcare providers to maintain relationships and to implement interventions based on the concept of partnership (Lee et al., 2013).

Noar, Benac, and Harris (2007) recommend the use of individualised messages that are informative and in line with patients' conditions and interests. Hence, daily situational feedback based on the electronic diaries may be considered as an element to emphasise the verbal persuasion and to tailor information based on the patient needs. It has been recommended by Kristjansdottir et al. (2013) to provide daily situational feedbacks for a minimum of four weeks excluding weekends. Furthermore, a protocol must be developed to assist with standardising feedback (Kristjansdottir et al., 2013). This can be carried out based on the evidence derived from a multi-disciplinary supporting group. To make feedback more effective, Kristjansdottir, et al. (2013) suggest that a protocol be divided into a number of topics and structured in a hierarchical way, with the first set of topics the most important in terms of intervention. These may be related to emotional, cognition and activity issues.

Feedback usually targets psychosocial factors that positively affect patient outcomes. It consists of information on patients to increase their attention to their disease and its successful management (Nes et al., 2012).There are three forms of feedback, namely, descriptive, comparative, and evaluation. Descriptive feedback provides information related to patient data. Comparative feedback compares patient data, progress and achievements with other patients with similar conditions. Evaluative feedback makes interpretations and judgments based on patient data and condition and then provides solutions for improvements (Kristjansdottir et al., 2013).

In addition to diaries, the situational information can also be drawn during the meetings with the participants when they express their overall aims. To inform the participant that his/her feedback is available and to stimulate effective self-management of the current situation, a personalised text message can be send to the participant (Kristjansdottir et al., 2013). The text messages may include a link to the page where the feedback was posted. No limitation has been considered on the length of the feedback and it may vary from a few sentences to a few paragraphs. A nurse may have immediate access to submitted diaries and use the situational information to formulate personalized feedback (Kristjansdottir et al., 2013).

Nes et al. (2012) indicated that the overall aim of giving feedback is to focus on the severity of signs and symptoms of patients, to provide positive thoughts, to avoid behaviours that worsen their conditions, and to assist patients to have a better understanding on what action they need to take. The purpose of the feedback is to stimulate self-management, to provide reassurance and comfort, and to give general information about coping with condition (Nes et al., 2012).

7.3.4. The interpretation of physiological and emotional responses

It is important to increase patients' awareness about their physiological responses to activities they undertake (Reigel & Carlson, 2002). This may include questioning the participants about their responses to a specific activity and helping the participant to interpret symptoms accurately (Alison & Keller, 2004; Reigel & Carlson, 2002) as elderly patients may wrongly relate their symptoms to their age. Furthermore, type and severity of symptoms varies among patients. Hence, they may have difficulties in understanding the meaning and implications of symptoms (subjective self-measurement) and hence may not make a valid decision to seek care (Jurgens, 2006). For example, symptoms such as dyspnoea and fatigue are subjective and can be impaired by poor sensitivity or awareness of body sensations (Reigel & Carlson, 2002).

Intervention is desirable that allows for objective self-measurement rather than subjective self-measurement to assist patients with better monitoring of their progress and physical and functional status (Jurgens, 2006). It should also help patients to take appropriate action to address a symptom and then evaluate the effectiveness of the action taken (Reigel & Carlson, 2002). If the outcome of the self-evaluation is negative, the intervention should contain instructions to potentially reduce patient delays in seeking health care (Jurgens, 2006).

In the current pilot study, there were a limited number of educational topics that could increase patient awareness about symptoms including measuring fluid intake, controlling their daily weight, and measuring salt. This range of educational topics needs expanding. For example, a patient needs to know which type of physical exercise is useful for their specific condition and how long it should take and how these affects symptoms.

7.4. Computer and Internet Training

To reduce barriers associated with the use of a computer and/or internet, face-to-face educational training session/s prior the involvement of participants with internet based research is required. This may decrease difficulties for patients in using a computer and/or internet and therefore may influence research results (Evangelista et al., 2006; Tomita et al., 2009).

7.5. Elements that need to be added to Web-based self-management intervention

The four information sources of Bandera’s SE theory were used to address elements of future web-based interventions designed to enhance levels of self-efficacy and to improve self-management skills. These include performance accomplishments, vicarious learning, social persuasion and interpretation of physiological and emotional responses.

To cover comprehensive information related to HF patients’ condition, sections for diet and nutrition, medications and their side effects need to be added to the educational tools. Furthermore, more information related to types and levels of physical activity are required to be addressed in future web-based intervention.

Vicarious learning or role modelling may be applied by drawing participant attention to the relative progress of other patients with a similar age and health condition. This can be provided in the form of written materials or video clips of patients with successful stories in educational tools.

To accurately interpret signs and symptoms associated with their condition, patients need to be aware about their physiological and emotional responses related to their daily activities. It is important therefore to provide patients with appropriate information and to assist them to accurately interpret signs and symptoms which have resulted from their behaviours. The information must be comprehensive and cover both physiological and emotional issues.

Figure 7.1 presents the overview of the existing educational tools within the proposed web-based intervention. It also contains the new components considered necessary to optimise the intervention in future studies. Encouraging performance accomplishment can be implemented through goal setting, self-monitoring and rehearsal of desired behaviours in the forms of e-diaries, or journals. The use of interactive workbook or action plans may also assist participants to monitor and accurately interpret signs and symptoms related to their conditions. As shown in Figure 7.2, the proposed intervention needs to be extended to more accurately reflect the materials used successfully in past studies.

Using an online discussion forum may also strengthen role modelling. To verbally encourage participants and to maintain patient-provider relationships, online chats with health care professionals is an element that can be incorporated in the web-based intervention. Furthermore, information on participant progress, task accomplishments and questioning about behaviours related to conditions can be provided through feedback and personalised messages. However, a protocol for the feedback based on the multidisciplinary advice is recommended. Figure 7.3 summarises a list of communication tools that can be used to enhance the quality of the intervention and ensure that a strong patient-health care provider relationship is secured.

7.6. Items that are recommended to consider in the design of future RCT

As mentioned in Chapter 6 of the current thesis, to assess the effectiveness of the web-based self-management intervention, it is required to conduct a powered RCT with a total sample size of 338 or 169 patients in each group. Furthermore, based on the current evidence, it is recommended to use at least six months follow-up. For RCT to be rigorous, it is needed to administer questionnaires at baseline, three and six month follow-up. This is to measure participants' adherence to the intervention and to resolve possible barriers or difficulties which may result when using the web-based application materials and tools. To ensure randomisation process is precise, it is suggested to use the computer generated randomisation technique. As blinding is very crucial in well designed RCTs, it is recommended to perform double blinding during the randomisation, assessments and analysis procedures.

The primary outcome measures may include knowledge, self-management and self-efficacy. Other physiological and functional measures such as ejection fraction, New York Heart Association Functional Classification and morbidity and mortality can be considered as secondary outcomes. Instruments that are needed to examine the effectiveness of the intervention are HF knowledge (van der Wal et al., 2005), self-care HF index (Riegel et al., 2000), self-efficacy for managing chronic disease (Lorig et al., 2001) and health care utilisation and cost for cardiac patients(Schweikert, Hahmann, & Leidl, 2008). Measuring quality of life is not recommended as six month follow-up is not adequate to measure this item. Furthermore, it is recommended to measure participant satisfaction with the use of web-based self-management intervention, drop-out rates in the control and intervention groups, numbers or percentage of people who did or did not consent to participate in the trial. To compare the web-based self-management intervention with the traditional mode of HF management system, it is recommended to perform the cost benefit analysis throughout the study. It is also recommended to identify a subgroup of HF patients that prefer and benefit from the web-based self-management intervention over traditional model.

