# Illness Perceptions of Heart Failure Patients as a Predictor of Self-Care Behaviours and Medication Adherence

A Dissertation Presented to the Faculty of Health Sciences in Part-Fulfilment of the Requirements for the Degree of Master of Science in Nursing at the University of Malta

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“Inside every chronic patient is an acute patient wondering what happened.”

(Brown, 2002, p. 1443)

# Abstract

**Background**: Self-care and medication adherence are two important principles in the management of Heart Failure. Along the path of living with Heart Failure the individual establishes a set of illness perceptions, believed to be important determinants of self-care and medication adherence. The Common-Sense Model of self-regulation of illness provides a theoretical framework to assess the relationship between the perceived illness perceptions and coping procedures, expressed by the actions taken to manage the illness.

**Objectives**: To determine whether the illness perceptions of individuals living with Heart Failure act as a predictor of self-care, including medication adherence, and to identify possible significant differences in illness perceptions, self-care, and medication adherence between subgroups of socio-demographic characteristics and clinical data.

**Study Design**: Descriptive correlational design.

**Setting**: Nurse-led Heart Failure clinic and specialised Heart Failure clinic at the national hospital in Malta, Europe.

**Sample**: A convenience sample of 280 individuals living with Heart Failure, aged 18 years or older, were recruited in this research study.

**Methods**: A survey including the Brief Illness Perception Questionnaire, the European Heart Failure Self-care Behaviour Scale, and the Medication Adherence Reporting Scale was constructed to measure the illness perceptions, self-care, and medication adherence, respectively. Research instruments were translated from their original language to the Maltese language. Data collected was analysed using SPSS version 26. Statistical tests used include the Shapiro-Wilk, Spearman correlation coefficient, Mann Whitney U, Kruskal Wallis with Dunn's Bonferroni post-hoc tests, and Generalised Linear Models assuming a gamma distribution and a reciprocal canonical link function.

**Results**: Overall, Heart Failure was perceived to be of moderate threat, with a chronic timeline, and can be controlled by treatment. Perceptions about Heart Failure on the consequences, timeline, personal control, identity, and emotions were correlated with self-care, while the perception of identity was correlated with medication adherence. Generalised Linear Models revealed that the illness perception of consequences, timeline, personal control, and illness comprehensibility as predictors of self-care, while perceptions on the consequences, timeline, illness comprehensibility, and emotions as predictors of medication adherence. Further analysis revealed that in addition to the mentioned predictors, NYHA Class and age were predictors of self-care, while occupation and living arrangement were predictors of medication adherence.

**Conclusions**: Illness perceptions are significant predictors of self-care and medication adherence, thereby suggesting that these perceptions should be the target of interventions aimed to improve self-care and medication adherence. Health-care professionals should practice a person-centred approach, to assist their clients in perceiving a set of helpful illness perceptions while assisting them to identify any barriers and solutions which may influence self-care and medication adherence.



**Keywords**: HEART FAILURE, ILLNESS PERCEPTIONS, ILLNESS REPRESENATIONS, SELF-CARE, MEDICATION ADHERENCE

# Dedication

I dedicate this dissertation to my parents Frans and Maria Diana and my future wife Rochelle who have encouraged and supported me throughout this whole process.

I also dedicate this dissertation to my working colleagues, especially to my charge nurses Ms. Michelle Cassar and Ms. Janet Caruana for encouraging me to pursue this Master, and Ms. Caroline Camilleri for her continuous support. I always appreciate all they have done, especially Dr. Alice Moore for helping me to develop my specialised nursing skills amongst individuals living with Heart Failure.

And lastly, I dedicate this work to the Almighty God, for giving me the protection, strength, patience, power of mind, and health. Writing this dissertation and finishing it on time was a great achievement. Thank You for being there with me all the time.

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# Abbreviations

| | |
|---|---|
| ACEi | Angiotensin Converting Enzyme inhibitors |
| B-IPQ | Brief Illness Perception Questionnaire |
| BMQ | Beliefs about Medicines Questionnaire |
| CI | Confidence Interval |
| CSM | Common-Sense Model |
| CVI | Content Validity Index |
| EF | Ejection Fraction |
| EHFScBs-9 | European Heart Failure Self-care Behaviour scale – 9-item |
| HF | Heart Failure |
| HFmrEF | Heart Failure with mir-ranged Ejection Fraction |
| HFpEF | Heart Failure with preserved Ejection Fraction |
| HFrEF | Heart Failure with reduced Ejection Fraction |
| ICC | Intraclass Correlation Coefficient |
| I-CVI | Item Content Validity Index |
| LVEF | Left Ventricular Ejection Fraction |
| MARS | Medication Adherence Reporting Scale |
| S-CVI/Ave | Scale-level Content Validity Index/Average |
| S-CVI/UA | Scale-level Content Validity Index/Universal Agreement |
| SPSS | Statistical Package for Social Sciences |
| WHO | World Health Organization |

# Chapter 1 – Introduction

## 1.1 Background to the Study

### *1.1.1 Definition of Heart Failure and its Aetiology*

Heart Failure (HF) is a chronic, progressive condition. It is defined as a condition in which the heart cannot pump enough blood to meet the metabolic requirements of body tissues (Lainscak et al., 2017). HF is considered as a clinical syndrome which can cause various symptoms, such as: shortness of breath, abdomen tightness, and fatigue. These can be accompanied by signs including pulmonary crackles, elevated jugular venous pressure, and peripheral oedema (Ponikowski et al., 2016).

HF can be the result of a structural and/or functional cardiac abnormality resulting in systolic and/or diastolic ventricular dysfunction (Ponikowski et al., 2016). The main causes of HF include abnormalities of the valves, coronary artery disease, hypertension, genetic cardiomyopathies, pericardial disease, congenital heart disease, and abnormalities in the heart rhythm and conduction (Ponikowski et al., 2016; Ziaeian & Fonarow, 2016).

### *1.1.2 The Incidence and Prevalence of Heart Failure*

**a. Incidence of Heart Failure.** Incidence rate of HF in European countries and the USA varies from 1 to 9 cases per 1000 person-years (Groenewegen et al., 2020). It is estimated that 64.3 million people worldwide are living with HF, and 3.6 million people are diagnosed with HF every year, in Europe alone (Groenewegen et al., 2020; López-Sendón, 2011).

HF is known to be causing a significant increase in mortality, morbidity, and healthcare expenditure costs. In 2012, HF health related costs in Malta were estimated at more than 13 million Euros (Cook et al., 2014). In addition, 5.7% of the deaths in

Malta in 2015 were attributable to HF (Department of Health Information and Research, 2015). In Mater Dei Hospital, Malta, the average admission rate of persons with HF, was reported to be 2500 patients per year between 2015 and 2019 (Hospital Activity Analysis Register, 2020). HF survival estimates vary from 50% after 5 years of diagnosis and 10% after 10 years of diagnosis (Roger, 2013). An increased risk of sudden death in 30 to 50% of individuals suffering from HF is seen among those with reduced ejection fraction (Packer, 2019).

**b. Prevalence of Heart Failure.** According to the Heart Disease and Stroke Statistics 2020, the prevalence of HF seems to be on the rise due to the aging population and its associated co-morbidities (Savarese & Lund, 2017; Virani et al., 2020). The prevalence rate of HF in Western European countries is known to be 0.4% to 2% of the population (López-Sendón, 2011). Consequently, in Europe more than 14 million people could be affected. In 2013, an overall prevalence of HF in both Europe and USA was reported to be ranging from 1 to 12% of the population, concluding that prevalence of HF is highly variable across the world (Roger, 2013). Hypertension appears to be the most prevalent risk factor of HF around the world, while ischaemic heart disease is most prevalent in Europe and North America (Virani et al., 2020).

## 1.2 Definitions of the Main key Terms

The main key terms were defined to ensure a common understanding of the terms and terminology between the author and the reader. The following key terms were used in this dissertation.

### *1.2.1 Illness Perceptions and Illness Representations*

Illness perceptions pertain to the individual's cognitive appraisal and personal understanding of a medical condition, and its potential consequences (Broadbent et al.,

2015; Sawyer et al, 2019). Illness perceptions are formed by the individual lived illness experiences (Sawyer et al., 2019). However, healthcare professionals, media, sociocultural norms, and attitudes also contribute to the formation of the individual's illness perceptions (Albert et al., 2014; Bonsaksen et al, 2013). The acquired information is processed through the individual's own selective mind, leading the individual to form his/her own illness representations.

In some instances, the term perception is interchangeably used with the term belief, however their definition differs significantly. It is not necessarily that those things which an individual believes in are perceived (Smith, 2001). Moreover, belief is defined as a dispositional state of mind which endures over time, and it may or may not be manifested. On the other hand, perceptions change over time (Smith, 2001). Owing to this variability in the use of the two terms, studies which used the term perceptions and/or beliefs, were included in the background to this research study.

### *1.2.2 Heart Failure Self-Care Behaviours*

The World Health Organization (WHO) defines self-care as "the ability of individuals, families and communities…. to cope with illness and disability with or without the support of a healthcare provider" (World Health Organization [WHO], 2020a, para. 1). In addition to this definition, the term self-care refers to those activities performed with the aim to improve or restore health and well-being (Strömberg et al., 2012).

### *1.2.3 Adherence*

In this dissertation, adherence was defined according to the WHO definition. The WHO defines adherence as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with

agreed recommendations from a health care provider" (WHO, 2003, p. 3). When comparing the term adherence to compliance, the main difference is the fact that adherence requires the patient's agreement to the recommendation.

## 1.3 Maintaining and Managing Heart Failure: The Association Between Illness Perceptions and Self-Care Behaviours

It is known and emphasised that individuals with HF must learn the necessary health related behaviours to face their chronic illness while being personally active in the monitoring of their health. It is imperative that individuals suffering from HF adhere to self-care behaviours and prescribed medications. The diagnosis of HF alone, however, can be of a great burden for the patient, and is compounded by the need to learn and practice the complex tasks necessary to manage the disease (Voelmeck, 2006). Owing to the complexity in HF self-care, it is not surprising that HF exacerbations are often related to nonadherence to self-care behaviours and HF medications (Cottrell et al., 2013).

According to the European Society of Cardiology Guidelines for the diagnosis and treatment of acute and chronic HF, self-care is the key to maintain and manage HF (Ponikowski et al., 2016). Individuals living with HF must implement several daily self-care behaviours. They may need to abstain, adapt, and maintain their behaviours (Toukhsati et al., 2015). They may need to abstain from smoking and alcohol intake; adapt a low sodium and low-fat diet while restricting the amount of fluids per day (1.5 to 2 Litres per day); maintain regular exercise, while monitoring their symptoms and adhering to their medication regimen. Individuals with HF are instructed to monitor their weight daily so that if an increase in weight >2Kg over three days is observed, they may manage accordingly (have an extra diuretic dose) or seek appropriate assistance (Toukhsati et al., 2015). They are also instructed to avoid any non-steroidal anti-

inflammatory drugs since they may cause hypervolaemia with the result of worsening HF (Varga et al., 2017).

The management of a condition, such as HF, is highly influenced by perceptions which the individual holds about his/her illness (Stanarević Katavić et al., 2016). Unfortunately, learning to live and manage a chronic illness, such as HF, is an exploratory process, since there is no specific road map which one can follow. In addition to the passively absorbed patient education provided by the healthcare professionals, learning self-care behaviours also involves the individual's daily illness experiences, where individuals learn how they respond to their illness (Kralik et al., 2004). These lived experiences, together with the acquired information, lead the individual to form a set of unique illness perceptions which the individual adopts as a representation of his/her illness. The development of these illness perceptions can be based on either accurate or inaccurate information. Information could be acquired from internal stimuli, such as experienced symptoms, and external stimuli, such as healthcare professionals and public opinion (Leone et al., 2016). For instance, the person might have his/her own illness representations about the causing factors of HF, how long it will last, how the illness can influence his/her current lifestyle and other routines, and how HF can be controlled or cured, either personally or therapeutically (Nur, 2018).

Illness perceptions have been reported to be important determinants of self-care behaviour with the result of improving self-care related outcomes, such as treatment adherence rates (Hagger & Orbell, 2003; Petrie et al., 2007). They can have a great impact on how the person living with HF understands the importance of self-care behaviours, with the result of influencing the individuals' motivation in being active in their own health (Albert et al., 2007; Mosleh & Almalik, 2014).

## 1.4 Purpose and Rationale of the Study

Despite the evidenced-based guidelines on the treatment of patients with HF (Ponikowski et al., 2016) and the several studies on the effectiveness of interventions to promote self-care in HF, recurrent hospitalisations remain a major concern for persons living with HF (Reeder et al., 2015). According to Fonarow et al. (2008), 70% of these recurrent hospitalisations can be prevented since they are attributed to poor self-care. Both the individuals living with HF and their healthcare professionals need to equip themselves with the necessary tools to increase the effectiveness of self-care behaviours with the aim to improve the quality of life. Knowing that assisting clients to learn self-care is not enough to achieve a behavioural change, led the researcher, to reflect on a more person-centred approach which is required to assist clients with their self-care and medication regimen (Artinian et al., 2002; Goodman et al., 2013; Moser & Watkins, 2008; Sneed & Paul, 2003).

From the researcher's experience, it is noted that every client has different approaches on how to implement and maintain self-care behaviours and medication adherence. Additionally, it is noted that some individuals are not adherent at all or they are selective of which HF self-care tasks to adhere to. On the other hand, some individuals are found to be highly adherent to both HF self-care behaviours and medications. There is not enough knowledge on why some people master their self-care behaviours and medication adherence, whilst some do not (Goodman et al., 2013). According to Nur (2018), these differences in behaviours can be the result of the illness perceptions which the patient exhibits towards his/her illness.

One proposed means to improve self-care, which this dissertation focuses on, is to have a better understanding of the individuals perceived perceptions towards their illness, and how these illness perceptions affect self-care behaviours and medication

adherence (Horowitz et al., 2004; Voelmeck, 2006). This approach of focusing on how the individuals' illness perceptions influence the adaptation to self-care behaviours, is defined as self-regulation, "i.e. how people direct their thoughts, feelings, and actions, so that strivings to obtain goals are effective" (Molloy et al., 2009, p. 716). Such approach assists the health-care professionals to better understand the individual's motivation to implement and maintain, or avoid self-care (Albert et al., 2014; Voelmeck, 2006). Only a few studies have explored the patients' perceptions towards HF, and how these perceptions may be associated with self-care, including medication adherence. Such studies include that of Albert et al. (2014), Goodman et al. (2013), Horowitz et al. (2004), MacInnes (2013), Mansouriyeh et al. (2017), Mei et al. (2019), Molloy et al. (2009) and Voelmeck (2006). A detailed appraisal of these studies together with their findings can be found in chapter 2.

As a health-care professional, it is of great importance to be sensitive enough to explore the illness perceptions of persons living with HF and how these illness perceptions relate to their self-care behaviours. By acknowledging both the perceptions and behaviours while adopting a person-centred approach, the health-care professionals can further assist their clients to achieve the necessary changes in their illness perceptions and self-care behaviours. Consequently, the therapeutic process can be enhanced by formulating interventions which assist those individuals living with HF in building a good understanding about HF and develop an accurate set of illness perceptions (Williams, 1995). This is beneficial to improve self-care and medication adherence. As a result, clinical outcomes, such as reduction in hospitalisations with exacerbations of HF and increase in adherence rates, can be improved (MacInnes, 2013).

## 1.5 Brief Overview of the Research Methodology

The main research question of this dissertation is: "Are the illness perceptions of persons living with HF related to their self-care behaviours, including medication adherence?" To accomplish this study, a descriptive correlation, cross-sectional design was used. A positivist (quantitative) epistemological perspective was utilised with a deductive approach. Original primary data was collected with the use of a questionnaire.

As a theoretical framework, this study was guided by the Common-Sense Model (CSM) of Self-Regulation of Health and Illness by Leventhal et al. (1980). The CSM was used to assist in the identification of the individuals' perceptions towards their illness (Vazini & Barati, 2014). Furthermore, it was used to further explain and predict whether the illness perceptions are related to self-care, including medication adherence. This was discussed in further detail in chapter 2.

## 1.6 Conclusion

In summary, HF is one of the chronic diseases where the affected individual must be knowledgeable about and personally active in his/her own care. Additionally, it is of great importance that individuals living with HF establish a set of accurate illness perceptions to self-maintain and self-manage HF effectively. This study is addressing the gap in literature regarding the individuals' perceptions towards their illness, HF, and how these same perceptions influence the maintaining of HF self-care behaviours and medication adherence. In the next chapter, a thorough literature search in relation to this dissertation was carried out to identify and critically analyse what is already known.

# Chapter 2 – Literature Review

## 2.1 Introduction

In the previous chapter, the purpose and the rationale of this dissertation were disclosed while introducing the main components of this dissertation. This chapter entailing the literature review, explains the choice of the Common-Sense Model (CSM) of Self-regulation of Illness as a conceptual framework for this dissertation. Existing literature on the illness perceptions, of persons living with HF, and their association with HF self-care behaviours, including medication adherence, was explored, and critically appraised. Moreover, their study findings were highlighted and compared to each other.

## 2.2 Theoretical Framework

Several health behaviour theories and models have been used to study the individual`s behaviour in managing his/her illness (Voelmeck, 2006). Such theories and models include: the Social Cognitive Theory (Bandura, 1986), the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), Theory of Reasoned Action (Ajzen & Fishbein, 1980), Social Support (House et al., 1988; Israel, 1982), the Health Belief Model (Hochbaum, 1958; Rosenstock, 1966), Theory of Planned Behaviour (Ajzen, 1991), and Health Locus of Control (Lau, 1982). These theories and models have concentrated on factors regarding the implementing, initiating, and maintaining, stress response, intention, social support, attitudes, beliefs, subjective norms, and control (Voelmeck, 2006).

In this dissertation the CSM of Self-regulation of Illness was used as a theoretical framework to explore the illness perceptions of individuals living with HF (Leventhal et al., 2001). The rationale for choosing this model is taken from the perspective that the CSM was developed to understand the individual who is

experiencing the illness and to reveal his/her unique illness perceptions (Tiemensma et al., 2011). Moreover, the CSM proposes that illness perceptions influence the way individuals cope with their illness, with the result of affecting the outcomes (Leventhal et al., 2001). Due to this fact, this theory was used to explain the association between the illness perceptions of persons living with HF and their self-care behaviours, including medication adherence. Another reason why this model was chosen is the fact that the CSM helps in the translation of intra- and interpersonal processes of HF management into objective indicators, thus allowing the generation and testing of hypotheses (Breland et al., 2012).

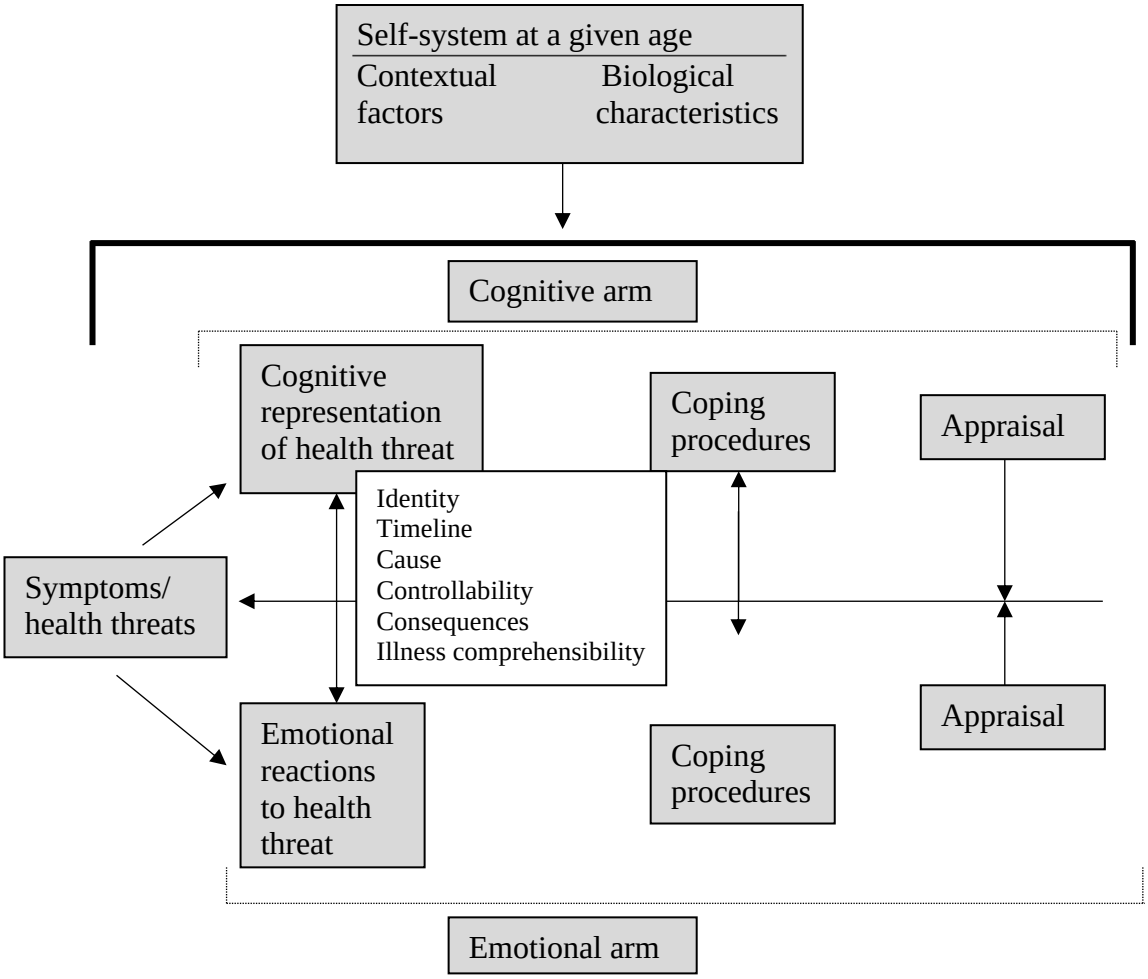
In illness perception, both the abstract (i.e. personal thoughts and reflections) and health information are integrated, leading to the formation of the individual's cognitive representations and emotional reactions to their illness (Leventhal et al., 2001). Furthermore, this leads to the formation of the individual's meaning of the disease and illness experience (Sawyer et al., 2019). According to Leventhal et al. (1984), illness perceptions are guided by three basic sources of information. The first is the general pool of information which has been already assimilated by the individual while being exposed to the everyday activities with others, and through cultural knowledge about the illness, attained from ideas, thoughts, education, and beliefs. The second source is the information attained from the external social environment, from perceived significant others and authoritative sources, such as healthcare professionals (Diefenbach & Leventhal, 1996). The third source of the illness perceptions is the current experience of the illness and its symptoms (Averous et al., 2018).

Over time, the individual conducts an assessment on how the illness is affecting him/her (Broadbent et al., 2015). This assessment can lead the individual to change his/her cognitive representations and emotional responses (Broadbent et al., 2015). The appraising and changing process is presented by a feedback loop (Broadbent et al.,

2015). The cognitive and emotional representations of illness perceptions which form the two arms of the CSM are presented in Figure 2.1.

**Figure 2.1**

*The Common-Sense Model of Self-Regulation of Illness*




*Note*. Extracted from Shifren (2003, p. 360)

### *2.2.1 The Cognitive arm of the Common-Sense Model of Self-Regulation*

The cognitive arm of the CSM consists of the cognitive representations of health threat, coping procedures, and appraisal. The cognitive representation of health threat incorporates six main components which describe the illness representations. These six

components include: the identity of the illness; cause, timeline, consequences, curability/controllability, and illness comprehensibility (Hale et al., 2007).

**a. Identity.** The first component, illness identity, refers to those statements or labels given by the individual to acknowledge his/her illness (e.g. "I think I have a weak heart"). Illness identity may also refer to the degree of experienced symptoms, and to the knowledge regarding the symptoms caused by the illness (e.g. "Heart Failure makes me tired and short of breath").

**b. Cause.** The dimension of cause looks at the individualistic ideas or assumptions about what has caused their HF (e.g. "HF was caused due to my stress" or "because I am obese" or "because I have inherited it from my father"). This may not be completely biomedically accurate and could be affected by the internal stimuli, such as experiences with HF symptoms, and external stimuli, such as knowledge about HF. Other examples of external stimuli include others' discourses with healthcare professionals, media sources, stress, and environmental pollution (Hale et al., 2007).

**c. Timeline.** When describing timeline, Diefenbach and Leventhal (1996) defined it as the perceptions about the expected timeframe that the condition may last. For example, whether HF is viewed as an acute or chronic condition.

**d. Consequences.** The dimension of consequences refers to the individuals' perceptions about the expected effects and outcomes of the illness (Broadbent et al., 2006). Perceptions of how the illness could affect their functional capacity, both physically and psychologically (Hale et al., 2007). In HF these consequences may include the lack of urge to do daily tasks due to fatigue or shortness of breath, which may lead to emotional disturbances.

**e. Personal Control and Treatment Control.** The curability/controllability dimension is the extent to which the individual perceives the illness as curable or at

least controllable (e.g. “If I restrict the amount of fluids per day I prevent my legs from getting swollen”). Additionally, it also takes into account the individuals’ self-input in achieving this cure/control (Personal control) through the performance of coping behaviours, such as HF self-care behaviours (e.g. daily weight monitoring, adherence to medication regime, and consumption of a low sodium diet) (Hale et al., 2007). The condition can also be perceived to be medically controlled (Treatment control), which refers to the perception regarding the utility of treatment in controlling the illness.

**f. Illness Comprehensibility.** The last cognitive representation, illness comprehensibility, refers to the individual’s coherent understanding of the illness. The illness comprehensibility perception may influence the individual to perceive his/her illness in such a way (Richardson et al., 2017).

The cognitive arm incorporates the coping procedures. These refer to the actual behaviour implemented by the individual to respond to the illness. The illness perceptions are the influential aspects for the choice which the individual makes to cope with and control the illness. It is important to acknowledge that the individual can have various options from which he/she can select to cope with the health threat. The appraisal for the cognitive arm is where the response to the health threat is evaluated; whether the threat has been lessened or eradicated. According to Leventhal (1990), it is a process implemented by the individual to evaluate the effectiveness of the chosen coping procedures.

In summary, the cognitive arm has three main stages. These include: the illness perceptions, represents the motivation; the coping procedures, represents the actions taken; and the appraisals, which evaluates whether the goals were met (Voelmeck, 2006).

### *2.2.2 The Emotional arm of the Common-Sense Model of Self-Regulation*

In addition to the cognitive illness representations, the CSM proclaims that emotional responses may result (Leventhal et al., 1984). Like the cognitive arm, the emotional arm is also divided into three stages (Figure 2.1). These include the perceived emotional reaction to the illness, coping procedures, and appraisals.

**a. Emotions and Concerns.** The emotional reaction to the health threat represents the dealing of emotions and concerns resulting from illness. The emotions perception refers to the perceived emotional disturbance caused by the illness, such as anger, fear and/or feeling depressed (Broadbent et al., 2006). On the other hand, the concern perception refers to the perceived level of preoccupation about the situation. The emotional reaction is a subjective manner which represents the response of an individual to a health threat. The coping procedures are the action plans taken to deal with the emotional response. These action plans could result from any received social support, re-evaluating the problem, and preventing the threat from happening (Leventhal, 1990). The appraisal part is the evaluation process taken to determine whether the action plans taken were appropriate and sufficient to deal with the emotional responses (Leventhal, 1990).

The CSM recommends that for an intervention to be effective, it must either be on the same wavelength of the individuals' perceptions or provide an appropriate intervention that assists the individual to achieve the necessary change needed in his/her own illness perceptions (Breland et al., 2012). In this way, the CSM can be used as a person-centred approach to target self-care behaviours and medication adherence.

## 2.3 Literature Search Strategy

Research on the relationship between the illness perceptions of persons living with HF and their self-care behaviours, including medication adherence was carried out. The following sections, of the literature review chapter, describe the whole process taken to retrieve the most eligible studies from the existing literature. The eligible studies were then critically appraised, and their findings were compared to each other.

### *2.3.1 Eligibility Criteria*

During the search process, the following inclusion and exclusion criteria were considered. These are shown in Table 2.1.

**Table 2.1**

*The Inclusion and Exclusion Criteria*

| Criterion themes | Inclusion criteria | Exclusion criteria |
|---|---|---|
| Participants | • Participants of ≥18 years of age. | • Participants of <18 years of age. |
| Exposure | • HF the main chronic disease studied.<br>• Studies who included HF patients who suffer from other comorbidities. | • Studies which focused solely on other conditions apart from HF. |

| Criterion themes | Inclusion criteria | Exclusion criteria |
|---|---|---|
| Outcome Exposure | • Studies which reported the illness beliefs or perceptions or representations of HF patients in relation with adherence to HF self-care<br>• and/ or adherence to medication. | • Studies which did not explore the illness beliefs or perceptions or representations of HF patients in relation to HF self-care behavioural outcomes of the same cohort of patients.<br>• And/or studies which did not explore the illness beliefs or perceptions or representations of HF patients in relation to medication adherence as a behavioural outcome.<br>• Evaluation of the intervention was the only outcome measured. |
| Language | • Studies written in English language. | • All other languages. |
| Text availability | • Available in full text. | • Not available in full text. |
| Time Frame | • January 1990 to March 2021. | • Studies published before January 1990. |

### *2.3.2 Information Sources*

Studies were retrieved from several electronic databases which can be accessed from the electronic library of the University of Malta. Databases searched included: CINAHL Complete, Academic Search Ultimate, AgeLine, Cochrane Central Register of

Controlled Trials, Cochrane Clinical Answers, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, MEDLINE Complete, APA PsycInfo, Scopus, PubMed and PubMed Central. Google Scholar and the University of Malta HyDi search engine were also used in the search strategy to retrieve any relevant literature. Grey literature was searched in Google search engine, Open Grey and Webinars through the European Society of Cardiology official website. Two other important databases used for the retrieval of literature were ResearchGate and Academia. Both HyDi and Google search engine were frequently used to retrieve any studies which were not found as full text in the searched database. Reference lists of both relevant and not relevant studies were screened to retrieve other relevant studies. In this case, HyDi, Google Scholar and Google search engine were used to retrieve such studies.

### *2.3.3 Search*

A thorough search in the mentioned databases was carried out. All the primary keywords were searched in the U.S. National Library of Medicine to retrieve any MeSH terms. This was beneficial to increase the sensitivity and specificity of the searching process. Boolean logic operators and Wildcards were used to retrieve any word combinations while narrowing and broadening the search where required. Using this search strategy, any synonym word and abbreviations were considered. The search terms are tabulated in Table 2.2.

**Table 2.2**

*Search Terms*

| |
|---|
| perception* OR representation* OR belief* |
| AND behavio?r* |
| AND “heart failure” OR “HF” OR “myo* failure” OR “cardi*” |
| AND “self-management” OR “self management” OR “self-care” OR “self care” OR “self-control” OR “self control” OR “self-regulat*” OR “self regulat*” OR “self-monitor*” OR “self monitor*” |
| AND complian* OR adheren* OR persisten* OR therap* manag* |

Table 2.3 represents the full search strategy for the CINAHL Complete database. This search strategy was performed in the 14 databases which were previously mentioned above.

**Table 2.3**

*CINAHL Complete Database Search Strategy*

| | |
|---|---|
| The Boolean logic - combinations used<br>AND<br>OR | perception*, behavio?r*, heart failure, self-care, adherenc* |
| MeSH terms used together with Boolean logic according to their respective field and Wildcards for any word combination | Field 1: belief* OR perception* OR representation*<br>Field 2: AND behavio?r*<br>Field 3: AND “heart failure” OR “HF” OR “myo* failure” OR “cardi*”<br>Field 4: AND “self-management” OR “self management” OR “self-care” OR “self care” OR “self-control” OR “self control” OR “self-regulat*” OR “self |

| | |
|---|---|
| | regulat*" OR "self-monitor*" OR "self monitor*"<br>Field 5: AND complian* OR adheren* OR persisten* OR therap* manag* |
| Year of publication | No limiter was used |
| Language | English |
| Text available | Full or not in full text |

### *2.3.4 Study Selection*

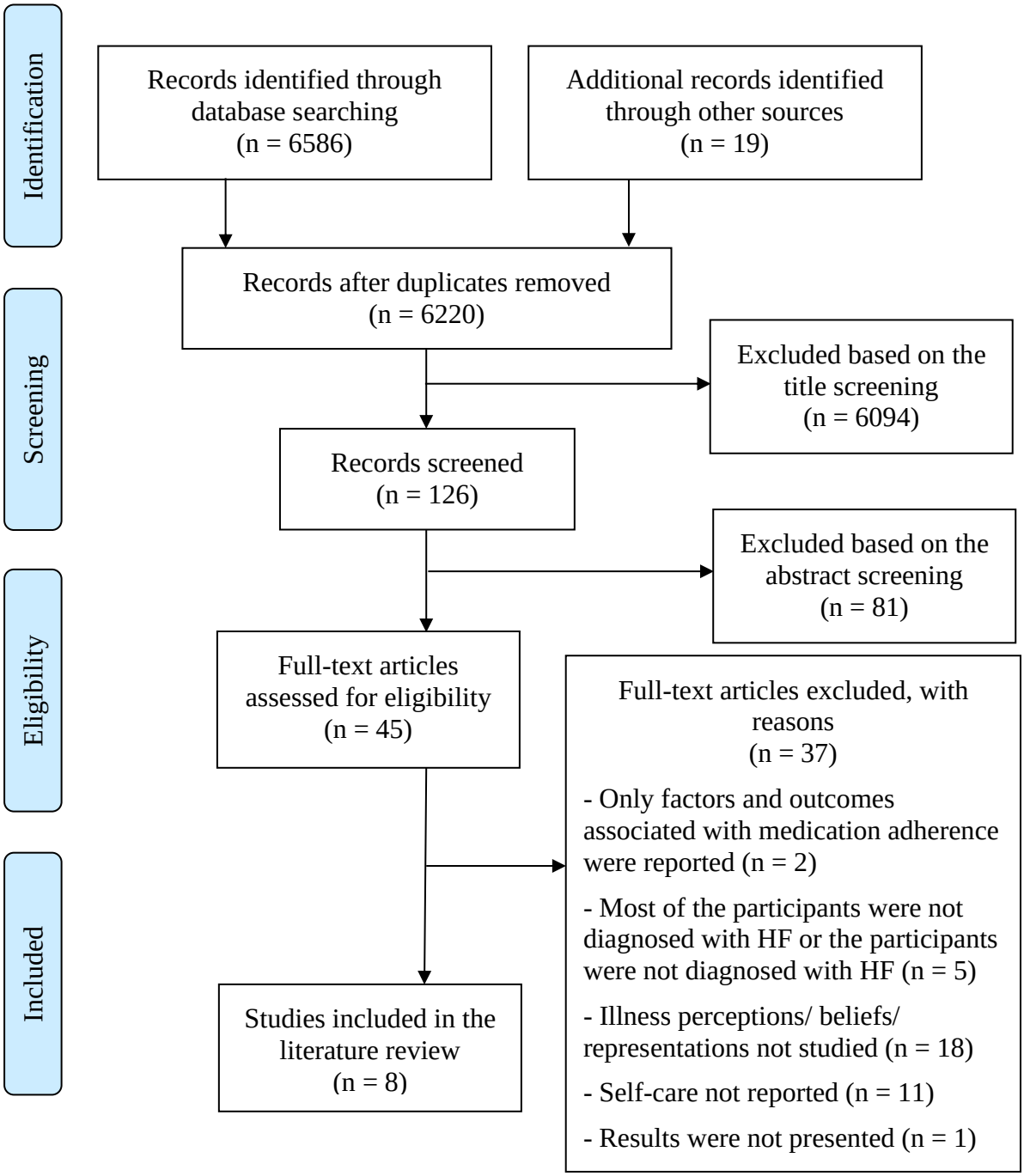
The search conducted in various databases yielded a total of 6586 studies. In addition to this, 19 other studies were retrieved from Google Scholar, ResearchGate and Academia. After eliminating any retrieved duplicates, a total of 6220 studies were left. From this total, 6094 studies were excluded after screening their title, leaving 126 studies for abstract screening. Eighty-one studies were removed after screening the abstract, leaving 45 studies to be full text screened in order to determine whether they reach the eligibility criteria. Another 37 articles were excluded. Reasons for exclusion included: 2 study focused only on the facilitators and barriers affecting medication adherence; 5 studies had the majority of the participants not diagnosed with HF or the recruited participants were not diagnosed with HF; 18 studies did not examine the illness beliefs or illness perceptions or illness representations; 11 studies did not report self-care adherence; and another 1 study did not present the results.

A total of 8 studies met the inclusion criteria and were included in this literature review. These included: Albert et al. (2014); Goodman et al. (2013); Horowitz et al. (2004); MacInnes (2013); Mansouriyeh et al. (2017); Mei et al. (2019); Molloy et al. (2009); and Voelmeck (2006). One of the included studies was an unpublished dissertation for a doctoral of philosophy (Voelmeck, 2006).

The PRISMA flow diagram by Liberati et al. (2009) was used as a visual diagram to present a summary of the above selection process (Figure 2.2).

**Figure 2.2**

*The PRISMA Flow Diagram*



### *2.3.5 Study Characteristics*

The 8 eligible articles which met the inclusion criteria were all published in the English language between 2004 and 2019. All the studies were observational studies with the majority being cross-sectional studies. Three studies were conducted in Europe (Scotland and 2 in England) (Goodman et al., 2013; MacInnes, 2013; Molloy et al., 2009), 3 in America (Texas, Ohio, Michigan and New Jersey) (Albert et al., 2014; Horowitz et al., 2004; Voelmeck, 2006), and 2 study were conducted in Asia (Iran and China) (Mansouriyeh et al., 2017; Mei et al., 2019). The total number of participants, included in the studies, varied from 19 (Horowitz et al., 2004) to 210 (Mei et al., 2019). Most of the participants were male (60%). All the participants were diagnosed with HF.

One study focused on the illness perceptions and medication adherence of individuals living with HF (Molloy et al., 2009). Since this study examined both the illness perceptions and the behaviours of HF patients concerning adherence to medications and since the title of this research also reflects the illness perceptions and behaviours concerning medication adherence, this study was classified as eligible. The other 7 studies (Albert et al., 2014; Goodman et al., 2013; Horowitz et al., 2004; MacInnes, 2013; Mansouriyeh et al., 2017; Mei et al., 2019; Voelmeck, 2006) studied the illness perceptions and behaviours of HF patients concerning self-care adherence, additionally they also had an element of medication adherence in the tools used for data collection.

A summary of the data extracted from these studies is presented in Table 2.4.

**Table 2.4**

*Summary of the Included Studies*

| **Title of the study** | Heart Failure beliefs and self-care adherence while being treated in an emergency department. | Illness perception, self-care behaviour and quality of life of Heart Failure patients: A longitudinal questionnaire survey. | A story of maladies, misconceptions and mishaps: effective management of Heart Failure. | Relationships between illness representations, treatment beliefs and the performance of self-care in Heart Failure: a cross-sectional survey. | The predictive roles of self-efficacy, illness perception, and social support in self-care of patients with Heart Failure. | Gender differences in self-care maintenance and its associations among patients with chronic Heart Failure. | Adherence to angiotensin-converting-enzyme inhibitors and illness beliefs in older Heart Failure patients. | The Relationship of illness representation and self-care behaviours to health-related quality of life in older individuals with Heart Failure. |
|---|---|---|---|---|---|---|---|---|
| **Authors** | Albert et al. | Goodman et al. | Horowitz et al. | MacInnes | Mansouriyeh et al. | Mei et al. | Molloy et al. | Voelmeck |
| **Year of publication** | 2014 | 2013 | 2004 | 2013 | 2017 | 2019 | 2009 | 2006 |
| **Language** | English | English | English | English | English | English | English | English |
| **Setting** | 3 large health care centres. | 3 hospitals. | Urban, academic, tertiary care hospital | Three community-based HF services. | Tabriz Research Treatment Centre of Heart | Hospital | Local specialist HF clinic and Medicine for the Elderly clinic | Multiple sites |
| **Country, Continent** | Ohio, Michigan, New Jersey America | England, Europe | America | South East, England, Europe | Tabriz, Iran Asia | Shandong, China Asia | Scotland, UK, Europe | Texas, America |
| **Study Design** | Cross-sectional–Observational study | Longitudinal survey–Observational study | Cross-sectional – Semi-structure interviews – Observational study | Cross-sectional–Observational study | Cross-sectional–Observational study | Cross-sectional–Observational study | Cross-sectional–Observational study | Cross-sectional – Observational study |

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| **Theoretical framework** | Common Sense Self-Regulation Model | *Not reported* | Common Sense Self-Regulation Model | Common Sense Self-Regulation Model | Common Sense Self-Regulation Model | Information-Motivation-Behavioural Skills model | Common Sense Self-Regulation Model | Common Sense Self-Regulation Model |
| **Inclusion and exclusion criteria** | **Inclusion criteria:**<br>HF of any aetiology or type (systolic or preserved EF), diagnosed with acute decompensated HF. | **Inclusion criteria:**<br>Patients admitted with decompensated HF.<br>>18 years of age<br>Fluent in English<br>Able to comprehend the questionnaires.<br>**Exclusion criteria:**<br><18 years of age.<br>Unable to understand English.<br>Patients who are cognitively impaired. | **Inclusion criteria:**<br>Patients admitted and/or treated for HF in the hospital, the emergency department or seen in internal clinics (Medicine or cardiology).<br>**Exclusion criteria:**<br><18 years of age.<br>Cannot speak English.<br>Living in a skilled nursing facility or nursing home.<br>Lived outside the local area.<br>Currently hospitalised. | **Inclusion criteria:**<br>Patients with an EF of ≤35%.<br>**Exclusion criteria:**<br>Unable to read or write in English. | **Inclusion criteria:**<br>Participants had to be able to speak Persian language.<br>Diagnosed with HF by an echocardiogram and cardiologist diagnosis, with ≥1 year experience. | **Inclusion criteria:**<br>A confirmed HF by cardiologist.<br>≥18 years of age, absence of cognitive impairment.<br>Fluent in Chinese.<br>**Exclusion criteria:**<br>Mentally or cognitively impaired.<br>Suffering from a serious or life-threatening disease, such as a malignancy or renal failure. | **Inclusion criteria:**<br>Patients aged ≥70 years who are diagnosed with HF according to the ESC guidelines.<br>Patients in NYHA Class II or III.<br>An evidence of left systolic dysfunction.<br>**Exclusion criteria:**<br>Patients with uncontrolled AF, significant aortic stenosis, sustained VT, recent MI.<br>Assisted in walking.<br>Mental test score >6 of 10.<br>Or attending physiotherapy or rehabilitation. | **Exclusion criteria:**<br>Unable to comprehend and speak English.<br>And/or were living in a long-term-care facility (Being 24-hour supervised and assisted with their activities of daily living). |

| **Participants** | HF patients | HF patients | HF patients | HF patients | HF patients | HF patients | HF patients | HF patients |
|---|---|---|---|---|---|---|---|---|
| **Age (years)** | *M* = 65, *SD* = 15.2 | *M* = 71, *SD* = 12.8 | 52 to 89 years | *M* = 71, *SD* = 1.99 | *M* = 64, *SD* = 10.32 | *M* = 62, *SD* = 12.8 | *M* = 80, *SD* = 4.6 | 55 to 97 years |
| **Gender** | M: 53.9%, F: 46.1% | M: 70%, F: 30% | M: 52.6%, F: 47.4% | M: 74.1%, F: 24.9% | M: 68.4%, F: 31.6% | M: 46%, F: 54% | M: 57%, F: 43% | M: 59%, F: 41% |
| **Ethnicity** | Caucasian, non-Caucasian | *Not reported* | African American, Latino, Caucasian | White British | *Not reported* | *Not reported* | *Not reported* | Anglo, 12% African-American, 9% Latino/Hispanic |
| **No. of participants** | 195 | Initial sample: 88<br>Followed-up sample: 50 | 19 | 169 | 149 | Initial sample: 225<br>Sample after final analyses: 210 | 58 | 98 |
| **Data recording methods used** | • Demographic and clinical data<br>• The Survey of Illness Beliefs in HF<br>• Self-Care Adherence Survey | • Demographic and clinical variables<br>• IPQ-R<br>• SCHFI<br>• HADS<br>• MLWHF | • Semi-Structure interviews | • Demographic and clinical data<br>• IPQ-R<br>• BMQ<br>• LAYHFQ | • Background data<br>• Self-care behaviour scale<br>• GSES<br>• B-IPQ<br>• Social support scale | • Demographic and clinical data<br>• SCHFI<br>• Knowledge of heart failure questionnaire<br>• IPQ-R<br>• MMSE | • Socio-demographic and clinical data.<br>• Blood results on ACE activity.<br>• IPQ-R | • Demographic data<br>• IPQ-R<br>• SCHFI<br>• LHFQ |
| **Risk of bias** | *Not reported* | *Not reported* | *Not reported* | *Not reported* | Self-reporting bias was declared. | Self-reporting bias was declared. | Social desirability or recall bias was declared. This could be the result of self-reporting on medication adherence. | Self-selection of individuals. |

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| **Ethical consideration** | An informed consent was provided.<br><br>Study was ethically approved. | Informed consent was collected.<br>Study was ethically approved. | Written informed consent was collected. | Witten informed consent was collected.<br>Study was ethically approved. | Signed consent and voluntary participation.<br>Study was ethically approved. | Signed written informed consent was collected.<br>Study was ethically approved. | Written informed consent was collected.<br>Study was ethically approved. | Informed consent was obtained.<br>Study was ethically approved. |
| **Funding sources** | *Not reported* | Funded. | *Not reported* | Not funded. | None was declared. | Funded. | Funded. | Partial funded. |
| **Declaration of conflict of interests** | *Not reported* | None were declared | *Not reported* | None were declared. | None were declared. | None were declared. | None were declared | *Not reported* |

**ACE** (Angiotensin Converting Enzyme); **AF** (Atrial Fibrillation); **B-IPQ** (Brief Illness Perception Questionnaire); **BMQ** (Beliefs about Medicines Questionnaire); **CHF** (Chronic Heart Failure); **EF** (Ejection Fraction); **ESC** (European Society of Cardiology); **F** (Female); **GSES** (General Self Efficacy Scale); **HADS** (Hospital Anxiety and Depression Scale); **HF** (Heart Failure); **IPQ-R** (Illness Perception Questionnaire-Revised); **LHFQ** (Living with Heart Failure Questionnaire); **LAYHFQ** (Looking After Yourself with Heart Failure Questionnaire); **M** (Male); ***M*** (Mean), **MI** (Myocardial Infarction); **MLWHF**: The Minnesota Living with Heart Failure Questionnaire; **MMSE** (Mini-Mental State Examination); **NYHA** (New York Heart Association); **SCHFI** (Self-Care of HF Index), ***SD*** (Standard deviation); **VT** (Ventricular Tachycardia).

## 2.4 Critical Appraisal of the Eligible Studies

The Strengthening the Reporting of Observational studies in Epidemiology (STROBE) guidelines were used to critically appraise the eligible studies (Appendix A). The STROBE guidelines were developed to aid the researcher when conducting an observational study whilst ensuring that adequate reporting with its strengths and weaknesses is done (Cuschieri, 2019). Furthermore, the STROBE guidelines enable the reviewers to critically appraise the study (Cuschieri, 2019; Vandenbroucke et al., 2007).

All the appraised studies addressed a clearly focused question. They clearly stated the population and outcomes being observed in their title or abstract or introduction. Moreover, the aims and objectives of their study were clearly revealed. The only two studies which indicated the study design in their title was that of MacInnes (2013), which was a cross-sectional study, and Goodman et al. (2013) which was a longitudinal questionnaire survey. Albert et al. (2014), Mansouriyeh et al. (2017), Mei et al. (2019) and Voelmeck (2006) revealed their study design in their abstract. The only two studies which pre-specified their hypothesis was that of Horowitz et al. (2004) and MacInnes (2013). Horowitz et al. (2004) categorised their hypothesis according to the Common-Sense Model of Self-regulation of Illness, which they used as a theoretical framework for their study, while MacInnes (2013) used the CSM as a theoretical framework to hypothesise that the illness representations about HF and its treatment, guide the individual to choose his/her coping procedures.

