Illness Perception and Quality of Life among Individuals with Chronic Heart Failure

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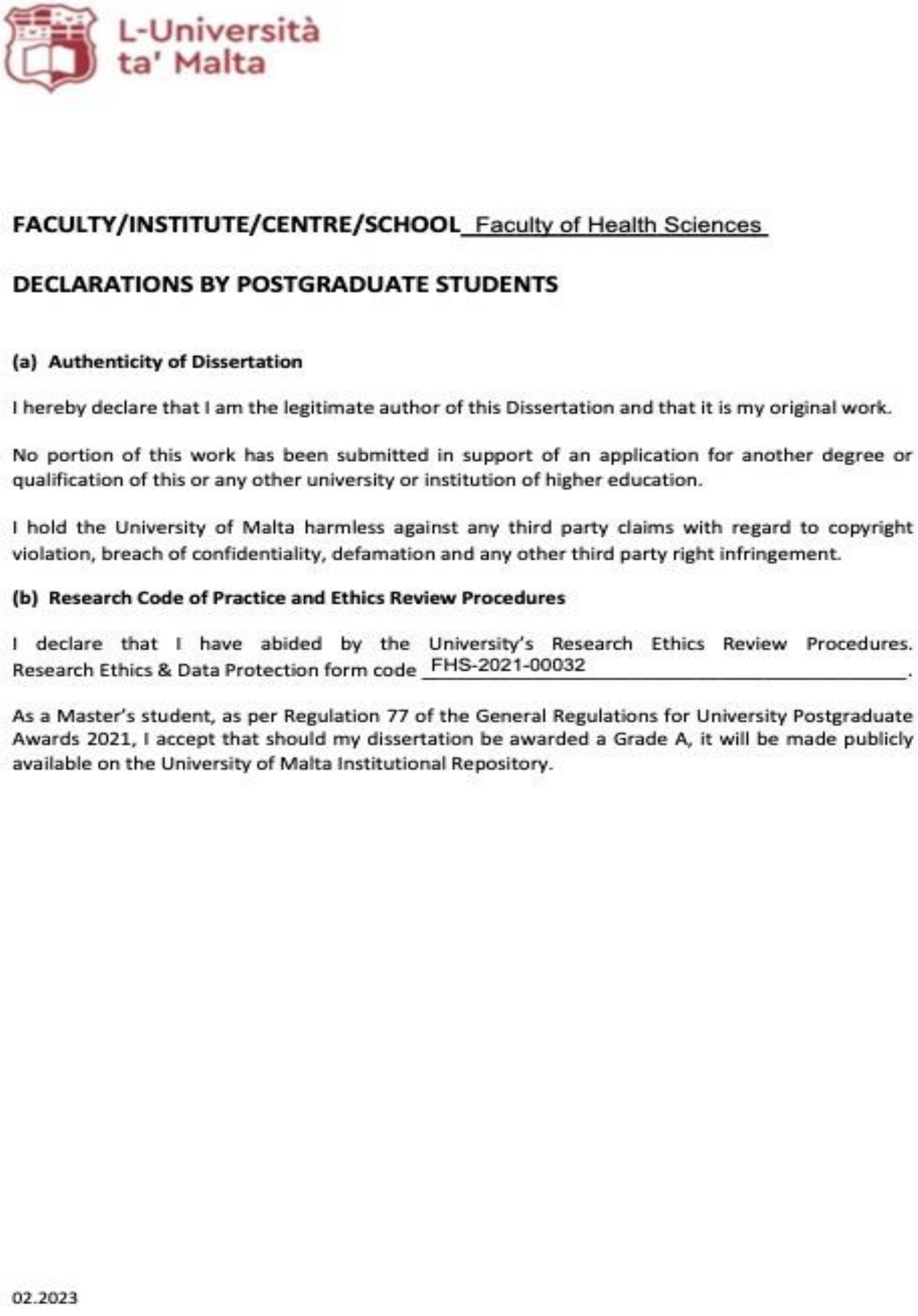

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Abstract

Background: Chronic heart failure contributes to multiple physical symptoms and limitations, altering illness perceptions and affecting the quality of life. Understanding what domains of illness perceptions and quality of life are affected by chronic heart failure is crucial in optimising disease management. Additionally, it is important to identify which demographic and clinical characteristics may affect this cohort's illness perceptions and quality of life.

Objectives: To assess the illness perception and quality of life of individuals with chronic heart failure, their relationship with demographic and clinical characteristics, and assess the correlation between illness perception and quality of life.

Study design: Cross-sectional study

Sample and setting: 248 individuals diagnosed with chronic heart failure, aged 18 years or over, of all genders were conveniently recruited from the Heart Failure Clinic at an acute general hospital in Malta.

