

Developing a Patient-Centred Management Program for People with Heart Failure in Jordan

Osama Ahmad Alkouri

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Abstract

Despite the medical advancement in heart failure (HF) management strategies, HF remains a condition that has significant physical, psychological, and social negative impacts on patients. Previous heart failure management programs have produced inconsistent results, and failed to determine an effective intervention that attains clinical stability. While the effectiveness of therapeutic options / elements for HF has been determined, a practice gap exists around how best to structure and deliver the therapeutic options.

As a developing country Jordan has a limited health budget and infrastructure, as well as a lack of well-structured health care services for chronic diseases. In addition, there have been dramatic increases in prevalence of ischemic heart disease, diabetes, and hypertension, and other risk factors for heart failure (HF) attributed to sedentary lifestyles and dietary shifts. Therefore, an effective HF management program that is contextualised and feasible is needed. According to the literature, patient-centred care can be effective in improving HF knowledge, adherence to self-care, communication between patients and healthcare provider, and psychological status. Tailoring interventions is an important part of patient empowerment or patient centredness in which the interventions are specifically designed for patients based on careful assessments.

This mixed methods study proposes a patient-centred HF management program that is tailored to the Jordanian context and patients' needs. It involved two studies. The first study was a cross sectional survey. The second study comprised two components: a Delphi study of clinicians and focus groups for patients. The cross sectional study (survey) was conducted with a convenience sample of 300 Jordanian patients with HF. The outcomes that were measured included: (i) heart failure knowledge, (ii) self-care, (iii) treatment adherence, and (iv) quality of life (QOL). The Delphi study utilised seven clinicians and policy makers. The two focus groups included the same seven HF patients recruited from cardiac out-patient clinics. The main purpose for study two was to derive consensus from clinicians (using the Delphi method) and understand the perspectives of patients (using focus groups) on a more patient-centred model of HF management.

Study I (quantitative study) showed that Jordanian HF patients had a moderate level of knowledge, a moderate self-care, poor adherence, and moderate quality of life. Males had higher knowledge than females. Only 3% of patients were informed to weigh themselves every day, and to watch the fluid status. Regarding self-care, most patients disagreed that they would

contact their doctor or nurse if they gained 2 kg in one week (92%), and 83% disagreed with monitoring their weight every day. Unmarried and illiterate patients had poorer self-care than their counterparts. Activities with the lowest levels of adherence were: reducing or quitting smoking, and self-weighing. The predictors of quality of life were insomnia, marital status, previous hospitalisation, and employment.

Regarding patients' focus groups, eight themes emerged from the first focus group, including emotional impact of HF, Motivation to change lifestyle, Adjustment to treatment, Physical impact of HF, Loss of social interaction, and Impact of religion. Three themes emerged from the second focus group, involving the effectiveness of teaching sessions in cardiac clinic, suggestions for improving the educational program, and appropriateness of educational material.

The Delphi study found consensus for the feasibility of different HF components: lifestyle brochure, nutrition card, and follow up phone call program, cardiac rehabilitation program, and group discussion session. The mixed methods study revealed that there were increased HF risk factors and sedentary behaviours for people with HF in Jordan, poor HF education, psychological distress, social isolation, and ineffective communication between patients and healthcare providers.

The Jordanian healthcare system will need to implement a patient-centred heart failure management program that is tailored to Jordan context and patient's needs. The proposed program from this study was determined to be feasible, appropriate, and applicable in Jordan, embracing three main elements that should be delivered to patients across the whole continuum of care process. These were targeted education, psychological support, and social support.

Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint award of this degree.

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Osama Alkouri

6/11/2019

Signature:

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Acronyms

AHA	American Heart Association
AF	Atrial Fibrillation
BP	Blood Pressure
CAD	Coronary Artery Disease
CDC	Centre for Disease Control and Prevention
CHVs	Community Health Volunteers
COPD	Chronic obstructive Pulmonary Disease
CR	Cardiac Rehabilitation
CVD	Cardiovascular Disease
DM	Diabetes
HF	Heart Failure
HTN	Hypertension
LMICs	Low-Middle Income Countries
Mhealth	Mobile Health
MOH	Ministry of Health
NCDs	None Communicable Diseases
NHFA	National Heart Foundation of Australia
PIS	Participant Information Sheet
QOL	Quality of Life
RMS	Royal Medical Services
US	United States
WHO	World Health Organisation

Definitions

Adherence: the extent to which the patient follows medical instructions provided by healthcare providers (Jimmy & Jose 2011, p. 155).

Patient-centred care: the provision of care that is respectful and responsive to a patient's preferences, needs, values, and perceives patients as leaders of their clinical care (Casimir et al. 2013, p. 109).

Self-care: the process by which individuals are likely to engage in daily activities to achieve clinical and functional stability, and has been described as a crucial component in the management of heart failure patients (Bidwell et al. 2015, p. 2).

Self-management: assisting patients with developing new knowledge and skills to perform new healthcare behaviours, and to maximise their capability in managing physical symptoms, psychosocial consequences, and changes in lifestyle (Grady & Gough 2014, p. 27).

Tailoring interventions: the individual customisation of interventions to particular needs preferences, and capabilities (Hawkins et al. 2008, p. 2)

Chapter 1: Introduction

1.1 Background to the study: Jordan

The research reported in this thesis was conducted using a mixed-methods approach to inform the development of a patient-centred heart failure program that is tailored to the Jordanian context. The first half of this chapter describes the Jordanian context including Jordan's geography, population, gender issues, religion, health system and political context. The second half will describe the burden of HF, the importance of HF management, the study's aims, its significance, and research questions

1.1.1 Geography of Jordan

Jordan is a low-to-middle income country located in the Middle East. It is bound by Syria to the north, Iraq to the northeast, Saudi Arabia to the east and south, the Red Sea to the south, and the occupied West Bank and Israel to the west (Figure 1.1) (World Health Organisation 2006). The area of Jordan is about 89,000 square kilometres, and it is characterised by a high diversity of natural and ecological systems (WHO 2006). The majority of the land in Jordan is desert plateau, but the Jordan Valley is semitropical (WHO 2006). Jordan has scarce natural resources and water supplies. Therefore, efforts have been made to develop the human resources of the country, considered the most valuable asset and a strategic pillar (World Health Organisation 2006).

The climate of Jordan is characterised by warm, dry summers and mild, wet winters, with annual average temperatures ranging from 12 to 25° C and summertime highs reaching 40° C in the desert regions. Rainfall averages vary from 50 mm annually in the desert to 800 mm in the northern hills, some of which falls as snow. Jordan is home to the Dead Sea, which is considered the lowest point on earth, lying 408 metres below sea level. The highest point in Jordan, in contrast, is Jebel Umm El Dami, which lies 1854 metres above sea level (World Health Organisation 2006).



Figure 1.1: Map of Jordan illustrating political borders

1.1.2 Population of Jordan

Jordan currently has a population of around 9,456,000 people (World Health Organisation 2016), nearly 17% of which reside in rural areas (World Health Organization 2015b). More than 70% of the population in Jordan are young (under 30 years of age), those between the age of 15 and 24 comprise 18.3% of the population. The population is distributed among 12 governorates, with the higher population densities in Amman and Irbid, the largest governorates in Jordan (World Health Organisation 2006). The census conducted in 2015 reported a large spike in Jordan's population in 2011 due to an intake of one million Syrian refugees (Jordan Population and Housing Census 2015). The Jordanian population is expected to increase dramatically over the next 50 years, attributed to high total fertility rates, and a declining mortality rate. The future population growth will place pressure on several pivotal sectors in the country such as the economy, the healthcare system and education (World Health Organisation & The High Health Council 2015-2019). In 2012, the literacy rate was 97.9

among adult males and 97.4 among adult females (World Health Organization 2015b). The unemployment rate is approximately 37% (Department of Statistics 2019).

1.1.3 Females in labour force in Jordan

In spite of the high adult female literacy rate (97.4%), women's involvement in the labour force is relatively low (15.3%), which is not unusual for a developing country (World Health Organization 2015b). Women who are or have been married have the lowest labour force participation rate of 11.8%, while the rate for women who are unmarried or never married stands at 20.5% (Kokusai Kogyo Co. 2016; World Health Organisation 2006). Approximately 50% of employed women work in the public sector, as government work offers better job security, shorter working hours, and is more flexible to accommodate family responsibilities. Only 4% of employees in the highest level of the civil service are women, indicating that women occupy the lower positions of the civil service (Kokusai Kogyo Co. 2016).

1.1.4 Religion in Jordan

Islam is the most common religion in Jordan. Muslims make up about 92% of the country's population, among which 93% identify as Sunnis (The Embassy of the Hashemite Kingdom of Jordan Washington 2016). Other minorities present include Ahmadi Muslims, and some Shiites. Many Shia are Iraqi and Lebanese refugees. Jordan also hosts one of the oldest Christian communities in the world, with Greek Orthodox and Roman Catholics comprising about 4% of the total population (The Embassy of the Hashemite Kingdom of Jordan Washington 2016). Jordan also includes around 20,000 to 32,000 Druze living mostly in the north of Jordan in addition to 800 Jordanian Bahá'ís, mainly living in Addassia village near the Jordan Valley. Bahá'ís and religious minorities practice freely in Jordan (The Embassy of the Hashemite Kingdom of Jordan Washington 2016). Although the Jordanian government has no legal restrictions on Jews, in 2006 there were reported to be no Jewish citizens in Jordan.

1.1.5 Jordanian health system

1.1.5.1 Governance of the health system

Within the Middle East, Jordan's health sector is considered one of the most advanced. There are three major sectors offering health: the public, private and international sectors. The public sector involves the Ministry of Health (MOH) and Royal Medical Services (RMS). University-based programs such as Jordan University Hospital in Amman and King Abdullah Hospital in Irbid are also included. The private sector offers healthcare services through private hospitals

and hundreds of private clinics, and therapeutic centres. The main international sector in Jordan is the United Nations Relief Works Agency (UNRWA), which offers primary care to about one million Palestinian refugees (World Health Organisation & The High Health Council 2015-2019; World Health Organization 2015b).

The MOH is the biggest provider of healthcare services in Jordan. The MOH is responsible for promoting public health through supplying the public with preventive, treatment and health control services, controlling health services provided by the public and private sectors, offering health insurance for the public, and establishing and controlling the management of health education and training institutes and centres (World Health Organisation & The High Health Council 2015-2019; World Health Organization 2015b). The MOH runs 30 hospitals in 11 governorates, with 4333 hospital beds (38.7% of the total hospital beds in Jordan). The RMS offers health services and a comprehensive medical insurance to military and security personnel. It runs 12 hospitals (7 general and 4 specialist) with a capacity of 2131 beds (19% of the hospital beds in Jordan). It has been estimated that 1,500,000 people, of whom less than 10% are active military and police personnel, are covered by the Military Health Insurance system (World Health Organisation & The High Health Council 2015-2019; World Health Organization 2015b). The private sector runs more than 60 hospitals in Jordan. UNRWA runs 24 medical clinics, and provides health insurance for about 6.8% of the population (World Health Organisation & The High Health Council 2015-2019; World Health Organization 2015b).

Most Jordanian healthcare services are focused on managing communicable diseases, which has led to a significant increase in the relative burden of non-communicable diseases (World Health Organisation & The High Health Council 2015-2019). In 2012, the burden of non-communicable illnesses was approximately 75.6% of the healthcare budget in Jordan, compared to the burden of 13.2% for communicable illnesses (World Health Organization 2015b).

The healthcare system in Jordan is still facing barriers to the use of telemedicine, such as the lack of healthcare education, lack of knowledge about technology, lack of money and poor technology (World Health Organisation 2006; World Health Organisation & The High Health Council 2015-2019). In addition, healthcare providers have difficulty utilising electronic information from the internet due to their skills deficit and lack of access to the internet (Ahmad, Musallam & Allah 2018).

1.1.5.2 Service provision

Jordan has established a comprehensive network of primary healthcare facilities, which includes 375 primary healthcare centres, 243 village health centres, 448 maternal and child-healthcare centres, 95 comprehensive healthcare centres, 12 chest clinics, 3500 private clinics and 1882 dental clinics (public and private). This is a high-density system by international standards. The private sector in Jordan is also active in curative primary care and covers about 40% of all initial patient contacts. There are 18 inpatient hospital beds per 10,000 population; 13.9% of the population is admitted annually to hospitals; the mean hospital length of stay is 3.2 days; and the hospital occupancy rate is 65.1%, but this ratio varies between the public sector (73%) and the private sector (53%) (Ajlouni 2010).

1.1.5.3 Challenges, opportunities, and priorities of the health system in Jordan

A number of key documents from both the World Health Organization (WHO) and the Jordanian MOH have summarised the key issues facing the Jordanian health system in the future. They have summarised the weaknesses, challenges and opportunities of the Jordanian healthcare system (World Health Organisation & The High Health Council 2015-2019; World Health Organization 2015b). The weaknesses include: (1) weak management performance, (2) inadequate health planning, (3) inequity in allocation of healthcare providers between rural and urban areas, (4) scarcity of research studies, (5) lack of comprehensive plans and strategies for combatting obesity, hypertension, diabetes and dyslipidemia, and (6) ineffective performance assessment and monitoring in public hospitals (World Health Organisation & The High Health Council 2015-2019; World Health Organization 2015b). The challenges faced by the Jordanian health system include: (1) the influx of a million Syrian refugees, which has imposed an excessive burden on the healthcare system, (2) the focus on disease treatment rather than health promotion, (3) the dramatic increase in non-communicable diseases and their risk factors, (4) high costs of hospital care and medication due to the lack of cost-effective approaches, (5) a high rate of sophisticated diagnostic facilities such as MRI units and CT scanners leading to increased healthcare costs, (6) inadequate coordination and cooperation among components of the health sector, and (7) overlaps in health regulation and legislation (World Health Organisation & The High Health Council 2015-2019; World Health Organization 2015b). The opportunities available include: (1) the government's commitment to achieving universal health coverage, (2) the High Health Council coordinating the activities of all health-related parties, (3) the MOH, which provides an environment of support for development partners, (4) the revenue of prosperous medical tourism, accounting for US\$1 billion, which helps to

subsidise the health sector, and (5) standards for all healthcare providers programs, which have been established by the Ministry of Higher Education to improve the quality of newly graduated healthcare providers (World Health Organisation & The High Health Council 2015-2019; World Health Organization 2015a, 2015b).

1.1.5.4 Healthcare financing

Statistical estimations made in 2007 showed that the total health expenses including both public and private sectors were 1016 million Jordanian dinars (JD), which is 177.5 JD per capita (253 US dollars) and this amount is equivalent to 9.1% of GDP. The government increased its share of health expenses from 43% in 1998 to 58% in 2007. Through the period 1998–2007, the government has increased its share of curative care from 79 to 82% of the total state health expenditure, while the proportion spent on primary healthcare was below 20%. Since healthcare facilities in Jordan do not have cost-accounting systems in place, these figures are mostly based on estimates and may not reflect the actual spending patterns on different categories (Ajlouni 2010; World Health Organisation 2016). Eighty six percent of the population has health insurance (World Health Organisation & The High Health Council 2015-2019). The MOH is considered the largest health insurer (44%), followed by RMS (27%), private firms (6.9%), UNRWA (6.8%), and university hospitals (1.3%) (World Health Organisation & The High Health Council 2015-2019).

1.1.5.5 Health information system

The Directorate of Information gathers basic health data from MOH facilities and other public and private hospitals. It also manages the National Cancer Registry and the National Death Registry. The directorate releases the MOH annual report, which is considered the main source of information about health services in Jordan including the health labour force. However, it has been reported that there is a lack of optimal utilisation of the data collected at the central level (Ajlouni 2010). Nevertheless, the Directorate of Information at MOH collects some human resources data from the public and private health sectors. The data collected covers a wide range of human resources (i.e. physicians, nurses, pharmacists, dentists, allied health personnel and administrative staff) without other details such as age, gender and specialty. The human resources data for the private sector is restricted to hospitals. However, most of the data are simply collected for onward transmission to the MOH. No standardised definitions and procedures for collecting human resources data are available (Ajlouni 2010; World Health Organisation 2006).

1.1.6 Political context

From January 1950, Jordan was enacted as a constitutional monarchy, which meant that the principal authority belonged to the king and his council of ministers. For example, the king appointed the minister of health and the prime minister, and executed, signed and administered all laws, amendments to the constitution, declarations of war and command of the armed forces. Alongside this, the king has the power to dismiss all judges and cabinet members (Ajlouni 2010; World Health Organisation 2006). Jordan's 12 governorates are each led by a governor appointed by the king. In February 1999, King Abdullah II succeeded his late father Hussein. Under the power of both King Hussein and King Abdullah II, Jordanian politics has undergone great reformation, leading to democracy. This has led to greater guarantees of the rights of the Jordanian people, resulting in further stability. The Governorates Development Plan and the Municipalities Reform Program have encouraged greater decentralisation of governance. In 2005, healthcare was not considered a top priority. Therefore, the King directed the prime minister and his government to prioritise health and combat poverty, with an emphasis on democracy, transparency, integrity and justice (Ajlouni 2010; World Health Organisation 2006).

1.2 Background to the study: heart failure

The second section of this chapter discusses the burden of heart failure (HF) and HF management. The final section sets out the research questions, the study's aims, its significance, and the thesis structure.

1.2.1 Burden of heart failure

Heart failure (HF) is a chronic, progressive and life-limiting condition (Page et al. 2014). The National Heart Foundation of Australia (NHFA) has defined heart failure as

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 of an underlying structural abnormality or cardiac dysfunction that impairs the ability of the ventricle to fill with or eject blood (particularly during physical activity) (Atherton et al. 2018, p. 1135).

Patients with HF may suffer from various symptoms such as dyspnoea, fluid retention, oedema and fatigue (Lindenfeld et al. 2010). HF is described as a global pandemic, affecting 26 million people worldwide (Ponikowski et al. 2014). It has a negative impact on quality of life (QOL) (Heo et al. 2009), and causes a considerable economic burden to patients and healthcare

systems due to high healthcare costs and the number of hospital readmissions (Lesyuk, Kriza & Kolominsky-Rabas 2018). Furthermore, there have been dramatic increases in HF risk factors in both developed and developing countries including coronary artery disease, hypertension, diabetes, smoking and obesity (Callender et al. 2014b; Celermajer et al. 2012; Dunlay et al. 2009; Gaziano et al. 2010; Gong et al. 2018; Page et al. 2014).

Despite advancements in HF treatment, there has been an increase in the prevalence, incidence and mortality rates of HF over the past 25 years, and it is still a life-changing condition that has negative physical and psychosocial impacts on patients (Page et al. 2014). The management of the condition is made more complex by factors relating to the patients themselves and those relating to the health system. Patient-related causes include: (1) poor knowledge by patients of HF symptoms, (2) poor adherence to treatments recommended by healthcare providers, and (3) inaccessibility or unavailability of effective education programs for patients. Health system-related causes include: (1) poor training of healthcare providers involved in patient education, and (2) healthcare providers lacking time to guide and teach patients during admissions or scheduled visits (Casimir et al. 2013; de Oliveira Azzolin et al. 2015).

1.2.2 Heart failure management

Effective management of HF reduces its burden, improves QOL, and reduces hospital readmissions (Inamdar & Inamdar 2016). The mainstays of HF management are patients' referral to HF programs and lifestyle modifications (Krum & Driscoll 2013). HF management programs started in the mid-1990s to enhance patient outcomes and decrease healthcare costs (Kalter-Leibovici et al. 2017). Various components can be included in these programs, including multidisciplinary care (Rich et al. 1995), follow-up phone calls (Blue et al. 2001), empowering patients, delivering education regarding self-care, coordinating care, utilising information systems, and relying on evidence-based practices (Kalter-Leibovici et al. 2017; Scott 2008). HF management programs have been shown to produce effective outcomes.

Two systematic reviews have reported HF management decreases hospital readmissions and mortality (McAlister et al. 2004; Takeda et al. 2012). A meta-analysis of 20 randomised controlled trials showed that self-management decreased the risk of all-cause death (hazard ratio, 0.80; 95% confidence interval (CI), 0.71–0.89), time to HF-related hospitalization (hazard ratio, 0.80; 95% CI, 0.69–0.92), and enhanced 12-month HF-related quality of life (standardised mean difference, 0.15; 95% CI, 0.00–0.30) (Jonkman et al. 2016). Another systematic review has shown that such programs improve QOL (Rees et al. 2004). The

National Heart Foundation of Australia's (2016) tool kit demonstrated how healthcare systems can better deliver the management of HF to prevent readmissions. The three pillars included: (1) the need for HF specialty and guideline based treatments, (2) patient education and engagement in self-care, and (3) transitions of care such as post-discharge follow-up.

Self-management is a key component of any HF management program (Toukhsati, Driscoll & Hare 2015). It is defined as assisting patients to develop new knowledge and skills to perform new healthcare behaviours, and to maximise their capability to manage physical symptoms, psychosocial consequences, and changes in lifestyle (Lorig 1993). Self-management is discussed in more detail in Chapter 2. Self-care is a main component of HF management. Self-care is defined as the process by which individuals are likely to engage in daily activities to achieve clinical and functional stability, and is a crucial component in HF management (Reeder et al. 2015). Optimal HF self-care reduces hospital readmissions and improves the survival rate (Ades et al. 2013; Keteyian et al. 2014; Lee et al. 2011; Tawalbeh et al. 2017). There are many factors affecting HF self-care. These include experience and skills of patients, motivation, habits, cognitive and functional abilities, level of confidence, cultural beliefs, support, and access to care (Jaarsma et al. 2017). Heart failure self-care is classified as self-care maintenance, self-care management, and self-care confidence. Self-care maintenance is an 'active process involving critical behaviors that help maintain physiologic homeostasis and prevent acute exacerbations' (Lee, Tkacs & Riegel 2009, p. 179). Self-care maintenance includes daily recommended practices such as symptom monitoring, adherence to diet and treatment regimen, daily weight monitoring, and routine exercise (Lee, Tkacs & Riegel 2009). Self-care management 'involves decision making in which patients engage in actions they take to effectively evaluate and manage symptoms when these occur' (Lee, Tkacs & Riegel 2009, p. 180). It includes the recognition of symptoms, evaluation of symptoms, treatment of symptoms, and evaluation the effectiveness of treatment (Lee, Tkacs & Riegel 2009). Self-care confidence refers to patient's ability to perform self-care behaviours (Massouh et al. 2020).

Overall, HF education, self-care, and adherence to recommended self-care behaviours are the main HF management components (Cowie et al. 2014; McGreal et al. 2014). Effective education is considered the core component of a HF management program and plays a crucial role in improving patients' knowledge, awareness and understanding of the disease, adherence to treatment and self-care (Boyde et al. 2011). Adherence to recommended self-care behaviours is a very important component of HF management. The World Health Organization (2003) has defined adherence as the 'the extent to which the patient follows medical instructions'. Systematic reviews have demonstrated that self-care adherence is significantly associated with

better HF-related QOL, reduced morbidity rate (Jonkman et al. 2016), and a reduced rate of hospital readmissions (Jovicic, Holroyd-Leduc & Straus 2006a). However, patients with HF have a tendency for poor adherence to dietary sodium restriction and fluid intake guidelines, treatment therapy, and follow-up recommendations, which leads to worsening symptoms, a deteriorating condition, and increasing rates of morbidity and mortality (Dunn 2015; van Der Wal, Jaarsma, Moser, Veeger, et al. 2005).

Despite the noteworthy progress made in management of HF after the release of the European Society of Cardiology (ESC) Guidelines, there remain major challenges worldwide in the structure of care provided to patients with HF, and a gap between the guidelines and practice (McDonald & Gallagher 2017). The practice gap has been shown to result from a lack of cohesive interaction between primary care providers, and a lack of involvement and advice from cardiologist on HF management (McDonald & Gallagher 2017). In the early 2000s, European studies showed that only 32% of the patients diagnosed with HF had further referral or investigation (Hobbs et al. 2000), and this has not significantly improved in a more recent study (Dahlstrom et al. 2009). The lack of specialists' involvement results in misdiagnosis of patients, incorrect therapy and insufficient investigation (McDonald & Gallagher 2017). Therefore, the ESC Guidelines recommend bridging the gap through interventions including implementation of a seamless patient-centred HF management program (McDonald & Gallagher 2017), which is defined as 'the provision of care that is respectful and responsive to a patient's preferences, needs, values, and perceives patients as leaders of their clinical care' (Casimir et al. 2013, p. 109). Sharing HF care between healthcare providers, and providing sufficient education to patients and their family members are also recommended (McDonald & Gallagher 2017).

Some previous HF management programs failed to demonstrate any positive economic (Smith et al. 2008) or clinical (Jaarsma et al. 2008; McCall & Cromwell 2011; Smith et al. 2008) outcomes. Systematic reviews of HF management programs have attributed the contradictory results to multiple reasons. Firstly, patients' needs, preferences and other influencing factors were not addressed by healthcare providers in most studies (Boren et al. 2009; Jovicic, Holroyd-Leduc & Straus 2006b; Srisuk et al. 2016). The vast majority of previous HF management programs were structured and not flexible in terms of dose and amount of intervention, duration of the program, and number of follow-ups irrespective of patients' needs and abilities (Ditewig et al. 2010). Secondly, improving knowledge of HF was the main objective of most previous studies. However, knowledge alone is not sufficient to improve self-care and QOL, especially for patients who have depressive symptoms or any other

psychological distress (Barnason, Zimmerman & Young 2012). Thirdly, patients with HF vary in age, psychological state, HF severity, financial state, New York Heart Association (NYHA) functional class, educational level and cognitive level. Therefore, a single intervention is unlikely to be suited to all patients, and will not be effective in achieving clinical and functional stability (Boren et al. 2009; Srisuk et al. 2016). Consequently, HF interventions should be tailored to patients' needs, preferences and capacity for self-care (Boren et al. 2009; Clark et al. 2016). Lastly, more than two thirds of previous studies only focused on pharmacological treatment, while interventions related to behaviours, lifestyle such as eating a 'heart-healthy' diet, limiting alcohol and caffeinated drinks, physical activity, monitoring blood pressure and blood sugar, managing stress, quitting smoking, and getting adequate rest were not addressed (American Heart Association 2017a; Aminde et al. 2018).

Jordan is a developing and low-income country (World Health Organization 2015b). There are no structured health management programs for patients with HF, which contributes to the worsening problem (Jordanian Ministry of Health 2012). Non-communicable diseases such as HF, hypertension (HTN), and diabetes mellitus (DM), have dramatically increased in Jordan because most healthcare services are focused on communicable disease management (World Health Organisation & The High Health Council 2015-2019). Furthermore, Jordanian patients with HF have different characteristics than those in other contexts. For example, the average age for patients with HF in Jordan is 40 to 70 years (Jordanian Ministry of Health 2012), compared to 70 to 80 years in other countries (Cocchieri et al. 2015; Ekman et al. 2011; Peters-Klimm et al. 2013; Shahrababaki et al. 2016). Due to an increase in a number of risk factors in Jordan, there have been dramatic increases in the prevalence of ischaemic heart disease, diabetes and HTN. This has been attributed to a more sedentary lifestyle, dietary shifts, obesity, lack of physical activity and smoking (Abu-Mweis et al. 2014; Abu-Zaiton & Al-Fawwaz 2013; Elhneiti & Al-Hussami 2017; Hammoudeh et al. 2006; Khader et al. 2019; Sharkas et al. 2016) and the lack of structured health management programs for non-communicable diseases (World Health Organisation & The High Health Council 2015-2019). Therefore, developing a HF management program that is tailored to patients' needs and preferences, and considering other factors that influence the effectiveness of HF self-management is a necessary step to improve outcomes for people with HF in Jordan.

In Jordan, patients who experience heart-related symptoms such as chest pain, difficulty breathing, and oedema go to emergency room for medical tests. The doctor in the emergency room takes a medical history, reviews chief complaints, performs physical examination, checks for having any HF risk factors, and orders blood tests and ECGs to determine the cause of

health problem. Patients with abnormal results are either admitted into the hospital for medical intervention or scheduled for a cardiac clinic to see the cardiologist for further medical tests. Usually, patients attend cardiac clinics monthly and receive general education with medication prescriptions.

1.3 Aims and objectives of the project

The study's aim was to develop a strategy to optimise management and self-care for patients with HF in Jordan.

1.3.1 Study objectives

There were three main objectives of the present study:

- 1) Based on the literature, to identify the most essential components and strategies that should be included in a HF management program.
- 2) To develop a patient-centred heart failure management program that is tailored for the Jordanian context based on the results of a patient survey.
- 3) To design the most effective (feasible, applicable, and appropriate) heart failure management program using the Delphi method (expert judgement).
- 4) To explore patients' experience with their HF disease and suggestions for improving self-care/self-management (patients' focus groups).
- 5) To explore patients' perspectives on the proposed heart failure model (patients' focus groups).

1.3.2 Research questions

The following research questions are addressed in the three phases of this study. Phase i is the literature review. Phase ii is the cross sectional study (survey). Phase iii is the patients' focus groups and the Delphi study.

Phase i

What are the most essential components and strategies reported in the literature that should be included in heart failure management programs in Jordan?

Phase ii

What is the level of HF knowledge, self-care, and adherence to self-care among Jordanian patients with heart failure?

What is the effect of heart failure symptoms on patients' lives?

What are the predictors of self-care, adherence to self-care and quality of life for people with heart failure in Jordan?

Phase iii

What is the most appropriate management program for patients with heart failure in Jordan based on the consensus of clinicians, policy makers, researchers and healthcare managers?

What are the patients' experience with their HF disease and suggestions for improving self-care/self-management?

What are the patients' perspectives on the proposed heart failure model?

1.3.3 Significance/contribution to the discipline

This study will inform the development of a patient-centred HF program that is tailored for the Jordanian context and supported by key stakeholders. The baseline information collected from this study can be used for future studies such as those that test the optimal intervention. This study will draw the attention of healthcare providers, researchers and health policy makers who are interested in supporting and implementing this program as well as developing new related strategies, in order to lower hospitalisations, readmissions and healthcare costs. This study will provide recommendations about how to implement the HF intervention.

1.3.4 Thesis structure

The research aimed to facilitate the development of a patient-centred HF program that is tailored to the Jordanian context and supported by key stakeholders, using a *mixed-methods* approach. This thesis is divided into two studies. The first study is a cross sectional survey. The second study comprises two components: a Delphi study of clinicians and focus groups for patients. The introduction, literature review and methodology chapters include a detailed presentation of both studies. The two studies are reported in ten chapters as follows.

Chapter 1, the *introduction*, has provided background information about the Jordanian context, including Jordan's geography, population, gender issues, workforce, employment, levels of literacy, and healthcare system. It has also highlighted the burden of HF, and the importance of HF management. The chapter has also outlined the study's aims, its significance, research questions, and the thesis structure.

Chapter 2, the *literature review*, provides a detailed literature review about the impact of HF, the importance and impact of HF management, HF self-management strategies, and factors supporting HF management.

Chapter 3, the *methodology* chapter, provides a detailed description of the historical development of mixed-methods approaches, types of mixed methods approaches, and the methodology employed in this study.

Chapter 4 describes the *methods* used in the quantitative study. It includes a presentation of the methods utilised for both data collection and analysis of the cross-sectional survey.

Chapter 5 presents the *results* of the survey. Chapter 6 discusses the results of the quantitative study. It interprets and discusses the survey results based on the research questions and related literature.

Chapter 7 sets out the *methods* of the qualitative study. It presents the methods utilised for data collection and analysis of the Delphi study and patients' focus groups.

Chapter 8 presents the *findings* of the Delphi study and patients' focus groups.

Chapter 9 *discusses and interprets* the results of the Delphi study and patients' focus groups.

Chapter 10, the *conclusion*, summarises and integrates the results of the two studies. It also discusses the implications and limitations and presents the recommendations of the study.

Chapter 2: Literature review

2.1 Search strategy

An extensive search was performed for relevant literature using the following keywords: heart failure, self-care, adherence, quality of life, HF management, feasible programs, HF components, HF interventions, centredness and tailoring, education, follow-up, healthcare, Jordan, Middle East. The online search engines used were: Cochrane, Scopus, Science Direct, CINAHL, and PubMed Central (PMC). The search was conducted in English language.

2.2 Burden of heart failure

Heart failure (HF), also known as congestive heart failure, is a chronic progressive condition reflecting the inability of the heart muscle to pump and meet the body's demands, affecting a patient's life and lifestyle (American Heart Association 2017b). Despite advancements in HF management strategies, pre-discharge education, post-discharge education and follow-up care (Barnason, Zimmerman & Young 2012; Feltner et al. 2014; Zamanzadeh et al. 2013), it remains a condition that has a significant negative physical, psychological and social impact on patients (Gorthi et al. 2014b; Rustøen et al. 2008; Shah et al. 2013).

Coronary artery disease (CAD) is considered to be one of the major causes of HF in both developed and developing countries. It is defined as the narrowing of the large blood vessels that supply the heart with oxygen, resulting in chest pain and difficulty breathing (Ambrose & Singh 2015). A US study also reported that the prevalence of HF risk factors is progressively increasing in the US (Komanduri et al. 2017). The prevalence of CAD was 38.5%, HTN was 81.9%, and DM was 40.1% (Komanduri et al. 2017). In addition to CAD, Zhai and Haddad (2017) showed that obesity is another major contributing factor for affecting with HF.

2.2.1 Burden of heart failure worldwide

HF has become a worrying health issue (Cowie et al. 2014). In the US, more than 5.7 million people are affected (Roger et al. 2011), while more than 15 million people are affected in Europe (Cowie et al. 2014), and half a million people in Canada (Casimir et al. 2013). In Australia, the prevalence is between 1 and 2%, equivalent to about 250,000 patients affected with HF (Sahle et al. 2016). The NHFA estimated in 2010 that about 30,000 Australians are diagnosed with HF annually (Page et al. 2014).

HF is a significant cause of morbidity and mortality worldwide. For example, in Australia, the NHFA estimated that the number of deaths per year associated with HF has increased from 2355 in 2006 to 2936 in 2011. Moreover, 20–30% of Australian patients with mild to moderate HF will die within one year, and 50% of the patients with severe HF will die within one year (Page et al. 2014). Survival rates may be a little better in the US, where 50% of patients with HF die within five years of diagnosis (Mozaffarian et al. 2016).

Providing healthcare for patients with HF is expensive. It has been estimated that the annual cost of HF in the USA is about \$37 billion, and it is expected to increase to \$53.1 billion by 2030 (Ambrosy et al. 2014; Heidenreich et al. 2013a; Lloyd-Jones et al. 2009). The cost of HF care accounts for about 1–3% of total healthcare expenditure in North America (Lloyd-Jones et al. 2009), Western Europe (Neumann et al. 2009), and Latin America (Bocchi et al. 2009). The NHFA estimated that in Australia HF care costs more than \$1 billion per year (Page et al. 2014).

2.2.2 Burden of heart failure in the Middle East

In the Middle East, there is insufficient literature addressing the prevalence of HF, mortality and self-care (Al-Shamiri 2013). But it has been reported that the prevalence of risk factors associated with HF is increasing in Middle Eastern countries (Al-Shamiri 2013; Callender et al. 2014a). These factors include CAD, HTN, diabetes and obesity. Furthermore, patients in the Middle East are likely to develop HF earlier than those in western countries by at least 10 years (Al-Shamiri 2013). This has been attributed to the earlier onset of CAD, which is considered the main cause of HF (Callender et al. 2014a). A systematic review of 42 studies published between 1995 and 2014 focusing on HF in low- and middle-income countries found that ischaemic heart disease and HTN were the predominant causes of HF in those countries (Callender et al. 2014a).

2.2.2.1 Burden of heart failure in Jordan

In Jordan, data on the prevalence of HF is limited. However, there have been dramatic increases in the prevalence of risk factors for HF, including ischaemic heart disease, diabetes, HTN, smoking, poor physical activity and obesity (World Health Organisation & The High Health Council 2015-2019). Ischaemic heart disease has been considered the main causal factor in the development of HF and is the most common cause of death in Jordan in 2013 (The Centers for Disease Control and Prevention CDC 2013). According to the World Health Organisation (2015), in 2015 the prevalence of diabetes in Jordan was 14.9%, HTN was 19.3%, tobacco

smoking was 38.4%, insufficient physical activity was 15.6%, overweight was 65.9%, and obesity was 30.5%. The high prevalence of HF risk factors can be attributed to increasingly sedentary lifestyles, higher levels of stress, and a shift in diet to fast and fatty food (Abu-Mweis et al. 2014; Abu-Zaiton & Al-Fawwaz 2013; Elhneiti & Al-Hussami 2017; Hammoudeh et al. 2006; Khader et al. 2019; Sharkas et al. 2016). Therefore, providing better evidence-based medical care as well as developing new health promotion and disease prevention HF programs across all groups is crucial (Al-Shamiri 2013; Celermajer et al. 2012; Riegel, Driscoll, et al. 2009).

2.3 Impact of HF on hospitalisation and readmissions

HF is highly prevalent in elderly patients aged over 65 years, and a primary cause of hospital readmissions (Al-Shamiri 2013; Davidson et al. 2010). A study conducted by Go et al. (2013) reported that approximately 80% of patients with HF are elderly. This definitely increases the demands on health resources, places a burden on the healthcare system, and increases healthcare expenditure (Page et al. 2014). In addition to the high frequency of hospitalisations, HF is responsible for large numbers of readmissions and deaths, and lower QOL.

Several studies have estimated that 25% of patients with HF are readmitted within 30 days after discharge from hospital, and 50% are readmitted within 6 months of hospital discharge (Bogaev 2010; Casimir et al. 2013). These readmissions can be attributed to less than optimal therapeutic options, insufficient educational strategies, poor participation in the medical regimen, deficient knowledge and inability to carry out self-care behaviours (Yehle & Plake 2010).

2.4 Impact of self-care on HF

Improvement in self-care is one of the major aims of any HF management program (Cowie et al. 2014; McGreal et al. 2014). Self-care includes activities performed intentionally by individuals, families and communities to promote health and prevent disease (Harkness et al. 2015). Appropriate self-care can reduce health problems, enhance QOL, and lower costs for patients with HF (Bidwell et al. 2015). In addition, patient engagement in HF self-care improves healthcare outcomes and results in 40% relative risk reduction in hospital readmissions (Jovicic et al. 2006). The effectiveness of management programs on self-care (self-care-outcomes, self-care strategies, self-care recommendations and the efficacy of self-care intervention) has been investigated in several systematic reviews (Barnason, Zimmerman & Young 2012; Buck et al. 2018; Harkness et al. 2015; McGreal et al. 2014).

Buck et al. (2018) conducted a systematic review in 2018 investigating the outcomes, context and components of dyadic self-care (patient and informal carer) interventions. The review included 15 complete studies published between 2000 and 2016. The outcomes of dyadic interventions were categorised into four groups: behavioural outcomes (carer tasks, self-care), cognitive outcomes (knowledge, perceptions control, readiness to care), affective outcomes (strain, social support, depression), and the utilisation of healthcare services (hospitalisations). The systematic review reported a number of limitations of these studies, including small sample sizes, poor quality of studies, methodological weaknesses, mixed intervention effects, significant lack of reliable and detailed information, and unclear descriptions of the dose and amount of HF intervention delivered. Therefore, Buck et al. (2018) recommended further mixed-methods studies be conducted with increased sample sizes in order to improve HF interventions and to identify effective solutions to sustain behavioural changes.

In another systematic review, Harkness et al. (2015) sought to identify strategies that assist with accommodating self-care recommendations into daily life. They found that healthcare providers need to understand that patients perceive self-care as an adaptation to their behaviours to maintain their QOL. It is also important that healthcare providers adopt individualised strategies for patients based on their different experiences, knowledge and self-management skills over time. The review demonstrated that negative emotions caused by HF such as depression and anxiety negatively affect patients' ability to engage in self-care. Therefore, emotional reactions of patients and their personal experiences with HF symptoms should be explored by healthcare providers to optimise self-care strategies. A fundamental conclusion made by this review is that individualised HF management should be adopted to improve HF self-care and QOL (Harkness et al. 2015).

With respect to the efficacy of self-care interventions, an integrative review of 19 randomised controlled trials published between 2000 and 2010 indicated that studies that augmented standard education with cognitive behavioural strategies demonstrated significant improvement in knowledge and self-care among patients with HF. In addition, the review concluded that standard education alone is not sufficient to improve self-care and self-efficacy (confidence). This finding highlights the importance of augmenting standard HF education by incorporating other approaches such as cognitive behavioural intervention, peer support and social support. These approaches aim to improve knowledge, self-efficacy, self-care and QOL (Barnason, Zimmerman & Young 2012). Similarly, McGreal et al. (2014) conducted a systematic review of nine randomised controlled trials published between 2010 and 2014 to examine the effectiveness of self-care interventions in patients with HF. They concluded that

self-care capacity varies significantly among HF patients, and consequently attention to factors affecting this capacity is very important. These factors include cognitive status, health literacy, depression, and self-efficacy or self-confidence. Therefore, HF management programs should consider these factors to tailor the best HF management to patients. In addition, knowledge alone is not sufficient to improve self-care, or to decrease clinical events and/or symptom burden. Thus, augmenting education with interventions that improve self-confidence and empower patients is effective in promoting optimal self-care and reducing symptom burden.

2.5 Impact of HF on quality of life

Quality of life reflects the physical and emotional impact of heart failure symptoms on patients. It is considered a core component of HF management, because patients experiencing severe physical or emotional symptoms are less likely to effectively carry out self-care practices (Heo et al. 2009). HF symptoms may impair tolerance of activity, cause depression, stress, and emotional disturbance, and consequently lead to negative impact on QOL (Lakdizaji et al. 2013). It has been reported that three quarters of patients with HF have a relatively poor QOL (Shojaei 2008). Improving QOL has become more relevant as the therapeutic options and lifespan of patients with HF have increased (Buapan 2008; Salehitali et al. 2010). A systematic review of 21 trials indicated that HF leads to psychological distress, poor QOL and social isolation. Therefore, structured interventions are needed such as face-to-face education sessions, psychological support, and education for patients to improve self-care activities such as frequent weight monitoring. In addition, the combination of a face-to-face intervention with follow-up phone calls contributes to a greater enhancement in QOL in comparison with using only one intervention (Cui et al. 2019).