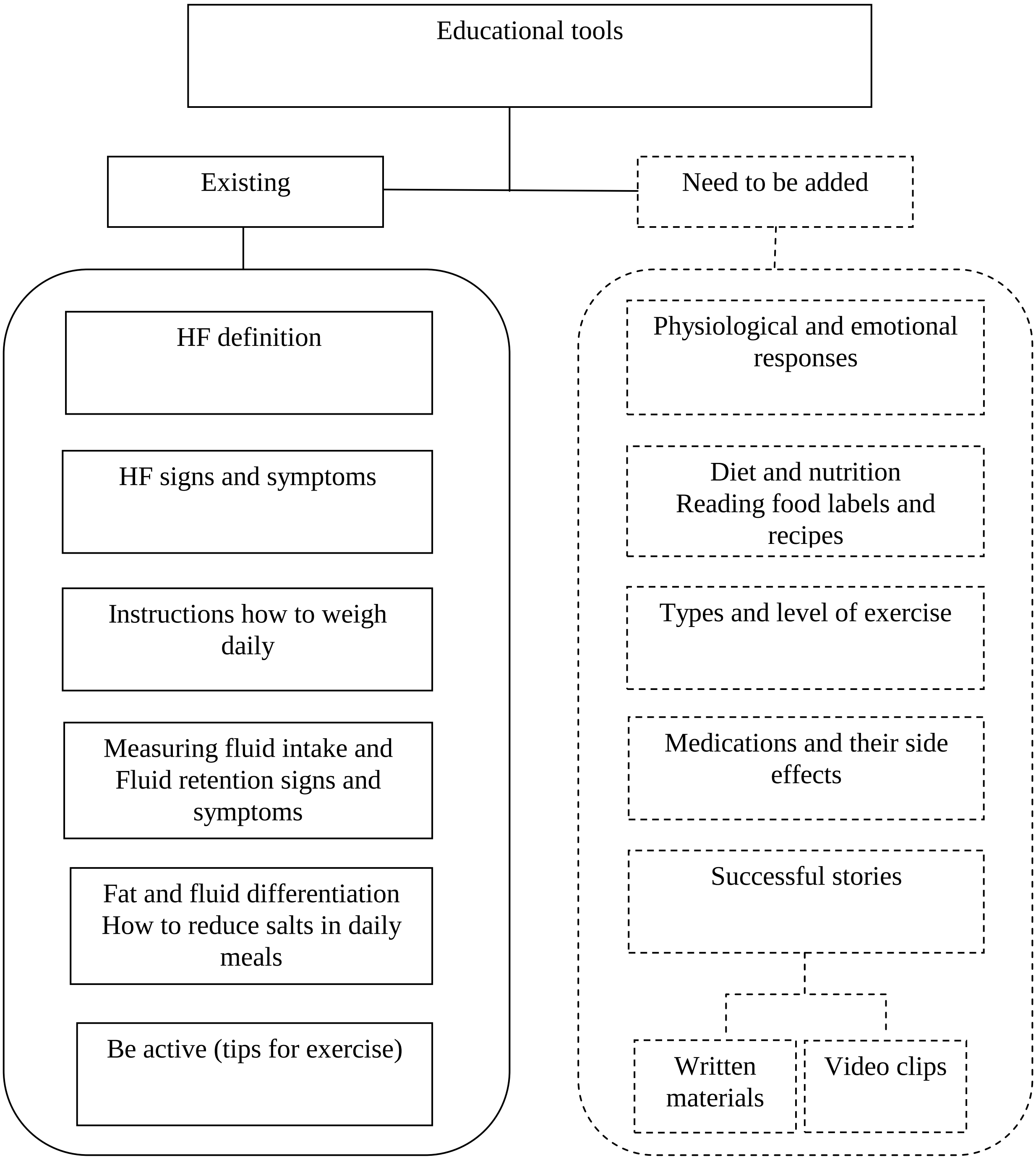

Figure 7.1 Modified Educational tools

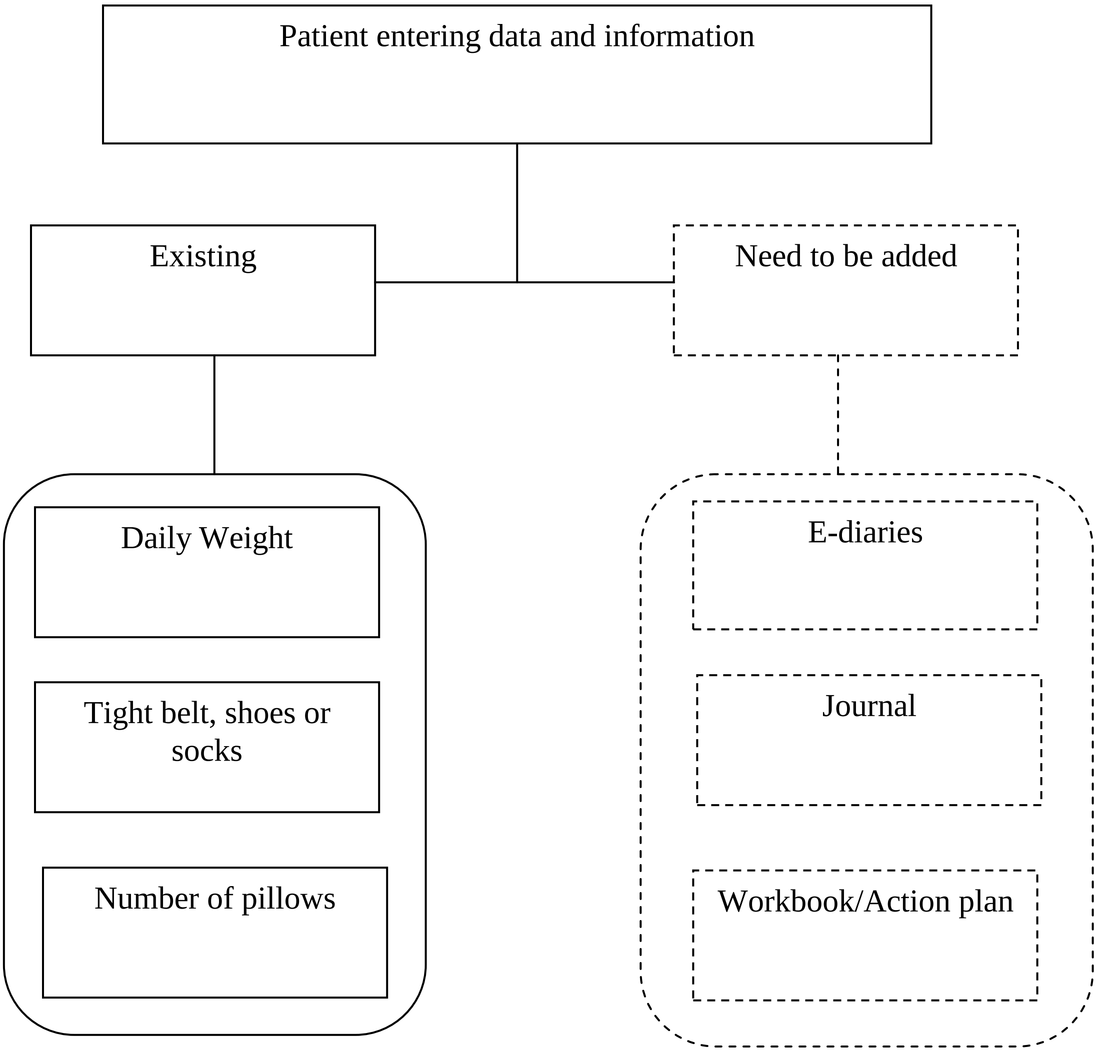

Figure 7.2 Patient Self-monitoring, motivation, and role modelling

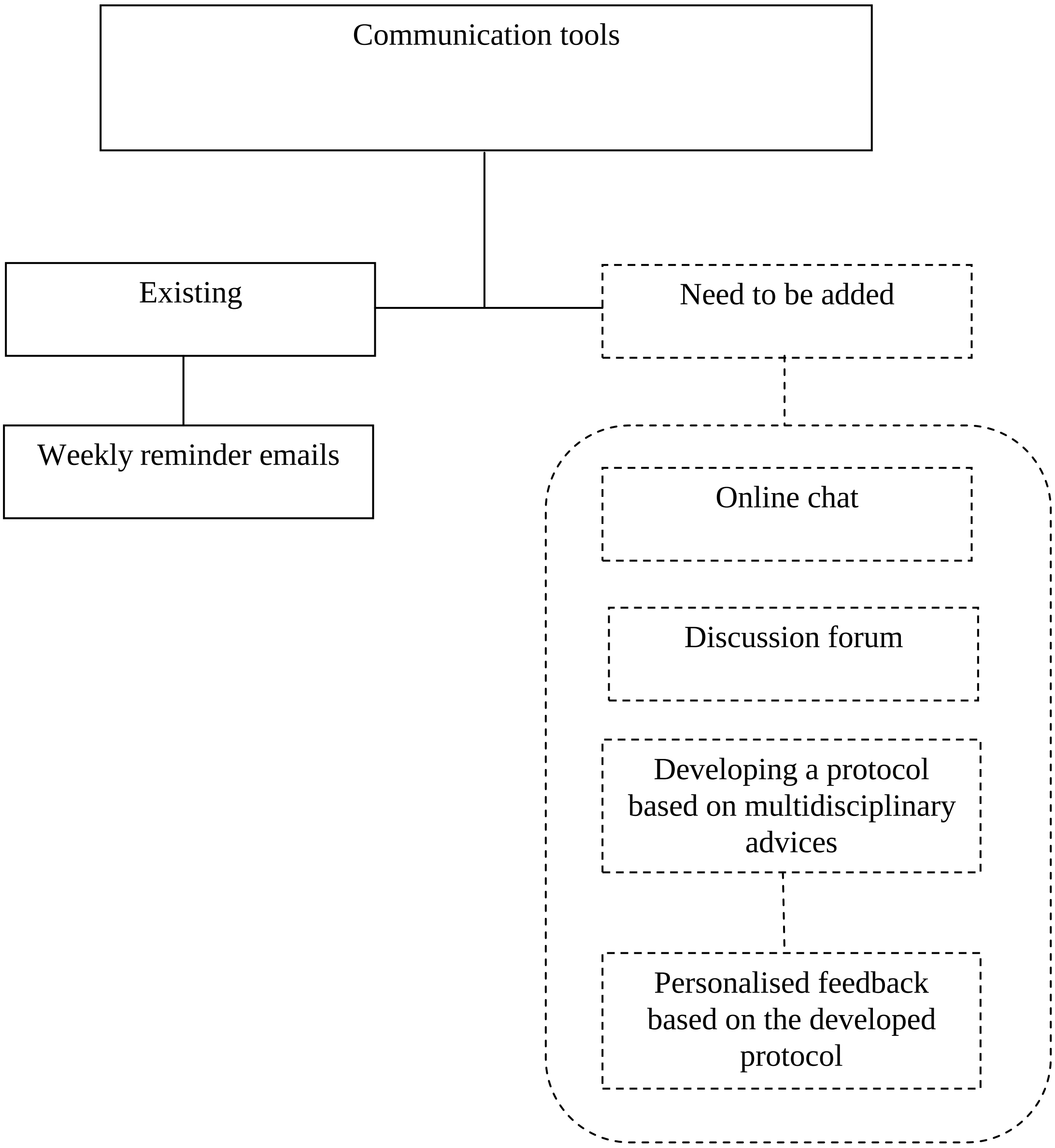

Figure 7.3 Communication tools

7.7. Summary

As the final stage of this pilot study, it is essential to assess the proposed web-based intervention and then to nominate modifications for future studies. Based on the outcomes of this study, obtained through a small sample size, it was found that the proposed intervention did not include all tools or methods required for more successful outcomes.

Consequently existing literature, related to self-management interventions based on Bandura's SE theory, was reviewed to identify the elements to be addressed in a revised web-based self-management intervention. It was found that previous research with successful outcomes used a more comprehensive educational tool, self-monitoring, verbal/ social persuasion, or communicating tool than that used in the proposed intervention. Hence, an intervention may be more resilient if it covers a combination of these methods and tools.

In arguing for the utilisation of these tools and methods in future studies, the discussion was organised around three critical areas, namely, educational tools; self-monitoring, motivation and role modelling; and communication tools.

Since it is essential for patients to be aware about their physiological and emotional responses related to their daily activities, it is important to provide them with appropriate information and that assists them to accurately interpret signs and symptoms associated with their condition. As a result, educational tools must be comprehensive and cover information related to nutrition and diet, physical activity, medication, effect of alcohol and smoking and emotional issues.

Performance accomplishments can be implemented through goal setting, self-monitoring and a rehearsal of desired behaviours through the use of diaries, journals and/or workbooks to assist participants to accurately monitor and interpret signs and symptoms. Furthermore, encouraging relative progress and task accomplishments could be based on participants' own abilities and questioning about their behaviours related to their condition through feedback and personalised messages.

Vicarious leaning or role modelling may be implemented in different ways. This may be applied by drawing participant attention to the relative progress of other patients of similar age and health condition. This can be done by providing successful stories. Another way to emphasise role modelling is through the use of an online discussion forum. This encourages participants to share their knowledge and experiences with peers.

It was also concluded that communication tools may consist of online chat, discussion forum, and personalised feedbacks. This will ensure good relationships between patients and health care providers.

7.8. Conclusion

A pilot study has been conducted to assess the feasibility of a web-based self-management intervention. The proposed intervention was developed based on the feedback from three groups including HF experts, IT team and HF patients. This process was to ensure that information and educational materials used in the proposed web-based application are valid and reliable.

Due to budgetary restriction, only key materials and tools were used in the proposed web-based intervention. This resulted in providing basic educational materials with limited self-monitoring tools and almost none effective communication tools.

Psychometrically validated instruments were used and appropriate research methodology was employed to examine the feasibility of the web-based self-management intervention. This was carried out by comparing two groups (intervention and control). Although sufficient time was considered for recruitment, the process was slow due to participants’ lack of internet access or ineligibility.

During the intervention, participants in the intervention group were asked to log-in to the web-based application every day and spend minimum 15 minutes to review the educational materials and enter their weight and possible HF signs and symptoms. The intervention group also received weekly email reminders from the researcher for four weeks. The control group received usual care. Outcomes of this study indicated that knowledge, self-management and self-efficacy of HF patients who received four weeks intervention did not change compared with that in the control group. This may be due to small sample size.

A more detailed comparison between the proposed intervention and previous research with successful outcomes showed that this pilot study suffered from number of limitations including but not limited to small sample size; short follow-up period; basic educational tools; inadequate self-monitoring and role modelling; and lack of proper communication tools. These may be reasons why participants didn’t effectively use the proposed intervention as results of this study showed that 50% of participants reviewed the web-based every day and 28% had no record of access.