All the studies collected their data using subjective measures, including, surveys, questionnaires, or interviews. Self-reporting of data could have resulted in bias, such as recall bias. One of the main strengths of Molloy et al. (2009) study, is the use of an objective measure to determine the medication adherence rates of their participants. They measured serum ACE in older persons living with HF while investigating the

association between the illness perceptions and the adherence with ACEi drugs. The advantage of using objective measures is the fact that they reduce the risk for recall bias and misclassification of results (Pannucci & Wilkins, 2010). Horowitz et al. (2004) collected their data by means of an interview. The data was collected by two physicians who were trained in qualitative research methods, hence minimising the risk of interviewer bias. Six of the studies used the Illness Perception Questionnaire-Revised (IPQ-R) or the Brief Illness Perception Questionnaire (B-IPQ) to collect data about the illness perceptions of individuals living with HF (Goodman et al., 2013; MacInnes, 2013; Mansouriyeh et al., 2017; Mei et al., 2019; Molloy et al., 2009; Voelmeck, 2006). Both questionnaires are considered reliable and valid (Broadbent et al., 2006). MacInnes (2013) study was the only study which reported the internal validity of the instruments, $\alpha = 0.74$ for the IPQ-R and $\alpha = 0.76$ for the Beliefs about Medicines Questionnaire (BMQ). By using the BMQ, participants' perceptions about their medicines were also acknowledged. Albert et al. (2014) used the HF Belief Scale to measure the illness perceptions of their participants. They indicated that the validity of the questionnaire was reported in a previous study by Albert and Zeller (2007), but they did not present it in their study. Moreover, Mansouriyeh et al. (2017) did not reveal the validity of the questionnaires used. To measure self-care behaviour, three studies used the Self Care of HF Index (SCHFI) (Goodman et al., 2013; Mei et al., 2019; Voelmeck, 2006) and one study used the Self-Care Adherence Survey (Albert et al., 2014). Only Voelmeck (2006) and Goodman et al. (2013) presented their validity of the questionnaire, $\alpha = 0.75$ and $\alpha = 0.784$, respectively. Mei et al. (2019) and Molloy et al. (2009) did not report the validity and reliability of their questionnaires which were used to collect their data. Therefore, one cannot determine whether the questionnaires had good psychometric properties.

All the eligible studies had declared their eligibility criteria together with the sources and methods used to select the participants. Goodman et al. (2013), Horowitz et al. (2004), MacInnes (2013) and Voelmeck, (2006), declared that they included only those participants who can speak or write in English, Mansouriyeh et al. (2017) included only participants who are fluent in Persian languages, and Mei et al. (2019) included only participants who can speak and write in Chinese. As a result, this inclusion criterion could result in selection bias. Two of the studies declared that they used a convenience sampling strategy for the selection of the participants (Albert et al., 2014; Voelmeck, 2006) while Horowitz et al. (2004) used a random sampling strategy, which was not necessary since their study was a grounded theory study.

Five of the studies had explained how they arrived at their actual sample size (Goodman et al., 2013; Horowitz et al., 2004; MacInnes, 2013; Molloy et al., 2009; Voelmeck, 2006). Both Voelmeck, (2006) and MacInnes (2013) had a power calculation of 0.8, with the later stating that they used the Cohen's d power calculation. Goodman et al. (2013) calculated their sample size by using assumptions to detect the association between the illness perception questionnaire and self-efficacy based on statistical tests of a previous study by Lau-Walker (2007). The other studies did not state their power analysis; thus, it is difficult to state whether their sample truly represents the defined population. Four of the studies acknowledged that they had recruited a small sample size which could had limited the significance and the generalisability of their findings (Goodman et al., 2013; Horowitz et al., 2004; MacInnes, 2013 Voelmeck, 2006).

All the studies reported the number of potential eligible participants while including their demographic and clinical data, except for Mansouriyeh et al.'s (2017) study in which demographic and clinical data were limited. Results with their *p*-value and confidence interval (CI) of 95% were reported in three of the studies (Albert et al.,

2014; Goodman et al., 2013; Molloy et al., 2009). Moreover, Mansouriyeh et al. (2017), Mei et al. (2019), Molloy et al. (2009) and Voelmeck (2006) presented the full test statistic. Such interpretation of results increases the reliability of the findings. On the other hand, three of the studies presented only the *p*-value for most of the results (Goodman et al., 2013) or the full test statistic for some of the results (Albert et al., 2014; MacInnes, 2013).

In the discussion section, all the eligible studies had summarised their key results while referring to their study objectives. Furthermore, their findings were discussed while being compared to other findings from previous studies. The most reported limitations which were common amongst the studies were a small sample size and self-reporting of questionnaires, which might account for over-reporting, socially desirable answers, and recall bias. Additionally, Albert et al. (2014) declared that their sample included mainly non-Caucasian participants and stated that their findings cannot be generalised to other ethnicities. Since Goodman et al.'s (2013) study was done in hospitals which provide a specialised HF service, they declared that their findings cannot be generalised to other district hospitals without a specialised HF service. Moreover, participants in Mei et al.'s (2019) study were recruited from one hospital, and this might also limit the generalisability of the findings. Voelmeck (2006) had also declared that the revealed findings cannot be generalised to all older individuals living with HF since their sample was confined to one geographical area. This limitation was also declared by Mei et al. (2019). To add on, Horowitz et al. (2004) and Mansouriyeh et al. (2017) declared that their study also cannot be generalised since it was focused on urban dwelling participants and due to personal differences of the participants, respectively.

In conclusion, one cannot determine whether the outcomes of the appraised studies could be implemented to the local individuals living with HF. The main reason

being is the fact that the Maltese population might have different illness perceptions which might be related in different ways to their behavioural outcomes, including adherence in HF self-care and medications. Another important confounding factor is the socio-demographic background, which brings with it, different cultural beliefs and values leading to different internal and external attributions to illness perceptions. Thus, it is recommended that further research on the illness perceptions and self-care behaviours of individuals living with HF should be conducted, especially amongst the Maltese population.

## 2.5 Results of Individual Studies

In this section, the literature findings were compared to each other, and reported according to the objectives of this dissertation. A summary of the literature results for each eligible study is presented in Table 2.5.

**Table 2.5**

*Results of Individual Studies*

| Author | Main findings |
|---|---|
| Albert et al. (2014) | The HF illness beliefs mean (SD) score reported was that of 2.77 (*SD* = 0.25) (95% CI 2.73 – 2.80), which was significantly lower than the cut-off score ($p < 0.001$). HF self-care adherence mean score was at mid-point 5.1 (Best adherence = score of 10). The highest behavioural adherence was that of taking medications without skipping or missing doses with a mean score of 7.8 (*SD* = 3.3). The lowest was that for daily weight monitoring with a mean score of 3.5 (*SD* = 3.5).<br><br>Higher education level (ρ, -0.28; $p = 0.01$), younger age (only $p$ -value was reported, $p < 0.001$) and choosing low sodium foods (only $p$ -value was reported, $p = 0.04$) were associated with higher |

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| | accuracy level of HF beliefs. HF illness beliefs were not found to be associated with self-care, $p = 0.15$ (only the $p$ -value was reported). |
| Goodman et al. (2013) | Patients reported that they believed the cause of their illness was outside their control.<br><br>The most common perceived causes of HF reported were aging, chance or bad luck, heredity, and stress or worry.<br><br>Perception that HF could be personally, and treatment controlled declined over time (only $p$ -value was reported, $p = 0.001$).<br><br>Perception that HF have a chronic timeline increased over time (only $p$ -value was reported, $p < 0.0001$).<br><br>Over time self-care maintenance (e.g. weighing daily) was improved, [baseline 54.2 ($SD$ = 12.1), at 2 months 61.2 ($SD$ =11.9), at 6 months 61.2 ($SD$ = 13.1); $p < 1x10^{-4}$], however self-care management (e.g. adjusting diuretic dose) (only $p$ -value was reported, $p = 0.78$) and self-care confidence (only $p$ -value was reported, $p = 0.45$) did not improve over time.<br><br>Self-care confidence was reported to be related with illness comprehensibility at both 2 and 6 months (Adj $R^2 = 0.25$, $p < 0.0001$, Adj $R^2 = 0.22$, $p = 0.001$, respectively) and negatively related with emotional representation at 6 months (Adj $R^2 = 0.36$, $p < 0.0001$). |
| Horowitz et al. (2004) | Three dominant themes which were identified from a total of 60 themes, include:<br><br>- Inadequate information was perceived by patients. This was related to the consequences, symptoms, management, and the perceived cause of HF.<br>- Patients were seen not to have the necessary knowledge to prevent, identify, or take actions to address episodes of exacerbations before they deteriorate.<br>- When patients noted that their symptoms had worsened, they had difficulty to reach care apart from the emergency department. |

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| | Patients perceived HF to be an acute condition. Additionally, symptoms were not being identified to be worsening over time.<br><br>Symptoms were not being managed on a routine basis thus exacerbations were not being prevented or minimised.<br><br>Barriers in seeking help were reported.<br><br>The generated themes clarified that the individual's perceived illness perceptions and their comprehension about HF influenced their behaviour. |
| MacInnes (2013) | Only perceived medication knowledge ($r = 0.51$, $p \leq 0.01$) and beliefs about the necessity of medication ($r = 0.45$, $p \leq 0.01$) were correlated with self-care.<br><br>Several illness representations were weakly correlated with self-care. These included: consequences ($r = 0.25$, $p \leq 0.01$), chronic timeline ($r = 0.21$, $p \leq 0.05$), cyclical timeline ($r = -0.22$, $p \leq 0.05$), illness coherence ($r = 0.39$, $p \leq 0.01$), treatment control ($r = 0.27$, $p \leq 0.01$), impact of medication use on lifestyle ($r = -0.39$, $p \leq 0.01$), and social influence ($r = -0.23$, $p \leq 0.01$).<br><br>As revealed by a multiple regression analysis 46% of the variance in self-care could be described by the illness perceptions and beliefs about the treatment (adjusted $R^2 = 0.46$, $F = 9.93$, $p < 0.001$).<br><br>Medication knowledge ($\beta = 0.319$, $p = 0.003$), illness perception of greater consequences ($\beta = 0.258$, $p = 0.008$) and the effect of medication use on lifestyle ($\beta = -0.231$, $p = 0.03$), were significant predicators of self-care. |
| Mansouriyeh et al. (2017) | Positive relationship between illness perception and self-care ($r = 0.649$, $p < 0.001$), and between age and self-care ($r = 0.506$, $p < 0.001$)<br><br>Negative relationship between self-efficacy and self-care ($r = -0.678$, $p < 0.001$), and between social support and self-care ($r = -0.518$, $p < 0.001$). |

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| | Standard coefficients: Illness perception - β = 0.274, social support - β = −0.237, self-efficacy - β = −0.230, and age - β = −0.231.<br><br>56% of self-care variance - Represented by illness perception, age, social support, and self-efficacy. |
| Mei et al. (2019) | Self-care maintenance mean score was 51.4 (*SD* = 14.8) in men and 55.6 (*SD* = 14.1) in women. When compared to women, men reported lower score of self-care maintenance (*t* = -2.066, *p* < 0.05). Higher social support was reported by men than in women (*t* = 2.005, *p* < 0.05). The illness perception mean scores reported were 117.3 (*SD* = 12.2) in men and 117.8 (*SD* = 12.1) in women, resulting in a total of 117.6 (*SD* = 12.1) of both genders.<br><br>Illness perception was not associated to self-care maintenance in both genders. However, in women illness perception score was negatively correlated with self-care maintenance score (Women: *r* = -0.184, *p* < 0.05). |
| Molloy et al. (2009) | Adherence to ACEi was that of 72%.<br><br>19% of the medication adherence variance was explained by timeline-acute/chronic (β= -0.92, SE = 0.51, Wald = 3.26, OR =0.4, *p* = 0.07) and consequences (β= -0.97, SE = 0.52, Wald = 3.47, OR = 0.38, *p* = 0.06) of HF, which were found to be marginally predictors of medication adherence. This indicated that participants who perceived a chronic timeline of illness and greater consequences of their illness were less likely to be adherent to ACEi. |
| Voelmeck (2006) | IPQ-R average scores per item indicated that participants perceive HF to have greater consequences (*M* = 3.57, *SD* = 0.88) and a chronic timeline (*M* = 3.89, *SD* = 1.03), can be personally (*M* = 4.11, *SD* = 0.55) and treatment (*M* = 3.65, *SD* = 0.63) controlled but still showing cyclical disruptions in their daily living (*M* = 2.84, *SD* = 0 .90). Internal (*M* = 2.55, *SD* = 0.78) and external (*M* = 2.44, *SD* = 0.59) causal attribution subscales were reported to be neutral. |

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| | There was no significant correlation between scores on the SCHFI and the IPQ-R subscales or with scores on the LHFQ.<br><br>Using hierarchical regression, SAS functional classification (β =9.96, $p < 0.01$), identity (β =2.01, $p < 0.01$), and consequences (β =1.20, $p < 0.01$) explained 64% of the total variance in LHFQ scores. SCHFI total scores did not account for a significant increase in the variance of the LHFQ scores. |

**ACEi** (Angiotensin Converting Enzyme inhibitor); **Adj $R^2$** (Adjusted R-Squared); **β** (Beta coefficient; **CHF** (Congestive Heart Failure); **HF** (Heart Failure); **IPQ-R** (Revised Illness Perception Questionnaire); **LHFQ** (Living with HF Questionnaire); **M** (Mean); **NYHA** (New York Heart Assocation); **OR** (Odds Ratio), ***P*** (*P*-value); Q**OL** (Quality Of Life); ***r*** (Correlation); **SAS** (Specific Activity Scale); **SCHFI** (Self-Care of Heart Failure Index); **SD** (Standard Deviation), **SE** (Standard Error); **t** (T-value).

### *2.5.1 Illness Perceptions of Individuals Living with Heart Failure*

**a. Identity.** In Albert et al. (2014) and Horowitz et al. (2004) studies, participants did not connect their chronic symptoms to their HF, and they perceived the presence of HF only when symptoms were present. On the other hand, Molloy et al. (2009) found that participants perceived that their HF had more than one symptom. However, this was only seen amongst the group which was not adherent to their ACEi drugs. Voelmeck (2006) reported that breathlessness, fatigue, and oedema of the lower extremities, were the top three symptoms reported by the participants which were recognised as related to their HF.

**b. Timeline.** MacInnes (2013), Molloy et al. (2009) and Voelmeck (2006) revealed that participants perceived HF to have a chronic timeline. Illness perception of chronic timeline was also reported by Goodman et al. (2013), where this perception was

noted to have increased by 2 months after discharge. In Molloy et al.'s (2009) study, it was noted that only participants who were not adherent to ACEi perceived that HF has a chronic timeline. This was not the case in Albert et al.'s (2014) study and in Horowitz et al.'s (2004) study, where participants perceived HF to have an acute rather than a chronic timeline.

**c. Personal and Treatment Control.** MacInnes (2013) and Voelmeck (2006) reported that participants perceived HF as an illness which could be controlled either personally or with treatment. Similarly, Molloy et al. (2009) reported high illness perceptions scores that HF is an illness which can be personally, and treatment controlled. However, this perception was strongly reported by the group of participants who were adherent to their ACEi drugs. Contrary to a longitudinal study by Goodman et al. (2013), it was observed that perception about HF, on whether it could be personally, or treatment controlled, had declined during the six-month follow-up.

**d. Cause.** In the study by Goodman et al. (2013), participants perceived that the causes of their HF were not related to their own control and this perception persisted between the baseline and follow-up period. The most reported causes were age, chance of bad luck, heredity, or stress or worry. These causes were also reported in Voelmeck (2006) with the addition of diet or eating. MacInnes (2013) also reported that ageing, and stress or worry were the main perceived causes of HF. Additionally, Horowitz et al. (2004) revealed that participants perceived inadequate knowledge on the cause of their illness. Similar to other studies, Horowitz et al. (2004) reported that some of the participants attributed stress to be the main cause of their illness.

**e. Consequences.** Three of the studies reported that HF was perceived to have serious consequences (MacInnes, 2013, Molloy et al., 2009; Voelmeck, 2006). Interestingly to notice is the fact that although most of the participants in Molloy et al.'s (2009) study perceived HF to have serious consequences, this perception was highly

reported amongst the group who was non-adherent to their ACEi drugs. Participants in Albert et al.'s (2014) study demonstrated inaccurate perceptions about the consequences of HF.

**f. Illness Coherence.** MacInnes (2013) and Molloy et al. (2009) demonstrated high scores for illness coherence, meaning that HF made sense to participants. It was noted that in Molloy et al (2009) study the non-adherent group reported higher scores for illness coherence than the adherent group. This indicates that although participants perceived a good understanding of their illness, they could have lack of understanding on the beneficial effects of ACEi drugs to the prognosis of their HF.

**g. Emotional Representation.** From the eight appraised studies, emotional representation of illness was only acknowledged by one study (Goodman et al., 2013). In this study, it was noted that participants who perceived a higher level of illness coherence, perceived a lower level of emotional reaction to their ill-health (Goodman et al., 2013).

### *2.5.2 Self-Care Behaviours of Individuals Living with Heart Failure*

MacInnes (2013) reported that overall participants were adherent to their recommended self-care behaviours. High scores were reported for reporting and seeking help, describing their trustful relationship with the health-care professionals. The most cited self-care behaviours were monitoring of deteriorating symptoms, and regular weighing. However regular weighing was less reported when compared to other behaviours. Both in MacInnes (2013) and Albert et al.'s (2014) study, participants reported low adherence scores for taking regular exercise. To add on, in Albert et al.'s (2014) study, participants reported low adherence scores for: reading food labels, choose low sodium foods when dining out, and to weigh themselves. In their

longitudinal study, Goodman et al. (2013) reported that self-care adherence, increased at 2 months after discharge. and was maintained at 6 months (Goodman et al., 2013).

Adherence to medications was explored by three studies (Albert et al., 2014; MacInnes, 2013; Molloy et al., 2009). The three studies reported high adherence medication rates with more than 70% of the participants being adherent to their medications. MacInnes (2013) reported that most of the time participants took their medication without forgetting a dose (unintentional non-adherence). To add on, Albert et al. (2013) reported that 78% of the participants took their medication without intentionally skipping or missing a dose.

### *2.5.3 Covariates Affecting Illness Perceptions and Self-Care Behaviours*

Albert et al. (2014) did not find an association between the demographic factors and the accuracy scores for illness beliefs. However, it was noted that participants who were young, and those who had higher education levels, perceived greater accuracy HF belief scores. Additionally, Mansouriyeh et al. (2017) revealed a positive relationship between age and illness perception, and between age and self-care. Gender differences in self-care maintenance was revealed in Mei et al. (2019) study, where it was disclosed that men reported a statistically significant lower score for self-care maintenance when compared to women. Additionally, in the same study, it was revealed that both men and women who were living in urban areas, unemployed, had higher educational levels, and an income of more than ¥3000 per month, scored significant higher scores for self-care maintenance (Mei et al., 2019). Furthermore, it was observed that women who were more than 65 years scored significantly higher scores for self-care. Marital status was brought up by Molloy et al. (2009), where no significant differences in adherence rates were reported between married and unmarried participants. Voelmeck (2006) revealed

significant high self-care scores amongst those participants who were classified as symptomatic.

Another covariate mentioned by three studies was social support (Albert et al., 2014; Horowitz et al., 2004; Mansouriyeh et al., 2017; Mei et al., 2019). Albert et al. (2014) observed higher HF self-care behaviours scores amongst those participants who had someone to confide in. Similarly, Mansouriyeh et al. (2017) reported that social support is related with enhanced self-care. Such association was also noted in Mei et al.'s (2019) study, where social support was found to be related with self-care maintenance, but only amongst the male participants. In fact, males were found to be more socially supported than females (Mei et al., 2019). Horowitz et al. (2014) described family members and friends as an integral part in patients' care, such as in the monitoring of symptoms, interpretation of medication regimes, and seeking help when needed.

### *2.5.4 The Relationship Between Illness Perceptions of Individuals Living With Heart Failure and Self-Care, Including Medication Adherence*

In MacInnes (2013) study, illness coherence was moderately correlated with self-care adherence ($r = 0.39$, $p \leq 0.01$). Additionally, in the same study it was revealed, that perception of greater consequences, was a significant predictor of self-care ($\beta = 0.258$, $p = 0.008$). In addition to MacInnes (2013), Molloy et al. (2009) reported that the perception of greater consequences was found to be marginally a predictor of medication adherence. Furthermore, timeline-acute/chronic perception ($\beta = -0.92$, SE = 0.51, Wald = 3.26, OR =0.4, $p = 0.07$) was also found to be marginally a predictor of medication adherence (Molloy et al., 2009). Horowitz et al. (2004) described timeline dimension as a critical factor in guiding health behaviours. In fact, in their study, those who perceived HF to have an acute timeline or had lack of comprehension about the

consequences and the causes, were seen to be non-adherent to the recommended self-care behaviours (Horowitz et al., 2004). Unfortunately, one cannot compare these results with other studies since this study was a qualitative study (Horowitz et al., 2004).

Goodman et al.'s (2013) study was the only study which reported a relationship between illness coherence and self-care confidence. This relationship was noted at both follow-up periods. In the same study, emotional representation was found to be negatively correlated with self-care confidence at 6 months (Goodman et al., 2013). On the other hand, Albert et al. (2014) reported that the more negative emotional impact, caused by HF, the lower self-care confidence rates were reported. It was observed that participants who had more accurate HF beliefs (representing one's illness perceptions) had lower self-care behaviours scores (Albert et al., 2014). Mansouriyeh et al. (2017), reported a positive relationship between illness perception and self-care, indicating that the more HF is viewed as a threatening illness, the less adherent the individual is to self-care. Mei et al. (2019) did not find an association between illness perceptions and self-care maintenance. Additionally, Voelmeck (2006) did not find any significant correlation between illness perceptions and self-care.

## 2.6 Gaps in the Literature

Reading through the literature, it was notable that several studies around the world were conducted to explore the illness perceptions of individuals living with HF or to study the behaviours concerning HF self-care and medication adherence. However, it was noted that there were few studies which were carried out to investigate if there is a relationship between the illness perceptions and behaviours of persons living with HF concerning self-care behaviours and medication adherence. Moreover, literature findings seem to be contradictory. There is not enough evidence to explain why some individuals master HF self-care while others do not. To add on, literature was conducted

in large countries with different cultures and values. To date, locally, over 900 clients living with HF attend specialised HF clinics to be followed-up. Illness perceptions and behavioural approach to self-care and medication adherence are still unknown among the Maltese HF population. In fact, no studies were traced to be originated from the Maltese HF population on this matter.

In view of all this, this current research study will be addressing the gap which is currently present in overseas and local literature. By exploring the perceptions (non-visible) about HF, and the behaviours (visible) concerning self-care and medication adherence of persons living with HF, this study will assist the healthcare professionals to gather as much information about their clients with the aim to assist them to improve and/or change both their perceptions and their behavioural outcomes in relation to their illness. As a result, the clinical outcomes can be improved, such as reducing hospitalisation rates and increasing adherence rates to self-care and medication with the result of improving the quality of life and mortality rates.

## 2.7 Conclusion

The retrieved studies were systematically appraised to evaluate their appropriateness to the population which is of interest to this dissertation. Most of the studies reported that illness perceptions do have a relationship with HF self-care and medication adherence. Perceiving that the illness has more chronic timeline, perceived more consequences and perceiving that medications are necessary, were some of the aspects which were found to be predicators of HF self-care and medication adherence. Hence, the retrieved findings seem to strengthen the hypothesis of this research study, that illness perceptions, of persons suffering from HF, do influence the behavioural approach concerning self-care and medication adherence.

# Chapter 3 – Research Methodology

## 3.1 Introduction

In the previous chapter a systematic analysis of the existing literature, in relation to this study, was conducted. This current chapter describes the whole process taken to design, plan, and conduct this research study. Explanation of the sample technique together with the reliability and validity of the instruments used in this study for data collection, were addressed. Additionally, any ethical considerations were also acknowledged.

## 3.2 The Aims and Objectives

The primary aims of this study were to explore and examine the illness perceptions and self-care behaviours of individuals living with Heart Failure (HF). The objectives of this research study were:

1. To assess the illness perceptions of individuals living with HF.
2. To identify any inter-relationships between the different illness representations of local individuals living with HF which included:
    i. Illness consequences
    ii. Timeline
    iii. Personal control
    iv. Treatment control
    v. Identity
    vi. Concern
    vii. Illness comprehensibility
    viii. Emotions.
3. To assess the level of HF self-care behaviours including the level of medication adherence.

4. To identify any possible differences in illness perceptions, self-care behaviours and medication adherence in individuals living with HF based on their demographic characteristics and clinical data.
5. To determine whether the illness perceptions of individuals living with HF act as a predictor of HF self-care behaviours, including medication adherence.

## 3.3 Research Design

### *3.3.1 The Rationale for the Chosen Research Approach*

After considering the three main research approaches, including the quantitative, qualitative, and mixed method approach, the quantitative research approach was seen to be the most appropriate approach to conduct this research study. Being a deductive approach, the quantitative approach is used to either back or disprove a hypothesis (Creswell, 2014). Its main aim is to measure and analyse any causal relationships between variables (Sale et al., 2002). Furthermore, the quantitative research findings are expected to be generalisable and replicable (Parahoo, 2014).

The rationale behind this selection is the fact that the researcher was mostly interested in studying concepts and variables objectively, and to examine the relationship between them. To conduct this research study a descriptive correlation, cross-sectional design was adopted. Since HF is considered to be a progressive disease, individuals living with HF may encounter various illness experiences, such as worsening of symptoms or changes in treatment. Over time these experiences may bring a change in their illness perceptions, with the result of influencing their approaches to self-care and medication adherence. Owing to this fact, a longitudinal study would have been more appropriate. However, due to the short time frame to carry out this research study, a cross-sectional design was chosen. In cross-sectional design, data is collected at

one specific point in time (Setia, 2016). Additionally, the exposures and outcomes of the study subjects are measured at the same time (Setia, 2016; Wang & Cheng, 2020a). A cross-sectional design allowed a larger sample size in this limited period of time, representing approximately one third of the total individuals known to be living with HF in Malta.

### *3.3.2 Research Setting and Necessary Approvals*

The research settings chosen for this research study were the nurse-led HF clinic and the Specialised HF clinic at the state general hospital in Malta. The nurse-led HF clinic caters for approximately 700 individuals, while the Specialised HF clinic caters for approximately 200 individuals. The main aims of the two clinics are: to prevent admissions with exacerbations of HF; to up-titrate the anti-HF medications to the maximal tolerated levels by the individual while monitoring any biochemical changes in blood tests; to educate on the monitoring of signs and symptoms; and to refer to other specialities when necessary, such as the electrophysiologist or heart valve clinic.

Since the proposed research settings were the nurse-led HF clinic and the Specialised HF clinic at the state general hospital in Malta, the institutional permissions from the hospital's Chief Executive Officer, the Data Protection Officer, and the Director for Nursing Services were acquired (Appendix B.1 - 3).

The copyright permissions to use the B-IPQ, the EHFScB-9 scale and the MARS-5 were obtained before submitting the research proposal (Appendix C.1 - 3). Since the study was planned to be carried out amongst participants were mostly Maltese, permission to translate the tools to the Maltese language was also acquired from the original authors (Appendix D.1 - 3). Other obtained permissions are listed in table 3.1.

**Table 3.1**

*Other Obtained Permissions*

| | |
|---|---|
| 1. | Permission from the chairperson of Cardiology Department and the chairperson of the Department of Medicine, and from all the Cardiology Consultants working at the hospital (Appendix E). |
| 2. | Permission from the Resident Specialist in HF who runs the Specialised HF clinic and guides the nurse-led HF clinic (Appendix F). |
| 3. | Permission from the Departmental Nursing Manager and Nursing officers of the Cardiac Laboratory Out-Patients Department, the Cardiac Rehabilitation Unit, and the Medical Outpatient 4 (Cardiology Outpatient Department) (Appendix G). |
| 5. | A psychotherapist was also contacted in case the questionnaire used in this study raised matters in which the participants felt the need for further help (Appendix H). |
| 6. | A total of nine intermediary persons were contacted to help the researcher with the data collection (Appendix I). |

To conduct this research study ethical permission was granted from both the Faculty of Health Sciences Research Ethics Committee (FREC) and University of Malta Research Ethics Committee (UREC) (Appendix J) [(Ethics number: 6002_13072020_Sheldon Attard) (Appendix K)].

### *3.3.3 Target Population and Sampling Technique*

A convenience sampling technique was chosen for this research study. Since non-response bias is a common type of selection bias in convenience sampling, this was

minimised by not using mailed questionnaires (Forster, 2001; Wang & Cheng, 2020b). Clients who were conveniently available at the HF clinic and the Specialised HF clinic between December 2020 and January 2021 were asked if they would like to participate in this research study. A non-probability sampling method was chosen since random sampling was not feasible due to data protection issues in accessing the sample list (Polit & Beck, 2010).

**a. Eligibility Criteria.** The eligible participants had to be diagnosed with HF. To minimise selection bias, participants had to be clients of either the nurse-led HF clinic or the Specialised HF clinic due to the consistent advice given to them regarding HF self-care, such as daily weight monitoring and monitoring of any signs and symptoms. Moreover, clients become familiar with their HF self-care during their visits to the nurse-led HF clinic and the Specialised HF clinic. The main strength of using the nurse-led HF clinic and Specialised HF clinic for data collection was the fact that HF self-care is provided to every individual in the same way by the same experienced professionals. This ensures consistent flow of information on the importance of HF self-care. Thus, individuals who were seen for the first time, at either the nurse-led HF clinic or the Specialised HF clinic, during the data collection period were excluded from the study to eliminate any confounding factors on the level and knowledge of self-care behaviours. Their age had to be more or equal to 18 years, so that participants themselves would be legally able to consent to participate in the study (Research Ethics Committee, Faculty of Health Science, 2020). Both Maltese and English-speaking participants were eligible to participate. The following table (Table 3.2) summarises the inclusion and exclusion criteria.

**Table 3.2**

*Eligibility Criteria*

| Inclusion criteria | Exclusion criteria |
|---|---|
| Diagnosed with HF: either systolic or diastolic HF | Not diagnosed with HF |
| Age: ≥18 years old | Age: <18 years old |
| Participants with previous visits at the nurse-led HF clinic or Specialised HF clinic | Participants who were seen for the first time at the nurse-led HF clinic or Specialised HF clinic |

**b. Sample Size.** The sample size was calculated by using an online sample size calculator (https://www.surveysystem.com/sscalc.htm). Since on commencing this research study the total number of individuals who attended the nurse-led HF clinic and the Specialised HF clinic was 900 individuals, a sample of 269 was determined to have a maximum margin of error +/- 5% and 95% confidence interval (CI). Since questionnaires with more than 10% of missing data are likely to cause statistical analysis bias, an additional 11 participants were recruited (Bennett, 2001). Thus, the final total of recruited participants was 280.

## 3.4 Procedures for Data Collection

After the follow-up appointment at the nurse-led HF clinic and/or the Specialised HF clinic, an intermediary person invited every individual who was eligible to participate in the study. Every eligible participant was first given an information letter, stating the aim of this research study and what it consisted of (Appendix L.1 – 2). To minimise social desirability response bias, which refers to the tendency of participants to give responses which are socially desirable, data was collected anonymously (Grimm, 2010). Anonymity and confidentiality were emphasised when the information letter and the consent form were explained to the eligible participant.

Moreover, participants were informed that participation in the study was completely voluntary. They were free to accept or refuse to take part without giving a reason.

On accepting to participate, participants were asked to read and voluntarily sign the consent form (Appendix M.1 – 2). The consent form was formulated by statements extracted from the information letter. A copy of the information letter together with a copy of the voluntarily signed consent form were given to every recruited participant.

The participants were then asked to answer a questionnaire consisting of four parts (Table 3.3). Participants were given the option to choose to answer either an English version of the questionnaire (Appendix N.1) or a Maltese version of the questionnaire (Appendix N.2). This option was planned when designing this study since the English and the Maltese languages are the two official languages in Malta. One can find that some people are more fluent in one of the two languages and thus it was decided that the questionnaires would be translated from their origin language to Maltese (Section 3.4.3). Providing the option to choose between the two languages helped to reduce the language barrier and to minimise selection bias while increasing the participation rate (Gayet-Ageron et al., 2011).

Two other measures taken to encourage participation were, the use of short instruments, which do not take a lot of time to complete, and the questionnaire format. The use of short instruments was beneficial to minimise participants' burden while increasing participation (Jones et al., 2013). Moreover, aesthetics and question order were considered since they are crucial in self-administered questionnaires (Jones et al., 2013). The questionnaires were designed with a large font size to be easily read by older adults and most of the questions were answerable by a circle or by checking the corresponding boxes for their answers.

To maximise the response rate, participants who asked for assistance to complete the questionnaire, were assisted by the intermediary person. In such cases participants' confidentiality was assured while responses to the questionnaire were anonymous. However, participants were encouraged to fill the questionnaire alone in a provided room. Participants' relatives were not encouraged to help in filling of the questionnaire, since they might reflect their own illness perceptions and behaviours, thus affecting the participants true responses.

To maximise confidentiality and anonymity, filled questionnaires were placed in a sealed box by the participants themselves while the signed consent forms were placed securely together away from the filled questionnaires.

Part A of the questionnaire, the socio-demographic data, and the clinic information (Appendix N.1.1 and N.2.1), was read to the participant by the intermediary person and answered by the participant him/herself while the interviewer ticked or wrote the answers according to the participants' responses. This was done, so that questions such as the NYHA Class, can be further explained to the participant, thus such data would be truly representing the participants' clinical information. Since participation in this study occurred after the nurse-led HF clinic follow-up and/or the Specialised HF clinic follow-up, questions related to aetiology, ejection fraction, and other comorbidities were answered by the participant or with the help of intermediary persons. This information was available to the participants and the intermediary person from the clinical report of the same visit which is usually handed to every client after his/her visit.

### *3.4.1 The Research Model*

To achieve the aims and objectives (Section 3.2), the Common-Sense Model (CSM) of Self-regulation of Illness was used as a theoretical framework. Figure 3.1

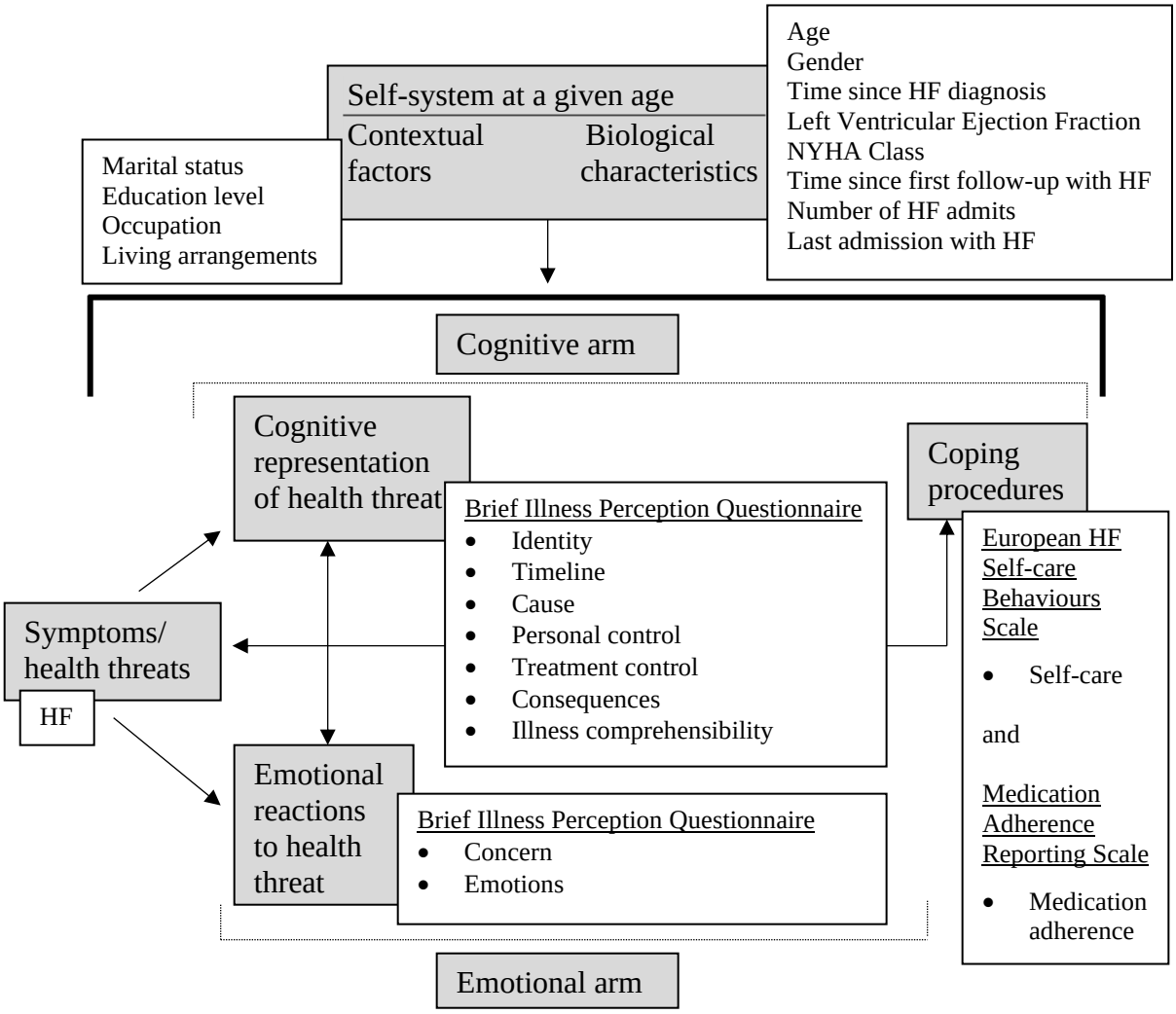
represents an illustration of the CSM used in this research study. This model represents a detailed overview of the necessary data to be collected.

As presented in figure 3.1, this research focused on both the cognitive representation and the emotional representation of the CSM. However, only the first two stages of the cognitive arm (Cognitive representations and coping procedures) and the first stage of the emotional arm (Emotional representations) were assessed (Figure 3.1). The cognitive and the emotional representations were investigated by the Brief Illness Perception Questionnaire (B-IPQ) (Appendix N.1.2 and N.2.2). The coping procedures, in this regard HF self-care behaviours and medication adherence, were assessed by the European Heart Failure Self-care Behaviour Scale (EHFScB-9) (Appendix N.1.3 and N.2.3) and the Medication Adherence Reporting Scale (MARS-5) (Appendix N.1.4 and N.2.4), respectively. Focusing on both arms led the researcher to explore the illness perceptions from both the cognitive and emotional representations of the illness, represented by individuals living with HF (Symptoms/health threats), and their coping mechanisms (Coping procedures) in relation to HF so that the disease can be controlled. Data on contextual factors and biological characteristics of the participants, representing the self-system at a given age, were collected by the socio-demographic and clinical information (Appendix N.1.1 and N.2.1).

The research model itself hypothesised that there is a relationship between the illness perceptions of individuals living with HF, and their self-care behaviours presented by the coping procedures. This hypothesis was further analysed and discussed in chapters 4 and 5.

**Figure 3.1**

*Illustration of the Research Model Used in This Dissertation*




*Note.* This model was extracted from Shifren (2003, p. 360)

### *3.4.2 The Research Instruments*

**a. Part A of the Questionnaire: The Socio-Demographic Data and Clinical Information.** Part A of the questionnaire, the socio-demographic data and clinical information, consisted of questions related to the contextual factors and the biological characteristics of the participants (Appendix N.1.1 and N.2.1). The contextual factors and the biological characteristics were two dimensions of the CSM used in this research

model to obtain data concerning the self-system at a given age (Figure 3.1: Top part). The contextual factors and the biological characteristics were obtained to identify if the illness perceptions, self-care behaviours, and medication adherence of individuals living with HF differ in relation to their socio-demographic data and clinical information (Objective 4).

**Table 3.3**

*The Questionnaire*

| |
|---|
| Part A: Socio-demographic and clinical information – 14 items |
| Part B: Brief Illness Perception Questionnaire (B-IPQ) – 9 items |
| Part C: European Heart Failure Self-care Behaviour scale (EHFScB-9) – 9 items |
| Part D: Medication Adherence Reporting Scale (MARS-5) – 5 items<br>+ 1 question on whether the participant prepares his/her own medicines<br>+ 1 question on polypharmacy (number of pills taken per day) |

**b. Part B of the Questionnaire: The Brief Illness Perception Questionnaire (B-IPQ).** The Brief Illness Perception Questionnaire (B-IPQ) was used to evaluate illness perceptions in persons living with HF (Appendix N.1.2 and N.2.2). The main aim of using the B-IPQ was to evaluate the cognitive representations of HF and the emotional reactions to HF as presented in the research model (Figure 3.1). This 9-item questionnaire is an abridged version of a longer Illness Perception Questionnaire Revised (IPQ-R) consisting of 80 items, and it is an extended version of the original Illness Perception Questionnaire (IPQ) (Broadbent et al., 2006; Weinman et al., 1996). Being a short questionnaire, the B-IPQ has the advantage of being completed quickly and is suitable to be filled by symptomatic individuals (Broadbent et al., 2006).

Furthermore, it has the advantage to study illness perceptions in a wider range of groups of individuals living with a particular condition (Broadbent et al., 2006).

Except for the causal question, this questionnaire uses a single-item scale to assess perceptions on an 11-point Likert scale [0 (less threatening view of the illness) to 10 (high threatening view of the illness)] (Broadbent et al., 2006). The questionnaire consists of five items which assess the cognitive illness representations, two of the items assess emotional representations, and one item assesses illness comprehensibility (Table 3.4). The ninth item is an open-ended question, adapted from the IPQ-R, assessing the causal representation. In the causal question, participants are asked to list the three most important causal factors of their illness.

Since this study was conducted amongst individuals living with HF, the word 'illness' was replaced with the term Heart Failure. The approval to replace the word 'illness' with the illness being studied, is clearly stated in the study by Broadbent et al. (2006). For the Maltese version, the phrase "Qalb għajjiena" was preferably used when compared to "Insuffiċjenza tal-qalb", since "Qalb għajjiena" is more commonly used amongst health-care professionals and the Maltese individuals living with HF.

**Table 3.4**

*The Objectives Analysed by the Cognitive and Emotional Representations of the CSM by the B-IPQ*

| Objectives | Illness representation as presented in Figure 3.1 | Questionnaire item number | Dimension |
|---|---|---|---|
| **Objective 1:** To assess the illness perceptions of individuals living with HF. **Objective 2:** To identify any inter-relationships between the different illness representations of local individuals living with HF | Cognitive illness representation of the CSM | Item 1 | Consequences |
| | | Item 2 | Timeline |
| | | Item 3 | Personal Control |
| | | Item 4 | Treatment Control |
| | | Item 5 | Identity |
| | | Item 9 | Cause |
| | | Item 7 | Illness Comprehensibility |
| | Emotional illness representation of the CSM | Item 6 | Concern |
| | | Item 8 | Emotions |

When the total perception score is calculated, items 1 to 8 are summed up with reverse scores of items 3, 4, and 7. The possible scores ranges from 0 to 80. Higher scores reflect the person`s perception that the illness is more threatening for him/herself (Broadbent et al., 2006).

**c. Part C of the Questionnaire: The European Heart Failure Self-care Behaviour Scale (EHFScBs-9).** The European Heart Failure Self-care Behaviour scale (EHFScB-9) was one of the research instruments used to measure the coping procedures of the cognitive arm presented by the CSM (Figure 3.1 – Coping procedures). The EHFScB-9 scale was used to measure self-care behaviours amongst individuals living

with HF (Objective 3) (Appendix N.1.3 and N.2.3). The EHFScB-9 scale was developed with the aim of measuring HF-related self-care behaviours performed by individuals living with HF to maintain life, healthy functioning, and well-being (Jaarsma et al., 2009). The EHFScB-9 scale contains questions relating to self-care maintenance (daily body weighing, restricting fluid intake, eating a low salt diet, taking the prescribed medications, and exercising regularly) and self-care management (reporting any aggravation in HF symptoms, such as dyspnoea, lower limb oedema, 2Kg weight gain over 1 week, and increase in fatigue) (Ok & Choi, 2015). The EHFScBs-9 is an abridged version of the EHFScB-12-item scale, published in 2003 (Jaarsma, et al., 2003; Jaarsma et al., 2009).

Being a short scale, the EHFScB-9 scale is considered easy to administer and practical to use amongst individuals living with HF, who can be symptomatic. The EHFScB-9 scale consists of 9 items rated on a 5-point scale between 1 (I completely agree) and 5 (I completely disagree). The EHFScBs-9 has a score from 9 to 45 with a higher score indicating worse self-care. To make the interpretation of the total self-care score easier, Jaarsma (2015) suggests using a standardised score from 0 to 100 with a higher score indicating better self-care. If a standardised score is chosen (0 – 100), reverse scoring of all the items must be done (Table 3.9).

**d. Part D of the Questionnaire: Medication Adherence Report Scale (MARS-5).** The Medication Adherence Report Scale (MARS-5), © Professor Rob Horne, was the second instrument used to measure the coping procedures of the cognitive arm presented by the CSM (Figure 3.1 – Coping procedures). The MARS-5 was used to further assess the self-reported adherence, representing the medication adherence (Objective 3) (Appendix N.1.4 and N.2.4) (Chan et al., 2020; Tommelein et al., 2014). The MARS-5 is a shorter version of the MARS-10, consisting of 5 items which describes non-adherent medication behaviours. The MARS-5 items are written in

a way that they are non-threatening and non-judgemental to normalise non-adherence (Chan et al., 2020). The scale used to respond each item allows the person to categorise their position along the "adherence dimension" (Chan et al., 2020). Consequently, the MARS-5 provides more detail and allows the individuals to differentiate themselves in their medication adherence dimension. The first statement of the MARS-5 represents unintentional nonadherence to medications, whereas the other 4 statements represent intentional nonadherence to medications (Chan et al., 2020).

Respondents are asked to score their answers on a 5-point Likert scale (1 = always, 2 = often, 3 = sometimes, 4 = rarely, and 5 = never). The total score can range from 5 to 25, with higher scores representing higher self-reported adherence of medications.

### *3.4.3 Translation of the Instruments*

Since the target population for this study was mostly Maltese, the 3 instruments used in this dissertation were translated from their language of origin, English, to Maltese. The procedure for the translation process for these three instruments was guided by the WHO (2020b) guidelines. This process was done by three translators. The instruments were first translated to Maltese by one of the translators who is familiar with terminology used in the instruments and is knowledgeable of the English-speaking culture, and his mother tongue is the Maltese language. The second translator who was an independent translator was employed as the editor of various publications, including books. His main role was to analyse and identify inadequate statements after the initial translation and the back-translation while resolving any discrepancies. After reviewing the translated instruments, a few amendments were done, allowing better understanding of the statements and to be as much similar as possible to the original phrases used in the original research instruments. Back-translation was then done by another

independent translator who had no knowledge about the instruments and who is professionally qualified in the English language.

The back-translations of the questionnaire were sent to their original authors to be verified. One minor amendment was requested to the back-translation of the MARS-5 instrument. The back-translation of question M3 in the MARS-5 instrument was “I stop taking them for a short time”. Since the original version of the MARS does not refer to a specific time frame, but rather states “I stop taking them for a while”, after a discussion with the two independent translators an agreement was reached. Question M3 was refined and translated in Maltese in different word format, “Jiena nwaqqafhom għal xi żmien” which was back translated to “I stop taking them for a while”. The new version of the back-translation of the MARS-5 instrument was accepted by its original authors.

The Maltese versions of the three instruments were then subject to face and content validity as described in the following sections.

## 3.5 Reliability and Validity of the Research Instruments

Reliability reflects the accuracy of an instrument, meaning that the same results will be obtained if the instrument is used repetitively in similar situations (Heale & Twycross, 2015). While validity assesses whether the concept is accurately measured (Heale & Twycross, 2015).

### *3.5.1 Reliability of the Research Instruments*

**a. Reliability of the B-IPQ.** The psychometric properties of the B-IPQ were examined internationally for use in different types of diseases and in different language versions (Chew et al., 2017; Hallegraeff et al., 2013; Karimi-GhasemAbad et al., 2020; Machado et al., 2019; Nowicka-Sauer et al., 2016; Thomson et al., 2020; Timmermans

et al., 2017; Valero-Moreno et al., 2020; Zhang et al., 2017). Thomson et al. (2020) used the English version B-IPQ to explore the illness perceptions of individuals living with Coronary Artery Disease. The Cronbach's α coefficient was used to measure the internal consistency of the B-IPQ (Thomson et al., 2020). Internal consistency refers to the extent that an instrument measures the same construct by its items (Polit & Beck, 2010). A Cronbach's α of ≥0.70 is required to have a good internal consistency, whereas higher values represent better reliability (Polit & Beck, 2010). Overall, the B-IPQ, in Thomson et al. (2020) study, showed a good internal consistency with a Cronbach's α of 0.75.

Test-retest reliability was not carried out in Thomson et al.'s (2020) study, thus one cannot conclude whether the instrument was stable or not. Test-retest reliability is the degree to which an instrument produces consistent results on different occasions, while making sure that individual characteristics are kept stable (Vilagut, 2014). Two measures which can be used to measure test-retest reliability are: the Pearson's Correlation Coefficient, and the Intraclass Correlation Coefficient (Table 3.5).