Methods: The Brief Illness Perception Questionnaire (Weinmann et al., 1996), and the brief Cardiomyopathy questionnaire (John Spertus 2012), were used to compile information on the participants characteristics, their illness perception on chronic heart failure and their level of quality of life. Research instruments were provided in both English and Maltese. Data was analysed using SPSS version 28.0.0.0. Statistical tests used were the Pearson correlation, the Spearman correlation, the independent sample t-test, the Mann-Whitney U test, the One-way ANOVA and the Kruskal-Wallis H.

Results: Results related to illness perception showed that participants felt that CHF had moderate effect on their lives. Levels of quality of lives were also found to be moderate. Additionally, an association between demographic variables and the measured attributes was found. A positive correlation between characteristics affected these results as well. A positive correlation was found between illness perception and quality of life ($p=<0.001$). The more positive the illness perceptions the better the quality of life, this trend was also identified among various demographic characteristics.

Conclusions: Health care professionals should consider patients' illness perception and quality of life as an essential assessment component to ensure a person-centred approach and improve the overall health.

Key words: CHRONIC HEART FAILURE, ILLNESS PERCEPTION, QUALITY IF LIFE

Dedication

I would like to dedicate this dissertation to all the patients I came across during my career as a nurse, especially those with Chronic Heart Failure and those yet to come under my care in the future.

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Abbreviations

ADLs	Activities of Daily Living
B-IPQ	Brief Illness Perception Questionnaire
BDI	Beck’s depression Inventory
CABG	Coronary Artery Bypass Graft
CASP	Critical Appraisal Skills Program
CHF	Chronic Heart Failure
COPD	Chronic Obstructive Pulmonary Disease
ECS	European of Cardiology Society
EFA	Exploratory Factor Analysis
HADS	Hospital Anxiety and Depression Scale
HBS	Health Belief Scale
HCP	Health Care Professionals
JBI	Joanna Briggs Institute
KCCQ-12	Cardiomyopathy Questionnaire (Kansas City) (Brief)
KCCQ-23	Cardiomyopathy Questionnaire (Kansas City) (Original version)
LVEF	Left Ventricular Ejection Fraction
MLHF	Minnesota Living with Heart Failure (questionnaire)
NYHA	New York Heart Association
QoL	Quality of Life
R-IPQ	Revised Illness Perception Questionnaire
SD	Standard Deviation
SPSS	Statistical Package for Social Sciences

SR	Systematic Reviews
TRI	Treatment Representations Inventory
WHS	Wishward Health Services

Chapter 1: Introduction

1.1 Introduction

This dissertation aims to assess illness perceptions and quality of life (QoL) among individuals living in Malta diagnosed with chronic heart failure (CHF) and the relationship between these two variables. Additionally, it evaluates the association of demographic and medical data with illness perception and QoL among individuals with CHF. This chapter aims to introduce the topic through background and foreground information, addressing the purpose of the study, identifying gaps in existing knowledge, introducing the research question while establishing the main objectives for this study, and introducing the methods to be used in this study.

1.2 Background and foreground information

1.2.1 Congestive Heart Failure

CHF is a chronic disease undergoing intermittent decompensation (Goodman et al., 2011), resulting in pulmonary vascular congestion and decreased cardiac output (Figueroa & Peters, 2006). Treatment for this condition includes alleviating suffering by relieving symptoms and improving prognosis (Juenger et al., 2002). These goals may be achieved by restoring cardiopulmonary physiology and reducing the hyperadrenergic state (Figueroa & Peters, 2006). However, it is still associated with multiple hospital readmissions, worsening QoL, and worsening prognosis over time (Obieglo, 2016).

1.2.2 Illness perceptions

Illness perceptions are defined as the personal understanding and cognitive appraisal of a health condition and its possible consequences (Broadbent et al., 2015). Illness perception focuses on how an individual experiences living with a disease and how they mentally frame it (Weinman & Petrie, 1997). These perceptions encompass both positive and negative illness beliefs which may influence the ability to cope with the illness and to perceive it as manageable or threatening.

The study of illness perception emerged from the common sense model of illness representation by Leventhal et al. (1980), in which patients comprehend the impact of the disease on their lives through their personal experience, (Hagger et al., 2017). Illness perceptions integrates the influences of both abstract and concrete health information on the individual’s emotional response and cognitive representation; this facilitates the meaning of the illness and its experience (Dempster et al., 2015). Individuals assess the effects of the illness on themselves, which leads to changes in their emotional responses and cognitive representations (Broadbent et al., 2015).

1.2.3 Quality of life

According to Coelho et al. (2005), subjective domains of QoL encompass physical capacity, occupational functioning, perceptions of health status, pyschologyical functioning and social functioning. In addition, objective QoL includes health status measured by a diagnostic test, psychopathology, social support and socioeconomic status. Measuring QoL evaluates how and how much the illness influences the individuals’ lives, and how they cope with it. These evaluations provide useful baseline and outcome measures to determine the impact on the lives of these individuals.