Quality of life has been shown to be affected by insomnia and obesity in patients with HF. Johansson et al. (2010) showed that 72% of patients with HF experienced difficulty maintaining sleep compared to 50% in those patients without HF, and 25% had daytime fatigue compared to 8% in those without HF. Furthermore, the study indicated that patients with HF who experienced insomnia had poorer QOL compared to those without insomnia (Johansson et al. 2010). In conclusion, insomnia is a critical issue for patients with HF that negatively impacts on QOL, functional capacity, and eventually impairs self-care. However, its importance is undervalued by healthcare providers, (Redeker et al. 2008). Regarding obesity, a study conducted to identify the association between obesity and QOL among patients with HF showed that obese patients (BMI \geq 30 kg/m²) had poorer QOL and higher scores of

depression compared with overweight (BMI 25-29.9 kg/m²) and normal weight patients (BMI 18.5-24.9 kg/m²) (Evangelista et al. 2006).

2.6 Heart failure self-management

Heart failure self-management refers to the patient's ability to recognise and respond to HF symptoms properly, cope with changes in lifestyle, and manage care needs through physical and emotional challenges (Riegel, Dickson & Faulkner 2016). HF management programs involving all classifications of self-care include treatment adherence, recognition of symptoms, physical exercise, diet control, self-monitoring, adjustment to treatment (Boren et al. 2009), quitting smoking, weight control, cutting down alcohol, and blood pressure control (Boren et al. 2009; Mudge et al. 2011; Smeulders et al. 2009). These programs have been adopted in poorly resourced health settings (Caldwell, Peters & Dracup 2005), for patients with low levels of education (DeWalt et al. 2006), elderly patients (Shao 2008), and outpatients (Otsu & Moriyama 2011). HF management programs have been shown to improve QOL, reduce mortality (Ditewig et al. 2010), and decrease hospital readmissions and healthcare costs (Jovicic, Holroyd-Leduc & Straus 2006b). In addition, patients' satisfaction, social functioning, learning and behaviour are improved by these programs (Boren et al. 2009). However, the systematic reviews targeting previous HF management indicated that most HF programs were conducted in developed countries, which highlights the significant need to further investigate HF management in developing countries like Jordan (Barnason, Zimmerman & Young 2012; Boren et al. 2009; Buck et al. 2018; Cui et al. 2019; Harkness et al. 2015; McGreal et al. 2014).

Effective HF self-management mainly depends on a patient's competency to recognise, understand and report early symptoms to healthcare providers (Friedman & Quinn 2008). However, HF patients often fail to recognise and respond to these symptoms. This might be attributed to the fact that those patients have not received effective education about how to interpret and report these symptoms (Reeder et al. 2015; Teo et al. 2016). The literature reports that 70% of hospitalisations are preventable, and can be attributed directly to ineffective HF self-management, including inability to recognise and report early symptoms (Fonarow et al. 2008; Reeder et al. 2015; Schiff et al. 2003). Regarding pharmacological management, patients with HF take multiple medications. Each one causes different symptoms, which highlights the need to adhere and comply with the instruction of treatment regimen. The healthcare provider should teach patients about the medication effects, side effects, dosage, and frequency (American Heart Association 2020). Accordingly, ineffective management can be associated

with non-compliance with the medical regimen, lack of self-care, low commitment to lifestyle recommendations, deficient knowledge of HF symptoms, and lack of understanding of how to recognise worsening symptoms and when to seek medical attention (Agvall, Alehagen & Dahlström 2013; Casimir et al. 2013).

Several interventions and strategies have been developed to improve self-management including pre-discharge education (Jessup et al. 2009; Manning, Wendler & Baur 2010) followed up with various interventions post-discharge, such as home visits, regular follow-up phone calls, outpatient clinics, support groups and community health volunteers (Barnason, Zimmerman & Young 2012; Feltner et al. 2014; Zamanzadeh et al. 2013). In addition, effective HF self-management can be achieved by providing intensive and long-term education, using a patient-centred care approach (Casimir et al. 2013; Cowie et al. 2014), changing lifestyle, supporting patient education through utilising different interventions, and providing social and emotional support (American Heart Association 2017a; Barnason, Zimmerman & Young 2012; Gorthi et al. 2014b).

A recent systematic review showed that HF self-management strategies should include: enhancing patients' understanding of HF illness, involvement of a family member in the care process, and providing patients with psychological and social support (Clark et al. 2016). Over 60% of the included studies showed that effective follow-up care or support provided by healthcare providers has a significant positive impact on self-care. The review indicated that the efficiency of HF strategies is decreased when healthcare providers concentrate too much on simply delivering information during follow-up visits, or prioritise treatment goals over the goals, preferences, values or cultural beliefs of patients (Clark et al. 2016). In addition, the lack of time given to patients and ineffective communication negatively affects HF management. The review had two main recommendations: (1) HF management programs should focus on designing interventions that produce effective outcomes instead of replicating previous management programs, and (2) future large-scale studies, including qualitative and mixed methods studies, should systematically explore the HF interventions that have positive outcomes and how other mechanisms and contextual factors can moderate these interventions. This review identified a number of limitations in the studies (Clark et al. 2016). For instance, none of the studies in the review used a systematic analysis to compare programs that use different strategies. Another limitation was that many of the studies had small sample sizes (Clark et al. 2016). Importantly, most of the studies included in the systematic reviews were not conducted in Middle Eastern countries. Overall, HF education, adherence, and self-care have been the main components of HF self-management (Cowie et al. 2014; McGreal et al.

2014). A number of components and interventions have been used to promote or support HF management. These include education, post-discharge follow-up (including home visits, outpatient clinics, phone calls, community health volunteers, support groups and cardiac rehabilitation).

2.6.1 Patient education

Education is considered one of the most important components of HF management. The prime objective of HF patient education is to promote and provide information that helps patients obtain knowledge and skills needed to understand and manage the disease (Ponikowski et al. 2016). The evidence-based practice guidelines outlined by the American College of Cardiology (ACC)/American Heart Association (AHA), the Heart Failure Society of America, and the European Society of Cardiology (ESC) emphasise the importance of providing tailored education for HF patients based on patients' needs in order to improve self-care and QOL (Ponikowski et al. 2016). A systematic review indicated that the effectiveness of HF education is influenced by patients' needs, preferences, and several other influencing factors (Boren et al. 2009). These include: HF knowledge, experience, socioeconomic status, culture, level of education and available resources. Therefore, identifying patients' needs and considering contextual factors can guide healthcare providers to tailor the most effective education suited to patients' needs. However, the review had a number of limitations, such as the small number of included studies, and the diversity of the educational strategies and outcome measures utilised (Srisuk et al. 2016). The major finding of this review is supported by an older systematic review, which indicated that teaching needs are rarely assessed over the duration of education programs, and which recommended adoption of personalised HF interventions that conform to patients' needs and preferences (Boren et al. 2009).

Some components of HF patient education have been determined by current practice guidelines from ACC/AHA, HFSA and ESC. These components include: a general understanding of HF aetiology and pathophysiology, medication adherence, ideal self-care behaviours, importance of medication, recognising and responding to symptoms, management strategies, fluid and sodium restriction, quitting smoking, and performing physical activity (Casimir et al. 2013; Dickstein et al. 2008; Lindenfeld et al. 2010). Education of patients plays a substantial role in improving knowledge and understanding of HF symptoms, empowering patients to be more involved in the care process, and improving self-care behaviours. This may reduce hospitalisation and readmission rates, minimise patients' suffering, improve QOL and treatment adherence, and reduce healthcare costs (Boyde et al. 2011). A systematic review

highlighted strategies that improve the educational outcomes of HF management programs (Boren et al. 2009). These include providing adequate social support, effective communication, as well as patients' involvement and participation in the process of care (Boren et al. 2009).

During hospital stays, the clinical, functional and psychological state of patients with HF should be assessed by a multidisciplinary team (Davidson et al. 2010; Davidson et al. 2015). In addition, instructional and educational materials concerning HF should be given to patients. Topics to be focused on include treatment adherence, sodium and fluid restriction, daily activity, daily weighing, smoking cessation, recognition of worsening HF symptoms, and early follow-up appointments with the cardiologist. Healthcare providers should ensure patients understand their discharge education plan in order to maintain their compliance and adherence to the treatment regimen. Moreover, families should also be involved in patients' discharge plan so they can support the patients and reinforce the plan (American College of Cardiology 2009; Davidson et al. 2010; Koshy 2014). A patient's education should start on the day of admission to hospital and continue over the period of their hospital stay. Furthermore, optimal discharge strategies such as home visits, outpatients clinics, regular phone calls, support groups, and community health volunteers also aim to extend care beyond the hospital setting and help the patient make a smooth transition to being an outpatient (Barnason, Zimmerman & Young 2012; Cowie et al. 2014; Davidson et al. 2010; Manning, Wendler & Baur 2010; Zamanzadeh et al. 2013).

2.6.1.1 Written materials on HF management

Using written materials along with verbal information in patients' education helps to improve knowledge and patient satisfaction more than verbal information alone (Boyde & Peters 2014). Furthermore, adding pictures to the written and verbal information is very helpful, and assists with improving the level of health literacy, treatment adherence and self-care (Boyde & Peters 2014).

A booklet is a common type of written educational material used to support patients' education. It reassures patients that life can be become full and active through taking prescribed medications, and complying with lifestyle changes. Information about HF can be explained in the booklet, such as surgical and non-surgical interventions, lifestyle modifications, risk factors, signs and symptoms, types of HF, and ejection fraction. In addition, the treatment regimen and all medications can be explained in terms of dose, frequency, time, and all other important information. Booklets or brochures are usually supported by pictures and graphs,

which help improve the patient's desire and motivation to read and understand the information (American Heart Association 2018; American Heart Association/American Stroke Association 2018). Some examples of written materials will now be described.

Controlling and reducing risk factors of HF brochure. A complete and readable brochure on HF risk factors can guide and empower patients to decrease their risks of cardiovascular disease and HF. Detailing the risk factors helps patients to manage HF effectively, seek medical attention when required, and reduce the likelihood of deterioration. Risk factors include obesity, increased cholesterol, physical inactivity, high blood pressure, high blood sugar and smoking. In addition, the symptoms of worsening HF, poorly controlled diabetes, poorly controlled HTN and heart attack can be explained in the brochure. The brochure should include information on how to respond to these symptoms (American Heart Association/American Stroke Association 2018).

Wallet card specially designed for HF. A wallet card is a simple, easy to carry record of blood pressure, blood sugar, cholesterol, weight, and any other personal health information recorded at each clinic visit. This card can also provide information about medication, and summarise the risk factors of HF. A wallet card has been shown to be an effective tool in HF management (American Heart Association/American Stroke Association 2018).

Weight and symptom diary for self-monitoring in HF clinic patients. A diary is a management tool used to record vital signs, weight, and symptoms of worsening HF such as oedema, fatigue, cough and dyspnoea. Keeping a diary helps patients to improve the evaluation of symptoms, disease-related self-care, adherence to their treatment regimen and QOL. In addition, various studies have demonstrated that patients who keep a diary have lower admission rates, shorter hospital stays, and closer contact with healthcare providers and live longer, compared to patients who do not keep a diary. The studies found that patients who kept a diary were more likely to adhere to daily weight checking than those who did not (Jones et al. 2014; Park et al. 2017).

2.6.1.2 Videos

Videos are considered an effective teaching strategy, because they can be viewed at the patient's own pace. In addition, the content is standardised in this modality, and the clinician does not require specific skills to deliver information. The literature has demonstrated that this technology plays an important role in communicating complex ideas to patients. Combining videos with written and verbal information has been found to be a successful strategy for

improving knowledge, adherence, self-care and QOL (Toth 2016). Two examples of educational videos will be described here.

Physical exercise video. A video can highlight lifestyle challenges and encourage patients to exercise. The video might also detail the benefits of exercise, the amount of exercise needed, a strategic plan for success, and advice for making exercise pleasant and enjoyable (American Heart Association/American Stroke Association 2018).

Weight management video. A video can also provide information and advice on managing weight by decreasing intake of foods high in calories and increasing physical exercise. The video can also show strategies to recognise good eating habits, avoid food ‘traps’, and establish a plan to eat healthy meals (American Heart Association/American Stroke Association 2018).

2.6.2 Post-discharge follow-up

The literature and systematic reviews of HF studies concerning strategies to reduce patients’ suffering and readmission rates highlight the importance of new HF management strategies, and strongly recommend implementation of transitional care in the immediate post-discharge period. Several meta-analyses of clinical trials have also suggested that using a single intervention and limiting education programs to inpatients with HF in one sitting are less likely to be successful (Feltner et al. 2014; Horwitz & Krumholz 2013; Vedel & Khanassov 2015).

Early post-discharge follow-up is a very important intervention and a key strategy to prevent worsening of HF symptoms, reduce hospital readmissions and healthcare costs, and improve QOL (DeLia et al. 2014; Jackson et al. 2015). Importantly, transition of care to the outpatient setting is considered an evidence-based strategy to reduce the impact of HF on patients (Jackson et al. 2015). Several types of intervention could be used in this phase including home visits, regular phone calls, outpatient clinics, support groups, cardiac rehabilitation programs and community health volunteers (Barnason, Zimmerman & Young 2012).

2.6.2.1 Home visits

The patient’s home has been described as a potential setting for providing effective education that is important for health promotion and disease prevention (Arcand et al. 2011; Jaarsma et al. 1999; Mussi et al. 2013) 2013). Home-based education programs stand out as a new effective approach for management of patients with HF to enhance compliance and adherence to the treatment regimen, which, in turn, leads to maintenance of clinical and physical stability (Trojahn et al. 2013). Furthermore, the healthcare provider is most likely to have sufficient

time during home visits to give full attention to assessing the patient's physical, psychological, social and other learning needs. This, in turn, enables healthcare providers to establish specific management programs based on the patient's learning needs, and consequently maintain clinical stability, which is reflected in lower readmission rates and healthcare costs (Whitty et al. 2012). Moreover, older, less mobile and more fragile patients have limited access to outpatient clinics and other interventions, whereas a home-based approach would be more feasible for those patients (Stacy 2016). Several HF management strategies can be performed by healthcare providers during home visits such as reinforcing the importance of fluid restrictions, regular weighing, physical exercise, regular use of medication, early recognition of signs and symptoms of worsening HF, and when to seek medical attention (Trojahn et al. 2013).

Azzolin et al. (2015) conducted a before-and-after study to assess the level of knowledge among patients with HF receiving home visits. They measured two outcomes: knowledge of medication and knowledge of the treatment regimen. Four home visits were conducted for patients over a six-month period on day 10, 30, 60 and 120. During each visit, nursing interventions were performed, outcome measures were evaluated, and level of knowledge was assessed using a HF knowledge questionnaire. Knowledge of medication included the patient's ability to recognise and report HF symptoms to healthcare providers, and describe the action and the adverse effects of the medications prescribed. Knowledge of the treatment regimen included the description of a good diet and exercise regime, and understanding the importance of taking medication. The study found that most patients had a lack of understanding and poor knowledge of HF symptoms and self-management strategies. The study also showed a significant improvement in this knowledge after the implementation of the face-to-face education program. Another before-and-after study was conducted to identify the effectiveness of in-home education on treatment adherence in 32 patients with HF. Patients received three home visits in 45 days. The most common HF-related topics covered in the education were fluid restriction, regular weighing and recognition of HF symptoms. The study found an increase in treatment adherence scores at the third home visit in comparison with first one (Mantovani et al. 2015). However, programs that used home visits for all types of patients as a single intervention or used one home visit with a limited amount of education and support appeared to be less effective (Feltner et al. 2014; Horwitz & Krumholz 2013).

2.6.2.2 Outpatient clinics

Outpatient clinics were established as an initiative to promote health and optimise HF management (Gustafsson & Arnold 2004). Several interventions are undertaken by clinics such as diagnosing patients and prescribing medication, educating patients and giving fluids. Patients in these clinics are mainly taught about topics such as smoking cessation, fluid and sodium restriction, adverse effects of medications, physical activity, regular weighing, and compliance with the treatment therapy (Donaho et al. 2015; Gustafsson & Arnold 2004). In addition, patients are also educated on how to recognise and respond to the early symptoms of worsening HF (Donaho et al. 2015). Furthermore, some clinics provide social and emotional support for patients especially for those who have limited social resources, and some incorporate multidisciplinary teams including physicians, specialised nurses, pharmacists and physiotherapists in order to provide information, and psychological and social support for patients (Donaho et al. 2015; Gustafsson & Arnold 2004). However, many patients with HF are older than 65 years, and have several comorbidities, thereby hindering their access to HF clinics. It is therefore important that some are able to receive care through other interventions such as home visits or other accessible interventions (Stewart et al. 2012). Interestingly, previous studies that evaluated the effectiveness of HF clinics on patients' outcomes have reported conflicting results. As a result, there is still a debate and inconclusive evidence about the effectiveness of these clinics as an intervention in providing optimal care and reducing readmission rates (Gorthi et al. 2014b).

2.6.2.3 Phone calls

Follow-up phone calls have been used in HF management programs in order to support patients' education and ensure that patients truly understand how to manage HF in terms of diet, physical activity, signs and symptoms, importance of adherence and compliance with treatment therapy, and others (American Heart Association 2011). Over a period of regular phone calls, healthcare providers including specialised nurses and pharmacists can identify whether patients are adherent to their treatment regimen, and consequently determine whether additional follow-ups and supportive interventions are needed (American Heart Association 2011). Importantly, phone calls were evaluated as a single approach in some previous studies, and combined with other interventions in other studies (Barnason, Zimmerman & Young 2012).

2.6.2.4 Community health volunteers

In the past, some researchers have introduced new technologies and advanced educational interventions to improve knowledge and self-care in patients with HF (Baker et al. 2011; Barnason, Zimmerman & Young 2012; Boyde et al. 2011). Most HF interventions have been established and evaluated in developed countries rather than in developing and low-income countries. In addition, high-tech interventions used in HF management like telemonitoring devices are not commonly used in most developing countries due to their financial inability to afford these technologies (De Geest et al. 2004). Therefore, education programs involving easily understood language and less advanced technologies, and provided by well trained and prepared community health volunteers in these countries is more feasible (Giugliani et al. 2011; Hadi 2003; Siabani et al. 2014b; Sirilak et al. 2013).

In Iran, the strategy of using community health volunteers has been newly developed to address the health needs of patients with HF and other conditions, particularly in rural areas and underprivileged urban areas (Asaei 2014; Siabani et al. 2014b). This strategy utilises educated people who have the motivation, desire and interest to work with and support community health services without pay. Community health volunteers in Iran have been considered to be a bridge between patients who need post-discharge follow-up care and the healthcare system. Each Iranian volunteer is responsible for about 50–100 families living in the district. The community health volunteers are prepared through attending health workshops and training sessions on the required health topics (Asaei 2014).

A three-armed controlled trial of 231 patients with HF was conducted in Iran in 2015 to evaluate the effectiveness of the home visits undertaken by community health volunteers, in comparison with formal education provided in hospital by healthcare providers, and with routine HF care. The study found a significant increase in self-care components among patients in both interventional groups after the provision of education compared with the usual care group, and there were no significant differences between the two interventional groups in relation to self-care (Siabani et al. 2014a). In other words, the strategy of using community health volunteers in low-income countries proved to be effective and feasible (Siabani et al. 2015).

2.6.2.5 Support groups and shared clinic appointments

Patients with HF are at high risk of psychological distress such as depression and anxiety, which consequently impairs patients' self-care, treatment adherence and QOL (Bekelman et al.

2007; Lockhart et al. 2014; Slyer & Ferrara 2013). Depression is significantly associated with increased hospital readmissions, morbidity and mortality. Importantly, the prevalence of depression in patients with HF in US and Europe varies between 16% and 22%, highlighting the importance of addressing this co-morbid condition in HF management (Bekelman et al. 2007; Frasure-Smith et al. 2009; Rutledge et al. 2006).

Patients with HF may experience social isolation and live with chronic debilitating symptoms on a negative trajectory (Emilsson et al. 2012). Therefore, a variety of management strategies have been developed and tailored to those patients such as support groups or shared clinic appointments (Dracup 2013; Emilsson et al. 2012; Slyer & Ferrara 2013). Support groups have been developed to assist patients with chronic progressive conditions to cope better with their health situations. Importantly, several studies have demonstrated that peer support plays an important role in reducing feelings of loneliness and isolation, preventing maladaptive responses, improving health promotion and patients' satisfaction, and preventing deterioration of HF or any other chronic condition (Dennis 2003; Emilsson et al. 2012; Heisler et al. 2013; Lockhart et al. 2014; Slyer & Ferrara 2013). This approach provides an opportunity for patients to meet and share their experiences, care plans, and other HF-related information. This can improve their psychosocial status, enhance their clinical outcomes, and minimise their feelings of loneliness and symptoms of depression (Dennis 2003; Lockhart et al. 2014; Slyer & Ferrara 2013). However, there is still a scarcity of studies evaluating the use of support groups in the management of HF. Some studies did not report favourable results (Heisler et al. 2013), while others found positive results (Barnason, Zimmerman & Young 2012; Dracup 2013). Interestingly, the studies that led to consistent and favourable results in terms of clinical and psychological outcomes incorporated several supporting and empowering factors such as using multidisciplinary team care, social support and emotional support, and those which provided intensive education with a higher dose, amount, and longer follow-ups (Barnason, Zimmerman & Young 2012; Dracup 2013).

2.6.2.6 Cardiac rehabilitation

Cardiac rehabilitation (CR) is a multidisciplinary approach used to slow or reduce worsening of cardiovascular disease (National Heart Foundation of Australia 2004). The European Association of Cardiovascular Prevention and Rehabilitation (Piepoli et al. 2010) and the American Association of Cardiovascular and Pulmonary Rehabilitation (Balady et al. 2007) have established the key constituents of CR, including management of risk factors (DM, HTN, obesity, smoking and dyslipidemia), psychosocial counselling, physical training and nutritional

counselling (Balady et al. 2007). These interventions can decrease the risk of deterioration of cardiovascular disease, promote health and healthy lifestyle behaviours, and enhance QOL (Balady et al. 2007; National Heart Foundation of Australia 2004). Robust evidence shows participation in CR can decrease mortality rates by up to 25% (Clark et al. 2005).

Patient counselling is an integral component of CR to help patients improve adherence to the treatment regimen and lifestyle recommendations as well as reducing the psychological impact of cardiac illness. Another study indicated that CR programs play an important role in improving QOL and self-care, and reducing hospital readmissions and healthcare costs (Gaalema et al. 2015). Furthermore, the duration of programs and number of sessions can be varied according to patients' needs (Balady et al. 2007; Wenger 2008).

2.6.3 Factors supporting heart failure management

2.6.3.1 Patient-centred care approach

Patient-centred care refers to patients' ability to manage their own care, and cooperate with the healthcare team to make treatment decisions (Casimir et al. 2013). Patient-centred care is viewed as being optimal care, the best quality care, and the most cost-effective care for a patient provided through a multidisciplinary team (Casimir et al. 2013). However, patient-centred care should be based on several factors including effective communication, empathy, and the development of a friendship and a trusting relationship between healthcare providers and the patient to optimise outcomes (Rickert 2012). The Institute of Medicine in America recommends such as consideration of patient's cultural traditions, preferences, values, social circumstances and lifestyle into the patient-centred approach to care (Richardson et al. 2001). Patient-centred care is a strategy directed towards achieving an individual patient's needs and preferences as an integral part of the treatment plan to satisfy desired outcomes (Greene, Tuzzio & Cherkin 2012). It concentrates on the patient rather than the disease and helps patients to be more knowledgeable and more informed about their diagnosis, in order to manage their symptoms and engage in self-care behaviours (Greene, Tuzzio & Cherkin 2012). Patient-centred self-care aims to improve patients' knowledge, self-care and QOL, which consequently maintain clinical stability, lower readmissions and reduce financial burdens (Casimir et al. 2013; Greene, Tuzzio & Cherkin 2012).

2.6.3.2 Multidisciplinary care

Multidisciplinary care has been considered to be a high-quality approach to providing optimal care to all patients with HF. Importantly, the NHFA, the international clinical practice guidelines, health policy makers in Australia, and consensus statements have endorsed this effective and evidence-based approach in HF management programs (Davidson et al. 2010; Davidson et al. 2015; Hare et al. 2006; McAlister et al. 2004). Several clinical trials targeting HF management programs have suggested that incorporating multidisciplinary teams can play an important role in reducing hospital readmissions (Smith et al. 2015). In addition, previous researchers have postulated that multidisciplinary care is a useful approach to provide comprehensive care for vulnerable patients with HF including older patients in advanced stage disease, and those with poor self-care skills (Davidson et al. 2010). In conclusion, this approach provides informational, psychological and social support in order to ensure the best HF care, which in turn will enable health policy makers in collaboration with healthcare providers to develop and implement new guidelines and protocols for treatment (Davidson et al. 2010).

2.6.3.3 Social support

Social support has been defined as a positive relationship that improves health and relieves stress especially in patients with chronic conditions such as HF (House, Umberson & Landis 1988). Several types of support can be provided to patients including informational, emotional and psychological support (Gallagher, Luttik & Jaarsma 2011).

HF management is a complex process, and patients affected with this condition are often isolated, psychologically distressed and burdened. Furthermore, those patients are required to take on many responsibilities such as improving their diet, physical activity, ceasing smoking, treatment regimen, daily weighing and other lifestyle changes, and it can be difficult to handle all these tasks without help and support from others (Gallagher, Luttik & Jaarsma 2011). Furthermore, patients are usually advised by healthcare providers to change their lives in terms of eating habits, traveling, remembering medication, giving full attention to their management plan, and avoiding stress. These changes may be easier for patients when loved ones such as family members and close friends are involved in providing physical, psychosocial and emotional support. Therefore, family members and loved ones are most likely to have a significant impact in supporting self-care, improving QOL, and reducing clinical burden among patients with HF.

Importantly, the success of social supports in disease management programs depends on several factors including the nature of the relationship, concern for the patient, and the type of support provided (Gallagher, Luttkik & Jaarsma 2011). However, there is a scarcity of studies that evaluate all of these aspects in order to assess the effectiveness of social support (Clark et al. 2009; Dunbar et al. 2008; Gallagher, Luttkik & Jaarsma 2011).

2.7 Analysis of gaps in the research

The extensive search and critique of six systematic reviews targeting HF management demonstrated that assessments of previous HF management programs are conflicting, and therefore it is difficult to determine the most effective components of care. The conflicting results can be attributed to multiple reasons (Barnason, Zimmerman & Young 2012; Boren et al. 2009; Buck et al. 2018; Cui et al. 2019; Harkness et al. 2015; McGreal et al. 2014). Firstly, the vast majority of previous HF management programs were structured and limited in terms of dose and amount of intervention, duration of the program, and number of follow-ups (Barnason, Zimmerman & Young 2012; Boren et al. 2009; Buck et al. 2018; Cui et al. 2019; Harkness et al. 2015; McGreal et al. 2014). Therefore, using a structured program with limited options is unlikely to be useful, because patients with HF have various levels of knowledge and self-care skills, and some need more effort and time to understand and comprehend self-management and treatment therapy. In other words, flexibility in management of patients already burdened with HF symptoms is important to ensure better and optimal care, and to avoid placing an additional burden on patients.

Secondly, improving patients' knowledge of HF was the main objective of most previous studies (Barnason, Zimmerman & Young 2012; Boren et al. 2009; Buck et al. 2018; Cui et al. 2019; Harkness et al. 2015; McGreal et al. 2014). However, knowledge alone is not sufficient to improve self-care and QOL, especially for patients who have depressive symptoms or any other psychological distress. Interestingly, interventions predominantly used to improve patients' psychological state, provide social support, and promote QOL were incorporated in few studies, in spite of their significant effect in improving patients' knowledge, recognition of symptoms, self-care and adherence to treatment. Importantly, patients with HF have individual variations in terms of age, psychological state, HF severity, financial state, and cognitive level. So, one specific intervention is unlikely to be suited to all patients, and will not be effective in achieving clinical and functional stability. Consequently, multiple types of interventions should be combined and tailored for patients in a flexible manner to ensure best care and prevent deterioration. For example, community health volunteers who conduct home

visits can be more feasible and appropriate than outpatient clinics for elderly patients who are severely ill and unable to pay for other available interventions. Another example of an effective HF intervention is non-compulsory regular phone calls, which could be utilised in combination with other interventions for the purpose of consultations, inquiries, follow-up appointments, patient support, as well as sharing experiences and care plans with peers. Thirdly, most studies exclude newly diagnosed patients, especially those who are classified in class I of the NYHA classification, because those patients are less likely to have clinical symptoms (Barnason, Zimmerman & Young 2012; Boren et al. 2009; Buck et al. 2018; Cui et al. 2019; Harkness et al. 2015; McGreal et al. 2014). However, these patients possibly have the most to gain from intensive education and comprehensive management, and are most likely to be motivated to learn and manage their condition. Fourthly, most patients with HF live with other chronic conditions such as diabetes, HTN and CAD. Although these conditions have been identified as risk factors for HF, management strategies and preventive measures for these conditions were not commonly addressed in previous HF management programs, and the topics most often highlighted were HF-related topics such as fluid and sodium restriction, and regular weighing. The core components of any disease management program should be patients' education, treatment adherence, and self-care. For example, patients with low self-confidence and poor treatment adherence may have sufficient knowledge of HF. However, engagement of those patients in self-care will be less effective than for patients who are confident and adherent. Fifthly, most of the previous studies only focused on HF management without highlighting the importance of changing lifestyle in terms of eating a heart-healthy diet, limiting alcohol and caffeinated drinks, physical activity, monitoring blood pressure and blood sugar, managing stress, avoiding flu and pneumonia with vaccinations, quitting smoking, and getting adequate rest (Barnason, Zimmerman & Young 2012; Boren et al. 2009; Buck et al. 2018; Cui et al. 2019; Harkness et al. 2015; McGreal et al. 2014). Patients' lifestyles could be improved through establishing CR programs and awareness campaigns in Jordanian medical centres using brochures, pictures, pamphlets and newspapers (American Heart Association 2017a). Finally, most HF programs were conducted in developed countries (Barnason, Zimmerman & Young 2012; Boren et al. 2009; Buck et al. 2018; Cui et al. 2019; Harkness et al. 2015; McGreal et al. 2014). Therefore, a new management program targeting HF in Jordan and other developing countries is warranted.

2.8 Summary

HF is a chronic debilitating condition, contributing to increased hospital readmissions and healthcare costs. Management of HF is crucial to promote health and reduce patient suffering. Despite advances in HF treatment, there is still a gap between guidelines and clinical practice in terms of the best structure of HF management programs. HF management programs can include various interventions: education, post-discharge follow-ups, home visits, outpatient clinics, phone calls, community health volunteers, support groups and CR. The factors that support HF self-management include: a patient-centred care approach, multidisciplinary care and social support. The next chapter will present the methodology utilised in this study.

Chapter 3: Methodology

Research designs determine how data are collected, analysed, interpreted and reported. Using the most suitable research design can lead to logical conclusions, allow easy interpretation of data, and produce reasonable results. A mixed-methods approach was selected as a rigorous research design to best answer the research questions and strengthen the breadth and depth of understanding of the research problem.

3.1 Mixed-methods approaches

3.1.1 Historical development of mixed-methods approaches

The complexity of healthcare delivery has been increasing globally, due to the rise in the aging population, patients with multiple comorbidities, increased technology and for many countries limited health resources. A diverse set of other forces, such as financial, socio-cultural, environmental and political factors, have also led to increased levels of complexity (Halcomb & Hickman 2015; Lavelle, Vuk & Barber 2013). Therefore, there has been increased recognition among researchers that using a single method is not sufficient to properly address complex research problems, and answer a variety of research questions. Subsequently, many researchers have embraced mixed-methods approaches as an effective research method within social sciences, health and health education (Glogowska 2015).

Mixed-methods research started in the fields of both anthropology and sociology in the early 1960s (Doorenbos 2014; Morse 1991). It has been considered as an alternative approach to explore complex phenomena, better answer research questions, address research issues clearly, and produce more comprehensive knowledge, in comparison to what is achieved using a single method (Halcomb & Hickman 2015). Historically, using a mixed-methods approach was prevented by a clash of paradigms within nursing inquiry. However, these clashes have now largely been surmounted through using a pragmatic approach, and implementing the methodologies that properly answer the research questions (Glogowska 2015; Maudsley 2011; McEvoy & Richards 2006). This is demonstrated by the observation that there has been a steady increase in the number of papers published by nursing researchers who have used mixed methods, reflecting the important role of this approach in research studies (Halcomb & Hickman 2015; Lipscomb 2008).

3.1.2 The definition of mixed-methods research

The term ‘mixed-methods research’ is widely accepted to indicate research that combines both qualitative and quantitative designs in one study (Andrew & Halcomb 2009; Halcomb & Hickman 2015; Wisdom et al. 2012). Simply put, in mixed-methods research numerical data are used in quantitative data collection and analysis, whereas narrative and textual forms of data are used in qualitative research (Hayes, Bonner & Douglas 2013). Mixed-methods research involves interlinking qualitative and quantitative designs to produce a comprehensive understanding, and provide a holistic approach to the research problem (Creswell 2013; Zhang & Creswell 2013). There have, however, been different definitions of mixed-methods research (Creswell & Plano Clark 2007). It has been defined as ‘Research in which the investigator collects and analyses data, and draws inferences using both qualitative and quantitative approaches and methods in a single study or a program of enquiry’ (Creswell & Plano Clark 2007, p. 4).

3.1.3 The benefits and advantages of using mixed methods

Mixed-methods research exploits the advantages and core competencies of both qualitative and quantitative research, while countering their weaknesses, to more effectively comprehend the research problem under investigation (Andrew & Halcomb 2009; Scammon et al. 2013; Wisdom et al. 2012). The utilisation of mixed-methods research has many benefits. Quantitative research can underpin the qualitative method by assisting the researcher to identify the participants who will be recruited in the qualitative phase, while the qualitative method assists with generating new insights, in order to corroborate research findings and provide a holistic image of the research problem. As an example, quantitative information can help researchers choose whom to interview in a qualitative component of a research study. Similarly, data collected qualitatively can help in the interpretation, clarification, description and validation of quantitative results (Doorenbos 2014; Tariq & Woodman 2013).

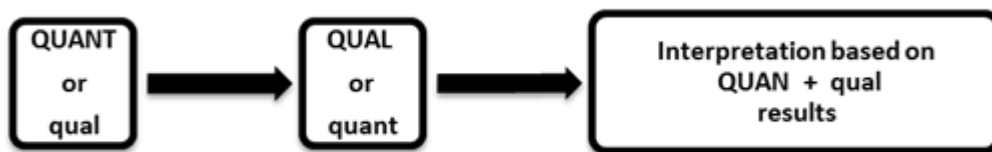
3.1.4 Situations that benefit from utilising mixed-methods approaches

There are four situations which benefit from the utilisation of mixed-methods research (Creswell & Plano Clark 2007). The first situation involves new terminology and concepts that are not well understood. Therefore, there is a necessity to fully explore and understand the new concepts. The second situation is when data from one particular method can help understand and clarify findings of another. The third situation is when the use of a single method, either qualitative or quantitative, is not sufficient to understand the concept. The last situation is when

the researchers have difficulty interpreting the quantitative results, and a qualitative method can be used to help them understand the results (Creswell & Plano Clark 2007).

3.1.5 Illustrating models of mixed-methods designs

A notation system has recently emerged in the literature discussing mixed-methods research, which helps to facilitate understanding of research designs. These notations introduced by Morse include (QUANT- quantitative method is dominant, qual- qualitative method is secondary a plus sign (+) to indicate the occurrence of methods at the same time, and arrows (→) to denote the occurrence of methods in sequential phases (Creswell & Plano Clark 2007). In addition, Creswell and Plano Clark (2017) introduced new diagrammatical formats to the notation system of mixed-methods design to reduce complexity and better explain the design. The steps employed in a mixed-methods design are illustrated by geometrical shapes such as ovals and boxes (Figure 3.1) (Creswell & Plano Clark 2007; West 2012).



QUANT-quantitative method is dominant, qual- qualitative method is secondary, (+) indicates the occurrence of both quantitative and qualitative methods at the same time (Creswell & Plano Clark 2007).

Figure 3.1: Notations used to describe mixed-methods approaches.

3.2 Considerations when selecting a research design

When selecting a mixed-methods design for a research study, researchers need to consider several factors. The most important consideration is that the design should fit and correspond with the research problem. Moreover, researchers should assess their own knowledge, skills and experience of using quantitative and qualitative methods (Abbas & Charles 2003; Creswell & Plano Clark 2007). Another consideration is the availability of resources, such as the time and funding needed to complete the study (Creswell & Plano Clark 2007). Further to these considerations, researchers need to select a research design based on three important factors. These include are the timing of data collection in both quantitative and qualitative methods,

the relative weight of both methods, and the method of mixing and connecting the two data sets (Creswell & Plano Clark 2007).

3.2.1 *Timing*

Researchers selecting a mixed methods design in research studies should identify the timing of the two data sets. The word timing, denoted as ‘implementation’ or ‘sequence’, involves the temporal relationship between the elements of the quantitative and qualitative methods within a study (Creswell & Plano Clark 2007, p. 81). It refers to the order of the data collection and interpretation/analysis (Creswell & Plano Clark 2007).

Timing may be classified as either concurrent or sequential (Figure 3.2) (Creswell & Plano Clark 2007, p. 80); Morse 1991). Concurrent timing occurs when both quantitative and qualitative methods are conducted in one phase. This means that both methods involving data collection, analysis and interpretation occur approximately at the same time. The timing is sequential if the two methods are implemented separately and sequentially. This means that one type of data is collected and analysed before beginning collection of the other type of data.

(a) What will the timing of the quantitative and qualitative methods be?

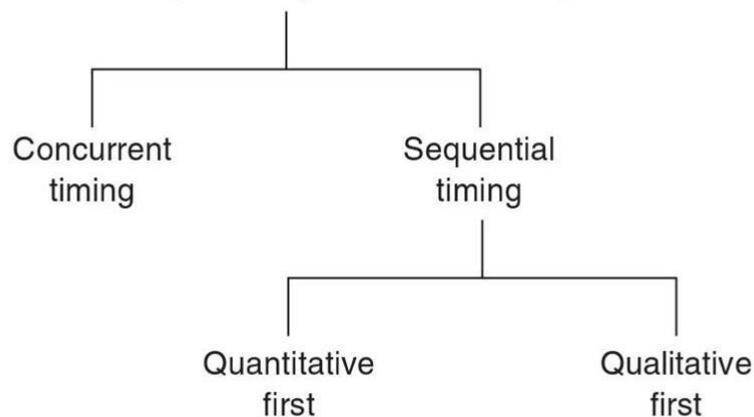


Figure 3.2: Illustration of concurrent and sequential timing (Creswell & Plano Clark 2007)

3.2.2 *The weighting decision*

After identifying the timing, researchers should also take into consideration the relative weighting of the two methods used in the study (Figure 3.3). Weighting indicates the relative significance of both methods, in which one method can be more complex, and one can be relied on to answer the research questions more than the other. In addition, researchers decide whether both methods will be given the same weight, or one a greater weight than the other (Creswell

& Plano Clark 2007, p. 80). There are two weighting options possible for mixed-methods designs. In the first option both methods are given the same priority so that they have equal roles in answering the research questions. The second option involves each method having different weights; either the quantitative or qualitative has a greater importance and impact in addressing the research problem (Creswell & Plano Clark 2007; Morse 1991). Morse (1991) suggests that weighting can be determined by the researcher's worldview. A post-positivistic worldview prioritises the quantitative method; a naturalistic worldview prioritises a qualitative method, whereas a pragmatic overview calls for flexibility in terms of choosing either equal or unequal weighting, based on the research question (Morse 1991).

(b) What will the weighting of the quantitative and qualitative methods be?

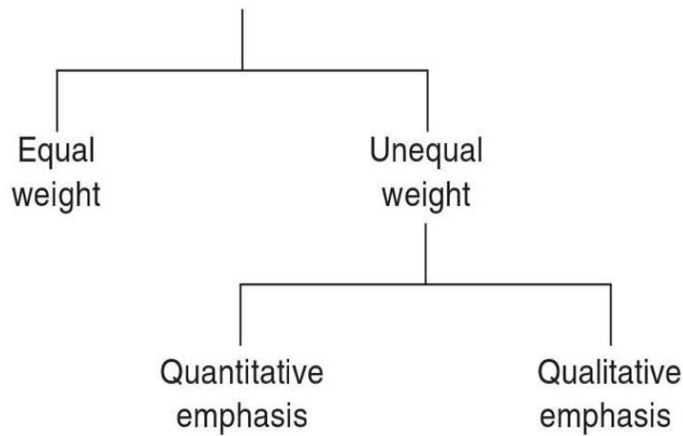


Figure 3.3: Illustration of the weighting of the quantitative and qualitative methods (Creswell & Plano Clark 2007)

3.2.3 The mixing decision

The means of mixing quantitative and qualitative methods has been considered an important factor when designing a mixed-methods study. A study that involves both methods without integrating data is merely considered multiple data collection methods. Therefore, researchers should address the approach to mixing (Figure 3.5), in order to ensure rigour in mixed-methods designs (Creswell & Plano Clark 2007). Different approaches to mixing are available; these include merging, embedding data methods, and connecting data (Creswell & Plano Clark 2007, p. 80).