Consequently, design and development of these types of interventions must be carefully executed in future research. Based on the existing literature and the use of a combination of the four primary sources of SE theory has the potential to improve patient outcomes. The proposed tools of a web-based intervention must function to assist patients to monitor and promote their behaviours and to demonstrate improvement in patients' clinical outcomes.

As the final stage of this study, a modified proposed web-based self-management intervention was developed based on outcomes of this pilot study and a comprehensive review of the literature. The proposed modifications include:

- Patient awareness about their physiological and emotional responses needs to be increased. Particular attention should be given to the relationship between patients' physiological and emotional responses and their daily activities. Thus it is important to provide appropriate information whereby patients can accurately interpret sign and symptoms associated with their condition. Hence, the educational tools shall not only consist of basic information but will be comprehensive and cover information related to nutrition and diet, physical activity, medication, effect of alcohol and smoking and emotional issues.

- The use of e-diaries and the preparation of a weekly journal can enhance performance accomplishment in patients with HF. Furthermore, interactive workbooks or action plans may assist participants to set goals and safely practice to gain desired behaviours. This will eventually lead to a better lifestyle. The use of above mentioned interventions may also encourage participants to more frequently use a self-management intervention and consequently may increase self-monitoring skills.

- Role modelling is another important factor that needs to be properly addressed through a web-based intervention. It may include stories from HF patients who successful managed their disease. This can be done by providing written materials or videos within the proposed intervention.

- Different types of communication tools may be used in a web-based intervention to maintain strong relationships between patients and health care providers and to strengthen social persuasion. These are online chat services that facilitate direct and real-time communication with health care professionals; online discussion forums that give opportunities to patients to be directly in contact with peers and facilitator/s; and personalised message services that enable healthcare professionals to send specific and encouraging messages to individual patients that are compatible with individual situations and are developed based on review of activity plans and e-diaries.

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Appendices

Appendix A: HREC Approval for Developing Web-based Application, Queensland Health

DARLING DOWNS –'WEST MORETON'
HEALTH SERVICE DISTRICT
HUMAN RESEARCH ETHICS COMMITTEE

To: Nazli Ghafouryan Gomish Bash (postgraduate research candidature)
School of Nursing and Midwifery,
Queensland University of Technology,
Institute of Health and Biomedical Innovation (IHBI)

Subject: (37-11) Teaching self-management in heart failure patients: development of prototype teaching tool and iPAD application. Nazli Ghafouryan Gomish Bashi, A/Prof Robyn Clark, Dr Jo Wu, L & HREC/11/QWMS/48, SSA/11/QWMS/49

Approval: under the National Statement on Ethical Conduct in Human Research 2007: 2.1.7 negligible risk

The Executive Director of Medical Services, Ipswich Hospital has now given formal approval for your study to commence in the DDWMHSD. This was upon the recommendation of the duly constituted, DD-WMHSD A/Chair & Research Governance Office (RGO). The DD-WMHSD Research Ethics Office operates and complies with the *NHMRC National Statement on Ethical Conduct in Research Involving Humans,* 2007 and is conducted according to the *ICH Harmonised Tripartite, Good Clinical Practice Guidelines* and the '*World Medical Association Declaration of Helsinki 2000'*.

IMMEDIATE NOTIFICATION

As a condition of approval, the Committee requires investigators to promptly report to the Research Governance Officer anything which might affect ethical acceptance of the study, including:

Proposed changes in the protocol.

Unforeseen events that might affect continued ethical acceptability of the study e.g. adverse effects on participants.

Any complaints or expressions of concern made in relation to the study.

Note: You are also required to notify Research Governance Officer on the completion or cessation of the study.

DATA COLLECTION

When conducting research within District facilities:

You are required to have this letter in your possession, as it is validation of research approval.