**Table 3.5**

*The Range of Values of the Intraclass Correlation Coefficient*

| Strength of correlation | Range of Intraclass Correlation Coefficient |
|---|---|
| Excellent reliability | >0.9 |
| Good reliability | 0.75 – 0.9 |
| Moderate reliability | 0.5 – 0.75 |
| Poor reliability | <0.5 |

*Note.* Extracted from Koo and Li (2016, p. 161)

**b. Reliability of the EHFScBs-9.** The psychometric properties of the EHFScB-9 scale, English version, as reported by Jaarsma et al. (2009) and Lee et al. (2012),

resulted in satisfactory results with a Cronbach's α coefficient ranging from 0.68 to 0.80 showing moderate to very good internal consistency (Table 3.6). However, both studies did not measure test-retest reliability, thus reliability of the EHFScBs-9 could not be determined.

**Table 3.6**

*Internal Consistency and Test-Retest Reliability Values of the EHFScBs-9 as Reported by International Studies*

| **Study** | **Data** | **Version** | **Cronbach's α coefficient** | **Intraclass correlation coefficient** |
|---|---|---|---|---|
| | | | **Nine-item total scale** | |
| Jaarsma et al. (2009) | | | 0.80 | N/A |
| | Separate data sets | English | 0.68 | N/A |
| Lee et al. (2012) | | English | 0.80 (95% CI: 0.76-0.84) | N/A |

**c. Reliability of the MARS-5.** The MARS-5 psychometric properties for the English version, as reported by Chan et al. (2020) and Owie et al. (2018), showed a moderate to very good internal consistency with a Cronbach's α coefficient ranging from 0.67 to 0.89. Test-retest reliability of the MARS-5 as analysed by Pearson's Correlation Coefficient was reported to have a very strong correlation ($r$ = 0.97) (Chan et al., 2020) (Table 3.7).

**Table 3.7**

*Internal Consistency and Test-Retest Reliability Values of the MARS-5 as Reported by Various International Studies*

| Study | Version | Illness | Cronbach's α coefficient | Test-retest reliability |
|---|---|---|---|---|
| | | | Overall total of MARS-5 | |
| Chan et al. (2020) | English | Hypertension (Group A) | 0.68 | $r = 0.97$, $p < 0.001$ |
| | | Hypertension (Group A) | 0.67 | N/A |
| | | Asthma | 0.84 | N/A |
| | | Diabetes | 0.89 | N/A |
| Owie et al. (2018) | English | Schizophrenia | 0.77 | N/A |

**d. Reliability of the Research Instruments as Used in This Study.** Internal consistency for the three research instruments used in this study was measured separately for each research instrument. Internal consistency was measured by calculating the Cronbach's α coefficient from the data collected by each instrument during the main data collection. During the pilot study (Section 3.7), test-retest reliability test was carried out amongst 50 subjects. With a sample size of 25 subjects for each version, test-retest reliability test was conducted on both the original version of the instruments (English version) and on the Maltese translated version of the instruments. Due to the COVID-19 circumstances participants were not asked to attend the clinic to fill the questionnaire again for the re-test. Instead, they were informed beforehand that they were going to be phoned and asked the same questions after two to

three weeks. After two weeks interval, test-retest reliability was calculated by the Intraclass Correlation Coefficient, which is the preferred index for test-retest reliability (Polit & Beck, 2018). The results are reported in chapter 4, section 4.2.

### *3.5.2 Validity of the Research Instruments*

**a. Face Validity.** Face validity is attained when an expert on the research project subjectively concludes that the questionnaire covers the concepts which it intends to measure (Bolarinwa, 2015). Additionally, face validity is the extent to which the questionnaire is viewed as being transparent and relevant to both the expert in the field of research and to the respondents (Gravetter & Forzano, 2012). Face validity of the questionnaire was attained by three experts who were also involved in the content validity of the same questionnaire. The first expert was a cardiologist specialised in HF, the second expert was a HF clinic nurse, while the third expert was a professionally qualified translator and was himself living with HF. These experts were selected on the basis of their experience in/with HF and/or significant working experience in HF management. A questionnaire both in Maltese and English version was given to them with the aim to face validate the Maltese translated version. They described the questionnaire as an instrument which truly represents the title of this dissertation. Moreover, they described the questionnaire as being highly relevant to the subjects being studied as it represents their necessary daily self-care behaviours. Respondents who answered the evaluation sheet handed during the pilot study gave positive comments on the questionnaire. These included that the questionnaire is to the point and none of the questions needed a change. Moreover, one of the respondents stated that the questionnaire is a true representation of the title of this dissertation and the questions asked are direct and focused.

**b. Content Validity.** Content validity is the degree to which the instrument is relevant and representative to fully assesses or measures the construct of interest (Bolarinwa, 2015; Yusoff, 2019). Content validation of the Maltese versions was conducted before the pre-test study. This was carried out between October and mid-November 2020. The same three experts who were involved in the face validity, had to assess the relevancy of the questions to measure their content validity. They were asked to judge the relevancy by using a 4-point scale. This scale consisted of 1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, and 4 = highly relevant.

The Content Validity Index (CVI) was used to estimate quantitatively the content validity. To calculate the Item Content Validity Index (I-CVI) the number of content valid experts who gave a rating score of either 3 or 4, were divided by the total number of experts. According to Polit and Beck (2006) when four or fewer experts are used to content validate the instrument, the I-CVI should be 1.00. The I-CVI for each question of the three instruments was 1.00 each (Table 3.8). This resulted in a scale-level content validity index based on universal agreement method (S-CVI/UA) and a scale-level content validity index based on the average method (S-CVI/Ave) to be 1.00, respectively. This demonstrated a total agreement amongst the content experts. The S-CVI/UA was calculated by adding up the universal agreement scores and dividing the total by the number of items (Yusoff, 2019). Furthermore, the S-CVI/Ave was calculated by adding up the I-CVI scores and dividing the total by the number of items (Yusoff, 2019) (Table 3.8).

**Table 3.8**

*Content Validity Index Values*

| Questionnaire/ Scale | Item Number | Question description | Expert | | | I-CVI |
|---|---|---|---|---|---|---|
| | | | 1 | 2 | 3 | |
| | | | Rated scale | | | |
| **B-IPQ** | 1 | Consequences | 4 | 4 | 4 | 1.00 |
| | 2 | Timeline | 3 | 3 | 3 | 1.00 |
| | 3 | Personal control | 4 | 4 | 3 | 1.00 |
| | 4 | Treatment control | 4 | 4 | 4 | 1.00 |
| | 5 | Identity | 4 | 4 | 4 | 1.00 |
| | 6 | Concern | 4 | 4 | 4 | 1.00 |
| | 7 | Illness comprehensibility | 4 | 4 | 3 | 1.00 |
| | 8 | Emotions | 4 | 4 | 4 | 1.00 |
| | 9 | Cause | 4 | 3 | 4 | 1.00 |
| **EHFScBS-9** | 1 | Weight monitoring | 4 | 4 | 4 | 1.00 |
| | 2 | Reporting an increase of shortness of breath | 4 | 4 | 4 | 1.00 |
| | 3 | Reporting an increase of swelling of the feet/legs | 4 | 4 | 4 | 1.00 |
| | 4 | Reporting an increase in weight by 2Kg in one week | 4 | 4 | 3 | 1.00 |
| | 5 | Restricting fluid intake (1.5/2L per day) | 4 | 4 | 4 | 1.00 |
| | 6 | Reporting an increase of fatigue | 4 | 4 | 4 | 1.00 |
| | 7 | Low salt diet | 4 | 4 | 4 | 1.00 |
| | 8 | Taking the prescribed medications | 4 | 4 | 4 | 1.00 |
| | 9 | Exercise regularly | 4 | 4 | 4 | 1.00 |
| **MARS-5** | 1 | Forgetting to take the medications | 4 | 4 | 4 | 1.00 |
| | 2 | Altering the dose | 4 | 4 | 3 | 1.00 |
| | 3 | Stop taking the medications for a while | 4 | 4 | 4 | 1.00 |
| | 4 | Decide to miss out a dose | 4 | 4 | 4 | 1.00 |
| | 5 | Take less than instructed | 4 | 4 | 4 | 1.00 |
| | | Overall S-CVI/Ave: 1.00 | | | | |

| | |
|---|---|
| | Overall S-CVI/UA: 1.00 |

*Note: I-CVI (Item Content Validity Index):* The number of content valid experts giving a rating of either 3 (quite relevant) or 4 (highly relevant), divided by the total number of experts.

*S-CVI/Ave (Scale Content Validity Index based on the average method):* The average I-CVIs for all the items in the questionnaire.

*S-CVI/UA (Scale-level Content Validity Index) based on the Universal Agreement method):* The total of items with an I-CVI of 1.00 divided by the total number of items to be validated in the questionnaire.

## 3.6 Ethical Considerations

To carry out a research study, especially when human subjects are involved, it must be assessed rigorously and precisely by an ethical board to ensure the ethical standards and scientific merit of research are met (Gelling, 1999). As stated in section 3.3.2, ethical institutional permissions were granted from the Faculty of Health Sciences Research Ethics Committee (FREC) and the University of Malta Research Ethics Committee (UREC) (Appendix J; Appendix K).

Ethics refers to the way of life or social norms which guide people to determine those behaviours which are acceptable and unacceptable (Akaranga & Makau, 2016). Thus, researchers have the responsibility to safeguard the dignity of their subjects and ensure that the information researched is published well (Fouka & Mantzorou, 2011). The main ethical principles which were followed during this research study are discussed in the below sub-sections.

### *3.6.1 Beneficence*

Beneficence is defined as "the obligation to provide benefits and to balance benefits against risks" (Hughes et al., 2010, p. 28). The Belmont Report emphasises that beneficence is not only to respect persons' decisions and protect them from any harm,

but also to secure their well-being (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). Participants in this study were not expected to suffer from any physical, emotional, social, or financial harm as a result of participating in the study (Polit & Beck, 2010). The researcher's contact details were provided by the intermediary person to every participant to be used in the event that information was required concerning the information letter and the consent form, and to provide assurance when needed. If it was the case, that a participant felt emotionally distressed by one of the questions, a psychotherapist was available at no financial cost.

Subjects' dignity was fully respected by not only providing them an information letter explaining the purpose of the research study and the anticipated benefits, but also by explaining the information letter and answering any question in relation to participation (Akaranga & Makau, 2016). Subjects who wished to participate were not rewarded with any monetary incentive, to prevent any undue pressures to participate, especially among those who were economically disadvantaged while respecting their autonomy (Polit & Beck, 2010).

### *3.6.2 Voluntary and Informed Consent*

Consent to participate in the study was collected for every participant while ensuring that the participants were provided with the necessary information on the research study, that they understood this information, and that they voluntarily signed the consent form (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). Furthermore, the information letter clearly stated that participants could withdraw from the study without giving a reason and that withdrawal would not have any negative repercussions on them. However, it was stated clearly that this could only be done while they were filling the questionnaire since the questionnaires were collected anonymously and thus, they could not be traced after

completion. Providing the necessary information and person`s right to refuse or withdraw from the study, respected the right to full disclosure and the right to self-determination, respectively (Polit & Beck, 2010). Additionally, the use of the intermediary persons was beneficial so that participants were not under duress to participate.

### *3.6.3 Confidentiality and Anonymity*

Confidentiality and anonymity were maintained throughout this research study. Measures on how confidentiality and anonymity were maintained, were stated clearly in the information letter provided to every participant. The intermediary persons provided an information letter to every participant and explained it well to them, before providing them a questionnaire. Participants were informed that the study was completely anonymous, and no personal identifiable data was going to be collected. Furthermore, to maintain confidentiality and anonymity, participants were instructed not to write their personal details on the questionnaire. Filled questionnaires were placed in a sealed box by the participant him/herself. The consent forms were filed separately from the questionnaires.

While ensuring confidentiality and anonymity till the end of the study, participants were assured that the gathered data would be used solely for this research study, by the researcher and by the researcher's supervisor. Moreover, participants were assured that the questionnaires and the signed consent forms will be shredded upon completion of the study. In addition, it was made clear that any retained data will be retained anonymously.

## 3.7 Pilot Study

A pilot study was carried out on 50 participants, representing 18% of the main sample size. An evaluation form, in both English and Maltese language, was developed and distributed during the pilot study, together with the questionnaire (Appendix O.1 – 2). The evaluation form included three questions, relating to the time taken for the participant to complete the questionnaire, any difficulties encountered to understand the questions, and invited the participant to provide suggestions for improvement.

The intermediary persons approached those subjects who matched the eligibility criteria (Table 3.2). These subjects were then provided with an information letter which was explained by the intermediary person. On accepting to participate, every participant was then provided with an informed consent form which was explained and voluntary signed. Participants were then provided with a questionnaire. The questionnaire was either filled alone by the participant or further explained and assisted by the intermediary person.

To complete the questionnaire, participants reported an average time of seven minutes. The minimum reported time taken to complete the questionnaire was four minutes while the maximum time taken was fifteen minutes. Most of the participants reported that they did not find any difficulties to complete the questionnaire. One participant stated that the questionnaire was simple to complete, to the point and easy to understand. The flow of the questions was also stated to be appropriate. Some participants were unable to figure out the second and the third causal factor of their HF. But this was not an issue with the formulation of the question which had to be solved since the author of the B-IPQ clearly stated that in that case the first-ranked cause can be analysed (Broadbent et al., 2006).

## 3.8 Data Analysis

Data analysis was carried out by using the Statistical Package for Social Sciences (SPSS) version 26. Numerical coding was conducted for categorical variables. To ensure accurate data entry, various checks were conducted prior any analysis was carried out. To determine test-retest reliability the Intraclass Correlation Coefficient was calculated on the total scoring of each tool collected during the pilot study. To determine the internal consistency of the research instruments, Cronbach's α Coefficient was calculated for each research instrument on the main data collection. The Shapiro-Wilk test was used to assess the normality of assumption. The Kolmogorov-Smirnov test was also considered; however, it was not used since it is considered less powerful when compared to the Shapiro-Wilk test (Razali & Wah, 2011).

Descriptive statistics were used (Frequency, percentage, mean, standard deviation and median) to describe the participant's socio-demographic and clinical data, and to present the reported scores on the B-IPQ, the EHFScB-9 scale and the MARS-5.

Total scoring for each research instrument, including the B-IPQ, the EHFScB-9 scale and the MARS-5, was calculated for each participant, and its descriptive statistics were presented. Reverse scoring for three items (Item 3, 4 and 7) of the B-IPQ questionnaire was done before calculating the total illness perception score. To calculate the total EHFScB-9 score representing self-care, all the items were reverse scored, to standardise the score from a score of 0 to 100, before conducting any analysis of data (Table 3.9).

**Table 3.9**

*Equations Used to Compute the Data of Each Scale/Questionnaire*

| Scale/Questionnaire | Equation |
|---|---|
| B-IPQ: reverse scoring for items 3, 4, and 7 ONLY | RECODE<br>Item.n (0=10) (1=9) (2=8) (3=7) (4=6) (5=5) (6=4) (7=3) (8=2) (9=1) (10=0) INTO R_BIPQ_n. |
| B-IPQ total scoring | SUM = Item 1 + item 2 + item 3 + item 4 + item 5 + item 6 + item 7 + item 8 |
| | |
| EHFScB-9 scale: reverse scoring for All the items | RECODE<br>Item.n (1=5) (2=4) (3=3) (4=2) (5=1) INTO R_EHFScB_n. |
| EHFScB-9 scale total scoring | COMPUTE<br>EHFScBS_9=(SUM(R_item_1,R_item_2,R_item_3,R_item_4,R_item_<br>5,R_item_6,R_item_7,R_item_8,R_item_9)-9)*2.7777.<br>EXECUTE. |
| | |
| MARS-5 total scoring | COMPUTE<br>MARS-5=(Item 1 + item 2 + item 3 + item 4 + item 5) |

Missing data was acknowledged by maximising the data collection by recruiting additional subjects (Kang, 2013). This action has the advantage of retaining the statistical power of the study. Pairwise or analysis by analysis were the options selected for any case exclusions during the statistical analysis. In this way, only data which is missing for the variable being analysed is excluded while other data is retained and analysed (Field, 2009). A 0.05 level of significance was chosen for all the tests, this means that a *p*-value less than 0.05 indicates a statistically significant result. To evaluate the proposed objectives, the following statistical tests were used (Table 3.10).

**Table 3.10**

*Statistical Tests Used for Data Analysis*

| Objective | Statistical Analysis |
|---|---|
| Internal Consistency | Cronbach's α coefficient |
| Test-retest reliability | Intraclass Correlation Coefficient |
| Normality assumption | Shapiro-Wilk test |
| Socio-demographic and clinical data. | Descriptive statistics: frequency, percentage, mean, standard deviation, and median |
| 1. To assess the illness perception of individuals living with HF as elicited by the Brief Illness Perception Questionnaire (Brief IPQ). | Descriptive statistics: mean, standard deviation, and median |
| 2. To identify any inter-relationships between the different illness representations of local individuals living with HF. | Spearman correlation coefficient |
| 3. To assess HF self-care behaviours as elicited by the EHFScB-9 scale and the level of medication adherence elicited by the MARS-5. | Descriptive statistics: frequency, percentage, mean, standard deviation, and minimum and maximum scores |
| 4. To assess any significant differences in illness perceptions, self-care behaviours and medication adherence in individuals living with HF in subgroups of socio-demographic characteristics and clinical data. | Spearman correlation coefficient, Kruskal Wallis test with the use of Dunn's (1964) procedure with a Bonferroni post-hoc as a correction method, and Mann Whitney U test |
| 5. To determine whether the illness perceptions of individuals living with HF acts as a predictor to self-care behaviours and medication adherence. | Spearman correlation coefficient, and Generalised Linear Models fitted by assuming a gamma distribution and a |

| | |
|---|---|
| | reciprocal canonical link function (Power -1) |

## 3.9 Conclusion

To explore and examine the illness perceptions and self-care behaviours of individuals living with HF, a descriptive correlation, cross-sectional design was used. Two hundred and eighty individuals living with HF, aged 18 years or older, were conveniently selected to participate in this research study. To explore the illness perceptions, the B-IPQ was used, while the EHScBs-9 and the MARS-5 were used to explore HF self-care behaviours and medication adherence, respectively. Data collected was analysed using SPSS version 26. Findings resulted from the statistical analysis are presented in the next chapter (Chapter 4).

# Chapter 4 – Results

## 4.1 Introduction

This chapter presents the analyses of the results obtained from the data collection. The internal consistency tests which were performed for each research instrument, together with the test-retest reliability testing for both the original version of the instruments and the translated Maltese version are presented in section 4.2. Section 4.3 presents a detailed account of the socio-demographic characteristics and the clinical information of the participants. The other sections entail a detailed analysis of the findings according to the aims and objectives of this research study.

## 4.2 Reliability of the Research Instruments

The research instruments used in this research study were subjected to scrutiny for their reliability. Their internal consistency was tested from the data gathered during the main data collection, while test-retest reliability was assessed during the pilot study (Section 3.7). Both internal consistency and test-retest reliability were tested for each instrument. Test-retest reliability was tested for the two language versions of the instrument, including the original version in English and the translated version in the Maltese language. Test-retest reliability was analysed by using the Intraclass Correlation Coefficient (ICC) and values were reported with their corresponding 95% Confidence Interval (CI). The ICCs were analysed by the two-way mixed model and an absolute agreement between average measures.

### *4.2.1 Internal Consistency of the B-IPQ*

The Cronbach's α coefficient of the B-IPQ was moderate (acceptable), reaching an α value of 0.63 (Ursachi et al., 2015). This moderate α value is likely to be due to the small number of item ($n$ = 8). Since, this study was carried out amongst individuals living with HF, the Cronbach's α obtained could not be compared to the study

mentioned in section 3.5.1 (a), as it was done amongst individuals suffering from coronary artery disease. If one of the B-IPQ items was deleted Cronbach's α coefficient would range between 0.53 to 0.66. Moreover, if items 2-4 (Timeline, personal control, and treatment control) were removed, Cronbach`s α could improve from 0.63 to 0.66. However, the change would be small and thus, due to theoretical importance, all items were kept.

### *4.2.2 Test-Retest Reliability of the B-IPQ – English Version and Maltese Version*

Test-retest reliability of the B-IPQ English version showed considerable agreement for the total score. This was presented by an ICC of 0.86, indicating good reliability. Its 95% CI ranged between 0.69 and 0.94, [F (24, 24) = 7.74, $p < 0.001$]. This means that the level of reliability, based on statistical inference, ranged between "moderate" to "excellent" (Koo & Li, 2016).

The test-retest analysis of the Maltese translated version showed an excellent reliability, with an ICC value of 0.98. Its 95% CI ranged between 0.95 to 0.99, [F (24, 24) = 48.66, $p < 0.001$], showing an excellent range of reliability (Koo & Li, 2016).

### *4.2.3 Internal Consistency of the EHFScBs-9*

The Cronbach's α coefficient obtained for the EHFScBs-9 was 0.75, showing a good internal consistency value. The Cronbach's α coefficient value obtained was similar to that reported by international studies [Section 3.5.1 (b)]. No improvement in the Cronbach's α coefficient could have been obtained by deleting any items.

### *4.2.4 Test-Retest Reliability of the EHFScBs-9 – English Version and Maltese Version*

On test-retest analysis, the EHFScBs-9 English version, showed a good reliability, with an ICC value of 0.83. Its 95% CI ranged between 0.51 and 0.93, [F (24, 24) = 7.79, $p < 0.001$], showing a reliability level ranging between "moderate" to "excellent" (Koo & Li, 2016).

On the other hand, the EHFScBs-9 Maltese version obtained an ICC value of 0.98, showing an excellent level of reliability. Moreover, an "excellent" range of reliability level was presented by its 95% CI which ranged between 0.96 and 0.99, [F (24, 24) = 58.40, $p < 0.001$] (Koo & Li, 2016).

### *4.2.5 Internal Consistency of the MARS-5*

In the current research study, the Cronbach's α coefficient for the MARS-5 was good, α = 0.70. This result was comparable with other international studies which used the English version MARS-5 [Section 3.5.1 (c)]. If item M1 (I forget to take them) was deleted, Cronbach's α coefficient would be 0.72. However, this item was retained since the total Cronbach's α coefficient score for MARS-5 was still a good value. Moreover, the M1 item was considered to be theoretically important.

### *4.2.6 Test-Retest Reliability of the MARS-5 – English Version and Maltese Version*

The obtained ICC value for the test-retest of the MARS-5 original version was 0.93, showing an excellent reliability. Its 95% CI ranged between 0.83 and 0.97, [F (24, 24) = 12.88, $p < 0.001$]. Therefore, the level of reliability ranged between "good" to "excellent" (Koo & Li, 2016).

On the other hand, the MARS-5 Maltese version obtained an ICC value of 0.76, showing good reliability. Its 95% CI ranged between 0.44 and 0.90, [F (24, 24) = 4.76, $p < 0.001$]. Therefore, its level of reliability, based on statistical inference, ranged between "poor" to "good" reliability (Koo & Li, 2016).

Overall, there were no major problems in the internal consistency and reliability of the research instruments. Moreover, for both language versions, no changes were made to their original construct.

## 4.3 Socio-Demographic Characteristics and Clinical Information of the Participants

A total of 280 individuals were conveniently invited and accepted to participate in this study. All the answered questionnaires were considered as valid since all the questionnaires were more than 95% filled (Bennett, 2001).

The socio-demographic characteristics for the sample ($n$ = 280) are summarised in Table 4.1. The age of the participants ranged between 30 and 92 years with a mean age of 69 years ($SD$ = 11) and a median age of 71 years. Participants were mostly between the age of 71 to 80 years (43%). Most of the participants were males, representing 78% ($n$ = 219) of the participants, while 22% ($n$ = 61) were females. The majority of the participants reported to have a secondary level of education ($n$ = 127, 45%) while 37% ($n$ = 104) reported a primary level of education. The advanced age of the participants reflected their occupation, as most of the participants reported that they were pensioners ($n$ = 209, 75%). Almost three quarters ($n$ = 206, 74%) of the participants reported that they were married or living with a partner, while 86% ($n$ = 241) were living with others.

**Table 4.1**

*Socio-Demographic Characteristics of the Study Sample (n = 280)*

| | | Frequency | Percent |
|---|---|---|---|
| **Age (years)** | 60 years or less | 54 | 19 |
| (*M* = 69, *SD* = 11, *Mdn* = 71) | 61 - 70 years | 82 | 29 |
| | 71 – 80 years | 120 | 43 |
| | 81 years or more | 24 | 9 |
| **Gender** | Male | 219 | 78 |
| | Female | 61 | 22 |
| **Educational Level** | Primary | 104 | 37 |
| | Secondary | 127 | 45 |
| | Post-Secondary | 24 | 9 |
| | Tertiary | 25 | 9 |
| **Occupation** | Unemployed | 28 | 10 |
| | Formally Employed | 36 | 13 |
| | Self-employed | 7 | 3 |
| | Pensioner | 209 | 75 |
| **Marital Status** | Married/ Living with partner | 206 | 74 |
| | Single/ Separated/ Divorced/ Widowed | 74 | 26 |
| **Living Arrangement** | Living alone | 39 | 14 |
| | Living with others | 241 | 86 |

*Note.* For each category frequencies all add up to 280 participants; percentages all add up to 100%.

The clinical information of the participants is summarised in Table 4.2. Participants reported that they were diagnosed with HF at a mean age of 59 years (*SD* = 14), with a median age of 60 years. This data revealed that the participants had been

living with HF for a median time of 6 years (*M* = 10, *SD* = 11). More than half of the participants were diagnosed with Coronary Artery Disease (CAD) (*n* = 158, 56%) while 12% (*n* = 33) were diagnosed with Hypertension, and 9% (*n* = 26) with Idiopathic Dilated Cardiomyopathy.

Participants were mostly diagnosed with HF with reduced ejection fraction (HFrEF) (*n* =205, 73%), while most of them were symptomatic as they classified themselves in NYHA Class II – IV (n = 201, 72%). Eighty six percent of the participants reported that they had been following-up their HF for more than 1 year, of which 28% (*n* = 78) had been following-up their HF for more than 10 years. Since diagnosis with HF participants experienced, on average, at least one admission due to HF (*M* = 1.56, *SD* = 2.03). In fact, a combined percentage of 62% (*n* = 173) of the participants reported an admission. However, 35% (*n* = 98) of participants in this sample reported an admission which occurred more than one year ago. Conversely, 38% (*n* = 107) of the sample reported no admissions since diagnosis with HF.

A total of 237 (85%) participants were suffering from other medical problems/comorbidities apart from HF. In some cases, multiple problems/comorbidities were reported. There were 43 (15%) participants who were not suffering from any other medical problems/comorbidities apart from HF. The three most reported other medical conditions were: Type II Diabetes Mellitus (*n* = 123, 44%), Hypertension (*n* = 92, 33%), and Atrial Fibrillation (*n* = 59, 21%).

Despite that participants reported that they take more than 10 pills a day (*M* = 10, *SD* = 2), most of the participants reported that they prepare their own pills without any support (*n* = 204, 73%).

**Table 4.2**

*Clinical and Medication Information of the Study Sample (n = 280)*

| | | Frequency | Percent |
|---|---|---|---|
| **Age of diagnosis (years) -** (*M* = 59, *SD* = 14, *Mdn* = 60) | | - | - |
| **Time since diagnosis with HF (years) -** (*M* = 10, *SD* = 11, *Mdn* = 6) | | - | - |
| **Aetiology** | Coronary Artery Disease | 158 | 56 |
| | Hypertension | 33 | 12 |
| | Idiopathic Dilated Cardiomyopathy | 26 | 9 |
| | Valvular | 19 | 7 |
| | Arrythmias | 17 | 6 |
| | Others | 27 | 9 |
| **Ejection Fraction** | HFrEF – LVEF <40% | 205 | 73 |
| | HFmrEF – LVEF 40-49% | 53 | 19 |
| | HFpEF – LVEF ≥50% | 22 | 8 |
| **NYHA Class** | I | 79 | 28 |
| | II | 143 | 51 |
| | III | 55 | 20 |
| | IV | 3 | 1 |
| **Followed-up period** | ≤ 6 months | 21 | 8 |
| | > 6 months but < 1 year | 18 | 6 |
| | 1 - 5 years | 88 | 31 |
| | >5 - 10 years | 75 | 27 |
| | ≥ 10 years | 78 | 28 |
| **Number of admissions -** (*M* = 1.56, *SD* = 2.03, *Mdn* = 1) | | - | - |
| **Last admission with HF** | Less than 1 month ago | 14 | 5 |
| | 1 to 6 months ago | 37 | 13 |

| | | | |
|---|---|---|---|
| | Less than 1 year but more than 6 months | 19 | 7 |
| | 1 year ago | 5 | 2 |
| | More than 1 year ago | 98 | 35 |
| | No admissions | 107 | 38 |
| **Other medical problems/comorbidities** | Type II Diabetes Mellitus | 123 | 44 |
| | Hypertension | 92 | 33 |
| | Atrial Fibrillation | 59 | 21 |
| | Dyslipidaemia | 40 | 14 |
| | Chronic Kidney disease | 30 | 11 |
| | Others | 178 | 64 |
| **Preparation of medication** | Yes – Not supported | 204 | 73 |
| | No - Supported | 76 | 27 |
| **Number of daily pills -** ($M$ = 10, $SD$ = 2, $Mdn$ = 10) | | - | - |

*Note.* For each category frequencies all add up to 280 participants; percentages all add up to 100%.

HFrEF – Heart Failure with reduced Ejection Fraction

HFmrEF – Heart Failure with mid-ranged Ejection Fraction

HFpEF – Heart Failure with preserved Ejection Fraction

LVEF – Left Ventricular Ejection Fraction

## 4.4 Objective 1: To Assess the Illness Perceptions of Individuals Living With Heart Failure

This section gives a detailed analysis of the illness perception dimensions as reported by the B-IPQ. For the illness perception dimension of consequences (Item 1),

timeline (Item 2), personal control (Item 3), treatment control (Item 4), identity (Item 5), concern (Item 6), illness comprehensibility (Item 7), and emotions (Item 8), the mean score together with the standard deviation, and their median score are reported in Table 4.3. A score between 0 to 3.33 indicates a low score, 3.34 to 6.66 indicates a moderate score, while 6.67 to 10 indicates a high score. Higher scores relate to stronger perception that the illness have greater consequences (Consequences), a chronic timeline (Timeline), greater personal control over the illness (Personal control), that treatment is highly effective in managing the illness (Treatment control), that the illness is affecting the individual to be more symptomatic (Identity), higher level of preoccupation about the situation (Concern), higher degree of understanding about the illness (Illness comprehensibility), and a higher level of emotional disturbance (Emotions).

For the total B-IPQ score (Overall illness perception), items 3, 4 and 7 were reversed scored and added with items 1, 2, 5, 6, and 8. Higher scores represents a greater perception that the illness is threatening. A score between 0 to 26.6 indicates a low threatening perception about the illness, 26.7 to 53.2 indicates a moderate threatening perception, while 53.3 to 80 indicates a high threatening perception.

The total B-IPQ score reported ranged between 37.5 and 67. The mean B-IPQ total score reported was 37.56 (*SD* = 11.48, *Mdn* = 37.50), signifying that participants perceived their illness as a moderate threat. For all the individual items, the minimum score was that of 0 while the maximum score was that of 10. Participants scored the highest scores in two illness representations, timeline (*M* = 8.10, *SD* = 3.23), indicating that they perceived HF as a chronic illness, and treatment control (*M* = 8.88, *SD* = 1.71), showing that participants perceived HF as an illness which can be controlled by treatment. The lowest mean score reported was that for illness identity with an average score of 4.32 (*SD* = 3.05) indicating a moderate perception of experiencing symptoms

due to HF, and that of emotions with an average score of 4.73 (*SD* = 3.80), suggesting a moderate emotional disturbance. Six dimensions were reported to be moderate; these include the dimension of consequences, personal control, identity, concern, illness comprehensibility, and emotions.

**Table 4.3**

*Scoring per Item and Total Scoring for the B-IPQ*

| Item no. | Illness perception dimensions | Mean score | SD | Median. |
|---|---|---|---|---|
| **1** | **Consequences** | [a.] 5.57 | 3.10 | 6 |
| **2** | **Timeline** | [b.] 8.10 | 3.23 | 10 |
| **3** | **Personal control** | [b.] 6.29 | 2.70 | 6 |
| **4** | **Treatment control** | [a.] 8.88 | 1.71 | 10 |
| **5** | **Identity** | [a.] 4.32 | 3.05 | 5 |
| **6** | **Concern** | [a.] 5.28 | 3.81 | 6 |
| **7** | **Illness comprehensibility** | [a.] 5.30 | 3.30 | 5 |
| **8** | **Emotions** | [a.] 4.73 | 3.80 | 5 |
| **Total B-IPQ score (Illness perception)** | | [c.] 37.56 | 11.48 | 37.50 |

[a.] *n = 280*

[b.] *n = 279*

[c.] *n = 278*

### *4.4.1 The Causal Factors*

The causal factors were analysed by an open-ended question where participants were asked to list the three most important causal factors which they believed caused their HF. From a total of 280 participants, 278 (99%) reported a primary causal factor for their HF. The most frequently mentioned causal factors of HF, which were ranked as the primary cause of HF, were: s*tress* (*n* = 36, 13%), *smoking* (*n* = 29, 10%), *hereditary*

(*n* = 28, 10%), and *work* (*n* = 19, 7%) (Table 4.4). Most of the participants reported that they *do not know* or had no idea of what had caused their HF (*n* = 42, 15%).

The second ranked causes most commonly mentioned were *smoking* (*n* = 21, 20%), *stress* (*n* = 21, 20%), *hereditary* (*n* = 9, 9%), *diet or eating habits* (*n* = 9, 9%), and *alcohol* (*n* = 5, 5%). More than half the participants did not report the second causal factor of their HF (*n* = 175, 63%).

Furthermore, the third ranked causal factor mostly mentioned was that of *stress* (*n* = 11, 23%), *diet or eating habits* (*n* = 7, 15%), *excessive weight* (*n* = 6, 13%), *smoking* (*n* = 5, 11%), and *sedentary lifestyle* (*N* = 4, 9%). The third ranked causal factor was only reported by 47 (17%) participants.

**Table 4.4**

*The Reported Causal Factors*

| Causal Factors | | | | | |
|---|---|---|---|---|---|
| **1st Ranked** | | **2nd Ranked** | | **3rd Ranked** | |
| | ***n* (%)** | | ***n* (%)** | | ***n* (%)** |
| **Do not know** | 42 (15) | **Smoking** | 21 (20) | **Stress** | 11 (23) |
| **Stress** | 36 (13) | **Stress** | 21 (20) | **Diet or eating habits** | 7 (15) |
| **Smoking** | 29 (10) | **Hereditary** | 9 (9) | **Excessive Weight** | 6 (13) |
| **Hereditary** | 28 (10) | **Diet or eating habits** | 9 (9) | **Smoking** | 5 (11) |
| **Work** | 19 (7) | **Alcohol** | 5 (5) | **Sedentary lifestyle** | 4 (9) |
| **Diet or eating habits** | 18 (6) | **Age** | 4 (5) | **Age** | 2 (4) |
| **Cardiovascular Disorders** | 16 (6) | **Sedentary lifestyle** | 4 (5) | **Lifestyle** | 2 (4) |
| **Alcohol** | 15 (5) | **Heart Attack** | 4 (5) | **Others** | 10 (21) |
| **Age** | 13 (5) | **Work** | 3 (3) | | |
| **Heart Attack** | 10 (4) | **Chemical** | 3 (3) | | |
| **Medicine/ Chemical** | 9 (3) | **Diabetes** | 3 (3) | | |
| **Virus** | 6 (2) | **Others** | 19 (18) | | |
| **Excessive Weight** | 6 (2) | | | | |
| **Congenital** | 5 (2) | | | | |
| **Others:** | 26 (19) | | | | |
| **Total** | 278 (100) | | 105 (100) | | 47 (100) |

## 4.5 Objective 2: To Identify any Inter-Relationships Between the Different Illness Representations of Local Individuals Living With Heart Failure

The illness perception dimensions were individually tested for the assumption of normality. The null hypothesis specifies that the score distribution is normal and is accepted if the *p*-value exceeds the 0.05 level of significance. The alternative hypothesis specifies that the score distribution is skewed, and the *p*-value is less than the 0.05 criteria. The Shapiro-Wilk test indicated that all the illness perception dimensions were not normally distributed (Table 4.5). Thus, Spearman's rank-order correlation was used as a non-parametric test to assess if the illness perception dimensions were intercorrelated.

**Table 4.5**

*Tests of Normality for the Illness Perception Dimensions*

| | | Shapiro-Wilk | | |
|---|---|---|---|---|
| **Item no.** | **Dimension** | **Statistic** | **df** | ***P*-value** |
| **Item 1** | **Consequences** | 0.91 | 278 | *<0.001** |
| **Item 2** | **Timeline** | 0.63 | 278 | *<0.001** |
| **Item 3** | **Personal control** | 0.94 | 278 | *<0.001** |
| **Item 4** | **Treatment control** | 0.71 | 278 | *<0.001** |
| **Item 5** | **Identity** | 0.93 | 278 | *<0.001** |
| **Item 6** | **Concern** | 0.86 | 278 | *<0.001** |
| **Item 7** | **Illness comprehensibility** | 0.92 | 278 | *<0.001** |
| **Item 8** | **Emotions** | 0.86 | 278 | *<0.001** |

* $p < 0.05$

The correlations among the illness perception dimensions are presented in Table 4.6. Several significant relationships were noted with a *p*-value less than 0.05 level of significance.

As shown in table 4.6, the consequences dimension was positively correlated with identity, $r_s = 0.390$, $p < 0.001$, illness comprehensibility $r_s = 0.236$, $p < 0.001$, and timeline, $r_s = 0.140$, $p = 0.02$. Additionally, the consequences dimension was positively correlated with concern, $r_s = 0.452$, $p < 0.001$, and emotions $r_s = 0.426$, $p < 0.001$.

A positive correlation was noted between identity and timeline dimensions $r_s = 0.160$, $p = 0.007$, while a negative correlation was noted between identity and treatment control, $r_s = -0.163$, $p = 0.006$. Personal control and treatment control were noted to be positively correlated with each other, $r_s = 0.220$, $p < 0.001$. Moreover, positive correlations were also noted between identity and concern, $r_s = 0.274$, $p < 0.001$, between identity and illness comprehensibility, $r_s = 0.217$, $p < 0.001$, and between identity and emotions, $r_s = 0.316$, $p < 0.001$.

Concern about the illness was positively correlated with illness comprehensibility, $r_s = 0.195$, $p = 0.001$. On the other hand, a positive correlation was noted between concern and emotions, $r_s = 0.506$, $p < 0.001$. The final correlation noted was that between illness comprehensibility and emotions, which was noted to be a positive correlation, $r_s = 0.258$, $p < 0.001$.

**Table 4.6**

*Spearman's Correlation Coefficient to Assess Correlation Between the B-IPQ Dimensions (Item 1 – 8)*

| | | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. |
|---|---|---|---|---|---|---|---|---|---|
| 1. Consequences | Correlation Coefficient | | | | | | | | |
| | *P*-value | — | | | | | | | |
| 2. Timeline | Correlation Coefficient | 0.140* | | | | | | | |
| | *P*-value | [b] 0.020 | — | | | | | | |
| 3. Personal control | Correlation Coefficient | 0.037 | -0.009 | | | | | | |
| | *P*-value | [b] 0.534 | [c] 0.878 | — | | | | | |
| 4. Treatment control | Correlation Coefficient | -0.095 | 0.036 | 0.220** | | | | | |
| | *P*-value | [a] 0.113 | [b] 0.551 | [b] <0.001 | — | | | | |
| 5. Identity | Correlation Coefficient | 0.390** | 0.160** | -0.088 | -0.163** | | | | |
| | *P*-value | [a] <0.001 | [b] 0.007 | [b] 0.143 | [a] 0.006 | — | | | |
| 6. Concern | Correlation Coefficient | 0.452** | 0.072 | 0.066 | -0.050 | 0.274** | | | |
| | *P*-value | [a] <0.001 | [b] 0.229 | [b] 0.275 | [a] 0.405 | [a] <0.001 | — | | |
| 7. Illness | Correlation Coefficient | 0.236** | 0.106 | 0.087 | 0.015 | 0.217** | 0.195** | | |
| comprehensibility | *P*-value | [a] <0.001 | [b] 0.078 | [b] 0.149 | [a] 0.797 | [a] <0.001 | [a] 0.001 | — | |
| 8. Emotions | Correlation Coefficient | 0.426** | 0.081 | 0.044 | -0.071 | 0.316** | 0.506** | 0.258** | |
| | *P*-value | [a] <0.001 | [b] 0.175 | [b] 0.460 | [a] 0.237 | [a] <0.001 | [a] <0.001 | [a] <0.001 | — |

* $p < 0.05$

** $p < 0.01$

[a]. $n = 280$

[b]. $n = 279$

[c]. $n = 278$

## 4.6 Objective 3: To Assess the Level of Heart Failure Self-Care Behaviours, Including the Level of Medication Adherence

### *4.6.1 Heart Failure Self-Care Behaviours – EHFScBs-9*

Table 4.7 represents the descriptive statistics for the EHFScBs-9 reported scores. To calculate the total EHFScBs-9 score items 1-9 were reverse scored, and then standardised from 0 - 100. A score between 0 to 33.3 indicates lack of self-care, 33.4 to 66.6 indicates a moderate self-care, while 66.7 to 100 indicates better HF self-care. The total standardised mean score (0 - 100) for the EHFScBs-9 was 76.74 (*SD* = 19.84) with a median score of 81, suggesting that overall participants were adherent to their recommended HF self-care behaviours.

When interpreting individual items (Item 1-9), a high score indicates lack of self-care adherence while a low score indicates better adherence to that recommended behaviour. Items 2 to 8 were mostly towards 1 and 2 score, indicating that the study population were adherent to the respective self-care behaviours as presented by each item. The highest score recorded was that of regular exercise, meaning that participants were mostly living a sedentary lifestyle (*M* = 3.07, *SD* = 1.60, *Mdn* = 3). In addition, a considerable number of participants (*n* = 127, 45%) reported that they do not weigh themselves daily (Item 1), this was also observed by the moderate score reported (*M* = 2.57, *SD* = 1.70). Taking medications as prescribed was the best score recorded, with a median score of 1 (*M* = 1.13, *SD* = 0.63), indicating that participants were mostly adherent to their prescribed medications.

**Table 4.7**

*EHFScBs-9 - Response to Each Item and Total Standardised Score*

| Item no. | Item description | *Mean score* (*SD*) | N (%) | | | | |
|---|---|---|---|---|---|---|---|
| | | | Completely agree | | | | I don't agree at all |
| | | | 1 | 2 | 3 | 4 | 5 |
| **1** | **I weigh myself everyday** | 2.57 (1.70) | 131 (47) | 22 (8) | 39 (14) | 12 (4) | 76 (27) |
| **2** | **If my shortness of breath increases, I contact my doctor or nurse** | 1.53 (1.25) | 230 (82) | 10 (4) | 6 (2) | 9 (3) | 25 (9) |
| **3** | **If my feet/legs become swollen than usual, I contact my doctor or nurse** | 1.43 (1.12) | 235 (84) | 12 (4) | 10 (4) | 3 (1) | 20 (7) |
| **4** | **If I gain 2Kg in one week, I contact my doctor or nurse** | 2.01 (1.61) | 191 (68) | 11 (4) | 16 (6) | 9 (3) | 53 (19) |
| **5** | **I limit the amount of fluid I drink (not more than 1.5/2L/day)** | 1.98 (1.41) | 168 (60) | 29 (10) | 38 (14) | 11 (4) | 34 (12) |
| **6** | **If I experienced increased fatigue, I contact my doctor or nurse** | 1.70 (1.36) | 211 (75) | 14 (5) | 14 (5) | 10 (4) | 31 (11) |
| **7** | **I eat a low salt diet** | 1.95 (1.38) | 168 (60) | 31 (11) | 39 (14) | 11 (4) | 31 (11) |
| **8** | **I take my medications as prescribed** | 1.13 (0.63) | 265 (95) | 7 (3) | 1 (<1) | 1 (<1) | 6 (2) |
| **9** | **I exercise regularly** | 3.07 (1.60) | 75 (27) | 36 (13) | 48 (17) | 36 (13) | 85 (30) |

| | | | |
|---|---|---|---|
| **Total EHFScBs-9 score (Self-care)** **(Standardised score 0 - 100)** | 76.74 (19.84) | **Minimum score** | **Maximum score** |
| | | 11 | 100 |

### *4.6.2 Medication Adherence – MARS-5*

The mean score for the MARS-5, representing medication adherence, was obtained from the average total scores as listed in table 4.8. Overall, participants reported that they were adherent to their prescribed medications ($M$ = 24.16, $SD$ = 1.77, $Mdn$ = 25). All the MARS-5 items were reported with an average score above 4 and with a standard deviation which do not exceed 1, indicating that participants rarely forget their medication, rarely alter the dose, rarely stop taking the medication, rarely decide to miss out a dose, and rarely take less than instructed.

**Table 4.8**

*MARS-5 - Response to Each Item and Total Score*

| **Item no.** | **Item description** | ***Mean score* (*SD*)** | ***n* (%)** | | | | |
|---|---|---|---|---|---|---|---|
| | | | **Always** | **Often** | **Sometimes** | **Rarely** | **Never** |
| **M1** | **I forget to take them** | 4.68 (0.61) | 0 (0) | 2 (1) | 15 (5) | 54 (19) | 209 (75) |
| **M2** | **I alter the dose** | 4.88 (0.51) | 2 (1) | 1 (<1) | 6 (2) | 10 (4) | 261 (93) |
| **M3** | **I stop taking them for a while** | 4.93 (0.34) | 0 (0) | 1 (<1) | 4 (1) | 9 (3) | 266 (95) |
| **M4** | **I decide to miss out a dose** | 4.81 (0.56) | 1 (<1) | 2 (1) | 11 (4) | 20 (7) | 246 (88) |
| **M5** | **I take less than instructed** | 4.86 (0.57) | 2 (1) | 3 (1) | 7 (3) | 8 (3) | 260 (93) |
| **Total MARS-5 score** | | 24.16 (1.77) | **Minimum score** | | | **Maximum score** | |
| | | | 12 | | | 25 | |

## 4.7 Objective 4: To Identify any Possible Differences in Illness Perceptions, Self-Care Behaviours and Medication Adherence in Individuals Living With Heart Failure Based on Their Socio-Demographic Characteristics and Clinical Data

In this section, the illness perception dimensions (Consequences, timeline, personal control, treatment control, identity, concern, illness comprehensibility, and emotions), overall illness perception, and self-care, including medication adherence, were analysed in relation to each socio-demographic characteristic and clinical information.

The Shapiro-Wilk test was used, to determine whether the scores distribution, including that of age, age of diagnosis, illness perception, self-care, and the medication adherence, was normal or skewed. The Shapiro-Wilk *p*-values for the 5 scores were less than 0.05 level of significance (Table 4.9), indicating that all 5 scores distributions violate the normality of assumption. For this reason, non-parametric tests were used to analyse the data.

**Table 4.9**

*Test of Normality for Age, Age of Diagnosis, Illness Perception, Self-Care, and Medication Adherence*

| | Shapiro-Wilk | | |
|---|---|---|---|
| | **Statistic** | **df** | ***P*-value** |
| **Age** | 0.95 | 280 | *<0.001** |
| **Age of diagnosis** | 0.95 | 280 | *<0.001** |
| **Illness perception** | 0.99 | 278 | *0.047** |
| **Self-care** | 0.89 | 278 | *<0.001** |
| **Medication adherence** | 0.53 | 278 | *<0.001** |

* $p < 0.05$

### *4.7.1 Age*

As presented in Table 4.10, the Spearman correlation test yielded 3 correlations with age. Age was negatively correlated with illness concern ($r_s$ = -0.139, $p$ = 0.02, and emotions ($r_s$ = -0.181, $p$ = 0.002), and positively correlated with self-care ($r_s$ = 0.154, $p$ = 0.01). However, age was not found to be significantly related to medication adherence ($r_s$ = 0.08, $p$ = 0.182).