3.2.3.1 Merging data sets

The researcher can merge the data. The two data methods are collected and analysed separately, and then the results are merged together in the interpretation phase, or during data analysis, by transforming one type of data into the other one (Figure 3.4) (Creswell & Plano Clark 2007, p. 80).

3.2.3.2 Embedding data

When embedding data, one type of data (either quantitative or qualitative) can be embedded within the dominant type of data. This form of mixing occurs concurrently in data collection. For example, qualitative data can be nested within a larger set of quantitative data (Figure 3.4) (Creswell & Plano Clark 2007, p. 80).

3.2.3.3 Connecting data

The data can be connected when the results of analysis of particular data indicate the need to include another type of data. This connection can be performed in one of two ways. Firstly, the quantitative results obtained by researcher can lead to the subsequent qualitative data collection and analysis. A researcher may also use the qualitative results to build the subsequent quantitative data collection and analysis of data. There are different ways of connecting data, such as in determining research questions, choosing participants or creating research tools (Figure 3.4) (Creswell & Plano Clark 2007, p. 80).

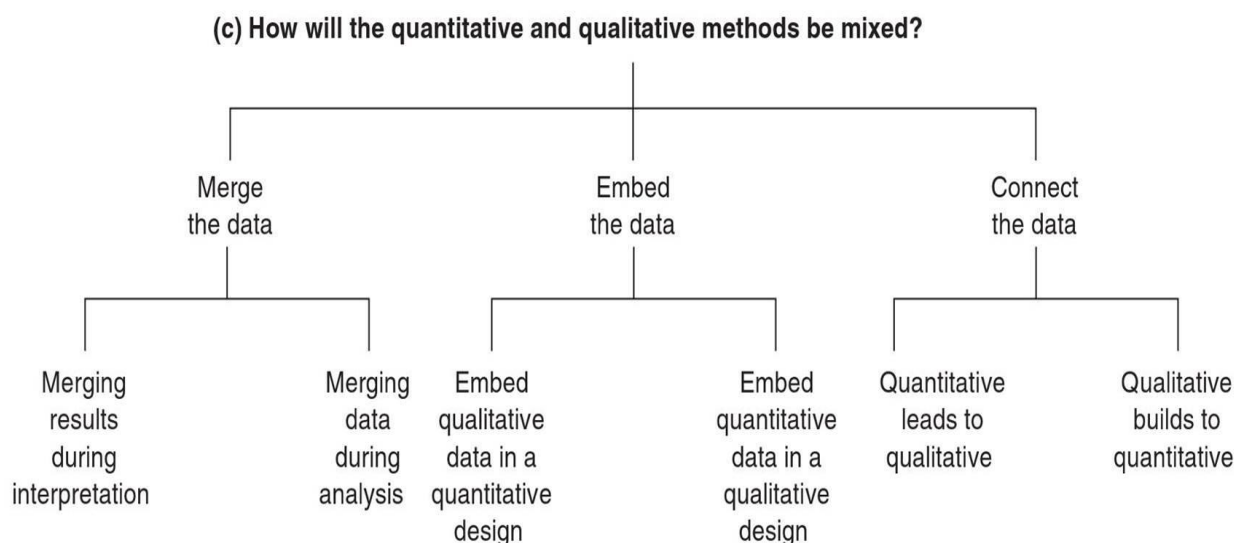


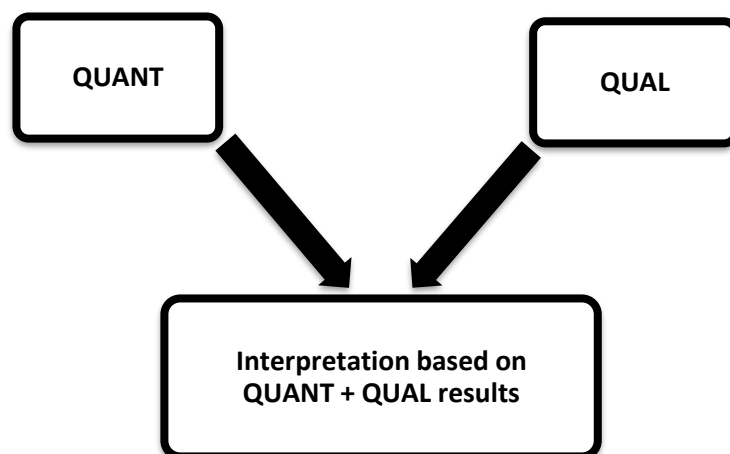
Figure 3.4: Ways of mixing quantitative and qualitative methods (Creswell & Plano Clark 2007).

3.3 Types of mixed-methods designs

Researchers conducting a mixed-methods study should be familiar with the main types of mixed-methods designs including the goals, the strengths and the challenges of each design. Researchers also need to be acquainted with certain aspects of mixed-methods design including the timing, weighting, and mixing decisions (Creswell & Plano Clark 2007). There are four types of mixed-methods designs: concurrent triangulation, embedded, explanatory and exploratory (Table 3.1) (Andrew & Halcomb 2009).

3.3.1 Concurrent triangulation

Concurrent triangulation involves data collection in a single phased study. In this design, quantitative and qualitative data collection and analysis occur concomitantly but separately. The researcher tries to combine the two data sets, typically by integrating the separate results in the interpretation phase (Figure 3.5). Furthermore, the quantitative and qualitative methods used in this design are given equal weight (Creswell 2013; Creswell & Plano Clark 2007). Researchers require significant effort and considerable experience to sufficiently implement both methods concurrently and separately. In addition, discrepancies and differences in the results of quantitative and qualitative methods are likely to occur. Consequently, researchers may face difficulty in comparing and integrating the results of the two separate analyses (Creswell & Plano Clark 2007).

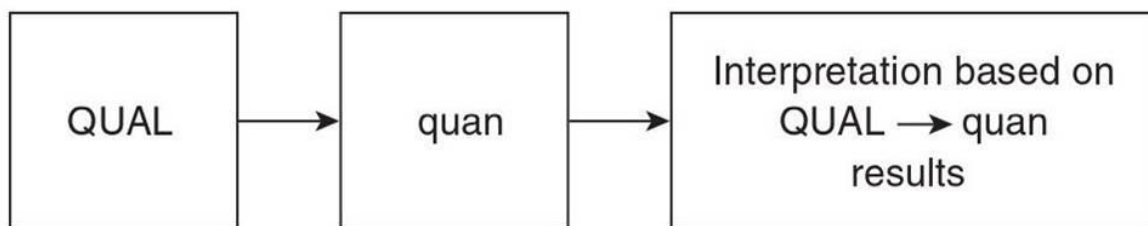


QUANT-quantitative method is dominant, QUAL- qualitative method, QUANT+QUAL- the results of both quantitative and qualitative methods are integrated at the same time (Creswell & Plano Clark 2007).

Figure 3.5: Illustration of the concurrent triangulation design.

3.3.2 Sequential exploratory design

Exploratory design consists of two different phases, starting with qualitative data collection and analysis, followed by quantitative data collection and analysis (Figure 3.6). Importantly, the qualitative phase is more influential and dominant in exploring the phenomenon, and guides researchers to conduct the quantitative phase (Table 3.1). This design is used to examine the elements of any theory that may develop after conducting qualitative research, to improve the generalisability of the qualitative findings, and to develop a new study tool (Creswell & Clark 2007). However, researchers using this design need a substantial length of time to completely collect and analyse the data in both phases. Furthermore, it may be difficult to develop new quantitative research questions based on qualitative findings (Andrew & Halcomb 2009; Creswell & Plano Clark 2007).

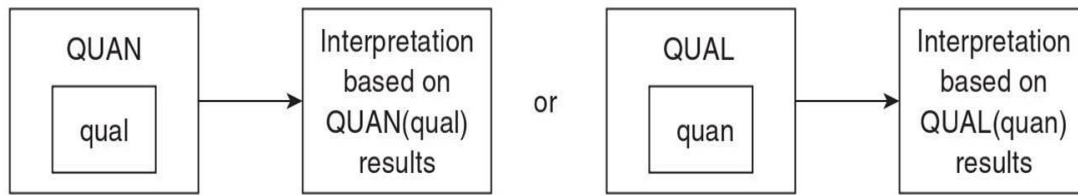


QUAL- the dominant qualitative method, quan- the secondary quantitative phase, QUAL → quan- the interpretation of qualitative and quantitative methods in sequential phases (Creswell & Plano Clark 2007).

Figure 3.6: Illustration of the mixed methods sequential exploratory design.

3.3.3 Concurrent nested

The nested method is used within a large qualitative or quantitative study, in order to answer research question, search for new information, and overcome the likely weakness of the dominant method. This type of mixed-methods design involves only one data collection time period, in which the less dominant method (either quantitative or qualitative) is embedded (nested) within the dominant method (Figure 3.7). This design may imply that one data set is not adequate, and the other type of data is needed to clearly address the research questions (Table 3.1). In concurrent nested studies, researchers may face difficulty in transforming and integrating both quantitative and qualitative data during the analysis. Moreover, interpreting the results may be not reliable due to the inequality between the two methods (Andrew & Halcomb 2009; Creswell 2013; Creswell & Plano Clark 2007).



QUAN - the dominant quantitative method, qual-secondary qualitative phase, QUAL- the dominant qualitative method, quan- the secondary quantitative method (Creswell & Plano Clark 2007).

Figure 3.7: Illustration of mixed-methods concurrent nested design

3.3.4 Mixed method sequential explanatory design

3.3.4.1 Procedures of explanatory design

Mixed-methods sequential explanatory design is comprised of two different phases, which both involve data collection and analysis. The first phase involves quantitative data, and the second phase involves qualitative (Figure 3.8). The two phases are conducted sequentially (Andrew & Halcomb 2009). In this design, the initial quantitative (numeric) data are collected and analysed. Then, a researcher conducts the qualitative method, involving data collection and analysis in sequence, to assist with explaining, or elaborating on, the quantitative results from the initial phase. The quantitative results help in building the qualitative phase, and both data sets are combined in the intermediate stage in the study (Rossman & Wilson 1985; Tashakkori & Teddlie 2010). This design can be employed when the quantitative results are not sufficient to explore the complex phenomenon, and do not provide a holistic picture of the study topic (Abbas & Charles 2003; Čížek 2009; Creswell & Plano Clark 2007). In addition, qualitative data assist researchers to explain, interpret and build on the initial quantitative results. Therefore, the qualitative design is needed to counter the weakness of the quantitative results or to explore findings from the initial quantitative results (Abbas & Charles 2003; Andrew & Halcomb 2009; Creswell & Plano Clark 2007). This ultimately highlights the importance of using another method such as a qualitative method to help interpret the results and complement the weakness of quantitative method (Andrew & Halcomb 2009).

3.3.4.2 The advantages and strengths of explanatory design

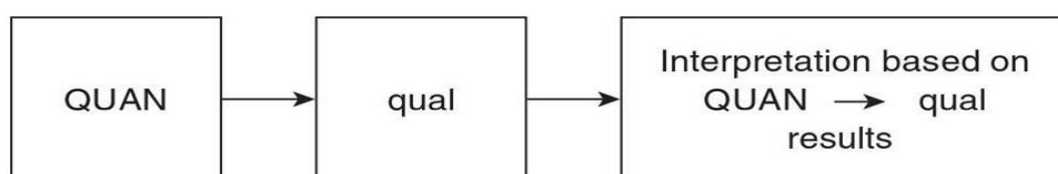
Creswell and Plano Clark (2007) state that the explanatory design facilitates the sampling process in the qualitative phase of a study through identifying the characteristics of participants from the quantitative phase (Figure 3.8). Importantly, the explanatory design has been identified as the theoretical driver of research studies, with a great emphasis on quantitative

results that could be utilised to better explore research problems, and steer the subsequent qualitative phase (Abbas & Charles 2003; Creswell & Plano Clark 2007; Doorenbos 2014). This design has been identified as the most easily understood of all mixed-methods designs. In the two phases, data collection and analysis are implemented sequentially and separately. The researcher can write the final report in two sequential phases, which in turn facilitates the understanding of the research problem, and provides a better delineation for readers (Creswell & Plano Clark 2007). In the literature, the number of healthcare and nursing studies using a mixed-methods sequential explanatory design is dramatically increasing (Ivankova, Creswell & Stick 2006).

3.3.4.3 Examples of research studies utilising an explanatory mixed-methods design

The following two examples of healthcare studies utilising explanatory mixed methods are provided to explore the design in more detail. Carr (2000) conducted a longitudinal research study using a mixed-methods sequential explanatory design. The study explored the impact of pain on patient outcomes for 85 women post-gynaecological surgery. In the first phase, a quantitative study using survey questionnaires was performed to assess patients' levels of anxiety, depression and pain. The second phase comprised a qualitative study using semi-structured interviews. The qualitative study was implemented to provide a holistic picture of the multidimensional experience of pain, and to better explore the effect of pain on other factors such as sleep, mood and general activity.

West's (2012) mixed-methods sequential explanatory study aimed to assess and explore family resilience when a family member experiences chronic pain. The first phase used four assessment tools on 67 patients and their families. Mean, standard deviation, percentages and other descriptive statistics were used to summarise the quantitative data. The next (qualitative) phase used semi-structured interviews with 10 families in order to assist the researchers to explain, understand and clarify the quantitative results. The qualitative data were analysed using content and thematic analysis.



QUAN – quantitative method is dominant, qual – qualitative method is secondary, QUAN → qual indicates the quantitative and qualitative methods are implemented in sequence (Creswell & Plano Clark 2007).

Figure 3.8: Illustration of mixed-methods sequential explanatory design

Table 3.1: The major types of mixed-methods design.

<i>Design Type</i>	<i>Variants</i>	<i>Timing</i>	<i>Weighting</i>	<i>Mixing</i>	<i>Notation</i>
Triangulation	<ul style="list-style-type: none"> • Convergence • Data transformation • Validating quantitative data • Multilevel 	Concurrent: quantitative and qualitative at same time	Usually equal	Merge the data during the interpretation or analysis	QUAN + QUAL
Embedded	<ul style="list-style-type: none"> • Embedded experimental • Embedded correlational 	Concurrent or sequential	Unequal	Embed one type of data within a larger design using the other type of data	QUAN(qual) or QUAL(quan)
Explanatory	<ul style="list-style-type: none"> • Follow-up explanations • Participant selection 	Sequential: Quantitative followed by qualitative	Usually quantitative	Connect the data between the two phases	QUAN → qual
Exploratory	<ul style="list-style-type: none"> • Instrument development • Taxonomy development 	Sequential: Qualitative followed by quantitative	Usually qualitative	Connect the data between the two phases	QUAL → quan

3.4 Pragmatism

3.4.1 Philosophical assumptions of pragmatism

In the pragmatic approach, the researcher uses what works best to find the most appropriate answers to the research question (Abbas & Charles 2003; Creswell & Plano Clark 2007). Subjective and objective observations are highly valued in this philosophy to identify the best answers to research questions (Aboulafia & Shook 2009; Andrew & Halcomb 2009; Creswell & Plano Clark 2007; West 2012; Feilzer 2010). This philosophical approach has been found to bridge the gap between the empirical approach and investigation of qualitative research theories (Tashakkori & Teddlie 2010; West 2012).

3.4.2 Historical overview of pragmatism

Historically, pragmatism was established as a philosophical movement in the late nineteenth century by American philosopher Charles Sanders Peirce (Rorty 1990; West 2012). Thereafter, this movement was expanded based on the initial work by William James, John Dewey, George Mead and Arthur Bentley. These pragmatists and other philosophers did not accept classical

assumptions concerning truth and research inquiry (Aboulaflia & Shook 2009; Shook & Solymosi ; West 2012). In addition, these early scientists believed that utilising a single method could not represent the real world. They were firmly of the belief that in order to achieve success in understanding the world, one must learn from one's experiences (West 2012). George Mead developed the concept of social behaviourism, which was one of the main influential movements in pragmatism, and had a significant impact on psychologists and social scientists. In addition, the concept of 'the act', mainly focusing on what is real and happening now, was another influential notion developed by Mead (Abbas & Charles 2003; Tashakkori & Teddlie 2010; West 2012). Dewey, who had the most significant effect on scientific research, voiced the importance of liberalism to discard traditional concepts associated with education, politics and world peace (Hickman & Alexander 1998; West 2012). Dewey developed the concept of 'learning by doing', which calls for the full integration of knowledge and skills into learners' lives. This concept has been more useful and beneficial for teaching than traditional ways of teaching (Dewey, Hickman & Alexander 1998; Tashakkori & Teddlie 2010; West 2012). In the late twentieth century, contemporary pragmatism has developed as a new pragmatic belief, and defined as some principles of the old pragmatic beliefs yet being 'deeply rooted in common sense and dedicated to the transformation of culture and the conflicts that divide us' (West 2012, p. 65). This has had a considerable impact on the methods of social science and philosophy of science (McDermid 2008; West 2012).

3.4.3 Philosophical debates and beliefs around pragmatism

In general, pragmatic philosophy holds that people's thoughts are intrinsically connected to actions (West 2012). Creswell and Plano Clark (2007) believe that developing a foundation is essential in all research and this can be established in the theoretical framework or worldview selected by the researcher. In addition, Creswell contends that worldviews do not have a standard level and evolve and change with time. Furthermore, Creswell believes that instead of viewing worldviews as rigid categories, researchers tend to classify types of worldview based on what they have in common. In addition, worldviews should be seen as organisational frameworks that provide different stances due to the variations found in the common components of each framework (Creswell & Plano Clark 2007). Using a multi-stance approach in pragmatism can allow researchers to involve both biased and unbiased views, and acknowledge that using subjective and objective data is very useful to the research (Creswell & Plano Clark 2007). Methodologically, researchers using the pragmatic approach are usually interested in using both quantitative and qualitative methods in data collection and analysis.

This consequently improves the value of the research, and gives the researchers an opportunity to be creative in addressing research problems and exploring complex phenomena (Abbas & Charles 2003; Creswell & Plano Clark 2007; Tashakkori & Teddlie 2010). Interestingly, pragmatism has been considered by Kaplan (1964) as an escape from the notion of empiricism, suggesting that knowledge comes from personal experiences (West 2012). Bernstein supports Kaplan's beliefs, stating that incorporating a mixed-methods approach is important to both social and health science inquiry (West 2012).

3.4.4 Pragmatism and mixed-methods approaches

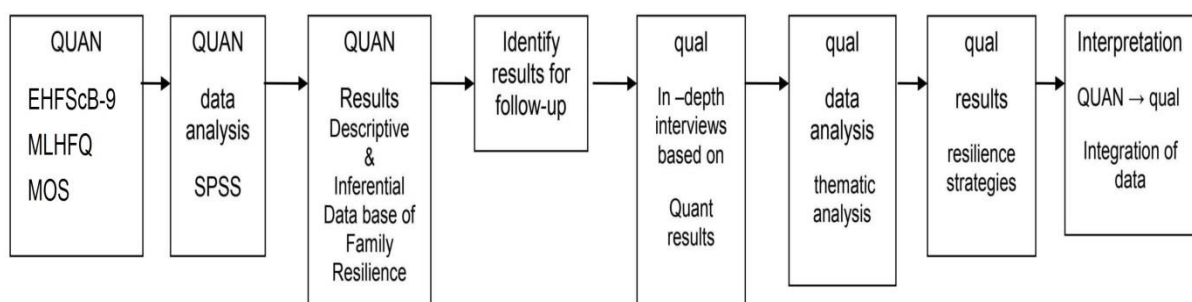
Recently, there has been an increase in the popularity and use of mixed-methods approaches as a separate design and it is considered a research methodology (Andrew & Halcomb 2009). Creswell and Plano Clark (2007) argue that employing a mixed-methods approach as a methodology adds flexibility and complexity to research, through using different worldviews and philosophical assumptions such as pragmatism. Creswell has also emphasised that all types of research studies have particular worldviews and philosophical assumptions, which in turn guide researchers in their scientific inquiry. Mixed-methods approaches have been viewed as a practical and flexible approach in scientific inquiry (Creswell & Plano Clark 2007). The practicality of this approach is congruent with the philosophical assumptions of pragmatism, and centred upon the notion that people tend to use both numbers and words in order to solve their problems (Creswell & Plano Clark 2007; West 2012). Pragmatism suits mixed-methods approaches, because research projects can be conducted without applying any constraints or laws recognising one truth (Tashakkori & Teddlie 2010; West 2012). The uniqueness of pragmatism requires that assumptions concerning reality are rejected, and languages of research and health science inquiry are subject to change and development. In addition, pragmatism aims to leave all possibilities of scientific inquiry open, focusing on the most practical way. Scientists and researchers supporting pragmatic beliefs have simply defined pragmatism as a philosophy of 'common sense', emphasising the crucial importance of purposeful human inquiry in data collection and analysis, and utilising mixed research approaches that involve both quantitative and qualitative methods (West 2012).

3.5 Employing a mixed-methods design in this study

This study aimed to develop a tailored patient-centred HF management program that is respectful and responsive to a patient's preferences, needs and values. In order to achieve the goals and objectives of this study, a mixed-methods sequential explanatory design, adopting

the philosophical assumptions of pragmatism, was employed as the most appropriate approach. Accordingly, the study was conducted over two sequential phases. The first phase involved collection of quantitative data through a survey, and analysis of this data, and the second involved qualitative data collection using a focus group and the Delphi method, and analysis (Figure 3.9). Focus groups are commonly used in mixed-methods studies to develop more information about constructing questionnaires or interpreting results (Creswell & Plano Clark, 2007; Kroll, Neri, & Miller, 2005).

Furthermore, the qualitative phase built on the initial quantitative phase, and helped to address the research problem and explore the real-life experiences of patients with their chronic illness, including their perceptions and needs. In regard to the weighting decision, both phases were given the same priority and weight. This decision was made for three important reasons. Firstly, the researcher adopted the philosophical assumptions of pragmatism that made the study more flexible. Secondly, the time and effort spent by the researcher to conduct this study involving data collection and analysis was similar in both phases. Thirdly, no phase was utilised more than the other. In relation to timing the quantitative data were collected and analysed before the qualitative data, allowing the results of the quantitative phase to inform the qualitative phase. Therefore, the interaction occurred during the formation of the qualitative phase, whereas the data integration took place in the interpretation phase. Figure 3.9 shows the explanatory mixed-methods design employed in this study.



European Heart Failure Self-Care Behaviour Scale-9 (EHfScB-9), Minnesota Living with Heart Failure Questionnaire (MLHFQ), Medical Outcome Scale (MOS), QUAN – quantitative method, qual – qualitative method (Creswell & Plano Clark 2007).

Figure 3.9: Sequence of both quantitative and qualitative phases used in the present study employing mixed-methods explanatory sequential design.

3.6 Survey

Survey research is defined as ‘the collection of information from a sample of individuals through their responses to questions’ (Ponto 2015, p. 186). This type of research assists researchers with recruiting participants, collecting data and utilising varied instrumentation methods (Ponto 2015). A survey can be utilised in quantitative studies such as numerical rated questionnaires, qualitative research studies such as open-ended questions, or in mixed methods. It is mainly used to gain information associated with preferences and behaviours (Singleton Jr et al. 1988). This allows the researcher to categorise their participants according to demographics including sex, religion, ethnicity and income to investigate various characteristics, behaviours or opinions within these demographics. This was shown in this study where self-care, adherence to self-care, knowledge and QOL were investigated according to the characteristics of the Jordanian patients with HF (Ponto 2015). Although a survey is a specific research tool, its capacity to gather a large quantity of data both quickly and cheaply have rendered it ubiquitous in the healthcare field, with approximately half of recently published articles utilising it (Blackstone 2012; Ponto 2015). The versatility of a survey allows it to be administered in a wide variety of ways including phone, in person, mail or email, depending on participant preferences. Even with these benefits, a survey can still be conducted with consideration to selecting a sampling frame, maximising the response rate, and accounting for non-response bias. These advantages were considered while constructing the current survey (Blackstone 2012; Ponto 2015).

3.7 The focus group method

Focus groups are a qualitative data collection method commonly used in health research (Flynn, Albrecht & Scott 2018; Morgan David 1997). Focus groups have been defined as ‘group discussions exploring a set of specific issues that are focused because the process involves some collective activity’ (Kitzinger 1994, p. 104). Large amounts of qualitative data can be generated through focus groups, in which face-to-face participant–researcher contact is maximised, in comparison with other qualitative methods (Parker & Tritter 2006).

This method is primarily conducted to explore the social dynamics and interactions between participants through verbal and observational data collection. In this sense, the focus group is different from other research methods, as the data generated and collected are the result of the interaction between participants (Doody, Slevin & Taggart 2013). The interaction helps researchers to explore topics that would be difficult using other methods, increasing the depth

of the enquiry, highlighting similarities and differences between participants, and understanding their perspectives and experiences. Analysis of interactions is critical to achieve the full potential of using this method (Freeman 2006; Lambert & Loiselle 2008). Focus groups are usually semi-structured. Research questions are created by the researchers to help guide the discussion (Stewart & Shamdasani 2014). The main purpose of focus groups is to promote discussion/interaction because the different shared perceptions are critical to understanding. Many benefits can be derived from the use of focus groups. Focus groups are cost effective, fast and effective methods of collecting data from a group of participants. Focus groups should be constructed according to the research design and research question of the study, and should involve enough participants to generate rich and varied information. However, the number should not be too large to prevent a quiet and comfortable environment for the participants that enables them to share their experiences, perceptions and beliefs regarding a particular issue (Acocella 2012).

Nursing issues such as perspectives of healthcare providers, education, clinical practice and management have been investigated using focus groups (Aveyard 2002; Doody, Slevin & Taggart 2013; Tausch & Menold 2016). Further to these issues, the views, perceptions and emotions of patients and healthcare providers have also been explored in focus groups (Doody, Slevin & Taggart 2013).

3.8 The Delphi method

The Delphi method is a technique for gathering opinions on a topic. It is based on the proposition that 'pooled intelligence improves the individual judgement and captures the collective opinion of experts' (De Villiers, De Villiers & Kent 2005, p. 639). The Delphi method is known as a consensus method to assist researchers with resolving contradictories in the results of research studies. This consensus technique aims to generate agreement among experts about a given issue (de Meyrick 2003).

In relation to healthcare, this technique has most frequently been utilised to assess the appropriateness of health-related interventions, identify measures for clinical trials, and solve inconsistencies in different contexts such as healthcare, education and social services (De Villiers, De Villiers & Kent 2005; Jones & Hunter 1995). In terms of the structure, this method can be conducted online or via a face-to-face group meeting. The face-to-face meeting should be a highly structured meeting to collect information from nine to twelve relevant experts. This

technique has been widely used to build up the consensus of relevant experts over at least two rounds, in which a group of items or questions are rated, discussed and then re-rated by experts (De Villiers, De Villiers & Kent 2005; Jones & Hunter 1995).

The face-to-face Delphi technique has many advantages. It assists with obtaining a greater number of ideas than in traditional group discussions, reducing pressure and competition through the group discussion, giving an equal opportunity to each expert to participate and contribute, and prioritising ideas democratically. In addition, this technique is distinguished by giving experts time to think about the idea in silence before generating their opinion, and ultimately closing the meeting with greater sense than with traditional group discussions (Jones 2004). In the online technique, questionnaires are used for interactions between experts rather than face-to-face discussions. This technique is convenient when the experts' judgements and opinions are needed, but when there are barriers which impede the panel of experts physically convening together in the same place such as distance and time (McMillan, King & Tully 2016).

3.9 Summary

This chapter presented an argument that a mixed methods approach, supported by the theory of pragmatism is the most suitable design to provide a holistic image about the most effective HF management program in Jordan. This study was conducted to collect three sets of data including survey, patients' focus groups, and the Delphi study to provide a deep understanding about the most feasible, applicable, and appropriate HF management interventions in Jordan. The next chapter will present the methods for the quantitative study.

Chapter 4: Methods for the quantitative study

4.1 The research design

The study used a cross-sectional design. This design has been widely utilised in previous studies to measure the levels of self-care, adherence to self-care and QOL in patients with HF at a single point in time (Conceição et al. 2015; Giezeman, Arne & Theander 2017; Oh et al. 2017). The design can facilitate the assessment of behaviour levels, and the prevalence of a condition in a population with different demographic characteristics such as age, gender and ethnicity (Setia 2016). This type of design has been utilised in diverse disciplines such as medicine, health and social education, psychology, and politics (Levin 2006). The use of a cross-sectional design has many advantages: i) it is relatively efficient in terms of cost and time, ii) data collected can be exploited and tested in further research studies, iii) it enables the researcher to prove or falsify particular assumptions, and iv) the research findings may have potential to develop new theories (Levin 2006; Sedgwick 2014a). However, a cross-sectional design has various weaknesses: i) limited generalisability, ii) vulnerable to low response rates, iii) difficulty of interpreting causal relationships (Sedgwick 2014b; Setia 2016).

4.2 Sampling

The target population for this study was patients with HF attending outpatient cardiac clinics in Jordan; however, the accessible population was HF outpatients attending the cardiac clinic in a university-affiliated hospital located in the north of Jordan. Non-probability convenience sampling was identified as the appropriate sampling technique to recruit participants. Convenience sampling is a non-random sampling technique, which gathers information from participants who are readily accessible to the researcher. This type of sampling is also notable for its simplicity, affordability and ease (Etikan, Musa & Alkassim 2016). It is helpful for conducting pilot studies, generating hypotheses and facilitating data collection in a short period of time (Etikan, Musa & Alkassim 2016).

The inclusion criteria were: patients aged 18 years or older, and diagnosed with HF by a cardiologist through the NYHA criteria, the signs and symptoms of HF, and echocardiograph. The exclusion criterion was inability to complete the survey due to conditions such as severe dementia. Illiterate participants were included if they had a companion with them who could complete the survey for them and they agreed to this process. A total of 300 patients were targeted to try to maximise the representativeness and generalisability of the study population. The rule of thumb was used to calculate the minimum sample size needed for this study, which

implies that ‘ten observations needed per category of predictor variables’. About twenty predictors (demographical characteristics and clinical factors) were measured in the study. Therefore, a minimum of 200 patients needed to be enrolled in the study. This sample size was used because the attributes that were assessed in this study were used to develop a HF management model specific for Jordan. A convenience sample of patients with HF (n = 333) attending a cardiac clinic in educational hospital in the north of Jordan was approached. Seven patients refused to participate, 3 withdrew, and 23 could not be approached because the researcher was busy with collecting the data from other participants. The final total sample was 300 participants, with a response rate of 91%.

4.3 Site and setting

This study was conducted in the largest hospital in the north of Jordan, the King Abdullah University Hospital (KAUH). This hospital serves approximately one million people who live in the northern governorates such as Ajloun, Mafrqa, Irbid and Jerash. It is a teaching hospital, affiliated with Jordan University of Science and Technology. The overall area of the hospital is 95,583 m², consisting of 13 floors, with a bed capacity of 800. Ten outpatient cardiac clinics are held every week, operated by experienced cardiologists and cardiac nurses (KAUH 2014). The sample enrolled in this study is likely to be representative of Jordan’s population because this hospital serves all classes of patients, and there are no differences between Jordanians who live in the north or south of Jordan, in terms of culture, language, and social class. The process of recruitment and data collection lasted five months starting from 20/3/2017 until 20/8/2017.

4.4 Study instruments

Five tools were used to collect the data for the purpose of this study (Appendix 1), including: (i) the demographic tool, (ii) the Minnesota Living with Heart Failure Questionnaire (MLHFQ) (Bilbao et al. 2016a), (iii) the European Heart Failure Self-Care Behaviour Scale_9 (Vellone et al. 2014), and (iv) the Medical Outcomes Study Specific Adherence Scale (MOSSAS) (Kravitz et al. 1993; Marti et al. 2013). In addition, a new tool was developed by the researcher to identify knowledge level and assess whether the participants had been taught about HF by healthcare providers. The demographic tool included clinical and demographic variables, which were considered independent variables. The clinical variables were body mass index (BMI), ejection fraction (EF), insomnia, and New York Heart Association (NYHA) classification. BMI was collected as a continuous variable, and calculated using the equation ‘body weight (kg)/height (m²)’. Based on the literature, BMI was categorised into 5 groups:

underweight (BMI: < 18.5), normal weight (BMI: 18.5–24.9), overweight (BMI: 25–29.9), mild obesity (BMI: 30–34.9) and morbid obesity (BMI: \geq 35). The EF is an important value used to diagnose HF and determine whether the heart muscle is sufficiently capable of pumping blood. This measurement can be identified through echocardiography during examination. HF with reduced ejection fraction when LVEF < 40 %; HF with mid-range EF when LVEF 40–49%; and HF with preserved ejection fraction when LVEF \geq 50 (Ponikowski et al. 2016). The NYHA classification is comprised of four categories from class I to class IV. This functional tool is used mainly to classify the impact of HF symptoms on patients' ability to walk or exercise, and to identify the level of limitation occurring when performing any physical activity (Raphael et al. 2007). Insomnia can be identified through reporting one of the following complaints occurring 16–30 nights per month (1) 'experience difficulty falling asleep', (2) 'wakening up during the night and having trouble getting back to sleep', (3) and 'inability to sleep without taking sleeping mediations' (Bertisch et al. 2018).

4.4.1 The Minnesota Living with Heart Failure Questionnaire (MLHFQ)

The Minnesota Living with Heart Failure Questionnaire (MLHFQ) (Bilbao et al. 2016b; Lee 2012) assesses the effect of HF symptoms on patients' lives. The questionnaire comprises 21 items assessing the impact of HF symptoms on health-related QOL over the past 4 weeks. These symptoms include shortness of breath, fatigue, oedema and depression. A 6-point Likert scale is used to rate each item from 0 (no) to 5 (very much), indicating different levels of impact on health-related QOL (Table). The score zero (no) indicates that the symptom has no impact on health-related QOL, while the score 5 (very much) indicates that the patients' lives are significantly affected by HF symptoms. MLHFQ has been found to have two dimensions: a physical dimension (8 items: 2, 3, 4, 5, 6, 7, 12, 13), and an emotional dimension (5 items: 17, 18, 19, 20, 21). The physical dimension ranges from 0 to 40, and the emotional dimension ranges from 0 to 25. The questionnaire also comprises eight items assessing levels of distress caused by HF symptoms that impact health-related QOL. These include oedema/ankle swelling, shortness of breath, fatigue/increased need to rest, fatigue/weakness, difficulty sleeping/insomnia, worrying, psychological distress and depression, and cognitive-related problems including ability to remember things or concentrate (Bilbao et al. 2016b; Lee 2012).

The total of the MLHFQ ranges from 0 to 105, with a lower score indicating a better health-related QOL. A total score that is lower than 24 is considered 'good', a score ranging between 24 and 45 is considered 'moderate', whereas a score over 45 indicates a 'poor' QOL due to the impact of HF symptoms (Bilbao et al. 2016b; Lee 2012; Middel et al. 2001). The total score is

the most reliable measure of how QOL has been affected by HF, even if the responses to the individual questions are not all consistent (Rector & Cohn 2004).

A large number of randomised controlled studies have demonstrated that the MLHFQ was able to identify differences between interventions (Lang et al. 2018; Rector et al. 2012; Rector & Cohn 1992). Many studies have measured the psychometric properties of the MLHFQ to assess its reliability. The reliability of the MLHFQ consistently shows a satisfactory level with α (Cronbach's alpha) ≥ 0.80 , and ranging between 0.79 and 0.94 (Middel et al. 2001). In addition, this questionnaire has been utilised in various studies targeting patients with HF in different settings such as cardiology clinics, general medical clinics, cardiology departments and internal medicine departments (Bilbao et al. 2016b; Gonzalez 2016; O'leary & Jones 2000). The tool was translated to Arabic language and found to be reliable and valid in Lebanese patients with HF (Zahwe et al. 2020).

4.4.2 The European Heart Failure Self-Care Behaviour Scale_9

The European Heart Failure Self-Care Behaviour Scale_9 (EHFSCBS_9) is a 5-point Likert scale used particularly to assess the level of self-care, identify whether patients performed recommended self-care behaviours, and evaluate the effectiveness of HF management programs. The scale consists of 9 items relating to self-care behaviour in patients affected with HF (Jaarsma et al. 2009). Each item is rated from 1 (I completely agree) to 5 (I completely disagree), with the total score ranging between 9 and 45. A low score indicates better self-care (Vellone et al. 2014). This scale has been translated into 14 languages, and used widely in many studies targeting HF management. Gonzalez employed the Spanish version to evaluate the impact of a HF clinic, and examine if there is a significant correlation between the follow-up time and score in the unit (González et al. 2006; Vellone et al. 2014). This scale has been demonstrated to be valid and reliable in previous studies. The reliability of the whole scale ranges between 0.77 to 0.95 and α ranges between 0.68 and 0.87 in different studies (Lee et al. 2013; Vellone et al. 2014). Several studies have used the scale to evaluate the effectiveness of education and other management strategies on patients affected with HF (Sedlar et al. 2017b; Vellone et al. 2014).

4.4.3 The Medical Outcomes Study Specific Adherence Scale

The Medical Outcomes Study Specific Adherence Scale (MOSSAS) consists of eight items, and is used to measure adherence with self-care behaviours recommended for patients affected with HF (Table 4.1). This scale has been shown to be adequately reliable and valid in previous

studies (DiMatteo et al. 1993; Kravitz et al. 1993; Marti et al. 2013). Eight self-care behaviours are measured. These are: performing exercise, taking medication as prescribed, drinking one or less alcoholic beverage per day, reducing or quitting smoking, following a diet low in sodium and fat, measuring weight daily, and close monitoring of symptoms (Marti et al. 2013). Patients completing this scale are asked how frequently they have adhered to each self-care behaviour in the last four weeks (0 'none of the time', 1 'a little of the time', 2 'some of the time', 3 'a good bit of the time', 4 'most of the time', or 5 'all of the time'). A cut-off score for this scale has been identified as $\geq 32/40$ (i.e. an average score of at least 80%), indicating good adherence to self-care behaviours (Kravitz et al. 1993; Marti et al. 2013). The Medical Outcomes Study Specific Adherence Scale was validated in a prospective cohort study targeting 308 patients with HF who regularly attend cardiac clinics, which assessed the adherence levels among those patients' specific self-care behaviours (Marti et al. 2013). The goal of the study was to compare outcomes between patients with different levels of adherence. The results revealed that patients with a good adherence had fewer hospitalisations, better health and good functional capacity (Marti et al. 2013). Despite some items of this scale overlapping with the items of the EHFSCBS_9, it was used due to its clarity, practicality, reliability, and validity. In addition, it is mainly used to assess the level of adherence which differs from the 'self-care'.

4.4.4 Knowledge tool

A knowledge tool was developed by the researcher to assess knowledge level and whether patients had been instructed to perform self-care behaviours, before assessing the level of adherence and self-care. The tool consists of eight items relating to recommended self-care behaviours for HF patients, which include performing exercise, taking medication as prescribed, drinking one or less alcoholic beverage per day, reducing or quitting smoking, following a diet low in sodium and fat, measuring weight daily, and close monitoring of symptoms. "Alcohol" item in this scale should be listed for Jordanian because there are many people who drink alcohol but they don't admit to it due to cultural or religion reasons. Patients completing this scale were asked if they had been taught to perform self-care.

4.5 Piloting

A pilot study has been defined by Polit and Beck (2008, p. 671) as a 'small-scale version, or trial run, done in preparation for a major study'. It is performed as a minor proposal study targeting similar inclusion criteria to the main study (Polit & Beck 2008). Researchers use the same setting, and similar data collection and analysis procedures. The current study was piloted

to test the feasibility of the study, and to identify and prevent any problems that might be encountered by the researcher during data collection. In addition, the pilot study was used to assess the clarity, readability, language and cultural appropriateness of the Arabic versions of the study tools (Grove, Burns & Gray 2012; Polit & Beck 2008). Due to time constraints a pilot study was conducted on a convenience sample of 7 patients affected with HF who met the inclusion criteria for the larger study. These were two females and five males who regularly visited the cardiac clinic. The pilot study was conducted at the participants' homes for their convenience. Patients were contacted via a phone call and invited to participate. Then, the researcher scheduled a time to visit the respondents at their home. The participants in the pilot study completed the five study tools within 40–50 minutes. Patients enrolled in the pilot study were not included in the main study. Based on the pilot study results, the items were generally clear and readable for the participants. In addition, the Arabic versions of the study tools were culturally appropriate, and the language was simple and understandable (Table 4.1).

Table 4.1: Description of the tools used in the study

Name	Number of items	Scale	Total possible score	Interpretation (direction)
MLHFQ (Bilbao et al. 2016b)	21	0–5	105	Higher score is lower quality of life
EHFSCBS_9 (Vellone et al. 2014)	9	1–5	45	Higher score is lower self-care
The Medical Outcomes Study Specific Adherence Scale (Kravitz et al. 1993; Marti et al. 2013)	8	0–5	40	Higher score is higher level of adherence
Knowledge tool developed by researcher	8	0–1	8	Higher score is higher level of knowledge

4.6 Translation

The official language spoken in Jordan is Arabic; therefore, data collection was performed in Arabic. The translation and back translation of the study tools into Arabic was performed by two experienced bilingual nursing academics. Both academics had master's degrees and doctorates from the United States, and considerable experience in writing and reviewing nursing research papers in the English language, supervising graduate and postgraduate students, and developing nursing policy at the national level. The first nursing academic, an Associate Professor specialised in acute nursing care, translated the tools from English to

Arabic. The back translation to English was then conducted by a different nursing academic, a Professor of Nursing. The supervisors of the research study were consulted to check the level of coherence between the original English version of the study tools and the back-translated tools.

4.7 Ethical considerations

The study was approved by the Human Research Ethics Committee of the University of Adelaide. The approval was also obtained from the Institutional Review Board of King Abdullah University Hospital, where the study was conducted. Potential participants were provided with a participant information sheet, detailing all information regarding the study. Then, the informed consent form was signed. The privacy and confidentiality of participants were protected during the data collection. Participant identifiers such as names and dates of birth were not collected, the survey was completed anonymously, and the completed questionnaires were stored in a secure, locked box. Only the researcher was able to access the data. Additionally, the list of names used for recruitment was destroyed following data collection and participant privacy and confidentiality were also maintained during data analysis using password-protected computers.