An ID needs to be worn.

The first point of contact on commencing research is the senior clinical staff person in the facility area.

MONITORING and REVIEW

An NHMRC requirement[1] is that ethics committees monitor approved research:

Every 12 months after initial approval you are required to complete and return an annual report form to maintain your approval status. The form may be found at the following URL address: http://www.health.qld.gov.au/ohmr/html/regu/reporting_templates.asp

---

[1] Please refer to your NEAF form section 9.3 Signatures and Undertakings

A report is required on completion of your research, this may take the form of a brief summary of findings or a paper submitted for publication. The form may be found at http://www.health.qld.gov.au/ohmr/documents/annual_rep_hrec.doc

The ethics committee may choose to conduct an interim audit of your research.

If the results of your project are to be published, please ensure that a copy of any publication or thesis is forwarded to the West Moreton Health Library for future reference.

You are required to sign and return this approval document (keep a copy for your files) to denote that you will follow all the conditions listed.

Please return the form to the Research Governance Officer DD-WMHSD Human Research Ethics Committee, The Park – Centre for Mental Health.

We wish you every success in your research project that you are now ethically sanctioned to commence.

Jacqueline Robinson, RN, BAA LLM

Jacqueline Robinson, RN, BAA, LLM

Acting -Chair, Ethics Officer, RGO, DD -WMHSD

Human Research Ethics Committee EC00184

The Park – Centre for Mental Health

Locked Bag 500

Sumner Park BC

QLD 4074

14th Dec 2011

Acceptance of Conditions of Approval

I Nazli G.G. Bashi acknowledge receipt of approval to undertake the above-mentioned study and agree to meet all of the above conditions.

__________ Title __________________ First name __________________________ Surname

______________________________ Position __________________________ Organisation name

………………………………………………………………… ……………………………………………

SIGNATURE DATE

Appendix B: HREC Approval for Developing Web-based Application, Queensland University of Technology

Ethics Application Approval -- 1200000062
QUT Research Ethics Unit
Sent:29 March 2012 17:25
To: NAZLI GHAFOURYAN GOMISH BASHI; Robyn Clark; Jo Wu
Cc: Janette Lamb
Dear Mrs Nazli Ghafouryan Gomish Bashi

Project Title:
Teaching self-management in heart failure patients: development and testing of a prototype teaching tool and iPad application

Approval Number: 1200000062
Clearance Until: 18/10/2012
Ethics Category: Human

This email is to advise that your application has been reviewed by the Chair, University Human Research Ethics Committee and confirmed as meeting the requirements of the National Statement on Ethical Conduct in Human Research.

Your application has received QUT administrative review approval based on the approval gained from the Queensland Health Human Research Ethics Committee (QH HREC). As such, QH HREC should be considered the lead HREC in terms of the ethical review of this project and all variations etc to the project should first be approved by the QH HREC and subsequently submitted to QUT for ratification.

If you require a formal approval certificate, please respond via reply email and one will be issued.

This project has been awarded ethical clearance until 18/10/2012 and a progress report must be submitted for an active ethical clearance at least once every twelve months. Researchers who fail to submit an appropriate progress report may have their ethical clearance revoked and/or the ethical clearances of other projects suspended. When your project has been completed please advise us by email at your earliest convenience.

For information regarding the use of social media in research, please go to:
http://www.research.qut.edu.au/ethics/humans/faqs/index.jsp

For variations, please ensure that approval has been sought from the lead university before completing and submit the QUT online variation form:
http://www.research.qut.edu.au/ethics/humans/applications.jsp#amend

Please do not hesitate to contact the unit if you have any queries.

Regards

Janette Lamb on behalf of the Chair UHREC

Research Ethics Unit | Office of Research
Level 4 | 88 Musk Avenue | Kelvin Grove
p: +61 7 3138 5123
e: ethicscontact@qut.edu.au
w: http://www.research.qut.edu.au/ethics/

Appendix C: Dutch Heart Failure Knowledge Questionnaire

1. How often should patients with severe heart failure weigh themselves?
☐every week
☐now and then
☐every day

2. Why is it important that patients with heart failure should weigh themselves regularly?

☐because many patients with heart failure have a poor appetite
☐to check whether the body is retaining fluid
☐to assess the right dose of medicines

3. How much fluid are you allowed to take at home each day?
☐1.5 to 2.5 liters at the most
☐as little fluid as possible
☐as much fluid as possible

4. Which of these statements is true?
☐when I cough a lot, it is better not to take my heart failure medication
☐when I am feeling better, I can stop taking my medication for heart failure.
☐it is important that I take my heart failure medication regularly

5. What is the best thing to do in case of increased shortness of breath or swollen legs?
☐call the doctor or the nurse
☐wait until the next check-up
☐take less medication

6. What can cause a rapid worsening of heart failure symptoms?
☐a high-fat diet
☐a cold or the flu
☐lack of exercise

7. What does heart failure mean?
☐that the heart is unable to pump enough blood around the body
☐that someone is not getting enough exercise and is in poor condition
☐that there is a blood clot in the blood vessels of the heart

8. Why can the legs swell up when you have heart failure?
☐because the valves in the blood vessels in the legs do not function properly
☐because the muscles in the legs are not getting enough oxygen
☐because of accumulation of fluid in the legs

9. What is the function of the heart?
☐to absorb nutrients from the blood
☐to pump blood around the body
☐to provide the blood with oxygen

10. Why should someone with heart failure follow a low salt diet?
☐salt promotes fluid retention
☐salt causes constriction of the blood vessels
☐salt increases the heart rate

11. What are the main causes of heart failure?
☐a myocardial infarction and high blood pressure
☐lung problems and allergy
☐obesity and diabetes

12. Which statement about exercise for people with heart failure is true?
☐it is important to exercise as little as possible at home in order to relieve the heart
☐it is important to exercise at home and to rest regularly in between
☐it is important to exercise as much as possible at home

13. Why are water pills prescribed to someone with heart failure?
☐to lower the blood pressure
☐to prevent fluid retention in the body
☐because then they can drink more

14. Which statement about weight increase and heart failure is true?
☐an increase of over 2 kilograms in 2 or 3 days should be reported to the doctor at the next check-up
☐in case of an increase of over 2 kilograms in 2 or 3 days, you should contact your doctor or nurse
☐in case of an increase of over 2 kilograms in 2 or 3 days, you should eat less

15. What is the best thing to do when you are thirsty?
☐suck an ice cube
☐suck a lozenge
☐drink a lot

Appendix D: Self-care Heart Failure Index Questionnaire

All answers are confidential.

- Think about how you have been feeling in the last month or since we last spoke as you complete these items.

SECTION A:

Listed below are common instructions given to persons with heart failure. How routinely 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. Keep doctor or nurse appointments?	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

SECTION B:

- Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure.
-
- In the past month, have you had trouble breathing or ankle swelling?

Circle one.

0) No

1) Yes

11. If you had trouble breathing or ankle swelling in the past month…

(circle **one** number)

	Have not had these	**I did not recognize it**	**Not Quickly**	**Somewhat Quickly**	**Quickly**	**Very Quickly**
How quickly did you recognize 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**
12. Reduce the salt in your diet	1	2	3	4
13. Reduce your fluid intake	1	2	3	4
14. Take an extra water pill	1	2	3	4
15. Call your doctor or nurse for guidance	1	2	3	4

16. 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 sure were you that the remedy helped or did not help?	0	1	2	3	4

SECTION C:

In general, how confident are you that you can:

	Not Confident	**Somewhat Confident**	**Very Confident**	**Extremely Confident**
17. Keep yourself free of heart failure symptoms?	1	2	3	4
18. Follow the treatment advice you have been given?	1	2	3	4
19. Evaluate the importance of your symptoms?	1	2	3	4
20. Recognize changes in your health if they occur?	1	2	3	4
21. Do something that will relieve your symptoms?	1	2	3	4
22. Evaluate how well a remedy works?	1	2	3	4

Appendix E: Self-efficacy for Managing Chronic Disease Questionnaire

We would like to know *how confident* you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