**Table 4.10**

*Spearman Correlation Test - Age by Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence*

| | Age | | |
|---|---|---|---|
| | ***n*** | ***r*** | ***P*-value** |
| **Consequences** | 280 | -0.016 | 0.784 |
| **Timeline** | 279 | -0.019 | 0.751 |
| **Personal control** | 279 | 0.086 | 0.154 |
| **Treatment control** | 280 | -0.026 | 0.663 |
| **Identity** | 280 | 0.061 | 0.306 |
| **Concern** | 280 | -0.139* | *0.020* |
| **Illness comprehensibility** | 280 | -0.056 | 0.353 |
| **Emotions** | 280 | -0.181** | *0.002* |
| **Illness perception** | 278 | -0.103 | 0.086 |
| **Self-care** | 280 | 0.154** | *0.010* |
| **Medication adherence** | 280 | 0.080 | 0.182 |

* $p < 0.05$

** $p < 0.01$

### *4.7.2 Gender*

The Mann Whitney U test was run to determine if there were differences in illness perception dimensions, illness perception, self-care, and medication adherence

scores between males and females (Table 4.11). Identity scores of females (*M* = 5.15, *SD* = 3.15) were significantly higher than those of males (*M* = 4.09, *SD* = 2.99), *U* = 5366.5, *z* = -2.37, *p* = 0.018, indicating that females perceived more experiences with symptoms due to HF than males. Personal control scores of females (*M* = 6.92, *SD* = 2.41) were just significantly higher than those of males (*M* = 6.12, *SD* = 2.75), *U* = 5492, *z* = -1.97, *p* = 0.049), indicating that females perceived HF to be more personally controlled than males. There were no significant differences in self-care and medication adherence between genders.

**Table 4.11**

*Mann-Whitney U Test to Assess Statistical Difference Between Gender and the Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence*

| | Gender | *n* (%) | Mean | SD | *U* | W | z | *P*-value |
|---|---|---|---|---|---|---|---|---|
| **Consequences** | Male | 219 (78) | 5.51 | 3.17 | 6512 | 30602 | -0.30 | 0.763 |
| | Female | 61 (22) | 5.79 | 2.85 | | | | |
| **Timeline** | Male | 219 (79) | 8.18 | 3.21 | 6243 | 8073 | -0.71 | 0.481 |
| | Female | 60 (22) | 7.83 | 3.35 | | | | |
| **Personal control** | Male | 219 (79) | 6.12 | 2.75 | 5492 | 29582 | -1.97 | *0.049** |
| | Female | 60 (22) | 6.92 | 2.41 | | | | |
| **Treatment control** | Male | 219 (78) | 8.86 | 1.74 | 6614 | 30704 | -0.13 | 0.897 |
| | Female | 61 (22) | 8.95 | 1.62 | | | | |
| **Identity** | Male | 219 (78) | 4.09 | 2.99 | 5366.5 | 29456.5 | -2.37 | *0.018** |
| | Female | 61 (22) | 5.15 | 3.15 | | | | |
| **Concern** | Male | 219 (78) | 5.23 | 3.77 | 6408 | 30498 | -0.49 | 0.622 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Female | 61 (22) | 5.46 | 3.99 | | | | |
| **Illness comprehensibility** | Male | 219 (78) | 5.42 | 3.26 | 6028 | 7919 | -1.17 | 0.241 |
| | Female | 61 (22) | 4.87 | 3.46 | | | | |
| **Emotions** | Male | 219 (78) | 4.6 | 3.84 | 6077.5 | 30167.5 | -1.10 | 0.273 |
| | Female | 61 (22) | 5.2 | 3.66 | | | | |
| **Illness perception** | Male | 219 (79) | 37.2 | 11.52 | 5817.5 | 29907.5 | -1.17 | 0.240 |
| | Female | 59 (21) | 38.92 | 11.32 | | | | |
| **Self-care** | Male | 219 (78) | 76.89 | 19.60 | 6628.5 | 8519.5 | -0.09 | 0.927 |
| | Female | 61 (22) | 76.23 | 20.85 | | | | |
| **Medication adherence** | Male | 219 (78) | 24.17 | 1.79 | 6671.5 | 8562.5 | -0.02 | 0.986 |
| | Female | 61 (22) | 24.15 | 1.74 | | | | |

*$p = 0.05$

### *4.7.3 Educational Level*

A Kruskal-Wallis H test showed that there was a significant difference in 3 illness perception dimensions scores between the different educational levels. These include that of treatment control ($\chi^2$ (3) = 8.14, $p = 0.043$), concern ($\chi^2$ (3) = 13.83, $p = 0.003$), and illness comprehensibility ($\chi^2$ (3) = 11.38, $p = 0.01$) (Table 4.12). There were no significant differences in self-care and medication adherence between the educational subgroups.

**Table 4.12**

*Kruskal-Wallis H Test to Assess Statistical Difference Between Educational Level, and the Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence*

| | Educ. level | *n* (%) | Mean | SD | $\chi^2$ | df | *P*-value |
|---|---|---|---|---|---|---|---|
| **Consequences** | Primary | 104 (37) | 5.49 | 3.10 | | | |
| | Secondary | 127 (45) | 5.50 | 3.17 | 1.03 | 3 | 0.795 |
| | Post-secondary | 24 (9) | 6.17 | 3.16 | | | |
| | Tertiary | 25 (9) | 5.64 | 2.75 | | | |
| **Timeline** | Primary | 104 (37) | 8.06 | 3.24 | | | |
| | Secondary | 127 (46) | 7.86 | 3.45 | 2.92 | 3 | 0.404 |
| | Post-secondary | 23 (8) | 9.00 | 2.61 | | | |
| | Tertiary | 25 (9) | 8.72 | 2.44 | | | |
| **Personal control** | Primary | 104 (37) | 6.47 | 2.65 | | | |
| | Secondary | 126 (45) | 6.12 | 2.82 | 1.24 | 3 | 0.744 |
| | Post-secondary | 24 (9) | 6.63 | 2.12 | | | |
| | Tertiary | 25 (9) | 6.08 | 2.78 | | | |
| **Treatment control** | Primary | 104 (37) | 8.72 | 2.00 | | | |
| | Secondary | 127 (45) | 9.14 | 1.38 | 8.14 | 3 | *0.043** |
| | Post-secondary | 24 (9) | 8.75 | 1.78 | | | |
| | Tertiary | 25 (9) | 8.32 | 1.75 | | | |
| **Identity** | Primary | 104 (37) | 4.46 | 3.02 | | | |
| | Secondary | 127 (45) | 4.15 | 3.08 | 0.86 | 3 | 0.836 |
| | Post-secondary | 24 (9) | 4.38 | 3.39 | | | |
| | Tertiary | 25 (9) | 4.52 | 2.83 | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Concern** | Primary | 104 (37) | 4.73 | 3.98 | | | |
| | Secondary | 127 (45) | 5.00 | 3.85 | 13.83 | 3 | *0.003** |
| | Post-secondary | 24 (9) | 7.33 | 2.69 | | | |
| | Tertiary | 25 (9) | 7.04 | 2.69 | | | |
| **Illness comprehensibility** | Primary | 104 (37) | 4.81 | 3.42 | | | |
| | Secondary | 127 (45) | 5.19 | 3.26 | 11.38 | 3 | *0.010** |
| | Post-secondary | 24 (9) | 6.29 | 3.26 | | | |
| | Tertiary | 25 (9) | 7.00 | 2.36 | | | |
| **Emotions** | Primary | 104 (37) | 4.28 | 4.03 | | | |
| | Secondary | 127 (45) | 4.77 | 3.68 | 5.47 | 3 | 0.140 |
| | Post-secondary | 24 (9) | 4.67 | 4.29 | | | |
| | Tertiary | 25 (9) | 6.44 | 2.33 | | | |
| **Illness perception** | Primary | 104 (37) | 37.02 | 12.22 | | | |
| | Secondary | 126 (45) | 36.93 | 11.14 | 4.27 | 3 | 0.233 |
| | Post-secondary | 23 (8) | 39.83 | 12.66 | | | |
| | Tertiary | 25 (9) | 40.96 | 8.20 | | | |
| **Self-care** | Primary | 104 (37) | 75.13 | 20.92 | | | |
| | Secondary | 127 (45) | 78.56 | 18.86 | 2.16 | 3 | 0.541 |
| | Post-secondary | 24 (9) | 73.61 | 22.52 | | | |
| | Tertiary | 25 (9) | 77.22 | 17.48 | | | |
| **Medication adherence** | Primary | 104 (37) | 24.29 | 1.62 | | | |
| | Secondary | 127 (45) | 24.28 | 1.55 | 4.47 | 3 | 0.215 |
| | Post-secondary | 24 (9) | 23.42 | 2.96 | | | |
| | Tertiary | 25 (9) | 23.80 | 1.89 | | | |

* $p = 0.05$

Pairwise comparisons were performed using Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. Table 4.13 presents the adjusted *p*-values. This Post Hoc analysis revealed that secondary educated participants scored (*M* = 9.14, *SD* = 1.38) significantly higher in treatment control than those with tertiary educational level (*M* = 8.32, *SD* = 1.75) (*p* = 0.039), indicating that secondary educated participants had a better perception that the illness can be controlled by treatment

Moreover, post-secondary level participants scored (*M* = 7.33, *SD* = 2.69) significantly higher in concern when compared to those with primary educational level (*M* = 4.73, *SD* = 3.98) (*p* = 0.021), and with secondary educational level (*M* = 5.00, *SD* = 3.85) (*p* = 0.038), indicating that post-secondary level participants were significantly more worried about their illness than those with secondary, and post-secondary educational level.

A statistically significant difference was also noted in illness comprehensibility, where tertiary educated participants (*M* = 7, *SD* = 2.36) reported significantly higher scores when compared to those with a primary educational level (*M* = 4.81 *SD* = 3.42) (*p* = 0.018), indicating that tertiary educated participants reported a better understanding of their illness than those with a primary educational level.

**Table 4.13**

*Post Hoc Test for the Treatment Control, Concern, and Illness Comprehensibility, by Educational Level as a Variable*

| | Sample 1-Sample 2 | Test Statistic | SE | Std. Test Statistic | *P*-value | Adj. *P*-value [a] |
|---|---|---|---|---|---|---|
| **Treatment control** | Tertiary-Post-Secondary | 26.80 | 20.85 | 1.29 | 0.199 | 1.000 |
| | Tertiary-Primary | 29.41 | 16.25 | 1.81 | 0.070 | 0.422 |
| | Tertiary-Secondary | 43.43 | 15.96 | 2.72 | *0.007** | *0.039* |
| | Post-Secondary-Primary | 2.62 | 16.52 | 0.16 | 0.874 | 1.000 |
| | Post-Secondary-Secondary | 16.64 | 16.24 | 1.03 | 0.306 | 1.000 |
| | Primary-Secondary | -14.02 | 9.65 | -1.45 | 0.146 | 0.877 |
| **Concern** | Primary-Secondary | -4.27 | 10.55 | -0.41 | 0.685 | 1.000 |
| | Primary-Tertiary | -44.45 | 17.77 | -2.50 | 0.012 | 0.074 |
| | Primary-Post-Secondary | -52.74 | 18.07 | -2.92 | *0.004** | *0.021* |
| | Secondary-Tertiary | -40.17 | 17.46 | -2.30 | 0.021 | 0.128 |
| | Secondary-Post-Secondary | -48.47 | 17.76 | -2.73 | *0.006** | *0.038* |
| | Tertiary-Post-Secondary | 8.29 | 22.80 | 0.36 | 0.716 | 1.000 |
| **Illness comprehensibility** | Primary-Secondary | -8.26 | 10.64 | -0.78 | 0.438 | 1.000 |
| | Primary-Post-Secondary | -36.61 | 18.22 | -2.01 | 0.044 | 0.267 |
| | Primary-Tertiary | -53.17 | 17.92 | -2.97 | *0.003** | *0.018* |

| | | | | | | |
|---|---|---|---|---|---|---|
| | Secondary-Post-Secondary | -28.35 | 17.91 | -1.58 | 0.113 | 0.680 |
| | Secondary-Tertiary | -44.91 | 17.60 | -2.55 | 0.011 | 0.064 |
| | Post-Secondary-Tertiary | -16.561 | 22.99 | -0.72 | 0.471 | 1.000 |

[a]. Significance values have been adjusted by the Bonferroni correction for multiple tests.

* $p \leq 0.008$

### *4.7.4 Occupation*

A Kruskal-Wallis H test showed that there was a significant difference in the medication adherence between the different occupations (unemployed, formally employed, self-employed, and pensioner), $\chi^2$ (3) = 13.88, $p$ = 0.003 (Table 4.14). However, there was no significant difference between self-care and the different subgroups of occupation.

A post hoc test was run to determine between which occupations, the medication adherence was statistically significant different (Table 4.15). This Post Hoc analysis revealed that pensioners reported a significantly higher medication adherence score ($M$ = 24.31, $SD$ = 1.66) than those who were formally employed ($M$ = 23.42, $SD$ = 2.38) ($p$ = 0.003), indicating that pensioners were significantly more adherent to their medications than formally employed participants.

**Table 4.14**

*Kruskal-Wallis H Test to Assess Statistical Difference Between Occupation, and the Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence*

| | Occupation | *n* (%) | Mean | SD | $\chi^2$ | df | *P*-value |
|---|---|---|---|---|---|---|---|
| **Consequences** | Unemployed | 28 (10) | 5.39 | 3.57 | 0.07 | 3 | 0.995 |
| | Formally employed | 36 (13) | 5.61 | 3.45 | | | |
| | Self-employed | 7 (3) | 5.43 | 4.39 | | | |
| | Pensioner | 209 (75) | 5.59 | 2.94 | | | |
| **Timeline** | Unemployed | 28 (10) | 7.21 | 3.54 | 6.80 | 3 | 0.079 |
| | Formally employed | 36 (13) | 8.08 | 3.40 | | | |
| | Self-employed | 7 (3) | 10.00 | 0.000 | | | |
| | Pensioner | 208 (75) | 8.16 | 3.20 | | | |
| **Personal control** | Unemployed | 28 (10) | 6.36 | 2.86 | 2.35 | 3 | 0.502 |
| | Formally employed | 36 (13) | 5.94 | 2.41 | | | |
| | Self-employed | 7 (3) | 5.14 | 3.08 | | | |
| | Pensioner | 208 (75) | 6.38 | 2.71 | | | |
| **Treatment control** | Unemployed | 28 (10) | 8.82 | 1.87 | 0.87 | 3 | 0.833 |
| | Formally employed | 36 (13) | 9.14 | 1.33 | | | |
| | Self-employed | 7 (3) | 9.29 | 1.25 | | | |
| | Pensioner | 209 (75) | 8.83 | 1.77 | | | |
| **Identity** | Unemployed | 28 (10) | 4.93 | 4.07 | 1.72 | 3 | 0.632 |
| | Formally employed | 36 (13) | 3.83 | 2.78 | | | |
| | Self-employed | 7 (3) | 3.71 | 2.50 | | | |
| | Pensioner | 209 (75) | 4.34 | 2.96 | | | |
| **Concern** | Unemployed | 28 (10) | 6.14 | 3.63 | 4.34 | 3 | 0.227 |
| | Formally employed | 36 (13) | 5.94 | 3.68 | | | |
| | Self-employed | 7 (3) | 6.43 | 3.95 | | | |
| | Pensioner | 209 (75) | 5.01 | 3.84 | | | |
| **Illness comprehensibility** | Unemployed | 28 (10) | 5.46 | 3.18 | 1.47 | 3 | 0.689 |
| | Formally employed | 36 (13) | 5.86 | 3.27 | | | |
| | Self-employed | 7 (3) | 5.00 | 3.51 | | | |
| | Pensioner | 209 (75) | 5.20 | 3.33 | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Emotions** | Unemployed | 28 (10) | 5.61 | 3.53 | 6.53 | 3 | 0.089 |
| | Formally employed | 36 (13) | 6.00 | 3.33 | | | |
| | Self-employed | 7 (3) | 4.00 | 5.03 | | | |
| | Pensioner | 209 (75) | 4.42 | 3.83 | | | |
| **Illness perception** | Unemployed | 28 (10) | 38.64 | 13.25 | 1.55 | 3 | 0.671 |
| | Formally employed | 36 (13) | 38.53 | 10.47 | | | |
| | Self-employed | 7 (3) | 40.14 | 7.27 | | | |
| | Pensioner | 207 (75) | 37.16 | 11.55 | | | |
| **Self-care** | Unemployed | 28 (10) | 78.87 | 15.97 | 6.39 | 3 | 0.094 |
| | Formally employed | 36 (13) | 69.29 | 21.58 | | | |
| | Self-employed | 7 (3) | 80.16 | 14.02 | | | |
| | Pensioner | 209 (75) | 77.63 | 19.99 | | | |
| **Medication adherence** | Unemployed | 28 (10) | 24.07 | 1.63 | 13.88 | 3 | *0.003** |
| | Formally employed | 36 (13) | 23.42 | 2.38 | | | |
| | Self-employed | 7 (3) | 24.00 | 1.16 | | | |
| | Pensioner | 209 (75) | 24.31 | 1.66 | | | |

* $p = 0.05$

**Table 4.15**

*Post Hoc Test for Medication Adherence, by Occupation as a Variable*

| | **Sample 1-Sample 2** | **Test Statistic** | **SE** | **Std. Test Statistic** | ***P*-value** | **Adj. *P*-value [a]** |
|---|---|---|---|---|---|---|
| **Medication adherence** | Formally employed-Self-employed | -5.73 | 28.18 | -0.20 | 0.839 | 1.000 |
| | Formally employed-Unemployed | 34.62 | 17.19 | 2.01 | 0.044 | 0.264 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | Formally employed-Pensioner | -43.42 | 12.31 | -3.53 | *<0.001** | *0.003* |
| | Self-employed-Unemployed | 28.89 | 28.83 | 1.00 | 0.316 | 1.000 |
| | Self-employed-Pensioner | -37.69 | 26.22 | -1.42 | 0.151 | 0.903 |
| | Unemployed-Pensioner | -8.80 | 13.73 | -0.64 | 0.522 | 1.000 |

[a]. Significance values have been adjusted by the Bonferroni correction for multiple tests.

* $p \leq 0.008$

### *4.7.5 Marital Status*

As presented in Table 4.16, the Mann-Whitney U test revealed no statistically significant differences in the illness perception dimensions' scores, illness perception, self-care, and medication adherence between the two categories of marital status (Married/Living with partner, and single/separated/divorced/widowed).

**Table 4.16**

*Mann-Whitney U Test to Assess Statistical Difference Between Marital Status and the Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence*

| | **Marital status** | ***n* (%)** | **Mean** | **SD** | ***U*** | **W** | **z** | ***P*-value** |
|---|---|---|---|---|---|---|---|---|
| **Consequences** | A | 206 (74) | 5.57 | 3.11 | 7603.5 | 10378.5 | -0.03 | 0.975 |
| | B | 74 (26) | 5.57 | 3.08 | | | | |
| **Timeline** | A | 205 (74) | 8.34 | 3.04 | 6679 | 9454 | -1.82 | 0.069 |
| | B | 74 (27) | 7.45 | 3.66 | | | | |
| **Personal control** | A | 205 (74) | 6.23 | 2.72 | 7273 | 28388 | -0.53 | 0.597 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | B | 74 (27) | 6.46 | 2.63 | | | | |
| **Treatment control** | A | 206 (74) | 8.80 | 1.78 | 6862 | 28183 | -1.41 | 0.158 |
| | B | 74 (26) | 9.11 | 1.50 | | | | |
| **Identity** | A | 206 (74) | 4.15 | 3.11 | 6774.5 | 28095.5 | -1.43 | 0.152 |
| | B | 74 (26) | 4.80 | 2.86 | | | | |
| **Concern** | A | 206 (74) | 5.33 | 3.81 | 7414 | 10189 | -0.35 | 0.724 |
| | B | 74 (26) | 5.14 | 3.84 | | | | |
| **Illness comprehensibility** | A | 206 (74) | 5.29 | 3.25 | 7478 | 28799 | -0.24 | 0.808 |
| | B | 74 (26) | 5.35 | 3.45 | | | | |
| **Emotions** | A | 206 (74) | 4.71 | 3.75 | 7528 | 28849 | -0.16 | 0.873 |
| | B | 74 (26) | 4.77 | 3.96 | | | | |
| **Illness perception** | A | 204 (74) | 37.84 | 10.97 | 7391.5 | 10166.5 | -0.26 | 0.792 |
| | B | 74 (27) | 36.80 | 12.84 | | | | |
| **Self-care** | A | 206 (74) | 77.80 | 18.98 | 6872 | 9647 | -1.26 | 0.208 |
| | B | 74 (26) | 73.80 | 21.94 | | | | |
| **Medication adherence** | A | 206 (74) | 24.24 | 1.68 | 6899.5 | 9674.5 | -1.44 | 0.151 |
| | B | 74 (26) | 23.95 | 2.01 | | | | |

A. Married/Living with partner

B. Single/ Separated/Divorced/Widowed

### *4.7.6 Living Arrangement*

Mann-Whitney U test revealed that only medication adherence was statistically significant different between the two categories of living arrangement [Living with others ($M$ = 24.24, $SD$ = 1.73), and living alone ($M$ = 23.72, $SD$ = 2.00)] $U$ = 3738.5, z = -2.43, $p$ = 0.015), indicating that individuals who were living with others were more adherent to their medications than those who were living alone (Table 4.17). There was no statistically significant difference in self-care between the two categories of living arrangement.

**Table 4.17**

*Mann-Whitney U Test to Assess Statistical Difference Between Living Arrangement and the Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence*

| | Living arrangement | *n* (%) | Mean | SD | *U* | W | z | *P*-value |
|---|---|---|---|---|---|---|---|---|
| **Consequences** | A | 39 (14) | 5.69 | 3.16 | 4548 | 33709 | -0.33 | 0.745 |
| | B | 241 (86) | 5.55 | 3.10 | | | | |
| **Timeline** | A | 39 (14) | 7.26 | 3.93 | 4138 | 4918 | -1.38 | 0.166 |
| | B | 240 (86) | 8.24 | 3.09 | | | | |
| **Personal control** | A | 39 (14) | 6.03 | 2.49 | 4291 | 5071 | -0.84 | 0.401 |
| | B | 240 (86) | 6.33 | 2.73 | | | | |
| **Treatment control** | A | 39 (14) | 9.05 | 1.56 | 4416 | 33577 | -0.67 | 0.502 |
| | B | 241 (86) | 8.85 | 1.74 | | | | |
| **Identity** | A | 39 (14) | 4.85 | 2.68 | 4187 | 33348 | -1.10 | 0.270 |
| | B | 241 (86) | 4.23 | 3.10 | | | | |
| **Concern** | A | 39 (14) | 5.54 | 3.59 | 4533 | 33694 | -0.36 | 0.719 |
| | B | 241 (86) | 5.24 | 3.85 | | | | |
| **Illness comprehensibility** | A | 39 (14) | 5.03 | 3.46 | 4488 | 5268 | -0.45 | 0.651 |
| | B | 241 (86) | 5.35 | 3.28 | | | | |
| **Emotions** | A | 39 (14) | 4.92 | 4.10 | 4501 | 33662 | -0.43 | 0.666 |
| | B | 241 (86) | 4.70 | 3.76 | | | | |
| **Illness perception** | A | 39 (14) | 38.15 | 13.10 | 4397.5 | 33077.5 | -0.57 | 0.572 |
| | B | 239 (86) | 37.47 | 11.22 | | | | |
| **Self-care** | A | 39 (14) | 70.51 | 24.96 | 4021 | 4801 | -1.45 | 0.147 |
| | B | 241 (86) | 77.75 | 18.75 | | | | |
| **Medication adherence** | A | 39 (14) | 23.72 | 2.00 | 3738.5 | 4518.5 | -2.43 | *0.015** |
| | B | 241 (86) | 24.24 | 1.73 | | | | |

A. Living alone

B. Living with others

*$p$ = 0.05

### *4.7.7 Age of Diagnosis With Heart Failure*

Several Spearman's correlation tests were carried out to assess if there was any relationship between the participants' age of diagnosis with HF and their illness perception dimensions, illness perception, self-care, and medication adherence. Table 4.18 illustrates that there were several significant correlations between the participants' age of diagnosis and the mentioned subscales. Age of diagnosis with HF was negatively correlated with timeline ($r_s$ = -0.148, $p$ = 0.013), concern ($r_s$ = -0.147, $p$ = 0.014), illness comprehensibility ($r_s$ = -0.125, $p$ = 0.036), emotions ($r_s$ = -0.209, $p$ < 0.001), and overall illness perception ($r_s$ = -0.173, $p$ = 0.004). On the other hand, age of diagnosis with HF was positively correlated with personal control ($r_s$ = 0.152, $p$ = 0.011), self-care ($r_s$ = 0.134, $p$ = 0.025), and medication adherence ($r_s$ = 0.136, $p$ = 0.023).

**Table 4.18**

*Spearman's Correlation Coefficient to Assess Correlation Between Age of Diagnosis with HF and the Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence*

| | **Age of diagnosis with HF** | | |
|---|---|---|---|
| | ***n*** | ***r*** | ***P*-value** |
| **Consequences** | 280 | -0.073 | 0.221 |
| **Timeline** | 279 | -0.148* | *0.013* |
| **Personal control** | 279 | 0.152* | *0.011* |
| **Treatment control** | 280 | -0.055 | 0.355 |
| **Identity** | 280 | -0.064 | 0.288 |
| **Concern** | 280 | -0.147* | *0.014* |

| | | | |
|---|---|---|---|
| **Illness comprehensibility** | 280 | -0.125* | *0.036* |
| **Emotions** | 280 | -0.209** | *<0.001* |
| **Illness perception** | 278 | -0.173** | *0.004* |
| **Self-care** | 280 | 0.134* | *0.025* |
| **Medication adherence** | 280 | 0.136* | *0.023* |

* $p < 0.05$

** $p < 0.01$

### *4.7.8 Left Ventricular Ejection Fraction*

As can be observed from Table 4.19, participants with a LVEF of <40% reported the highest scores for treatment control when compared to the other two LVEF groups. Those with a LVEF of 40-49% scored the highest in 5 illness perception dimensions, including personal control, identity, concern, illness comprehensibility, and emotions, and in self-care. While those with an EF of ≥50% scored the highest in consequences, timeline, illness perception, and medication adherence. None of these scores were statistically significant different between the 3 LVEF categories.

**Table 4.19**

*Kruskal-Wallis H Test to Assess Statistical Difference Between LVEF, and the Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence*

| | **LVEF** | ***n* (%)** | **Mean** | **SD** | $\chi^2$ | **df** | ***P*-value** |
|---|---|---|---|---|---|---|---|
| **Consequences** | <40% | 205 (73) | 5.48 | 3.06 | | | |
| | 40-49% | 53 (19) | 5.74 | 3.20 | 0.98 | 2 | 0.612 |
| | ≥50% | 22 (8) | 6.00 | 3.27 | | | |
| **Timeline** | <40% | 205 (73) | 8.13 | 3.23 | | | |
| | 40-49% | 52 (19) | 7.73 | 3.45 | 2.18 | 2 | 0.337 |
| | ≥50% | 22 (8) | 8.77 | 2.71 | | | |
| **Personal control** | <40% | 205 (73) | 6.11 | 2.69 | | | |
| | 40-49% | 53 (19) | 6.96 | 2.60 | 5.78 | 2 | 0.056 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | ≥50% | 21 (8) | 6.38 | 2.85 | | | |
| **Treatment control** | <40% | 205 (73) | 8.92 | 1.75 | 2.22 | 2 | 0.329 |
| | 40-49% | 53 (19) | 8.92 | 1.50 | | | |
| | ≥50% | 22 (8) | 8.41 | 1.84 | | | |
| **Identity** | <40% | 205 (73) | 4.11 | 3.01 | | | |
| | 40-49% | 53 (19) | 4.98 | 2.92 | 3.43 | 2 | 0.180 |
| | ≥50% | 22 (8) | 4.64 | 3.593 | | | |
| **Concern** | <40% | 205 (73) | 5.33 | 3.76 | | | |
| | 40-49% | 53 (19) | 5.60 | 3.90 | 2.41 | 2 | 0.300 |
| | ≥50% | 22 (8) | 4.09 | 4.02 | | | |
| **Illness comprehensibility** | <40% | 205 (73) | 5.32 | 3.31 | 0.15 | 2 | 0.927 |
| | 40-49% | 53 (19) | 5.36 | 3.33 | | | |
| | ≥50% | 22 (8) | 5.05 | 3.30 | | | |
| **Emotions** | <40% | 205 (73) | 4.67 | 3.81 | | | |
| | 40-49% | 53 (19) | 5.06 | 3.79 | 0.56 | 2 | 0.757 |
| | ≥50% | 22 (8) | 4.45 | 3.91 | | | |
| **Illness perception** | <40% | 205 (73) | 37.38 | 11.25 | | | |
| | 40-49% | 53 (19) | 37.83 | 12.29 | 0.47 | 2 | 0.792 |
| | ≥50% | 22 (8) | 38.76 | 12.17 | | | |
| **Self-care** | <40% | 205 (73) | 75.57 | 20.37 | | | |
| | 40-49% | 53 (19) | 80.29 | 17.16 | 2.81 | 2 | 0.246 |
| | ≥50% | 22 (8) | 79.16 | 20.52 | | | |
| **Medication adherence** | <40% | 205 (73) | 24.18 | 1.80 | 1.52 | 2 | 0.469 |
| | 40-49% | 53 (19) | 24.04 | 1.75 | | | |
| | ≥50% | 22 (8) | 24.36 | 1.62 | | | |

LVEF = Left Ventricular Ejection Fraction

### *4.7.9 NYHA Class*

A Kruskal-Wallis H test was conducted to determine if there were any difference in the reported scores between the NYHA Class groups. As indicated in Table 4.20, the average score for consequences, identity, concern, emotions, illness perception, and self-care were statistically different between the NYHA Class groups.

**Table 4.20**

*Kruskal-Wallis H Test to Assess Statistical Difference Between NYHA Class, and the Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence*

| | **NYHA Class** | ***n* (%)** | **Mean** | **SD** | **$\chi^2$** | **df** | ***P*-value** |
|---|---|---|---|---|---|---|---|
| **Consequences** | I | 79 (28) | 3.73 | 3.17 | 35.95 | 3 | *<0.001** |
| | II | 143 (51) | 6.09 | 2.86 | | | |
| | III | 55 (20) | 6.76 | 2.48 | | | |
| | IV | 3 (1) | 7.00 | 2.65 | | | |
| **Timeline** | I | 79 (28) | 7.34 | 3.80 | 4.82 | 3 | 0.185 |
| | II | 142 (51) | 8.43 | 2.92 | | | |
| | III | 55 (20) | 8.25 | 3.07 | | | |
| | IV | 3 (1) | 10.00 | 0.00 | | | |
| **Personal control** | I | 78 (28) | 6.59 | 2.81 | 2.76 | 3 | 0.430 |
| | II | 143 (51) | 6.16 | 2.63 | | | |
| | III | 55 (20) | 6.29 | 2.59 | | | |
| | IV | 3 (1) | 4.67 | 5.03 | | | |
| **Treatment control** | I | 79 (28) | 9.19 | 1.47 | 7.35 | 3 | 0.061 |
| | II | 143 (51) | 8.89 | 1.72 | | | |
| | III | 55 (20) | 8.42 | 1.95 | | | |
| | IV | 3 (1) | 8.67 | 1.16 | | | |
| **Identity** | I | 79 (28) | 2.46 | 2.73 | 54.62 | 3 | *<0.001** |
| | II | 143 (51) | 4.53 | 2.87 | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | III | 55 (20) | 6.35 | 2.47 | | | |
| | IV | 3 (1) | 6.00 | 2.00 | | | |
| **Concern** | I | 79 (28) | 4.24 | 3.86 | 12.79 | 3 | *0.005** |
| | II | 143 (51) | 5.34 | 3.74 | | | |
| | III | 55 (20) | 6.49 | 3.56 | | | |
| | IV | 3 (1) | 8.00 | 3.46 | | | |
| **Illness comprehensibility** | I | 79 (28) | 4.72 | 3.27 | 4.02 | 3 | 0.259 |
| | II | 143 (51) | 5.45 | 3.26 | | | |
| | III | 55 (20) | 5.75 | 3.43 | | | |
| | IV | 3 (1) | 5.67 | 3.79 | | | |
| **Emotions** | I | 79 (28) | 3.09 | 3.39 | 21.17 | 3 | *<0.001** |
| | II | 143 (51) | 5.25 | 3.82 | | | |
| | III | 55 (20) | 5.62 | 3.57 | | | |
| | IV | 3 (1) | 6.67 | 5.77 | | | |
| **Illness perception** | I | 78 (28) | 30.44 | 11.19 | 43.96 | 3 | *<0.001** |
| | II | 142 (51) | 39.13 | 10.28 | | | |
| | III | 55 (20) | 43.02 | 9.76 | | | |
| | IV | 3 (1) | 48.67 | 16.07 | | | |
| **Self-care** | I | 79 (28) | 82.42 | 17.39 | 14.05 | 3 | *0.003** |
| | II | 143 (51) | 75.95 | 18.05 | | | |
| | III | 55 (20) | 72.78 | 23.12 | | | |
| | IV | 3 (1) | 37.96 | 39.32 | | | |
| **Medication adherence** | I | 79 (28) | 24.27 | 1.86 | 5.17 | 3 | 0.160 |
| | II | 143 (51) | 24.02 | 1.86 | | | |
| | III | 55 (20) | 24.35 | 1.42 | | | |
| | IV | 3 (1) | 25.00 | 0.00 | | | |

*$p$ = 0.05

A Post Hoc test was conducted using the Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. The adjusted *p*-values are presented in Tables 4.21 to 4.26.

The consequences dimension was significantly reported with higher scores by those participants who categorised themselves in NYHA Class II (*M* = 6.09, *SD* = 2.86) than those who categorised themselves in NYHA Class I (*M* = 3.73, *SD* = 3.17) (*p* = <0.001) (Table 4.21). Moreover, the consequences dimension was significantly reported with higher scores by those participants who categorised themselves in NYHA Class III (*M* = 6.76, *SD* = 2.48) than those who categorised themselves in NYHA Class I (*M* = 3.73, *SD* = 3.17) (*p* = <0.001) (Table 4.21), indicating that participants who are symptomatic (NYHA Class II – III) perceived HF to have more serious consequences.

**Table 4.21**

*Post Hoc Test for Consequences by NYHA Class as a Variable*

| | **Sample 1-Sample 2** | **Test Statistic** | **SE** | **Std. Test Statistic** | ***P*-value** | **Adj. *P*-value[a]** |
|---|---|---|---|---|---|---|
| **Consequences** | **NYHA Class I-NYHA Class II** | -56.57 | 11.25 | -5.03 | *<0.001** | *<0.001* |
| | **NYHA Class I-NYHA Class IV** | -73.94 | 47.20 | -1.57 | 0.117 | 0.703 |
| | **NYHA Class I-NYHA Class III** | -75.14 | 14.09 | -5.33 | *<0.001** | *<0.001* |
| | **NYHA Class II-NYHA Class IV** | -17.37 | 46.81 | -0.37 | 0.711 | 1.000 |
| | **NYHA Class II-NYHA Class III** | -18.57 | 12.73 | -1.46 | 0.145 | 0.868 |
| | **NYHA Class IV-NYHA Class III** | 1.20 | 47.58 | 0.03 | 0.980 | 1.000 |

* $p \leq 0.008$

[a]. Significance values have been adjusted by the Bonferroni correction for multiple tests.

The identity dimension was significantly perceived higher by participants who categorised themselves in NYHA Class II (*M* = 4.53, *SD* = 2.87) and in NYHA Class III (*M* = 6.35, *SD* = 2.47) than those who categorised themselves in NYHA Class I (*M* = 2.46, *SD* = 2.73) (*p* = <0.001, for both classes) (Table 4.22). Moreover, NYHA Class III participants reported significantly higher identity scores (*M* = 6.35, *SD* = 2.47) than those in NYHA Class II (*M* = 4.53, *SD* = 2.87) (*p* = <0.001). Such results indicate that the more symptomatic the individual is (NYHA Class II – III) the more he/she perceives HF to be affecting them symptomatically.

**Table 4.22**

*Post Hoc Test for Identity by NYHA Class as a Variable*

| | **Sample 1-Sample 2** | **Test Statistic** | **SE** | **Std. Test Statistic** | ***P*-value** | **Adj. *P*-value [a]** |
|---|---|---|---|---|---|---|
| **Identity** | **NYHA Class I-NYHA Class II** | -52.08 | 11.25 | -4.63 | *<0.001** | *<0.001* |
| | **NYHA Class I-NYHA Class IV** | -93.99 | 47.20 | -1.99 | 0.046 | 0.279 |
| | **NYHA Class I-NYHA Class III** | -102.10 | 14.09 | -7.25 | *<0.001** | *<0.001* |
| | **NYHA Class II-NYHA Class IV** | -41.91 | 46.81 | -0.90 | 0.371 | 1.000 |
| | **NYHA Class II-NYHA Class III** | -50.02 | 12.73 | -3.93 | *<0.001** | *<0.001* |
| | **NYHA Class IV-NYHA Class III** | 8.10 | 47.57 | 0.17 | 0.865 | 1.000 |

* $p \leq 0.008$

[a]. Significance values have been adjusted by the Bonferroni correction for multiple tests.

NYHA Class III participants reported significantly higher score for concern (*M* = 6.49, *SD* = 3.56) than those who were in NYHA Class I (*M* = 4.24, *SD* = 3.86) (*p* = 0.006) (Table 4.23), suggesting that the more symptomatic the individual is the more he/she perceived HF to be a worrying situation.

**Table 4.23**

*Post Hoc Test for Concern by NYHA Class as a Variable*

| | Sample 1-Sample 2 | Test Statistic | SE | Std. Test Statistic | *P*-value | Adj. *P*-value[a] |
|---|---|---|---|---|---|---|
| **Concern** | **NYHA Class I-NYHA Class II** | -22.66 | 11.18 | -2.03 | 0.043 | 0.257 |
| | **NYHA Class I-NYHA Class III** | -46.17 | 14.011 | -3.30 | *0.001** | *0.006* |
| | **NYHA Class I-NYHA Class IV** | -82.69 | 46.93 | -1.76 | 0.078 | 0.468 |
| | **NYHA Class II-NYHA Class III** | -23.52 | 12.66 | -1.86 | 0.063 | 0.379 |
| | **NYHA Class II-NYHA Class IV** | -60.04 | 46.54 | -1.29 | 0.197 | 1.000 |
| | **NYHA Class III-NYHA Class IV** | -36.52 | 47.30 | -0.77 | 0.440 | 1.000 |

* $p \leq 0.008$

[a]. Significance values have been adjusted by the Bonferroni correction for multiple tests.

NYHA Class II and NYHA Class III participants reported significantly higher score in emotions (*M* = 5.25, *SD* = 3.82 – *M* = 5.62, *SD* = 3.57, respectively) than those who were in NYHA Class I (*M* = 3.09, *SD* = 3.39) (*p* = <0.001, for both classes), suggesting that the more symptomatic the individual is the more HF is perceived to be causing emotional disturbance (Table 4.24).

**Table 4.24**

*Post Hoc Test for Emotions by NYHA Class as a Variable*

| | Sample 1-Sample 2 | Test Statistic | SE | Std. Test Statistic | *P*-value | Adj. *P*-value [a] |
|---|---|---|---|---|---|---|
| **Emotions** | **NYHA Class I-NYHA Class II** | -45.01 | 11.14 | -4.04 | *<0.001** | *<0.001* |
| | **NYHA Class I-NYHA Class III** | -52.52 | 13.96 | -3.76 | *<0.001** | *<0.001* |
| | **NYHA Class I-NYHA Class IV** | -79.32 | 46.74 | -1.70 | 0.090 | 0.538 |
| | **NYHA Class II-NYHA Class III** | -7.51 | 12.61 | -0.60 | 0.552 | 1.000 |
| | **NYHA Class II-NYHA Class IV** | -34.31 | 46.36 | -0.74 | 0.459 | 1.000 |
| | **NYHA Class III-NYHA Class IV** | -26.80 | 47.11 | -0.57 | 0.569 | 1.000 |

* $p \leq 0.008$

[a]. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Illness perception was significantly reported with higher score by those participants who were in NYHA Class II (*M* = 39.13, *SD* = 10.28) and NYHA Class III (*M* = 43.02, *SD* = 9.76), than those who were in NYHA Class I (*M* = 30.44, *SD* = 11.19) (*p* = <0.001, for both classes) (Table 4.25), indicating that the more symptomatic the individual is the more HF is perceived as a threatening illness.

**Table 4.25**

*Post Hoc Test for Illness Perception by NYHA Class as a Variable*

| | Sample 1-Sample 2 | Test Statistic | SE | Std. Test Statistic | *P*-value | Adj. *P*-value[a] |
|---|---|---|---|---|---|---|
| **Illness perception** | **NYHA Class I-NYHA Class II** | -55.46 | 11.32 | -4.90 | *<0.001** | *<0.001* |
| | **NYHA Class I-NYHA Class III** | -87.91 | 14.15 | -6.21 | *<0.001** | *<0.001* |
| | **NYHA Class I-NYHA Class IV** | -102.66 | 47.27 | -2.17 | 0.030 | 0.179 |
| | **NYHA Class II-NYHA Class III** | -32.45 | 12.76 | -2.54 | 0.011 | 0.066 |
| | **NYHA Class II-NYHA Class IV** | -47.20 | 46.88 | -1.01 | 0.314 | 1.000 |
| | **NYHA Class III-NYHA Class IV** | -14.75 | 47.64 | -0.31 | 0.757 | 1.000 |

* $p \leq 0.008$

[a]. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Participants who classified themselves in NYHA Class I reported that they were more adherent to self-care ($M$ = 82.42, $SD$ = 17.39) than those who classified themselves in NYHA Class II ($M$ = 75.95, $SD$ = 18.05) and NYHA Class III ($M$ = 72.78, $SD$ = 23.12) ($p$ = 0.019, $p$ = 0.042, respectively) (Table 4.26). This implies that symptomatic individuals reported to be less adherent to self-care.

**Table 4.26**

*Post Hoc Test for Self-Care by NYHA Class as a Variable*

| | Sample 1-Sample 2 | Test Statistic | SE | Std. Test Statistic | *P*-value | Adj. *P*-value[a] |
|---|---|---|---|---|---|---|
| **Self-care** | **NYHA Class IV-NYHA Class III** | 73.98 | 47.92 | 1.54 | 0.123 | 0.735 |
| | **NYHA Class IV-NYHA Class II** | 78.90 | 47.15 | 1.67 | 0.094 | 0.565 |
| | **NYHA Class IV-NYHA Class I** | 112.26 | 47.54 | 2.36 | 0.018 | 0.109 |
| | **NYHA Class III-NYHA Class II** | 4.92 | 12.82 | 0.38 | 0.701 | 1.000 |
| | **NYHA Class III-NYHA Class I** | 38.28 | 14.19 | 2.70 | *0.007** | *0.042* |
| | **NYHA Class II-NYHA Class I** | 33.36 | 11.33 | 2.95 | *0.003** | *0.019* |

* $p \leq 0.008$

[a]. Significance values have been adjusted by the Bonferroni correction for multiple tests.

### *4.7.10 Followed-up Period for Heart Failure*

As can be observed in Table 4.27, the illness perception dimensions score of timeline, personal control, and identity, were statistically different between the groups of followed-up period for HF, $\chi^2$ (4) = 29.16, $p$ <0.001, $\chi^2$ (4) = 10.04, $p$ = 0.04, and $\chi^2$ (4) = 10.81, $p$ = 0.029, respectively.

**Table 4.27**

*Kruskal-Wallis H Test to Assess Statistical Difference Between Followed-up Period, and the Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence*

| | Followed-up period | *n (%)* | Mean | SD | $\chi^2$ | df | *P*-value |
|---|---|---|---|---|---|---|---|
| **Consequences** | ≤6 months | 21 (8) | 5.62 | 3.26 | | | |
| | >6 months | 18 (6) | 3.83 | 3.50 | | | |
| | 1 to 5 years | 88 (31) | 5.43 | 2.94 | 6.72 | 4 | 0.151 |
| | >5 up to 10 years | 75 (27) | 5.76 | 3.00 | | | |
| | ≥10 years | 78 (28) | 5.92 | 3.17 | | | |
| **Timeline** | ≤6 months | 21 (8) | 4.67 | 4.08 | | | |
| | >6 months | 18 (6) | 7.50 | 3.42 | | | |
| | 1 to 5 years | 87 (31) | 7.74 | 3.54 | 29.16 | 4 | *<0.001** |
| | >5 up to 10 years | 75 (27) | 8.89 | 2.57 | | | |
| | ≥10 years | 78 (28) | 8.82 | 2.43 | | | |
| **Personal control** | ≤6 months | 21 (8) | 7.33 | 2.83 | | | |
| | >6 months | 18 (6) | 5.94 | 3.17 | | | |
| | 1 to 5 years | 87 (31) | 6.40 | 2.57 | 10.04 | 4 | *0.040** |
| | >5 up to 10 years | 75 (27) | 6.59 | 2.68 | | | |
| | ≥10 years | 78 (28) | 5.68 | 2.62 | | | |
| **Treatment control** | ≤6 months | 21 (8) | 9.00 | 1.48 | | | |
| | >6 months | 18 (6) | 9.00 | 1.19 | | | |
| | 1 to 5 years | 88 (31) | 8.95 | 1.67 | 0.96 | 4 | 0.916 |
| | >5 up to 10 years | 75 (27) | 8.85 | 1.92 | | | |
| | ≥10 years | 78 (28) | 8.76 | 1.73 | | | |
| **Identity** | ≤6 months | 21 (8) | 2.86 | 3.02 | | | |
| | >6 months | 18 (6) | 3.72 | 2.82 | | | |
| | 1 to 5 years | 88 (31) | 4.03 | 3.06 | 10.81 | 4 | *0.029** |
| | >5 up to 10 years | 75 (27) | 4.37 | 3.26 | | | |
| | ≥10 years | 78 (28) | 5.12 | 2.71 | | | |
| **Concern** | ≤6 months | 21 (8) | 5.90 | 3.77 | 4.98 | 4 | 0.290 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | >6 months | 18 (6) | 4.56 | 3.43 | | | |
| | 1 to 5 years | 88 (31) | 5.50 | 3.69 | | | |
| | >5 up to 10 years | 75 (27) | 4.56 | 3.99 | | | |
| | ≥10 years | 78 (28) | 5.73 | 3.82 | | | |
| **Illness comprehensibility** | ≤6 months | 21 (8) | 5.10 | 3.79 | | | |
| | >6 months | 18 (6) | 4.89 | 3.34 | | | |
| | 1 to 5 years | 88 (31) | 4.85 | 3.14 | 4.41 | 4 | 0.354 |
| | >5 up to 10 years | 75 (27) | 5.40 | 3.35 | | | |
| | ≥10 years | 78 (28) | 5.87 | 3.27 | | | |
| **Emotions** | ≤6 months | 21 (8) | 5.05 | 4.14 | | | |
| | >6 months | 18 (6) | 4.44 | 3.42 | | | |
| | 1 to 5 years | 88 (31) | 4.88 | 3.64 | 1.09 | 4 | 0.896 |
| | >5 up to 10 years | 75 (27) | 4.35 | 4.00 | | | |
| | ≥10 years | 78 (28) | 4.91 | 3.84 | | | |
| **Illness perception** | ≤6 months | 21 (8) | 32.67 | 12.33 | | | |
| | >6 months | 18 (6) | 34.22 | 12.83 | | | |
| | 1 to 5 years | 86 (31) | 37.49 | 11.49 | 7.14 | 4 | 0.129 |
| | >5 up to 10 years | 75 (27) | 37.09 | 10.51 | | | |
| | ≥10 years | 78 (28) | 40.19 | 11.40 | | | |
| **Self-care** | ≤6 months | 21 (8) | 83.99 | 17.70 | | | |
| | >6 months | 18 (6) | 82.87 | 11.44 | | | |
| | 1 to 5 years | 88 (31) | 75.44 | 21.30 | 9.20 | 4 | 0.056 |
| | >5 up to 10 years | 75 (27) | 73.48 | 19.26 | | | |
| | ≥10 years | 78 (28) | 77.99 | 20.26 | | | |
| **Medication adherence** | ≤6 months | 21 (8) | 24.57 | 1.12 | | | |
| | >6 months | 18 (6) | 23.83 | 2.12 | | | |
| | 1 to 5 years | 88 (31) | 24.17 | 1.88 | 3.97 | 4 | 0.411 |
| | >5 up to 10 years | 75 (27) | 24.16 | 1.91 | | | |
| | ≥10 years | 78 (28) | 24.13 | 1.58 | | | |

*$p$ = 0.05

A post hoc test was conducted using the Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons (Tables 4.28 to 4.30).

Timeline dimension was significantly reported with higher scores by those participants who had a follow-up period of 1 year to 5 years (*M* = 7.74, *SD* = 3.54), >5 years up to 10 years (*M* = 8.89, *SD* = 2.57), and ≥10 years (*M* = 8.82, *SD* = 2.43), than those with ≤6 months follow-up period (*M* = 4.67, *SD* = 4.08) (*p* = 0.006, *p* = <0.001, *p* = <0.001, respectively) (Table 4.28). Such results suggest that participants with longer follow-up periods (1-5 years, >5 years up to 10 years, and ≥10 years) had more perception that HF is a chronic illness.