4.8 Data collection procedure

Data collection commenced after obtaining ethics approval from the site and the University of Adelaide. Administrators of outpatient clinics in the hospital were then approached for approval to conduct the study in their clinic. The researcher indicated the benefits of the study and emphasised that their patients would not be harmed through participating. Furthermore, the burden on the outpatient staff would be minimised. The outpatient administrator referred the researcher to the general/assistant physician who works with the cardiologist and has access to patients' computerised medical records. The physician searched the hospital records for eligible patients and provided this database to the clinic nurse. The clinic nurse then approached eligible patients on the day of their appointment and provided them with the information sheet regarding the study. This process was followed based on the ethics committee's recommendations that the researcher should not approach patients directly for recruitment, or have access to the medical records system. The researcher tried to reduce any source of bias through reducing the interaction between participants. In addition, in the beginning of data collection, the researcher clearly explained the purpose of the research study, and assured the patients that the survey is anonymous and confidential.

The researcher then introduced himself to the patient and described the rationale, benefits and aims of the project in simple language. Furthermore, the researcher gave the patient a dedicated contact number for the project to contact him for more information or enquiries. Before starting, the researcher informed the patient that the survey is comprised of five questionnaires and each takes about 10 minutes to complete, totalling 50 minutes. If the participant was illiterate and they had a relative or friend with them the relative or friend was allowed to complete the survey on behalf of the participant. Excluding illiterate patients will significantly impact the validity of the results and representativeness of the sample, because they account for a high percentage of older patients affected with HF. The clinic nurse collected the following information for each participant: the BMI, EF, and functional class according to the NYHA classification.

4.9 Data analyses

The Statistical Package of Social Science (SPSS) Version 22 was used to analyse the data. Descriptive statistics including means, standard deviation, frequency, percentages and range were used to describe the demographic and clinical characteristics of the sample. Before conducting the inferential analysis, kurtosis and skewness values were calculated for continuous variables, and histograms were visually inspected to check the normality of distributions. In addition, the data were precisely checked in terms of having missing values and outliers of all variables included in the study. Outliers are defined as extreme observation points or values that are far or numerically distant from the other values in the sample. These extreme values can be visualised or detected through using scatterplots and histograms in SPSS, which both show data distribution. All major assumptions of parametric tests were examined and met. Firstly, the dependent variables including knowledge, adherence to self-care, self-care and QOL were measured on a continuous level, and data were normally distributed. Secondly, a linear relationship with all variables measured at a continuous level was found. To answer the first three questions regarding the levels of knowledge, self-care, adherence to a healthy lifestyle and impact of symptoms on Jordanian patients with HF, descriptive statistics including means and standard deviations were used. In addition, stacked bar charts were used to present the percentage of each self-care behaviour or healthy lifestyle pattern listed in the knowledge, self-care and adherence tools. To answer the fourth question related to the predictors of knowledge, self-care, adherence to self-care and impact of symptoms on Jordanian patients with HF, a number of inferential statistical tests including an independent t-test, Pearson's correlation, analysis of variance (ANOVA), and multiple linear

regression were used. An independent sample t-test and one-way ANOVA were used to examine whether there was a significant difference in the level of knowledge, self-care, adherence and impact of symptoms on patients' lives in terms of selected sociodemographic and/or clinical variables. Post-hoc analysis using the Bonferroni test was done to identify if there were any statistically significant differences among the levels of the demographic or clinical factors. Product-moment correlation was used to assess the relationship between knowledge, self-care, adherence to a healthy lifestyle, impact of symptoms on patients' lives, and selected sociodemographic and clinical factors. Multiple linear regression analysis was used to determine the predictors of knowledge, self-care, adherence to a healthy lifestyle and impact of symptoms for patients with HF in Jordan. The variables included in the multiple regression were derived from univariate analysis and $P < 0.2$.

4.10 Summary

This chapter has presented the quantitative methods (survey) that were used in this study. Information related to sampling process, setting, data collection procedures, translation of the instruments, piloting, data analysis, and ethical considerations was presented for each study. The next chapter will present the results of the quantitative study.

Chapter 5: Results of the quantitative study

This study was designed to measure the level of knowledge, self-care, adherence to a healthy lifestyle and the impact of symptoms on the lives of patients with heart failure (HF) in Jordan. The relationships between the dependent variables (level of knowledge, self-care, adherence to a healthy lifestyle, QOL) and independent variables (sociodemographic: gender, marital status, occupation, previous hospitalisation, education) and clinical factors (insomnia, HTN, DM, angina, myocardial infarction [MI], HF classification) were examined. In addition, the predictors of knowledge, self-care, adherence to a healthy lifestyle and QOL were determined.

5.1 Sample characteristics

A convenience sample of patients with HF (N = 333) from the cardiac clinic in an educational hospital in the north of Jordan were eligible to participate in the study. Seven patients refused to participate, three withdrew and 23 could not be approached by the researcher, resulting in a 91% response rate. The demographics are presented in Table 5.1. The mean age of patients was 61.9 years (range 21–91, SD = 12.6), two thirds were male (n = 202), most patients were unemployed 37.3% (n = 113) or retired 40.0 % (n = 120) and most were married 79.0 % (n = 237). A majority of patients were illiterate; however, 22% had a bachelor's degree. The majority had been classified in the NYHA class II or III and nearly a third required assistance with activities of daily living. Their mean monthly income is 495.2 dinars (SD 327.9).

5.2 Clinical factors

As shown in Table 5.1, the participants' mean body mass index (BMI) was 29.0 (SD = 5.2). The mean for the ejection fraction was 41.7% (SD = 9.5) and ranged from 15 to 60. Slightly more than quarter (34%, n = 102) of the patients were current smokers, with a mean smoking duration of 34.1 years (SD = 13.11). The mean for the number of cigarettes per day was 29.8 (SD = 15.8). The actual range was 2–80 cigarettes per day. Just over a quarter (27.7%, n = 83) of the sample had a past history of smoking, with a mean duration of smoking cessation of 10.7 years (SD = 9.0). Less than one third of the sample (n = 86) had a previous hospitalisation or admission related to HF. A third of patients complained of insomnia (n = 110), the major cause of which was difficulty breathing (28.7%).

Table 5.1: Sample characteristics and Clinical factors; mean (M), standard deviation (SD) and percentage (%) for 300 patients with heart failure in Jordan.

Variable		Patients (n = 300)	Percentage (%)
NYHA classification	Class I	38	12.7
	Class II	110	36.7
	Class III	127	42.3
	Class IV	25	8.3
Mean age (SD), range		61.2 (12.6), 21–91	
Gender	Male	202	67.3
	Female	98	32.7
Employment	Full-time	55	18.3
	Part-time	1	0.3
	Student	1	0.3
	Unemployed	113	37.3
	Retired	120	40.0
	Other	10	3.3
Marital status	Single	5	1.7
	Married	237	79.0
	Divorced	2	0.7
	Widow	55	18.3
	Separated	1	0.3
Educational level	Illiterate	72	24.0
	Primary education	43	14.3
	Secondary education	80	26.7
	Diploma	33	11.0
	Baccalaureate degree	66	22.0
	Master's degree	4	1.3
	Doctorate	2	0.7
Assistance for activity of daily	Living with others	96	32.0
	Living alone	5	1.7
Mean monthly income (SD)		495.2 (327.9)	
Body mass index, M(SD)		29.0 (5.2)	
Ejection fraction		41.7 (9.5)	
Smoking (%)			34.0
Cigarettes per day, M (SD)		29.8 (15.8)	
Ever smoking (%)			27.7
Smoking cessation, years, M (SD)		10.7 (9.0)	
Duration of smoking, years M (SD)		34.1 (13.1)	
Previous hospitalisation due to HF (%)			28.7

Insomnia (%)		36.7
Causes of insomnia		
Difficulty breathing (%)		28.7
Difficulty breathing and fatigue (%)		6.7
Fatigue (%)		0.3
Pain (%)		0.3
Difficulty breathing and pain (%)		0.3
Difficulty breathing pain and cough (%)		0.3
Hypertension, M (SD)	1.36 (0.5)	
Diabetes, M (SD)	1.5 (0.5)	
Angina , M (SD)	1.3 (0.5)	
Myocardial infarction , M (SD)	1.5 (0.5)	
Irregular heartbeat	1.8 (0.4)	
Chronic lung disease , M (SD)	1.9 (0.3)	
Hypercholesterolemia , M (SD)	1.8 (0.4)	

5.3 Outcomes for people with HF

The knowledge, self-care, adherence and QOL scores were all normally distributed. As shown in Table 5.2, the mean knowledge score was moderate 4.0 (1.3 SD) and ranged from 1 to 8. A higher score indicates a better knowledge level. The mean self-care score was moderate 27.5 (4.7) and ranged from 12 to 42, in which a lower score indicates better self-care. The mean score for adherence to a healthy lifestyle was poor 15.2 (5.1) (range 4–34), in which a higher score indicates better adherence. The mean QOL score was moderate (36.6), with very high variability between the patients (SD = 20.63). The scores ranged from 0 to 88, in which a higher score indicates worse (poorer) QOL (Table 5.2). According to the tool instruction, the mean scores in the current study indicated that the level of knowledge was moderate, self-care was moderate, adherence was poor, and QOL was moderate in patients with HF (Bilbao et al. 2016b; Kravitz et al. 1993; Marti et al. 2013; Sedlar et al. 2017a; Vellone et al. 2014).

Table 5.2: Knowledge, self-care, adherence to a healthy lifestyle and QOL in Jordan

Variable	Mean (standard deviation)	Possible range	Actual range
Knowledge	4.0 (1.3)	0–8	1–8
Self-care	27.5 (4.7)	9–45	12–42
Adherence to a healthy lifestyle	15.2 (5.1)	0–40	4–34
QOL	36.6 (20.4)	0–105	0–88

Number (n) used is 300 = total number of patients.

5.4 Knowledge

The knowledge tool consisted of nine items relating to self-care behaviours, and was used to assess whether the patients had been taught by healthcare providers about HF. A stacked bar chart is used to present the breakdown of responses for each item in the knowledge tool (Figure 5.1). As shown in Figure 5.1, the majority of patients were informed that they should take medication as prescribed (96%), and reduce smoking (75%). Regarding the self-care behaviours with the lowest levels of instruction, only 24.3% of patients were taught to pay attention to symptoms every day, and only 2.7% were informed that they should weigh themselves every day and watch their fluid status (Figure 5.1).

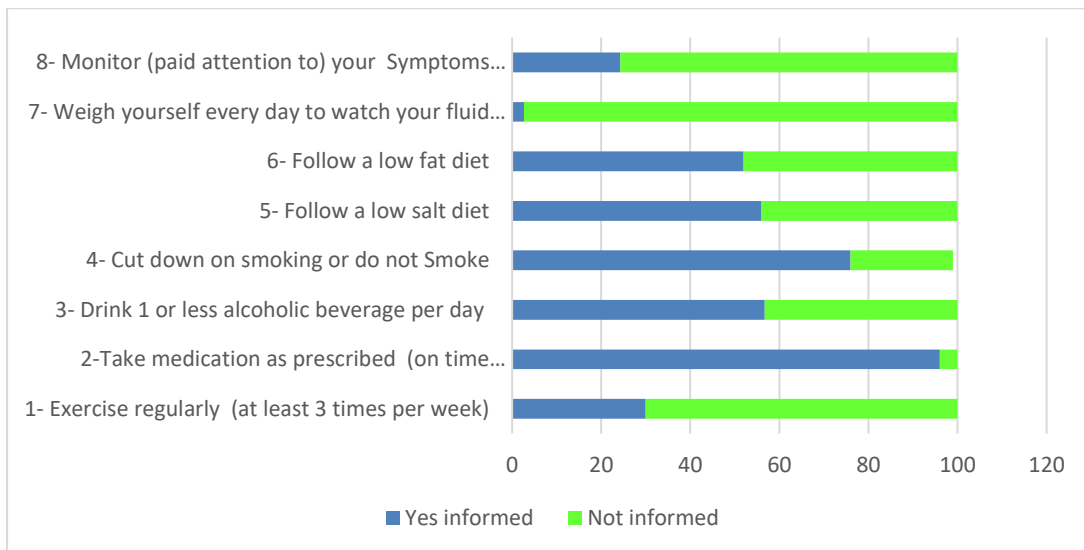


Figure 5.1: Percentage of patients with HF who had been instructed about recommended self-care behaviours

5.4.1 Univariate analysis

5.4.1.1 The difference in knowledge level by selected sociodemographic and clinical factors

Independent t-tests were used to test for differences in the level of knowledge by selected sociodemographic (gender, marital status, occupation, previous hospitalisation) and clinical (HTN, DM, angina, MI) factors (Table 5.3). All assumptions of t test were examined and met. First the knowledge level was measured on continuous level and it was normally distributed. Histogram and skewness level (0.14) indicated that QOL was normally distributed. Second, the scores were independent of each other and the groups of the independent variables were mutually exclusive. The level of significance was set at $p \leq .05$. Males had higher knowledge

scores (M = 4.1, SD = 1.3) than females (M = 3.7, SD = 1.3), $t(298) = 2.66$, $p = <0.01$). However, there were no significant differences in other variables.

Table 5.3: Independent t-test to examine difference in knowledge by selected sociodemographic (gender, marital status, occupation, previous hospitalisation) and clinical (HTN, DM, angina, MI) factors among patients with HF in Jordan (n = 300).

Variable		Number (%)	Mean (standard deviation)	t	p
Gender	Male	202	4.1 (1.3)	2.66	0.008**
	Female	98	3.7 (1.3)		
Marital status	Married	237	3.9 (1.3)	0.05	0.96
	Unmarried	63	3.9 (1.4)		
Employment	Employed	56	4.0 (1.0)	0.56	0.57
	Unemployed	244	3.9 (1.3)		
Previous hospitalisation	Yes	86	4.1 (1.5)	1.24	0.21
	No	214	3.9 (1.2)		
HTN	Yes	193	4.0 (1.3)	1.5	0.13
	No	107	3.8 (1.2)		
DM	Yes	160	3.9 (1.2)	-.71	0.47
	No	140	4.0 (1.3)		
Angina	Yes	214	3.9 (1.2)	-.28	0.77
	No	86	3.9 (1.4)		
Myocardial infarction	Yes	163	4.0 (1.2)	.20	0.84
	No	137	3.9 (1.4)		

* $P \leq .05$, ** $P \leq .001$

5.4.1.2 The difference in mean knowledge based on educational level and heart failure classification

One-way analysis of variance (ANOVA) was used to compare the mean score for knowledge based on educational level (illiterate, low education and high education) and HF classification (class I, class II, class III and class 4) (Table 5.4). All assumptions of ANOVA were examined and met. Knowledge was measured as quantitative and continuous variables. The education and HF classification were categorized into three and four categories respectively. Histogram and skewness level (0.14) indicated that knowledge was normally distributed and box plot showed that there were no outliers. The Levene test for the homogeneity of variance

assumption was used to examine whether there were serious violations of the assumption of homogeneity of variance across the categories of the education variable, but no significant violation was found.

There were no statistically significant differences in knowledge scores across the educational group means as determined by one-way ANOVA ($F(2,297) = 0.30, p = 0.74$). The mean knowledge scores of patients with NYHA class II was significantly lower than patients with NYHA class IV $F(3,296) = 2.63, p=0.03$ (Table 5.4).

Table 5.4: ANOVA to examine the difference in mean knowledge by educational level and heart failure classification ($n = 300$).

Variable	Number	Mean (standard deviation)	F	p	Bonferroni p
Education			F (2, 297) = .30	0.74	
Illiterate	72	4.0 (1.3)			
Low education	123	3.9 (1.4)			
High education	105	4.0 (1.1)			
HF classification			F(3, 296) = 2.63	.03	
Class I	38	3.9 (1.3)			
Class II	110	3.8 (1.2)			
Class III	127	3.9 (1.3)			
Class IV	25	4.6 (1.5)			With class II .032

5.4.2 Multivariable analysis

5.4.2.1 Predictors of knowledge among patients with HF in Jordan

A multiple linear regression was calculated to predict the level of HF knowledge based on gender among patients with HF in Jordan (Table 5.5). The assumptions of regression analysis were examined and met. The dependent variable (knowledge) was measured on continuous level and it was normally distributed. A linear relationship with all variables, measured at continuous level, was found. Patients' predicted HF knowledge is equal to 0.431 for gender ($p=0.001$), where gender is coded as 1= Male, 2= Female. Males scored 0.43 points higher in knowledge than females, indicating better knowledge (Table 5.5).

Table 5.5: Multiple linear regression analysis to examine the significant predictors of knowledge among patients with heart failure in Jordan (n = 300)

Variable	Unstandardised beta (B)	Std. error	p	Confidence interval (lower–upper)
Gender	0.431	0.152	0.001	0.133, 0.730

5.5 Self-care

The self-care tool consists of nine items relating to self-care behaviour in patients affected with HF and is used to assess changes in self-care behaviours. A stacked bar chart is used to present the breakdown of responses for each item in the self-care tool (Figure 5.2).

Patients’ response on the self-care tool indicated that the majority (92.4%) agreed that they take their medication as prescribed, 73% agreed that they contact their doctor or nurse if their shortness of breath increases, and 62% agreed if their feet/legs become swollen. Regarding the least performed self-care behaviours, 91.7% would not contact their doctor or nurse if they gained 2 kilos in one week, 83.4% did not monitor their weight every day, and 60% indicated that they did not exercise regularly (Figure 5.2).

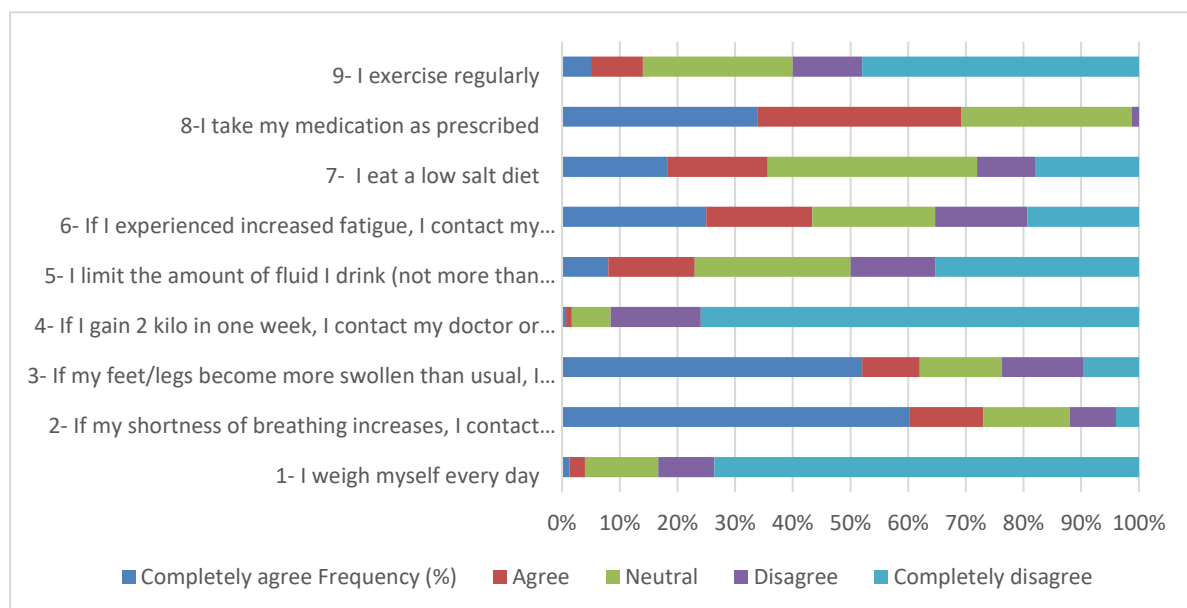


Figure 5.2: The percentage of agreement with nine statements about self-care behaviours.

5.5.1 Univariate analysis

5.5.1.1 The difference in self-care by selected sociodemographic and clinical factors

Independent t-tests were used to test for differences in the level of self-care by selected sociodemographic (gender, marital status, occupation, previous hospitalisation) and clinical (HTN, DM, angina, MI) factors (Table 5.6). The Levene test was not significant ($F(298) = 1.21$, $P = 0.27$), which indicated that the homogeneity assumption was met. Females had significantly worse self-care ($M = 28.3$, $SD = 4.9$) than males ($M = 27.0$, $SD = 4.6$), $t(298) = -2.23$, $p = 0.04$ (Table 5.6). Married patients had better self-care than unmarried. Other predictors of better self-care were: being employed, and no previous hospitalisations. However, there was no significant difference in self-care by previous admission, and by clinical factors including HTN, DM, angina and MI (Table 5.6).

Table 5.6: Independent t-test to examine difference in self-care by selected sociodemographic (gender, marital status, occupation, previous hospitalisation) and clinical (insomnia, HTN, DM, angina, MI) factors among patients with HF in Jordan ($n = 300$).

Variable		Number (%)	Mean (SD)	t	p
Gender	Male	202	27.0 (4.6)	-2.23	0.04*
	Female	98	28.3 (4.9)		
Marital status	Married	237	27.0 (4.6)	-3.24	0.001**
	Unmarried	63	29.1 (4.7)		
Employment	Employed	56	26.3 (4.3)	-2.16	.030*
	Unemployed	244	27.7 (4.7)		
Previous hospitalisation	Yes	86	28.7 (5.2)	2.89	.004**
	No	214	26.9 (4.4)		
Insomnia	Yes	110	29.0 (4.8)	4.50	< .001**
	No	190	26.6 (4.2)		
HTN	Yes	193	27.7 (5.0)	1.30	0.20
	No	107	27.0 (4.1)		
DM	Yes	160	27.9 (4.6)	1.80	0.07
	No	140	26.9 (4.8)		
Angina	Yes	214	27.5 (4.6)	.30	0.77
	No	86	27.3 (5.1)		

SD = standard deviation. * $P \leq .05$, ** $P \leq .001$
t represents an independent test carried out.

5.5.1.2 *The difference in self-care by educational level and HF classification among patients with HF in Jordan*

One-way analysis of variance (ANOVA) was used to compare the mean score for self-care with educational level and HF classification. All assumptions of ANOVA were examined and met. Self-care was measured as quantitative and continuous variable. The Levene test was not significant for educational level ($F(3, 296) = 0.86, p = 0.46$), and HF classification ($F(3, 296) = 0.86, p = 0.46$), which indicated that there is no significant violation of the homogeneity of variance assumption.

All possible pairwise comparisons were made using the Bonferroni test. Regarding educational level, illiterate patients had a higher self-care score, indicating poorer self-care than patients with low education and high education (Table 5.7). In relation to HF classification, patients who were in HF class III had a higher self-care score, indicating poorer self-care than patients in classes I and II. Also, patients in HF class IV had a higher self-care score than patients in classes I, II, and III (Table 5.7).

Table 5.7: ANOVA to examine the difference in mean self-care by educational level and HF classification ($n = 300$).

Variable		Number	Mean (standard deviation)	F	p	Bonferroni p
Education	Illiterate	72	29.3 (5.0)	F (2, 297) = 9.15	≤ .001	With low education 0.01
	Low education	123	27.4 (4.3)			
	High education	105	26.3 (4.6)			
HF classification	Class I	38	25.2 (3.9)	F(3, 296) = 8.50	≤ .001	With illiterate ≤ 0.001 With class III .001
	Class II	110	26.7 (4.4)			
	Class III	127	28.3 (4.7)			
	Class IV	25	30.1 (5.1)			

5.5.2 Multivariable analysis

5.5.2.1 Predictors of self-care among patients with HF in Jordan

A multiple linear regression was calculated to predict the level of HF self-care based on insomnia, marital status, and DM (Table 5.8). The assumptions of regression analysis were examined and met. The dependent variable (Self-care) was measured on continuous level and it was normally distributed. A linear relationship with all variables, measured at continuous level, was found. Patients' predicted HF self-care is equal to 2.066 (insomnia) - 1.555 (marital status) + 0.910 (DM), where insomnia was coded as 1= Yes, 2= No, marital status as 1= Married, 2=Unmarried, and DM 1= Yes, 2= No. Insomnia ($p < .001$) and marital status ($p = 0.018$) were the significant predictors of HF self-care (Table 5.8). The self-care score for patients with insomnia was 2.07 points higher than patients without insomnia, indicating poorer self-care (Table 5.8). Unmarried patients scored 1.56 points lower than married patients, indicating better self-care. Diabetes was not a significant predictor of self-care ($p = 0.08$) (Table 5.8).

Table 5.8: Multiple linear regression analysis to examine the significant predictors of self-care among patients with HF in Jordan ($n = 300$).

Variable	Unstandardised beta	Std. error	p	Confidence interval (lower–upper)
Insomnia	2.066	0.555	< .001**	0.977, 3.555
Marital status	-1.555	0.656	0.018*	-2.842, -0.268
DM	0.910	0.519	0.080	-3.571, -1.489

* $p \leq .05$, ** $p \leq .001$.

5.6 Adherence

The adherence tool consisted of eight items, particularly used to measure adherence to self-care behaviours recommended for patients affected with HF. A stacked bar chart is used to present the breakdown of responses for each item in the tool (Figure 5.3). Showing the highest levels of adherence to self-care, 87.7% of the patients took medication as prescribed most/all of the time, 32.7% followed a low-salt diet most/all of the time, and 27.7% followed a low-fat diet most/all of the time. The following activities had the lowest levels of adherence, with most participants indicating they did not perform at them at all or only a little of the time: 75.3% for reducing smoking or not smoking, 83.7% for weighing themselves to watch their fluid status, and 84.3% for drinking one or less alcoholic beverages per day (Figure 5.3).

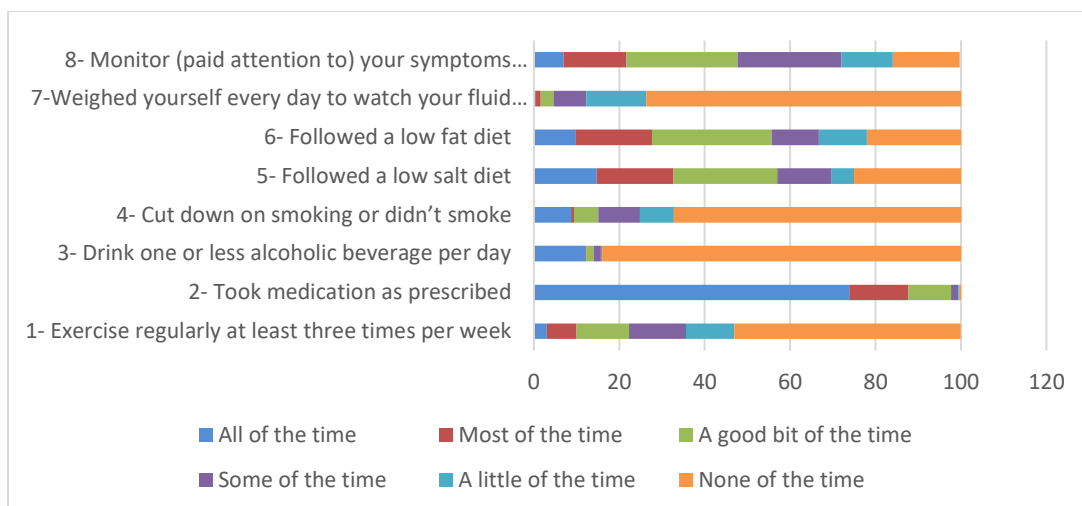


Figure 5.3: The percentage of adherence to each healthy lifestyle pattern.

5.6.1 Univariate analysis

5.6.1.1. The difference in adherence level by selected sociodemographic and clinical factors

Independent t-tests were used to test for differences in the level of adherence to a healthy lifestyle in terms of selected sociodemographic (gender, marital status, occupation, previous hospitalisation) and clinical (insomnia, HTN, DM, angina, MI) factors (Table 5.9). The Levene test was not significant $F(298) = 0.75, p = 0.38$, which indicated that the homogeneity assumption was met and the variance of the scores around the mean was not significant. There were no statistically significant differences in adherence to a healthy lifestyle in terms of the selected sociodemographic and clinical factors among patients with HF in Jordan (Table 5.9).

Table 5.9: Independent t-test to examine the difference in healthy lifestyle by selected sociodemographic (gender, marital status, occupation, previous hospitalisation) and clinical (insomnia, HTN, DM, angina, MI) factors in Jordan (n = 300).

Variable		Number (%)	Mean (SD)	t	p
Gender	Male	202	15.3 (5.1)	.49	0.62
	Female	98	15.0 (5.2)		
Marital status	Married	237	15.4 (5.2)	1.65	0.10
	Unmarried	63	14.2 (5.0)		
Employment	Employed	56	15.8 (4.8)	.94	0.35
	Unemployed	244	15.0 (5.2)		
Previous hospitalisation	Yes	86	15.3 (5.5)	.36	0.72
	No	214	15.1 (5.0)		
Insomnia	Yes	110	14.5 (4.)	-1.77	0.07
	No	190	15.6 (5.2)		
HTN	Yes	193	15.3 (5.0)	.80	0.42
	No	107	14.9 (5.4)		
DM	Yes	160	14.9 (4.9)	-.79	0.42
	No	140	15.4 (5.4)		
Angina	Yes	214	14.8 (4.6)	-1.80	0.07
	No	86	16.1 (6.2)		
Myocardial infarction	Yes	163	15.2 (4.9)	.19	0.85
	No	137	15.1 (5.4)		

SD = standard deviation

5.6.1.2 The difference in adherence to a healthy lifestyle by educational level and HF classification

One-way analysis of variance (ANOVA) was used to compare the mean score for adherence based on educational level and HF classification. All assumptions of ANOVA were examined and met. Adherence was measured as quantitative and continuous variables. The Levene test was not significant for educational level ($F(2, 297) = 0.22, P = 0.80$), and HF classification ($F(3, 296) = 1.50, p = 0.21$), which indicated that there is no significant violation of the homogeneity of variance assumption.

All possible pairwise comparisons were run using the Bonferroni test (Table 5.10). In relation to educational level, the mean adherence of patients who were illiterate 13.8 (4.9) was

significantly lower than the mean adherence of patients with high education 16.5 (5.1), indicating poorer adherence $F(2,297) = 7.04$, $p=0.001$ (Table 5.10). In addition, the mean adherence for patients with a low level of education was significantly lower than the mean adherence for patients with high education. However, there was no significant difference between the mean adherences of patients with low education versus illiterate patients. In relation to HF classification, the overall F was not statistically significant $F(3, 296) = 1.76$, $p=0.15$ (Table 5.10).

Table 5.10: ANOVA to examine the difference in mean adherence to a healthy lifestyle by educational level and HF classification (n = 300).

Variable		Number	Mean (standard deviation)	F	p	Bonferroni p	
Education	Illiterate	72	13.8 (4.9)	F (2, 297) = 7.04	0.001	With high education .001	
	Low education	123	14.8 (5.2)				With high education .03
	High education	105	16.5 (5.1)				
HF classification				F(3, 296) = 1.76	0.15		
	Class I	38	16.5 (5.6)				
	Class II	110	15.3 (4.7)				
	Class III	127	14.5 (5.1)				
	Class IV	25	15.8 (6.1)				

* $p \leq 0.05$

5.6.2 Multivariable analysis

5.6.2.1 Predictors of adherence to a healthy lifestyle among patients with HF in Jordan

A multiple linear regression was calculated to predict the level of adherence to self-care based on angina and insomnia (Table 5.11). The assumptions of regression analysis were examined and met. The dependent variable (adherence) was measured on continuous level and it was normally distributed. A linear relationship with all variables, measured at continuous level, was found. Patients' predicted adherence is equal to -1.473 (angina) - 1.358 (insomnia), where angina was coded as 1= yes, 2= No, and insomnia as 1= Yes, 2= No (Table 5.11). The adherence score for patients with insomnia ($p= 0.026$) was 1.36 points lower than patients without insomnia, indicating poorer adherence. Patients with angina ($p= 0.024$) scored 1.47 points lower than those without angina (Table 5.11).

Table 5.11: Multiple linear regression analysis to examine predictors of adherence to a healthy lifestyle among patients with HF in Jordan (n = 300).

Variable	Unstandardised beta	Std. error	P	Confidence interval (lower–upper)
Angina	-1.473	0.651	0.024*	-2.749, -0.196
Insomnia	-1.358	0.611	0.026*	-2.557, -0.160

*p ≤ 0.05

5.7 Quality of life

5.7.1 The difference in quality of life by selected sociodemographic and clinical factors

Independent t-tests were used to test for differences in the level of QOL by selected sociodemographic (gender, marital status, occupation, previous hospitalisation) and clinical (HTN, DM, angina, MI) factors (Table 5.12). Female patients had significantly poorer QOL (M = 46.6, SD = 19.5) than males M = 31.8, SD = 19.4). Unmarried patients had significantly poorer QOL than those who were married. The unemployed patients (M = 40.0, SD = 19.9) had significantly poorer QOL than those who were employed (M = 22.2, SD = 17.5). Other significant predictors of QOL were previous hospitalisation, insomnia, HTN and MI. However, there were no significant differences in QOL by clinical factors such as DM and angina (Table 5.12).

Table 5.12: Independent t-test to examine difference in quality of life by selected sociodemographic (gender, marital status, occupation, previous hospitalisation) and clinical (insomnia, HTN, DM, MI) factors among patients with HF in Jordan (n = 300).

Variable		Number (%)	Mean (standard deviation)	t	p
Gender	Male	202	31.8 (19.4)	-6.18	P < 0.001**
	Female	98	46.6 (19.5)		
Marital status	Married	237	33.1 (19.9)	-6.07	P < 0.001**
	Unmarried	63	49.9 (17.7)		
Employment	Employed	56	22.2 (17.5)	-6.54	P < 0.001**
	Unemployed	244	40.0 (19.9)		
Previous hospitalisation	Yes	86	58.2 (13.9)	15.29	P < 0.001**
	No	214	28.0 (16.1)		
Insomnia	Yes	110	54.7 (15.1)	15.52	P < .001**
	No	190	26.2 (15.5).		
HTN	Yes	193	41.8 (20.3)	6.43	P < .001**
	No	107	27.3 (17.8).		
DM	Yes	160	38.6 (20.3)	1.74	0.08
	No	140	34.4 (20.8)		
Angina	Yes	214	35.5 (20.3)	-1.45	0.15
	No	86	39.4 (21.3)		
Myocardial Infarction	Yes	163	33.8 (19.8)	-2.59	0.01*
	No	137	40.0 (21.1).		

*p ≤ .05, **p ≤ .001

5.7.2 The difference in quality of life by educational level and HF classification among patients with HF in Jordan

One-way analysis of variance (ANOVA) was used to compare the mean score for QOL by educational level and HF classification (Table 5.13). All possible pairwise comparisons were conducted using the Bonferroni test. Patients who were illiterate scored higher than those with low education and high education, indicating poorer QOL. In addition, patients with low education had a higher QOL score than patients with high education (Table 5.13). Patients with HF class I had lower QOL scores than patients with HF class II, class III and class IV. Moreover, patients with HF class III scored significantly lower for QOL than patients with HF class IV, indicating better QOL (Table 5.13).

Table 5.13: ANOVA to examine the difference in mean quality of life by educational level and HF classification (n = 300).

Variable	Number	Mean (SD)	F	p	Bonferroni p
Education			F (2, 297) = 29.72	≤.001	
Illiterate	72	50.2 (17.4)			With low education ≤.001
Low education	123	36.1 (20.2)			With high education .004
High education	105	27.9 (18.4)			With illiterate ≤.001
HF Classification			F(3,296) = 193.70	≤.001	
Class I	38	12.1 (8.9)			With all classes ≤.001
Class II	110	24.1 (12.0)			With all classes ≤.001
Class III	127	48.5 (13.6)			With all classes ≤.001
Class IV	25	69.0 (6.8)			With all classes ≤.001

SD is the standard deviation

5.7.3 Predictors of quality of life among patients with HF in Jordan

A multiple linear regression was calculated to predict the QOL based on insomnia, marital status, previous hospitalisations, and employment. The assumptions of regression analysis were examined and met. The dependent variable (QOL) was measured on continuous level and it was normally distributed. A linear relationship with all variables, measured at continuous level, was found. Patients' predicted QOL is equal to 16.256 (insomnia) - 6.266 (marital status) + (16.748) previous hospitalisations - 7.202 (employment), where insomnia was codes as 1= yes, 2= No, marital status as 1= Married, 2= Unmarried, previous hospitalisations as 1= yes, 2= No, and employment as 1= employed, 2= Unemployed (Table 5.14). The QOL score for patients with insomnia (p= < .001) was 16.26 points higher than patients without insomnia, indicating poorer QOL. The score of married patients (P=0.002) was 6.27 points lower than unmarried patients, indicating better QOL (Table 5.14). Patients with previous hospitalisation (p < .001) scored 16.75 points higher, indicating poorer QOL. Lastly, the QOL score for employed patients (p= 0.001) was 7.20 points lower than unemployed patients, indicating better QOL (Table 5.14).

Table 5.14: Multiple linear regression analysis to examine the significant predictors of quality of life among patients with heart failure in Jordan (n = 300).

Variable	Unstandardised beta	Std. error	Confidence interval (lower–upper)	p
Insomnia	16.256	2.061	12.214, 20.297,	< .001**
Marital status	-6.266	1.981	-10.150, -2.382	0.002*
Previous hospitalisation	16.748	2.190	-11.313, -3.091	< .001**
Employment	-7.202	2.097	-11.313, -3.091	0.001**

*p ≤ .05, **p ≤ .001.

5.8 The relationship between knowledge, self-care and adherence to a healthy lifestyle among patients with HF in Jordan

Pearson product-moment correlation was used to examine the relationship between knowledge and self-care and adherence to a healthy lifestyle among patients with HF in Jordan (Table 5.15). Three tools were used to examine the correlation including knowledge tool, self-care tool, and adherence tool. There was a statistically significant positive weak correlation between knowledge and adherence to a healthy lifestyle. This indicated that patients with higher knowledge had higher self-care and higher adherence than their counterparts (Table 5.15).

Table 5.15: Pearson to examine the correlation between knowledge, self-care, adherence to a healthy lifestyle, and QOL.

Variable	Knowledge	Self-care	Adherence
Knowledge			
Self-care	-0.15*		
Adherence	0.32**	-0.47**	

* p ≤ .05, ** p ≤ .001

5.9 Summary

The study results demonstrated that the level of knowledge (mean, SD) was moderate 4.0 (1.3), self-care was a moderate (27.5 (4.7), adherence was poor 15.2 (5.1), and the quality of life was moderate 36.6 (20.4). Males had higher knowledge than females. Only 3% of patients were informed to weigh themselves every day, and to watch the fluid status. Regarding self-care, most patients disagreed that they would contact their doctor or nurse if they gain 2 kg in one week, and to monitor their weight every day. Married patients had better self-care than

unmarried. Illiterate patients had poorer self-care than those with some education. Activities with the lowest levels of adherence were: reduce or quit smoking, and self-weighing. The predictors of quality of life were Insomnia, marital status, previous hospitalisation, and employment. These findings indicate the substantial need to better understand patients' responses on the survey, further assess patterns of responses, and explain and corroborate the meaning and the reasons behind the results of the quantitative study. Accordingly, a qualitative study using patient focus groups was conducted to explore patients' experience with HF symptoms, their perspectives on the current HF management program in Jordan, and their suggestions to improve HF management. In addition, the Delphi study was then performed to build up a consensus about the most feasible and applicable HF management programs in Jordan.

Chapter 6: Discussion of the quantitative study

This chapter discusses the findings which emerged from the analysis of the quantitative study (chapter 4) guided by the research questions and aims. It explains, interprets and compares the findings with other studies from the HF literature in order to develop a tailored patient-centred HF management program in Jordan. Four main questions were used to guide this chapter. These were:

1. What is the level of self-care among Jordanian patients with heart failure?
2. What is the level of adherence to a healthy lifestyle among Jordanian patients with heart failure?
3. What is the effect of heart failure symptoms on patients' lives?
4. What are the predictors of self-care, adherence to a healthy lifestyle and quality of life for people with heart failure in Jordan?

6.1 General characteristics

The mean age of the participants was 61.2 ± 12.6 years (range 21–91). This is slightly lower than that reported by a Jordanian study on outpatients conducted by Al-Sutari and Ahmad (2017) who reported the mean age of HF patients as 63.79 ± 10.67 years, and the findings reported by Hayeah et al. (2017) in which the mean age of patients with HF was 63 years. Other studies reported that HF increases among people aged over 65 years (Al-Shamiri 2013; Heidenreich et al. 2013b; Ponikowski et al. 2014). However, a cross-sectional study on 226 Jordanian outpatients with HF conducted by Tawalbeh et al. (2017) indicated that the mean age of Jordanian patients with HF was lower than those in the current study; the mean age was 57 and ranged from 40 to 70 years old.

Two thirds of the sample were male (67.3%), which is similar to other HF studies in Jordan (Al-Sutari & Ahmad 2017; Tawalbeh et al. 2017). After the age of 40, the prevalence of HF is higher among men than women at a ratio of approximately 2:1 (Azevedo 2008). Most participants were married (79%), and this result is congruent with studies by Elhneiti and Al-Hussami (2017); Tawalbeh et al. (2017) reported that 65.9% of patients with HF were married. The educational level was generally low in the current study. This result was also reported by Tawalbeh et al. (2017), who reported that about 52% of patients with HF in Jordan had secondary education or less. In their study, Al-Sutari and Ahmad (2017) reported a low educational level in approximately 83% of patients with HF. The mean monthly income of patients with HF was \$700 US (495.2 ± 327.9 JD). However, a study conducted in Amman

governorate (the capital of Jordan) by Tawalbeh et al. (2017) reported a higher monthly income; the mean monthly income for patients with HF was around \$1000 US (700 JD). This may be attributed to the fact that people who live in Amman have higher salaries due to the higher living expenses in this city compared to Irbid governorate. In addition, Amman is considered the centre of trade in Jordan, and most people with high socioeconomic status live in this city. A third of patients complained of insomnia (36.7%), the major cause was difficulty breathing (28.7%). This result is congruent with a study by Krakow et al. (2006), which showed that difficulty breathing was the most common cause of insomnia in patients with HF. Additionally, Johansson et al. (2010) demonstrated that 42% of patients with HF experienced difficulty breathing compared to 8% in those without HF. Another study reported the main factors associated with insomnia including difficulty breathing, fatigue, nocturia, and pain (Santos et al. 2012).