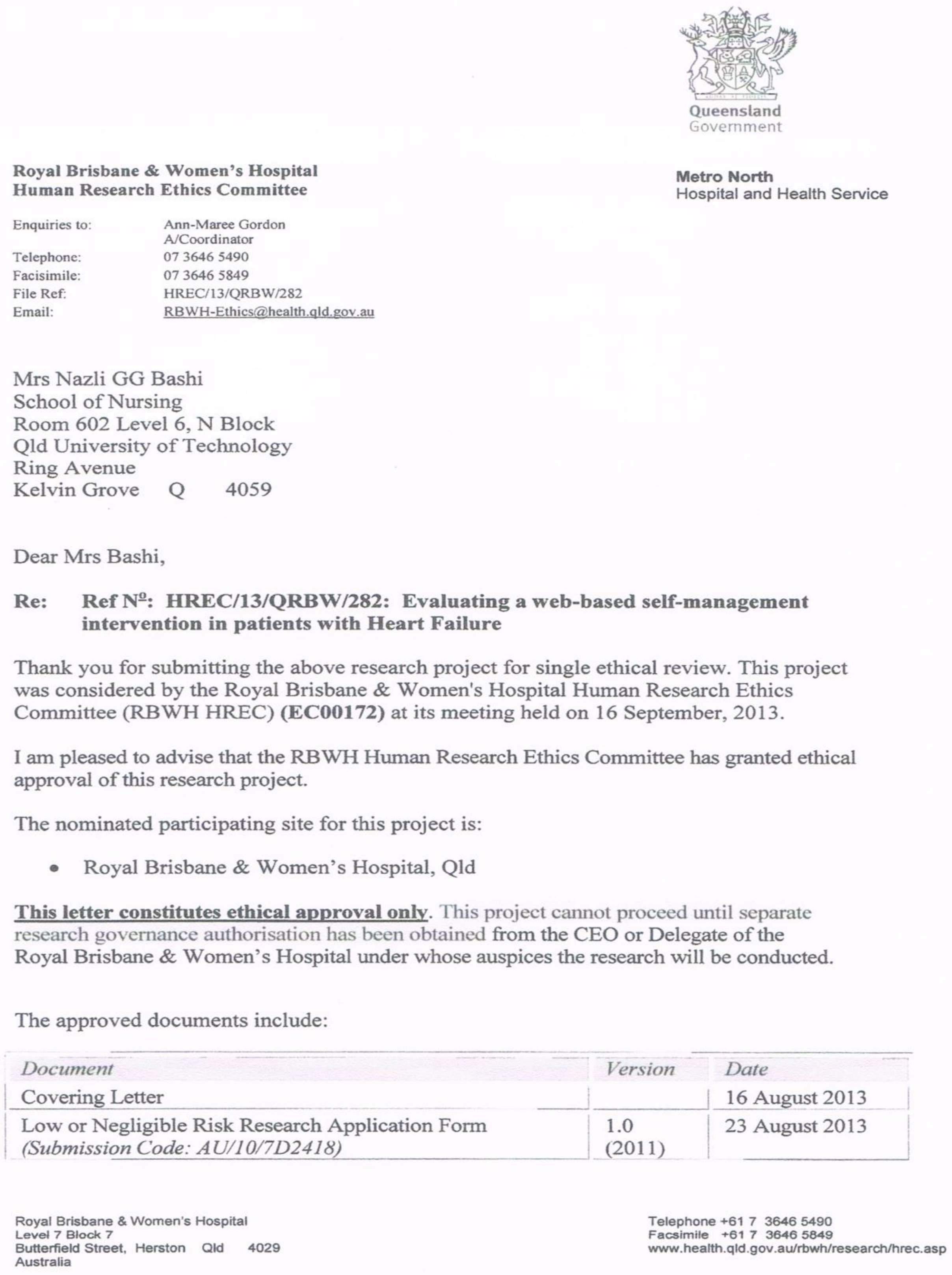
Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

Items (using the same format as above):

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?
3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?
5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?

6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?

Appendix F: HREC Approval for Evaluating Web-based self-management Intervention, Queensland Health



Queensland
Government

Royal Brisbane & Women's Hospital
Human Research Ethics Committee

Metro North
Hospital and Health Service

Enquiries to:	Ann-Maree Gordon A/Coordinator
Telephone:	07 3646 5490
Facisimile:	07 3646 5849
File Ref:	HREC/13/QRBW/282
Email:	RBWH-Ethics@health.qld.gov.au

Mrs Nazli GG Bashi
School of Nursing
Room 602 Level 6, N Block
Qld University of Technology
Ring Avenue
Kelvin Grove Q 4059

Dear Mrs Bashi,

Re: Ref Nº: HREC/13/QRBW/282: Evaluating a web-based self-management intervention in patients with Heart Failure

Thank you for submitting the above research project for single ethical review. This project was considered by the Royal Brisbane & Women's Hospital Human Research Ethics Committee (RBWH HREC) **(EC00172)** at its meeting held on 16 September, 2013.

I am pleased to advise that the RBWH Human Research Ethics Committee has granted ethical approval of this research project.

The nominated participating site for this project is:

- Royal Brisbane & Women's Hospital, Qld

This letter constitutes ethical approval only. This project cannot proceed until separate research governance authorisation has been obtained from the CEO or Delegate of the Royal Brisbane & Women's Hospital under whose auspices the research will be conducted.

The approved documents include:

Document	*Version*	*Date*
Covering Letter		16 August 2013
Low or Negligible Risk Research Application Form *(Submission Code: AU/10/7D2418)*	1.0 (2011)	23 August 2013

Royal Brisbane & Women's Hospital
Level 7 Block 7
Butterfield Street, Herston Qld 4029
Australia

Telephone +61 7 3646 5490
Facsimile +61 7 3646 5849
www.health.qld.gov.au/rbwh/research/hrec.asp

Document	*Version*	*Date*
Self-efficacy for Managing Chronic Disease Questionnaire		
Self-Care of Heart Failure Index Questionnaire		
Dutch Heart Failure Knowledge Questionnaire		
Curriculum Vitae of Nazli GG Bashi		
Response to Request for Further Information *(received 10 October 2013)*		
Withdrawal of Participation Form	1	08 October 2013
"Living well with Chronic Heart Failure" Advertising Poster		
Response to Request for Further Information		24 October, 2013
Study Protocol	R3	October 2013
Participant Consent Form	3	18 November 2013
Response to Request for Further Information		01 November 2013
Participant Information Sheet	4	29 November 2013

Approval of this project from the RBWH HREC is valid from **04.11.2013** to **04.11.2016** subject to the following conditions being met:

- The Coordinating Principal Investigator will immediately report anything that might warrant review of ethical approval of the project.
- The Coordinating Principal Investigator will notify the RBWH HREC of any event that requires a modification to the protocol or other project documents and submit any required amendments in accordance with the instructions provided by the HREC. These instructions can be found at http://www.health.qld.gov.au/rbwh/research/hrec.asp.
- The Coordinating Principal Investigator will submit any necessary reports related to the safety of research participants in accordance with the RBWH HREC policy and procedures. These instructions can be found at http://www.health.qld.gov.au/rbwh/research/hrec.asp.
- In accordance with Section 3.3.22 (b) of the National Statement the Coordinating Principal Investigator will report to the RBWH HREC annually in the specified format, the first report being due on **04.11.2014** and a final report is to be submitted on completion of the study. These instructions can be found at http://www.health.qld.gov.au/ohmr/html/regu/reporting_templates.asp.
- The Coordinating Principal Investigator will notify the RBWH HREC if the project is discontinued before the expected completion date, with reasons provided.
- The Coordinating Principal Investigator will notify the RBWH HREC of any plan to extend the duration of the project past the approval period listed above and will submit any

associated required documentation. Instructions for obtaining an extension of approval can be found at http://www.health.qld.gov.au/rbwh/research/hrec.asp.

- The Coordinating Principal Investigator will notify the RBWH HREC of his or her inability to continue as Coordinating Principal Investigator including the name of and contact information for a replacement.
- A copy of this ethical approval letter together with completed Site Specific Assessment (SSA) and any other requirements must be submitted by the Coordinating Principal Investigator to the Research Governance Office at the Royal Brisbane & Women's Hospital in a timely manner to enable the institution to authorise the commencement of the project at its site.
- Should you have any queries about the RBWH HREC's consideration of your project please contact the HREC Coordinator on 07 3646 5490. The RBWH HREC's Terms of Reference, Standard Operating Procedures, membership and standard forms are available from http://www.health.qld.gov.au/rbwh/research/hrec.asp.

The RBWH HREC wishes you every success in your research.

Yours sincerely,

Dr Conor Brophy
Chairperson RBWH Human Research Ethics Committee
Metro North Hospital and Health Service
04.11.2013

Appendix G: HREC Approval for Evaluating Web-based self-management Intervention, Queensland University of Technology and Variation

QUT Research Ethics Unit

Actions
To: Clint Douglas ;Nazli Ghafouryan Gomish Bashi
Cc: Janette Lamb

27 November 2013 14:44

You forwarded this message on 27/11/2013 14:58.
Dear Dr Clint Douglas and Mrs Nazli Ghafouryan Gomish Bashi

Project Title: Evaluating a web-based self-management intervention in patients with heart failure

Ethics category: Human - Administrative Review
QUT approval number: 1300000753 (As per Royal Brisbane and Women's Hospital, Approval number: HREC/13/QRBW/282)
QUT clearance until: 4/11/2016

We are pleased to advise that your administrative review application has been reviewed by the Chair, University Human Research Ethics Committee (UHREC), and confirmed as meeting the requirements of the National Statement on Ethical Conduct in Human Research (2007).