**Table 4.28**

*Post Hoc Test for Timeline by Followed-up Period as a Variable*

| | **Sample 1-Sample 2** | **Test Statistic** | **SE** | **Std. Test Statistic** | ***P*-value** | **Adj. *P*-value[a]** |
|---|---|---|---|---|---|---|
| **Timeline** | ≤6 months - >6 months | -49.00 | 21.72 | -2.26 | 0.024 | 0.241 |
| | ≤6 months - 1 year to 5 years | -56.34 | 16.44 | -3.43 | *0.001** | *0.006* |
| | ≤6 months - ≥10 years | -78.73 | 16.62 | -4.74 | *<0.001** | *<0.001* |
| | ≤6 months - >5 up to 10 years | -80.86 | 16.69 | -4.84 | *<0.001** | *<0.001* |
| | > 6 months - >1 to 5 years | -7.33 | 17.51 | -0.42 | 0.675 | 1.000 |
| | >6 months - ≥10 years | -29.72 | 17.68 | -1.68 | 0.093 | 0.928 |
| | > 6 months - >5 up to 10 years | -31.86 | 17.75 | -1.80 | 0.073 | 0.726 |
| | 1 - 5 years - ≥10 years | -22.39 | 10.54 | -2.12 | 0.034 | 0.337 |
| | 1 to 5 years - >5 up to 10 years | -24.53 | 10.66 | -2.30 | 0.021 | 0.213 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | ≥10 years - >5 up to 10 years | 2.14 | 10.94 | 0.20 | 0.845 | 1.000 |

*$p \leq 0.005$

[a]. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Personal control dimension scores were statistically different between the ≥10 years ($M$ = 5.68, $SD$ = 2.62) and ≤6 months follow-up period ($M$ = 7.33, $SD$ = 2.83) ($p$ = 0.045) (Table 4.29), indicating that HF is perceived to be more personally controlled by participants with a follow-up period of ≤6 months.

**Table 4.29**

*Post Hoc Test for Personal Control by Followed-up Period as a Variable*

| | **Sample 1-Sample 2** | **Test Statistic** | **SE** | **Std. Test Statistic** | ***P*-value** | **Adj. *P*-value[a]** |
|---|---|---|---|---|---|---|
| **Personal control** | ≥10 years - >6 months | 10.59 | 20.91 | 0.51 | 0.612 | 1.000 |
| | ≥10 years - 1 to 5 years | 21.96 | 12.47 | 1.76 | 0.078 | 0.782 |
| | ≥10 years - >5 up to 10 years | 27.59 | 12.93 | 2.13 | 0.033 | 0.329 |
| | ≥10 years - ≤6 months | 55.81 | 19.66 | 2.84 | *0.005** | *0.045* |
| | >6 months - 1 to 5 years | -11.37 | 20.70 | -0.55 | 0.583 | 1.000 |
| | >6 months - 5 to 10 years | -17.00 | 20.99 | -0.81 | 0.418 | 1.000 |
| | > 6 months - ≤6 months | 45.22 | 25.68 | 1.76 | 0.078 | 0.783 |
| | 1 to 5 years - >5 to 10 years | -5.63 | 12.60 | -0.45 | 0.655 | 1.000 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | 1 – 5 years - ≤6 months | 33.86 | 19.44 | 1.74 | 0.082 | 0.816 |
| | 5 to 10 years - ≤6 months | 28.23 | 19.74 | 1.43 | 0.153 | 1.000 |

*$p \leq 0.005$

[a]. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Identity dimension scores were statistically different between the ≤6 months ($M$ = 2.86, $SD$ = 3.02) and ≥10 years follow-up period ($M$ = 5.12, $SD$ = 2.71) ($p$ = 0.033) (Table 4.30). This implies that participants with ≥10 years follow-up period perceived HF to be affecting them with more symptoms than those with a follow-up period of ≤6 months.

**Table 4.30**

*Post Hoc Test for Identity by Followed-up Period as a Variable*

| | **Sample 1-Sample 2** | **Test Statistic** | **SE** | **Std. Test Statistic** | ***P*-value** | **Adj. *P*-value[a]** |
|---|---|---|---|---|---|---|
| **Identity** | ≤6 months - >6 months | -23.52 | 25.77 | -0.91 | 0.362 | 1.000 |
| | ≤6 months - 1 to 5 years | -30.81 | 19.49 | -1.58 | 0.114 | 1.000 |
| | ≤6 months - >5 to 10 years | -36.96 | 19.81 | -1.87 | 0.062 | 0.621 |
| | ≤6 months - ≥10 years | -57.95 | 19.73 | -2.94 | *0.003** | *0.033* |
| | >6 months - 1 to 5 years | -7.30 | 20.76 | -0.35 | 0.725 | 1.000 |
| | >6 months - 5 to 10 years | -13.44 | 21.06 | -0.64 | 0.523 | 1.000 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | >6 months - ≥10 years | -34.43 | 20.98 | -1.64 | 0.101 | 1.000 |
| | 1 to 5 years - >5 to 10 years | -6.15 | 12.61 | -0.49 | 0.626 | 1.000 |
| | 1 to 5 years - ≥10 years | -27.14 | 12.48 | -2.18 | 0.030 | 0.296 |
| | 5 to 10 years - ≥10 years | -20.99 | 12.98 | -1.62 | 0.106 | 1.000 |

*$p \leq 0.005$

[a]. Significance values have been adjusted by the Bonferroni correction for multiple tests.

### *4.7.11 Number of Admissions With Heart Failure*

Table 4.31 shows the Spearman's correlation coefficient to identify if there were any relationships between the number of admissions with HF, and the studied sub-scales.

The number of admissions with HF was positively correlated with consequences ($r_s = 0.132$, $p = 0.027$), identity ($r_s = 0.141$, $p = 0.018$), and overall illness perception ($r_s = 0.191$, $p = 0.001$), indicating that the higher the number of admissions with HF is the more HF is perceived to have greater consequences, results in more symptoms, and is perceived to be a greater threat.

A negative correlation was noted between the number of admissions with HF and personal control ($r_s = -0.162$, $p = 0.007$), indicating that the higher the number of admissions with HF is, the lesser HF is perceived to be personally controlled.

**Table 4.31**

*Spearman's Correlation Coefficient - Number of Admissions With HF by Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence.*

| | Number of Admissions With HF | | |
|---|---|---|---|
| | ***n*** | ***r*** | ***P*-value** |
| **Consequences** | 280 | 0.132* | *0.027* |
| **Timeline** | 279 | 0.094 | 0.119 |
| **Personal control** | 279 | -0.162** | *0.007* |
| **Treatment control** | 280 | -0.051 | 0.399 |
| **Identity** | 280 | 0.141* | *0.018* |
| **Concern** | 280 | 0.087 | 0.146 |
| **Illness comprehensibility** | 280 | 0.073 | 0.224 |
| **Emotions** | 280 | 0.089 | 0.136 |
| **Illness perception** | 278 | 0.191** | *0.001* |
| **Self-care** | 280 | -0.117 | 0.051 |
| **Medication adherence** | 280 | -0.050 | 0.408 |

* $p < 0.05$

** $p < 0.01$

### *4.7.12 Last Admission With Heart Failure*

A Kruskal-Wallis test was conducted to determine if there were differences in the studied sub-scales between the six categories representing the last admission with HF. Distributions of scores for each sub-scale mentioned, were different between the studied categories. However, as Table 4.32 shows, score for each sub-scale was not statistically significantly different between the six categories.

**Table 4.32**

*Kruskal-Wallis H Test to Assess Statistical Difference Between Last Admission With HF, and the Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence*

| | Last admission with HF | *n* (%) | Mean | SD | $\chi^2$ | df | Asymp. *P*-value |
|---|---|---|---|---|---|---|---|
| **Consequences** | No admissions | 107 (38) | 5.25 | 3.23 | 5.63 | 5 | 0.344 |
| | Less than 1 month ago | 14 (5) | 6.36 | 3.00 | | | |
| | 1 to 6 months ago | 37 (13) | 5.57 | 2.86 | | | |
| | Less than 1 year but more than 6 months | 19 (7) | 4.79 | 3.16 | | | |
| | 1 year ago | 5 (2) | 6.60 | 2.07 | | | |
| | More than 1 year ago | 98 (35) | 5.90 | 3.07 | | | |
| **Timeline** | No admissions | 107 (38) | 7.98 | 3.44 | 4.940 | 5 | 0.423 |
| | Less than 1 month ago | 14 (5) | 7.93 | 3.54 | | | |
| | 1 to 6 months ago | 37 (13) | 7.11 | 4.01 | | | |
| | Less than 1 year but more than 6 months | 19 (7) | 9.16 | 2.06 | | | |
| | 1 year ago | 5 (2) | 9.00 | 2.24 | | | |
| | More than 1 year ago | 97 (35) | 8.39 | 2.79 | | | |
| **Personal control** | No admissions | 106 (38) | 6.73 | 2.48 | 8.45 | 5 | 0.133 |
| | Less than 1 month ago | 14 (5) | 5.50 | 2.65 | | | |
| | 1 to 6 months ago | 37 (13) | 6.43 | 2.99 | | | |
| | Less than 1 year but more than 6 months | 19 (7) | 5.47 | 2.97 | | | |
| | 1 year ago | 5 (2) | 7.60 | 1.52 | | | |
| | More than 1 year ago | 98 (35) | 5.97 | 2.75 | | | |
| **Treatment control** | No admissions | 107 (38) | 8.89 | 1.79 | 7.24 | 5 | 0.203 |
| | Less than 1 month ago | 14 (5) | 8.93 | 1.73 | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | 1 to 6 months ago | 37 (13) | 8.54 | 2.02 | | | |
| | Less than 1 year but more than 6 months | 19 (7) | 8.11 | 2.21 | | | |
| | 1 year ago | 5 (2) | 8.40 | 1.82 | | | |
| | More than 1 year ago | 98 (35) | 9.16 | 1.31 | | | |
| **Identity** | No admissions | 107 (38) | 4.14 | 3.01 | | | |
| | Less than 1 month ago | 14 (5) | 5.57 | 2.34 | | | |
| | 1 to 6 months ago | 37 (13) | 4.22 | 3.21 | 4.77 | 5 | 0.445 |
| | Less than 1 year but more than 6 months | 19 (7) | 3.63 | 2.79 | | | |
| | 1 year ago | 5 (2) | 3.40 | 2.30 | | | |
| | More than 1 year ago | 98 (35) | 4.55 | 3.20 | | | |
| **Concern** | No admissions | 107 (38) | 4.89 | 3.93 | | | |
| | Less than 1 month ago | 14 (5) | 5.29 | 4.03 | | | |
| | 1 to 6 months ago | 37 (13) | 4.84 | 3.31 | 4.84 | 5 | 0.436 |
| | Less than 1 year but more than 6 months | 19 (7) | 4.95 | 4.02 | | | |
| | 1 year ago | 5 (2) | 6.80 | 1.92 | | | |
| | More than 1 year ago | 98 (35) | 5.87 | 3.84 | | | |
| **Illness comprehensibility** | No admissions | 107 (38) | 5.03 | 3.29 | | | |
| | Less than 1 month ago | 14 (5) | 6.00 | 3.62 | | | |
| | 1 to 6 months ago | 37 (13) | 5.27 | 3.47 | 2.37 | 5 | 0.796 |
| | Less than 1 year but more than 6 months | 19 (7) | 5.00 | 3.61 | | | |
| | 1 year ago | 5 (2) | 5.80 | 2.59 | | | |
| | More than 1 year ago | 98 (35) | 5.55 | 3.23 | | | |
| **Emotions** | No admissions | 107 (38) | 4.34 | 3.89 | | | |
| | Less than 1 month ago | 14 (5) | 5.50 | 3.72 | 4.46 | 5 | 0.486 |
| | 1 to 6 months ago | 37 (13) | 4.86 | 3.68 | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | Less than 1 year but more than 6 months | 19 (7) | 4.53 | 3.98 | | | |
| | 1 year ago | 5 (2) | 3.00 | 2.74 | | | |
| | More than 1 year ago | 98 (35) | 5.12 | 3.78 | | | |
| **Illness perception** | No admissions | 106 (38) | 36.07 | 12.46 | | | |
| | Less than 1 month ago | 14 (5) | 40.21 | 10.48 | | | |
| | 1 to 6 months ago | 37 (13) | 36.35 | 11.67 | 5.94 | 5 | 0.312 |
| | Less than 1 year but more than 6 months | 19 (7) | 38.47 | 8.81 | | | |
| | 1 year ago | 5 (2) | 37.00 | 7.38 | | | |
| | More than 1 year ago | 97 (35) | 39.13 | 11.00 | | | |
| **Self-care** | No admissions | 107 (38) | 79.20 | 17.50 | | | |
| | Less than 1 month ago | 14 (5) | 69.84 | 21.62 | | | |
| | 1 to 6 months ago | 37 (13) | 80.18 | 19.39 | 6.64 | 5 | 0.249 |
| | Less than 1 year but more than 6 months | 19 (7) | 77.19 | 17.58 | | | |
| | 1 year ago | 5 (2) | 61.11 | 30.99 | | | |
| | More than 1 year ago | 98 (35) | 74.46 | 21.50 | | | |
| **Medication adherence** | No admissions | 107 (38) | 24.21 | 1.68 | | | |
| | Less than 1 month ago | 14 (5) | 23.86 | 1.52 | | | |
| | 1 to 6 months ago | 37 (13) | 23.89 | 2.02 | 4.57 | 5 | 0.470 |
| | Less than 1 year but more than 6 months | 19 (7) | 24.58 | 0.61 | | | |
| | 1 year ago | 5 (2) | 25.00 | 0.00 | | | |
| | More than 1 year ago | 98 (35) | 24.13 | 1.98 | | | |

## 4.8 Objective 5: To Determine Whether the Illness Perceptions of Individuals Living With Heart Failure Acts as a Predictor of Self-Care Behaviours, Including Medication Adherence

### *4.8.1 Correlations Between Illness Perception Dimensions, Illness Perception, Self-Care, and Medication Adherence.*

The Spearman correlation coefficient test revealed several statistically significant correlations between the illness perceptions and self-care, including medication adherence (Table 4.33). Self-care was negatively correlated with the illness perception dimensions of consequences ($r_s$ = -0.134, $p$ = 0.025), timeline ($r_s$ = -0.167, $p$ = 0.005), identity ($r_s$ = -0.138, $p$ = 0.021), and emotions ($r_s$ = -0.118, $p$ = 0.049). In addition, the identity dimension was also negatively correlated with medication adherence, $r_s$ = -0.122, $p$ = 0.042. The only positive correlation which was statistically significant was noted between the personal control dimension and self-care, $r_s$ = 0.218, $p$ < 0.001.

Illness perception was negatively correlated with self-care ($r_s$ = -0.236, $p$ < 0.001) and negatively correlated with medication adherence ($r_s$ = -0.135, $p$ = 0.024). A positive significant relationship was noted between self-care and medication adherence, $r_s$ = 0.247, $p$ < 0.001.

**Table 4.33**

*Spearman's Correlation Coefficient to Assess Correlation Between Illness Perceptions and HF Self-Care Behaviours, Including Medication Adherence*

| | | Self-care | Medication adherence |
|---|---|---|---|
| **Consequences** | *r* | -0.134* | 0.021 |
| | *P*-value [a] | 0.025 | 0.723 |
| **Timeline** | *r* | -0.167** | -0.095 |
| | *P*-value [b] | 0.005 | 0.114 |
| **Personal control** | *r* | 0.218** | 0.083 |
| | *P*-value [b] | <0.001 | 0.165 |
| **Treatment control** | *r* | 0.080 | 0.033 |
| | *P*-value [a] | 0.184 | 0.581 |
| **Identity** | *r* | -0.138* | -0.122* |
| | *P*-value [a] | 0.021 | 0.042 |
| **Concern** | *r* | -0.036 | -0.010 |
| | *P*-value [a] | 0.554 | 0.866 |
| **Illness comprehensibility** | *r* | 0.080 | 0.074 |
| | *P*-value [a] | 0.184 | 0.219 |
| **Emotions** | *r* | -0.118* | -0.108 |
| | *P*-value [a] | 0.049 | 0.070 |
| **Illness perception** | *r* | -0.236** | -0.135* |
| | *P*-value [c] | <0.001 | 0.024 |
| **Self-care** | *r* | — | 0.247** |
| | *P*-value [a] | | <0.001 |
| **Medication adherence** | *r* | — | — |
| | *P*-value [a] | | |

* $p < 0.05$

** $p < 0.01$

[a]. $n = 280$

[b]. $n = 279$

[c]. $n = 278$

### *4.8.2 Illness Perceptions as a Predicator to Self-Care and Medication Adherence*

To assess if illness perceptions act as a predicator to self-care and medication adherence, generalised linear models were used. Since both distributions violate the normality assumption, as indicated in Table 4.9, linear transformations were used to flip the two distributions horizontally to become right skewed. The transformation formula $\frac{1}{(101-y)}$ guaranteed a right skewed distribution and a reciprocal link function for self-care (Model 1, Model 3, and Model 5). Additionally, the transformation formula $\frac{1}{(26-y)}$ guaranteed a right skewed distribution and a reciprocal link function for medication adherence (Model 2, Model 4, and Model 6). This enabled the use of generalised linear models to relate each dependent variable, including self-care and medication adherence, to a number of predictors representing the illness perception dimensions (Model 1, Model 2).

Moreover, another two models were built to fit in those variables which were found to be significantly different in or related to self-care, and medication adherence. Such models were built to assess which illness perception dimensions, as the main predictors, rendered a very important contributor in explaining variations in the dependent variable in the presence of other predictors. As can be observed in sections 4.7.1, 4.7.7, and 4.7.9, self-care was found to be significantly positively correlated with age and age of diagnosis with HF, and significantly different amongst the NYHA Class subgroups. Moreover, medication adherence was found to be significantly different amongst the occupation, and living arrangement subgroups, and significantly positively correlated with age of diagnosis (Sections 4.7.4, 4.7.6, and 4.7.7). Furthermore, another two models were built to fit in only the significant socio-demographic variables and clinical information without the illness perceptions (Model 5 and Model 6). Such

criterion was taken to identify if such models render different results from the ones which included the illness perceptions.

The six models were fitted by assuming a gamma distribution and a reciprocal canonical link function (Power -1). The parsimonious models (which include solely the significant predictors) were identified using a backward procedure.

**a. Model 1: Self-Care as the Dependent Variable and Illness Perception Dimensions as the Predictors.** The first generalised linear model relating overall self-care score to the 8 dimensions of illness perceptions as predictors, identified consequences [$\chi^2(1) = 5.57$, $p = 0.018$], timeline [$\chi^2(1) = 5.00$, $p = 0.025$], personal control [$\chi^2(1) = 10.15$, $p = 0.001$], and illness comprehensibility [$\chi^2(1) = 6.26$, $p = 0.012$] as significant predictors of overall self-care (Table 4.34). Table 4.33 and table 4.34 indicate that personal control and illness comprehensibility positively predicted self-care, while consequences and timeline negatively predicted self-care.

**Table 4.34**

*Model 1 Hypothesis Test – Illness Perceptions as Predictors of Self-Care*

| | | | Hypothesis Test | | |
|---|---|---|---|---|---|
| **Parameter** | **Regression Coefficient** | **SE** | **Wald Chi-Square** | **df** | ***P*-value** |
| **(Intercept)** | 0.045 | 0.0091 | 24.98 | 1 | *<0.001** |
| **Consequences** | -0.002 | 0.0007 | 5.57 | 1 | *0.018** |
| **Timeline** | -0.002 | 0.0008 | 5.00 | 1 | *0.025** |
| **Personal control** | 0.002 | 0.0007 | 10.15 | 1 | *0.001** |
| **Illness comprehensibility** | 0.002 | 0.0006 | 6.26 | 1 | *0.012** |
| **(Scale)** | 0.729[a] | 0.0559 | | | |

[a]. Maximum likelihood estimate.

* $p < 0.05$

**b. Model 2: Medication Adherence as the Dependent Variable and Illness Perception Dimensions as the Predictors.** The second generalised linear model relating medication adherence to the 8 dimensions of illness perceptions as predictors, identified consequences [$\chi^2$ (1) = 5.38, $p$ = 0.020], timeline [$\chi^2$ (1) = 3.87, $p$ = 0.049], illness comprehensibility [$\chi^2$ (1) = 12.00, $p$ = 0.001], and emotions [$\chi^2$ (1) = 16.91, $p$ < 0.001] as significant predictors (Table 4.35). Table 4.33 and table 4.35 indicate that consequences and illness comprehensibility positively predicted medication adherence, while timeline and emotions negatively predicted medication adherence.

**Table 4.35**

*Model 2 Hypothesis Test - Illness Perceptions as Predictors of Medication Adherence*

| | | | Hypothesis Test | | |
|---|---|---|---|---|---|
| **Parameter** | **Regression Coefficient** | **SE** | **Wald Chi-Square** | **df** | ***P*-Value** |
| **(Intercept)** | 0.586 | 0.0705 | 69.13 | 1 | *<0.001** |
| **Consequences** | 0.016 | 0.0069 | 5.38 | 1 | *0.02** |
| **Timeline** | -0.014 | 0.0071 | 3.87 | 1 | *0.049** |
| **Illness comprehensibility** | 0.022 | 0.0062 | 12.00 | 1 | *0.001** |
| **Emotions** | -0.024 | 0.0058 | 16.91 | 1 | *<0.001** |
| **(Scale)** | 0.403[a] | 0.0322 | | | |

[a]. Maximum likelihood estimate.

* $p$ < 0.05

**c. Model 3: Self-Care as the Dependent Variable and Illness Perception Dimensions, NYHA Class, Age, and Age of Diagnosis With Heart Failure as the Independent Variables.** The third generalised linear model relating the self-care to 11 predictors, including the 8 illness perception dimensions, NYHA Class, age, and age of diagnosis with HF (Table 4.36), identified NYHA class [$\chi^2$ (3) = 15, $p$ = 0.002], age [$\chi^2$ (1) = 7.48, $p$ = 0.006], timeline [$\chi^2$ (1) = 4.76, $p$ = 0.029], personal control [$\chi^2$ (1) = 5.24, $p$ = 0.022], and illness comprehensibility [$\chi^2$ (1) = 5.11, $p$ = 0.024] as significant predictors (Table 4.37).

Parameters estimates for Model 3 are presented in Table 4.38. As presented in section 4.7.1 and 4.7.9, age positively predicted self-care, and NYHA Class I participants scored significantly higher for self-care when compared to the other three classes, respectively.

**Table 4.36**

*Model 3 - Tests of Model Effects (Full Model to Test if Illness Perceptions, NYHA Class, Age, and Age of Diagnosis With HF are Predictors to Self-Care)*

| | Wald Chi-Square | df | *P*-value |
|---|---|---|---|
| **(Intercept)** | 0.06 | 1 | 0.809 |
| **NYHA Class** | 7.05 | 3 | 0.070 |
| **Consequences** | 0.90 | 1 | 0.344 |
| **Timeline** | 3.34 | 1 | 0.068 |
| **Personal control** | 4.68 | 1 | *0.031** |
| **Treatment control** | 1.42 | 1 | 0.234 |
| **Identity** | 0.13 | 1 | 0.696 |
| **Concern** | 1.31 | 1 | 0.252 |
| **Illness comprehensibility** | 5.88 | 1 | *0.015** |
| **Emotions** | 1.10 | 1 | 0.295 |
| **Age** | 3.04 | 1 | 0.081 |
| **Age of diagnosis with HF** | 0.19 | 1 | 0.664 |

* $p < 0.05$

**Table 4.37**

*Model 3 - Parsimonious Model Representing the Significant Illness Perceptions, NYHA Class, and Age as Predictors of Self-Care*

| | Wald Chi-Square | df | *P*-value |
|---|---|---|---|
| **(Intercept)** | 0.06 | 1 | 0.808 |
| **NYHA Class** | 15.00 | 3 | *0.002** |
| **Timeline** | 4.76 | 1 | *0.029** |
| **Personal control** | 5.24 | 1 | *0.022** |
| **Illness comprehensibility** | 5.11 | 1 | *0.024** |
| **Age** | 7.48 | 1 | *0.006** |

* $p < 0.05$

**Table 4.38**

*Model 3 Hypothesis Test - Illness Perceptions, NYHA Class, and Age as Predictors of Self-Care*

| | | | Hypothesis Test | | |
|---|---|---|---|---|---|
| **Parameter** | **Regression Coefficient** | **SE** | **Wald Chi-Square** | **df** | ***P*-value** |
| (Intercept) | -0.012 | 0.0169 | 0.49 | 1 | 0.484 |
| [NYHA Class=1] | 0.032 | 0.0093 | 11.57 | 1 | *0.001** |
| [NYHA Class=2] | 0.018 | 0.0082 | 4.94 | 1 | *0.026** |
| [NYHA Class=3] | 0.012 | 0.0085 | 1.83 | 1 | 0.177 |
| [NYHA Class=4] | 0[a] | . | . | . | . |
| Timeline | -0.002 | 0.0008 | 4.76 | 1 | *0.029** |
| Personal control | 0.002 | 0.0007 | 5.24 | 1 | *0.022** |
| Illness comprehensibility | 0.001 | 0.0006 | 5.11 | 1 | *0.024** |
| Age | 0.0005 | 0.0002 | 7.48 | 1 | *0.006** |
| (Scale) | 0.704[b] | 0.0542 | | | |

[a]. Set to zero because this parameter is redundant.

[b]. Maximum likelihood estimate.

* $p < 0.05$

**d. Model 4: Medication Adherence as the Dependent Variable and Illness Perception Dimensions, Occupation, Living Arrangements, and Age of Diagnosis With Heart Failure as the Independent Variables.** The fourth generalised linear model relating medication adherence to 11 predictors, including the 8 illness perception dimensions and the significant variables in medication adherence, including that of occupation, living arrangement, and age of diagnosis with HF (Table 4.39), identified occupation [$\chi^2(3) = 18.20$, $p < 0.001$], living arrangement [$\chi^2(1) = 7.65$, $p = 0.006$], timeline [$\chi^2(1) = 4.93$, $p = 0.026$], illness comprehensibility [$\chi^2(1) = 17.46$, $p < 0.001$], and emotions [$\chi^2(1) = 7.64$, $p = 0.006$] as significant predictors (Table 4.40). Parameters estimates for Model 4 are presented in Table 4.41. As presented in section 4.7.4 and 4.7.6, pensioners were significantly more adherent when compared to the other three occupations, and participants who were living with others were significantly more adherent when compared to those who were living alone, respectively.

**Table 4.39**

*Model 4 - Tests of Model Effects (Full Model to Test if Illness Perceptions, Occupation, Living Arrangement, and Age of Diagnosis With HF are Predictors to Medication Adherence*

| | Wald Chi-Square | df | *P*-value |
|---|---|---|---|
| **(Intercept)** | 9.36 | 1 | *0.002** |
| **Occupation** | 14.46 | 3 | *0.002** |
| **Living Arrangement** | 7.83 | 1 | *0.005** |
| **Consequences** | 3.91 | 1 | *0.048** |
| **Timeline** | 4.65 | 1 | *0.031** |
| **Personal control** | 0.28 | 1 | 0.595 |
| **Treatment control** | 0.47 | 1 | 0.492 |
| **Identity** | 3.06 | 1 | 0.080 |
| **Concern** | 0.76 | 1 | 0.382 |
| **Illness comprehensibility** | 11.24 | 1 | *0.001** |
| **Emotions** | 10.58 | 1 | *0.001** |
| **Age of diagnosis with HF** | 0.09 | 1 | 0.762 |

* $p < 0.05$

**Table 4.40**

*Model 4 - Parsimonious Model Representing the Illness Perceptions, Occupation, and Living Arrangement as Predictors of Medication Adherence*

| | Wald Chi-Square | df | *P*-value |
|---|---|---|---|
| **(Intercept)** | 56.07 | 1 | *<0.001** |
| **Occupation** | 18.20 | 3 | *<0.001** |
| **Living Arrangement** | 7.65 | 1 | *0.006** |
| **Timeline** | 4.93 | 1 | *0.026** |
| **Illness comprehensibility** | 17.46 | 1 | *<0.001** |
| **Emotions** | 7.64 | 1 | *0.006** |

* $p < 0.05$

**Table 4.41**

*Model 4 Hypothesis Test - Illness perceptions, Occupation, and Living Arrangement as Predictors of Medication Adherence*

| | | | Hypothesis Test | | |
|---|---|---|---|---|---|
| **Parameter** | **Regression Coefficient** | **SE** | **Wald Chi-Square** | **df** | ***P*-value** |
| **(Intercept)** | 0.693 | 0.0682 | 103.42 | 1 | *<0.001** |
| **[Occupation=1]** | -0.077 | 0.0647 | 1.40 | 1 | 0.236 |
| **[Occupation=2]** | -0.199 | 0.0468 | 18.13 | 1 | *<0.001** |
| **[Occupation=3]** | -0.042 | 0.1180 | 0.129 | 1 | 0.720 |
| **[Occupation=4]** | 0[a] | . | . | . | . |
| **[Living Arrangement=1]** | -0.132 | 0.0478 | 7.65 | 1 | *0.006** |
| **[Living Arrangement=2]** | 0[a] | . | . | . | . |
| **Timeline** | -0.015 | 0.0069 | 4.93 | 1 | *0.026** |
| **Illness comprehensibility** | 0.025 | 0.0059 | 17.46 | 1 | *<0.001** |
| **Emotions** | -0.015 | 0.0054 | 7.64 | 1 | *0.006** |
| **(Scale)** | 0.384[b] | 0.0307 | | | |

[a]. Set to zero because this parameter is redundant.
[b]. Maximum likelihood estimate.
Occupation=1: Unemployed, Occupation=2: Formally employed, Occupation=3: Self-employed, Occupation=4: Pensioner,
Living Arrangement=1: Living alone, Living Arrangement=2: Living with others
* $p < 0.05$

**e. Model 5: Self-Care as the Dependent Variable and NYHA Class, Age, and Age of Diagnosis With Heart Failure as the Independent Variables.** The fifth generalised linear model relating the self-care to 3 predictors, including the NYHA Class, age, and age of diagnosis with HF (Table 4.42), identified NYHA class [$\chi^2(3) = 20.38$, $p$ <0.001], and age [$\chi^2(1) = 7.52$, $p = 0.006$], as significant predictors (Table 4.43). This concludes that the same variables as in Model 3, were found to be significant predictors to self-care. Parameters estimates for Model 5 are presented in table 4.44.

**Table 4.42**

*Model 5 - Tests of Model Effects (Full Model to Test if NYHA Class, Age, and Age of Diagnosis With HF are Predictors of Self-Care)*

| | Wald Chi-Square | df | *P*-value |
|---|---|---|---|
| **(Intercept)** | 0.06 | 1 | 0.815 |
| **NYHA Class** | 17.79 | 3 | *<0.001** |
| **Age** | 3.01 | 1 | 0.083 |
| **Age of diagnosis with HF** | 0.41 | 1 | 0.520 |

* $p < 0.05$

**Table 4.43**

*Model 5 - Parsimonious Model Representing NYHA Class and Age as Predictors of Self-Care*

| | Wald Chi-Square | df | *P*-value |
|---|---|---|---|
| **(Intercept)** | 0.04 | 1 | 0.834 |
| **NYHA Class** | 20.38 | 3 | *<0.001** |
| **Age** | 7.52 | 1 | *0.006** |

* $p < 0.05$

**Table 4.44**

*Model 5 Hypothesis Test – NYHA Class and Age as Predictors of Self-Care*

| | | | Hypothesis Test | | |
|---|---|---|---|---|---|
| **Parameter** | **Regression Coefficient** | **SE** | **Wald Chi-Square** | **df** | ***P*-value** |
| **(Intercept)** | -0.019 | 0.0147 | 1.587 | 1 | 0.208 |
| **[NYHA Class=1]** | 0.040 | 0.0094 | 18.115 | 1 | *<0.001** |
| **[NYHA Class=2]** | 0.026 | 0.0083 | 9.371 | 1 | *0.002** |
| **[NYHA Class=3]** | 0.019 | 0.0088 | 4.690 | 1 | *0.030** |
| **[NYHA Class=4]** | 0[a] | . | . | . | . |
| **Age** | 0.0005 | 0.0002 | 7.515 | 1 | *0.006** |
| **(Scale)** | 0.734[b] | 0.0561 | | | |

[a]. Set to zero because this parameter is redundant.

[b]. Maximum likelihood estimate.

* $p < 0.05$

### f. Model 6: Medication Adherence as the Dependent Variable and Occupation, Living Arrangements, and Age of Diagnosis With Heart Failure as the Independent Variables.

The sixth generalised linear model relating the medication adherence to 3 predictors, including the occupation, living arrangement, and age of diagnosis with HF (Table 4.45), identified occupation [$\chi^2(3) = 18.11$, $p < 0.001$], and living arrangement [$\chi^2(1) = 6.85$, $p = 0.009$], as significant predictors (Table 4.46). This concludes that the same variables as in Model 4, were found to be significant predictors to medication adherence. Parameters estimates for Model 6 are presented in table 4.47.

**Table 4.45**

*Model 6 - Tests of Model Effects (Full Model to Test if Occupation, Living Arrangement, and Age of Diagnosis With HF are Predictors of Medication Adherence)*

| | **Wald Chi-Square** | **df** | ***P*-value** |
|---|---|---|---|
| **(Intercept)** | 26.35 | 1 | *<0.001** |
| **Occupation** | 11.96 | 3 | *0.008** |
| **Living Arrangement** | 6.61 | 1 | *0.010** |
| **Age of diagnosis with HF** | 0.34 | 1 | 0.561 |

* $p < 0.05$

**Table 4.46**

*Model 6 - Parsimonious Model Representing Occupation and Living Arrangement as Predictors of Medication Adherence*

| | **Wald Chi-Square** | **df** | ***P*-value** |
|---|---|---|---|
| **(Intercept)** | 148.40 | 1 | *<0.001** |
| **Occupation** | 18.11 | 3 | *<0.001** |
| **Living Arrangement** | 6.85 | 1 | *0.009** |

* $p < 0.05$

**Table 4.47**

*Model 6 Hypothesis Test – Occupation and Living Arrangement as Predictors of Medication Adherence*

| | | | Hypothesis Test | | |
|---|---|---|---|---|---|
| **Parameter** | **Regression Coefficient** | **SE** | **Wald Chi-Square** | **df** | ***P*-value** |
| **(Intercept)** | 0.614 | 0.0281 | 476.30 | 1 | *<0.001** |
| **[Occupation=1]** | -0.072 | 0.0678 | 1.13 | 1 | 0.287 |
| **[Occupation=2]** | -0.207 | 0.0487 | 18.07 | 1 | *<0.001** |
| **[Occupation=3]** | -0.069 | 0.1235 | 0.31 | 1 | 0.576 |
| **[Occupation=4]** | 0[a] | . | . | . | . |
| **[Living Arrangement=1]** | -0.131 | 0.0500 | 6.85 | 1 | *0.009** |
| **[Living Arrangement=2]** | 0[a] | . | . | . | . |
| **(Scale)** | 0.412[b] | 0.0327 | | | |

[a]. Set to zero because this parameter is redundant.

[b]. Maximum likelihood estimate.

* $p < 0.05$

## 4.9 Conclusion

This chapter illustrated the results obtained from the findings of this research study, to achieve the aims and objectives. Descriptive and inferential statistics were mostly used to describe the obtained findings.

Several cognitive illness perceptions were found to be affected by various socio-demographic characteristics and clinical information. Such associations included: gender differences, were female perceived to have better personal control of HF and to be experiencing more symptoms than males; educational level, where participants with secondary educational level perceived better treatment control while participants holding a tertiary education perceived higher comprehensibility about HF; age of diagnosis with HF, which was found to be positively correlated with personal control, and negatively correlated with timeline and illness comprehensibility; NYHA Class, where symptomatic participants (NYHA Class II – III) perceived HF to have greater

consequences and were experiencing more symptoms; longer follow-up periods for HF, which were found to be associated with perception of chronic timeline and experiences of more symptoms, while shorter follow-up periods were associated with perception of better personal control; and number of admissions, which was found to be positively correlated with greater consequences and experiences of more symptoms, and negatively correlated with personal control.

The emotional illness perceptions represented by the perception of concern and emotions were found to be affected by: NYHA Class, where symptomatic (NYHA Class II – III) participants perceived HF to have greater emotional impact on them, and perceived a higher level of preoccupation about the situation (NYHA Class III); educational level, where participants with post-secondary educational level perceived to be more preoccupied about their illness; while both age and age of diagnosis with HF were negatively correlated with concern and emotions, indicating that as age and age of diagnosis increases, individuals living with HF perceive less emotional disturbance and a lower degree of preoccupation about their illness.

Several illness perceptions were found to be negatively correlated to self-care, including perceptions of greater consequences, chronic timeline, experiences of more symptoms, and higher emotional disturbance, while perception of greater personal control was found to be positively correlated with self-care. Perceiving HF to be causing more symptoms was found to be negatively correlated to medication adherence. Moreover, perceiving HF to be a greater threat was negatively correlated to both self-care and medication adherence.

Perceptions of greater consequences, chronic timeline, greater personal control, and a higher level of comprehensibility about HF were identified as predictors of self-care, while perceptions of greater consequences, chronic timeline, a higher level of comprehensibility about HF, and greater emotional impact were identified as predictors

to medication adherence. Moreover, being asymptomatic (NYHA Class I) and an increase in age were identified as significant predictors to HF self-care, while living arrangements (Living alone and living with others) and occupation (Formally employed and being a pensioner) were identified as significant predictors of medication adherence.

The following chapter entails a thorough discussion of the main findings of this research study, in which any differences and similarities between the reported findings and those found in literature were highlighted and discussed.

# Chapter 5 – Discussion

## 5.1 Introduction

This study intended to apply the Common-Sense Model (CSM) of self-regulation of illness, which theorises that individuals develop cognitive and emotional illness perceptions that guide and regulate the coping procedures of persons living with a condition (Leventhal et al., 2001). In this study the coping procedures were represented by HF self-care and medication adherence. This chapter provides a detailed discussion on the main findings to address the aims and objectives of this research study. Since studies on this research topic were scarce, apart from referring to the studies appraised in chapter 2, this chapter refers to literature on other chronic diseases besides HF, where either the illness perceptions or self-care behaviours, including medication adherence were explored. Additionally, since to the researcher's knowledge this is the first study done in Malta on this topic amongst individuals living with HF, only international studies were referenced. This chapter is divided according to the objectives presented in chapter 3. Participants' socio-demographic characteristics together with their clinical information are discussed in section 5.2. A brief discussion on the strengths and limitations is presented at the end of this chapter.

## 5.2 Participants' Socio-Demographic Characteristics and Clinical Information

Two hundred and eighty individuals living with HF participated in this study at the national hospital of Malta. The mean age of the participants was 69 years (*SD* = 11) and ranged between 30 and 92 years. This mean age was comparable to other studies carried out internationally amongst individuals living with HF (Albert et al., 2014; Goodman et al., 2013; MacInnes, 2013; Mansouriyeh et al., 2017). Most of the participants were males (*n* = 219, 78%). This male majority was consistent with that

reported by earlier studies of individuals living with HF (Albert et al., 2014; Goodman et al., 2013; Horowitz et al., 2004; MacInnes, 2013; Molloy et al., 2009; Voelmeck, 2006) and reflects the higher incidence rate of HF among men when compared to women (Groenewegen et al., 2020; Strömberg & Mårtensson, 2003).

The educational level of the participants in this study was low, with the majority of the participants possessing either a primary (*n* = 104, 37%) or secondary (*n* = 127, 45%) level of school education. Only 18% (*n* = 49) of the participants held a post-secondary (*n* = 24, 9%) or tertiary (*n* = 25, 9%) level of education. This could be due to the fact that education in Malta became compulsory till 14 years of age in 1944 and increased to 16 years of age with the introduction of the Education Act in 1988 (Bezzina, 2015).

Being that the pension age in Malta ranges between 62 to 65 years according to the birthyear, the participants' mean age (*M* = 69 years, *SD* = 11) reflected their occupation, where most of the participants were pensioners (*n* = 209, 75%) (WageIndicator, 2021). A considerable number of participants reported that they were married or living with a partner (*n* = 206, 74%), and that they were living with others (*n* = 241, 86%). When considering the mean age together with the reported data on marital status and living arrangement, such trend was expected, since the life expectancy of Maltese women is 84.6 years and 80.2 years for men (OECD/European Observatory on Health Systems and Policies, 2019). Thus, incidence rate of being widowed and living alone, increases after 80 years of age.

The mean age of diagnosis with HF was 59 years (*SD* = 14) with a mean length of time since diagnosis of 10 years (*SD* = 11). This corresponds to the increased incidence rate of HF as age increases, in fact it is considered as a disease of the elderly (Strait & Lakatta, 2012).

The three most common reported aetiological factors of HF amongst the participants were Coronary Artery Disease, Hypertension, and Idiopathic Dilated Cardiomyopathy. These aetiological factors are known to be the most common predictors of HF (Kobayashi et al., 2020; Lip et al., 2000).

It was reported that 73% of the participants were diagnosed with HFrEF (LVEF <40%). An explanation for this, is the fact that both the HF nurse-led clinic and the specialised HF clinic at the national hospital cater mostly for those individuals diagnosed with HFrEF. Owing to this fact, this is the main reason why this sample was mostly dominated by participants who were diagnosed with HFrEF and who were males, since males have a higher incidence rate of being diagnosed with HFrEF (Lam et al., 2019).

Approximately 51% (*n* = 143) of the participants classified themselves in the NYHA Class II, that is they get short of breath or tired, or have palpitations (fast heartbeat) when performing more strenuous activities. This could be reflected by the mean age of the participants, which might lead to advanced HF and other comorbidities predisposed with age causing them to be symptomatic. Moreover, this could also be explained by the fact that asymptomatic (NYHA Class I) individuals are given a distant follow-up appointment by the specialised HF clinics with the aim to treat those who are symptomatic (NYHA Class II-IV).

This sample consisted of participants living with HF who have been following-up their HF for more than 1 year (a combined percentage of 86%). Only 8% (*n* = 21), reported that they started to be followed-up for their HF less than or equal to 6 months. Moreover, most of the participants reported that they were never admitted with HF (*n* = 107, 38%), and if admitted most of the participants were admitted more than 1 year ago (*n* = 103, 37%). In a previous study, the association between follow-up period and last admission with HF was found to be positively linked (Lupón et al., 2005). Hence,

follow-up period is considered as a pivotal factor in reducing admissions with exacerbations of HF (Lupón et al., 2005). This could be due to closer monitoring and providing consistent educational and pharmacological interventions, which are known to prevent acute exacerbations of HF (Lupón et al., 2005).

A considerable number of participants listed one or multiple comorbidities, including Cardiovascular and Non-Cardiovascular comorbidities (*n* = 237, 85%). The reported medical problems/comorbidities are considered as highly prevalent in HF, especially those commonly listed, such as Type II Diabetes, Hypertension, Atrial Fibrillation, and Dyslipidaemia (Angermann, 2009). Moreover, multiple comorbidities in HF are associated with adverse outcomes, as they accelerate disease progression, and lessen the response to treatment. This results in an increase in hospitalisation rates and an increase morbidity and mortality rates (Comin-Colet et al., 2020).

## 5.3 Objective 1: Illness Perceptions of Individuals Living With Heart Failure

The first objective of this research study was to assess the illness perceptions of individuals living with HF. This objective was purposely formulated to assess the cognitive and emotional representations of the CSM, which can be found in the first stage of the cognitive arm and the emotional arm, respectively (Figure 3.1). The findings support the theory of CSM, which posits that individuals cognitively and emotionally process the gathered information about HF in different ways and develop their own illness perceptions (Leventhal et al., 2001).

Individuals living with HF perceived their illness as a moderate threat to their wellbeing. This could be explained by the fact that participants were clients of the specialised HF clinics, with the possible consequence that they might receive the necessary knowledge and skills from health-care professionals about HF and practical

ways to self-manage any signs and symptoms. As the CSM implies, such discussions about the illness, acquired information, together with other somatic sensations including past experiences and symptoms, could have led the individual to perceive HF in such a way (Leventhal et al., 2001). This was shown by a longitudinal study, where it was reported that over time individuals had improved their symptom control through self-care (Goodman et al., 2013). Individuals with HF accurately perceived their illness to have a chronic timeline, which however could be controlled with treatment. This may include diuretics, beta-blockers, angiotensin converting enzyme inhibitors or angiotensin receptor blockers, and mineralocorticoid-receptor antagonists (Ponikowski et al., 2016). Such results on timeline and treatment control, coincide with other international studies (Lerdal et al., 2019; MacInnes, 2013; Molloy et al., 2009; Voelmeck, 2006).

HF was perceived to be more treatment controlled than personally controlled. This indicates that participants may had positive experiences with treatment, such as alleviating shortness of breath or fluid retention, which influenced them to perceive treatment to be more effective to control HF than with personal methods. This could result in individuals finding it difficult to perceive that they could personally do something to better the situation. Moreover, this could indicate that individuals with HF rely more on, or find it easier, to control HF with their prescribed treatment than by controlling their illness themselves, where they need their own motivation and energy. Such personal methods used to control HF include daily weighing, restriction of fluids (1.5L in winter and 2L in summer) and cut down on salt and salty foods (Ponikowski et al., 2016; Toukhsati et al., 2015). Likewise, Lerdal et al. (2019) reported a moderate score for personal control and a higher score for treatment control. Such findings imply the need that educational interventions should focus on how HF can be controlled while

stressing the importance that, whilst it is important to adhere to drug treatment control, it is also important to personally control HF with self-care.

In general, HF was perceived to impose moderate consequences on their life and health. This could indicate that individuals with HF adjusted their lives in such a way that they find HF to be moderately affecting their daily living. On the other hand, this could indicate a lack of understanding regarding the seriousness of the illness and the possible consequences which could be the result of HF (Horowitz et al., 2004). Contrary to these findings, previous three studies, reported that participants perceived HF to have devastating consequences (MacInnes, 2013, Molloy et al., 2009; Voelmeck, 2006).

Individuals with HF had the perception that their illness makes them experience moderate symptoms, indicating that either they were not experiencing threatening symptoms precipitated by their HF, in fact most of the participants were classified in NYHA Class II, or they did not correlate their symptoms to their illness. The CSM suggests that individuals suffering from other comorbidities could incorrectly link their current symptoms, which are related to HF, with their other comorbidities (Leventhal et al., 2016a). Shortness of breath, lethargy, and lower limb oedema are signs of HF for a health-care professional, but they can be likely interpreted as signs of aging (Leventhal et al., 2001). Similar results were seen by Albert et al. (2014) and Horowitz et al. (2004), where it was revealed that individuals with HF did not connect their chronic symptoms to their illness, and presence of HF was only perceived when symptoms were present.

In this study, participants perceived a moderate comprehension about HF, indicating that to a certain extent, HF made sense to participants. This finding suggests that for most of the individuals, HF is still an ambiguous illness that they did not comprehend well. Former studies reported higher levels of understanding, indicating

that participants had better comprehension of their HF (MacInnes, 2013; Molloy et al., 2009). The CSM explicates that better illness comprehensibility may help the individual to initiate habitual performance behaviours, which are coherently perceived and performed on a daily basis (Leventhal et al., 2001). Thus, the findings of this current study imply the need to empower the individual's knowledge on HF through educational programs with the aim to optimise their perception of understanding. This could be done by formulating leaflets and booklets about HF and its management, while explaining the rationale behind each recommended action, without using any medical jargon.

Various causative opinions were reported by the individuals with HF which they perceived to be the main cause of their illness. For most participants, the cause of their HF remained a mystery. Likewise, Horowitz et al. (2004) and MacInnes (2013) reported that a considerable number of participants did not know the cause of their HF. The four most commonly causal factors of HF mentioned were: stress, smoking, heredity, and work. When comparing these findings with other studies, stress was also perceived to be the main cause of HF (Goodmann et al., 2013; Horowitz et al., 2004; MacInnes, 2013; Voelmeck, 2006). Stress might not really be the main cause of their HF; however, a hectic lifestyle may have influenced participants' perception that stress was the main cause of HF. In fact, stress was also perceived as one of the most common causes which were secondly and thirdly ranked, together with smoking and diet, respectively. Perceiving stress as a causal factor has a dual nature, having both external uncontrollable elements, and internal controllable elements (French et al., 2001; Scerri et al., 2019). Due to the external uncontrollable elements, individuals may avoid blaming themselves or others for their HF, whilst at the same time through the internal controllable elements, they find ways to control their illness (Scerri et al., 2019). This suggests that individuals should be aware of the real cause which have resulted in them

to develop HF. Being mistaken on the real cause of HF, the individual may make unnecessary changes which may result in no improvements. Thus, perceiving an accurate cause of HF can help the individual to determine and develop the required lifestyle changes, with the possible consequence of reducing any future decompensations. Accurate causes of HF may include hypertension, dyslipidaemia, recreational drugs, excessive alcohol intake, and heredity (Ponikowski et al., 2016).