6.2 Heart failure patient outcomes

6.2.1 Knowledge

The present study showed that the knowledge level of Jordanian HF patients was moderate (4.0 ± 1.3 , possible range 0-8). This result is inconsistent with studies by Hayeah et al. (2017); Tawalbeh and Ahmad (2014); Tawalbeh et al. (2017), who reported a low knowledge level among Jordanian HF patients, but this may be related to heterogeneity in the use of a knowledge scales. The knowledge tool indicated that, for some self-care behaviours, the patients had received little instruction from healthcare providers, and this can be attributed to the lack of a well-structured education program or cardiac rehabilitation program, which are needed to enhance patient knowledge of HF. Furthermore, the low level of general education in Jordan may negatively affect patients' capability to understand HF information. This result is confirmed by previous studies that reported a positive relationship between knowledge of specific cardiovascular diseases and educational level (Huyen, Jullamate & Kangchai 2011; Kayaniyil et al. 2009; Sneed & Paul 2003; van der Wal, Jaarsma, Moser & van Veldhuisen 2005; van Der Wal, Jaarsma, Moser, Veeger, et al. 2005; Zeng et al. 2017). The results of the current study concerning the level of education provide a rationale for this finding, in which 65% of patients had a secondary education or less. This highlights the importance of healthcare providers delivering comprehensive, continuous and appropriate education, and tailoring different educational strategies to the patients' educational level and learning needs, in order to improve understanding and ensure retention of information.

6.2.2 Self-care level

The study showed a moderate level of self-care (27.5 ± 4.7 , possible range 9-45). These scores are comparatively low compared to other studies (Cocchieri et al. 2015; Hu et al. 2015; Jaarsma et al. 2017; Tawalbeh et al. 2017). The moderate levels of self-care might be attributed to the moderate HF knowledge in this study, and the correlation between self-care and knowledge has been reported in other studies including Beker et al. (2014); González et al. (2014); Taulbee (2009); Zeng et al. (2017). Improvements in HF self-care can be measured through assessing patients whether they agree or disagree with performing recommended self-care behaviours, and through measuring patients outcomes such as hospital readmissions. A randomised controlled trial of patients with HF showed that the risk of readmission at 12 months was significantly reduced by 30% compared with those who did not receive educational interventions (Boyde et al. 2018).

6.2.3 Level of adherence to a healthy lifestyle

In this study, the level of adherence to a healthy lifestyle was poor (15.2 ± 5.1). This may be due to psychological distress including depression and anxiety, which is likely to impact on self-care, adherence and QOL (Bekelman et al. 2007; Lockhart et al. 2014; Yancy et al. 2013). This was consistent with the study conducted by Alakhali et al. (2013) that indicated low adherence among patients with HF in Yemen. It has been shown that poor adherence to a healthy lifestyle can be associated with other factors, including a higher number of comorbid conditions, poor sleep and older age (Bellman et al. 2009; Knafl & Riegel 2014). Another explanation is that patients' adherence to self-care is significantly associated with their HF knowledge toward self-care behaviours. A study in Ethiopia reported that patients with high HF knowledge were 2.5 times more adherent to self-care behaviours compared to those who had poor HF knowledge (Seid, Abdela & Zelek 2019). This indicates that patients who were well instructed about self-care behaviours and treatment regimen are more likely to perform better self-care than those who were not instructed (Matsuoka et al. 2016; Ok & Choi 2015; Sewagegn, Fekadu & Chanie 2015). Therefore, enhancing HF knowledge is crucial to improve patients' adherence and to decrease hospitalisations (Dracup et al. 2014; Lee, KS et al. 2017). This indicates the requirement for healthcare providers to fully assess patients' physical, psychosocial and learning needs to ensure optimal and suitable HF management.

6.2.4 Quality of life level

The results of this study showed a moderate QOL among patients with HF in Jordan. Different studies report that HF is a life-disturbing condition, and has significant negative physical, psychological and social impacts on patients (Gorthi et al. 2014a). The physical and emotional symptoms of HF include coughing, sleep disturbance, difficulty breathing, chest pain, fatigue, anxiety and depression, and restricted daily physical and social activities, which all ultimately lead to poor QOL (Heo et al. 2009; Vaccarino et al. 2001; Wilson et al. 1999). In addition, QOL might be adversely affected by the increased number of readmissions (Alla et al. 2002). The combination of limited knowledge, poor adherence to a healthy lifestyle, and older age in addition to a HF diagnosis impacts on QOL. This is supported by the findings of studies conducted by Gonzalez (2016); (Hwang, Liao & Huang 2014; Kessing et al. 2017; Pelegrino, Dantas & Clark 2011).

6.2.5 Level of education

The current study indicated that illiterate patients had poorer adherence to healthy lifestyle than those patients with a higher level of education. This result was consistent with the univariate correlation analysis in the studies of Bryson et al. (2005); Tawalbeh et al. (2015), which indicated that greater adherence was positively correlated with higher levels of education. Patients with higher educational levels are more likely to understand health-related information, and to read printed educational material, which ultimately assists with improving knowledge and adherence to a healthy lifestyle. Therefore, the level of literacy is an important element to be considered in HF education. It has been found to improve communication, treatment adherence, health status and self-care. Furthermore, poor literacy has a negative effect on patients' ability to learn and comprehend the information delivered, leading to adverse health outcomes (Safeer, Cooke & Keenan 2006; Sudore & Schillinger 2009). Therefore, the patient's literacy level should be identified and documented, in order to help healthcare providers provide the most effective strategies and special educational material that can be tailored to their learning needs and preferences.

In relation to self-care, illiterate patients had poorer self-care than patients with low education and high education. This finding is consistent with the results of (Riegel, Moser, et al. 2009) and Tawalbeh et al. (2017), who indicated that a lower educational level correlates with lower self-care. The literature indicated that people with more education have more knowledge about HF, which may affect self-care positively (González et al. 2014; Tawalbeh et al. 2017). Patients

with less education may have difficulty in processing items that impact management of disease such as reading and understanding educational materials (Dennison et al. 2011; Schillinger et al. 2002). In addition, people with a low level of education have difficulties in comprehending educational content, and this may worsen their health physically and emotionally, increase the negative health-related consequences (Wu et al. 2013), and therefore negatively affect self-care (Barbareschi et al. 2011) (Macabasco-O'Connell et al. 2011). Patients who were illiterate had poorer QOL than patients with low levels of education and those who were well educated. This is consistent with the findings of DeWalt et al. (2006); Gazmararian et al. (2003); Macabasco-O'Connell et al. (2011).

Previous studies have demonstrated an association between lower educational levels in patients with HF and different aspects of QOL, such as poor physical functioning, higher anxiety and poorer health (Riedinger, Dracup & Brecht 2000). Another study reported that patients with poor levels of education had 50% higher levels of hospitalisations, in comparison with those who had higher levels of education, which can lead to poor QOL (Sui et al. 2008). Furthermore, educational level was a significant predictor for recognition of HF symptoms, HF knowledge and QOL (Macabasco-O'Connell et al. 2011). As previously mentioned, higher levels of education have a strong association with HF knowledge, self-care and adherence to a healthy lifestyle, which ultimately affects QOL. The level of education correlates with socioeconomic status, which is considered to be a determinant for QOL. A possible explanation is that educated people are more likely to have financial sources (good socioeconomic status), and have the ability to read and comprehend medical instructions, which helps improve the effectiveness of disease management, adherence to treatment and QOL (Audi et al. 2017; Beverly et al. 2013; Nesbitt et al. 2014b).

There are several approaches that can be utilised for patients with a low level of education, to achieve optimal outcomes. These include improving communication between healthcare providers and patients, and promoting self-care interventions. The communication practices are recommended to be direct and collaborative, and involve conversation. In addition, both the healthcare provider and the patients should understand the importance of effective communication to convey the intended message (Roberts 2015). The other approach that can be useful is designing special HF educational material for patients with low level of education. The literature showed that the majority of HF education materials are not sufficiently appropriate for patients due to the lack of understandability. This highlights the substantial need to carefully assess and revise these education materials for relevancy to patients with low level of education (Roberts 2015).

6.3 Impact of some demographic and clinical factors on HF outcomes

6.3.1 Insomnia

This study found that insomnia was a predictor of adherence to a healthy lifestyle among patients with HF in Jordan. The insomnia-related symptoms in patients with HF, including lack of concentration, worsening functional performance and fatigue (Redeker et al. 2010), may adversely impact QOL and adherence to treatment regimen (Riegel et al. 2012; Tsuchihashi-Makaya & Matsuoka 2016). This indicates the importance of identifying and treating the cause of insomnia through utilising the most appropriate and tailored interventions. Patients without insomnia had higher self-care than patients who had insomnia. This result is in line with numerous studies (Dickson, Tkacs & Riegel 2007; Riegel & Weaver 2009) which showed that sleep disturbance is a leading factor for cognitive impairment, which negatively affects patients' capability to self-care. In turn, poor self-care may result in impaired QOL, limited functional capacity and increased burden of symptoms (Riegel & Weaver 2009). Furthermore, poor sleep has been found to be associated with anxiety, depression, impaired motor skills and social discomfort, which ultimately lead to poor self-care, adherence to a healthy lifestyle and QOL (Altevogt & Colten 2006). Insomnia was identified as a major risk for depression, dementia (de Almondes et al. 2016; Fernandez-Mendoza et al. 2015), unhealthy lifestyle and neuroendocrine disturbance (Laugsand et al. 2013). These changes are contributing factors for HTN, obesity, diabetes and arteriosclerosis, which ultimately have a profound effect on QOL. Moreover, deterioration in functional performance (Redeker et al. 2010) and fatigue have been shown to be associated with low adherence to HF treatment and decreased QOL (Hayes et al. 2009; Riegel et al. 2011; Riegel et al. 2012). Another possible explanation is that older patients and those with multiple comorbidities are at higher risk of insomnia (Kanno et al. 2016). Overall, these consequences affect patients' lives and lead to poorer QOL. These findings indicate the importance of treating mental and psychological conditions caused by HF, which may help in improving HF prognosis and QOL. An effective strategy to treat insomnia and improve QOL can be to address the causes of insomnia, managing mental and psychological HF-related symptoms, and establishing effective collaboration between healthcare providers (Tsuchihashi-Makaya & Matsuoka 2016). With respect to QOL, patients with insomnia had significantly poorer QOL than their counterparts. This is congruent with the studies of Baldwin et al. (2001); Redeker et al. (2010), who found that approximately 50% of patients with HF had insomnia which, in turn, was associated with negative symptoms. In addition, insomnia has

been associated with more health problems such as depression symptoms and anxiety (Cukrowicz et al. 2006; Tsuchihashi-Makaya & Matsuoka 2016), and correlated with significant impact on health, QOL, social and occupational functions, finances, and community safety (Kyle, Morgan & Espie 2010; Rosekind et al. 2010).

6.3.2 Marital status

Social causation theories show that married people are more likely to receive social and psychological spousal support, which assists with improving adherence to treatment, changing lifestyle and seeking treatment (Quinones et al. 2014). Stress-related theories demonstrate that the quality of the relationship and the loss of a partner may affect patients psychologically and thus affect adherence to treatment and health (Berntsen 2011; Brockmann & Klein 2004; Manzoli et al. 2007). The results highlight the necessity of providing patients with social support as married patients had a better level of self-care. This result is consistent with the result of studies by Dunbar et al. (2008); Tawalbeh et al. (2017), who indicated that married patients are more likely to receive social and psychological support from their partners, which can lead to better self-care. Other studies found that unmarried patients are at higher risk of depression, lower QOL and poorer self-care (Havranek et al. 2004; Luttk et al. 2006). The result indicates patients' need for social support in order to improve their self-care and adherence to healthy HF recommendations. In addition, social support can be provided by other family members and/or friends who may significantly assist patients with HF by reinforcing the information provided, and improving self-care (Cowie et al. 2014). This study found that married patients had higher QOL than unmarried patients. This result is consistent with the findings of Luttk et al. (2006), who showed that the majority of unmarried patients living alone were elderly and at risk of worsening HF symptoms, and consequently poor QOL. In addition, being married has been found to reduce the impact of negative feelings and this has been attributed to the influence of social support (Cohen & McKay 1984). The finding supports the health promotion model, which postulates that adequate social support, reflected by the presence of family members, friends and healthcare providers, is a vital source of interpersonal influence that increases health-promoting behaviour and ultimately improves patients' QOL (Pender et al. 2006). Furthermore, social support has been positively associated with clinical outcomes and QOL through its influence on emotional well-being, adherence to self-care (Simpson et al. 2000), and self-care behaviours (Heo et al. 2012). In a meta-analysis, emotional and social support, family relationships, and being married were all significantly associated with better adherence to treatment regimens (DiMatteo 2004). Positive social support assists

with improving QOL (Bennett et al. 2001) and achieving better health-related outcomes (Lett et al. 2007). Various studies have suggested the strategy of increasing social support for patients with HF, in order to protect them from the stressful environment that may result in harmful outcomes, decrease morbidity and mortality rates, and subsequently improve QOL (Chung et al. 2009; Dunbar et al. 2008). It has been indicated that married patients with HF had 2.1–3.8 times lower risk of death or readmission than unmarried patients (Chin & Goldman 1997; Chung et al. 2009; Cohen & Wills 1985). Another study showed that patients living alone had 12% more events in the nine-month follow-up period than patients living with a partner (Luttik et al. 2006). In conclusion, family members can play a crucial role in assisting patients with controlling disease and performing self-care. In addition to social and emotional support, family can help in teaching and empowering patients in performing health-related behaviours such as stress management, nutrition, and sport (Khachian et al. 2016). Therefore, healthcare providers can develop effective management programs through involving patient's family in the patients' care plan (Khachian et al. 2016).

6.3.3 Gender

Females in this study had poorer self-care than males. A possible explanation is the effect of the Jordanian cultural expectation that men are responsible for the expenses of daily living, and this may drive them to aim to live longer through engaging in daily self-care behaviours to ensure they provide for their families (Razzolini & Dal Lin 2015). Another possible explanation is that women have family responsibilities, and therefore self-care is secondary for them. In addition, they tend to have less opportunity for education.

Previous studies showed that women are more likely to develop psychological problems, poorer physical function, dysphoria and social isolation, which ultimately contribute to poorer self-care compared to men (Chriss et al. 2004; Davidson et al. 2003; Heo et al. 2008; Vaccarino et al. 2001). Furthermore, previous studies conducted in Africa and Netherlands demonstrated that males were more adherent to perform self-care behaviours than females (Seid, Abdela & Zeleke 2019).

Knowledge has been found to be a substantial factor for improving patients' ability to perform self-care behaviours (Artinian et al. 2002; Ni et al. 1999; van Der Wal, Jaarsma, Moser, Veeger, et al. 2005). The overall literacy rate in Jordan among men is better than women (Azzeh 2018; Organization 2006), which is reflected in the finding of the current study that men have higher HF knowledge than women. This result is consistent with a study by Chen et al. (2013), who

indicated that better literacy is associated with higher HF knowledge. It has been considered a cultural norm in Jordan for males to continue their education while females take over domestic chores/responsibilities, which has led to different levels of education between men and women. This result highlights the importance of focusing education on both women and men, providing optimal and effective care for patients regardless of their gender, and ensuring their understanding and recognition of their HF condition. This can be by considering their level of literacy and increasing the awareness of healthcare providers of this issue. Therefore, effective HF education and social support are important to improve self-care. Female patients had significantly poorer QOL than males. This finding is confirmed by previous studies including the studies of Azad et al. (2011); Luttik, Lesman-Leegte and Jaarsma (2009), who found that women are more affected by negative symptoms than males and need support for their QOL. It has been found that women are more symptomatic than men (Heo, Moser & Widener 2007), and experience higher rates of oedema, shortness of breath, restricted physical activity and depression (Gustafsson et al. 2004; Juenger et al. 2002; Moser, Macko & Worster 2000). In addition, women are more likely to experience fatigue and general weakness when performing an intermediate level of daily living activities, which ultimately contributes to worse QOL (Alla et al. 2002). Although females have a greater need for emotional, psychological and social support, they are less likely to have a partner or close family member available to provide care than males, and this will negatively their QOL (Chin & Goldman 1998; Riegel et al. 2003). This may be confirmed by a Jordanian study that reported that women in Jordan have one of the lowest employment rates in the Arab world (11%), and this was attributed to the low levels of education among women (Majcher-Teleon & Slimene 2009). Therefore, the major roles for women in Jordan are housekeepers, housewives and primarily mothers, and women's responsibility for these activities may impact on their QOL (Majcher-Teleon & Slimene 2009).

6.3.4 Employment

Employed patients had higher self-care than those who were unemployed. Various studies have shown that employment has a significant positive impact on HF self-care (Lei & Cai 2018; Siabani, Leeder & Davidson 2013). Cocchieri et al. (2015) conducted a study on 1192 patients with HF to identify self-care determinants. The study found that unemployment was a strong predictor of poor self-care. Regarding QOL, unemployed patients with HF had a significantly poorer QOL (Nesbitt et al. 2014a). This could be explained by the fact that most patients with HF lose their jobs, do not receive a monthly income, and cannot afford costly HF treatment. This may consequently lead to lower socioeconomic status. The effect of socioeconomic status

on QOL and clinical outcomes in patients with HF has not been widely studied. A careful review of eight clinical studies conducted by Blair, Lloyd-Williams and Mair (2002) in England showed that lower socioeconomic status was correlated with more severe illness. Rathore et al. (2000) demonstrated that patients with financial hardship were less likely to receive the prescribed medication on admission or discharge. Philbin et al. (2001) studied 41,776 patients with HF to identify the association between clinical outcomes and income. They found that poor patients and those with a low income had more comorbidities (Philbin et al. 2001). This indicates that more attention should be paid to those who are unemployed and who have lower incomes and education because they are less likely to perform optimal and proper self-care, which leads to poorer QOL (Simpson et al. 2000).

6.3.5 HF classification

In relation to HF classification, patients who were in HF class III had poorer self-care than patients in class I and II. This result is congruent with studies performed by Cocchieri et al. (2015); (Dickson, Buck & Riegel 2013; Jurgens et al. 2009), which found an association between a worse NYHA class and poor self-care. The possible explanation is that patients with a worse NYHA class are more likely to develop depression, cognitive impairment and have more associated comorbidities, which adversely impacts symptom recognition and patients' ability to perform self-care. The observed trend is that the impact of symptoms increases as the disease progresses; this is a logical finding because the tolerability of disease may decrease with disease progression. This is consistent with the findings of previous studies (Adebayo et al. 2017; Carels 2004). This could be because worsening HF increases the risk of physical impairment, functional impairment and psychological distress, which negatively affect QOL (Carels 2004). Another explanation is that severely ill patients are at higher risk of more morbidities, HF-related complications, and increased hospital readmissions. Previous studies found a significant association between depression and poor self-care (Holzapfel et al. 2009). It has been reported that increased depressive symptoms are associated with high adverse health-related outcomes in patients with HF. These symptoms, including feelings of helplessness, worthlessness, hopelessness and loss of energy, may negatively affect patients' capability to adhere to recommended self-care behaviours (Chang et al. 2017; Kronish et al. 2006). In addition, depressive patients are less likely to have motivation for self-care due to distorted symptom perceptions.

6.4 The relationship between knowledge, self-care and adherence to a healthy lifestyle among patients with HF in Jordan

The study indicated that patients with higher knowledge had higher self-care and higher adherence than their counterparts. Knowledge plays a substantial role in improving patients' commitment to self-care (Beker et al. 2014; Jaarsma et al. 2017), and helps in increasing precise understanding of their illness and supporting adherence to a healthy lifestyle. This result is in line with studies conducted by (Macabasco-O'Connell et al. 2011; Mosca et al. 2006). On the other hand, lack of knowledge will prevent lifestyle modifications, and increase the risk of morbidity and mortality (Kayaniyil et al. 2009). HF knowledge helps in motivating patients to carry out healthy behaviours, and improving adherence to a healthy lifestyle (Zeng et al. 2017). One of the studies reported that patients with poor HF knowledge had 2.5 times less adherence to recommended self-care behaviours than patients with high knowledge. In addition, those patients with appropriate knowledge about self-care behaviours, and the signs and symptoms of HF are more likely to carry out more serious self-care. This result is congruent with studies conducted by Matsuoka et al. (2016); Seid, Abdela and Zeleke (2019); Sewagegn, Fekadu and Chanie (2015), which reported a significant association between poor adherence to recommended self-care behaviours and lower knowledge in patients with HF. Enhancing patients' knowledge about HF is essential to improve adherence and self-care and reduce negative health-related consequences (Dracup et al. 2014; Lee et al. 2017). This highlights the importance of developing effective and comprehensive education programs, consisting of different delivery modes and educational strategies, to improve self-care, adherence to a healthy lifestyle and QOL (Liou et al. 2015).

6.5 Summary

This chapter discussed the findings that emerged from the analysis of the quantitative study in light of the relevant literature. The impact of some demographics and clinical factors including educational level, insomnia, marital status, gender, employment, and HF classification were presented. The relationship between knowledge, self-care and adherence to a healthy lifestyle among patients with HF in Jordan was also discussed. This discussion indicated the need for a qualitative study to help in verifying the quantitative results. Patients' focus groups can help understand the nature of the current HF management programs implemented in Jordan, explore patients' emotions and experience with their HF disease, and identify their suggestions to improve HF to ensure effective HF management. The methods for this part of the thesis are presented in the next chapter.

Chapter 7: Methods for the qualitative study

7.1 The research design

The second stage of this study used a descriptive qualitative approach. Colorafi and Evans (2016) indicate that qualitative research helps researchers to share the experience of individuals and to better understand the context, and informs the results of quantitative studies, facilitating the development of theories. A descriptive approach has been found to be amenable to health environments, because it provides a holistic image and comprehensive summary of particular phenomena or events (Colorafi & Evans 2016). Sandelowski (2010) indicates that a descriptive approach is an excellent choice for health research studies because it focuses on the perspectives of subjects and provides rich descriptive data.

Two methods were used during the qualitative phase of this study. The first was focus groups (n = 2) with HF patients, and the second was the Delphi method, which included clinicians and policy makers.

7.2 Site and setting

This study was conducted in the largest hospital in the north of Jordan, the King Abdullah University Hospital (KAUH), described in Section 4.3.

7.3 Patient focus groups

7.3.1 Population and sampling

The target population was patients with HF visiting cardiac outpatient clinics located in the north of Jordan. With respect to the sampling technique, convenience sampling was selected by the researcher to recruit participants. The first focus group involved seven Jordanian patients with HF, while the second involved only six patients, because one patient could not attend the second focus group due to family commitments. The seven patients were different from those who were enrolled in the cross sectional study (study I). The inclusion criteria were: a patient of King Abdullah University Hospital, diagnosed with HF by a cardiologist based on the NYHA criteria, and aged 18 years and above. The exclusion criteria were illiterate and/or cognitively impaired patients.

7.3.2 Study instruments

A list of questions was generated by the researcher for each focus group discussion session. The questions were first written in English and translated into Arabic by the researcher. Both Arabic and English versions were given to an expert translator to ensure coherence between the two versions. The first focus group discussed six questions that targeted patients' experience with their disease, their emotions and their motivations for self-care/self-management. Patients shared their perspectives about different issues. These were: making changes in lifestyle, looking after their own health, the impact of heart disease, and the impact of religion and culture on lifestyle and ability to make changes to improve one's health. The second focus group discussed another six questions, which targeted patients' perspectives on the proposed HF model. Different issues were discussed such as the impact and usefulness of the previous teaching sessions, suggestions for developing the HF program, and interventional strategies that could be incorporated into the HF management program.

7.3.3 Recruitment and data collection

The researcher asked the administrator of the outpatient clinics to refer him to the general or assistant physician who works with the cardiologist and has access to patients' medical records through a specialised medical program on the hospital's computer system. Then, the researcher asked the physician to provide the clinic nurse with a list of eligible patients. The clinic nurse approached eligible patients on the day of their appointment and provided them with the Participant Information Sheet (PIS) to give them the opportunity to discuss their involvement in the study with their family members.

The PIS included the researcher's dedicated contact details for the project to allow them to contact the researcher for more information. Patients who agreed to participate called the researcher to arrange for a focus group at a time that was suitable for most to meet. Recruitment lasted about ten days for the first focus group, and the second focus group was conducted about four days later. On the day of the meeting, the researcher introduced himself to the patients and described the rationale, benefits and aims of the project in simple language. Then consent was obtained prior to starting the discussion. Thereafter, the researcher collected some demographic information from each participant such as age, gender, educational level, and the duration since being diagnosed with HF. At the end of the first focus group, the researcher arranged for the second focus group to be conducted about four days after the first focus group, at a time that

was suitable for all patients. The same participants were invited to the second focus group. The duration of the first focus group was 50 minutes, and the second was 45 minutes.

7.3.4 Analysis

The focus groups were audio-recorded and transcribed verbatim. For the verification of the data, each transcript was read while listening to the audio file to ensure familiarisation with, and immersion in, the data. The transcripts were qualitatively analysed using thematic analysis (Braun & Clarke 2012). Analysis was conducted over several phases. First, the transcripts were carefully read and re-read several times for familiarisation with data and notation of initial ideas and analysis. Second, codes were iteratively generated from the interview text and grouped. Third, a number of potential themes were extracted (collated) from the codes. Fourth, the themes were checked for their relation or relevance to the codes. Lastly, the ongoing analysis yielded refined and specific themes and subthemes with clear definitions and names.

7.3.4.1 Trustworthiness

Guba and Lincoln (1981, 1994) demonstrated four trustworthiness issues that need to be considered by qualitative researchers irrespective of their research paradigm. These are credibility, transferability, dependability and confirmability.

7.3.4.1.1 Credibility

Credibility is defined as ‘the confidence that can be placed in the truth of the research findings’ (Korstjens & Moser 2018, p. 121). Credibility shows whether the findings of any research represent reasonable information extracted from the original data from the participants and is a correct interpretation of their original views (Graneheim & Lundman 2004). The rigour of the inquiry is usually established by qualitative researchers through adopting the strategies of credibility (Shenton 2004). In this study, the focus group discussion was transcribed in Arabic. The Arabic transcript was shown to the participants to ensure that the written information reflected what they had said in the focus group. Additionally, both Arabic and English transcripts were given to a professional translator to check the level of coherence between the two transcripts, which ensured the credibility of the data.

7.3.4.1.2 Transferability

Transferability refers to the extent of transferability of the qualitative results to other contexts with other respondents, which helps to ensure the generalisability of the data (Guba & Lincoln 1981, 1994). In this study, participants’ characteristics such as age, gender, employment,

education level and marital status varied. Furthermore, the participants had differences in clinical factors such as body mass index, ejection fraction and smoking. This variety can suggest that the findings of this study are generalisable to another sample of patients with HF under the same conditions. In addition, transferability can be facilitated through the thick description of the research process (Guba & Lincoln 1981, 1994). This thick description can assist other researchers to replicate the study in other settings under similar conditions. Therefore, as part of this study, the research process has been elucidated and completely described, involving data collection, methods, methodology and context of the study.

7.3.4.1.3 Dependability

Dependability refers to ‘the stability of findings over time’ (Guba & Lincoln 1981, 1994). Dependability is necessary for trustworthiness, by ensuring that the findings of research studies are repeatable and consistent (Shenton 2004). Therefore, researchers strive to verify the consistency of their research findings, interpretations and recommendations with the raw data gathered. This is important to ensure they have not missed anything in the research study, and that they were systematic, structured and guided in writing the final report (Cohen, Manion & Morrison 2007; Tobin & Begley 2004). In this study, each step, involving data collection, data analysis and the results, has been carefully examined and discussed with the supervision team. The congruence of the methods and methodology with the process of analysis was closely evaluated. All phases of data analysis involving extracting initial ideas, themes and subthemes were carefully reviewed and discussed with the supervisors. This ensured the accuracy of the findings, and the trustworthiness and dependability of the study.

7.3.4.1.4 Confirmability

Confirmability indicates to what extent the findings of a study can be confirmed by other studies (Guba & Lincoln 1981, 1994). Confirmability implies that the findings are real and not derived from the imagination or perception of the researcher. It must be clear that the results are derived from the data. The literature has demonstrated that confirmability can be established through confirming the congruence between the real evidence and interpretation of the results, and that the findings and conclusions are explained and rationalised by the data (Tobin & Begley 2004). In this study, all possible measures were considered to verify that all research processes were reasonably conducted, recorded and confirmed with the research supervisors. The data collected were interpreted based on how the perceptions, emotions and experiences were expressed by the participants, and from the researcher’s understanding of the real context that the patients live in. Furthermore, the knowledge and experience of the

researcher and the supervision team played a significant role in understanding what was expressed by patients, either verbally or non-verbally.

7.4 The Delphi study

7.4.1 Study aims

The aim of the Delphi study was to build up the experts' consensus about the feasibility, appropriateness, and applicability of the proposed HF intervention in Jordan.

7.4.2 Research questions

The study has one main research question which is:

‘What are the HF interventions, strategies, components that could be feasible, applicable, and appropriate in Jordan health context’.

7.4.3 Population and sampling

The target population for the Delphi study was medical and nursing clinicians, and health policy makers at KAUH. Regarding the sampling technique, non-probability purposive sampling was selected by the researcher to recruit participants. Purposeful sampling is largely utilised in qualitative research studies to identify and select cases rich in information about the phenomenon of interest. This includes determining and choosing individuals or groups of individuals who are specialised, experienced and knowledgeable about a particular topic (Creswell & Plano Clark 2011). The inclusion criteria were: staff of King Abdullah University Hospital; experience and knowledge in making health policies and decisions in Jordan; clinical experience and background; and involvement in health policy decisions related to the delivery of care to patients with HF. The aim was to find staff with sufficient expertise and understanding of the local context to articulate the potential facilitators and barriers to the use and implementation of the proposed HF model. Exclusion criteria were: anyone who does not have adequate experience and knowledge about HF care, and in making health policies, and/or is unable to meet and provide useful information. There was no age range set for health policy makers and clinicians. Ten health policy makers and clinicians were invited to participate in the study. Those were: one physiotherapist (the head of the physiotherapy department), one dietician (the head of the nutrition department), one registered nurse (head of the continuous education department), the general administrator of the hospital, the general administrator of the nursing department, two cardiologists, one experienced cardiac nurse, and two PhD-

educated nursing academics specialised in critical care nursing (cardiopulmonary). However, only seven agreed to participate. Three did not respond to the invitation email, including the general administrator of the nursing department, the general administrator of the hospital, and one academic. The final sample was seven clinicians and health policy makers.

7.4.4 Study instruments

A list of HF strategies, interventions and components were included in the proposed HF program in Jordan. The HF strategies, interventions, and components were drawn from primary studies, targeting HF management programs that resulted in effective and successful outcomes, extensive critique and review of five systematic reviews targeting HF management, the European HF guidelines, the recommendations and limitations of previous primary and secondary studies including systematic reviews and meta-analysis, and the results of the quantitative phase of the study. These sources were primarily used to identify the gaps and shortcomings in previous HF management programs, and to shape and structure the potential tailored interventional program. The information that was critical to inform the development of the Delphi instrument included the individual variations between patients (age, level of education, financial status, and marital status), financial capability and availability of resources in Jordanian healthcare system, and the significant results of the quantitative study which included the need to change lifestyle (increased HF risk factors), lack of patients knowledge about certain self-care behaviours, poor adherence to self-care, and the emotional and social impact of HF symptoms on patients' lives. The HF components proposed in the HF program included education for outpatients and admitted patients, monthly follow-up appointments with the cardiologist, the use of a group of HF interventions and strategies including educational materials (HF booklet, video), follow up phone calls, home visits, one-hour educational session, the utilisation of healthcare clinics to launch awareness campaigns, the use of a multidisciplinary team, and the use of tele-monitoring devices. The HF components are detailed in Table 8.20.

The three main dimensions of the proposed management program were lifestyle change, follow-up interventions tailored to patients' needs and demands, and psychological care. SurveyMonkey software was used to allow Delphi participants to rate these components and strategies in terms of their feasibility and appropriateness in Jordan, using a five-point Likert scale, in which zero means 'not feasible at all', and 5 means 'very feasible'. It was used to provide instant feedback, help provoke discussion, and collect responses.

7.4.5 Recruitment and data collection

The administrators of outpatient clinics and the medical department were approached to obtain approval to conduct the study. The researcher indicated to them the potential benefits of the study and emphasised that their patients and healthcare providers would not be harmed through participating. Furthermore, the burden on the outpatient staff would be minimised. Thereafter, the researcher provided the administrator of the medical department the inclusion criteria. , the researcher asked the administrator to send an invitation letter via email to all eligible healthcare policy makers and clinicians. The invitation letter included a dedicated contact number and email for the researcher so that they could ask questions, and to decide on an appropriate time to conduct the Delphi study. Experts who agreed to participate called the researcher to arrange the best time that suited all participants. After that, the researcher informed them of the place where the Delphi study would be held.

On the day of the meeting, the researcher gave the participants the Participant Information Sheet, and obtained their consent. When starting the meeting, the researcher presented the tailored HF model proposed, and explained how this model has been developed. Thereafter, the experts were given the statement of the problem that included two main questions. The first question was: ‘What are your first impressions of the proposed model especially in relation to its feasibility in Jordan?’ The second question was: ‘What are the components of the most feasible and effective program for heart failure patients in Jordan to maximise self-management skills?’ Then, the experts were asked to write down their responses and views on the proposed model to collect their responses in SurveyMonkey, and present their ideas in real time in a table for ranking. This was the first round of the Delphi method. The second round was conducted in the same meeting and included a discussion of the responses from the first round, followed by repetition of the SurveyMonkey.

7.5 Ethical considerations

The qualitative component was approved by the Human Research Ethics Committee of the University of Adelaide. Approval was also obtained from the Institutional Review Board of KAUH, where the study was conducted. The privacy and confidentiality of participants were protected during recruitment, data collection and data analysis. In order to ensure voluntary participation, consent was obtained before conducting the Delphi and focus groups. After explaining and clarifying the goals of the project to participants, and providing a participant information sheet, those who consented to be involved signed the consent form. The Delphi

and focus groups were conducted in the waiting room next to the cardiac clinic and/or rooms designed for meetings, and there were no possible risks to the participants, and no expected health and safety risks for the researcher. The data collected from the focus groups and the Delphi were recorded and stored according to the policy of the University of Adelaide. The audio recording was saved in the researcher's personal computer. This computer was protected by password and inaccessible to others. The data were accessed only by the researcher and academic supervisors, who did not know any information about the participants.

At completion of the study, data in an electronic format such as audio-recorded materials and verbatim transcribed data from the focus groups and the Delphi will be electronically stored on a password-protected computer network at the Adelaide Nursing School in the University of Adelaide in non-identifiable format. Any hard copies of data are stored in a locked filing cabinet in the Adelaide Nursing School offices at the University of Adelaide. At the beginning of the focus group with patients, the researcher asked the participants to respect the confidentiality of others in the group and all information discussed. The researcher only collected the data that were related to HF management. During data analysis each participant was given a code, and the code is used in reporting the results.

7.6 Summary

This chapter has presented both the qualitative (patients focus groups) and the Delphi methods that were used in this study. Information related to sampling process, setting, data collection procedures, data analysis, and ethical considerations was clearly presented for each study. The findings of the patients' focus groups and the Delphi study are presented in the next chapter.

Chapter 8: Results from the qualitative study

8.1 Findings of the patient focus groups

The findings shown in this chapter were based on the thematic analysis of transcripts of both of the focus groups. The data were transcribed from spoken Arabic, and carefully translated by the researcher to ensure the original meaning, and then checked by an expert translator.

8.1.1 *The first patient focus group: description of participants*

Seven patients with HF participated in the first focus group. The mean age of the patients was 65.6 years (range 61–78, SD = 7.1). As can be seen in Table 8.1, the mean time since diagnosis with HF was 6.9 years (SD = 3.7), and the majority of the sample were males (71.4%). Regarding education level, slightly more than half of the sample had only completed primary or secondary education and only one (14.3%) had a bachelor's degree (Table 8.1).

Table 8.1: Sample characteristics; mean, standard deviation (SD), and number (n) and percent (%) for the first patient focus group

	Mean (SD)	Range
Age	65.6 (7.1)	61–87
Duration since diagnosis with HF, years	6.9 (3.7)	4–14
	N (%)	
Gender		
Male	5 (71.4)	
Female	2 (28.6)	
Level of education		
Illiterate	1 (14.3)	
Primary education	1 (14.3)	
Secondary education	3 (42.9)	
Diploma	1 (14.3)	
Bachelor	1 (14.3)	

8.1.2 *Findings of the first patient focus group*

Five themes and fifteen sub-themes were extracted from the transcribed text of the first focus group. Patients' experiences with HF, emotions, and their motivation to self-care were embedded within each theme and subtheme. These themes are described below in detail (Table 8.2).

Table 8.2: Themes and subthemes from the first focus group

Theme	Subtheme
Emotional impact of HF	Worry
	I hate my life
	Loss of abilities
	Changed lives
Motivation to change lifestyle	Fear of deterioration
	Religion as a motivation
	Love of family
Adjustment	Adjusting to the treatment regimen
	Fear of consequences
	I can't give it up
Physical impact of HF	Tiredness
	Shortness of breath
	Sleep disturbance
	Loss of manliness
	Loss of social interaction
Impact of religion	-

8.1.2.1 Emotional impact of HF

Worry. Some participants expressed feelings of worry as a psychological response to their chronic condition, which were related to their reduced physical capacity and to the complications or health consequences that might occur in the future.

My disease has become the source of my worry because the doctor told me to undergo open heart surgery and the people told me that my chest would be opened and my heart would be taken and put in a plate. (C)

Lack of money makes me worried because I cannot afford the medical costs in case I develop further health complications, so I am trying my best to look after myself. (D)

I hate my life. Some participants have come to hate their life, and have become depressed and frustrated due to the consequences and symptoms of HF, which involved difficulty breathing, sleep disturbances and feelings of loneliness.

Until the last day before the surgery, the difficult breathing and lack of sleep made me hate my life, and I even preferred death and food was like a poison. (A)

I have come to hate myself ... I feel loneliness and never leave the house, my feelings and interests are not like before. (B)

Loss of abilities. Some participants conveyed feelings of powerlessness and talked about their limitations because they no longer have the abilities they used to have in the past.

I am not able to work and get money to spend on me and my wife ... all life has changed, I do not have the ability to work as before. (D)

I feel weakness and inability because I became ashamed of asking my sons to drive me, and I am ashamed to ask for their help for doing daily activities, even though they are good and never say no, but they are always busy. I am afraid of being completely unable to move, and care for myself. (F)

I wish I could play sport like my son, who weighed 140 kg and then he signed up at a gym and played sports and his weight reduced and became fit. I have lost my power. (B)

Changed lives. Some participants expressed feelings of bitterness about how they were before and how they had become, in terms of their eating habits, appetite, health condition and lifestyle.

I take a long time to fall asleep, because I think about the life process and how it ends up with disease! How I was and how weak and sick I have become. (F)

My feelings and eating habits have changed a lot, and this is what I did not used to do with my life. My illness deprived me ... and my appetite has decreased. (E)

8.1.2.2 Motivation to change lifestyle

Fear of deterioration. Some participants expressed fear of deterioration and its negative consequences. Worries about suffering and living with aggressive symptoms were motivating factors to make changes to their lifestyle.

Because I know if I do not adhere to my treatment regimen, I would suffer like what happened in the past, and I would not eat, and will have short breath and difficult sleeping, so ... what is forcing me to act like this? If I eat like before, heart attack will come back and my condition will worsen. (A)

My fear of the disease outcomes and the worry of having more surgeries drive me to take my medication. But even when I have pain or feel tired, and if I don't take my medicine, I would not worry, I thought that my pain would go and I would be better after taking it. (C)

Religion as a motivation. Some participants considered the religion of Islam to be a motivating factor to adopt healthy lifestyle recommendations, particularly regarding eating and performing exercise.

The prophet Mohammad said, 'The stomach is the house of disease' and our Islamic religion has called for the man to reduce his food and care about his health ... Frankly we eat in Jordan a lot of heavy and fat and sugary foods. Even the konafa are all sugar and fat. (A)

I believed in words of Prophet Muhammad: 'We do not eat till feeling hunger, and if we eat, we do not fill our stomach.' And he also said: 'Stomach is the worst place to be completely filled by food.' And hence we have to eat less food, do exercise to maintain our health. (Z)

Love of family. Some participants stated that loving relationships with their families helped them to comply with the recommended lifestyle.

I am trying to commit because I don't want to make my sons sad and also to avoid getting overtired. (B)

The increased attention and love of my children and my daughters encourage me to take care of myself and adhere. (D)

8.1.2.3 Adjustment

Adjusting to the treatment regimen. Most participants declared their commitment to their treatment regimen, particularly the medication. They sometimes forgot to take medications on time or to stick with their regimen as prescribed.