I can therefore confirm that your application has received QUT administrative review approval based on the approval gained from the responsible Human Research Ethics Committee (HREC). We note this HREC has awarded the project ethical clearance until 4/11/2016.

CONDITIONS OF APPROVAL
Please ensure you and all other team members read through and understand all UHREC conditions of approval prior to commencing any data collection:
- Standard: Please see attached or www.research.qut.edu.au/ethics/humans/stdconditions.jsp
- Specific: None apply

Projects approved through an external organisation may be subject to that organisation's review arrangements. Researchers must immediately notify the QUT Research Ethics Unit if their project is selected for investigation / review by an external organisation.

VARIATIONS
All variations must first be approved by the responsible HREC before submission to QUT for ratification. Once approval has been obtained please submit this to QUT using our online variation form:
www.research.qut.edu.au/ethics/humans/var/

MONITORING
Please ensure you also provide QUT with a copy of each adverse event report and progress report submitted to the responsible HREC.

Administrative review decisions are subject to ratification at the next available UHREC meeting. You will only be contacted again in relation to this matter if UHREC raises additional questions or concerns.

Please don't hesitate to contact us if you have any queries.

We wish you all the best with your research.

Kind regards

Janette Lamb on behalf of the Chair UHREC
Research Ethics Unit | Office of Research | Level 4 88 Musk Avenue
Kelvin Grove | Queensland University of Technology
p: +61 7 3138 5123 | e: ethicscontact@qut.edu.au | w:
www.research.qut.edu.au/ethics/

QUT Research Ethics Unit

Actions
To: Clint Douglas; Nazli Ghafouryan Gomish Bashi
Cc: Janette Lamb

10 April 2014 09:30
Dear Dr Clint Douglas and Mrs Nazli Ghafouryan Gomish Bashi

Approval #: 1300000753
End Date: 4/11/2016
Project Title: Evaluating a web-based self-management intervention in patients with heart failure

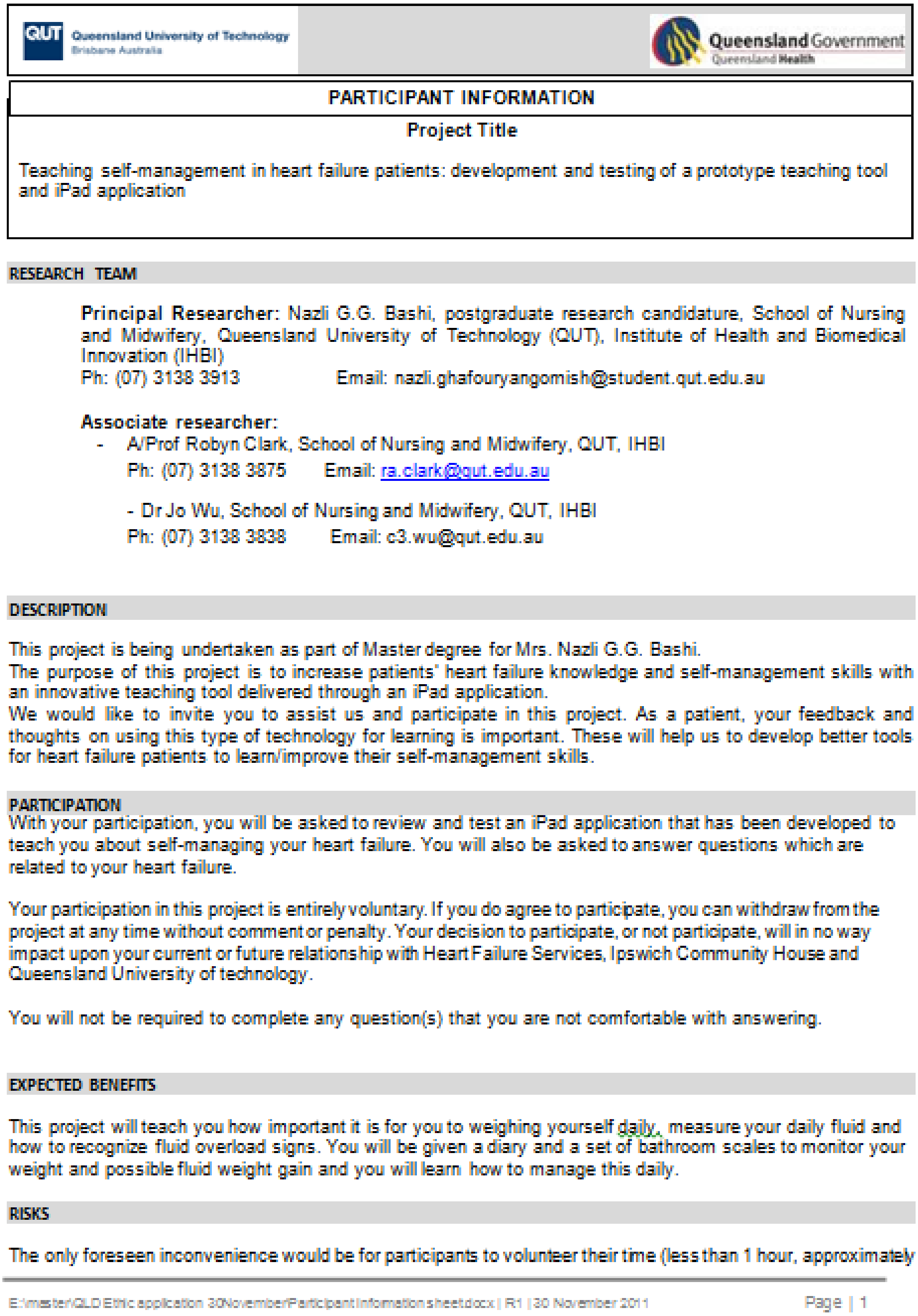
This email is to advise that your variation has been considered by the Chair, University Human Research Ethics Committee.

Approval has been provided to:

< Add the QUT Health Clinic as a study site (approval from Clinic received).
< We note the anticipated end date is 01/07/2014.

Please submit a variation to RBWH to approve the above.

Appendix H: Patient Information Form – Phase One



QUT Queensland University of Technology
Brisbane Australia

Queensland Government
Queensland Health

PARTICIPANT INFORMATION

Project Title

Teaching self-management in heart failure patients: development and testing of a prototype teaching tool and iPad application

RESEARCH TEAM

Principal Researcher: Nazli G.G. Bashi, postgraduate research candidature, School of Nursing and Midwifery, Queensland University of Technology (QUT), Institute of Health and Biomedical Innovation (IHBI)
Ph: (07) 3138 3913 Email: nazli.ghafouryangomish@student.qut.edu.au

Associate researcher:

- A/Prof Robyn Clark, School of Nursing and Midwifery, QUT, IHBI
  Ph: (07) 3138 3875 Email: ra.clark@qut.edu.au
- Dr Jo Wu, School of Nursing and Midwifery, QUT, IHBI
  Ph: (07) 3138 3838 Email: c3.wu@qut.edu.au

DESCRIPTION

This project is being undertaken as part of Master degree for Mrs. Nazli G.G. Bashi.
The purpose of this project is to increase patients' heart failure knowledge and self-management skills with an innovative teaching tool delivered through an iPad application.
We would like to invite you to assist us and participate in this project. As a patient, your feedback and thoughts on using this type of technology for learning is important. These will help us to develop better tools for heart failure patients to learn/improve their self-management skills.

PARTICIPATION

With your participation, you will be asked to review and test an iPad application that has been developed to teach you about self-managing your heart failure. You will also be asked to answer questions which are related to your heart failure.

Your participation in this project is entirely voluntary. If you do agree to participate, you can withdraw from the project at any time without comment or penalty. Your decision to participate, or not participate, will in no way impact upon your current or future relationship with Heart Failure Services, Ipswich Community House and Queensland University of technology.

You will not be required to complete any question(s) that you are not comfortable with answering.