Individuals living with HF perceived a moderate negative emotional response, and a moderate level of preoccupation related to HF (Concern). Such findings coincide with a previous study, where participants reported that their HF was moderately affecting them emotionally (Lerdal et al., 2019). This implies the need for psychosocial care from day one of diagnosis, and since the CSM signifies that illness perceptions change over time, this should be continued throughout the follow-up periods (Leventhal et al., 2016b).

## 5.4 Objective 2: The Inter-Relationships Between the Different Illness Representations of Local Individuals Living With Heart Failure

In general, there were various small correlations between different illness representations which were comparable with those reported in other studies carried out amongst individuals with different chronic illnesses (Chen et al., 2020; Chew et al., 2017; Jansen et al., 2010; Shim et al., 2020; Yu et al., 2015).

Individuals living with HF who perceived that their illness can be personally controlled, also perceived that their illness can be treatment controlled, indicating that individuals perceived HF as a manageable illness. Such relationship between the two illness perceptions, reflecting the controllability of illness, was also noted in other studies carried out amongst other individuals living with different chronic illnesses

besides HF (Chen et al., 2020; Chew et al., 2017; Jansen et al., 2010; Shim et al., 2020; Voelmeck, 2006; Yu et al., 2015). Since participants were all clients of the specialised HF clinics, they might be knowledgeable that HF could be both personally and treatment controlled. Furthermore, they might be knowledgeable about the positive resultant implications when practicing self-care and being adherent to their prescribed medications.

Perceiving HF to have greater consequences was related with perceptions of a chronic timeline, experiencing more symptoms, higher level of understanding about HF, higher levels of emotional disturbances and a higher degree of preoccupation about the situation. The positive relationship between consequences and emotions was also revealed in several previous studies (Chen et al., 2020; Chew et al., 2017; Jansen et al., 2010; Shim et al., 2020; Yu et al., 2015). Such findings imply the need of thorough assessment of the degree to which the illness is affecting the individual while involving a psychologist in the care plan to assist the individual with any negative emotional disturbance which may arise. Additionally, perceiving HF to have a chronic timeline and that it cannot be medically controlled were related with experiences of more symptoms. This suggests that individuals who were symptomatic, accurately perceived HF as a chronic condition but due to the presence of symptoms they did not perceive HF as a condition which could be medically controlled. This implies the importance of frequent follow-ups to assess symptoms, and to plan while discuss with the clients the benefits of pharmacological treatment in HF.

Perception of higher levels of emotional disturbance resulting from HF, was related with higher level of preoccupation about the situation. Similar results were reported by Chew et al. (2017) and Jansen et al. (2010) studies which were carried out amongst pre-dialysis and dialysis individuals, respectively. Moreover, in this study, it

was noted that a higher level of comprehension about HF, is related with perceptions of experiencing more symptoms, higher levels of negative emotional disturbances, and a higher level of preoccupation about the situation. This may indicate that being more knowledgeable about HF, individuals may relate well their symptoms with their illness, with the consequence of being negatively emotionally affected. This suggests that although it is known that health-care professionals should educate their clients about their condition, they should be aware of any emotional disturbances which may arise. Thus, such findings imply the need that education about HF should be given gradually while assessing the individuals' emotional impact at each stage.

These correlations imply the need of the importance for health-care professionals to further assist those clients who perceive HF to have greater consequences. Moreover, it is important that the illness perceptions should be the backbone of person-centred care in order to develop educational and practical interventions with the aim to assist the clients to perceive a set of accurate illness perceptions.

## 5.5 Objective 3: Heart Failure Self-Care Behaviours, Including Medication Adherence

In the part of the questionnaire covering the coping procedures of the CSM represented by the self-care behaviours and medication adherence in HF (Figure 3.1), participants reported that they are highly adherent to HF self-care and to their prescribed medications.

### *5.5.1 Heart Failure Self-Care Behaviours*

Similar to that reported in MacInnes (2013) study, it was noted that individuals with HF reported high scores for the consulting behaviours (Items 2-4, and item 6), indicating the reliance on health-care professionals (MacInnes, 2013). Although, regular weighing and regular exercise are two important self-care behaviours in HF, these were the least reported self-care behaviours to be practiced when compared to other behaviours (Flynn et al., 2009; Lu et al., 2016; O'Connor et al., 2009). These findings were also seen in Albert et al. (2014) and MacInnes (2013) studies. Such findings on regular weighing may suggest that, although participants were clients of the specialised HF clinics, the required effort on the part of the individual; a change in routine; and the required commitment, may be limiting the individual from performing such behaviour. Additionally, factors such as illiteracy and/or visual impairment may act as barriers in reading or in understanding the weighing scale (Jaarsma et al., 2013).

More than half of the participants reported that they were not engaged in doing regular exercise. Such findings were consistent with that of Jaarsma et al. (2013) where more than half the patients did not exercise regularly, and Albert et al. (2014) and MacInnes (2013) studies where high rates of not doing any exercise were reported. For individuals living with HF, it is not always easy to exercise regularly especially in the presence of symptoms, such as shortness of breath or lethargy, let alone when exercising was not a typical behaviour which was practiced before (Conraads, et al., 2012). It is moreover known that the Maltese population is one of the inactive populations in Europe (López-Valenciano et al., 2020). Assisting clients in achieving a change in behaviours is quite challenging for health-care professionals (Collins et al., 2007). It is not enough to tell the clients that they need to change a behaviour. This implies the need of methods to initiate, achieve, and maintain an effective behavioural

change based on promising alternatives, such as the Transtheoretical Model of Intentional Behaviour Change (Prochaska & DiClemente, 1983) and Motivational Interviewing techniques (Miller & Rollnick, 2002) (Collins et al., 2007).

### *5.5.2 Medication Adherence*

Overall participants were highly adherent to their prescribed medications. This finding was in line to that revealed by the EHFScBs-9. Taking the medications as prescribed was the most self-care behaviour reported to be performed ($n$ = 272, 98%). High adherence rates to medications reported in this study were consistent with those reported by other studies carried out amongst individuals living with HF (Albert et al., 2014; Jaarsma et al., 2013; MacInnes, 2013; Molloy et al., 2009). This may indicate that individuals living with HF are more likely to adhere to and practice those self-care behaviours which require the least effort and lifestyle change (Gatt & Sammut, 2008). Moreover, this may also indicate that individuals living with HF are more adherent to those behaviours which might be more effective to alleviate the presence of signs and symptoms, such as taking diuretics, than to monitor for any signs of decompensation, which may be viewed as ineffective strategies to alleviate symptoms. Thus, such findings imply the need for educational and practical interventions aimed to increase the knowledge on the importance of HF self-care. The individual's monitoring of signs and symptoms can be pivotal for health-care professionals to develop an appropriate individual-based pharmacological treatment plan. Furthermore, although the reported data on adherence to medications in this study is high, education and support concerning medication use is still recommended (Jaarsma et al., 2013).

## 5.6 Objective 4: Differences in Illness Perceptions, Self-Care and Medication Adherence in Individuals Living With Heart Failure Based on Their Socio-Demographic Characteristics and Clinical Information

The following sections consist of a detailed discussion of the differences in the illness perceptions, self-care and medication adherence as reported by the subgroups of different socio-demographic characteristics and clinical information, representing the contextual factors and biological characteristics of the CSM (Figure 3.1). The CSM conceptualises that internal and external changes can determine how the individual perceives his/her illness (Leventhal et al., 2001). Such hypothesis is supported by differences in several contextual and biological factors studied in this dissertation.

### *5.6.1 Age*

It was noted that as age increases, individuals with HF tend to perceive a lower level of emotional disturbance and a lower level of preoccupation about HF. This may indicate that they view HF as a natural consequence of getting older. Moreover, literature revealed that older adults use more emotional regulation strategies, than younger individuals, to select out those negative emotional situations (Hudson et al., 2016). These may include passive responses to stressor, and preserving goodwill (Charles et al., 2009). This finding was consistent with that reported by Nah et al. (2019) in individuals with chronic kidney disease. On the other hand, Ünal et al. (2019) revealed a positive relationship between the emotional representations and age, amongst chronic low back pain individuals. The findings of this study imply the need of a psychotherapist as part of the multidisciplinary team, with the aim to assist the clients along the path of living with a chronic illness, especially amongst those who are diagnosed with HF at a younger age.

Additionally, it was revealed that as age increases, individuals with HF, tend to be more adherent to self-care. This was not the case for other studies, where this relationship was not present, and for others on the contrary to this study, younger HF individuals were found to have better self-care (Asadi et al., 2019; González et al., 2006). Such findings indicate that older individuals might be more aware that by practicing self-care they could lessen any decompensations which are more likely to happen at an older age (Butrous & Hummel, 2016). Moreover, they might have less time constraints in practicing self-care, and a more regular schedule than younger individuals.

### *5.6.2 Gender*

Females in this study significantly perceived a higher degree of personal control, and perceived HF to be affecting them with more symptoms than males. Similar findings were reported amongst the females in the study by Lerdal et al., (2019); however perceiving HF to be personally controlled was not found to be significantly different between genders. This finding may suggest the need for targeted interventions, especially when discussing the signs and symptoms related to HF and the importance of perceiving that HF can be personally controlled. It should be emphasised that such signs and symptoms can be managed by one's own input through self-care.

### *5.6.3 Educational Level*

Higher educated individuals (Secondary to tertiary education level) perceived to have a higher level of comprehension about HF (Tertiary level), a greater perception that HF can be treatment controlled (Secondary level), and perceived HF to be a more worrying situation (Post-secondary level). Such findings on the perceptions of illness comprehensibility, treatment control, and concern were comparable to other international studies (Boonastean et al., 2016, Strugała et al., 2019). This trend was

expected since due to their high illiteracy level, individuals living with HF can have better understanding about their illness and about their prescribed treatment which is known to be pivotal in controlling HF (Ruppar et al., 2016). Moreover, as the findings suggest, better comprehension about HF can lead to a higher level of preoccupation about the present situation. This indicates that health-care professional must use a person-centred approach when delivering informative educational interventions about HF. A person-centred approach where the person is placed at the centre of the service, and together with the professional, they develop a care plan while considering any potential barriers (Ekman et al., 2012). Such interventions should be tailor made, since not every individual can process the acquired information the same.

### *5.6.4 Occupation*

The only, significant difference recorded between participants' occupation was that of medication adherence. Pensioners were found to be more adherent to their medications when compared to the other occupational subgroups, with a significant difference noted between pensioners and formally employed participants. Similarly, Platt et al. (2008) reported that medication adherence was significantly higher amongst retired individuals. It seems that formally employed individuals are less adherent to their medications; this may be due to not having a fixed daily routine or having more time constraints. This implies the need for educational interventions on time planning, the use of reliable mobile applications which can be used as a reminder or data log, and the beneficial effects of being adherent to the prescribed medications (Shah et al., 2020).

### *5.6.5 Marital Status*

There were no significant differences in the illness perceptions, self-care, and medication adherence between participants with different marital status. Literature to compare the illness perceptions between marital status was limited. As regards to

medication adherence, similar findings were reported by Molloy et al. (2009) where it was reported that there was no significant difference in medication adherence between marital status. On the other hand, literature on self-care is quite conflicting. Shojaei et al. (2009) reported better HF self-care amongst married individuals while Asadi et al. (2019) reported that single individuals had better self-care when compared to those who were married. These conflicting findings may be due to different sociocultural backgrounds.

### *5.6.6 Living Arrangements*

This study did not find any significant differences in illness perceptions, and self-care between the living arrangement subgroups. However, individuals who were living with others reported to be more adherent to their prescribed medications. Similarly, studies reported that medication adherence is highly facilitated by living with others (da Silva et al., 2015; Wu et al., 2007). A qualitative study revealed that spouses or informal care givers contributed to medication adherence, through support in preparing the prescribed medicines, being present during medication administration, assisting in refilling the prescriptions, and ensuring attendance to health care appointments to update the prescriptions (Wu et al., 2013). This implies the need of practical and emotional support from both the families when possible and health-care professionals, to encourage the clients to be more adherent while explaining the beneficial effects of their medications (Dunbar et al., 2008; Wu et al., 2007). Additionally, health-care professionals need to inform their clients about the services which are available in the community, such as the domiciliary nursing, to assist them with their medication preparation and administration. These services are of great advantage in increasing adherence to medications (Verloo et al., 2017).

### *5.6.7 Age of Diagnosis With Heart Failure*

It was noted that when individuals are diagnosed with HF at an older age (shorter duration of illness), they perceive less comprehension about HF, and view HF to have an acute timeline. The lack of understanding about the illness could be the cause of perceiving HF to have an acute timeline rather than chronic. Moreover, it was noted that individuals with shorter duration of illness, perceive less emotional disturbance and lower level of preoccupation about their current situation, while perceiving HF to be a less threatening illness. This could be the consequence of viewing the diagnosis of HF as a normal part of aging. Furthermore, the lack of experience of living with HF may affect the individual to perceive HF in a different way (Norfazilah et al., 2013).

Additionally, it seems that when individuals are diagnosed with HF at an older age (shorter duration of illness), they perceive a higher degree of personal control, and are more adherent to self-care behaviours, including to their medications. Such findings indicate the importance of perceiving HF to be personally controlled from the early days of diagnosis, and maintain this perception throughout the path of diagnosis, as this can affect the individual's adherence to self-care and medications in the future. On the contrary, Tawalbeh et al. (2017) reported that shorter duration of HF was a significant predictor of diminished self-care. Such findings support the CSM which posits that the illness perceptions together with the selected coping procedures change over time. Thus, longitudinal studies in this regard would be beneficial to study the change in illness perceptions and self-care behaviours over time.

### *5.6.8 Left Ventricular Ejection Fraction*

There were no significant differences in the illness perceptions, self-care, and medication adherence between participants with different LVEF. There is conflicting literature on the differences in self-care between LVEF subgroups. Lycholip et al.

(2018) reported that lack of self-care was found to be associated with lower LVEF, on the contrary da Conceição et al. (2015) revealed that adherence to self-care was associated with lower LVEF. These conflicting findings in the literature could suggest that individuals with lower LVEF may be more symptomatic and thus they may have lack of strength to perform the recommended self-care behaviours. On the other hand, diagnosis with low LVEF may act as a precursor to have better self-care with the aim to alleviate any signs and symptoms.

### *5.6.9 NYHA Class*

Asymptomatic individuals (NYHA Class I) perceived HF to have lower consequences, to result in experiencing less symptoms, to be causing them lower emotional disturbances, and lower preoccupation levels (Concern). Overall, asymptomatic individuals (NYHA Class I) significantly perceived HF as a more benign illness when compared to those classified in NYHA Class II and III (Symptomatic). These findings indicate that the presence of symptoms may negatively affect individuals to perceive their illness to be quite threatening to them. This implies the need to develop assessment tools, while using the NYHA Class and the illness perceptions as their backbone, to identify the presence of symptoms and to explore how these symptoms are affecting the individual in perceiving their illness. The difference in the emotional representations between NYHA Class sub-groups suggests again the importance of psychological care in the care plan of diagnoses with HF. Agreeing with results of this study, Lerdal et al. (2019) associated the same illness perceptions with asymptomatic HF (NYHA Class I). Moreover, similar to that reported in this study, individuals who were symptomatic (NYHA Class II – IV) reported a more negative illness perception (Lerdal et al., 2019). This negative perception about HF could be the main cause of diminished self-care adherence.

In fact, asymptomatic individuals reported to be more adherent to self-care when compared to those who were symptomatic (NYHA Class II – III). Such results were similar to that reported by Lycholip et al. (2018). Diminished self-care in those who are symptomatic, implies the need of frequent follow-ups, with the aim of assisting whilst encouraging the clients to monitor and manage the present signs and symptoms, to alleviate any decompensations while preventing hospitalisations.

### *5.6.10 Followed-up Period*

Individuals with longer follow-up periods perceived HF as a more chronic illness, lower perception of personal control, and to experience more symptoms than those with shorter follow-up periods. Similar results were observed in a longitudinal study by Goodman et al. (2013), where it was observed that as time progressed individuals with HF changed their perception regarding the chronicity of their illness from acute to chronic. Moreover, although identity perception score increased over time, indicating that HF was viewed to cause moderate severe symptoms, personal control declined (Goodman et al., 2013). This implies the need that individuals with HF should be informed about the chronicity of their illness at the early stages of diagnosis. The fact that lower personal control, and experiences of more symptoms, were perceived in those with longer follow-up periods, suggests the need of continuous support throughout the follow-up period to increase their perception of personal control, with the result of lessening their symptoms by practicing consistent self-care. Additionally, differences in illness perceptions perceived by individuals with different follow-up periods, implies the need of future studies with a longitudinal design to explore the change in illness perceptions over time. Such change in illness perceptions could also be due to natural progression of the condition.

### *5.6.11 Number of Admissions With Heart Failure and Time Since Last Admission*

Individuals with HF frequently decompensate, leading them to have recurrent admissions to a hospital, therefore the number of admissions reflects the severity of their HF (Braga et al., 2018). There were several relationships between the number of admissions with HF and the studied variables. However, there were no significant differences in the illness perceptions, self-care, and medication adherence, between the sub-groups of last admission with HF.

It was noted that as the number of admissions with HF increases, HF is perceived to have greater consequences, and resulting in experiencing more severe symptoms. Additionally, individuals perceive HF to be more threatening to their life. These findings imply the need of a detailed assessment of the perceived illness perceptions, with the possible consequence of identifying those illness perceptions which may be precursor of recurrent admissions.

Individuals with HF, who experience multiple hospitalisations, perceive HF as an illness which cannot be personally controlled. This may indicate the loss of their perception that they can control well their illness, with the result of being less adherent to self-care. In fact, it was noted that recurrent admissions can result in diminished self-care and medication adherence. However, in this study this relationship was not found to be statistically significant. Similar results were found by Linn et al. (2016), where a negative significant relationship was reported between self-care and previous hospitalisations with acute HF.

Such results emphasise the importance of developing interventions which take into consideration the individual's illness perceptions, with the aim of decreasing recurrent hospitalisations. Transitional care interventions, such as in-hospital planning,

post discharge follow-up, and supportive care via telephone or home visits, could be considered as they are known to be beneficial in bridging the acute care in hospital to care at home (Mai et al., 2020; Phelps, 2016). This process may act as a pivotal factor to bring change in one's perceived illness perceptions, with the consequence of improving self-care behaviours and medications adherence (Carrington & Stewart, 2010).

## 5.7 Objective 5: The Relationship Between the Illness Perceptions and Heart Failure Self-Care Behaviours Including Medication Adherence

The findings of this study highlight that a more threatening perception of HF is associated with diminished self-care, including medication adherence. Similar results were reported by Mansouriyeh et al. (2017), where illness perception was positively correlated with diminished self-care. The impact of perceiving HF to be a threatening illness could lead the individual to adopt a negative permanent view of their illness, with the result of not putting enough effort to perform self-care in order to manage their illness (Kugbey et al., 2017).

Furthermore, the intercorrelations between the illness perceptions and self-care adherence, including that of medication adherence were also identified. Individuals' perceptions about HF of greater consequences, more chronic timeline, experience more symptoms, and have greater emotional impact, were found to be related with diminished self-care. Moreover, perceiving that HF can be more personally controlled was found to be associated with better self-care adherence. These correlations were consistent to those reported by MacInnes (2013) with the difference that they were all found to be related to enhanced self-care. Such negative relationships with self-care may suggest that Maltese individuals living with HF may tend to give up on practicing self-care when they perceive HF to be negatively affecting them. This implies the need of frequent follow-ups by a multi-disciplinary team, including specialised HF nurses,

cardiologist, and psychologist, with the aim to ensure self-care adherence. The involvement of psychological interventions is known to improve self-care in individuals living with HF (Jiang et al., 2018).

In addition to diminished self-care, individuals who perceive to be experiencing more symptoms due to HF are less adherent to their prescribed medications. This is consistent to that explained in the CSM by Leventhal et al. (1998), who stated that individuals who perceive experiencing more symptoms, may view their treatment to be ineffective, with the result of being less adherent to their treatment. This suggests the need of practical interventions involving approaches such as motivational interviewing. Using motivational interviewing principles as a guide, health-care professionals can assist the individual to develop the rationale about the importance of self-care and medication adherence, with the aim to improve adherence especially when the individual is perceiving to be experiencing more symptoms (Chen et al., 2018; Delamater & Marrero, 2020). The importance of identifying the signs and symptoms of HF decompensation should be discussed with the client. Moreover, the beneficial effects of self-care and medication adherence should be discussed within the context of how they are perceiving their illness. As a result, this can improve clinical outcomes.

### *5.7.1 Illness Perceptions as Predictors to Heart Failure Self-Care Behaviours, Including Medication Adherence.*

Findings of this research study are consistently supported by the CSM which hypothesises that an individual's illness perceptions are related to the coping procedures, represented in this study by self-care and medication adherence.

Figure 5.1 indicates that although individuals perceived HF to have greater consequences, they are not viewing these consequences to be lessened by self-care. Additionally, perceiving HF to have a chronic timeline is observed to be a consequence

of giving up on practicing self-care. In fact, illness perception of consequences and timeline were identified to be significant predictors to diminished self-care.

On the other hand, this prediction analysis proved the importance of perceiving HF to be personally controlled, and perceiving a higher illness comprehensibility about HF, as these were identified to be significant predictors of enhanced self-care (Figure 5.1).

**Figure 5.1**

*Illness Perceptions as Predictors of Self-Care*

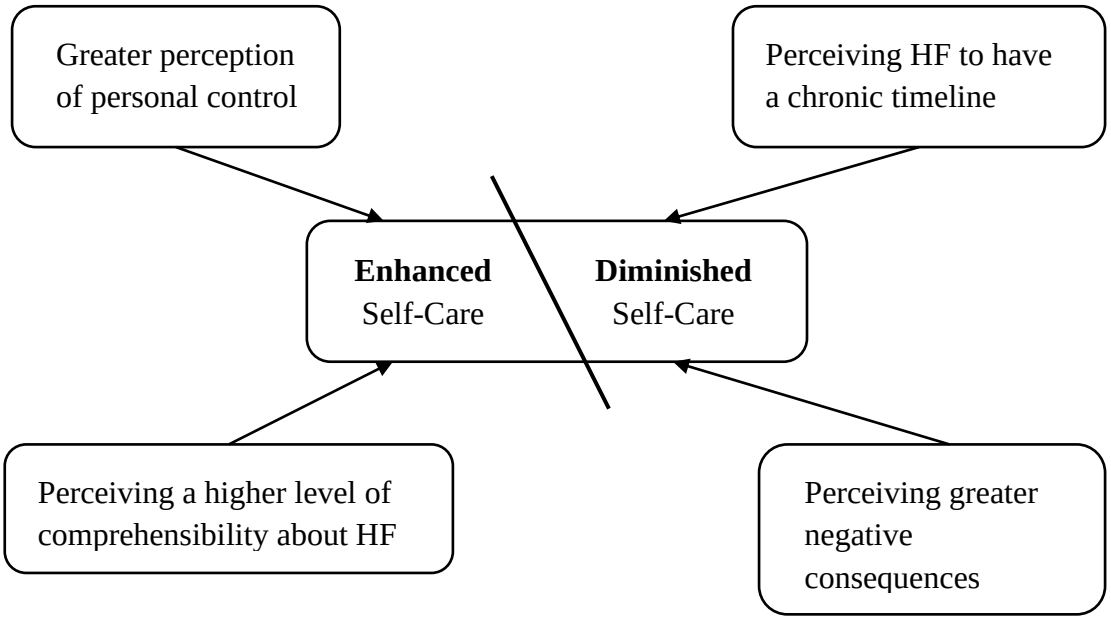
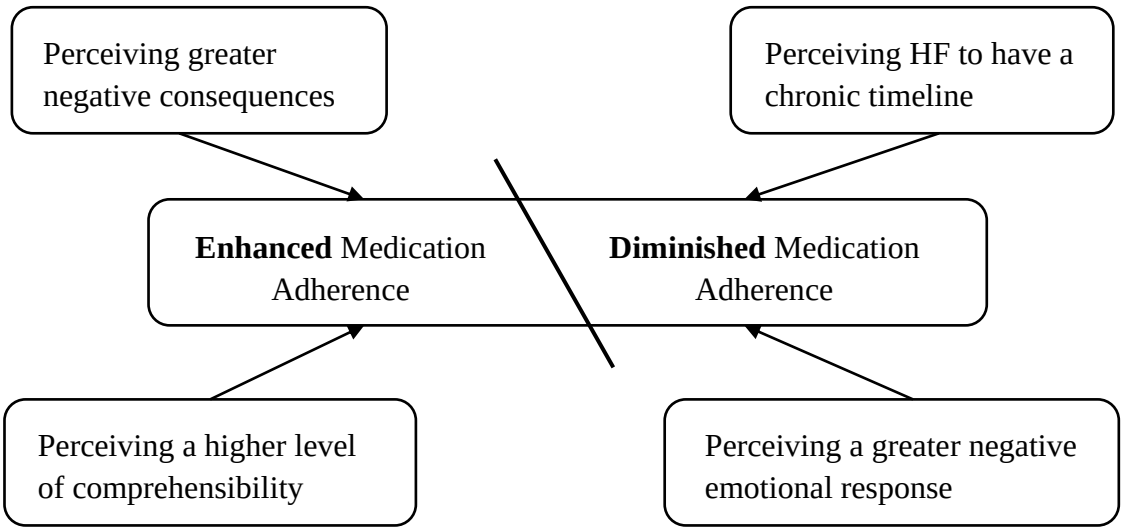



Figure 5.2 indicates that, on the contrary to self-care, perceiving HF to have greater consequences is seen to be a predictor to view these consequences to be lessened with medication adherence. This could indicate the reliance on the prescribed medications, manifested by medication adherence, which is also seen to be enhanced by perceiving a high degree of understanding about HF. Similar to self-care, perceiving HF to have a chronic timeline was identified to be predictor of diminished medication adherence. This implies the need of cognitive behavioural interventions to recognise that self-care and medication adherence are pivotal in preventing or lessening any signs

and symptoms of this accurately perceived long-lasting disease. Additionally, perception of higher degree of negative emotional disturbance due to HF identified to be predictor of diminished medication adherence. This implies the need that as a health-care professional one needs to recognise the importance of psychosocial care in the caring process, which is seen to be crucial to enhance medication adherence.

**Figure 5.2**

*Illness Perceptions as Predictors to Medication Adherence*




This study also provides additional input to the literature by identifying which contextual factors and biological characteristics together with one's illness perceptions can be predictive to both self-care and medication adherence. It was identified that 'NYHA Class category' and 'age' as a predictor to self-care, with those individuals classified in NYHA Class I, being asymptomatic, and as the individual gets older were identified to be more adherent to self-care (Figure 5.3). Furthermore, 'occupation' and 'living arrangement' were identified to be predictors of medication adherence, with those being pensioners and living with others identified as being more adherent to medications (Figure 5.4).

**Figure 5.3**

*Illness Perceptions, NYHA Class, and Age as Predictors of Self-Care*

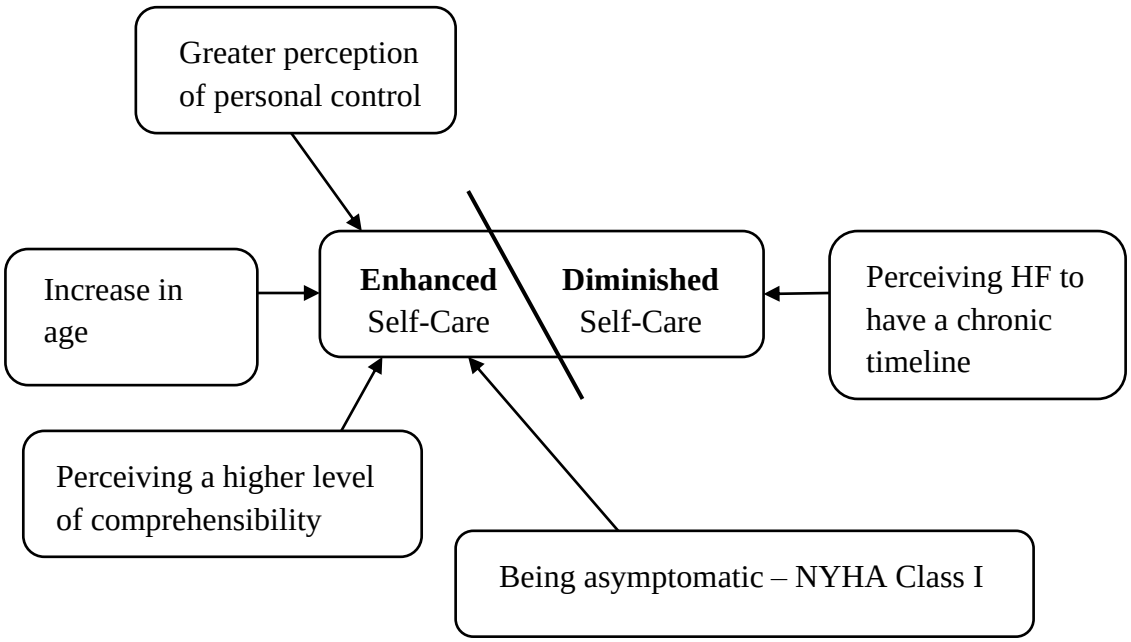
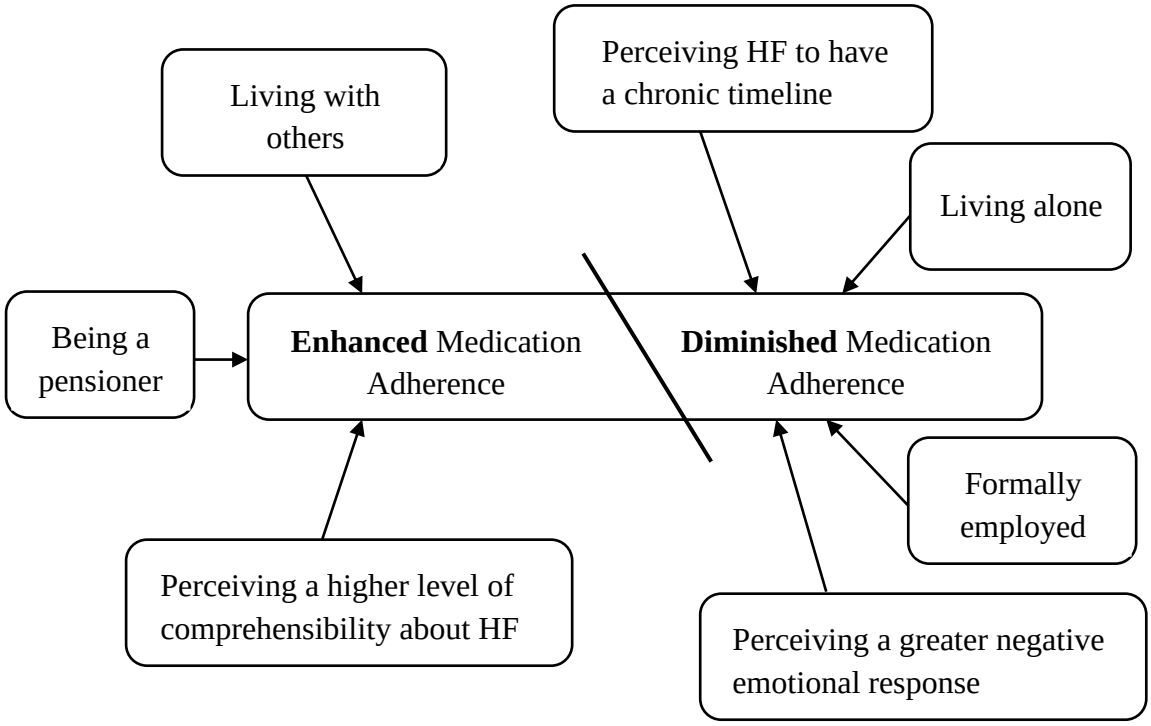



**Figure 5.4**

*Illness Perceptions, Occupation, and Living Arrangement, as Predictors of Medication Adherence*



The prediction analysis suggests that individuals with HF are quite personally active in their own care. This is reflected well by the CSM, which conceptualises individuals to be active rather than passive in regulating their illness (Leventhal et al., 1980). Thus, health-care professionals need to recognize that their clients are active informed targets, rather than a passive uninformed object (Leventhal et al., 1980). Before making any conclusions, regarding self-care and medication adherence rates, the discussed findings suggest that health-care professionals should explore how the individual is perceiving his/her illness and identify any possible contextual factors and biological characteristics which could be affecting the individual to perceive and respond to his/her illness in such a different way. As the CSM implies, identifying the perceived illness perceptions is pivotal to understand how these are influencing the coping strategies, which represents the people responses to their illness. It is also suggested that health-care professionals should adopt a person-centred approach, to view each client as a unique individual with a different background and biological factors which may influence his/her perceived illness perceptions which in-turn affecting the ways of how he/she is responding to his/her illness. In this way the health-care professional can adopt a truly holistic care process.

## 5.8 Strengths and Limitations

### *5.8.1 Strengths*

The main strength of this research study is that it addressed the gap in literature related to the relationship between the illness perceptions about HF and HF self-care behaviours, including medication adherence. Moreover, with the help of this study the illness perceptions and self-care behaviours, including medication adherence of the Maltese HF population were revealed.

A quantitative design and a convenience sample approach allowed a large sample size in the limited amount of time available to complete this study. The fact that the questionnaires were translated to the Maltese language helped to reduce the language barrier and to minimise selection bias while increasing the participation rate. Moreover, the use of short questionnaires/scales was of great benefit to encourage participation while reducing participants' burden.

This research study explored the existing differences in illness perceptions, and self-care, including medication adherence amongst different variables, such as followed-up period, age of diagnosis with HF and number of admissions, which were not explored before even more amongst the Maltese HF population.

Another strength of this research study is that both the cognitive and the emotional representations of the CSM were explored. Additionally, to further explore self-care amongst the Maltese HF population, medication adherence was also added to the analysis. By exploring both the illness perceptions and self-care behaviours, the representation of illness, in this regard HF, together with the coping procedures of individuals with HF, represented by the CSM, were beneficial to identify the association between them.

### *5.8.2 Limitations*

The potential limitation of this study is the poor internal consistency of the B-IPQ which could be related to the small number of items in this scale. Since illness perceptions and adherence to self-care can change over time, choosing a longitudinal study design would have been more appropriate to study any differences in the mentioned variables from baseline to follow-up period. However, this could not be done due to the limited amount of time to complete this study. Another limitation of this study is the risk of social desirability response bias by using self-reported

questionnaires/scales. The addition of objective or observation measurements to evaluate self-care behaviours and medication adherence from both health-care professionals and family members might strengthen the findings. Nevertheless, such objective or observational measurements might be time consuming, expensive, and complicated for family members/informal carers.

Moreover, generalisability of the findings might be impacted since participants were conveniently recruited from one hospital. However, since this hospital is the only national hospital in Malta, a wide variety of individuals with HF from different areas of Malta visits the nurse-led HF clinic and the specialised HF clinic.

## 5.9 Conclusion

This study highlighted the illness perceptions and self-care behaviours, including medication adherence of individuals living with HF. The theory which supported the above findings was the CSM of self-regulation of illness by Leventhal et al. (1980).

The CSM illustrates that the development of the illness perceptions, representing the threats to health, is influenced by somatic changes and deviations from one's normality. This was well highlighted by the findings of this research study, which suggest that the way the individual perceives HF is influenced by several demographic and clinical characteristics. Moreover, the predictive analysis results support the CSM, which proved a relationship between the perceived illness perceptions and the coping procedures.

In conclusion, the above findings suggest that individual's illness perceptions about HF, may influence the way of how each illness perception is perceived, and how the individual respond to their illness, through self-care and medication adherence.

Thus, it is essential for health-care professionals to identify the individuals' perceived illness perceptions from day one of diagnoses with HF and continue to assess these perceptions through transitional care process, from hospital to home. This is beneficial to provide the necessary assistance to help the client in achieving and maintaining the needed changes in his/her perceived illness perceptions with the aim to increase self-care and medication adherence.

The following chapter entails the conclusion of this research study, illustrating that all the aims and objectives were accomplished. In addition, it highlights the novelty of the findings and their influence on practice, while eliciting the recommendations for further research, and the implications for practice and education.

# Chapter 6 – Conclusion and Recommendations

## 6.1 Introduction

This chapter presents the conclusions of this research study. It starts by highlighting the novelty of the findings and their influence on practice (Section 6.2) and continues by representing the emerged recommendations (Section 6.3). The strengths and limitations are summarised in section 6.4.

## 6.2 Novelty of the Findings and Their Influence on Practice

To the researcher's knowledge this is the first study carried out on this topic amongst the Maltese HF population. Thus, this study is an asset to the local literature, since it identified the illness perceptions perceived by Maltese individuals living with HF. Moreover, it also identified how these illness perceptions relate to each other, and to HF self-care, including medication adherence. These findings may influence the current health-care practice by considering the importance of exploring the individual's illness perceptions since these play a significant role in how Maltese individuals living with HF self-manage their illness.

This study has highlighted the importance of assessing the illness perception of consequences, since it was found to be related to most illness perceptions. This finding may have a great impact on practice, since by assessing the individual's consequences perception about HF, the health-care professional may have a perspective about how the person perceives his/her illness. However, since illness perceptions change over time, and are unique for every individual, this trend should not be taken for granted, and thus it is recommended that all the illness perceptions should be assessed at every patient contact.

The individual's age, level of education, age of diagnosis, and functional status reflected by NYHA Class, were identified to be important determinants of perceiving

HF to be causing differences in emotional response. These findings may have a great impact on the local practice of care amongst individual's living with HF since they identify particularly vulnerable groups at risk of not implementing self-care, allowing referral to a psychologist who should be part of the multidisciplinary team of HF management.

One of the novelties of the present findings is the fact that the older the age of diagnosis is, the more the person is adherent to self-care and medications. Such findings may influence the health-care professional to deliver consistent and regular educational follow-ups on self-care and medication adherence during the early phases of diagnosis with HF.

The major novelty of this study is the predicted interplay between illness perceptions and self-care, including medication adherence. The fact that individual's illness perception on consequences was identified as a predictor of diminished self-care and enhanced medication adherence may act as an influential measure for health-care professionals to emphasise the beneficial effects of self-care especially when the current consequences resulted from HF are perceived to be detrimental to wellbeing. Moreover, an accurate illness perception of chronic timeline about HF, was identified to be a predictor of diminished self-care and medication adherence while a higher level of illness comprehensibility was identified as a predictor of enhanced self-care and medication adherence. Thus, these findings may act as a stimulus for health-care professionals to deliver educational programs focusing on the importance of both self-care and medication adherence especially when the condition is known and accurately perceived to be chronic.

In addition, the findings of this study highlighted the importance of perceiving HF to be within the person's control since this perception was identified as a predictor of self-care. This could be influential in constructing an intervention which is based on

the importance of assisting the client to perceive HF as a chronic illness which can be personally controlled through self-care. Moreover, another novel finding is the fact that perceiving HF to be causing emotional disturbance was identified as a predictor of diminished medication adherence. As already mentioned earlier, this should act as a motive for health-care professionals to assess the individual's emotional response and its impact on the adherence to self-care and medication.

Another unique finding of this study is the identification of socio-demographic and clinical variables together with one's illness perceptions as predictors to both self-care and medication adherence. This finding is pivotal for health-care professionals to ensure effectiveness of HF management program by practicing a more person-centred approach, involving a detailed formal assessment of the individual's illness perceptions, personal experiences and history of the condition, and the behaviour chosen to manage their illness. As a result, such programs can be tailor made according to the individual needs, with the aim to increase self-care and medication adherence, while improving clinical outcomes.

## 6.3 Recommendations

### *6.3.1 Recommendations for Future Research*

- Conducting a longitudinal study to explore the changes in illness perceptions and self-care, including medication adherence over an extended period of time.
- In view of HF being a chronic condition, future research should focus on the impact of interventions targeted to improve the cognitive and emotional representations of the CSM and to assess whether such changes influence the way of how the individual perceives HF. Moreover, such changes should be

assessed along with the individual's actions taken represented by the coping procedures, including self-care and medication adherence.

- Qualitative research should be considered to explore how the individual living with HF perceives his/her illness, while identifying any barriers and facilitators influencing one's adherence to self-care and medications.
- In addition to the illness perceptions, future studies, amongst Maltese individuals living with HF, should consider other measures to assess the social support, self-efficacy, and anxiety and/or depression, to identify if such variables are indicative predictors of self-care and medication adherence.

### *6.3.2 Recommendations for Education*

- Develop educational and training programmes for health-care professionals to understand the importance of person-centred care while raising awareness on the cognitive and emotional representations representing the individual's unique illness perceptions.
- Providing a case-by-case discharge plan and educational interventions while considering the socio-demographic and clinical information of the individual, such as educational level, and NYHA Class (Functional status). This should help the health-care professionals in revealing the individuals' illness perceptions while assisting them to initiate and maintain self-care.
- According to the individual's will, informal carers should be part of the educational interventions as they can play a pivotal role in increasing adherence to self-care and medications. One must be aware that informal carers may perceive HF in a different way to that perceived by the affected individual. Thus, their illness perceptions should also be assessed.

### *6.3.3 Recommendation for Practice and Management*

- The implications for nursing practice should be based on the CSM of self-regulation, as it focuses on a person-centred approach while being the foundation to build a therapeutic relationship between the individual with HF and the health-care professional.
- Develop transitional care interventions from the time of admission based on the cognitive and emotional representations of the CSM. This could include the illness perception of consequences (the seriousness of the illness), timeline (duration of the illness), personal control (own degree of control, importance of self-care), treatment control (utility of the cure, beneficial effect of the treatment), identity (any possible experienced symptoms), illness comprehensibility (degree of understanding about the illness), cause/s (precise causal attributions), concern (assess level of preoccupation), and emotions (assess level of emotional response). Moreover, such interventions should identify the needs required to enhance self-care at home while assisting the individual with HF to draw an accurate practice of coping procedures with the aim of decreasing future decompensations with HF.
- Interventions to assist the individual living with HF to identify any barriers and facilitators known to be influencing the way of how the illness is perceived with the consequence of affecting self-care and medication adherence. This should help the individual to find solutions, with the aim of initiating and maintaining the required change/s in behaviour. Such interventions may include Cognitive Behavioural Therapy along with Motivational Interviewing techniques.
- Develop individual-focused interventions to tackle any misconceptions about the accuracy level of how HF is perceived. Such practice should be incorporated

into the HF plan of care, with the aim of enhancing self-care and medication adherence while preventing any recurrent episodes of decompensations.

- Increase episodes of follow-up, especially for individuals who are classified in NYHA Class II – IV (Symptomatic). These individuals might perceive their illness in a different way from those who are in NYHA Class I (Asymptomatic), with the result of being less adherent to self-care and their prescribed medications. Thus, such recommendation is pivotal in decreasing hospitalisations.
- Importance needs to be given for the perceived emotional representations. This implies the need of psychosocial care along the path of diagnosis with HF.

## 6.4 Strengths and Limitations

The strengths of this research study include:

- This study addressed the current gap in local literature related to the objectives of the same study.
- A large sample size was ensured while using a cross-sectional design and a convenience sample approach.
- Translating the research instruments to the Maltese language helped to reduce language barriers and minimised selection bias.
- The use of short questionnaires/scales was of great benefit to encourage participation while reducing participants' burden.
- Several covariates and subgroups of socio-demographic characteristics and clinical information were considered to further assess the study variables.
- Both the cognitive and emotional representations of the CSM were analysed.

The limitations of this research study include:

- Poor internal consistency of the B-IPQ.
- A longitudinal design would have been more appropriate to study changes in illness perceptions and self-care over time.
- Increased risk of social desirability bias by using self-reported questionnaires.
- Generalisability of the findings might be impacted since participants were conveniently recruited from one hospital.

## 6.5 Conclusion

This study was of great importance in revealing the illness perceptions of individuals living with HF and to identify the self-care behaviours and medication adherence of the Maltese HF population. Consequently, this study not only adds to previous literature but also acts as a key in determining which illness perceptions act as predictors of both HF self-care and medication adherence. Since, this study was the first to reveal the illness perceptions of the Maltese individuals living with HF, it can provide a basis for future studies on this topic.

The cognitive and emotional representations of the CSM formed the backbone for most of the emerged recommendations with the primary aim to increase self-care and medication adherence. It is recommended that health-care professionals should reflect more and practice a person-centred approach with the aim to assess one's illness perceptions which are known to influence self-care and medication adherence. Such practice should start from day one of the diagnosis with HF and continue during the follow-up periods through the transitional care process.

Furthermore, health-care professionals should equip themselves with the necessary tools to provide continuous and consistent follow-up care to support their clients while considering their unique perceived illness perceptions. This is beneficial to

improve self-care and medication adherence. This should reduce in hospitalisation with HF decompensation, morbidity, and mortality rates.

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# Appendices

## Appendix A: The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Checklist

| Section and item | Item No. | Recommendation | (Albert et al., 2014) | (Goodman et al., 2013) | (Horowitz et al., 2004) | (MacInnes,2013) | (Mansouriyeh et al., 2017) | (Mei et al., 2019) | (Molloy et al., 2009) | (Voelmeck et al., 2006) |
|---|---|---|---|---|---|---|---|---|---|---|
| **Title and Abstract** | **1** | (a) Indicate the study's design with a commonly used term in the title or the abstract | **Y** | **Y** | **N** | **Y** | **Y** | **Y** | **N** | **Y** |
| | | (b) Provide in the abstract an informative and balanced summary of what was done and what was found | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |
| **Introduction** | **2** *Background/ rationale* | Explain the scientific background and rationale for the investigation being reported | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |
| | **3** *Objectives* | State specific objectives, including any pre-specified hypotheses | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |
| **Methods** | **4** *Study design* | Present key elements of study design early in the paper | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |

| Section and item | Item No. | Recommendation | (Albert et al., 2014) | (Goodman et al., 2013) | (Horowitz et al., 2004) | (MacInnes,2013) | (Mansouriyeh et al., 2017) | (Mei et al., 2019) | (Molloy et al., 2009) | (Voelmeck et al., 2006) |
|---|---|---|---|---|---|---|---|---|---|---|
| | **5** *Setting* | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |
| | **6** *Participants* | (a) Cohort study—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up | **N/A** | **Y** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** |
| | | Cross-sectional study—Give the eligibility criteria, and the sources and methods of selection of participants | **Y** | **N/A** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |
| | | (b) Cohort study—For matched studies, give matching criteria and number of exposed and unexposed | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** |
| | **7** *Variables* | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | **Y** | **Y** | **N/A** | **Y** | **Y** | **Y** | **Y** | **Y** |

| Section and item | Item No. | Recommendation | (Albert et al., 2014) | (Goodman et al., 2013) | (Horowitz et al., 2004) | (MacInnes,2013) | (Mansouriyeh et al., 2017) | (Mei et al., 2019) | (Molloy et al., 2009) | (Voelmeck et al., 2006) |
|---|---|---|---|---|---|---|---|---|---|---|
| | **8** *Data sources /measurement* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |
| | **9** *Bias* | Describe any efforts to address potential sources of bias | **N** | **N** | **Y** | **N** | **N** | **N** | **N** | **Y** |
| | **10** *Study Size* | Explain how the study size was arrived at | **N** | **Y** | **Y** | **Y** | **N** | **N** | **N** | **Y** |
| | **11** *Quantitative variables* | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | **Y** | **Y** | **N/A** | **Y** | **Y** | **Y** | **Y** | **Y** |
| | **12** *Statistical methods* | (a) Describe all statistical methods, including those used to control for confounding | **Y** | **Y** | **N/A** | **Y** | **Y** | **Y** | **N** | **Y** |
| | | (b) Describe any methods used to examine subgroups and interactions | **Y** | **Y** | **N/A** | **N/A** | **N/A** | **Y** | **N** | **N/A** |
| | | (c) Explain how missing data were addressed | **N** | **N** | **N/A** | **N** | **N** | **N** | **N** | **Y** |
| | | (d) Cohort study—If applicable, explain how loss to follow-up was addressed | **N/A** | **Y** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** |

| Section and item | Item No. | Recommendation | (Albert et al., 2014) | (Goodman et al., 2013) | (Horowitz et al., 2004) | (MacInnes,2013) | (Mansouriyeh et al., 2017) | (Mei et al., 2019) | (Molloy et al., 2009) | (Voelmeck et al., 2006) |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | |
| | | Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** |
| | | (e) Describe any sensitivity analyses | **Y** | **Y** | **N/A** | **Y** | **Y** | **Y** | **Y** | **Y** |
| **Results** | **13** *Participants* | (a) Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |
| | | (b) Give reasons for non-participation at each stage | **N/A** | **Y** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** |
| | | (c) Consider use of a flow diagram | **N** | **N** | **N** | **N** | **N** | **N** | **N** | **N** |
| | **14** *Descriptive data* | (a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |

| Section and item | Item No. | Recommendation | (Albert et al., 2014) | (Goodman et al., 2013) | (Horowitz et al., 2004) | (MacInnes,2013) | (Mansouriyeh et al., 2017) | (Mei et al., 2019) | (Molloy et al., 2009) | (Voelmeck et al., 2006) |
|---|---|---|---|---|---|---|---|---|---|---|
| | | (b) Indicate number of participants with missing data for each variable of interest | **N** | **N** | **N/A** | **N** | **N** | **N** | **N** | **N** |
| | | (c) Cohort study—Summarise follow-up time (e.g., average and total amount) | **N/A** | **Y** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** |
| | **15** *Outcome data* | Cohort study—Report numbers of outcome events or summary measures over time | **N/A** | **Y** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** |
| | | Cross-sectional study—Report numbers of outcome events or summary measures | **Y** | **N/A** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |
| | **16** *Main results* | (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included | **Y** | **Y** | **N/A** | **Y** | **Y** | **Y** | **Y** | **Y** |
| | | (b) Report category boundaries when continuous variables were categorized | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** |

| Section and item | Item No. | Recommendation | (Albert et al., 2014) | (Goodman et al., 2013) | (Horowitz et al., 2004) | (MacInnes,2013) | (Mansouriyeh et al., 2017) | (Mei et al., 2019) | (Molloy et al., 2009) | (Voelmeck et al., 2006) |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | |
| | | (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | **N/A** | **N** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** | **N/A** |
| | **17** *Other analysis* | Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses | **Y** | **Y** | **N/A** | **Y** | **Y** | **Y** | **Y** | **Y** |
| **Discussion** | **18** *Key results* | Summarise key results with reference to study objectives | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |
| | **19** *Limitations* | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |
| | **20** *Interpretation* | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** |
| | **21** *Generalisability* | Discuss the generalisability (external validity) of the study results | **Y** | **Y** | **Y** | **Y** | **Y** | **Y** | **N** | **Y** |

| Section and item | Item No. | Recommendation | (Albert et al., 2014) | (Goodman et al., 2013) | (Horowitz et al., 2004) | (MacInnes,2013) | (Mansouriyeh et al., 2017) | (Mei et al., 2019) | (Molloy et al., 2009) | (Voelmeck et al., 2006) |
|---|---|---|---|---|---|---|---|---|---|---|
| **Other information** | **22** *Funding* | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | **N** | **Y** | **N** | **Y** | **Y** | **Y** | **Y** | **Y** |

# Appendix B: Permissions From the Hospital's Chief Executive Officer, the Data Protection Officer, and the Director for Nursing Services

## *Appendix B.1: Permission From the Hospital's Chief Executive Officer*

L-Università ta' Malta

**Sheldon Attard <sheldon.attard.09@um.edu.mt>**

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**RE: [EXTERNAL] - Reg. Approval for: The beliefs and behaviours of Heart Failure patients concerning self-management and treatment.**

1 message

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**CEO at Health-MDH** <ceo.mdh@gov.mt> 7 July 2020 at 21:08
To: Sheldon Attard <sheldon.attard.09@um.edu.mt>

Dear Mr Attard,

Kindly be informed that Ms Celia Falzon has granted approval for you to conduct this study in line with applicable hospital protocols.