I am committed to my medication, but sometimes I forget to take it on time ... medications are very important, otherwise, I would be in my grave. (E)

I try to eat as little as I can. *What food did you reduce?* Salty foods ... I am committed to my recommended diet on most days, but on some occasions I forget myself and eat more than usual. (F)

I take my medicines on time ... After the operation I have become more concerned ... Sometimes my wife makes the foods that I love like Almkora but I do not eat much. (A)

I take the medication regularly according to the prescription of my doctor. (Z)

Weight monitoring is important ... the only time I became obese was in 1993 when my weight was 85 kg ... I followed a diet program and I ran daily 3 km and during the month I lost 10 kg. (Z)

I am committed to my medicines ... I take my medicines immediately after eating. (C)

If I do not take my medicine, I would not feel better. I have to take my medicine, otherwise, why should I visit my doctor? (B)

I take my medications regularly; otherwise, my health would deteriorate. (D)

Fear of consequences. Some participants changed their eating habits because of fear of the consequences of heart disease.

I have stopped eating meat and sugars. I have started a new healthy diet three months ago. This was after the increase in the blockage of my heart vessels and I have acute clots. (A)

I tried to stop eating since the doctor told me I had to change my heart valve. (C)

I can't give it up. Most participants who were smokers had tried to stop smoking, but had failed. They believed that smoking is a way to relax, relieve stress, and cope with the negative emotions and feelings caused by heart disease. Others could not give up their favoured foods.

I wish I could stop smoking ... but failed ... I have smoked for 50 years ... I tried to stop several times but failed ... Smoke makes me forget my disease, and how can I stop it. (A)

My children are butchers, and they bring a lot of meat to the house and I love the fat because it gives the food a lot of taste ... I would not like to deprive myself ... One age and one Lord ... I love the meat a lot. (B)

I could never stop smoking even after I tried several times to quit. When I was religiously committed, I tried to quit but failed. I wish I could stop smoking, but I can't help the nicotine addiction in my blood ... Why? Because I have nervousness with less concentration. Even in Ramadan, I cannot fast when I don't smoke. I could only fast for three days, but I can't do it without smoking. (Z)

Although I know smoking is harmful, it makes me relaxed ... I do not know how to stop. I have been smoking for 40 years. I know I have to stop it, and I have tried to stop it several times. I stopped it for 18 days. (D)

8.1.2.4 Physical impact of HF

Tiredness. All participants complained about feeling tired, which was connected to the HF.

Sports and excess movement make me tired ... I feel my heart is tired when I do much physical activity. (B)

I feel weakness and I would get tired if I make a great effort. I do not want to exhaust my heart muscle. (Z)

I cannot exercise ... my legs are very soft and I have a disc problem on my spine. (The patient started laughing) (C)

I like to exercise but I feel tired. (Z)

I used to move much and I am still walking and visit my brothers and neighbours, but I cannot do much exercise because I feel tired. (D)

I get tired and exhausted when I walk for a long distance ... or when I perform large physical activity ... Sometimes I walk a few steps at my house. (A)

I know that exercise is useful for health reasons, but I am afraid to move a lot because I get tired and feel difficulty breathing, especially if I walk down the street which is uphill or has a staircase. (F)

Shortness of breath. One participant complained about the feeling of difficulty breathing with movement.

When my son invites me, I have to climb the stairs and to stop at different times to rest before I get to his apartment because I have difficulty breathing. (B)

Sleep disturbance. Most participants experienced difficulty sleeping due to HF-related symptoms such as a cough or shortness of breath. One patient linked his difficult sleeping with thinking about the path of his life (how his health was before the disease and how it had changed).

I was unable to sleep before the cardiac catheterisation surgery, and I had weakness and a cough and felt chest pain. (A)

I cannot sleep on my back, because I feel difficulty breathing and have a cough. I have to put up to 3 pillows under my head to sleep. (B)

I get good sleep when I have deep sleep, but it takes a long time to sleep deeply, I need about 1 hour to 1.30 hour to go to sleep. *Why do you take so long to fall asleep?* Sometimes I think about the human life path and how it ends up with disease! How I was and how I have become. (F)

Sleeping is fragmented. I wake up in the night to take a breath. (C)

My sleep was very difficult due to the pain and shortness of breath. (Z)

My sleep is good, but sometimes I feel pain on my left side. I prefer my head being raised during sleep to get comfortable. (E)

Loss of manliness. Some participants complained a loss of manliness (sexual function), due to their heart illness, weak body and old age.

Yes, it had a great effect on my sexual activities because my heart muscle became weak, and because I had a blockage in the arteries of the two legs. (Z)

My days of strength and youth have gone, I am weak ... my sexual relationship with my wife has declined. (A)

My sexual activity is zero and I have lost it for a long time. (E)

Loss of social interaction. Participants reported reduced capability to socialise with their family members and friends due to their heart disease. Some patients expressed feelings of loneliness and isolation.

Sometimes I have felt lonely because of the inability to sit with relatives and friends as usual. (B)

My illness affected my activity, especially. I was very social and my disease symptoms prevented me from visiting my friends and spending nights as before. (E)

My relationships with people declined and I do not like visiting ones whose homes have stairs. (Z)

For sure I had more relationships before ... Now I am not able to participate in events and I have not been able to be involved in invitations as before ... I feel alone. (A)

During Eid, I used to visit all my sisters and brothers and friends ... but now, they visit me ... because they do not want to get me tired. (A)

My social relations are not like before, because I have not been able to sit and talk a lot. (E)

8.1.2.5 Impact of religion

Some participants reported that religion gives them feelings of peace and hope, which helps them cope with their disease, increases their patience, and redirects their life.

My patience is due to religion because this is my fate and it is examination by God ... so I have to be patient. No escape from fate; nothing will happen except what has been determined by God. (D)

If I were not Muslim, I may commit suicide. All hopes are in God. (Z)

8.1.3 The second patient focus group: description of participants

Six patients with HF participated in the second focus group, all but one of the seven participants from the first focus group. As can be seen in Table 8.3, the majority of the sample was males

(83.3%). Regarding education level, approximately half of the sample had primary or secondary education but only one had a bachelor's degree (Table 8.3).

Table 8.3: Sample characteristics; mean, standard deviation (SD) and number and percent (%) for the second patient focus group

	Mean (SD)	Range
Age	66.2 (7.7)	61–87
Duration since diagnosis with HF, years	7 (4.0)	4–14
	n (%)	
Gender		
Male	5 (83.3)	
Female	1 (16.7)	
Level of education		
Illiterate	1 (16.7)	
Primary education	1 (16.7)	
Secondary education	2 (33.3)	
Diploma	1 (16.7)	
Bachelor	1 (16.7)	

8.1.4 Findings of the second focus group

Three themes and eleven sub-themes were extracted from the analysis of the second focus group. Patients' perspectives on the proposed HF model were embedded within each theme and subtheme. These themes are described below in detail (Table 8.4).

Table 8.4: Themes and subthemes from the second focus group

Theme	Subtheme
The effectiveness of education in the cardiac clinic	Weight: no advice. Dietary advice: not effective Exercise: variable effect Medication: importance recognised Smoking continued, despite advice No education
Suggestions for improving the education program	Communication: time and respect
Appropriateness of educational material	Value of booklets Some would like videos Good face-to-face sessions are helpful Support provided by phone

8.1.4.1 The effectiveness of education in the cardiac clinic

Weight: no advice. The doctors did not give priority to discussing weight problems, and did not instruct patients to weigh themselves regularly.

During my visits to the hospital, I have never been told to reduce my weight or to weigh myself regularly. During my life, I have been weighed a limited number of times. (A)

The doctor has not advised me about my weight before. He only advised me to do physical activity and cut down salt. These were the only things that doctor said. *Did he instruct you to weigh yourself?* No he did not; I remember that he asked me not to eat heavy meals. *How often do you weigh yourself?* Occasionally when I go to the cardiac clinic, but not every time. (D)

Dietary advice: not effective. The patients in general were not happy with the instructions they received from their doctors about their diet and healthy eating habits. However, some patients despite advice did not follow instructions about diet.

The doctor did not focus on my eating habits, but advised me to eat everything because I have anaemia. His talk was general without details, (A)

I was following the doctor's recommendations for a few days after the clinic visit ... then I go back to my old habits ... I don't watch my diet unless I get worse health issues ... when I feel better I go back to my old eating habits. (E)

You could say that there has been no effect from these sessions, no effect at all.
(C)

Exercise: variable effect. Most patients had been instructed by their doctors about exercising. However, some patients said that they did not receive clear and detailed instructions, while others could not perform these exercises due to their heart disease and other health problems.

Yes, the teaching sessions had positive effects. I began walking more at home and in the garden ... I tried to walk up to 300 metres a day to improve circulation. (A)

Yes my doctors' instructions have had an impact on exercise and I walk regularly. (D)

The teaching sessions have not had any impact on my activity levels ... I am not sure how these sessions will help me since I can't exercise due to my heart problems. (E)

Although the doctor advised me to do exercise, I cannot because I have a disc problem in my back, and I have difficulty breathing and feel tired when I do any strenuous work. (C)

Medication: importance recognised. The doctors gave clear instructions when prescribing medication and the patients followed their advice.

Yes, the doctor focused on the importance of medications, so I am adherent to it. (A)

I am compliant with the medication regimen; however I miss doses occasionally ... the doctor's recommendations were mainly focused on the medicine, that's why I stick to it ... I also feel better when I take it. (E)

I take my medicine as prescribed, and sometimes the doctor increases or decreases the dose of the medicine according to my body's needs and health status. (D)

Smoking continued, despite advice. The doctors' advice to quit smoking was not effective with the smokers, who were either unable or unwilling to quit smoking. Instead, the smokers focused on the benefits of smoking, such as reduced stress, feeling relaxed and enjoyment.

Doctor advised me to stop smoking, but I could not do that. I stopped it for 8 months, and then I started smoking again. I have been smoking for 50 years. How can I stop it at once? (F)

My doctor advised me to quit smoking but I could not do it ... but on some occasions I tried to cut down but it did not work. (Z)

I wish I could stop smoking. Why? My doctor advised me to stop smoking but I don't have strong determination to quit. When I smoke I feel relaxed, stop thinking of this life, and my stress is relieved, although I know that it's harmful. (D)

I stopped smoking after I had a stroke a year ago which was the main reason ... my children have been advising me to stop smoking more than my doctor. (E)

No education. One patient indicated that he had not received any education.

Where is the educational program? (He rolled his eyes and showed surprise.) I only go to the clinic to do a routine ECG test and take my prescription, and then the doctor asks me if I experience any symptoms before I leave. (*What about your weight?*) No he did not talk about it. There is no education program. My relatives, friends, sons and daughters provide me with some information about food and the importance of exercise for my heart. Yes, I have to take my medicine; I go to the hospital every month especially to take my medicine. (F)

8.1.4.2 Suggestions for improving the education program

Most patients indicated their need to be treated respectfully and wanted doctors give them more time and to explain their instructions in more detail.

Communication: time and respect. The patients felt that the short visit with their doctors does not allow for any meaningful education program, and the quality of content and information delivered suffers. Therefore, they suggested longer visits, and more empathy and respect from doctors.

Most of the doctors do not effectively explain treatment to the patients. My doctor only checks blood results, heart charts, prescribes the monthly treatment ... and if he wants to advise or educate, it will be quick, give the prescription and call for the next patient. The nurse only measures my heart pressure. They

lack an education program. My suggestion is to give more care for their patient, respect us and give us extra time. (A)

I suggest giving enough time to patients for questions. Frankly, I drink herbal teas to feel better and not to go to the hospital. (C)

I suggest that they treat me more like a human being, respected and valued. Also the doctor should sit with me and teach me what to do and give me the opportunity to ask questions. (F)

I suggest that they have more clear instructions and the doctors should choose the right time to educate the patient. There are times that the patient cannot receive education and may need more time to understand instructions. (Z)

I advise that doctors become better communicators, and be more sensitive to patients' emotions ... one time in the past I had cardiac surgery and the doctor told me that all my heart vessels were obstructed without showing any empathy in a disrespectful way. I suggest that the health ministry should educate the doctors on proper communication. Also, when I feel disrespected and ignored by my doctor, I am stressed and my health suffers. (E)

8.1.4.3 Appropriateness of educational material

Value of booklets. Some patients would like the information to be given in a booklet. None of them have been given any booklets on heart disease. One patient was given a booklet about his diabetes, and he found it very helpful. Another patient liked the idea of a booklet but unfortunately he can't read due to his poor vision.

Although I did not see any of these strategies, I prefer booklets because I used to read books. (A)

Booklets are beneficial to remind me to adhere to the treatment regimen ... one day in the past I went to the diabetes clinic, my doctor gave me a booklet about diabetes ... it was very helpful for me. (C)

I have known the value of booklets when I was in [another country]. I prefer it more than lectures ... because the lectures can take long and be boring ... I like to read it in my own time. (Z)

I like the booklet but I cannot read it, because I have poor vision due to the DM ... and have poor concentration as well. (E)

Some would like videos. Some participants were happy to watch educational videos, while others indicated they were afraid of watching such programs related to their disease.

A video is a good way to provide information, if it is well prepared, using simple language and of short duration. (A)

I don't like to see TV shows or programs about any disease ... because it increases my fears and thinking about my condition ... when I see any program related to this I usually ask my grandchildren or sons to change the channel. (C)

Why not ... video is good strategy as well ... I know how to use the computer ... And sometimes watch some documentary about my disease. (Z)

Good face-to-face sessions are helpful. Most participants liked the strategy of face-to-face education, and expressed that this strategy is useful, particularly if the educator is respectful and has effective communication skills.

Face-to-face education is a good approach if the educator is a good person, respectful, gentle, and has good knowledge. (A)

Lectures are important as well ... A few years ago, I was admitted into a hospital, and a dietitian met with me for 20 minutes and taught me about the foods that I have to eat and avoid ... she helped me a lot. (C)

I prefer that the doctor explains or teaches me face to face to feel more relaxed and comfortable. (D)

I only prefer face-to-face discussion. (F)

Support provided by phone. Most participants liked the idea of a phone call strategy, and reported that this would be beneficial for educational and emotional support.

I have never received a follow-up call asking about me, but in case it happens, it will be a good idea. (A)

It is going to be like a dream if I have someone calling me to offer help or assistance ... I don't think that this will happen ... I even feel happy when they call me to postpone my appointment with the doctor. (C)

I like to be followed up by the doctor via phone ... if I have had any complaints or concerns, then the doctor can help or guide me to do the right thing. Also, this would save my time and money. (Z)

Yes it would be great that someone calls me to ask about my disease and if I need any help regarding my heart disease. (E)

It happened once before. One of the private clinics operated by the United Nations gave me my medicine, but [after] I went home they called me via my phone and asked me not to take the medicine, and to come back to the clinic to take another medicine. I felt very satisfied and surprised that there are people in my life who care about me. (D)

8.2 The Delphi study

SurveyMonkey software was used to collect and describe the data, using percentages and weighted ratios. Content analysis was used to verify and analyse the notes written by the experts in the first round, and the transcribed record from the group discussion in the second round. The experts' notes and quotations were extracted from the first round (written comments) and from the second round (transcribed group discussion) to improve the depth and clarity of the explanation of the results and to gain full insight into the proposed HF model.

8.2.1 The first round

In first round Delphi discussions, seven experts individually offered their written notes and perspectives on the 20 component original proposed program that was derived from the literature (Table 8.5). These components included the sequential steps managing inpatient and outpatient care for people with HF, starting from diagnosing patients and extending to post follow-up care. There were various HF interventions proposed in this program. These included: one-hour educational session delivered by a cardiac nurse, educational material (booklet, lifestyle brochure, video), follow-up phone calls, monthly home visits for patients with severe HF, utilising the healthcare centres to conduct health awareness campaigns and to provide follow-up care for patients who cannot access heart clinics, and the use of a multidisciplinary team and tele-monitoring devices (Table 8.5). Of the 20 components, the experts made their written perspectives and suggestions on 13 components (LR-1 to LR-13), while seven literature components were excluded from the model (LR-14 to LR-20) (Table 8.5).

Table 8.5: The proposed tailored heart failure management model derived from the literature review and the consensus position following discussion in round one of the Delphi study.

ID	Explanation of the component	Consensus
LR-1	After diagnosing patients with HF, they should be referred to a cardiologist.	I
LR-2	During the first visit to the cardiologist that will be scheduled every month, patients should be taught by the cardiologist about HF, and the importance of adhering to the healthy lifestyle recommendations.	I
LR-3	Thereafter, patients should be referred to a cardiac nurse or experienced registered nurse for a one-hour education session, which will be held after each cardiologist visit in a special meeting room next to the cardiac clinic. The emphasis will be on the influence of lifestyle on cardiac disease, and how to control the potential risk factors associated with HF.	I
LR-4	During the first education session each patient should be given a booklet and lifestyle brochure containing information on how to change their lifestyle and explaining the best strategies to improve their lifestyle in terms of daily weight monitoring, exercise, lowering cholesterol, following a low-fat and low-salt diet, and quitting smoking.	I
LR-5	In each one-hour education session, the nurse educator should carefully review the lifestyle brochure with the patient. Patients' relatives should also be involved in the education.	I
LR-6	A video presenting information on health and lifestyle recommendations and strategies could be played to patients to standardise the educational content and communicate the complex ideas.	I
LR-7	The patient should be scheduled monthly follow-up appointments with the cardiologist, unless the patient experiences HF exacerbation or deterioration.	I
LR-8	Patients who are in a stable condition (class I, II or III) are recommended to be scheduled for a 2-year follow-up phone call program to support and reinforce their education, and assess their adherence to healthy lifestyle recommendations.	I
LR-9	If the nurse who performs follow-up phone calls has any major concerns about the patient's condition, or it is necessary to start a new treatment or modify the existing one, the nurse should schedule an additional clinic visit with the cardiologist. (Family medicine or internal medicine physicians will be an alternative if the cardiologist is not available.)	I
LR-10	The frequency of phone calls is weekly for the 1 st four weeks, then biweekly for eight weeks, then monthly for the remaining period.	I
LR-11	If a patient has poor literacy, the nurse should give the patient an educational booklet designed for low literacy patients (written below 6 th grade level and extensively studied in focus groups and pilot studies). It was developed by DeWalt et al. (2004) and investigated in a randomised controlled trial by DeWalt et al. (2006).	I
LR-12	For patients with poor literacy, the cardiologist and the nurse are recommended to use simple language, and pedagogic strategies to improve patients' comprehension (DeWalt et al. 2006; DeWalt et al. 2004). Examples of pedagogic strategies are:	I

ID	Explanation of the component	Consensus
	<ul style="list-style-type: none"> - The nurse or physician can help the patient to use a teach-back strategy. - The nurse can engage the patient in filling out a notebook, and use brainstorming to help patients incorporate healthy lifestyle changes in their lives. Then the nurse will fill in a management plan in the patient's notebook that emphasizes the patient's lifestyle changes. 	
LR-13	<p>For patients with severe HF (class IV) who are unable to see their cardiologist every month, they are recommended to be scheduled for monthly home visits for the entire 2 years. (Home visit intervention was proposed for class IV because those patients have physical mobility limitations and have symptoms at rest, which negatively affects their ability to go to the hospital (American Heart Association 2020).</p> <ul style="list-style-type: none"> - The monthly home visit will be performed by an experienced registered nurse (cardiac nurse). <p>At each visit:</p> <ol style="list-style-type: none"> 1- The patient should be assessed for their adherence to the treatment regimen and healthy lifestyle recommendations. 2- The medical history from discharge time or from visit to visit will also be assessed. 3- Based on the assessment, the patient should be educated to fill the learning gaps. 4- If there is a major concern regarding the patient's condition, the nurse or health volunteer should refer the patient to the nearest healthcare centre to follow up with a cardiologist or family medicine specialist. 5- Vital signs should be checked. 	I
LR-14	<p>For admitted patients:</p> <ul style="list-style-type: none"> - A one-hour education session will be performed by an experienced nurse before discharge. - The nurse educator should consider the patient's needs, HF severity and level of literacy to schedule an appropriate follow-up strategy for the patient, and to give them educational material designed for their characteristics. - A lifestyle brochure and discharge plan, containing information on HF management, healthy lifestyle recommendations, and follow-up appointments with the cardiologists, should be given to the patient. <p>The patient should be given a HF brochure and booklet before discharge. Then the patient will follow the program that has been tailored to his/her needs, requirements and other individual characteristics.</p>	E
LR-15	<p>The extensive primary healthcare network, consisting of 260 village health clinics, 340 primary healthcare centres, 353 maternity and child centres, and 53 comprehensive health centres can be utilised to conduct follow-up clinics for patients who have access problems.</p>	E
LR-16	<p>The healthcare centres geographically distributed in urban and rural areas can be utilised to conduct health awareness campaigns that aim to increase awareness and knowledge about the risk factors of HF or heart disease, and emphasise the necessity of changing the current lifestyle in Jordan through giving people lifestyle brochures, and holding education sessions, led by experienced healthcare providers, either GPs or registered nurses.</p>	E

ID	Explanation of the component	Consensus
LR-17	Family medicine and internal medicine clinics, held in primary and secondary health centres, will be used to implement a ‘support group’ strategy that allows patients to meet altogether and share their feelings, care plans and experiences about their condition.	E
LR-18	These clinics that have experienced healthcare providers such as GPs, family medicine and internal medicine specialists can be utilised to follow-up severely ill patients who can’t access heart clinics.	E
LR-19	The use of a multidisciplinary team is recommended if possible.	E
LR-20	The use of tele-monitoring devices is recommended if possible.	E

I – included in some format in the final proposed model of care

E – Excluded from the final proposed model of care

LR – Literature review

After suggestions from these experts, the proposed program was modified and these modifications were summarised as 13 components for discussion and rating in the second round (Table 8.6). Of the 13 components discussed in the second round, the first five components (FD-1 to FD-5) had a high level of consensus, scoring between four and five, and all five of these were accepted and unchanged by the experts and consequently retained in the final model. The remaining eight of the 13 components were subjected to written review and discussion as a group.

Eight comments written by the experts in the first Delphi round were briefly explained and justified (Table 8.6). The dietician indicated that the most popular meals in Jordan are too fatty and oily, and therefore people need to be given nutrition cards that include names of healthy foods and unhealthy foods that should be avoided (FD-1). The head of continuous education advised that follow-up phone calls program can be helpful and supportive for patients. In addition, if the nurse who is performing a follow-up phone call finds any major concerns, he/she should schedule an additional clinic visit for the patient with a cardiologist (FD-2). The registered nurse suggested that there should be a clear division of tasks between cardiologists and nurses (FD-3). The cardiologist should focus on medical concepts such as causes, medication, signs and symptoms, and disease process, whereas the nurse should focus on the influence of changing lifestyle and recommended health patterns. This would decrease the workload of hospital staff. The physiotherapist indicated that these educational materials can be useful. However, they may be insufficient to achieve heart rehabilitation, and therefore they recommended that each patient needs to be referred to a cardiac rehabilitation centre monthly for at least six months or up to one full year (FD-5) (Table 8.6). With respect to the use of tele-monitoring devices, a

cardiologist indicated that these devices are not financially feasible in Jordan, due to the cost to health insurance companies. From the perspective of the cardiac nurse, tele-monitoring devices are very expensive and would cost the government millions of dinars, but the cost of these cardiac devices could be justified for patients with post-cardiac events or at risk of complications (FD-10). The cardiac nurse also indicated his uncertainty whether the MOH would agree to the budget for these devices. The head of continuous education advised that it would be better for the patients to receive CDs so that they could avoid viewing the video in a stressful environment such as a hospital and could watch them at their convenience (FD-11). In addition, the nurse academic who specialised in critical nursing care pointed out that the frequency of watching videos or reading brochure should be clearly mentioned, because the literature showed that hearing and seeing educational material leads to knowledge retention of 20–30% each time (FD-8) (Table 8.6).

Due to the reach of the education program, the head of the continuous education department advised that awareness campaigns, such as through social media, state media, newspapers, or conferences, would not be required. The most feasible option for all HF patients irrespective of education, disease severity or age would be the distribution of simple and colourful education materials at hospitals or clinics (FD-4). Regarding the home visits program, a cardiologist stated that the applicability and effectiveness of conducting this intervention for patients with class IV should be studied and discussed (FD-13). The responses raised in round one were discussed by the experts within the same group session in round two (Table 8.6).

Table 8.6: Thirteen components of a HF model of care derived from the first Delphi (FD) round discussions including: rating on a 5-point scale from 1 (completely unfeasible, CU) to 5 (completely feasible, CF), number and (percent), average and consensus following discussion.

ID	HF component	CU (1)	(2)	(3)	(4)	CF (5)	Ave	Consensus
FD-1	Every patient should be given a card that includes the healthy food recommended for patients with heart disease, and the unhealthy food that should be avoided. The hospital will be responsible for printing out these cards. The cards will be reviewed at each education session.	0	0	0	0	7(100.0)	5.00	AU
FD-2	Follow-up phone call program can be helpful and supportive. If the nurse who is performing a follow-up phone call finds any major concerns, he/she should schedule an additional clinic visit for the patient with a cardiologist.	0	0	0	0	7 (100.0)	5.00	AU
FD-3	The emphasis of the cardiologist in patients' education should be on medical concepts such as aetiology, disease process and medication, while the nurses should focus on lifestyle recommendations and recommended self-care behaviours.	0	0	0	1 (14.3)	6 (85.7)	4.86	AU
FD-4	Patients should be provided with a lifestyle brochure after the first cardiac clinic visit, where the hospital will take responsibility for printing out the brochure. The brochure was designed and accredited by the American Heart Association. Any amendments or modifications to the content should be piloted for content validity by three cardiologists. Patients will be asked about their preferred educational material. If they don't like the brochure, other options will be provided.	0	0	0	2 (28.6)	5 (71.4)	4.71	AU
FD-5	Patients should be referred to a cardiac rehabilitation centre inside the hospital to improve their awareness of the importance of changing their lifestyle and to support their understanding, at least once per month for six months up to one full year, and as needed. This strategy will be conducted by a competent healthcare providers.	0	0	0	3(42.7)	4 (57.1)	4.57	AU

ID	HF component	CU (1)	(2)	(3)	(4)	CF (5)	Ave	Consensus
FD-6	Support groups are recommended to be held in the primary and comprehensive centres. They should be led by an experienced nurse. The secondary hospital where the patients visit the cardiologist should refer the patient to the health centre nearest to the patient's residence.	0	0	0	3(42.9)	4(57.1)	4.57	E
FD-7	A one-hour education session for each patient (one-to-one) should be carried out by a competent cardiac nurse, where the focus should be on the influence of lifestyle on cardiac disease and how to change lifestyle. This session should be held after each cardiologist visit in a special meeting room.	5 (71.4)	1 (14.3)	1 (14.3)	0	0	1.43	E
FD-8	Patients will be instructed to watch a video at least ten times over a six-month period.	0	0	1(14.3)	2(28.6)	4(57.1)	4.43	AM
FD-9	Patients with class I, II or III are recommended to be scheduled for a two-year follow-up phone call program to support and reinforce their education, and to ensure the successful outcomes of the program in terms of diet, smoking, physical activity, etc. This intervention should be performed by a competent registered nurse.	0	0	0	5(71.4)	2(28.6)	4.29	AM
FD-10	Tele-monitoring devices could be provided to patients whose conditions are unstable, and those who can't afford the cost of the device.	0	1(14.3)	1(14.3)	3(42.9)	2(28.6)	3.86	E
FD-11	CDs should be distributed to patients, presenting information on healthy lifestyle recommendations and strategies, if they prefer this type of education.	0	2 (28.6)	3 (42.9)	1(14.3)	1(14.3)	3.14	AM
FD-12	Multidisciplinary care should be utilised in providing care for patients. Pharmacists, cardiologists, nurses and physiotherapists will be involved in coordinating care.	0	4(57.1) 4	3(42.7)	0	0	2.43	E
FD-13	Patients with severe HF (class IV) should be scheduled for monthly home	5 (71.4)	1 (14.3)	1(14.3)	0	0	1.43	E

ID	HF component	CU (1)	(2)	(3)	(4)	CF (5)	Ave	Consensus
	visits, performed by a competent cardiac nurse, for the entire two years.							

AU – Accepted and unchanged components in the first Delphi round

AM – Accepted and modified components in the first Delphi round

E – Excluded components in the first Delphi round

8.2.2 The second round

A group discussion was conducted to further explain and discuss the experts' individual responses raised in the first Delphi round (Table 8.21) plus their ideas and new suggestions. All 13 components (Table 8.6) were discussed and explained in an orderly manner. Regarding the use of printed education materials (FD-1, FD-2) (Table 8.6), a cardiologist stated that photocopying and printing in Jordan is cost effective because there are many printers and photocopiers available, so this strategy can be applicable in Jordan. In addition, the ink of these devices is available and cheap, and photocopiers are financially supported by the Jordanian government. From the perspective of the second cardiologist, reading and following the instructions in brochures and on cards could help to reduce HF complications and hospital readmissions, and ultimately save millions of dinars spent on healthcare.

The cardiac nurse suggested that it would be helpful if patients find someone such as a friend, nurse or family member, who can explain the contents of these materials and follow up with them. The head of the education department pointed out the importance of writing these materials in a simple way, which assists with achieving positive outcomes. With respect to the strategy of distributing educational content (FD-3), the cardiac nurse stated that there will be programs and lectures regularly directed to the patients, and hence sharing the topics between cardiologists and nurses will be more helpful and appropriate, which eventually helps reduce the cardiologists' workload. However, the dietician indicated that some patients trust their doctor more than the nurse, so the nurse educator should be competent and learn how to deliver education effectively. Accordingly, most experts advised that the nurse should have adequate knowledge and teaching skills to apply this strategy. Therefore, a two-day workshop or training program was suggested for health educators, in order to ensure consistency of content. The experts discussed that the sessions could be conducted in the hospital or online, and there could be an exam to ensure the competency of the healthcare provider who is going to be involved in the HF education program. Regarding its feasibility, one of the experts indicated that conducting a training program would not be too costly. The rehabilitation program (FD-5) was

extensively discussed by the experts. The physiotherapist advised that the cardiac rehabilitation program will be beneficial, and helps patients understand the importance of changing their lifestyle. It was indicated that rehabilitation centres already exist in most secondary hospitals in Jordan but their resources are focused on orthopaedic patients and post-operative patients. In addition, these centres could refocus on HF patients to improve patient outcomes with existing infrastructure. A cardiologist endorsed the rehabilitation program as it would help to improve patients' capability to perform different types of tolerable exercises, even for patients who think they are not able to engage in any physical activity due to their heart problem.

Most experts supported the use of a support group strategy (FD-6), in order to reduce the financial and physical burden on patients and health educators. There was a difference of opinion between the experts on the topic of individual education sessions (FD-7). Most experts did not support this strategy. Individual education sessions were considered not feasible due to the costs and the insufficient number of experienced health educators. Thus, a cardiologist suggested conducting group discussions which should provide emotional and social support for patients. Group sessions were considered a viable alternative to the individual education sessions. However the dietician raised the issue that some patients may not wish to discuss their disease in front of other patients; therefore it was considered feasible to use 30-minute individual education sessions for this patient cohort. The second nursing academic advised that the proposed group session component would perform the same function as the support group component; therefore the support group strategy was dropped from the proposal.

In relation to the frequency of watching the video (FD-8), it was advised that the frequency of replaying the video should be varied, because there will be individual variation between patients such as cognitive and education levels and these factors affect patients' capability to understand and absorb the information received. The phone call strategy (FD-9) was considered feasible for the Jordan HF program as it does not require the purchase of new health devices or employing new qualified staff. A cardiologist emphasised the effectiveness of this strategy, stating that providing patients with information about their HF condition and the influence of changing their lifestyle can help reduce complication rates, readmission rates and healthcare expenses. In addition, it was suggested that the nurse assigned to make phone calls should have the necessary interpersonal and communication skills. It was also recommended that this intervention should be optional, and the frequency of follow-up calls should be arranged according to the cardiologist's recommendation and the patient's desire. The feasibility of tele-monitoring devices (FD-10) was discussed. It was indicated that these devices are expensive and not widely available in Jordan, and that the Jordanian government does not have the

financial capability to afford these devices. Regarding the use of CDs (FD-11), the dietician and the head of the education department proposed that since most people in Jordan have internet access, smart phones and computers, the use of CDs would be an unnecessary cost. The cardiac nurse suggested giving the patients links to reliable internet educational resources. However, both cardiologists advised that this strategy should be optional according to patients' learning needs and preferences. Regarding illiterate patients or those not familiar with computers or smart phones, the experts concluded that these patients can utilise a different educational strategy if they do not have people such as family members, relatives or friends to play the video. Concerning the use of multidisciplinary care (FD-12), the cardiac nurse advised that starting with a complex management program before having an initial structured and clear HF program is not reasonable. Most experts indicated that this strategy needs further investigation in terms of how it will be implemented, who would be involved, how much it will cost, how many health educators should be employed, and whether all specialities required are available. The head of the education department advised that employing new trained staff for the purpose of this strategy will not be feasible due to the high cost to the MOH. Therefore, one of the experts indicated that competent nurses and physicians are sufficient to provide patients with the most important HF-related information. Lastly, most experts indicated that implementing home nursing visits (FD-13)(Table 8.6) is financially and physically not feasible, because it will require employment of new qualified and experienced staff, which would increase the financial burden on the healthcare system and healthcare providers. It was also suggested that patients in class IV may require additional advanced and sophisticated healthcare procedures, and hence home visits may not be sufficient for these patients. Consequently, one of the experts suggested establishing a phone hotline for all patients who are extremely unstable to answer disease-related queries, because it can be more beneficial and feasible. This strategy was supported by the other experts, who indicated that it is more financially feasible, more appropriate and suitable, and it just needs one experienced cardiac nurse to answer the patients' calls.

8.2.3 Consensus components to a patient-centred HF management program

The discussion in the second round led to six components being recommended (Table 8.7). Three new components were suggested and approved (SD-1, SD-3 and SD-6) (Table 8.7), and three components from the first round were adjusted and approved (SD-2, SD-4 and SD-5) (Table 8.7). Five of these six components scored between four and five, but component SD-6 was the least feasible component, scoring between three and five.

Table 8. 7: Six components of a HF model of care derived from the second Delphi round discussions including rating on a 5-point scale from 1 (completely unfeasible) to 5 (completely feasible), number and (percent), average and consensus following discussion.

ID	HF component	(1)	(2)	(3)	(4)	(5)	Weighted ratio
SD-1	Training program or workshop will be conducted in the hospital to prepare healthcare providers involved in health education, and improve their teaching skills and HF knowledge.	0	0	0	1(14.3)	6 (85.7)	4.9
SD-2	The nurse should give the patients or their relatives or friends, links to online educational resources to watch, if they prefer this type of education. The videos will present information on healthy lifestyle recommendations and strategies. [Derived from FD-11]	0	0	0	0	7 (100.0)	5.0
SD-3	The recommended frequency of watching the video will vary, in order to consider individual variations between patients. [Derived from FD-11]	0	0	0	3 (42.9)	4 (57.1)	4.6
SD-4	One-hour group education sessions, involving patients who come to the cardiac clinic, should be carried out by a competent cardiac nurse, where the focus will be on the influence of lifestyle on cardiac disease and how to change one's lifestyle. This session should be held after each cardiologist visit in a special meeting room, and will also be utilised as a support group strategy which helps provide emotional and social support for patients.	0	0	0	1(14.3)	6 (85.7)	4.9
SD-5	Patients with class I, II or III will be scheduled for a 2-year follow-up phone call program to discuss diet, smoking, physical exercise, etc. The calls will be made by a competent registered nurse, and at the patient's convenience. The frequency of follow-ups should be arranged according to the patient's desire.	0	0	0	1 (14.3)	6 (85.7)	4.9
SD-6	A phone hotline will be established for patients who are in class IV and those who experience worsening in their condition, in order to answer their enquires and facilitate patients' transportation to hospital. The health education department will also be involved to coordinate the patient's delivery to hospital if needed. A competent nurse	0	0	1(14.3)	4 (28.6)	2 (28.6)	4.1

	should be assigned to conduct this strategy. [Derived from FD-2]							
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8.3 Summary

This chapter has presented the results of the both patient focus groups and the Delphi study. Regarding the patient focus groups, six themes emerged from the first focus group, including emotional impact of HF, Motivation to change lifestyle, Adjustment to treatment, Physical impact of HF, Loss of social interaction, and Impact of religion. Three themes emerged from the second focus group including, the effectiveness of education in the cardiac clinic, suggestions for improving the education program, and appropriateness of educational material. The Delphi results found consensus for the feasibility of different HF components. These were: educational materials (brochure, diet card, and video), follow up phone call program, cardiac rehabilitation program, group educational session, and training courses for staff. The components that were not feasible were: multidisciplinary team, educational session, awareness campaigns, and tele monitoring devices. Identifying patients' needs, emotions, suggestions, perspectives, and the most feasible HF interventions increase the depth of understanding the best HF management that can be appropriate and applicable in Jordan. These findings were discussed and compared with other studies in the next chapter.

Chapter 9: Discussion of the qualitative study

This chapter discusses the findings that emerged from the analysis of the both patient focus groups and Delphi study. The findings are discussed, interpreted and compared with other studies to assist with developing a patient-centred HF program that is tailored for the Jordanian context.

9.1 Patient focus groups

Two main questions were used to guide this chapter, each of which was addressed in a patient focus group. The first question was ‘What are the patients’ experience with their HF disease and suggestions for improving self-care/self-management?’ The second question was ‘What are the patients’ perspectives on the proposed heart failure model’.

9.1.1 Patients’ experiences and suggested self-care improvements

9.1.1.1 Emotional impact of heart failure

Most participants expressed emotional responses to their symptoms and negative health consequences. These feelings included: worry due to reduced physical capacity, depression and hating life, powerlessness and loss of abilities, and feelings of bitterness about how their lives had changed. The study finding is congruent with others that reported negative emotional reactions among patients with HF (Evangelista, Kagawa-Singer & Dracup 2001; Holzapfel et al. 2009; Hopp, Thornton & Martin 2010; Måtensson, Karlsson & Fridlund 1997; Pattenden, Roberts & Lewin 2007; Rhodes & Bowles 2002). Various factors can impact on the emotional reaction of patients with HF including low economic status, aging and lack of social support (Pattenden, Roberts & Lewin 2007). Older people are more emotionally impacted by HF and less able to cope than younger patients, because they are more likely to have co-morbidities and are at higher risk of rehospitalisation (Naylor et al. 2004). In addition, these feelings could be attributed to the HF-related symptoms and physical limitations, which compromise patients’ ability to engage in self-care behaviour (Ryan & Farrelly 2009). Previous studies showed another two significant contributing factors to negative emotions, including the fear of death (Allen, Arslanian-Engoren & Lynch-Sauer 2009; Falk, Wahn & Lidell 2007) and the negative trajectory of HF (Naylor et al. 2004; Nordgren, Asp & Fagerberg 2007; Welstand, Carson & Rutherford 2009). However, some patients do not experience any emotional impact, which enables them to be more independent in carrying out the recommended self-care behaviours and daily activities (Aldred, Gott & Gariballa 2005; Rhodes & Bowles 2002; Thornhill et al.

2008). This positive attitude assists patients to achieve well-being and satisfaction and enables them to engage in positive coping strategies (Evangelista, Kagawa-Singer & Dracup 2001).

Various strategies have been shown to be effective in managing emotional and depressive symptoms: providing psychological support, referring patients to CR centres, establishing a trust relationship between the healthcare provider and patient, and providing necessary education for patients and their families to empower them to cope and to make changes in their lifestyle (Dekker 2014; Olano-Lizarraga et al. 2016). Furthermore, these strategies help patients to better understand their illness, enhance their adherence to self-care, and ultimately improve their QOL (Dekker 2014; Olano-Lizarraga et al. 2016). In support of the existing literature, the current Delphi study also showed the feasibility and applicability of some supportive HF components that may be utilised to manage patients' emotional reactions, such as referring patients to a CR program, group education sessions, and follow-up phone calls.

9.1.1.2 Social isolation

Participants reported reduced capability to socialise with their family members and friends due to their heart disease and expressed feelings of loneliness and isolation. This finding is supported by the studies of Evangelista, Kagawa-Singer and Dracup (2001); Hägglund, Boman and Lundman (2008); Jeon et al. (2010); (Manemann et al. 2018); Olano-Lizarraga et al. (2016); Thornhill et al. (2008), who reported social isolation among patients living with HF. The loss of social interaction can be linked to numerous factors including changes in lifestyle, medication, emotional distress, and physical restrictions such as fatigue and breathing difficulties (Bentley et al. 2005). Another study conducted by Brännström et al. (2006) found that patients with HF had limited capacity to be involved in social occasions and socialise with relatives and friends due to their disease. Bennett et al. (2000) and Zambroski (2003) showed that social isolation can be attributed to the adverse effects of HF medications. For example, diuretics cause frequent and urgent urination, which in turn prevents participation in social events and/or socialising with friends. The negative impact of HF on patients' social life highlights the importance of implementing patient-centred care, which assists with empowering patients through addressing their needs, preferences and feelings, and ensuring more successful and appropriate management (Findlay 2003; Landeiro et al. 2017). In addition, support groups and a regular phone call program have been found to be effective strategies in developing social behaviours and improving social interaction (Dickens et al. 2011; Landeiro et al. 2017; Mendieta & Martin 2003; Stewart et al. 2001). Previous health promotion studies that were designed to reduce social isolation have indicated that group interventions are more

effective than individual interventions for elderly patients to increase opportunities for social interaction (Dickens et al. 2011; Franck, Molyneux & Parkinson 2016; Landeiro et al. 2017).