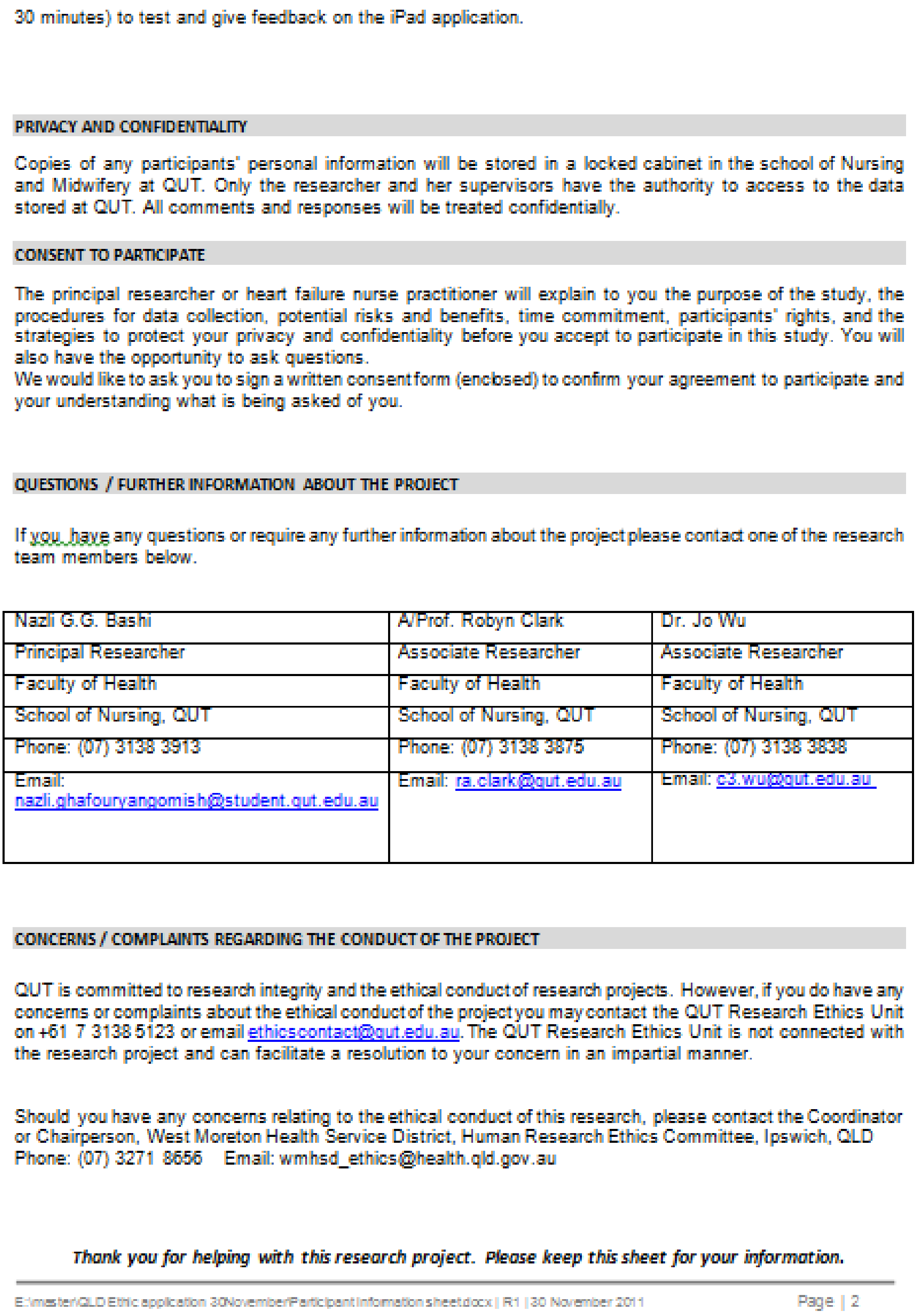
EXPECTED BENEFITS

This project will teach you how important it is for you to weighing yourself daily, measure your daily fluid and how to recognize fluid overload signs. You will be given a diary and a set of bathroom scales to monitor your weight and possible fluid weight gain and you will learn how to manage this daily.

RISKS

The only foreseen inconvenience would be for participants to volunteer their time (less than 1 hour, approximately

E:\master\QLD Ethic application 30November\Participant Information sheet.docx | R1 | 30 November 2011 Page | 1



30 minutes) to test and give feedback on the iPad application.

PRIVACY AND CONFIDENTIALITY

Copies of any participants' personal information will be stored in a locked cabinet in the school of Nursing and Midwifery at QUT. Only the researcher and her supervisors have the authority to access to the data stored at QUT. All comments and responses will be treated confidentially.

CONSENT TO PARTICIPATE

The principal researcher or heart failure nurse practitioner will explain to you the purpose of the study, the procedures for data collection, potential risks and benefits, time commitment, participants' rights, and the strategies to protect your privacy and confidentiality before you accept to participate in this study. You will also have the opportunity to ask questions.
We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate and your understanding what is being asked of you.

QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If you have any questions or require any further information about the project please contact one of the research team members below.

Nazli G.G. Bashi	A/Prof. Robyn Clark	Dr. Jo Wu
Principal Researcher	Associate Researcher	Associate Researcher
Faculty of Health	Faculty of Health	Faculty of Health
School of Nursing, QUT	School of Nursing, QUT	School of Nursing, QUT
Phone: (07) 3138 3913	Phone: (07) 3138 3875	Phone: (07) 3138 3838
Email: nazli.ghafouryangomish@student.qut.edu.au	Email: ra.clark@qut.edu.au	Email: c3.wu@qut.edu.au

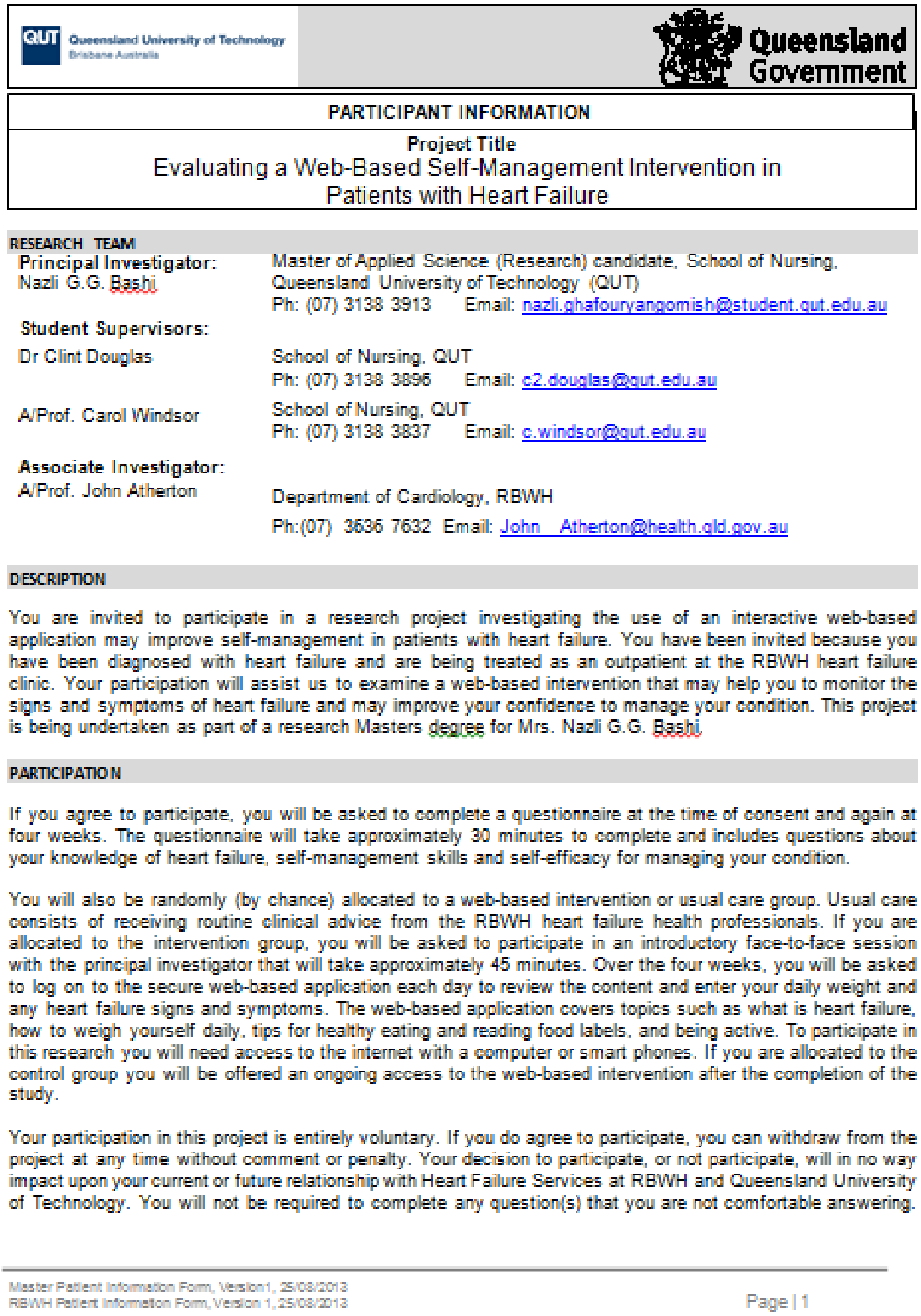
CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT

QUT is committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Unit on +61 7 3138 5123 or email ethicscontact@qut.edu.au. The QUT Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Should you have any concerns relating to the ethical conduct of this research, please contact the Coordinator or Chairperson, West Moreton Health Service District, Human Research Ethics Committee, Ipswich, QLD
Phone: (07) 3271 8656 Email: wmhsd_ethics@health.qld.gov.au

Thank you for helping with this research project. Please keep this sheet for your information.