Regards

Carmen Farrugia

Personal Assistant To CEO

SPTAR MATER DEI

**T** +356 25454102

**E** carmen.farrugia@gov.mt

Mater Dei Hospital, Triq Id-Donaturi Tad-Demm, Msida, Malta MSD 2090 | Tel +356 2545 0000 |

https://careandcure.gov.mt/

*Appendix B.2: Permission From the Data Protection Officer*

Gmail **Sheldon Attard <sheldatt@gmail.com>**

## RE: [EXTERNAL] - Approval re. The beliefs and behaviours of Heart Failure patients concerning self-management and treatment

11 messages

**Data Protection at MDH** <datapro.mdh@gov.mt> Tue, Jul 7, 2020 at 8:51 AM
To: Sheldon Attard <sheldon.attard.09@um.edu.mt>
Cc: Young Sharon at Health-MDH <sharon.young@gov.mt>, Data Protection Approval Form at Health-MDH
<dpaform.mdh@gov.mt>, Attard Sheldon at Health-MDH <sheldon.attard@gov.mt>

Dear Mr Attard

On the basis of the documentation you submitted, from the MDH data protection point of view you have been cleared to proceed with your study titled "***Beliefs and behaviours of Heart Failure patients concerning self-management and treatment"*** provided that you obtain approval from MDH CEO (ceo.mdh@gov.mt - please provide the relevant documents including the Chair's approval and this letter).

**All data stored must be anonymized** and in no way should you retain any personal details you obtain from your research and this should be destroyed at the end of your study and /or if any of your participants decides to withdraw. Remember that participants reserve the right to be forgotten.

You are requested to submit a copy of your findings to this office at the end of your study.

**Anonymisation and Data minimisation**

**Participant consent forms must be separated from the answered questionnaires at source meaning that there will be no correlation between one and the other that will indicate how participants replied.**

**ALL data presented to your supervisors / tutors or examiners or any other personnel from UOM or anyone else must be already anonymized; meaning that you must not divulge to anyone the identity of your participants and / or how they replied.**

**Consent Criteria**

**This clearance does not allow viewing of medical records nor access to Health Information Systems since you haven't declared so in the consent form.**

**Re: In both information letters and consent forms (Maltese and English) *"There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes."* please either state who the examiners are or else add a contact number / email so the participant can enquire on who will access / accessed his / her personal data from UOM.**

**Since you haven't declared otherwise, all your participants must be reached and approached when physically at MDH grounds and NOT via postal services, email, telephone or any other means. You cannot be handed any contact details of potential participants, otherwise consent would be bypassed and breach GDPR.**

**Potential participants must be approached by your declared intermediaries for invitation and not directly by your good self. If potential participants decide to participate, then you approach.**

**Audio recordings are not allowed in this research**

**Clarifications**

**This clearance does not cover ethical approval.**

**All documents presented to your participants must include UOM's logo.**

**Your submitted documentation must remain unchanged.**

**What was declared during this clearance process is what you will abide to.**

**You must abide with all the articles of the GDPR 2016 throughout the data collection process and thereafter.**

**Please communicate with the respective Charge Nurse before you start. You must also present this clearance letter.**

*To sign the data protection form, please contact us through* dpaform.mdh@gov.mt *and provide the following:*

- *This clearance letter*
- *A copy of the CEO's approval*
- *State the period of data collection*
- *Title of your research*

[Quoted text hidden]

---

**Data Protection at MDH** datapro.mdh@gov.mt Thu, Jul 9, 2020 at 6:39 PM

To: Sheldon Attard <sheldon.attard.09@um.edu.mt>
Cc: Young Sharon at Health-MDH <sharon.young@gov.mt>, Aquilina Graziella at Health-MDH <graziella.aquilina@gov.mt>, Attard Sheldon at Health-MDH <sheldon.attard@gov.mt>

Dear Mr Attard,

Your amendments have been added to our records.

Please add this email as an addendum to our clearance letter.

You are cleared to proceed with the same terms and conditions.

[Quoted text hidden]

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## *Appendix B.3: Permission From the Director for Nursing Services*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 24th June 2020

Ms. Carmela D'Amato

[*Title - Name - Surname*]

Director Nursing

[*Position*]

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Ms. Carmela D'Amato,

[*Title - Name - Surname*]

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

widely in a number of research studies. Permissions for the mentioned scales were granted from their respective original author.

It is envisaged that data collection is carried out between the months of October till November 2020. To be eligible for the study, the participants need to be classified as HF, either diastolic or systolic dysfunction or both. Age of patients should be ≥18 years of age. Since I am one of the HF clinic nurses, recruitment of participants and informed consent is going to be done and obtained by the cardiologists and/or other nurses. During data collection I will only be recruiting and obtaining informed consents for those patients who are labelled as new cases at Medical Out-Patient 4 (MOP4), at Cardiac Rehab and Specialised HFC but not at HFC, to eliminate any obligations. Questionnaires will be handed to cardiologists, at MOP4, Specialised HF Clinic and nurse-led clinics (HF clinic and Cardiac Rehab) to be filled by the participant themselves or with the help of the cardiologist or nurse, when help is needed. The first part, which entails the demographic data and the clinical information, will be filled by the cardiologist or the nurse him/herself. I will be helping the participants, when help is needed, in filling the questionnaire after an informed consent is obtained by the cardiologists or nurses. In order to respect anonymity and confidentiality of the participants, filled questionnaires are placed in a sealed box by the participants themselves, before they leave the attended clinic.

This research will be conducted under the supervision of Dr. Roberta Sammut (roberta.sammut@um.edu.mt). Ethical approvals will be pursued from the Faculty of Research Ethics Committee and the University of Research Ethics Committee.

I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Ms. Carmela D'Amato

***[Title - Name - Surname]***

Ms. Carmen D'amato
Director Nursing & Midwifery Services
Mater Dei Hospital
Tel. 25454202

## Appendix C: Permissions to use the Chosen Research Tools

### *Appendix C.1 Permission to use the Brief Illness Perception Questionnaire*

**Sheldon Attard <sheldon.attard.09@um.edu.mt>**

**The Brief Illness perception questionnaire (Brief IPQ)**
5 messages

**Sheldon Attard** <sheldon.attard.09@um.edu.mt> 22 May 2020 at 06:30

To: e.broadbent@auckland.ac.nz

Dear Dr. E. Broadbent,

I am Sheldon Attard from Malta. I am 29 years old and qualified both as a nurse with a Bachelor's Degree in Nursing (2012) and a Nutritionist with a Post-Graduate Diploma in Nutrition and Dietetics (2014).

I am currently pursuing a Masters Degree in Nursing. Now I am in the final year and part of my studies entails a dissertation. Being a nurse in the Heart Failure Clinic, the only Heart Failure Clinic in Malta, I chose a title which is quite related.

The title of my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment.**

Throughout my literature search a came across the questionnaire which you devised to study illness perceptions and have been cited for in a number of research studies. I am thus asking your permission to use your **Brief Illness Perception Questionnaire (Brief IPQ)** so I will be able to use the questions as part of my research tool. I will

appreciate a lot if you grant me this permission to use your tool inorder to study the Heart Failure patients in Malta.

I will definitely acknowledge you in my research studies for your kind permission.

Thanks in advance.

Regards,

Sheldon Attard

Masters Degree in Nursing student (2018-2021)

166, El Dorado, Flat 5,

Lorenzo Manche street,

Attard, Malta

ATD 2901

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**Elizabeth Broadbent** <e.broadbent@auckland.ac.nz> 22 May 2020 at 06:59

To: Sheldon Attard <sheldon.attard.09@um.edu.mt>

You may use it for your dissertation

Kind regards

Liz

Elizabeth Broadbent
Professor of Health Psychology
Department of Psychological Medicine
Faculty of Medical and Health Sciences
The University of Auckland
New Zealand
e.broadben
t@aucklan
d.ac.nz

***Appendix C.2 Permission to use the European Heart Failure Self-Care Behaviour Scale 9-Item***

L-Università ta' Malta

**Sheldon Attard**

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The European Heart Failure Self-care Behaviour nine-item scale (EHFScB-9)

2 messages

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**Sheldon Attard** <sheldon.attard.09@um.edu.mt> 21 May 2020 at 21:13

To: tiny.jaarsma@liu.se

Dear Professor Tiny Jaarsma,

I am Sheldon Attard from Malta. I am 29 years old and qualified both as a nurse with a Bachelor's Degree in Nursing (2012) and a Nutritionist with a Post-Graduate Diploma in Nutrition and Dietetics (2014).

I am currently pursuing a Masters Degree in Nursing. Now I am in the final year and part of my studies entails a dissertation. Being a nurse in the Heart Failure Clinic, the only Heart Failure Clinic in Malta, I chose a title which is quite related.

The title of my dissertation is: Beliefs and behaviours of Heart Failure patients concerning self-management and treatment

Throughout my literature search a came across the scale which you devised to study Heart Failure self-care behaviours and have been cited for in a number of research studies. I am thus asking your permission to use your scale named: **The European Heart Failure Self-care Behaviour nine-item scale (EHFScB-9)** so I will be

able to use the questions as part of my research tool. I will appreciate a lot if you grant me this permission to use your tool inorder to study the Heart Failure patients in Malta.

I will definitely acknowledge you in my research studies for your kind permission.

Thanks in advance.

Regards,

Sheldon Attard

Masters Degree in Nursing student (2018-2021)

166, El Dorado, Flat 5,

Lorenzo Manche street,

Attard, Malta

ATD 2901

---

**Tiny Jaarsma** <tiny.jaarsma@liu.se> 4 June 2020 at 12:53

To: Sheldon Attard <sheldon.attard.09@um.edu.mt>

Dear Sheldon Attard

Thank you for your interest in the EHFScB scale. You are very welcome to use the EHFSB scale. Please find the version and instructions at this website

http://www.isv.liu.se/pp/at/jaarsma-tiny?l=sv

Tiny Jaarsma

*Appendix C.3 Permission to use the Medication Adherence Reporting Scale 5-Item*

L-Università ta' Malta

**Sheldon Attard <sheldon.attard.09@um.edu.mt>**

## Medication Adherence Report Scale -5 (MARS-5)

9 messages

**Sheldon Attard** <sheldon.attard.09@um.edu.mt> 25 May 2020 at 23:08

To: r.horne@ucl.ac.uk

Dear Professor Robert Horne,

I am Sheldon Attard from Malta. I am a 29 years old male, qualified both as a nurse with a Bachelor's Degree in Nursing (2012) and a Nutritionist with a Post-Graduate Diploma in Nutrition and Dietetics (2014).

I am currently pursuing a Masters Degree in Nursing. Now I am in the final year and part of my studies entails a dissertation. Being a nurse in the Heart Failure Clinic, the only Heart Failure Clinic in Malta, I chose a title which is quite related.

The title of my dissertation is: Beliefs and behaviours of Heart Failure patients concerning self-management and treatment

Throughout my literature search a came across the scale which you devised to study medication adherence and have been cited for in a number of research studies. I am thus asking your permission to use your Medication Adherence Report Scale -5 (MARS-5) ) so I will be able to use the questions as part of my research tool. I will appreciate a lot, if you provide me this permission to use your tool in order to study the Heart Failure patients in Malta.

I will definitely acknowledge you in my research studies for your kind permission.

Thanks in advance.

Regards,

Sheldon Attard

Masters Degree in Nursing student (2018-2021)

166, El Dorado, Flat 5,

Lorenzo Manche street,

Attard, Malta

ATD 2901

---

**Horne, Robert** <r.horne@ucl.ac.uk> 26 May 2020 at 08:40

To: Sheldon Attard <sheldon.attard.09@um.edu.mt>

Cc: "Sowemimo, Tami" <t.sowemimo@ucl.ac.uk>, "Clarke, Amy Louise" <amy.clarke@ucl.ac.uk>

Dear Attard

Thank you for your interest in our questionnaire(s). I am copying this to the Questionnaire Management Team who will be in touch to arrange permissions. They work part-time but aim to respond with five working days

Good luck with your research. Please feel free to keep in touch. I would be interested to hear of your findings, when you publish. Best wishes

Rob Horne

**Professor of Behavioural Medicine**

Director, Centre for Behavioural Medicine

**UCL School of Pharmacy, University College London**

http://www.ucl.ac.uk

# Appendix D: Permission to Translate the Tools to Maltese Language

## *Appendix D.1 Permission to Translate the Brief Illness Perception Questionnaire*

**Sheldon Attard** <sheldon.attard.09@um.edu.mt> 10 July 2020 at 16:17

To: Elizabeth Broadbent <e.broadbent@auckland.ac.nz>

Dear Dr. E. Broadbent,

I am sending this email as a gentle reminder for the previous email which was sent to you on 2nd July 2020.

Thanks a lot for your kind cooperation.

Kind regards,

Sheldon Attard

[Quoted text hidden]

---

**Elizabeth Broadbent** <e.broadbent@auckland.ac.nz> 11 July 2020 at 00:30

To: Sheldon Attard <sheldon.attard.09@um.edu.mt>

Yes you can translate it

Regards

Liz

Elizabeth Broadbent

Professor of Health Psychology

Department of Psychological Medicine

Faculty of Medical and Health Sciences

The University of Auckland

New Zealand

e.broadbent@auckland.ac.nz google scholar

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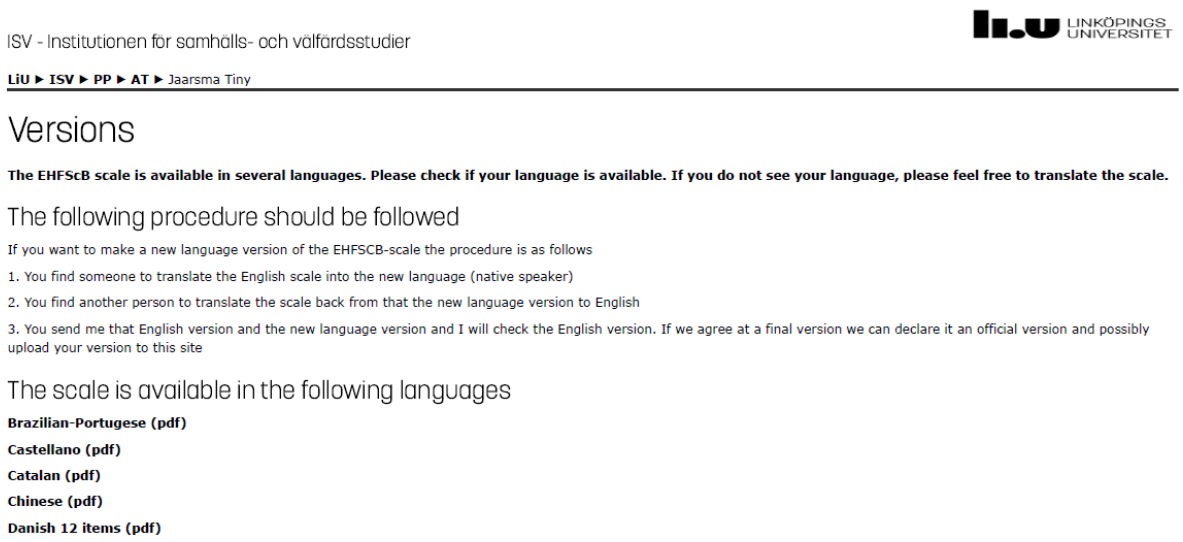
## *Appendix D.2 Permission to Translate the European Heart Failure Behaviour Scale 9-Item*



ISV - Institutionen för samhälls- och välfärdsstudier

LiU ▶ ISV ▶ PP ▶ AT ▶ Jaarsma Tiny

# Versions

**The EHFScB scale is available in several languages. Please check if your language is available. If you do not see your language, please feel free to translate the scale.**

## The following procedure should be followed

If you want to make a new language version of the EHFSCB-scale the procedure is as follows

1. You find someone to translate the English scale into the new language (native speaker)

2. You find another person to translate the scale back from that the new language version to English

3. You send me that English version and the new language version and I will check the English version. If we agree at a final version we can declare it an official version and possibly upload your version to this site

## The scale is available in the following languages

**Brazilian-Portugese (pdf)**

**Castellano (pdf)**

**Catalan (pdf)**

**Chinese (pdf)**

**Danish 12 items (pdf)**

***Appendix D.3 Permission to Translate the Medication Adherence Reporting Scale 5-Item***

**Sheldon Attard** <sheldon.attard.09@um.edu.mt> 2 July 2020 at 18:31

To: "Horne, Robert" <r.horne@ucl.ac.uk>

Cc: "Sowemimo, Tami" <t.sowemimo@ucl.ac.uk>, "Clarke, Amy Louise" <amy.clarke@ucl.ac.uk> Dear Professor Robert Horne,

First of all thanks for granting me the permission to use the Medication Adherence Report Scale - 5. I have been contacted by your team, however till now I did not send them the signed Conditions for use and/or translation of the Medication Adherence Report Scale (MARS) , since I am waiting from the Faculty Research Ethics Committee to approve my study.

Since I am going to conduct the study mentioned in Malta, I have to translate the tool in Maltese language. Thus, I would like to ask you to grant me your permission to translate the MARS-5 in Maltese language?

Thanks a lot for your kind cooperation.

Kind Regards,

Sheldon Attard

On Tue, 26 May 2020 at 08:40, Horne, Robert <r.horne@ucl.ac.uk> wrote:

[Quoted text hidden]

---

**Sowemimo, Tami** <t.sowemimo@ucl.ac.uk> 6 July 2020 at 18:35

To: Sheldon Attard <sheldon.attard.09@um.edu.mt>

Cc: "Clarke, Amy Louise" <amy.clarke@ucl.ac.uk>, "Horne, Robert" <r.horne@ucl.ac.uk>

Dear Sheldon,

Thank you for your email.

Please see the attached conditions for usage and translate on form, which also sets out our requirements for translating the MARS.

In order to grant permission to translate the scale, you would need to sign and return the form, ensuring that you are happy to agree to the conditions set out.

Best wishes,

Tami

Tami Sowemimo

Research Assistant

UCL School of Pharmacy

Department of Prac ce and Policy | Centre for Behavioural Medicine BMA House, Tavistock Square London, WC1H 9JP

Email: t.sowemimo@ucl.ac.uk

Please note that my usual working hours are between 09:30 and 17:30 on a Monday.

[Quoted text hidden]

**MARS CONDITIONS for translation and usage form RH 0604.pdf**
341K

---

**Sheldon Attard** <sheldon.attard.09@um.edu.mt> 11 July 2020 at 13:14

To: "Sowemimo, Tami" <t.sowemimo@ucl.ac.uk>

Cc: "Horne, Robert" <r.horne@ucl.ac.uk>, "Clarke, Amy Louise"

<amy.clarke@ucl.ac.uk>

Dear Tami Sowemimo,

Thanks a lot for your assistance. Attached you can find the signed document of the

Conditions for use and/or translation of the Medication Adherence Report Scale

(MARS).

Thanks again.

Kind regards,

Sheldon Attard

[Quoted text hidden]

**Conditions for use and/or translation of the Medication Adherence Report**
839K

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**Sheldon Attard** <sheldon.attard.09@um.edu.mt> 25 October 2020

## Appendix E: Permission From the Chairperson of Cardiology Department and the Chairperson of the Department of Medicine, and From all the Cardiology Consultants Working at the Hospital

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 14th June 2024

Dr. Robert G. Xuereb

*[Title - Name - Surname]*

Chairman, Department of Cardiology

*[Position]* President, Maltese Cardiac Society

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Robert G. Xuereb,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

widely in a number of research studies. Permissions for the mentioned scales were granted from their respective original author.

It is envisaged that data collection is carried out between the months of October till November 2020. To be eligible for the study, the participants need to be classified as HF, either diastolic or systolic dysfunction or both. Age of patients should be ≥18 years of age. Since I am one of the HF clinic nurses, recruitment of participants and informed consent is going to be done and obtained by the cardiologists and/or other nurses. During data collection I will only be recruiting and obtaining informed consents for those patients who are labelled as new cases at Medical Out-Patient 4 (MOP4), at Cardiac Rehab and Specialised HFC but not at HFC, to eliminate any obligations. Questionnaires will be handed to cardiologists, at MOP4, Specialised HF Clinic and nurse-led clinics (HF clinic and Cardiac Rehab) to be filled by the participant themselves or with the help of the cardiologist or nurse, when help is needed. The first part, which entails the demographic data and the clinical information, will be filled by the cardiologist or the nurse him/herself. I will be helping the participants, when help is needed, in filling the questionnaire after an informed consent is obtained by the cardiologists or nurses. In order to respect anonymity and confidentiality of the participants, filled questionnaires are placed in a sealed box by the participants themselves, before they leave the attended clinic.

This research will be conducted under the supervision of Dr. Roberta Sammut (roberta.sammut@um.edu.mt). Ethical approvals will be pursued from the Faculty of Research Ethics Committee and the University of Research Ethics Committee.

I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard

Master of Nursing student

Signature: _____

Dr. Robert G. Xuereb MD FRCP FASA FESC FACC Chairman Dept. of Cardiology Consultant Cardiologist

D. ROBERT G XUEREB

*[Title - Name - Surname]*

CHAIRMAN DEPARTMENT OF CARDIOLOGY

PRESIDENT MALTESE CARDIAC SOCIETY

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 7th July 2020

Prof. STEPHEN FAVA

[*Title - Name - Surname*]

CHAIRPERSON, Dept. of Medicine

[*Position*]

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Profs. Stephen Fava,

[*Title - Name - Surname*]

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

widely in a number of research studies. Permissions for the mentioned scales were granted from their respective original author.

It is envisaged that data collection is carried out between the months of October till November 2020. To be eligible for the study, the participants need to be classified as HF, either diastolic or systolic dysfunction or both. Age of patients should be ≥18 years of age. Since I am one of the HF clinic nurses, recruitment of participants and informed consent is going to be done and obtained by the cardiologists and/or other nurses. During data collection I will only be recruiting and obtaining informed consents for those patients who are labelled as new cases at Medical Out-Patient 4 (MOP4), at Cardiac Rehab and Specialised HFC but not at HFC, to eliminate any obligations. Questionnaires will be handed to cardiologists, at MOP4, Specialised HF Clinic and nurse-led clinics (HF clinic and Cardiac Rehab) to be filled by the participant themselves or with the help of the cardiologist or nurse, when help is needed. The first part, which entails the demographic data and the clinical information, will be filled by the cardiologist or the nurse him/herself. I will be helping the participants, when help is needed, in filling the questionnaire after an informed consent is obtained by the cardiologists or nurses. In order to respect anonymity and confidentiality of the participants, filled questionnaires are placed in a sealed box by the participants themselves, before they leave the attended clinic.

This research will be conducted under the supervision of Dr. Roberta Sammut (roberta.sammut@um.edu.mt). Ethical approvals will be pursued from the Faculty of Research Ethics Committee and the University of Research Ethics Committee.

I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Prof. Stephen FAVA
*[Title - Name - Surname]*

Prof. Stephen Fava
MD MRCP (U.K) MPhil., FACP
FEFIM, FRCP (Lond.) FRCP (Edin.)
Consultant Physician, Diabetologist & Endocrinologist
Mater Dei Hospital

Page 2 of 2

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 24th June 2020

Dr Andrew Cassar

*[Title - Name - Surname]*

Consultant

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr Andrew Cassar,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

widely in a number of research studies. Permissions for the mentioned scales were granted from their respective original author.

It is envisaged that data collection is carried out between the months of October till November 2020. To be eligible for the study, the participants need to be classified as HF, either diastolic or systolic dysfunction or both. Age of patients should be ≥18 years of age. Since I am one of the HF clinic nurses, recruitment of participants and informed consent is going to be done and obtained by the cardiologists and/or other nurses. During data collection I will only be recruiting and obtaining informed consents for those patients who are labelled as new cases at Medical Out-Patient 4 (MOP4), at Cardiac Rehab and Specialised HFC but not at HFC, to eliminate any obligations. Questionnaires will be handed to cardiologists, at MOP4, Specialised HF Clinic and nurse-led clinics (HF clinic and Cardiac Rehab) to be filled by the participant themselves or with the help of the cardiologist or nurse, when help is needed. The first part, which entails the demographic data and the clinical information, will be filled by the cardiologist or the nurse him/herself. I will be helping the participants, when help is needed, in filling the questionnaire after an informed consent is obtained by the cardiologists or nurses. In order to respect anonymity and confidentiality of the participants, filled questionnaires are placed in a sealed box by the participants themselves, before they leave the attended clinic.

This research will be conducted under the supervision of Dr. Roberta Sammut (roberta.sammut@um.edu.mt). Ethical approvals will be pursued from the Faculty of Research Ethics Committee and the University of Research Ethics Committee.

I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard

Master of Nursing student

Signature: _____

_____

*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 24th June 2020

Dr. Tiziana Felice

*[Title - Name - Surname]*

Consultant

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Tiziana Felice,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

widely in a number of research studies. Permissions for the mentioned scales were granted from their respective original author.

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This research will be conducted under the supervision of Dr. Roberta Sammut (roberta.sammut@um.edu.mt). Ethical approvals will be pursued from the Faculty of Research Ethics Committee and the University of Research Ethics Committee.

I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

DR TIZIANA FELICE

*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 24/6/2020

Dr. Andrew Cassar Maempel

*[Title - Name - Surname]*

Consultant

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Andrew Cassar Maempel,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Dr. Andrew Cassar Maempel

*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 25th June 2020

DR MARYANNE CARUANA

*[Title - Name - Surname]*

CONSULTANT CARDIOLOGIST

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Maryanne Caruana

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

DR MARYANNE CARUANA

*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 25th June 2020

Dr. CAROLINE J. MAGRI

[*Title - Name - Surname*]

Consultant Cardiologist

[*Position*]

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Caroline J. Magri,

[*Title - Name - Surname*]

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment.** The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 25/6/2020

DR. OSCAR AGUILERA

[*Title - Name - Surname*]

CONSULTANT CARDIOLOGIST

[*Position*]

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Oscar Aguilera,

[*Title - Name - Surname*]

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment.** The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

DR OSCAR AQUILINA
*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 25/06/2020

Dr MARK SAMMUT

*[Title - Name - Surname]*

Consultant Cardiologist

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Mark Sammut,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard

Master of Nursing student

Signature: _____

Dr. Mary Sammut

*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 25th June 2020

DR. ALEXANDER BORG

**[*Title - Name - Surname*]**

CONSULTANT CARDIOLOGIST

**[*Position*]**

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Alexander Borg,

**[*Title - Name - Surname*]**

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard

Master of Nursing student

Signature: _____

Dr Alex Borg

*[Title - Name - Surname]*

## Appendix F: Permission From the Resident Specialist in Heart Failure who Runs the Specialised Heart Failure Clinic and Guides the Nurse-led Heart Failure Clinic

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 26/06/2020

Dr Alice Mary Peters Moore

*[Title - Name - Surname]*

Cardiologist, Heart Failure Specialist

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Alice Mary Peters Moore,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard

Master of Nursing student

Signature: _____

Dr Erica Mary Reuss Mook

***[Title - Name - Surname]***

**Appendix G: Permission From the Departmental Nursing Manager and Nursing Officers of the Cardiac Laboratory Out-Patients Department, the Cardiac Rehabilitation Unit, and the Medical Outpatient 4 (Cardiology Outpatient Department).**

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 25th June 2020

Mr. Mario Farrugia
Senior Nursing Manager
Mater Dei Hospital

*[Title - Name - Surname]*

S.N.M.

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Mr. Mario Farrugia,
*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Mr. Mario Farrugia
Senior Nursing Manager
Mater Dei Hospital

[Title, Name, Surname]

Mr. Mario Farrugia
Senior Nursing Manager
Mater Dei Hospital

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 24/6/2020

Ms Michelle Cassar

*[Title - Name - Surname]*

Charge Nurse

*[Position]* Cardiac Lab Out-Patients Department

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Ms Michelle Cassar,

*[Title - Name - Surname]*

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This research will be conducted under the supervision of Dr. Roberta Sammut (roberta.sammut@um.edu.mt). Ethical approvals will be pursued from the Faculty of Research Ethics Committee and the University of Research Ethics Committee.

I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard

Master of Nursing student

Signature: _____

Ms. Michelle Cassar

*[Title - Name - Surname]*

MICHELLE CASSAR
CHARGE NURSE

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 24th June 2020

Ms Janet Cassana

*[Title - Name - Surname]*

Deputy Charge Nurse / Heart failure Clinic Nurse

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Ms Janet Cassana,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard

Master of Nursing student

Signature: _____

Ms. Janet Cavana

*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 25th June 2020

Ms. DOREEN SCERRI

*[Title - Name - Surname]*

Senior Staff Nurse (charge nurse) (MOPS)

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Ms. Doreen Scerri,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Mrs Doreen Scerri
***[Title - Name - Surname]***

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 26th June 2020

Ms Josette Desira
**[*Title - Name - Surname*]**

Charge Nurse - Cardiac Rehab
**[*Position*]**

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Ms Josette Desira,
**[*Title - Name - Surname*]**

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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I would appreciate if you sign below to grant me the permission needed to carry out such research.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Ms. Josette Pesira
***[Title - Name - Surname]***

## Appendix H: Counsellor Agreement

Counsellor Agreement

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

**Title of the dissertation:** Beliefs and behaviours of Heart Failure patients concerning self-management and treatment

**Dissertation Supervisor:** Dr. Roberta Sammut

**Researcher:** Mr. Sheldon Attard

I Mariella Meachen *[Title - Name - Surname]* declare that the above research project was described to me in detail by Mr. Sheldon Attard. I understand that participants from the study who feel that the questionnaire handed in this study has raised matters in which they feel the need for further help, are referred to me for counselling. This would be without any financial cost for both the researcher and the participant.

Psychotherapist's signature: _____ Date: 2/09/2020

Psychotherapist's name and surname [Block letters]: MARIELLA MEACHEN

Psychotherapist's contact details: Email address: Mariella.meachen@gov.mt

Telephone number: 79521344

Thank you for your kind co-operation in signing this agreement.

Yours sincerely,

Signature: _____ Date: 2nd July 2020

Mr. Sheldon Attard
Master of Nursing student

Page 1 of 1

# Appendix I: Approvals From the Intermediary Persons

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 24/6/2020

Ms. Michelle Cassar

*[Title - Name - Surname]*

CCare Nurse

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Ms. Michelle Cassar,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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I would appreciate if you will be my intermediary person who will obtain the written informed consent and collect the filled questionnaires while keep them under lock and key in a secure place.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Ms. Michelle Cassar

*[Title - Name - Surname]*

MICHELLE CASSAR
CHARGE NURSE

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 24th June 2020

Ms. Janet Caruana

*[Title - Name - Surname]*

Deputy Charge Nurse / Heart failure Clinic Nurse.

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Ms Janet Caruana,

*[Title - Name - Surname]*

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Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Ms. Janet Carvana
*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 25/06/2020.

Dr LISA LAUREN BUTTIGIEG.

*[Title - Name - Surname]*

HST CARDIOLOGY

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Lisa Lauren Buttigieg,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Dr Lija Mifsud

*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 25th June 2020

Dr DANIELA CASSAR DEMARCO

*[Title - Name - Surname]*

CARDIOLOGIST

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr Daniela Cassar Demarco,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Dr Daniela Cassar Demarco
*[Title - Name - Surname]*

Dr Daniela Cassar Demarco
Reg. No. 2872
Mater Dei Hospital

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 26/06/2020

Dr Alice May Paris Moore

*[Title - Name - Surname]*

Cardiologist, Heart Failure Specialist

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr Alice May Paris Moore.

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

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Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Dr Alice May Paris Moore
*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 26th June 2020

Ms Josette Vazzo
*[Title - Name - Surname]*

Charge Nurse - Cardiac Rehab
*[Position]*

Mater Dei Hospital
Msida

**Re: Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Ms. Josette Vazzo,
*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

widely in a number of research studies. Permissions for the mentioned scales were granted from their respective original author.

It is envisaged that data collection is carried out between the months of October till November 2020. To be eligible for the study, the participants need to be classified as HF, either diastolic or systolic dysfunction or both. Age of patients should be ≥18 years of age. Since I am one of the HF clinic nurses, recruitment of participants and informed consent is going to be done and obtained by the cardiologists and/or other nurses. During data collection I will only be recruiting and obtaining informed consents for those patients who are labelled as new cases at Medical Out-Patient 4 (MOP4), at Cardiac Rehab and Specialised HFC but not at HFC, to eliminate any obligations. Questionnaires will be handed to cardiologists, at MOP4, Specialised HF Clinic and nurse-led clinics (HF clinic and Cardiac Rehab) to be filled by the participant themselves or with the help of the cardiologist or nurse, when help is needed. The first part, which entails the demographic data and the clinical information, will be filled by the cardiologist or the nurse him/herself. I will be helping the participants, when help is needed, in filling the questionnaire after an informed consent is obtained by the cardiologists or nurses. In order to respect anonymity and confidentiality of the participants, filled questionnaires are placed in a sealed box by the participants themselves, before they leave the attended clinic.

This research will be conducted under the supervision of Dr. Roberta Sammut (roberta.sammut@um.edu.mt). Ethical approvals will be pursued from the Faculty of Research Ethics Committee and the University of Research Ethics Committee.

I would appreciate if you will be my intermediary person who will obtain the written informed consent and collect the filled questionnaires while keep them under lock and key in a secure place.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Ms. Josette Pedro
***[Title - Name - Surname]***

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 26/6/2020

Consultant Caroline

*[Title - Name - Surname]*

Senior Nurse

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Ms. Caroline Camilleri,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

widely in a number of research studies. Permissions for the mentioned scales were granted from their respective original author.

It is envisaged that data collection is carried out between the months of October till November 2020. To be eligible for the study, the participants need to be classified as HF, either diastolic or systolic dysfunction or both. Age of patients should be ≥18 years of age. Since I am one of the HF clinic nurses, recruitment of participants and informed consent is going to be done and obtained by the cardiologists and/or other nurses. During data collection I will only be recruiting and obtaining informed consents for those patients who are labelled as new cases at Medical Out-Patient 4 (MOP4), at Cardiac Rehab and Specialised HFC but not at HFC, to eliminate any obligations. Questionnaires will be handed to cardiologists, at MOP4, Specialised HF Clinic and nurse-led clinics (HF clinic and Cardiac Rehab) to be filled by the participant themselves or with the help of the cardiologist or nurse, when help is needed. The first part, which entails the demographic data and the clinical information, will be filled by the cardiologist or the nurse him/herself. I will be helping the participants, when help is needed, in filling the questionnaire after an informed consent is obtained by the cardiologists or nurses. In order to respect anonymity and confidentiality of the participants, filled questionnaires are placed in a sealed box by the participants themselves, before they leave the attended clinic.

This research will be conducted under the supervision of Dr. Roberta Sammut (roberta.sammut@um.edu.mt). Ethical approvals will be pursued from the Faculty of Research Ethics Committee and the University of Research Ethics Committee.

I would appreciate if you will be my intermediary person who will obtain the written informed consent and collect the filled questionnaires while keep them under lock and key in a secure place.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Caroline Camilleri
*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 1st July 2020

Dr. Tiziana Felice.

*[Title - Name - Surname]*

Consultant cardiologist

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Tiziana Felice,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

widely in a number of research studies. Permissions for the mentioned scales were granted from their respective original author.

It is envisaged that data collection is carried out between the months of October till November 2020. To be eligible for the study, the participants need to be classified as HF, either diastolic or systolic dysfunction or both. Age of patients should be ≥18 years of age. Since I am one of the HF clinic nurses, recruitment of participants and informed consent is going to be done and obtained by the cardiologists and/or other nurses. During data collection I will only be recruiting and obtaining informed consents for those patients who are labelled as new cases at Medical Out-Patient 4 (MOP4), at Cardiac Rehab and Specialised HFC but not at HFC, to eliminate any obligations. Questionnaires will be handed to cardiologists, at MOP4, Specialised HF Clinic and nurse-led clinics (HF clinic and Cardiac Rehab) to be filled by the participant themselves or with the help of the cardiologist or nurse, when help is needed. The first part, which entails the demographic data and the clinical information, will be filled by the cardiologist or the nurse him/herself. I will be helping the participants, when help is needed, in filling the questionnaire after an informed consent is obtained by the cardiologists or nurses. In order to respect anonymity and confidentiality of the participants, filled questionnaires are placed in a sealed box by the participants themselves, before they leave the attended clinic.

This research will be conducted under the supervision of Dr. Roberta Sammut (roberta.sammut@um.edu.mt). Ethical approvals will be pursued from the Faculty of Research Ethics Committee and the University of Research Ethics Committee.

I would appreciate if you will be my intermediary person who will obtain the written informed consent and collect the filled questionnaires while keep them under lock and key in a secure place.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Dr. Tiziana Feliċe

*[Title - Name - Surname]*

Mr. Sheldon Attard
166, El Dorado Apartments, Flat 5,
Lorenzo Manché Street,
Attard, ATD 2901, Malta
Mobile number: +356 79334956
sheldon.attard.09@um.edu.mt

Date: 01/07/2020.

Dr Mark Sammut

*[Title - Name - Surname]*

Consultant Cardiologist

*[Position]*

Mater Dei Hospital
Msida

Re: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**

Dear Dr. Mark Sammut,

*[Title - Name - Surname]*

I am currently pursuing a Master Degree in Nursing at the University of Malta and as part of my studies, I have to conduct a dissertation. My proposed title for my dissertation is: **Beliefs and behaviours of Heart Failure patients concerning self-management and treatment**. The aim of this dissertation is to explore and examine the beliefs and behaviours of Heart Failure (HF) patients concerning self-management (SM) and its treatment. The research objectives which are going to be answered include: What are the beliefs of HF patients concerning their illness? What are the behaviours of HF patients concerning their SM? What are the behaviours of HF patients regarding adherence of treatment? Which are the variables associated with the beliefs and behaviours concerning SM and adherence to treatment? Is there a relationship between the beliefs and behaviours of HF patients? Is there an association between the beliefs and behaviours of HF patients and the number of HF related admissions? For this purpose I have chosen to use the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item. These scales have been validated and used

widely in a number of research studies. Permissions for the mentioned scales were granted from their respective original author.

It is envisaged that data collection is carried out between the months of October till November 2020. To be eligible for the study, the participants need to be classified as HF, either diastolic or systolic dysfunction or both. Age of patients should be ≥18 years of age. Since I am one of the HF clinic nurses, recruitment of participants and informed consent is going to be done and obtained by the cardiologists and/or other nurses. During data collection I will only be recruiting and obtaining informed consents for those patients who are labelled as new cases at Medical Out-Patient 4 (MOP4), at Cardiac Rehab and Specialised HFC but not at HFC, to eliminate any obligations. Questionnaires will be handed to cardiologists, at MOP4, Specialised HF Clinic and nurse-led clinics (HF clinic and Cardiac Rehab) to be filled by the participant themselves or with the help of the cardiologist or nurse, when help is needed. The first part, which entails the demographic data and the clinical information, will be filled by the cardiologist or the nurse him/herself. I will be helping the participants, when help is needed, in filling the questionnaire after an informed consent is obtained by the cardiologists or nurses. In order to respect anonymity and confidentiality of the participants, filled questionnaires are placed in a sealed box by the participants themselves, before they leave the attended clinic.

This research will be conducted under the supervision of Dr. Roberta Sammut (roberta.sammut@um.edu.mt). Ethical approvals will be pursued from the Faculty of Research Ethics Committee and the University of Research Ethics Committee.

I would appreciate if you will be my intermediary person who will obtain the written informed consent and collect the filled questionnaires while keep them under lock and key in a secure place.

Thank you for your kind co-operation.

Yours sincerely,

Signature: _____

Mr. Sheldon Attard
Master of Nursing student

Signature: _____

Dr. Mark Sammut.
*[Title - Name - Surname]*

# Appendix J: Approvals From the Faculty of Health Sciences Research Ethics Committee and University of Malta Research Ethics Committee

L-Università ta' Malta

**Sheldon Attard <sheldon.attard.09@um.edu.mt>**

## UREC FORM V_15062020 6002 Sheldon Attard

**Ritienne Grima** <ritienne.grima@um.edu.mt> 24 October 2020 at 18:35

To: Sheldon Attard <sheldon.attard.09@um.edu.mt>
Cc: Roberta Sammut <roberta.sammut@um.edu.mt>, Research Ethics HEALTHSCI <researchethics.healthsci@um.edu.mt>

Dear Sheldon

Thank you for sending the amended information letters. I confirm that you have made the changes requested by UREC-DP and you have approval on behalf of FREC. You can commence data collection.

Best wishes for your study.

Ritienne Grima

*Ritienne Grima, Ph.D*
*Senior lecturer*
*Head, Department of Communication Therapy*
*Faculty of Health Sciences*
*University of Malta*
*Tel.: (+356) 2340 1142*

On Thu, 22 Oct 2020 at 18:57, Sheldon Attard <sheldon.attard.09@um.edu.mt> wrote:

[Quoted text hidden]

L-Università ta' Malta

**Sheldon Attard <sheldon.attard.09@um.edu.mt>**

## Change in dissertation title

6 messages

**Sheldon Attard** <sheldon.attard.09@um.edu.mt> 4 November 2020 at 13:52

To: Ritienne Grima <ritienne.grima@um.edu.mt>

Cc: Roberta Sammut <roberta.sammut@um.edu.mt>

Dear Dr. Ritienne Grima,

I am Sheldon Attard, a student from the Master in Nursing. I am sending you this email to notify you about a change in the dissertation title.

After a discussion with my supervisor, Dr. R. Sammut, it was agreed to change the dissertation title to:

**Illness perceptions of Heart Failure patients as a predictor of self-care behaviours and medication adherence.**

This change is not going to affect the methodology of this dissertation and it is reflecting the tools which are planned to be used for data collection.

Additionally, due to this current situation, I think it is not ethically and safe to get chronically ill patients (Heart Failure patients) for the second time to fill the questionnaire for the re-test. Thus, together with my supervisor, we have agreed to use a phone interview, only for the retest of the questionnaire. They will be asked directly if they would like to give their phone number so that they can be phoned 3 weeks after.

Thanks a lot for your assistance.

Kind regards,

Sheldon Attard

ID: 0256690M

---

**Sheldon Attard** <sheldon.attard.09@um.edu.mt> 9 November 2020 at 16:23

To: Ritienne Grima <ritienne.grima@um.edu.mt>

Cc: Roberta Sammut <roberta.sammut@um.edu.mt>

Dear Dr. R. Grima,

I am sending you this email as a polite reminder regarding the email which I sent you last week.

Thanks in advance.

Kind regards,

Sheldon Attard

[Quoted text hidden]

---

**Ritienne Grima** <ritienne.grima@um.edu.mt> 12 November 2020 at 17:54

To: Sheldon Attard <sheldon.attard.09@um.edu.mt>, Research Ethics HEALTHSCI <researchethics.healthsci@um.edu.mt>

Cc: Roberta Sammut <roberta.sammut@um.edu.mt>, Christabel Vella <christabel.vella@um.edu.mt>, Rita Pace Parascandalo <rita.pace-parascandalo@um.edu.mt>

Dear Sheldon
Apologies for the late reply.

In view of the current COVID-19 circumstances I confirm that you have approval, on behalf of FREC, to amend the title of your dissertation and also to conduct the re-test of the questionnaire via telephone interview.
Kindly send an updated UREC/REDP form to reflect the changes that you have described to research-ethics.healthsci@ um.edu.mt in order to ensure that FREC has updated records of your application.

The new title will also require approval from Faculty Board. Dr Sammut may be able to confirm this. Best wishes for your research
Ritienne Grima

*Ritienne Grima, Ph.D*
*Senior lecturer*
*Head, Department of Communication Therapy*
*Faculty of Health Sciences*
*University of Malta*
*Tel.: (+356) 2340 1142*

On Wed, 4 Nov 2020 at 13:52, Sheldon Attard <sheldon.attard.09@um.edu.mt> wrote:

[Quoted text hidden]

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**Sheldon Attard** <sheldon.attard.09@um.edu.mt> 12 November 2020 at 18:05

To: Ritienne Grima <ritienne.grima@um.edu.mt>

Cc: Research Ethics HEALTHSCI <research-ethics.healthsci@um.edu.mt>, Roberta Sammut

<roberta.sammut@um.edu.mt>, Christabel Vella <christabel.vella@um.edu.mt>, Rita Pace Parascandalo <rita.paceparascandalo@um.edu.mt>

Dear Dr. R. Grima,

Thanks a lot for your email. Much appreciated.

Kind regards,

Sheldon Attard

[Quoted text hidden]

---

**Sheldon Attard** <sheldon.attard.09@um.edu.mt> 13 November 2020 at 19:16

To: Research Ethics HEALTHSCI <research-ethics.healthsci@um.edu.mt>

Cc: Roberta Sammut <roberta.sammut@um.edu.mt>, Christabel Vella

<christabel.vella@um.edu.mt>, Rita Pace

Parascandalo <rita.pace-parascandalo@um.edu.mt>, Ritienne Grima <ritienne.grima@um.edu.mt>

To whom it may concern,

As discussed earlier last week with Dr. Ritienne Grima via an email, I have requested to amend the title of my dissertation (which is not going to affect the methodology of the study). Also in view of the current circumstances of COVID-19, I have asked for the permission to do the retest of the questionnaire via a telephone interview. These were approved by Dr. Ritienne Grima, on behalf of FREC on the 12th Nov 2020.