9.1.1.3 Physical consequences

In this study, participants reported feelings of tiredness, breathing difficulties, difficulty sleeping, and, for men, reduced masculinity. The study findings are in line with numerous studies, for example those conducted by Aldred, Gott and Gariballa (2005); Costello and Boblin (2004); Hopp, Thornton and Martin (2010); Nordgren, Asp and Fagerberg (2007); Olano-Lizarraga et al. (2016); Welstand, Carson and Rutherford (2009), which showed that patients with HF experienced multiple physical symptoms. Furthermore, previous studies reported that patients with HF may experience memory loss, difficulties in concentration, and intellectual dysfunction (Bosworth et al. 2004; Pattenden, Roberts & Lewin 2007; Rodriguez et al. 2008). These symptoms are distressing and develop in unpredictable ways, causing progressive gradual deterioration of body health and vitality (Boyd et al. 2004). In addition, physical symptoms can cause life limitations, reduce patients' autonomy, and decrease patients' independence in performing self-care activities (Olano-Lizarraga et al. 2016). These symptoms negatively affect several aspects of life including social, physical, vocational and emotional. However, despite the disabilities and limitations caused by HF, some patients are more active and satisfied than others, and these variations between patients may be associated with several factors such as level of treatment adherence, level of knowledge, and how patients perceive their illness (Falk, Wahn & Lidell 2007; Nordgren, Asp & Fagerberg 2007; Tyni-Lenné 2004). Positive perceptions enable patients to find a meaning in their disease experience, cope with the disease, and better engage in self-care activities (Falk, Wahn & Lidell 2007; Nordgren, Asp & Fagerberg 2007; Tyni-Lenné 2004). This confirms the need for a tailored flexible management program that conforms to patients' needs and perceptions, and ultimately ensures optimal treatment (Falk, Wahn & Lidell 2007; Nordgren, Asp & Fagerberg 2007; Tyni-Lenné 2004).

9.1.2 Patients' perspectives on the proposed heart failure model

9.1.2.1 Effectiveness of current education

The second focus group revealed that HF education in Jordan is not adequate or comprehensive. Some self-care activities are not addressed at all, while others are not prioritised. This can be attributed to the fact that Jordan is a developing country, and the healthcare system still faces challenges in delivering adequate care for patients with chronic diseases such as HF. In

addition, there is no well-structured management program or specialised health services to deliver supportive and comprehensive healthcare interventions such as follow-up care and printed educational material (Tawalbeh et al. 2017). The participants reported their perspectives about the effectiveness of current education on regular weighing, dietary advice and smoking. They stated that their doctors did not make it a priority to discuss how body weight relates to fluid retention and to instruct patients to weigh themselves regularly. This finding is in contrast to a study of 954 patients with HF in Dutch hospitals, which reported that 48% of the patients recognised that daily weight monitoring can decrease hospital readmissions (van der Wal et al. 2007); however, only 33% of the patients measured their weight regularly due to the lack of guidance and supervision (van der Wal et al. 2007). Another study of 90 patients with HF in two hospitals in China reported that 47% of those patients have never or rarely been weighed (Tian & He 2005). This finding was attributed to the lack of an effective education program and lack of post-discharge follow-up care. Therefore, patients and caregivers should be instructed about the importance of measuring weight regularly, how to compare readings, normal and exceptional limits of increasing weight, and actions that should be taken when weight gains indicate volume overload (Association 2011; Krum et al. 2006; Rabelo et al. 2007; White, Kirschner & Hamilton 2014). The standard instructions for checking weight daily are, firstly, patients should measure their weight each morning before eating. Secondly, the amount of clothing worn each time should be approximately the same. Thirdly, the weight readings should be documented (recorded) on a chart. Lastly, patients should contact their doctor or seek medical attention if their weight increases by 3 lbs (1.4kg) in 3 days, which probably indicates fluid retention (White, Kirschner & Hamilton 2014).

Some focus group participants had received dietary advice but did not follow it. Various Jordanian studies reported a low knowledge level among Jordanian patients with HF (Hayeah et al. 2017; Tawalbeh & Ahmad 2014; Tawalbeh et al. 2017). Healthcare providers can provide patients with information about the association of obesity with insulin resistance, HTN and heart dysfunction. Furthermore, the content of education sessions should involve information about eating a well-balanced diet, which is low in saturated fat (cholesterol), low in sugar and salt, and high in fruit and vegetables (Krum et al. 2006; Rabelo et al. 2007; White, Kirschner & Hamilton 2014).

Doctors' advice to quit smoking was not effective with the participants who smoked, who were either unable or unwilling to quit smoking. It has been reported that smoking prevalence in patients with an acute cardiac condition is 36% in comparison with 18% in the general adult population (Agaku et al. 2014; Leifheit-Limson et al. 2013). A study of 300 outpatients with

coronary heart disease, performed in Irbid governorate in the north of Jordan, showed that 48.3% of patients were current smokers before being affected with the disease. Interestingly, after the occurrence of disease, 60.7% persisted with smoking, 29.7% stopped smoking, and 9.6% relapsed. The main reasons for not quitting smoking were nicotine dependence and cigarette craving (Gaalema et al. 2015). Smoking cessation has been associated with various factors including socioeconomic status (McAlister et al. 2001), risk behaviours (Abu-Baker, Haddad & Mayyas 2010), years of smoking (Luepker et al. 1993), number of cigarettes smoked per day, and psychological factors (Abu-Baker, Haddad & Mayyas 2010). However, CR has been found to be an effective strategy to help patients quit smoking through patient counselling, improving education, behaviour modification, and change of lifestyle and diet (Ades 2001; Balady et al. 2007; Gaalema et al. 2015; Hamm et al. 2011).

9.1.2.2 Appropriateness of educational material

In the current study, participants' perspectives and preferences varied on the appropriateness of educational material, including a brochure, video, and follow-up phone calls. This is supported by a study showing that the majority of patients with HF lack a clear understanding or comprehension of recommended self-care behaviours in spite of receiving education (Strömberg 2005). Therefore, patients' needs and capabilities should be carefully assessed to establish the foundation for a tailored education program (Holst et al. 2007; Zamanzadeh et al. 2013). Some patients need further support to learn and maintain self-care behaviours and cope with HF. This can be achieved through tailoring the educational material to patients based on their needs (Zamanzadeh et al. 2013).

Booklet/nutrition card. A booklet is a type of educational material which may be used to support patients' education. The study found that some patients would like information to be given in booklet form and that none had been given such information on heart disease. A range of information associated with HF can be provided in a booklet such as surgical and non-surgical interventions, lifestyle modifications, risk factors, signs and symptoms, types of HF, and the ejection fraction. In addition, the treatment regimen and all medications can be explained in terms of dose, frequency and time. Booklets are usually supported by pictures and graphs, which help to improve patients' desire and motivation to read and understand the information (American Heart Association 2018; American Heart Association/American Stroke Association 2018). Previous studies have shown that using written materials along with verbal information in patient education helps in improving knowledge and patient satisfaction in comparison with verbal information alone (Boyde & Peters 2014; Koelling et al. 2005).

Furthermore, adding pictures to the written and verbal information is very helpful, and assists with improving levels of health literacy, treatment adherence and self-care (Boyde & Peters 2014). Well-written materials assist with improving patients' adherence to instructions following discharge, reducing hospital readmissions, decreasing time of recovery, improving confidence of patients, and decreasing anxiety (McKenna & Tooth 2006).

All patients attending cardiac clinics could be given a card that includes the healthy foods recommended for patients with heart disease and the unhealthy foods that should be avoided. Written materials can be explained to patients by the physician or any qualified healthcare provider during a hospital stay and/or just before discharge. In order to ensure the implementation of a tailored and patient-centred management program, patients should be asked about their preferred educational material. If they do not like written material, other options can be provided. There are guidelines for developing well-written educational material. Guidelines for printed education materials for patients affected with HF are categorised into design, content, presentation and layout (Boyde & Peters 2014). Recommendations for each category are presented below (Table 9.1).

Table 9.1: Recommendations for printed educational materials (Boyde & Peters 2014)

Design	<ul style="list-style-type: none"> • The title should be short. • The purpose of the printed material should be clear to the reader. • The font size should be at least 12 point. • The material should be written in the active voice. • The reading level should be for year/grade 5 to 6.
Content	<ul style="list-style-type: none"> • The content should be concise, simple and clear. • Simple language should be used. • A table of contents should be included. • Learning objectives should be outlined. • Topic headings should be used. • Sentences should not be long, with one idea to each sentence. • Paragraphs should be short and important ideas should be discussed first. • Jargon should be avoided and medical terminology should be defined. • The content should be relevant to the information needs of the target audience.
Layout	<ul style="list-style-type: none"> • The information should be structured with obvious headings. • Headings should be clearly highlighted. • Subheadings should be used. • Bullet points are recommended.

Presentation

- Adequate spacing should be used, with adequate white space.
 - Light background should have dark print.
 - Illustrations should be identifiable, clearly labelled, useful and complementary to the written text.
-

Despite the absence of HF self-management booklets in Jordan, the guidelines above can be used to modify and adapt existing materials based on Jordan's culture and patients' needs. Studies have indicated that culturally adapted educational materials have a significant positive impact on the effectiveness of education (Hölzel et al. 2016). Therefore, healthcare providers should utilise culturally sensitive educational material to empower patients and promote their engagement in education (Benish, Quintana & Wampold 2011; Hawthorne et al. 2008; Hölzel et al. 2016; McCallum et al. 2017). A randomised controlled trial comparing standard and tailored culturally sensitive education materials for African-American smokers showed that culturally sensitive materials had more promising results (Orleans et al. 1998). The quitting rates among smokers who received tailored culturally sensitive education (25.0%) were significantly higher than for those who received the standard education (15.4%). In addition, tailored culturally sensitive materials were more attractive for smokers and more suitable for their family members (Orleans et al. 1998).

Follow-up phone calls. In the current study, most participants liked the idea of a follow-up phone call strategy, and reported that this would be beneficial, and would help to provide educational and emotional support. Follow-up phone calls are often provided in conjunction with other HF interventions (Srisuk et al. 2016), which assists with improving knowledge, enhancing QOL and reducing hospital readmissions (DeWalt et al. 2006; Koelling et al. 2005; Krumholz et al. 2002; Mårtensson et al. 2005; Tsuyuki et al. 2004). Phone call interventions are mainly focused on providing education, assessing and reinforcing patients, monitoring any worsening in HF symptoms, and providing psychosocial support. Follow-up phone calls can help provide patients with HF with a sense of security, and encourage them to perform self-care (Mårtensson et al. 2005; Thomas et al. 2008). This sense of security improves emotional feelings, adherence to treatment regimens and health-related QOL and consequently contributes to better physical and functional capacity. Follow-up phone calls have also been found to decrease levels of depression and anxiety among Turkish patients with HF (Kulcu et al. 2007). A study performed in a Chinese department of cardiology by Yu et al. (2015) found that the use of a health educational booklet tailored to patients' needs, along with follow-up phone calls is feasible and can improve patients' outcomes and assist them to achieve a degree

of physical and psychosocial well-being. In addition, this program improved patients' QOL and adherence to medication. Similarly a randomised controlled trial conducted in Iran showed that phone calls plus education sessions improved patients' self-care and helped them reach optimal behaviours (Zamanzadeh et al. 2013). The developing and relatively immature healthcare system in China (Li et al. 2012) shares the challenges faced by the Jordanian healthcare system. Accordingly, these studies performed in Turkey, China and Iran should capture the attention of healthcare providers in other under-resourced countries and provide insight to develop supportive health strategies such as follow-up phone calls while conducting clinical work. The findings of the Turkish, Chinese and Iranian studies regarding the effectiveness of follow-up phone calls are supported by the findings of the current qualitative study which showed that all patients liked the idea of a phone call strategy to provide further educational and emotional support.

Video. Some participants were comfortable with watching educational videos related to their disease while others indicated the opposite. The use of educational videos has been considered an effective teaching strategy, because they can be watched at the patient's own pace. In addition, the content is standardised in this modality, and the delivery is not dependent on the skills of the clinician. This visual representation facilitates education delivery and improves HF knowledge and self-care (Knowles, Holton III & Swanson 2012). Importantly, incorporating video with written and verbal recommendations has been found to be a successful strategy because it helps in communicating complex ideas, and consequently improves knowledge, adherence, self-care and QOL (Boyde & Peters 2014; Boyde et al. 2013; Knowles, Holton III & Swanson 2012; Toth 2016). Educational videos have been shown to be an effective strategy for older patients. A study reported that the use of videos was associated with significant improvement in knowledge among elderly patients in.

Australia (Boyde et al. 2013). Therefore, the use of videos has been shown to be effective as a patient-centred strategy in a comprehensive HF management program (Boyde et al. 2013).

9.2.2.3 Patients' needs and suggestions to improve the education program

Most patients indicated their need to be treated respectfully and wanted doctors to take more time to explain their instructions in more detail, reflecting others' findings that health communication strategies should be tailored to patients' needs, preferences and literacy level (Epstein, Taylor & Seage III 1985; Kourakos et al. 2017). Effective patient communication with healthcare providers enables patients to enhance their knowledge, adherence, compliance,

and QOL (Kourakos et al. 2017). It helps in improving patients' confidence, controlling emotions, and increasing satisfaction. Previous studies have shown the conditions required to establish effective communication: instructions should be given to patients in a calm and clear voice, in simple language, and in a way that is convenient to each patient (Kourakos et al. 2017). Timely, sufficient and proper communication is important to improve self-care and compliance with treatment, decrease physical morbidity, reduce psychological distress, and prevent unplanned readmissions (Harding et al. 2008). For example, using medical terms in patient education will negatively affect the level of understanding. As a result, patients might not have the capability to comprehend and recall the information delivered during clinic visits (Ha & Longnecker 2010). Furthermore, when the information given to patients is not sufficiently understood, patients are likely to be embarrassed to admit their limitations (Ha & Longnecker 2010). Healthcare providers who have poor communication skills cannot effectively assess patient's needs, levels of literacy and their preferences. Ineffective communication may also lead to overestimation or underestimation of patients' abilities to understand the information given (Glogowska et al. 2015). Therefore, healthcare providers must be skilled in appropriately identifying the patient's level of literacy, and be aware of patient behaviours that may indicate the existence of any limitations such as psychological distress or a handicap. These behaviours include: delaying decision making until the next appointment ('I want to understand this more at home') or postponing the next appointment, non-adherence to advice (such as not limiting the amount of fluid), and making excuses such as 'I have no desire to read anything now' (Glogowska et al. 2015). Therefore, communicating effectively with patients, along with showing respect, giving them time and attention for discussions, and acknowledging their feelings, are requirements for delivering patient-centred care and educating patients successfully. Furthermore, having a companion present during the care process, either a family member or a friend, provides support for the patient's care, results in a positive experience, and improves their treatment adherence (Rosland et al. 2011; Williams, Deci & Ryan 1998).

In conclusion, effective communication considering factors that can affect patients' education, and integrating patient-centred care interventions, can enable Jordanian patients with HF to enhance adherence with their treatment regimen and perform better self-care.

9.2 The Delphi discussion

The Delphi method was used in the current study to identify the most feasible and appropriate HF management interventions for Jordanian patients. The Delphi study found a consensus on

the feasibility and appropriateness of five main HF interventions: educational materials (brochure, diet card and video), a follow-up phone call program, a cardiac rehabilitation program, a group discussion session, and training course for staff.

9.2.1 Educational materials including printed and video

Cardiac health information can be unfamiliar to patients and can be delivered under stressful circumstances. This may overwhelm patients, even those with high levels of literacy (Taylor-Clarke et al. 2012). Poor health literacy may increase non-adherence to the treatment regimen of cardiovascular disease and contribute to suboptimal control of risk factors such as hyperlipidaemia and HTN, eventually leading to undesirable health outcomes (Berkman et al. 2004; Cho et al. 2008; Chobanian et al. 2003; Insull 1997). This highlights the need to develop printed educational material that is understandable and suitable for patients (Taylor-Clarke et al. 2012).

Printed educational materials have been developed to assist patients to understand health information, perform effective self-management (Taylor-Clarke et al. 2012), and improve treatment adherence and QOL (Boyde & Peters 2014). However, there is still a debate about whether these materials provide sufficient health information and have the potential to empower patients to become more aware and responsible for self-care (Taylor-Clarke et al. 2012). Poor readability and poor suitability (ease of comprehension and acceptance) have been found to be knowledge barriers among patients with cardiovascular disease (Safeer, Cooke & Keenan 2006). A study assessed the readability and suitability levels of educational materials particularly designed for HF and related to a heart-healthy lifestyle (Taylor-Clarke et al. 2012). The results demonstrated that the patient educational materials utilised by major healthcare organisations are not suitable, and have suboptimal readability (Taylor-Clarke et al. 2012). Therefore, improvement of the materials' suitability and readability is essential to enhance patients' understanding (Taylor-Clarke et al. 2012).

In low-income countries, printed material has been found to be an effective and feasible patient-centred intervention (Siddharthan, Nassali, et al. 2016). A study of 95 outpatients with HF in Uganda showed that an educational booklet including interactive prompts and review with a trained health educator improved patients' HF knowledge and overall satisfaction (Siddharthan, Nassali, et al. 2016). Furthermore, the results indicated that the HF booklet was feasible for implementation, readable and acceptable by patients in low-to-middle-income countries (Siddharthan, Nassali, et al. 2016). Furthermore, patient-centred education can

enhance confidence in self-management, and improve satisfaction with patient–physician communication. This approach is likely to have a significant influence on economically or socially disadvantaged patients, particularly those who live with their families as they are likely to tolerate the burden of non-communicable illnesses (Siddharthan, Rabin, et al. 2016).

9.2.2 Follow-up phone calls

The increasing prevalence of non-communicable diseases, particularly in low-to-middle-income countries, imposes a burden on well-being and health (Peiris et al. 2014). Low–middle income countries tend to overcome some of the dilemmas faced by high-income countries through new healthcare delivery interventions that reduce healthcare costs, including new technologies (Peiris et al. 2014). For example, mobile phones can overcome communication barriers caused by limited access to fixed-line phones. These technologies assist with delivering healthcare where access to traditional health services is restricted. Mobile health (mHealth) is a multidimensional field embracing various healthcare delivery models and technologies (Peiris et al. 2014). Most of the studies targeting the effectiveness of mHealth were performed in high-income countries (Free et al. 2013). These studies showed that mHealth can improve the delivery of healthcare services (Free et al. 2013), and change behaviours (specifically smoking cessation) (Free et al. 2013; Krishna, Boren & Balas 2009). In low-to-middle-income countries, mobile phones are mainly used to collect information related to maternal, sexual and child health (Aranda-Jan, Mohutsiwa-Dibe & Loukanova 2014; Goel et al. 2013). However, the use of mHealth was investigated in only one systematic review of nine randomised controlled trials in low-to-middle-income countries, focusing only on the utilisation of automated voice and text (Beratarrechea et al. 2014). The review demonstrated significant enhanced clinical outcomes (e.g., control of glycemia, lung function for patients with asthma, and symptoms of HF) and care process (e.g., rates of attendance for follow-up appointments), and a few studies showed a reduction in healthcare costs and improvement in QOL measures (Beratarrechea et al. 2014). Mechael et al. (2010) concluded that mHealth assists with integrating all health information across the continuum of care, instead of focusing on a single solution. In particular, mHealth is important to strengthen the capacity of the health workforce, and to improve workflows and health communication.

Follow-up phone calls are a key part of mHealth interventions. This strategy has been found to reduce hospital readmissions for HF patients in Arizona, USA (Ota et al. 2013). This observational study reported that the strategy of follow-up phone calls was feasible and effective (Ota et al. 2013). The results showed that this strategy can reduce the number of

emergency room visits, hospitalisations, and healthcare costs. In addition, it assists with quickly assessing patients, and giving them immediate access to healthcare providers (Ota et al. 2013). An earlier systematic review of 25 randomised controlled trials reported that structured phone calls markedly decreased hospital readmissions and healthcare costs, and improved QOL among patients with HF (Inglis et al. 2011). Of the 25 studies, the strategy of structured telephone calls was investigated in 16 studies. The countries where the studies were conducted included the US, Canada and Europe.

9.2.3 Cardiac rehabilitation

Cardiac rehabilitation (CR) has been found to be successful and cost-effective in high-income countries (Grace, Turk-Adawi, Contractor, Atrey, Campbell, Derman, Ghisi, Sarkar, et al. 2016). Health expenditures related to CR in high-income countries are significantly higher than those in low-income countries (Grace, Turk-Adawi, Contractor, Atrey, Campbell, Derman, Ghisi, Oldridge, et al. 2016). The International Council of Cardiovascular Prevention and Rehabilitation Consensus Statement stated that CR programs can be affordable in low-to-middle-income countries and should be more widely performed. In addition, the WHO (2013) reported that all patients with coronary heart disease in low-to-middle-income countries need to access CR programs, and to realise with their families and healthcare providers the importance of engagement in these programs (World Health Organization 2013). However, not all CR interventions delivered in high-income countries are feasible and applicable in low-resource settings (Grace, Turk-Adawi, Contractor, Atrey, Campbell, Derman, Ghisi, Oldridge, et al. 2016). This can be attributed to several reasons including insufficient budgets, the scarcity of randomised controlled trials on the impact of CR (Anderson et al. 2016; Grace, Turk-Adawi, Contractor, Atrey, Campbell, Derman, Ghisi, Sarkar, et al. 2016), and the lack of clinical practice guidelines concerning how to implement CR programs in settings with low resources (Cortes-Bergoderi et al. 2013; Organization 1993). Therefore, CR interventions should be delivered based on the resources available in each healthcare system, and should be delivered to patients in practical and cost-effective ways (Grace, Turk-Adawi, Contractor, Atrey, Campbell, Derman, Ghisi, Oldridge, et al. 2016; World Health Organization 1993, 2013).

CR programs should be tailored to patients based on their level of literacy, cultural context, gender and religion (Grace, Turk-Adawi, Contractor, Atrey, Campbell, Derman, Ghisi, Sarkar, et al. 2016). Thus, the program should begin with a comprehensive assessment, which should involve motivational interviews (Hancock et al. 2005). Patients' assessments must be goal-oriented and patient-centred (Grace, Turk-Adawi, Contractor, Atrey, Campbell, Derman,

Ghisi, Sarkar, et al. 2016). The elements that need to be addressed in the assessment include knowledge of coronary heart disease, smoking, level of education, diet, overweight/obesity, physical activity, psychological status, blood pressure, DM, medications, lipid profile and return to work (Grace, Turk-Adawi, Contractor, Atrey, Campbell, Derman, Ghisi, Sarkar, et al. 2016). After the assessment, the findings should be documented. Accordingly, the CR provider should discuss a treatment plan with the patient. Importantly, elements related to behaviour and lifestyle should be considered across the whole continuum of CR delivery (Grace, Turk-Adawi, Contractor, Atrey, Campbell, Derman, Ghisi, Sarkar, et al. 2016). Furthermore, elements associated with secondary prevention such as management of cholesterol and blood pressure should be integrated across all the CR recommendations (Grace, Turk-Adawi, Contractor, Atrey, Campbell, Derman, Ghisi, Sarkar, et al. 2016).

A recent review of CR programs in low–middle income countries showed that CR is cost-effective in patients with HF (Shields et al. 2018). Interestingly, sub-groups of patients, differentiated on the basis of heart risk, reason for referral, needs and gender, were only considered in a single study in that review (Papadakis et al. 2008) This highlights the need for further studies to analyse patient subgroups, and indicates that one treatment or care approach cannot be used for all patients. In addition, the review recommended the need to conduct further studies to identify the most cost-effective psychological interventions in CR (Shields et al. 2018). The single study that considered sub-groups involved a randomised controlled trial of patients with CAD, who were randomly allocated into two groups. The first group received a standard CR program for three months. The second group received a CR program for 12 months. The study also analysed the cost-effectiveness of the two groups (Papadakis et al. 2008). The study's aims were: (1) to compare the incremental cost-effectiveness ratio of the two groups, and (2) to identify the impact of patients' characteristics (demographics, cardiac diagnosis and cardiac risk) on the cost-effectiveness of CR programs. The study found that the cost-effectiveness of the two programs varied based on patients' characteristics, referral reason, and level of cardiac risk. The standard CR program was more cost-effective for patients at high risk of exacerbation, patients undergoing open heart surgery, and for men. In contrast, the distributed CR program was more cost-effective for patients at lower risk and for women. The study concluded that analysis of subgroups assisted with identifying cost-effectiveness differences between the two CR programs. Therefore, the study highlighted the importance of triaging patients to CR programs based on their characteristics and needs (Papadakis et al. 2008).

9.2.4 Group education sessions (peer support)

The strategy of group education sessions has been found to be feasible and cost effective in chronic disease. Also called peer support or group support strategy, group education is defined as the support provided by other patients who live with the same health condition and experience the same challenges (Dennis 2003). The peer support strategy gives patients informational, social and emotional support. Informational support can enhance patients' knowledge, comprehension and coping skills (Campbell, Phaneuf & Deane 2004). Emotional support is provided through empathic communication between patients, assisting with improving self-esteem, self-confidence and minimising negative feelings (Gray et al. 1997; Helgeson & Cohen 1996). Peer support has been found to improve mental health (Hibbard et al. 2002) and enhance health-related QOL among patients with brain injury in the US. Several studies have reported that peer support had a positive significant impact on eating habits (Anderson-Loftin et al. 2005; Glasgow et al. 2003), BMI (Anderson-Loftin et al. 2005), depression (Glasgow et al. 2003), health distress (Lorig et al. 2008; Lorig et al. 2009), and blood pressure (Murrock, Higgins & Killion 2009) among patients with diabetes in the US and Spain. A systematic review has shown that peer support for patients with heart disease improves self-efficacy, enhances activity, decreases pain and reduces emergency room visits (Parry & Watt-Watson 2010).

One study found that the peer support strategy is supportive and feasible after cardiac events (Hildingh & Fridlund 2001). Another study showed that the peer support strategy is cost-effective, acceptable and flexible for patients with diabetes (Aziz et al. 2018), because it improves QOL, strengthens recommended lifestyle behaviours, and reduces hospitalisations and length of stay (Aziz et al. 2018; Johansson et al. 2016).

9.2.5 Training courses for staff

Continuing education/training of healthcare providers is an important component of practice development. It assists with maintaining, updating, and improving professional knowledge, skills, values, and attitudes (Giri et al. 2012). The Institute of Medicine of the National Academies (2009) indicated that effective training programs should equip healthcare providers to deliver patient-centred care, improve quality of care, utilise evidence-based practices, utilise health informatics, and improve quality of care. Continuing education can be formal or informal (World Federation for Medical Education 2003). Formal education is carried out through on-the-job training and integrating medical facility protocols (World Federation for

Medical Education 2003). The emphasis of this type of education is mainly on improving competencies and roles, organising work, medical ethics, and communication (World Federation for Medical Education 2003). Informal education can be achieved through spontaneous interactions between healthcare providers, professional dialogue and reflections on their experiences with certain medical situations, and professional reading (Giri et al. 2012). These approaches of training and education have been found to be effective when combined in the same program. On-the job training is effective in reducing the amount of time that healthcare providers spend away from their workplace (Giri et al. 2012; Schaefer 2005).

In order to get the greatest benefit from education programs, healthcare providers should be fully assessed in terms of their past education, knowledge gaps, and needs. In addition, health managers should support (reinforce) healthcare providers to engage in these programs. Lastly, training materials should cover the area of interest, and within the job description of healthcare providers (Schaefer 2005; World Federation for Medical Education 2003).

In high income countries, engagement in continuing professional development requires certification or licensure, which increases the odds of engagement in these activities. In contrary, healthcare providers in low resource countries are not obliged to be involved in these programs, and there is no need for ongoing training/education (Hudspeth et al. 2015). In addition, those working in these countries face barriers accessing health information resources, books, internet, and libraries. Therefore, conducting on job training program, including group presentations and educational sessions, and facilitating accessibility to health information and educational materials can address these barriers. This will improve the quality of healthcare and patient outcomes (Hudspeth et al. 2015).

9.3 Summary

This chapter discussed the findings that emerged from the analysis of the both patient focus groups and Delphi study. The findings were discussed, interpreted and compared with other studies to assist with developing a patient-centred HF program that is tailored for the Jordanian context. Regarding focus groups, patients' experiences and suggested self-care improvements were discussed in terms of emotional impact of HF, social isolation, and physical consequences. Patients' perspectives on the proposed heart failure model were presented in terms of effectiveness of current education, appropriateness of educational material, and patients' needs and suggestions to improve the education program. In relation to the Delphi study, the five main HF interventions were discussed including educational materials including

printed and video, a follow-up phone call program, a cardiac rehabilitation program, a group discussion session, and training course for staff. The discussion for the findings of the both qualitative and the Delphi studies assisted with integrating the both quantitative and qualitative studies to increase the depth of understanding the proposed HF program patient-centred care for HF patients that is tailored to patients and the Jordanian healthcare system.

Chapter: 10 Integration

This chapter will discuss how the studies included in this thesis (quantitative and qualitative) and research from western healthcare systems can be integrated to provide patient-centred care for HF patients that are tailored to patients and the Jordanian healthcare system.

10.1 The HF issue

Cardiovascular diseases (CVDs) account for 37% of total deaths in Jordan but detailed data evaluating the prevalence of HF and documenting self-care practices of HF patients are limited (World Health Organisation 2018). There have been dramatic increases in the prevalence of ischemic heart disease and HF risk factors such as diabetes mellitus, smoking, obesity, and hypertension (The Centers for Disease Control and Prevention CDC 2013; World Health Organisation 2015; World Health Organisation & The High Health Council 2015-2019). Heart failure increases the economic burden on Middle Eastern healthcare systems as it is a causal factor for increased hospital readmissions and increased healthcare costs (AlHabeeb et al. 2018).

While the effectiveness of therapeutic options / elements for HF has been determined, a practice gap exists around how best to structure and deliver these therapeutic options (McDonald & Gallagher 2017). According to McDonald and Gallagher (2017), the practice gap stems from a lack of cohesion between primary care in the hospitals and specialist cardiologist input. The lack of structure in HF care can impact on correct diagnosis, and result in sub-optimal pharmacological strategies, or poorer education for patients and family in self-care strategies (McDonald & Gallagher 2017).

Although there is generally supportive evidence for the effectiveness of self-management strategies for HF patients and other chronic diseases, some findings are ambiguous or even contradictory (Jonkman et al. 2014). This can be attributed to the complexity of self-management interventions (Anderson 2008), in addition to the wide variety of studies in terms of procedural aspects, management intervention, populations of patients, and measured outcomes (Jonkman et al. 2014). The question of the effectiveness of self-management interventions cannot be answered without identifying which intervention or strategy may have a significant impact, and determining in which types of patient the intervention is most effective (Jonkman et al. 2014). However, differences in the effectiveness of interventions may not only be related to the type of intervention, but also related to the characteristics of the population being investigated (Jonkman et al. 2014). Meta-analysis or meta-regression studies could

identify which interventions are likely to be effective and differences between “subgroups of patients in whom the intervention will be most effective and the effects of relevant components of the studied (complex) interventions” (Jonkman et al. 2014, p. 2). Knowledge of overall effectiveness and differences between populations or sub-groups will enable healthcare providers to tailor (personalise) the most effective and appropriate interventions for patients (Jonkman et al. 2014). For patients with HF in Jordan, this tailored approach needs to consider: the Jordanian healthcare system, healthcare in Jordan compared to developed countries, and why the western model won't work in Jordan.

10.2 Jordan's health care system

As a developing country Jordan has limited budget and health infrastructure, as well as lack of well-structured healthcare services for chronic diseases (World Health Organisation 2006; World Health Organisation & The High Health Council 2015-2019). Therefore, a feasible HF management program that does not require a large financial or infrastructure investment is needed.

10.3 Healthcare in Jordan compared to developed countries

In contrast to the Jordanian system, western countries have more advanced and standardised healthcare interventions to manage chronic diseases like HF such as tele monitoring devices (Adler-Milstein et al. 2014; Blair, Huffman & Shah 2013; Cook et al. 2014). The healthcare systems of developed nations have largely addressed the issues of HF through allocation of funds and resources (Cook et al. 2014; Kabbani et al. 2019). The industrialised nature of these nations has allowed them to spend more resources to develop technology, training, and informational systems to limit the mortality and morbidity of HF (Cook et al. 2014; Pillai & Ganapathi 2013). In contrast, developing countries like Jordan tend to spend less on initial management of HF but incur greater costs overall through readmissions and other indirect costs per patient (Cook et al. 2014; Kabbani et al. 2019).

10.4 Why the western model won't work in Jordan

A meta-analysis involving 53 randomised trials (Jonkman et al. 2016), and a recent review of 28 studies (Bos-Touwen et al. 2015) have shown that HF interventions can be more applicable and appropriate in specific patients and contexts, indicating that “one size does not fit for all”. In other words, more tailored interventions may provide better outcomes (Bos-Touwen et al. 2015; Jonkman et al. 2016). The meta-analysis identified a number of potential effect modifiers

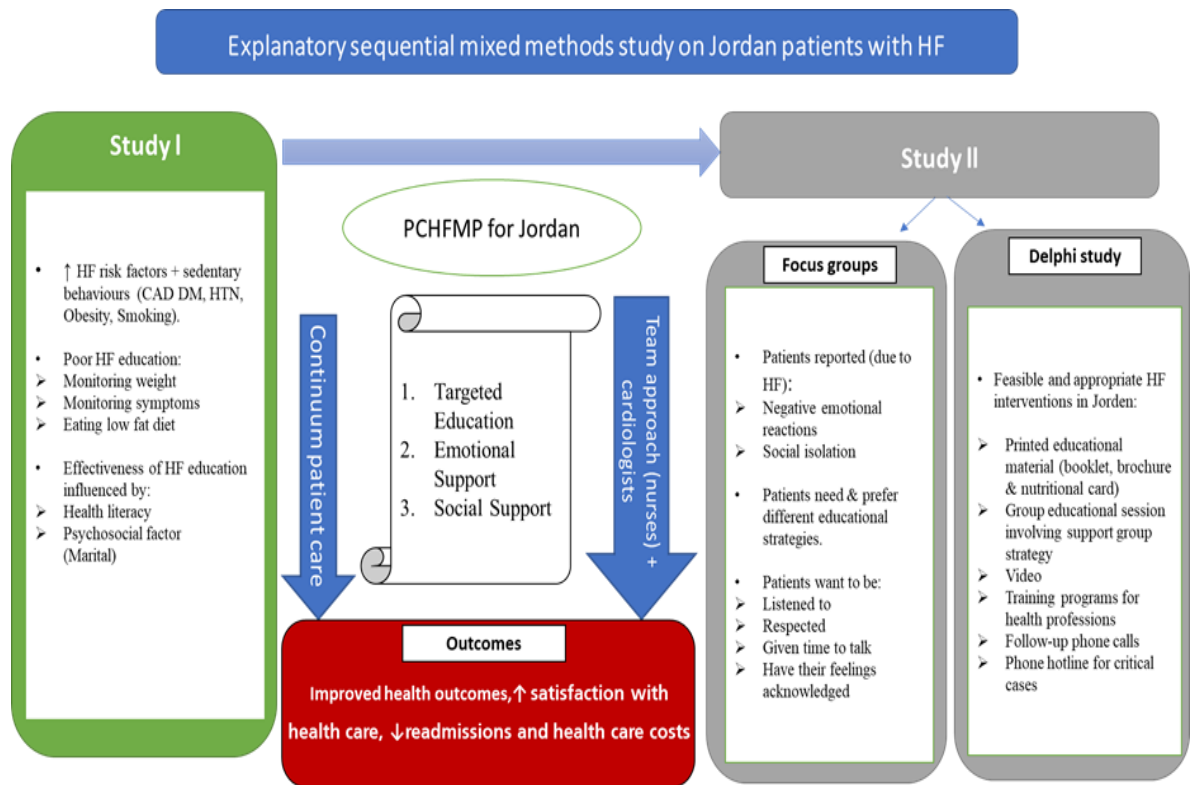
that significantly impact self-management behaviours in patients with chronic diseases. The modifiers include level of education, depression, gender, age, and severity of disease (Jonkman et al. 2016). This finding is supported by other systematic reviews targeting HF management, indicating that patients' characteristics (level of education, income, social status, and psychological status) and needs vary and can influence the effectiveness of HF education (Boren et al. 2009; Clark et al. 2016). Therefore, identifying these factors and tailoring interventions can improve HF self-management (Boren et al. 2009; Clark et al. 2016).

A systematic review to assess the efficacy of cardiovascular disease management (CVD) and quality improvement interventions in low-middle income countries (LMICs), indicated that quality improvement of CVD can be successfully achieved in LMICs (Lee et al. 2016). The review demonstrated that for poor resource settings such as LMICs “the imperative of clinical quality improvement is to *get the most out of known effective interventions within the limitations of available resources* rather than recommending unproven interventions that would require early phase studies or those that would require substantial financial and human resource investment for implementation” (Lee et al. 2016, p. 2). In addition, interventions and strategies should align with the context and capacity of the health system, and adaptation to the health sector is required to achieve patient satisfaction and improve clinical outcomes (Lee et al. 2016). For example, adapting clinical goals and HF interventions to different conditions in a LMIC (Georgia, formerly the Georgian Soviet Socialist Republic) required flexibility and sensitivity to the regional culture (Hebert et al. 2011). The study demonstrated that importing a Western management program and considering the resources available, was feasible and produced favourable outcomes. It increased utilisation of prescribed therapies, decreased blood pressure, reduced ER visits and hospitalisations. The program was staffed by cardiologists and nurses. Verbal teaching (lectures) and written materials were delivered to patients. The educational instructions were about taking medication and recording daily weight. Therefore, further research study is required to investigate (evaluate) local context, affordability of intervention, sustainability, and acceptability to patients and healthcare system (Lee et al. 2016).

Accordingly, heart failure management models used in developed or high income countries will not fit in Jordan healthcare system - due to different context factors and varied patients characteristics, including poor economy, employment rates, population density, level of education, patients' needs, preferences, and challenges – unless the model is modified. Therefore, interventions should be tailored, contextualised, and feasible for patients with HF in Jordan.

10.5 The proposed HF model for Jordan

This study is proposing a specific heart failure program, which is patient-centred and tailored to the context of the Jordanian healthcare system (Figure 10.1). The findings of this mixed methods study were utilised to develop the most feasible, applicable, and appropriate management model for Jordanian patients with HF. The results of study 1 (cross sectional study) showed a diversity of demographics (age, gender, and educational level, marital status), insufficient HF knowledge, poor education about certain self-care behaviours, and poor adherence to self-care. These results indicated the lack of effective HF management program in Jordan, and the need for further investigation. Therefore, the qualitative study (patients' focus groups) was performed to explore patients' experience with their HF disease and suggestions for improving self-care/self-management, and to explore their perspectives on the proposed heart failure model. The Delphi was performed in order to identify the most applicable, feasible, and appropriate HF interventions and strategies in the proposed program. In addition to the Jordanian health system, the patient-level contextual issues to be addressed in this approach are the lack of education among HF patients and healthcare providers. The anticipated outcomes would include improved physical and functional status for patients, reduction in hospital readmissions, and decreased healthcare costs. The concepts of patient centredness and tailoring interventions are clarified in the following consecutive sections.



PCHFMP: Patient-centred heart failure management program for Jordan.

Figure 10.1: Patient-centred HF management program for Jordan

10.5.1 Patient-centred care

Patient-centred care can be effective in improving quality of healthcare (McMillan et al. 2013). Stewart et al. (2004) showed that patient-centred care is comprised of six interrelated aspects: (i) exploration of the illness and its experience; (ii) comprehending the whole person; (iii) identifying common ground between patient and the healthcare providers; (iv) including health promotion and prevention; (v) improving the relationship between patient and health-care provider, and (vi) considering personal limitations and other influencing factors such as availability of resources and time. A systematic review of randomized controlled trials investigated the effectiveness of patient-centred care among patients with coronary heart disease (McMillan et al. 2013). The review findings demonstrated that patient-centered care was significantly associated with improved adherence to perform physical exercise, reduced smoking, and enhanced patients' health-related quality of life (McMillan et al. 2013).

The systematic review was guided by a concept analysis performed by Morgan and Yoder (2012) to identify the attributes of patient-centred care, particularly for patients with chronic diseases. The attributes included empowering, personalised care, holistic care, and treating patients respectfully. Empowering care involves encouraging patients to be self-confident, self-determined, and to participate in making treatment decision through effective negotiation and

communication. Holistic care refers to valuing and recognising the patients through comprehensive assessment of their psychosocial, cognitive, physical, family, and culture needs. Personalised care can be delivered through considering patients' preferences, needs, health concerns, and their personality traits, prior to establishing their care plan. Respectful care implies supporting patients' capabilities, strengths, preferences, and actively listening to, and engaging with them in conversation. Morgan and Yoder (2012) reported three primary outcomes of patient centred care including improved health outcomes, increased satisfaction with healthcare, and enhanced perceptions of the quality of care.

10.5.2 Tailoring interventions

Tailoring involves designing strategies and interventions to achieve favourable health outcomes after assessment of the influencing factors associated with healthcare practice (Wensing, Bosch & Grol 2010). Systematic tailoring includes three major steps: identifying the factors affecting healthcare practice, designing appropriate interventions for the identified factors, and implementing strategies that are specifically designed for the factors (Wensing et al. 2011). Tailoring interventions refers to individual customization of care for patient's particular needs, preferences, and capabilities. It is an important part of patient-empowerment and patient-centredness in which the interventions are specifically designed for patients based on careful assessments (Hawkins et al. 2008). Tailoring has also been defined as any information or interventions specifically tailored to one person, "based on characteristics that are unique to that person, related to the outcome of interest, and derived from an individual assessment" (Kreuter, Strecher & Glassman 1999, p. 276). Intervention customisation empowers patients to comply with instructions and adhere to the treatment regimen. A systematic review showed that tailored interventions have the potential to enhance healthcare practices (Baker et al. 2010). The use of tailoring interventions is increasing and has produced favorable outcomes (Bennett & Glasgow 2009).

In a tailored approach, HF management is dynamic rather than fixed for all patients. In addition, patients' characteristics and needs are assessed in order to customise HF interventions based on these characteristics. This approach assists with producing better patient outcomes (Bos-Touwen et al. 2015; Kreuter, Strecher & Glassman 1999).