Appendix I: Patient Information Form – Phase Two



Queensland University of Technology
Brisbane Australia

Queensland Government

PARTICIPANT INFORMATION

Project Title

Evaluating a Web-Based Self-Management Intervention in Patients with Heart Failure

RESEARCH TEAM

Principal Investigator: Nazli G.G. Bashi	Master of Applied Science (Research) candidate, School of Nursing, Queensland University of Technology (QUT) Ph: (07) 3138 3913 Email: nazli.ghafouryangomish@student.qut.edu.au
Student Supervisors:	
Dr Clint Douglas	School of Nursing, QUT Ph: (07) 3138 3896 Email: c2.douglas@qut.edu.au
A/Prof. Carol Windsor	School of Nursing, QUT Ph: (07) 3138 3837 Email: c.windsor@qut.edu.au
Associate Investigator: A/Prof. John Atherton	Department of Cardiology, RBWH Ph:(07) 3636 7632 Email: John_Atherton@health.qld.gov.au

DESCRIPTION

You are invited to participate in a research project investigating the use of an interactive web-based application may improve self-management in patients with heart failure. You have been invited because you have been diagnosed with heart failure and are being treated as an outpatient at the RBWH heart failure clinic. Your participation will assist us to examine a web-based intervention that may help you to monitor the signs and symptoms of heart failure and may improve your confidence to manage your condition. This project is being undertaken as part of a research Masters degree for Mrs. Nazli G.G. Bashi.

PARTICIPATION

If you agree to participate, you will be asked to complete a questionnaire at the time of consent and again at four weeks. The questionnaire will take approximately 30 minutes to complete and includes questions about your knowledge of heart failure, self-management skills and self-efficacy for managing your condition.

You will also be randomly (by chance) allocated to a web-based intervention or usual care group. Usual care consists of receiving routine clinical advice from the RBWH heart failure health professionals. If you are allocated to the intervention group, you will be asked to participate in an introductory face-to-face session with the principal investigator that will take approximately 45 minutes. Over the four weeks, you will be asked to log on to the secure web-based application each day to review the content and enter your daily weight and any heart failure signs and symptoms. The web-based application covers topics such as what is heart failure, how to weigh yourself daily, tips for healthy eating and reading food labels, and being active. To participate in this research you will need access to the internet with a computer or smart phones. If you are allocated to the control group you will be offered an ongoing access to the web-based intervention after the completion of the study.

Your participation in this project is entirely voluntary. If you do agree to participate, you can withdraw from the project at any time without comment or penalty. Your decision to participate, or not participate, will in no way impact upon your current or future relationship with Heart Failure Services at RBWH and Queensland University of Technology. You will not be required to complete any question(s) that you are not comfortable answering.

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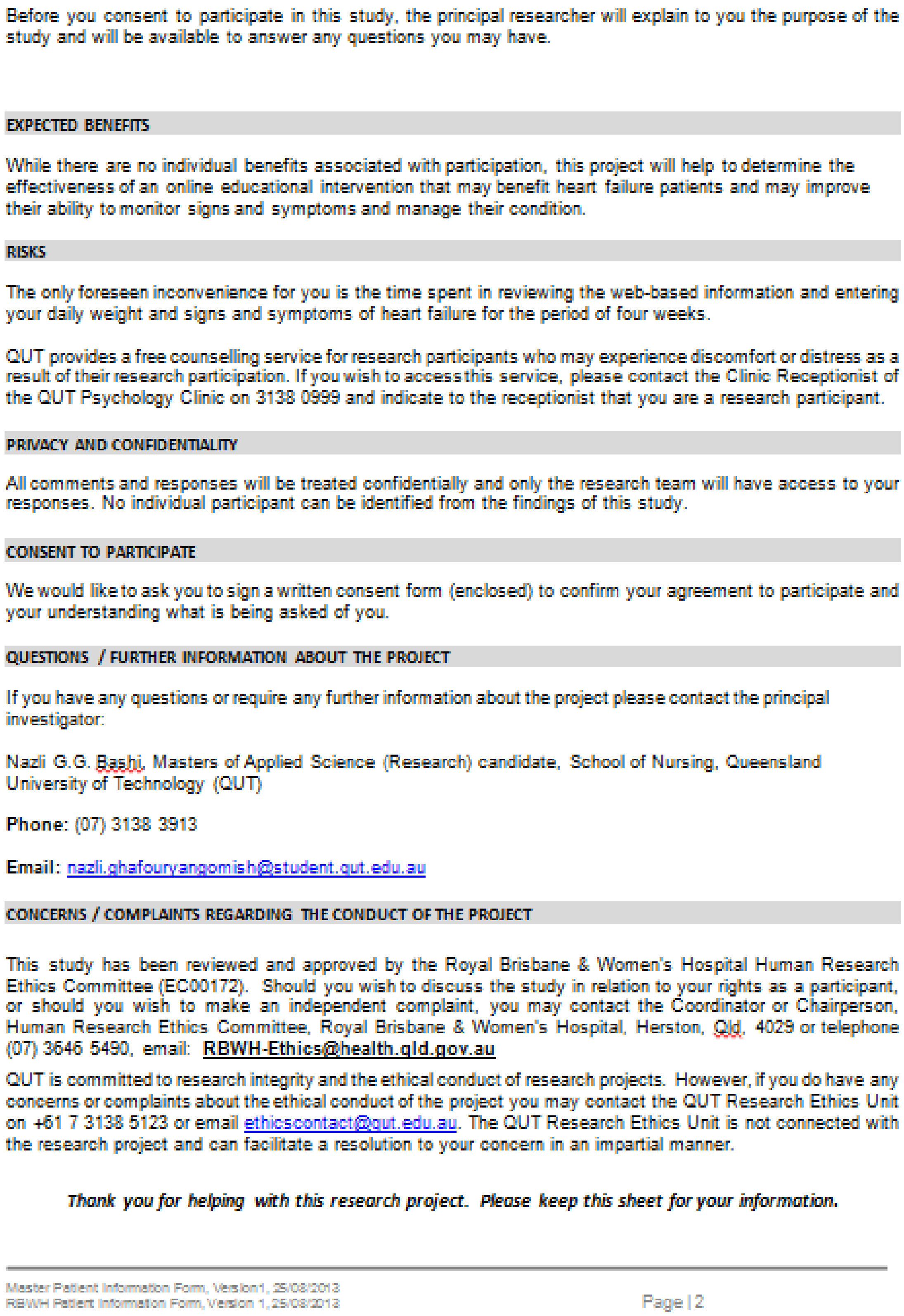

Before you consent to participate in this study, the principal researcher will explain to you the purpose of the study and will be available to answer any questions you may have.

EXPECTED BENEFITS

While there are no individual benefits associated with participation, this project will help to determine the effectiveness of an online educational intervention that may benefit heart failure patients and may improve their ability to monitor signs and symptoms and manage their condition.

RISKS

The only foreseen inconvenience for you is the time spent in reviewing the web-based information and entering your daily weight and signs and symptoms of heart failure for the period of four weeks.

QUT provides a free counselling service for research participants who may experience discomfort or distress as a result of their research participation. If you wish to access this service, please contact the Clinic Receptionist of the QUT Psychology Clinic on 3138 0999 and indicate to the receptionist that you are a research participant.

PRIVACY AND CONFIDENTIALITY

All comments and responses will be treated confidentially and only the research team will have access to your responses. No individual participant can be identified from the findings of this study.

CONSENT TO PARTICIPATE

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate and your understanding what is being asked of you.

QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If you have any questions or require any further information about the project please contact the principal investigator:

Nazli G.G. Bashi, Masters of Applied Science (Research) candidate, School of Nursing, Queensland University of Technology (QUT)

Phone: (07) 3138 3913

Email: nazli.ghafouryangomish@student.qut.edu.au

CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT

This study has been reviewed and approved by the Royal Brisbane & Women's Hospital Human Research Ethics Committee (EC00172). Should you wish to discuss the study in relation to your rights as a participant, or should you wish to make an independent complaint, you may contact the Coordinator or Chairperson, Human Research Ethics Committee, Royal Brisbane & Women's Hospital, Herston, Qld, 4029 or telephone (07) 3646 5490, email: **RBWH-Ethics@health.qld.gov.au**

QUT is committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Unit on +61 7 3138 5123 or email ethicscontact@qut.edu.au. The QUT Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

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