As requested, the UREC/REDP was updated and is attached to this email.

Thanks a lot for your kind assistance. Kind regards,

Sheldon Attard

On Thu, 12 Nov 2020 at 17:54, Ritienne Grima <ritienne.grima@um.edu.mt> wrote:
[Quoted text hidden ]

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**Updated UREC_REDP - 6002_13072020_Sheldon Attard.pdf**
110K

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**Research Ethics HEALTHSCI** <research-ethics.healthsci@um.edu.mt> 1 December 2020 at 13:21

To: Sheldon Attard <sheldon.attard.09@um.edu.mt>

Dear Sheldon,

Your email was received with thanks and your REDP Form + title have been updated accordingly.

**Christabel Vella**
FREC Secretary

University of Malta
**Faculty of Health Sciences**
Room 76, Block A, Level 1
Mater Dei Hospital

https://www.um.edu.mt/healthsciences/students/researchethics

[Quoted text hidden]

# Appendix K: Research Ethics and Data Protection Form

UNIQUE FORM ID: 6002_13072020_Sheldon Attard
Ticked one or more self-assessment issues. Submitting to FREC for review.

L-Università ta' Malta

## ETHICS & DATA PROTECTION

### PART 1: APPLICANT AND PROJECT DETAILS

1. Name and surname: Sheldon Attard
Email Address: sheldon.attard.09@um.edu.mt
2. Applicant status: UM student
3. Faculty: Health Sciences
4. Department: Nursing
If applicable
5. Principal supervisor's name: Dr. Roberta Sammut
6. Co-supervisor's name:
7. Name of Degree and Study-unit code: Master of Science in Nursing - NUR5020-YR-A-2021
8. Student number: 0256690M

9. Title of research project: Illness perceptions of Heart Failure patients as a predictor of self-care behaviours and medication adherence.
10. Research question/statement & method: Research question: What are the perceptions and behaviours of Heart Failure patients concerning self-care and medication adherence?

Method: The research design will entail a cross-sectional approach since it is going to measure the prevalence of health perceptions and behaviours, of a specific population [Heart Failure (HF) patients], at a point in time (October to December 2020). A positivist (positivism/quantitative) epistemological perspective is going to be utilised with a deductive approach. As a design, it is going to be a descriptive study since it is going to establish the associations between variables. Original primary data is going to be collected with the use of a questionnaire. The questionnaire will consists of 4 main parts.
Part A: Socio-demographic and clinical information
Part B: The Brief Illness Perception Questionnaire – 9-item
Part C: The European HF Self-Care Behaviour Scale – 9-item
Part D: The Medication Adherence Report Scale – 5-item + two questions reflecting on polypharmacy

11. Collection of primary data from human participants?
Yes/Unsure (PLEASE ANSWER NEXT QUESTION)
12. If applicable, explain: To be eligible for the study, the participants need to be classified as Heart Failure, either diastolic or systolic dysfunction or both. Age of participants should be ≥18 years of age. Both male and female gender participants can be included in the study. A convenience sampling strategy will be used. A sample size of a minimum 269 participants should be satisfactory to have a maximum margin of error +/-5% and 95% confidence level. The maximum sample size is that of 300 participants. Questionnaires will be handed to cardiologists or nurses, at Medical Out-Patient 4 (MOP4), Specialised Heart Failure clinic and nurse-led clinics (Heart Failure Clinic and Cardiac Rehab) to be filled by the

participant themselves or with the help of the cardiologist or nurse, when help is needed. The first part (A) entails the socio-demographic data and the clinical information. This will be filled by the cardiologist or the nurse him/herself and in order to enhance consistency, the questions are asked in the same format as they are on the questionnaire. In view of the current COVID-19 circumstances the retest of the questionnaire will be carried out via a telephone interview so that participants will not have to come physically to hospital for the second time in 2 to 3 weeks after the test. They will be asked directly if they would like to give their phone number so that they can be phoned 2 to 3 weeks after the test. No inducements or rewards or compensations will be offered neither to the participants nor the intermediary persons. By revealing both the perceptions and the behaviours of Heart Failure patients regarding their self-care and medication adherence, the health-care professionals may enhance the therapeutic process by formulating an intervention to empower self-care. As a result, clinical outcomes can be improved such as reduced hospitalisations rates and increase compliance rates. Additionally, exploring both the perceptions and behaviours of Heart Failure patients can lead the health-care professionals to gain as much information about the patients' perceptions to assist them to improve their behavioural outcomes.

**PART 2: SELF-ASSESSMENT**

**Human Participants**

1. Risk of harm to participants: Yes or Unsure
2. Physical intervention:
3. Vulnerable participants: Yes or Unsure
4. Identifiable participants:
5. Special Categories of Personal Data (SCPD): Yes or Unsure
6. Human tissue/samples:
7. Withheld info assent/consent:
8. Opt-out consent/assent:
9. Deception in data generation:
10. Incidental findings:

**Unpublished secondary data**

11. Was the data collected from human participants?
12. Was the data collected from animals?
13. Is written permission from the data controller still to be obtained?

**Animals**

14. Live animals out of habitat:
15. Live animals, risk of harm:
16. Dead animals, illegal:

**General considerations**

17. Cooperating institution: Yes or Unsure

**UNIQUE FORM ID:** 6002_13072020_Sheldon Attard
Ticked one or more self-assessment issues. Submitting to FREC for review.

18. Risk to researcher/s:
19. Risk to environment:
20. Commercial sensitivity
21. Other potential risks: Yes or Unsure

**Self-assessment outcome: Ticked one or more self-assessment issues. Submitting to FREC for review.**

**PART 3: DETAILED ASSESSMENT**

1. Risk of harm to participants: Participants may have a minimal risk of psychological harm when they are answering the questionnaire, especially the Brief Illness Perception questionnaire. Such risk is unavoidable since the participant is answering the questionnaire which is the main and only tool of data collection in the study. As a safeguard, a psychotherapist, Ms. Mariella Meachen has been contacted and accepted that if any issues regarding psychological distress is encountered the participant can be referred to her.
2. Physical intervention on participants:
3. Vulnerable participants: All the participants in the study are going to be Heart Failure patients and who can also have other comorbidities. Participants are not going to be pressured to take part in the study. If participants encounter psychological issues when answering the questionnaire they can be referred to Ms. Mariela Meachen, a psychotherapist at no cost for both the participants and the researcher.
4. Identifiable participants: All data is going to be collected and stored anonymised. The data files will be stored on the researcher's personal computer that is password protected and in an encrypted format. Any material in hard-copy form will be placed in a locked cupboard. Data will then be erased completely after completion of the study.
5. Special Categories of Personal Data (sensitive personal data): Special Categories of Personal Data (sensitive personal data) which are going to be collected include: the health status regarding Heart Failure symptoms; asking the participants to list other comorbidities if any; and the sex/gender of the participant.
6. Collection of human tissue/samples:
7. Withholding information at consent/assent:
8. Opt-out consent/assent:
9. Deception in data generation:
10. Incidental findings:
11. Unpublished secondary data - human participants :
12. Unpublished secondary data - animals:
13. Unpublished secondary data - no written permission from data controller:
14. Lasting harm to animals out of natural habitat:
15. Risk of harm to live animals :
16. Use of non legal animals/tissue:
17. Permission from cooperating institution: The cooperating institution, which is Mater Dei Hospital, will be contacted by an email to the Data Protection Officer (DPO) and another email to the Chief executive officer.
18. Risk to researcher/team:
19. Risk of harm to environment:
20. Commercial sensitivity:

**UNIQUE FORM ID**: 6002_13072020_Sheldon Attard

Ticked one or more self-assessment issues. Submitting to FREC for review.

21. Other issues

21a. Dual use and/or misuse:

21b. Conflict of Interest:

21c. Dual role:

21d. Use research tools: Permission to use the three tools, including: the Brief Illness Perception Questionnaire – 9-item, the European HF Self-Care Behaviour Scale – 9-item and the Medication Adherence Report Scale – 5-item, has been granted from their respective authors by communicating to them by email.

21e. Collaboration/data/material collection in low/lower-middle income country:

21f. Import/export of records/data/materials/specimens: Since participation to this study is going to be asked after the cardiology appointment, aetiology of Heart Failure and ejection fraction are going to be determined/verified during the same appointment. Thus, there is no need for any viewing of medical records to fill the questionnaire or any access to Health information Systems. If the participant wishes these are going to be answered in the same questionnaire (Part A: Clinical Information). This will embrace the information letter as there is written "You are not obliged to participate in this study or to answer all the questions...".

21g. Harvest of data from social media:

21h. Other considerations:

**PART 4: SUBMISSION**

1. Which FREC are you submitting to? : Health Sciences

2. Attachments: Information and recruitment letter*, Consent forms (adult participants)*, Data collection tools (interview questions, questionnaire etc.), Licence/permission to use research tools (e.g. constructs/tests), Letter granting institutional approval for access to participants, Letter granting institutional approval from person directly responsible for participants, Other (please specify in remarks below)

3. Cover note for FREC : Additional attachments include: the psychotherapist agreement letter; intermediary persons approvals; permission from both the Director of Nursing and Midwifery and the Senior Nursing Manager; approval from the cardiologist, Heart Failure specialist; and the heads of out-patients units approvals.

4. Declarations: I hereby confirm having read the University of Malta Research Code of Practice and the University of Malta Research Ethics Review Procedures., I hereby confirm that the answers to the questions above reflect the contents of the research proposal and that the information provided above is truthful., I hereby give consent to the University Research Ethics Committee to process my personal data for the purpose of evaluating my request, audit and other matters related to this application. I understand that I have a right of access to my personal data and to obtain the rectification, erasure or restriction of processing in accordance with data protection law and in particular the General Data Protection Regulation (EU 2016/679, repealing Directive 95/46/EC) and national legislation that implements and further specifies the relevant provisions of said Regulation.

5. Applicant Signature: Sheldon Attard

6. Date of submission: 13072020

7. If applicable data collection start date: 01102020

8. E-mail address (Applicant): sheldon.attard.09@um.edu.mt

9. E-mail address (Principal supervisor): roberta.sammut@um.edu.mt

10. Conclude: Proceed to Submission

# Appendix L: Copy of the Information Letter

## *Appendix L.1: Copy of the Information Letter in English Language*


Participants` Information Sheet

Dear Participant,

My name is Sheldon Attard and I am currently reading for a Master of Science in Nursing at the University of Malta. As part of my course requirements I am conducting a research study entitled, "*Illness perceptions of Heart Failure patients as a predictor of self-care behaviours and medication adherence*". The aim of this study is to investigate the perceptions and behaviours of Heart Failure patients concerning self-care and medication adherence**.** Your participation in this study would help us gain a better understanding about one's perceptions and behaviours. This will help us to enhance the therapeutic process while helping in improving one's behavioural outcomes. Furthermore, all data collected from this research shall be used solely for the purpose of this study.

You are being invited to participate in a study which will investigate your perceptions and behaviours about your Heart Failure. You are going to be asked a set of questions and you are also going to fill a questionnaire. If you agree to participate, you will meet the researcher Sheldon Attard or the intermediary person once, after your cardiology appointment, either at Medical Out-Patients 4 (MOP4), Cardiac Rehab, Heart Failure Clinic at Cardiac Lab or Specialised Heart Failure Clinic. This will take approximately 30 minutes.

During the visit I, as the researcher, or one of the intermediary persons will provide you a questionnaire:

1. **First you will be asked some general questions about you, such as your age, education, occupation history, and clinical information on Heart Failure.**

2. **Then you will be handed a questionnaire consisting of 3 parts, which you will fill either independently or with the help of the intermediary person or my help as the researcher:**

   **- <u>Part B</u> consists of questions about your perceptions concerning your Heart Failure,**

   **- <u>Part C</u> consists of questions about your behaviour regarding self-care of**

**Heart Failure,**

- **And <u>Part D</u> consists of a set of questions regarding your adherence to your medicines.**

You are not obliged to participate in this study or to answer all the questions. The data will be collected anonymously, and you may withdraw from the study without giving a reason, until your data is identifiable, e.g while you are filling the questionnaire. This means that, since the questionnaire is going to be collected anonymously, withdrawal from the study after the questionnaire is submitted is impossible, because it cannot be traced. Furthermore, withdrawal from the study will not have any negative repercussions on you and any data collected will be erased. Data will be stored anonymously if it is impossible to delete (e.g. if it has already been anonymised). No codes will be recorded on the questionnaire that will link it to your personal data (including your consent form). I can assure you that confidentiality will be maintained throughout the study and that your identity and personal information will not be revealed in any publications, reports or presentations arising from this research.

There may be exceptional circumstances which allow the supervisor and examiners to have access to the anonymised data, for verification purposes. The data files will be stored on the researcher`s personal computer that is password protected and in an encrypted format. Any material in hard-copy form, including your anonymised filled questionnaire and your signed consent form, will be placed in a secured locked cabinet and can be accessed only by the researcher. Data will be destroyed while the questionnaires and the signed consent forms will be shredded upon completion of the study.

In the event that you feel distressed due to participation in this study the service of a healthcare professional, Ms. Mariella Meachen, a psychotherapist, will be available at no financial cost on your part.

Participation in this study is completely voluntary and you are free to accept or refuse to take part without giving a reason. A copy of the information sheet and consent form will be provided for future reference. Once the study is completed and the results are published, the data will be retained in anonymous form. Any personal details will be destroyed.

This study has been approved by the Research Ethics Committee of the Faculty of Health Sciences at the University of Malta.

Thank you for your time and consideration. Should you have any questions or concerns do not hesitate to contact me on +356 79334956 or by e-mail sheldon.attard.09@um.edu.mt or my supervisor Dr. Roberta Sammut on +356 2340 1851/1831 or roberta.sammut@um.edu.mt.

Yours Sincerely,

| | |
|---|---|
| **Mr. Sheldon Attard**<br>Researcher | **Dr. Roberta Sammut**<br>Research Supervisor |

## *Appendix L.2: Copy of the Information Letter in Maltese Language*

L-Università ta' Malta

Formula ta' Informazzjoni għall-Parteċipanti

Għażiż/a Parteċipant/a,

Jiena Sheldon Attard, fil-preżent qed insegwi Masters fin-Nursing fl-Università ta' Malta. Bħala parti mir-rekwiżiti tal-kors, qed nagħmel riċerka bit-titlu, "*Perċezzjonijiet tal-mard ta' pazjenti li għandhom insuffiċjenza tal-qalb bħala tbassir ta' l-awto-kura u aderenza tal-medikazzjoni*". L-għan ta' dan l-istudju hu li ninvestiga l-perċezzjonijiet u l-imġiba tal-pazjenti bil-qalb għajjiena li jikkonċernaw l-awto-kura u l-aderenza tal-medikazzjoni. Is-sehem tiegħek f'dan l-istudju jista' jgħin biex ikollna aktar għarfien dwar l-perċezzjonijiet u l-imġiba dwar il-qalb għajjiena**.** Dan jgħinna biex intejbu l-proċess tat-terapija filwaqt li ntejbu r-riżultati fl-imġiba dwar il-qalb għajjiena. Kull informazzjoni miġbura tintuża biss għall-għan jew l-għanijiet ta' dan l-istudju.

Bħala parteċipant/a inti se tintalab tieħu sehem f'dan l-istudju sabiex ninvestigaw il-perċezzjonijiet u l-imġiba dwar il-qalb għajjiena. Jekk taċċetta li tieħu sehem, inti tintalab sabiex tiltaqa' mar-riċerkatur Sheldon Attard jew mal-persuna li qed tgħin (Il-persuna intermidjarja) f`dan il-proġett, wara l-appuntament tiegħek tal-Kardjoloġija: fil-*Medical Out-Patients 4 (MOP4)*; jew fil-*Cardiac Rehab;* jew fil-*Heart Failure Clinic,* fil-*Cardiac Lab;* jew fl-i*Specialised Heart Failure Clinic*. Din il-laqgħa se tieħu madwar 30 minuta.

Waqt din il-laqgħa, jiena bħala r-riċerkatur jew il-persuna li qed tgħin f`dan il-proġett (Il-persuna intermidjarja) nkun/tkun nista'/tista':

1. **Nistaqsi/tistaqsi xi mistoqsijiet dwarek, pereżempju l-età' tiegħek, informazzjoni dwar l-edukazzjoni u x-xogħlijiet tiegħek u xi mistoqsijiet dwar kif thossok bil-qalb għajjiena.**

2. **Imbagħad ħa tkun provdut bi kwestjonarju li jikkonsisti fi 3 partijiet. Dan tista' timlih waħdek jew inkella bil-għajnuna tal-persuna li qed tgħin f`dan il-proġett (Il-persuna intermidjarja) jew l-għajnuna tiegħi bħala r-riċerkatur:**

   **- Parti B tikkonsisti f` mistoqsijiet dwar l-perċezzjonijiet tiegħek li jikkonċernaw fuq il-qalb għajjiena,**

   **- Parti Ċ tikkonsisti f`mistoqsijiet dwar l-imġiba tiegħek fuq kif tieħu ħsieb lilek innifsek minħabba li qalbek għajjiena,**

   **- U Parti D tikkonsisti f`mistoqsijiet dwar l-aderenza tal-medikazzjoni tiegħek.**

M'intix obbligat/a li twieġeb il-mistoqsijiet kollha u sakemm id-data tkun tista' tiġi ddentifikata (e.ż. meta tkun qed timla l-kwestjonarju) tista' twaqqaf l-istudju x'ħin trid mingħajr ma tagħti l-ebda raġuni. Dan ifisser li minħabba r-raġuni li d-data ser tinġabar b' mod anonimu jekk il-kwestjonarju jiġi sottomess, ikun impossibli li jiġi traċċat. Li twaqqaf l-istudju mhux ħa jkollu riperkussjonijiet negattivi fuqek u l-informazzjoni li tinġabar mingħandek titħassar. Id-data se tinħażen/tinġabar b'mod anonimu kemm-il darba jkun impossibbli li titħassar (eż. jekk diġà kienet anonimizzata). Fuq il-kwestjonarju mhux ħa jitniżżlu l-ebda kodiċi li jirrelataw mad-data personali tiegħek (inkluż il-formula tal-kunsens). Nassigurak li se tinżamm il-kunfidenzjalità matul l-istudju kollu u l-identità tiegħek u kull informazzjoni personali miġbura mhuma se jiġu żvelati mkien fit-teżi, ir-rapporti, il-preżentazzjonijiet u/jew il-pubblikazzjonijiet li jistgħu jirriżultaw minnha.

Ir-riċerkatur biss ser ikollu aċċess għall-informazzjoni miġbura. Għal skop ta' verifikazzjoni dwar din l-informazzjoni miġbura, is-Superviżura akkademika (jew is-Superviżuri akkademiċi) u l-eżaminaturi se jkollhom dan l-aċċess għal din l-informazzjoni miġbura anonimizzata.

Id-data kollha se tinħażen/tinġabar fuq il-kompjuter personali tar-riċerkatur permezz ta' kodifikazzjoni tad-data (data encryption) u li hi protetta b'password. Barra minn hekk, il-materjal stampat (Il-kwestjonarju u l-formula tal-kunsens) se jinqafel f'post sigur li jista' jiġi aċċessat mir-riċerkatur biss. Wara li l-istudju jiġi ppubblikat, id-data tiġi mħassra, waqt li l-kwestjonarji u l-formuli tal-kunsens jiġu mqatta'.

F'każ li tħoss li l-istudju ħoloqlok diffikultà u tixtieq li tiddiskuti x'qed tħoss ma' professjonista mill-qasam tal-kura tas-saħħa, Ms. Mariella Meachen, psikoterapista se tkun qed tipprovdilek servizz ta' għajnuna mingħajr ħlas min-naħa tiegħek.

Il-parteċipazzjoni tiegħek f'dan l-istudju hija għażla għal kollox volontarja u inti ħieles/ħielsa li taċċetta jew tirrifjuta li tieħu sehem mingħajr ma jkun hemm konsegwenzi fil-konfront tiegħek. Se tingħata kopja tal-ittra ta' informazzjoni u tal-formula ta' kunsens sabiex tkun tista' taċċessahom fil-futur. L-informazzjoni personali kollha se titħassar hekk kif jintemm dan l-istudju ta' riċerka u jkunu ppubblikati r-riżultati miksuba.

Dan l-istudju ġie approvat mill-Kumitat għall-Etika fir-Riċerka fi ħdan il-Fakultà tax-Xjenzi tas-Saħħa fl-Università ta' Malta.

Grazzi ħafna tal-ħin u s-sehem tiegħek f'dan l-istudju. F'każ li jkollok xi mistoqsijiet jew tixtieq tiċċara xi ħaġa, tista' ċċempilli fuq +356 79334956 jew tibgħatli email fuq sheldon.attard.09@um.edu.mt. Tista' wkoll tikkuntattja lis-Superviżura Dr. Roberta Sammut fuq +356 2340 1851/1831 jew billi tibgħat email fuq roberta.sammut@um.edu.mt.
Dejjem tiegħek,

| | |
|---|---|
| **Mr. Sheldon Attard** | **Dr. Roberta Sammut** |
| Ir-Riċerkatur | Is-Superviżura tar-riċerka |

# Appendix M: Copy of the Informed Consent

## *Appendix M.1: Copy of the Informed Consent in English Language*

Participants` Consent Form

**Illness perceptions of Heart Failure patients as a predictor of self-care behaviours and medication adherence.**

I, the undersigned, give my consent to take part in the study conducted by Sheldon Attard. The purpose of this document is to specify the terms of my participation in this research study.

1. I have been given written and verbal information about the purpose of the study and all questions have been answered.
2. I understand that I have been invited to participate in a study, in which the researcher will ask questions to investigate the perceptions and behaviours of Heart Failure patients concerning self-care and medication adherence**.**
3. I am aware that the meeting will take approximately 30 minutes. I understand that the meeting is to be conducted in a place and at a time that is convenient for me.
4. I am aware that my responses will be written on the prepared record forms.
5. I am aware that the data collected will be anonymised and that this data will be stored securely.
6. I am aware that the researcher is the only person who has access to this data. The academic supervisor/s and examiners are the only other persons who will typically have access to this anonymised data in case there is the need for any verification.
7. I am also aware that the anonymised data files will be stored on the researcher`s personal computer that is password protected and in an encrypted format. Any material in hard-copy form will be placed in a locked cupboard and kept until results are published.
8. I am aware that my identity and personal information will not be revealed in any publications, reports or presentations arising from this research.
9. I also understand that I am free to accept, refuse or stop participation at any time without giving any reason, until my data is identifiable, e.g while I am filling the questionnaire.
10. I also understand that, since the questionnaire is going to be collected anonymously, withdrawal from the study after my questionnaire is submitted is impossible, because it cannot be traced. Withdrawal from the study will have no negative repercussions on myself and that any data collected form me will be erased. Data will be stored anonymously if it is impossible to delete (e.g. if it has already been anonymised).
11. I also understand that my contribution will serve to highlight the perceptions and behaviours of Heart Failure patients on both self-care and medication adherence.
12. If I feel distressed as a result of participation in this study a psychotherapist, Ms. Mariella Mechean, will be available to provide a service at no financial costs on

my part. Such risks could be due to the result of being asked personal health-related questions on Heart Failure.

13. I also understand that once the study is completed and results are published the data will be retained in anonymous form. Any personal details will be destroyed.
14. I will be provided with a copy of the information letter and consent form for future reference.
15. I have read and understood the points and statements of this form. I have had all the questions answered to my satisfaction, and I agree to participate in this study.

Participant: _____

Signature: _____

Date: _____


**Mr. Sheldon Attard**
Researcher
**Tel: +356 79334956**
**Email:** sheldon.attard.09@um.edu.mt

**Dr. Roberta Sammut**
Research Supervisor
**Tel: +356 2340 1851/1831**
**Email:** roberta.sammut@um.edu.mt


Signature: _____

Date: _____

Signature: _____

Date: _____

## *Appendix M.2: Copy of the Informed Consent in Maltese Language*

Formula ta' Kunsens tal-Parteċipanti

**Perċezzjonijiet tal-mard ta' pazjenti li għandhom insuffiċjenza tal-qalb bħala tbassir ta' l-awto-kura u aderenza tal-medikazzjoni.**

Jien, hawn taħt iffirmat/a, nagħti l-kunsens tiegħi biex nieħu sehem fl-istudju mmexxi minn Sheldon Attard. L-għan ta' dan id-dokument hu li jiġu speċifikati t-termini tal-parteċipazzjoni tiegħi f'dan l-istudju ta' riċerka.

1. Jien ingħatajt informazzjoni miktuba u verbali dwar l-għan tal-istudju u l-mistoqsijiet kollha twieġbu.
2. Nifhem li se nkun qed nipparteċipa fi studju, fejn ir-riċerkatur ħa jinvestiga l-perċezzjonijiet u l-imġiba tal-pazjenti bil-qalb għajjiena li jikkonċernaw l-awto-kura u l-aderenza tal-medikazzjoni.
3. Naf li l-istudju se jieħu madwar 30 minuta. Nifhem, li l-laqgħa se ssir f'post u ħin konvenjenti għalija.
4. Jien konxju/a li r-risposti tiegħi se jinkitbu fuq formuli apposta.
5. Naf ukoll li din id-data ħa tkun anonimizzata u li din l-istess data ser tinżamm sigura.
6. Naf ukoll li r-riċerkatur hu l-uniku persuna li se jkollu aċċess għal din l-informazzjoni, filwaqt li s-Superviżura akkademika (jew is-Superviżuri akkademiċi) u l-eżaminaturi se jkollhom aċċess għal din l-istess data anonimizzata. Is-Superviżuri akkademiċi u l-eżaminaturi jistgħu jkollhom bżonn aċċess għall-informazzjoni miġbura anonimizzata għal skop ta' verifika.
7. Barra min hekk, naf li d-data se tinħażan fuq il-kompjuter personali tar-riċerkatur permezz ta' kodifikazzjoni tad-data (data encryption) u li hi protetta b'password. Barra minn hekk, naf li l-materjal stampat se jitqiegħed f'post sikur u se jinżamm sakemm joħorġu r-riżultati.
8. Naf li l-identità tiegħi u l-informazzjoni personali mhuma se jinkixfu mkien fit-teżi, fir-rapporti, fil-preżentazzjonijiet u/jew fil-pubblikazzjonijiet li jistgħu jirriżultaw minnha.
9. Nifhem ukoll li jien liberu/a li naċċetta, nirrifjuta jew inwaqqaf il-parteċipazzjoni f'kull ħin bla ma nagħti raġuni, sakemm id-data tkun tista' tiġi ddentifikata (e.ż. meta nkun qed nimla l-kwestjonarju).
10. Nifhem ukoll li minħabba r-raġuni li d-data ser tinġabar b' mod anonimu, jekk il-kwestjonarju jiġi sottomess, ikun impossibli li jiġi traċċat. Li nwaqqaf l-istudju mhux ħa jkollu riperkussjonijiet negattivi fuqi. Nifhem ukoll li la darba nirtira minn dan l-istudju, l-informazzjoni miġbura se titħassar. Id-data se tkun maħżuna/miġbura b'mod anonimu kemm-il darba jkun impossibbli li titħassar (eż. jekk diġà kienet anonimizzata).
11. Nifhem ukoll li l-kontribuzzjoni tiegħi ser isservi biex jiġu enfasizzati l-perċezzjonijiet u l-imġiba tal-pazjenti bil-qalb għajjiena li jikkonċernaw l-awto-kura u l-aderenza tal-medikazzjoni**.**

**12.** Madanakollu, jekk inħoss li l-istudju ħoloqli diffikultà u nixtieq li niddiskuti x'qed inħoss, naf li Ms. Mariella Meachen psikoterapista se tkun qed tipprovdi servizz ta' għajnuna mingħajr ħlas min-naħa tiegħi. Dawn ir-riskji jistgħu jkunu riżultat ta' mistoqsijiet personali dwar is-saħħa tiegħi tal-qalb għajjiena.

**13.** Naf ukoll li meta jintemm l-istudju u r-riżultati jkunu ppubblikati, l-informazzjoni personali miġbura titħassar.

**14.** Fl-aħħarnett, naf ukoll li se ningħata kopja tal-ittra ta' informazzjoni u tal-formula ta' kunsens sabiex inkun nista' naċċessahom fil-futur.

**15.** Jien qrajt u fhimt il-punti u d-dikjarazzjonijiet f'din il-formula. Inħossni sodisfatt/a bit-tweġibiet li ngħatajt għall-mistoqsijiet li kelli, u qed naċċetta minn jeddi li nipparteċipa f'dan l-istudju.

Parteċipant:_____

Firma:_____

Data:_____


**Mr. Sheldon Attard**

Ir-Riċerkatur

**Tel: +356 79334956**

**Email:** sheldon.attard.09@um.edu.mt

**Dr. Roberta Sammut**

Is-Superviżura

**Tel: +356 2340 1851/1831**

**Email:** roberta.sammut@um.edu.mt


Firma: _____

Data: _____

Firma: _____

Data: _____

## Appendix N: Copy of the Questionnaire

### *Appendix N.1: Copy of the Questionnaire in English Language*

*Appendix N.1.1: Socio-Demographic Data and Clinical Information*

# Part A

*(To be filled by the nurse/ cardiologist)*

## Socio-demographic Data

Please mark with an (X) were appropriate or fill in when needed.

| | |
|---|---|
| **1. What is your age?** | _____years |

| | | | | | |
|---|---|---|---|---|---|
| **2. What is your gender?** | Male: ☐ | Female: ☐ | Other: ☐ | | |

| | | | | | |
|---|---|---|---|---|---|
| **3. What is your highest educational level?** | Primary: ☐ | Post-Secondary ☐ | Secondary: ☐ | Tertiary: ☐ | |

| | | | | | |
|---|---|---|---|---|---|
| **4. What is your occupation?** | Unemployed: ☐ | Pensioner: ☐ | Formally employed: ☐ | Student: ☐ | |

| | | | | |
|---|---|---|---|---|
| | Self-employed: | ☐ | | |
| **5. What is your current marital status?** | Married/ Living with partner: | ☐ | Single/ Separated/ Divorced/ Widowed: | ☐ |
| **6. What are your current living arrangements?** | Alone: | ☐ | With others: | ☐ |

# Clinical information

Please mark with an (X) were appropriate or fill in when needed.

| | |
|---|---|
| **7. How old were you, when you were diagnosed with Heart Failure?** | _____years |

| | | | | |
|---|---|---|---|---|
| **8. Aetiology: Main cause of Heart Failure** | Coronary Artery Disease: | ☐ | Congenital heart disease: | ☐ |
| | Hypertension: | ☐ | Alcohol: | ☐ |
| | Arrhythmias: | ☐ | Recreational drugs: | ☐ |
| | Valvular: | ☐ | Genetic: | ☐ |
| | Chemotherapy - induced: | ☐ | Other: _____ | |

| | | |
|---|---|---|
| **9. Ejection Fraction** | HFrEF - LVEF <40% | ☐ |
| | HFmrEF - LVEF 40-49% | ☐ |
| | HFpEF - LVEF ≥ 50% | ☐ |

| | | |
|---|---|---|
| **10. NYHA Class I** | Do you perform all physical activity without getting short of breath or tired, or have palpitations (fast heart beat)? | ☐ |
| **NYHA Class II** | Do you get short of breath or tired, or have palpitations (fast heart beat) when performing more strenuous activities? For example, walking on steep inclines or walking up several flights of steps? | ☐ |
| **NYHA Class III** | Do you get short of breath or tired, or have palpitations (fast heart beat) when performing day to day activities? For example, walking on the flat? | ☐ |
| **NYHA Class IV** | Do you feel breathless at rest, and you are mostly housebound? Are you unable to carry out any physical activity without getting short of breath or tired, or having palpitations (fast heart beat)? | ☐ |

| | | | | |
|---|---|---|---|---|
| **11. How long have you been followed-up for your Heart failure?** | Less than or equal to 6 months: | ☐ | 5 – 10 years: | ☐ |
| | More than 6 months: | ☐ | More than or equal to 10 years: | ☐ |
| | 1 - 5 years: | ☐ | | |

| | |
|---|---|
| **12. How many times you were admitted to hospital because of Heart Failure?** | _____admissions |

| | | | | |
|---|---|---|---|---|
| **13. When was your last admission related to Heart Failure?** | Less than 1 month ago: | ☐ | 1 year ago: | ☐ |
| | 1 to 6 months ago: | ☐ | More than 1 year ago: | ☐ |

| | | |
|---|---|---|
| | Less than 1 year but more than 6 months ago: | ☐ |

| | | |
|---|---|---|
| **14. Other comorbidities**<br><br>**Do you suffer from any other chronic diseases?** | a. _____ | f. _____ |
| | b. _____ | g. _____ |
| | c. _____ | h. _____ |
| | d. _____ | i. _____ |
| | e. _____ | j. _____ |

*Appendix N.1.2: Brief Illness Perception Questionnaire*

## Part B

*(To be filled by the participant)*

For the following questions, please circle ( ◯ ) the number that best corresponds to your views:

**1. How much does your Heart Failure affect your life?**

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| no affect at all | | | | | | | | | | severely affects my life |

**2. How long do you think your Heart Failure will continue?**

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| a very short time | | | | | | | | | | forever |

**3. How much control do you feel you have over your Heart Failure?**

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| absolutely no control | | | | | | | | | | extreme amount of control |

**4. How much do you think your treatment can help your Heart Failure?**

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| not at all | | | | | | | | | | extremely helpful |

**5. How much do you experience symptoms from your Heart Failure?**

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| no symptoms at all | | | | | | | | | | many severe symptoms |

**6. How concerned are you about your Heart Failure?**

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| not at all concerned | | | | | | | | | | extremely concerned |

**7. How well do you feel you understand your Heart Failure?**

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| don't understand at all | | | | | | | | | | understand very clearly |

**8. How much does your Heart Failure affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)**

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| not at all affected emotionally | | | | | | | | | | extremely affected emotionally |

**9. Please list in rank-order the three most important factors that you believe caused <u>your Heart Failure</u>. The most important causes for me:-**

a. _____

b. _____

c. _____

---

*The Brief Illness Perception Questionnaire (Broadbent, Petrie, Main & Weinman, 2006)*

*Appendix N.1.3: European Heart Failure Self-Care Behaviour Scale 9-Item*

## Part C

*(To be filled by the participant)*

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.

**1. I weigh myself every day.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I completely agree | | | | I don't agree at all |

**2. If my shortness of breath increases, I contact my doctor or nurse.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I completely agree | | | | I don't agree at all |

**3. If my feet/legs become swollen than usual, I contact my doctor or nurse.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I completely agree | | | | I don't agree at all |

**4. If I gain 2Kg in one week, I contact my doctor or nurse.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I completely agree | | | | I don't agree at all |

**5. I limit the amount of fluids I drink (not more than 1.5/2L/day).**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I completely agree | | | | I don't agree at all |

**6. If I experience increased fatigue, I contact my doctor or nurse.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I completely agree | | | | I don't agree at all |

**7. I eat a low salt diet.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I completely agree | | | | I don't agree at all |

**8. I take my medications as prescribed.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I completely agree | | | | I don't agree at all |

**9. I exercise regularly.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| I completely agree | | | | I don't agree at all |

*The European Heart Failure Self-care Behavior Scale (Jaarsma, Stomberg, Martensson, Dracup, 1999)*

*Appendix N.1.4: Medication Adherence Reporting Scale 5-Item*

## Part D

*(To be filled by the participant)*

MARS_5

# QUESTIONS ABOUT USING YOUR MEDICINES

- **Many people find a way of using their medicines which suits them.**
- **This may differ from the instructions on the label or from what their doctor has said.**
- **We would like to ask you a few questions about how you use your medicines.**

Here are some ways in which people have said that they use their medicines.

For each of the statements, please tick the box which best applies to you.

| | Your own way of using your medicines | Always | Often | Sometimes | Rarely | Never |
|---|---|---|---|---|---|---|
| M1 | I forget to take them | | | | | |
| M2 | I alter the dose | | | | | |
| M3 | I stop taking them for a while | | | | | |
| M4 | I decide to miss out a dose | | | | | |
| M5 | I take less than instructed | | | | | |

| **1. Do you prepare your own pills?** | Yes | No |
|---|---|---|

| **2. How many pills do you take regularly?** | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | +10 |

---

Thanks for participating and filling up this questionnaire.

Thanks for your support and co-operation.

*Appendix N.2: Copy of the Questionnaire in Maltese Language*

*Appendix N.2.1: Socio-Demographic Data and Clinical Information*

# Parti A

*(Timtela mill-Kardjologu/infermier)*

## Informazzjoni Soċjodemografika

Għal mistoqsijiet ta` hawn taħt jekk jogħġbok niżżel it-tweġieba jew għamel sinjal (X) fil-kaxxa skond it-tweġiba.

| | |
|---|---|
| **1. Kemm għandek żmien?** | _____ snin |
| **2. X'inhu s-sess tiegħek?** | Raġel: ☐ Mara: ☐ Oħrajn: ☐ |
| **3. X'inhu l-livell tal-edukazzjoni tiegħek?** | Primarja: ☐ Post-Sekondarja: ☐<br>Sekondarja: ☐ Terzjarja: ☐ |
| **4. X'inhi s-sitwazzjoni tax-xogħol tiegħek?** | Ma taħdimx: ☐ Penzjonant(a): ☐<br>Taħdem: ☐ Student(a): ☐ |

| | | |
|---|---|---|
| | Taħdem għar-rasek: ☐ | |
| **5. X'inhu l-istatus matrimonjali tiegħek?** | Miżżewweġ(a)/ Tgħix mal-partner: ☐ | Waħdek/ Separat(a) Divorzjat(a)/ Armel/Armla: ☐ |
| **6. X'inhuma l-arranġamenti tal-għajxien tiegħek?** | Tgħix waħdek: ☐ | Tgħix ma' ħaddieħor: ☐ |

# Informazzjoni klinika

Għal mistoqsijiet ta` hawn taħt jekk jogħġbok niżżel it-tweġieba jew għamel sinjal (X) fil-kaxxa skond it-tweġiba.

| | |
|---|---|
| **7. Kemm kellek żmien meta qalulek li għandek qalbek għajjiena?** | _____ snin |

| | | | | |
|---|---|---|---|---|
| **8. Etjoloġija: Il-kawża tal-mard ta' qalbek** | Mard tal-Arterji Koronarji: | ☐ | Mard konġenitali tal-qalb: | ☐ |
| | Pressjoni għolja: | ☐ | Alkoħol: | ☐ |
| | Arritmiji/Taħbit irregolari tal-qalb: | ☐ | Drogi għall-użu rikreattiv: | ☐ |
| | Valvulari: | ☐ | Ġenetika: | ☐ |
| | Kimoterapija: | ☐ | Oħrajn: _____ | |

| | | |
|---|---|---|
| **9. Ejection Fraction** | HFrEF - LVEF <40% | ☐ |
| | HFmrEF - LVEF 40-49% | ☐ |
| | HFpEF - LVEF ≥ 50% | ☐ |

| | | |
|---|---|---|
| **10. NYHA Class I** | Inti tagħmel kull attività fiżika mingħajr ma taqta' nifsek jew tħossok għajjien/a, jew tħoss l-palpitazzjonijiet (qalbek tħabbat mgħaġġla)? | ☐ |
| **NYHA Class II** | Inti tħoss qtugħ ta' nifs, u jkollok il-palpitazzjonijiet (qalbek tħabbat mgħaġġla) meta tagħmel attività qawwija? Eżempju: meta titla' xi telgħa jew meta titla' t-taraġ? | ☐ |
| **NYHA Class III** | Inti tħoss qtugħ ta' nifs, u jkollok il-palpitazzjonijiet (qalbek tħabbat mgħaġġla) meta tagħmel l-attivitajiet ta' kuljum? Eżempju: timxi fiċ-ċatt? | ☐ |
| **NYHA Class IV** | Inti tħossok bla nifs meta tkun mistrieħ(a), u ħafna drabi tibqa' ġewwa d-dar? Tħossok ma tistax tagħmel attività fiżika mingħajr ma taqta' nifsek jew tħossok għajjien(a), jew tħoss il-palpitazzjonijiet (qalbek tħabbat mgħaġġla)? | ☐ |

**11. Kemm ilek tiġi segwiet(a) minħabba l-qalb għajjiena?**

6 xhur jew inqas: ☐

Iktar minn 6 xhur: ☐

Minn sena sa 5 snin: ☐

Minn 5 sa 10 snin: ☐

10 snin jew iktar: ☐

**12. Kemm-il darba kellek tidħol l-isptar minħabba l-qalb għajjiena?**

_____ amissjonijiet

**13. Meta kienet l-aħħar darba li kellek tidħol l-isptar minħabba li qalbek għajjiena?**

Inqas minn xahar: ☐

Minn xahar sa 6 xhur: ☐

Inqas minn sena imma iktar minn 6 xhur: ☐

Sena ilu: ☐

Iktar minn sena ilu: ☐

| | | |
|---|---|---|
| **14. Komorbiditajiet oħrajn**<br><br>**Tbati minn xi mard kroniku ieħor?** | a. _____ | f. _____ |
| | b. _____ | g. _____ |
| | c. _____ | h. _____ |
| | d. _____ | i. _____ |
| | e. _____ | j. _____ |

*Appendix N.2.2: Brief Illness Perception Questionnaire*

## Parti B

*(Timtela mil-parteċipant)*

Għal mistoqsijiet ta` hawn taħt jekk jogħġbok għamel ċirku ( ◯ ) man-numru li juri l-iktar il-fehma tiegħek:

**1. Kemm taffetwalek ħajtek il-qalb għajjiena?**

0 1 2 3 4 5 6 7 8 9 10

ma taffettwani xejn — taffettwali ħajti ħafna

**2. Kemm taħseb li ser iddum b`qalbek għajjiena?**

0 1 2 3 4 5 6 7 8 9 10

ftit żmien — għal dejjem

**3. Kemm thoss li għandek kontroll fuq il-qalb għajjiena?**

0 1 2 3 4 5 6 7 8 9 10

assolutament bla kontroll — ammont estrem ta' kontroll

**4. Kemm taħseb li t-trattament tiegħek (Eżempju: l-mediċina) jista' jgħin lill-qalb għajjiena tiegħek?**

0 1 2 3 4 5 6 7 8 9 10

l-anqas xejn — utli ħafna

**5. Kemm tħoss sintomi minħabba l-qalb għajjiena tiegħek?**

0 1 2 3 4 5 6 7 8 9 10

ebda sintomi ta' xejn — sintomi severi ħafna

**6. Kemm int imħasseb dwar li għandek qalbek għajjiena?**

0 1 2 3 4 5 6 7 8 9 10

ma tħassibni xejn — tħassibni ħafna (estrem)

**7. Kemm taħseb li tħoss li taf fuq il-qalb għajjiena tiegħek?**

0 1 2 3 4 5 6 7 8 9 10

ma nifhem xejn — nifhem b'mod ċar ħafna

**8. Kemm taħseb li l-qalb għajjiena qed taffetwak emozzjonalment? (Eżempju: tagħmlek irrabjat, imbeżża', imdejjaq jew dipressat)?**

0 1 2 3 4 5 6 7 8 9 10

ma taffettwani xejn emozzjonalment — taffettwani ħafna emozzjonalment

**9. Jekk jogħġbok niżżel tlett fatturi li temmen li huma l-iktar importanti li għamlulek il-qalb għajjiena. Ibda billi tniżżel l-iktar fattur importanti mbagħad it-tieni u tielet.**

**- L-aktar kawżiet importanti għalija li kkawżawli l-qalb għajjiena huma:**

a. _____

b. _____

c. _____

---

*The Brief Illness Perception Questionnaire (Broadbent, Petrie, Main & Weinman, 2006)*

*Appendix N.2.3: European Heart Failure Self-Care Behaviour Scale 9-Item*

# Parti Ċ

*(Timtela mil-parteċipant)*

Din l-iskala fiha dikjarazzjonijiet dwar l-awto-kura tal-insuffiċjenza tal-qalb. Wieġeb għal kull dikjarazzjoni billi tagħmel ċirku madwar in-numru li inti taħseb li japplika l-aħjar għalik. Innota li t-tweġibiet alternattivi differenti jikkonstitwixxu fi skala li tvarja bejn iż-żewġ estremitajiet: "Jien naqbel kompletament" (1) sa "Jien ma naqbel xejn" (5). Anke jekk tħossok inċert dwar dikjarazzjoni partikolari, għamel ċirku madwar in-numru li tħoss li jgħodd l-aktar għalik.

**1. Jiena nintiżen kuljum.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Jien naqbel kompletament | | | | Jiena ma naqbel xejn |

**2. Jekk il-qtugħ ta` nifs iżiedli, jiena nikkuntattja t-tabib jew l-infemier.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Jien naqbel kompletament | | | | Jiena ma naqbel xejn |

**3. Jekk saqajja/riġlejja jintefħu iktar mis-soltu, jiena nikkuntattja t-tabib jew l-infemier.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Jien naqbel kompletament | | | | Jiena ma naqbel xejn |

**4. Jekk inżied 2Kg f`ġimgħa, jiena nikkuntattja t-tabib jew l-infemier.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Jien naqbel kompletament | | | | Jiena ma naqbel xejn |

**5. Jiena nillimita l-ammont ta` likwidi li nixrob (mhux aktar min 1.5/2L f' ġurnata).**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Jien naqbel kompletament | | | | Jiena ma naqbel xejn |

**6. Jekk l-għeja tiżdiedli, jiena nikkuntattja t-tabib jew l-infemier.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Jien naqbel kompletament | | | | Jiena ma naqbel xejn |

**7. Jiena niekol dieta baxxa fil-melħ.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Jien naqbel kompletament | | | | Jiena ma naqbel xejn |

**8. Jiena nieħu l-mediċini kif preskritt.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Jien naqbel kompletament | | | | Jiena ma naqbel xejn |

**9. Jiena nagħmel eżerċizzju regolari.**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Jien naqbel kompletament | | | | Jiena ma naqbel xejn |

*The European Heart Failure Self-care Behavior Scale (Jaarsma, Stomberg, Martensson, Dracup, 1999)*

*Appendix N.2.4: Medication Adherence Reporting Scale 5-Item*

## Parti D

*(Timtela mil-parteċipant)*

MARS_5

# MISTOQSIJIET DWAR L-UŻU TAL-MEDIĊINI TIEGĦEK

- **Ħafna nies isibu mod ta' kif jużaw il-mediċini tagħhom.**
- **Dan jista' jvarja mill-istruzzjonijiet ta' fuq it-tabella jew minn dak li t-tabib ikun qalilhom.**
- **Aħna nixtiequ nsaqsuk ftit mistoqsijiet dwar kif inti tuża l-mediċini tiegħek.**

Hawn taħt hawn ftit modi ta' kif in-nies qalu li jużaw il-mediċini tagħhom.

Għal kull waħda, jekk jogħġbok immarka l-kaxxa li tapplika l-aħjar għalik.

| | Il-mod tiegħek ta' kif tuża l-mediċini. | Dejjem | Spiss | Kultant | Rari | Qatt |
|---|---|---|---|---|---|---|
| M1 | Jiena ninsa noħodhom | | | | | |
| M2 | Jiena nbiddel id-doża | | | | | |
| M3 | Jiena nwaqqafhom għal xi żmien | | | | | |
| M4 | Jiena niddeċiedi li naqbeż xi doża | | | | | |
| M5 | Jiena nieħu nqas milli ġejt preskritt | | | | | |

MARS_5 2018 Medication Adherence Report Scale (MARS_5) © Professor Rob Horne

| **1. Inti tipprepara l-pinolli tiegħek?** | Iva | Le |
|---|---|---|

| **2. Kemm tieħu pinolli regolari?** | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | +10 |

---

Grazzi talli pparteċipajt u mlejt dan il-kwestjonarju.

Grazzi mill-ġdid tas-sapport u l-kooperazzjoni tiegħek.

## Appendix O: Evaluation of the Questionnaire – Pilot Study – Form

### *Appendix O.1: Evaluation of the Questionnaire – Pilot Study – English Language Version*

Evaluation of the Questionnaire – Pilot Study

1. How long did it take you to complete this questionnaire? - _____

2. Were there any questions in this questionnaire that you have found them difficult to understand?

   _____

   _____

   _____

   _____

3. Do you have any suggestions how one can improve this questionnaire?

   _____

   _____

   _____

   _____

***Appendix O.2: Evaluation of the Questionnaire – Pilot Study – Maltese Language Version***

## Evalwazzjoni tal-Kwestjonarju – Studju Pilota

1. Kemm ħadlek ħin biex timla dan il-kwestjonarju?

   _____

2. Kien hemm xi mistoqsijiet minn dan il-kwestjonarju li kienu diffiċli biex tifimhom?

   _____

   _____

   _____

   _____

3. Għandek xi suġġerimenti kif wieħed jista' jtejjeb dan il-kwestjonarju?

   _____

   _____

   _____

   _____