10.6 Research questions

As outlined in section (1.3.2) of the Introduction, there were five research questions. Each is answered separately in the following phases.

Study one addressed the following questions: (1) levels of knowledge, self-care, and adherence, among Jordanian patients with HF, (2) the effect of HF symptoms on patients' lives, and (3) predictors of knowledge, self-care, adherence and quality of life for people with HF in Jordan. Study two investigated: (4) patients' experience with their HF disease and suggestions for improving self-care/self-management, and (5) patients' perspectives on the proposed HF model.

10.7 Incorporating a patient-centred HF management program, based on the results of this mixed methods study

This chapter integrates the results of study I (quantitative study) and study II (qualitative study) to develop a model of a feasible and appropriate HF management program for Jordan (Figure 10.1). The HF interventions found feasible and appropriate in the Delphi study, are incorporated in this proposed HF management program. As demonstrated in Figure 10.1, there are three main elements that should be delivered across the whole continuum of HF care process in this proposed program. These include targeted education, emotional support, and social support. The projected outcomes for this program are defined as improved health outcomes for patients, increased satisfaction with healthcare, reduction in hospital readmissions, and decreased healthcare costs (Figure 10.1). The blue arrows in the figure denote the integration between both studies and how this results in the anticipated outcomes.

10.7.1 Targeted education

10.7.1.1 Increased HF-risk factors and sedentary lifestyle behaviours in Jordan

A shown in PCHFMP: Patient-centred heart failure management program for Jordan.

Figure 10.1, study I indicated that HF risk factors (DM, HTN, high cholesterol, obesity, smoking) and sedentary lifestyle behaviours in Jordan are prevalent and increasing. In addition, more than a third of patients had insomnia, and most had insomnia due to difficulty breathing. Study II showed that patients needed different educational strategies. Therefore, delivering targeted (personalised) education care based on patients' needs, preferences, and characteristics, through implementation of patient-centered care is likely to improve patients education, emotional status, and level of satisfaction (Boren et al. 2009; Clark et al. 2016; Kuipers, Cramm & Nieboer 2019; Srisuk et al. 2016). Accordingly, a patient-centred management program that is tailored to Jordan patients and context, can be utilised to change patients' lifestyle in based on their needs and preferences.

The interventions, which were demonstrated to be feasible in the current Delphi study, such as printed materials, cardiac rehabilitation programs, and telephone follow ups can be utilised for this purpose. The Delphi findings demonstrated that patients can be scheduled for a monthly cardiac visit. During the first monthly visit to the clinic, the cardiologist should teach patients about HF, and the importance of lifestyle change. In addition, each patient should be fully assessed in terms of age, learning needs, and preferences, in order to tailor the most suitable education material or intervention for them. Based on the assessment, each patient should be provided with the preferred educational material, which may include lifestyle brochures, nutritional cards, videos (internet link sources), containing information on how to change lifestyle and explaining the best strategies to improve lifestyle in terms of daily weight monitoring; exercise; sleeping; lowering cholesterol; following a low fat, low salt diet; and quitting smoking. A competent cardiac nurse will discuss and review these materials with the patients in a special meeting room in the hospital, based on their needs, in a one hour group educational session. Considering the large number of patients attending cardiac clinics and shortage of cardiologists in Jordan, educational contents can be allocated between cardiologist and cardiac nurse. As mentioned in Delphi findings, the hospital will be financially responsible for printing the materials.

The other proposed HF component in the Delphi study is referring patients to CR programs inside the hospital. As previously discussed, CR program can be delivered to change unhealthy lifestyle behaviours such as smoking and poor physical activity. Furthermore, each patient referred to the program will be thoroughly assessed in order to deliver the most appropriate CR intervention. For example, smokers who are not able to quit smoking would be specifically educated about this by a competent healthcare provider. The frequency and duration of CR sessions will be based on patients' needs and psychological status.

Follow up phone calls, found feasible in this study, have been found to improve patient's adherence to healthy lifestyle recommendations. Phone calls could be made by a competent registered nurse, specifically for those patients who wish to receive this education intervention or who have problems accessing health clinics.

10.7.1.2 Poor HF education in Jordan

Study one demonstrated that HF education of patients in Jordan was poor, particularly education on monitoring weight, monitoring symptoms, and eating low fat diet. Study two showed that education on some self-care behaviours was rarely conducted by doctors. This can

be attributed to the lack of a well-structured education program and lack of well-equipped healthcare providers in Jordan. As mentioned in the current Delphi findings, a training program or workshop could be conducted to prepare healthcare providers, and improve their teaching skills, their communication skills, their lifestyle behaviours, and their heart failure knowledge. The program can be delivered by any competent healthcare providers such as a cardiologist or cardiac nurse at the hospital. Importantly, healthcare providers should be trained on how to appropriately assess patients and promote their involvement in the care process, which assists with identifying and filling knowledge gaps as well as tailoring the best suited interventions (Barello et al. 2017).

10.7.1.3 Effectiveness of HF education influenced by health literacy

Study one showed that many patients with HF in Jordan had low levels of education, and illiterate patients had poorer self-care than patients with either low or high education. Assessing level of education among patients with HF can further improve self-care. People with a low level of education have difficulties in comprehending educational content, and this may worsen their health physically and emotionally (Wu et al. 2013). A systematic review by Cajita, Cajita and Han (2016) showed that higher health literacy is significantly associated with better self-care and knowledge, compared to those with lower literacy. Therefore, Matsuoka et al. (2016) indicated the important need to assess the level of literacy before delivering education, in order to develop individualized HF interventions. Badarudeen and Sabharwal (2010); Boyde and Peters (2014) showed that the level of complexity of printed educational materials should not be higher than grade six to ensure patients' understanding and prevent confusion. Another systematic review indicated that tailoring heart failure interventions to health literacy level can improve comprehension and implementation of the patient-centered communication approach, which consequently enhances knowledge, self-care, and disease control (Schapira et al. 2017). As mentioned in the current Delphi study, patients with a low level of education should be provided with printed educational materials (booklet, brochure, nutritional card) designed for low literacy patients (written below the 6th grade) and extensively modified in focus groups and pilot studies. In addition, healthcare providers should communicate in a simple and clear language to improve patients' understanding. In order to tailor the best HF strategies, level of education should be assessed and considered during the first cardiologist visit.

10.7.2 Social Support

Study I indicated that married patients had better self-care and quality of life than those unmarried. Tawalbeh et al. (2017) indicated that married patients are more likely to receive social support through their partners, which can lead to better self-care and quality of life. Other studies found that unmarried patients are at higher risk for psychological distress, depression, lower quality of life, and poorer self-care (Havranek et al. 2004; Luttik et al. 2006). Study II demonstrated that most patients reported feelings of loneliness and social isolation. This highlights the importance of providing patients with social support. The current Delphi results found consensus for the feasibility of involving family members or friends in HF care processes, which provides patients with not only social support but even emotional and educational support (Heart Failure Society of America 2016). Family members (spouse or non-spouse) and friends aid through: (1) monitoring and recognising any changes in HF symptoms, (2) following the recommended heart-diet, (3) performing physical exercise, (4) taking prescribed medication, (5) performing daily activities (driving, going to hospital, participating in social events), and (6) providing emotional and social support) (Heart Failure Society of America 2016). Patients can be supported by others to monitor their HF symptoms through: (1) informing them about any changes in symptoms that they may notice such as ankle swelling and increased breath shortness, and then encouraging them to go to the hospital, (2) reminding patients to self-weigh every day and document their daily weight (3) observing if the patient uses many pillows to reduce shortness of breath. Family or friends can provide emotional/social support for patient through: (1) talking with them about their treatment plan, (2) avoiding critical criticism if the patient doesn't adhere to treatment regimen, (3) allowing them to express their opinions, (4) encouraging them make their decisions regarding their lifestyle behaviours and treatment plan, and (5) recognising and acknowledging their feelings (Heart Failure Society of America 2016). Importantly, family members or friends should ask patients about what type of support/assistance they need, because each patient has different needs, preferences, capacities, and goals (Heart Failure Society of America 2016).

10.7.3 Emotional (psychological) support

Study II indicated that most patients had negative emotional reactions as a consequence of their illness. In addition, they expressed their need to be treated respectfully and that doctors should give them more time to explain instructions in more detail. Thus, patient-centred communication is a crucial element in patient centredness, because it significantly empowers (enables) patient-centred care (Zill et al. 2015), and ideally embraces the aspects mentioned

above. The Picker Institute (1993) placed patient-centred care at the forefront of its research, in order to emphasise the importance of respecting needs and values, providing emotional support, alleviating anxiety and fear, communicating effectively with patients, and involving a family member or friend in care process. This approach has improved healthcare quality due to its flexibility in tailoring care to patients' needs (Australian Commission on Safety Quality in Health Care 2011).

Patient-centred communication improves patient's adherence, satisfaction, psychosocial status, mental status, and reduces discomfort level (Brouwers et al. 2017; Oates, Weston & Jordan 2000). McCabe (2004) showed that the key components of patient-centred communication should involve using the skills of non-verbal communication that show empathy, genuineness, warmth, respect, and readiness to listen to patients.

Various systematic reviews demonstrated that patient-centred communication can be implemented through using effective communication between doctors and patients (Reader, Gillespie & Roberts 2014), involving family members or friends in care process (Cowie et al. 2014), providing them immediate systematic feedback regarding their performance during education (Brouwers et al. 2017), and listening to patients and asking them to express their complaints (Fleischer et al. 2009).

Peer support strategy (group educational session), found feasible in this Delphi, can be utilised to provide patients with emotional and psychological support. This strategy can be utilised to relieve feelings of stress and worry among patients through sharing feelings and care plans between peers who have the same condition.

10.8 Study Implications

10.8.1 Implications for health policy in Jordan

Lobbying various interest groups will be required to implement this HF model in Jordan. The lobbying should focus on heads of government and institutions, in addition to patient advocacy groups such as charities, opinion leaders, and consumer groups in Jordan. The target for lobbying should be the MOH and president of the High Medical Health Council to enact the policy changes; and healthcare providers such as hospitals and doctors' groups to implement this policy. Since the lobbying approach will focus on the providers of Jordanian healthcare, its implementation will focus on improved outcomes for patients and the whole health system, and reduced overall cost via reduced readmissions for HF patients. In relation to the

management costs of cardiovascular diseases, Brouwer et al. (2015) conducted a systematic review to evaluate the treatment and management costs of cardiovascular diseases and its related risk factors in LMICs. The review indicated that treatment of advanced and complicated cardiovascular diseases is very costly. In addition, management of these diseases and their risk factors is more cost-effective than treatment of acute and complicated diseases. The review identified very few economic studies evaluating the costs of cardiovascular disease management, and recommended additional research to: (1) conduct rigorous studies in countries with limited resources and provide clear estimates of cardiovascular treatment costs to assist with informing allocation of resources and improving efficiency, and (2) focus on management and prevention of these conditions to decrease healthcare expenditures associated with high costs of hospital readmissions and expensive clinical procedures. Such economic studies enable health policy makers to understand the main cause of health expenditure in order to enact new health-related decisions or policies.

In Jordan, healthcare costs are growing due to increased prevalence of non-communicable diseases. Therefore, there is a substantial need to establish strategies to better manage healthcare expenditure. The patient centred model described here should require minimal resources and investment by the government. Furthermore, it is expected to reduce the overall costs of treating each HF patient. This is achieved by promoting self-care and quality of life, which can reduce the burden on healthcare providers by limiting complications and the overall healthcare system by limiting expensive hospital readmissions. The considerations for the implementation of this model in the Jordanian healthcare system will, however, require both staff and funding. The healthcare providers that would be directly employed by the model would be cardiologists and nurses that deal directly with the HF patients. The funding for this model is primarily expected to come from the Jordanian government with potential supplementation by charities and donors.

10.8.2 Implications for healthcare in Jordan

There are several implications for healthcare in Jordan from adopting a patient-centred HF management program that is tailored to both patients' needs and the Jordanian context. Prior to delivering HF education, patients' needs, preferences, level of education, age and socioeconomic status must be known. In addition, the psychosocial aspects of care such as negative emotional reactions, social isolation, and sense of control and identity should be addressed. These considerations are essential to ensure effective tailoring of interventions and successful implementation of patient-centred HF program, and to choose the most appropriate

intervention, which consequently helps in reducing hospital readmissions and healthcare expenditure. The results of this study will also be of interest to healthcare providers, as it highlights the importance of effective communication with patients, showing respect and attention, listening to patients and acknowledging their feelings, and giving them enough time to express their feelings. . The results of this study could be used as a foundation for conducting training programs for healthcare providers to improve skills in exploring patients' preferences and empowering them to make their decisions, and be better equipped with HF knowledge to deliver the most effective care. Most patients reported negative emotions and feelings of social isolation due to their illness, therefore new strategies are needed to incorporate and enhance emotional and social support for patients which in turn contribute to refinement of HF management. Furthermore, the results can be utilised to raise awareness of healthcare providers to focus education on self-care behaviours such as daily weighing, diet, and seeking medical attention. Printed education materials such as booklets can be designed to better cover HF topics that have not been adequately addressed such as weight and symptom monitoring.

10.8.3 Implications for future research

The study has numerous implications for future research studies on HF management. The effectiveness of HF educational programs has not been investigated in Jordan, therefore this study provides a basis to undertake research studies in this field. Systematic reviews showed that the results of previous heart failure management programs were conflicting, thus the study results can be utilised to examine effectiveness of the proposed HF model through performing large and more rigorous randomised controlled trials to compare tailoring and patient centredness with usual care. The process undertaken for Delphi could be replicated for other chronic diseases, and the actual findings of the Delphi could potentially be used for other chronic diseases. Lastly, the research may provide a basis to conduct further studies to identify the factors that may improve HF knowledge, self-care, adherence, and quality of life.

10.9 Recommendations

The study has five main recommendations. These are:

1. Validating the current quantitative study (study I) using larger sample size selected randomly from multiple hospitals across the whole of Jordan to ensure representativeness and generalizability of the results.
2. Considering patients' learning needs, level of education, health literacy, emotions, and preferences to ensure effectiveness of the HF interventions tailored to patients.

3. Involving family members or friends in patients' education as source of physical, social, and emotional support.
4. Increasing community awareness about HF self-management such as eating low fat diet, measuring blood pressure, regular weighing, and recognizing signs of worsening HF.
5. Performing a comparison between the standard patient care model and the tailored, patient centered model proposed by the study to evaluate the model's effectiveness and impact on patients' outcomes including HF knowledge, self-care, adherence, and quality of life.

10.10 Limitations

The study has a number of limitations. First, data were collected in one educational hospital in Irbid, which limits the representativeness of a study sample and generalizability of the results to other patients living in different settings. Second, the use of cross-sectional design and convenience sampling reduces the external validity of the results. In the quantitative study, patients were not asked about any other forms of smoking such as water pipe. Third, although the use of qualitative focus groups promotes discussion, there could be a reluctance to speak up by some participants if they felt that their responses would not be acceptable to the group. The group discussion environment might not encourage honest perspectives in some patients. The conclusion or ideas resulted from the focus groups can be limited if moderator is unable to lead the conversation. The output of focus groups might not be represented and generalisable (Breen 2006; Vicsek 2010). The limitation of Delphi study includes that the experts' perspectives may be influenced by the perspectives of the other experts involved in the group discussion.

10.11 Conclusion

The mixed methods study demonstrated significant issues that should be carefully addressed among patients with HF in Jordan. These include: increased HF risk factors and sedentary behaviours, poor HF education, psychological distress, social isolation, and ineffective communication between patients and healthcare providers. For better patient outcomes, The Jordanian healthcare system should implement a patient centered heart failure management program that is tailored to the Jordanian context and patients' needs. The proposed program suggested in this study is feasible, appropriate, and applicable in Jordan, embracing three main elements that should be delivered to patients across the whole continuum of care process. These

include targeted education, psychological support, and social support. This program should improve patients' knowledge, adherence, self-care, and quality of life. Anticipated long term outcomes should include improved physical and functional status of patients, and reduced hospital readmissions and related healthcare costs.

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Appendices

11.1. Appendix 1: Questionnaire

Demographic Tool

Data Completed by the Cardiac Nurse

Clinical Variables

NYHF class:

- Class I
- Class II
- Class III
- Class IV

Ejection fraction: ----- %

Body Mass Index (BMI) (kg/m²)

Demographic Data

Please indicate your gender:

- Male
- Female

What is your age years?

Please indicate the following:

Educational Level:

- No education

- Primary education
- Secondary education
- Diploma
- Bachelor
- Masters
- PhD
- other

Marital status:

- Single
- Married
- Divorced
- Widowed
- Separated
- other

Care giver:

- Patient
- Family
- other

Do you live alone?

- Yes
- No

Smoking History:

Do you smoke?

- No
- Yes

If yes, please complete the following:

How long have you been smoking..... Years

How many cigarettes do you usually smoke

- Have stopped smoking

How long did you stop smoking?

Do you have difficulty in sleeping?

- Yes
- NO

What causes of difficult sleeping do you have?

Income:

- 300 or less JDs
- 301- 1000 JDs
- more than 1000 JDs

Have you ever been admitted to hospital for heart failure?

- Yes
- NO

If yes, please complete the following:

How many times

History of chronic diseases:

Have you ever been diagnosed by a doctor with the following conditions:

- High blood pressure
- Diabetes
- Angina
- Heart attack
- Irregular heart beat
- Chronic breathing problem
- High cholesterol
- Other

Thank you very much for completion the questionnaire

Have you been informed about the following items before?

Please indicate your answer with yes or no

	Yes	No
1. Exercised regularly (at least 3 times per week)		
2. Took medication as prescribed (on time without skipping doses)		
3. Drank 1 or less alcoholic beverage per day If you don't drink, please circle number 5		
4. Cut down on smoking or didn't Smoke If you don't smoke, please circle number 5		
5. Followed a low salt diet		
6. Followed a low fat diet		
7. Weighed yourself every day To watch your fluid status		
8. monitored (paid attention to) your Symptoms every day		

THE MEDICAL OUTCOMES STUDY SPECIFIC ADHERENCE SCALE

How often have you done each of the following in the past 4 weeks?

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1. Exercised regularly (at least 3 times per week)						
2. Took medication as prescribed (on time without skipping doses)						
3. Drank 1 or less alcoholic beverage per day If you don't drink, please circle number 5						
4. Cut down on smoking or didn't Smoke If you don't smoke, please circle number 5						
5. Followed a low salt diet						
6. Followed a low fat diet						
7. Weighed yourself every day To watch your fluid status						
8. monitored (paid attention to) your Symptoms every day						

The European Heart Failure Self-Care Behavior Scale_9

This scale contains statements about heart failure self-care. Respond to each statement by circling the number you think best applies to you. Note that the different answer alternatives constitute a scale ranging between the extremes of "I completely agree" (1) to "I don't agree at all" (5). Even if you feel uncertain about a particular statement, Circle the number you feel is most true for you.

	I Completely agree				I don't agree at all	
	1	2	3	4	5	
1. I weigh myself every day	1	2	3	4	5	
2. If my shortness of breath increases I contact My doctor or nurse.	1	2	3	4	5	
3. If my feet/ legs become more swollen than Usual I contact my doctor or nurse.	1	2	3	4	5	
4. If I gain 2 kilo in one week I contact my doctor or nurse.		1	2	3	4	5
5. I limit the amount of fluids I drink (not More than 1 ½ -2 l/day)	1	2	3	4	5	
6. If I experience increased fatigue I contact My doctor or nurse	1	2	3	4	5	
7. I eat a low salt diet	1	2	3	4	5	
8. I take my medication as prescribed	1	2	3	4	5	
9. I exercise regularly	1	2	3	4	5	

MINNESOTA LIVING WITH HEART FAILURE® QUESTIONNAIRE

The following questions ask how much your heart failure (heart condition) affected your life during the past month (4 weeks). After each question, circle the 0, 1, 2, 3, 4 or 5 to show how much your life was affected. If a question does not apply to you, circle the 0 after that question.

Did your heart failure prevent you from living as you wanted during the past month (4 weeks) by -	No	Very Little	2	3	4	Very Much
1. causing swelling in your ankles or legs?	0	1	2	3	4	5
2. making you sit or lie down to rest during the day?	0	1	2	3	4	5
3. making your walking about or climbing stairs difficult?	0	1	2	3	4	5
4. making your working around the house or yard difficult?	0	1	2	3	4	5
5. making your going places away from home difficult?	0	1	2	3	4	5
6. making your sleeping well at night difficult?	0	1	2	3	4	5
7. making your relating to or doing things with your friends or family difficult?	0	1	2	3	4	5
8. making your working to earn a living difficult?	0	1	2	3	4	5
9. making your recreational pastimes, sports or hobbies difficult?	0	1	2	3	4	5
10. making your sexual activities difficult?	0	1	2	3	4	5
11. making you eat less of the foods you like?	0	1	2	3	4	5
12. making you short of breath?	0	1	2	3	4	5
13. making you tired, fatigued, or low on energy?	0	1	2	3	4	5
14. making you stay in a hospital?	0	1	2	3	4	5
15. costing you money for medical care?	0	1	2	3	4	5
16. giving you side effects from treatments?	0	1	2	3	4	5
17. making you feel you are a burden to your family or friends?	0	1	2	3	4	5
18. making you feel a loss of self-control in your life?	0	1	2	3	4	5
19. making you worry?	0	1	2	3	4	5
20. making it difficult for you to concentrate or remember things?	0	1	2	3	4	5
21. making you feel depressed?	0	1	2	3	4	5

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11/10/04

11.2 Appendix 2: Ethics 1



RESEARCH SERVICES
OFFICE OF RESEARCH ETHICS, COMPLIANCE AND
INTEGRITY

SABINE SCHREIBER
SECRETARY
HUMAN RESEARCH ETHICS COMMITTEE
THE UNIVERSITY OF ADELAIDE
LEVEL 4, RUNDLE MALL PLAZA
50 RUNDLE MALL
ADELAIDE SA 5000 AUSTRALIA
TELEPHONE +61 8 8313 6028
FACSIMILE +61 8 8313 3700
email: hreo@adelaide.edu.au
CRICOS Provider Number 00123M

8 March 2017

Dr T Schultz
Adelaide Nursing School

Dear Dr Schultz

ETHICS APPROVAL No: **H-2017-025**
Developing a tailored patient centred intervention for heart failure patients in Jordan

The ethics application for the above project has been reviewed by the Human Research Ethics Committee and is deemed to meet the requirements of the *National Statement on Ethical Conduct in Human Research (2007)*.

The ethics expiry date for this project is: 31 March 2020


Ethics approval is granted for three years and is subject to satisfactory annual reporting. The form titled *Annual Report on Project Status* is to be used when reporting annual progress and project completion and can be downloaded at <http://www.adelaide.edu.au/research-services/oreci/human/reporting/>. Prior to expiry, ethics approval may be extended for a further period.

Participants in the study are to be given a copy of the Information Sheet and the signed Consent Form to retain. It is also a condition of approval that you **immediately report** anything which might warrant review of ethical approval including:

- serious or unexpected adverse effects on participants,
- previously unforeseen events which might affect continued ethical acceptability of the project,
- proposed changes to the protocol; and
- the project is discontinued before the expected date of completion.

Please refer to the following ethics approval document for any additional conditions that may apply to this project.

Yours sincerely

 Professor Paul Veirabro
Convenor
Human Research Ethics Committee



General Director Office

مكتب المدير العام

ص.ب (٦٢٠٠١) إربيد (٢٢١١٠) الأردن

هاتف : ٧٢٠٠٦٠٠ (٢-٩٦٢) فاكس : ٧٠٩٥٧٧٧ (٢-٩٦٢)

Ref. 13131816
Date: 21-2-2017

الرقم :
التاريخ :
الموافق :

Dr. Tim Schultz,

Associate Professor
Postgraduate Coordinator
School of Nursing
University of Adelaide
Tel.: +61-8-83136270
Email: tim.schultz@adelaide.edu.au

Dear Dr.

In reference to your letter, in which you confirmed that Mr. Osama Ahmad Alkouri is a PhD student, under supervision of Prof. Judy Magarey and Dr. Jeroen Hendriks, from the faculty of Health and Medical Science, University of Adelaide, and will be undertaking a project entitled:

Developing a Tailored Patient Centered Intervention for Heart Failure Patients in Jordan

We would like to inform you that the IRB Committee has granted Mr. Osama Alkouri the approval to conduct his proposal at King Abdullah University Hospital with coordination with Medical Department, for the purpose mentioned above, under the following conditions:

1. Commitment to the Scientific Research Policy at Jordan University of Science and Technology and King Abdullah University Hospital.
2. Maintaining data confidentiality and using it only for scientific purposes.
3. Provide us with the final executive study report including copy of participants' consent form, and keep another copy with the researcher.
4. This approval will be canceled if the principle investigator doesn't provide IRB with the final executive study report about the results of the research after one year.

Sincerely,,,

Prof. Ismail Matakah

CEO KAUH

Tel.: (962-2) 7200600 Fax: (962-2) 7095777 P.O.Box: (630001) Irbid (22110) Jordan E-mail : kauh@just.edu.jo

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Developing a tailored patient centred Intervention for Heart Failure patients in Jordan.

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2016-***

PRINCIPAL INVESTIGATOR: Tim Schultz

STUDENT RESEARCHER: Osama Ahmad Alkouri

STUDENT'S DEGREE: PhD

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

We are seeking to develop a patient centred program which would be used to meet patients' individual needs to assist them in managing their illness and improving heart health. As you are a patient attending the cardiac clinic we are seeking your participation in a survey designed to assess the needs of patients with a heart problem.

Who is undertaking the project?

This project is being conducted by the primary researcher Osama Ahmad Hamdan Alkouri. This research will form the basis for the degree of PhD at the University of Adelaide in the South of Australia and is being conducted under the supervision of Dr Tim Schultz, A/Prof Judith Magarey, and Dr Jeroen Hendriks, of the University of Adelaide.

Why am I being invited to participate?

You are invited to participate in this study if you are over 18 years old and have been diagnosed with heart failure by your cardiologist.

What will I be asked to do?

You will be asked to complete a confidential paper survey. The survey will ask questions about how you currently manage your treatment, cope with your illness and its effect on your life. You will not be asked to provide your name or any other information which might identify you as an individual. The Clinic Nurse will be asked to enter your weight, a measure of how well your heart is pumping (the ejection fraction) and your New York Heart Failure Classification (this is a measure of your condition used by the cardiologist). The nurse will then give you the survey to complete. Once you have completed the survey you will put it in a confidential box for collection. All responses will be combined for the results.

How much time will the project take?

Completion of the survey will take approximately 40 minutes.

Are there any risks associated with participating in this project?

There are no risks associated with you completing this survey. The information completed by the Clinic Nurse on the survey will have been discussed by the cardiologist with you. You will be asked to sign a consent form to participate in the study. The survey is anonymous and no information which may identify you as an individual will be recorded or reported. The survey is voluntary and for your convenience can be completed in the waiting room of the clinic.

What are the benefits of the research project?

There will be no immediate benefits to you as an individual. However, the information collected will be utilised in the development of a patient centred program used to meet the individual needs of patients with heart failure. Patient centred program aims to provide you with the care that is respectful and responsive to your preferences, needs, and values. It also helps people manage their own care, and coordinate with physicians and nurses and other health care providers. To create treatment decisions is anticipated this will help them to reduce the symptoms of heart failure such as shortness of breath and fatigue.

Can I withdraw from the project?

Participation in this project is completely voluntary. There will be no impact on your care now or in the future should you choose not to participate. If during completion of the survey you decide not to continue you are free to withdraw from the study, and the health services you receive will not be affected.

What will happen to my information?

Your information will be combined with that of the other participants and the result will be reported in papers for publication and presentations. You will not be identified as an individual. The information will be confidentially stored on a University of Adelaide computer for five years and deleted at that time. The hard copies will be stored by the Adelaide Nursing School for a period of five years and then will be confidentially destroyed. Only the researcher and his supervisors will access the information during the study. Your information will not be accessed again after the project is completed.

Who do I contact if I have questions about the project?

All researchers will have a dedicated mobile number for the project. In addition, you can contact the researchers through their emails or phone numbers. Here are their access information:

Email: Tim Schultz	tim.schultz@adelaide.edu.au	Phone:	00618/ 831 36270
Email: Judy Magarey	judy.magarey@adelaide.edu.au	Phone:	00618/83138055
Email: Jeroen Hendriks	Jeroen.hendriks@adelaide.edu.au	Phone:	00618/ 8222 2723
Email: Osama Alkouri	Osama.alkouri@adelaide.edu.au	Phone:	00618/13628373

In Jordan if you have any question contact Yousef Khader on the following number +962/796802040
Email: ykhader@just.edu.jo, Head of Institution Review Board.
Osama Alkouri Email (Osama.alkouri@adelaide.edu.au), dedicated phone number +962/788326584

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2016-xxx). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding a concern or complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

If you agree to participate, the clinic nurse will give you the questionnaires in order to complete them during your visit today. In addition, you will sign the consent form and your identity will remain confidential and you will not be identified in the reporting of the results.

Yours sincerely,

All RESEARCHERS NAME(S) and TITLE(S)

Dr Tim Schultz
Assoc. Prof. Judy Magarey
Dr Jeroen Hendriks
Osama Alkouri

11.3 Appendix 3: Ethics 2



RESEARCH SERVICES
OFFICE OF RESEARCH ETHICS, COMPLIANCE
AND INTEGRITY
THE UNIVERSITY OF ADELAIDE

LEVEL 4, RUNDLE MALL PLAZA
50 RUNDLE MALL
ADELAIDE SA 5000 AUSTRALIA

TELEPHONE +61 8 8313 5137
FACSIMILE +61 8 8313 3700
EMAIL hrec@adelaide.edu.au

CRICOS Provider Number 00123M

Our reference 33045

20 July 2018

Dr Tim Schultz
Nursing

Dear Dr Schultz

ETHICS APPROVAL No: H-2018-147
PROJECT TITLE: Developing a tailored patient centered intervention for heart failure patients in Jordan

The ethics application for the above project has been reviewed by the Human Research Ethics Committee and is deemed to meet the requirements of the *National Statement on Ethical Conduct in Human Research (2007)*.

You are authorised to commence your research on: 20/07/2018
The ethics expiry date for this project is: 31/07/2021

NAMED INVESTIGATORS:

Chief Investigator:	Dr Tim Schultz
Student - Postgraduate Doctorate by Research (PhD):	Mr Osama Ahmad Hamdan Alkouri
Associate Investigator:	Associate Professor Judith Magarey
Associate Investigator:	Dr Jeroen Hendriks

CONDITIONS OF APPROVAL: Thank you for the amended application dated 20 July 2018 in response to the matters raised by the Committee.

Ethics approval is granted for three years and is subject to satisfactory annual reporting. The form titled Annual Report on Project Status is to be used when reporting annual progress and project completion and can be downloaded at <http://www.adelaide.edu.au/research-services/oreci/human/reporting/>. Prior to expiry, ethics approval may be extended for a further period.

Participants in the study are to be given a copy of the information sheet and the signed consent form to retain. It is also a condition of approval that you immediately report anything which might warrant review of ethical approval including:

- serious or unexpected adverse effects on participants,
- previously unforeseen events which might affect continued ethical acceptability of the project,
- proposed changes to the protocol or project investigators; and
- the project is discontinued before the expected date of completion.

Yours sincerely,

Professor Paul Delfabbro
Convenor

The University of Adelaide



جامعة العلوم والتكنولوجيا الأردنية
Jordan University of Science and Technology



مستشفى الملك المؤسس عبدالله الجامعي
King Abdullah University Hospital

لجنة أخلاقيات البحث على الإنسان
Institutional Review Board

Ref.: 47/117/2018, date 9.7.2018

Date: ١٠. ٧. ٢٠١٨

Dr. Tim Schultz
Postgraduate Coordinator
School of Nursing/ University of Adelaide

In reference to the scientific research which is presented by **Mr. Osama Ahmad Alkouri**, who is a PhD Student in the Adelaide Nursing University, Faculty of Health and Medical Sciences, University of Adelaide, entitled:

Developing the Most Effective Intervention for Heart Failure Patients in Jordan

We would like to inform you that the above research proposal has granted IRB approval, under the following conditions:

1. Commitment to the Scientific Research Policy at Jordan University of Science and Technology and King Abdullah University Hospital.
2. Maintaining data confidentiality and using it only for scientific purposes.
3. Consent Form is required.
4. This approval will be canceled if the principle investigator doesn't provide IRB with the final report about the results of the research after one year.

Sincerely,

Prof. Yousef Al-Gaud

Chairman of the Institutional Review Board

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Developing a patient centred Heart Failure program in Jordan: clinician Delphi study.

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2018-
PRINCIPAL INVESTIGATOR: Tim Schultz
STUDENT RESEARCHER: Osama Ahmad Alkouri
STUDENT'S DEGREE: PhD

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

We are seeking to develop a patient tailored centred program which could be used to meet patient needs to assist them in managing this illness and improving health.

Who is undertaking the project?

This project is being conducted by the primary researcher Osama Ahmad Hamdan Alkouri. This research will form the basis for the degree of PhD at the University of Adelaide in the South of Australia and is being conducted under the supervision of Dr Tim Schultz, A/Prof Judith Magarey, and Dr Jeroen Hendriks, of the University of Adelaide.

What am I being invited to do?

You are invited to participate in this study if you are clinicians specialising in cardiovascular disease, or health system policymakers currently working at King Abdalla University Hospital. Appropriately accredited staff with experience and knowledge relevant to delivering healthcare to people with HF is invited to participate.

What will I be asked to do?

This part forms the third phase of a PhD project. You will be asked to participate in the Delphi study that will be performed over two rounds to build up your consensus regarding the most feasible and effective heart failure intervention in Jordan. The Delphi is a technique that uses a highly structured meeting to gather information from relevant experts (usually 9-12 in number) about a given issue. It consists of two rounds in which panelists rate, discuss, and then rerate a series of items or questions. The method was developed in the United States in the 1960s and has been applied to problems in social services, education, government, and industry. In the context of health care the method has most commonly been used to examine the appropriateness of clinical interventions, but has also been applied in education and training, in practice development, and for identifying measures for clinical trials¹.

During the Delphi study, the researcher will first present the tailored heart failure model proposed based on extensive literature, the survey results of the second phase of this project, and the European heart failure guidelines. Then the experts will be given an explanation about how

Jones, J & Hunter, D 1995, 'Consensus methods for medical and health services research', *BMJ: British Medical Journal*, vol. 311, no. 7001, p. 376.

this model has been developed. Then the experts will be asked two main questions. **The first question** is "what is your first impression about the proposed model especially in relation to its feasibility in Jordan?" The second question is "what is the most feasible and effective program for heart failure patients to maximise HF management skills in Jordan?" After that, you will be asked to write down your responses and views on the proposed model. After that, the main researcher will collect your responses, and present your ideas in a table for ranking. For example, five point likert scale, zero means "not feasible", and item number 5 means "highly feasible". Thereafter, you will be given the table back to rank (rate) each idea in relation to their feasibility (This is the first round). The survey monkey will be used to provide instant feedback, help provoke discussion, and collect responses.

The second round will be conducted and will include the following:

- Discussing your responses from first round
- Recording the discussion
- Repeating the survey monkey of the overall discussion

How much time will my involvement in the project take?

Each round will approximately take 60 to 90 minutes.

Are there any risks associated with participating in this project?

The anticipated burden on you by participating in this study is the time you will spent in the focus groups. To mitigate this burden, the schedule of the focus group will be flexible based on the time that suites you. The researcher will discuss the appropriate time focus group with you to avoid interfering with any work, family or social commitments. You and your group will be given an opportunity to schedule the time of your focus group discussion.

What are the potential benefits of the research project?

There will be no immediate benefits to this project. The information collected will be utilised in building up the expert's consensus regarding the feasibility of the proposed tailored heart failure management model.

Can I withdraw from the project?

Participation in this project is completely voluntary. *If during focus group you decide not to continue you are free to withdraw from the study.*

Who do I contact if I have questions about the project?

Contact details (email address and phone numbers) for all researchers are provided at the end of this information sheet. The best local contact for any questions about the project is Mr Osama Alkouri, who will be in Jordan to conduct the study (Osama.alkouri@adelaide.edu.au, +962/772876762).

What will happen to my information?

published. Your information will be saved based on the policy of The University of Adelaide for five years

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-xxx). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

All researchers can be contacted about the project through their email or phone numbers (see below). *The best local contact for any questions about the project is Mr Osama Alkouri, who will be in Jordan to conduct the study.* Here are the contact details for the whole team:

Email: Osama Alkouri	Osama.alkouri@adelaide.edu.au	Phone:	00618/13628373
Email: Tim Schultz	tim.schultz@adelaide.edu.au	Phone:	00618/831 36270
Email: Judy Magarey	judy.magarey@adelaide.edu.au	Phone:	00618/83136055
Email: Jeroen Hendriks	Jeroen.hendriks@adelaide.edu.au	Phone:	00618/ 8222 2723

If I want to participate, what do I do?

If you are interested to participate please reply or call the main researcher (Osama Alkouri)

Yours sincerely,
Dr Tim Schultz
Assoc. Prof. Judy Magarey
Dr Jeroen Hendriks
Osama Alkouri

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Developing a patient centred Heart Failure Program in Jordan:
focus groups of patients
HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2018-
PRINCIPAL INVESTIGATOR: Tim Schultz
STUDENT RESEARCHER: Osama Ahmad Alkouri
STUDENT'S DEGREE: PhD

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

Heart failure is when the heart is not able to effectively pump blood to the body. You may have experienced the result of this with shortness of breath and fatigue. We are seeking to develop a patient tailored centred program which could be used to meet patient needs to assist them in managing this illness and improving health. Patients who have been diagnosed with heart failure by a cardiologist and who have attended a HF clinic in Jordan will be eligible to participate.

Who is undertaking the project?

This project is being conducted by the primary researcher Osama Ahmad Hamdan Alkouri. This research will form the basis for the degree of PhD at the University of Adelaide in the South of Australia and is being conducted under the supervision of Dr Tim Schultz, A/Prof Judith Magarey, and Dr Jeroen Hendriks, of the University of Adelaide.

What am I being invited to do?

You are invited to participate in a group discussion about your experience of your HF care. The researcher (Osama Alkouri) will assist and guide the group discussion. Two group discussions will be conducted and the same participants will participate in the same two groups. The first group discussion will include questions that target your experience with your disease, your emotions, and your motivations for self-care/self-management. In the second group discussion, you will share your perspectives on a newly proposed HF program. The discussion will be audio-recorded. The interactions within the group will also be captured to draw attention to differences in opinions. The group discussion will be conducted in a special meeting room in the hospital.

How much time will my involvement in the project take?

Two focus groups will be carried out. Each focus group will take approximately 90 minutes.

Are there any risks associated with participating in this project

The anticipated burden on you by participating in this study is the time you will spent in the focus group.

To mitigate this burden, the schedule of the focus group will be flexible based on the time that suites you. The researcher will discuss the appropriate time focus group with you to avoid interfering with any work, family or social commitments. You and your group will be given an opportunity to schedule the time of your focus group discussion.

interfering with any work, family or social commitments. You and your group will be given an opportunity to schedule the time of your focus group discussion.

What are the potential benefits of the research project?

There will be no immediate benefits to you as an individual. However, the information collected will be utilised in the development of a patient centred program used to meet the individual needs of patients with heart failure, and finalising tailoring of heart failure intervention. Patient centred program aims to provide patients with the care that is respectful and responsive to their preferences, needs, and values. It will also help manage your own care, and cooperate with the physicians and nurses and other health care providers. In addition, this program will mainly focus on using effective communication, and developing a friendship and trusting relationships between you and health care providers. The first focus group will help the researcher to identify and explore your experience with the disease process of heart failure, your emotions, and motivation to do a proper self-care.

Can I withdraw from the project?

Participation in this project is completely voluntary. There will be no impact on your care now or in the future should you choose not to participate. If during the focus group you decide not to continue you are free to withdraw from the study. In addition, the health services you receive will not be affected.

What will happen to my information?

Please be assured that your identity will be anonymous and will not be able to be identified throughout the study. Your real name will not be used and you will be given a code, for example, participant A or participant B. Your information will be accessed by the research team members only. The results of the study will be used for a PhD thesis, and journal paper/s may be published.

Who do I contact if I have questions about the project?

Contact details (email address and phone numbers) for all researchers are provided at the end of this information sheet. The best local contact for any questions about the project is Mr Osama Alkouri, who will be in Jordan to conduct the study (Osama.alkouri@adelaide.edu.au, 00618/13628373).

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-xxx). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

11.4 Appendix 4: Focus groups questions' guide

Questions for the first group discussion

In order to manage your heart problem, you will need to have received education and understand the effect of lifestyle on your condition.

- 1- How do you feel about your heart Problem?

Divide this into

- 2- What do you think about making changes in your life style required for your heart problem in terms of changing your diet, increasing exercise, not drinking alcohol and not smoking?
- 3- What do you think about looking after your own health in terms of medications and monitoring your weight and symptoms such as any difficulty in breathing?
- 4- What has been the impact of your heart problem on sleeping, sexual activities and family and social interactions?
- 5- What are the things would help you make the changes to your life style which we have discussed.
- 6- How does being Arab Muslim impact your lifestyle and your ability to make changes to improve your health

Questions for the second group discussion

In order to help you manage your HF and improve your quality of life you will have received some advice from the staff in the cardiac care clinic.

- 1- How did the teaching sessions you received in the cardiac care clinic help you to manage your condition? For example in terms of your weight, diet, exercise, and taking medications.
- 2- Did they help you give up smoking and drinking alcohol?
- 3- Do you have any suggestions about how this education could be done better?
- 4- Do you think any of the following strategies would help? Booklets, videos, and face to face sessions, or phone follow up calls?
- 5- If you think follow up phone calls would assist how often would you like them to occur?
- 6- Do you think that how you are feeling at the time impacts on what education strategies will help you make lifestyle changes?