Conventional aims in treating HF are to relieve symptoms, improve prognosis, and maximise everyday functioning to achieve the highest level of QoL despite the limiting factors imposed by the illness. Studying QoL is a scientific measurement which evaluates the efficacy of treatment strategies and the course of the illness (Juenger et al., 2002).

1.2.4 Local context

CHF is one of Malta's most common conditions, affecting 1-2% of the Maltese population. Despite improvements in medical therapy, re-hospitalisation rates concerning CHF in Malta remain high (Moore, 2020). According to the chairman of the cardiology department and president of the Maltese Cardiac Society, Dr Robert Xuereb (2018), around 700 individuals attend the local nurse-led heart failure clinic, as cited by Grech (2018). According to Moore (2020), the nurse-led heart failure clinic was set up to optimise medical therapy concerning CHF and educate the patients, to decrease re-hospitalisation.

1.3 Importance of the study

According to Goodman et al. (2011), CHF imposes a challenge on the patients when coping with the deterioration of this progressive disease. Understanding the patients' perception of their condition facilitates a more personalized approach to their stressors, anxieties and possible misconceptions about their condition and treatment. CHF is associated with negative emotions leading to problems in social, mental and physical functioning, resulting in limitations in activities of daily living (ADLs); for this reason, due to the increasing incidence of CHF, QoL deserves particular attention among individuals affected by this condition. Furthermore, the European Society of Cardiology (ECS) guidelines suggest that improving QoL should represent one of the main objectives of CHF treatment.

1.4 Purpose of the study

When diagnosed with chronic diseases, individuals are inclined to formulate mental illness perceptions and attributions interpreting their condition in an individualised way. In addition, CHF summons several challenges that affect the patient's psychological well-being. Research shows that the patient's psychological state affects symptom occurrence and severity (Smith et al., 2015). Therefore, addressing psychological factors arising from illness beliefs may improve the clinical condition. Furthermore, the ESC emphasizes that addressing psychological issues through rehabilitation improves the patients' psychological well-being and achieves better QoL outcomes (as cited by Greco et al., 2014).

This study has been chosen as illness beliefs may be given little importance when caring for individuals with CHF and consequently may be overlooked. Therefore, carrying out this study and exploring this area may aid in identifying factors affecting the patients' clinical status so as to improve prognosis, mortality rates and decrease hospital re-admissions (Bleumink et al., 2004).

1.5 Gaps in existing knowledge

Previous studies have explored the correlation between illness perception and QoL among different chronic conditions, including cardiac illnesses. However, no studies were conducted in Malta. According to Ruiz-Montero (2015), sociocultural differences influence the experience of one's health, including their perception of illness. Therefore, this would provide a better understanding of perceptions of illness which might limit healing and decrease QoL. Ultimately, this would enhance the care provided to these individuals.

1.6 Research Question

Among individuals with chronic heart failure, what is the correlation between illness perceptions and quality of life?

1.7 Aim and objectives

1.7.1 Aim

This research study aimed to assess illness perceptions and QoL among individuals with CHF and their relationship between these two variables as well as their relationship with demographic characteristics and medical status.

1.7.2 Objectives

- The assessment of illness perception of individuals with CHF
- The assessment of QoL of individuals with CHF
- The assessment of the relationship between the participants' characteristics with illness perception and QoL
- The correlation between illness perception and QoL

1.8 Overview of the methodology

This study sought objective data, represented numerically through a quantitative approach (Goertzen, 2017). Data was collected with the use of two validated score-point questionnaires. 'The brief illness perception questionnaire (B-IPQ)' developed by Weinman et al. (1996) and revised by Moss-Moris et al. (2002) was used to assess illness perception and the 'Cardiomyopathy Questionnaire (Kansas City) (KCCQ-12)' developed by John Spertus (2012) was used to assess QoL. In addition, ten additional questions related to demographic characteristics and medical status were provided with the questionnaires to uncover trends among different characteristics and demographics.

A cross-sectional design was deemed appropriate as this study was carried out at one point in time, through a large sample size, without any experimental manipulation. Data was colleted by distributing the questionnaires at the nurse-led heart failure clinic at Materdei Hospital through an intermediary person.

1.9 Conclusion

In conclusion, this chapter provided an introduction of the research topic to the reader, explaining its importance and highlighting its need in the research field while exploring gaps in the literture and explaining the intended methodology. Furthermore, the following chapter encompasses a step-by-step explanation of the literature review by analysing the evidence-based literature related to the topic. It encompasses information on the research being conducted and provides a detailed account of the literature search used to retrieve relevant studies conducted on the topic.

Chapter 2

2.1 Introduction

This chapter analyses the evidence-based literature relevant to the research topic. It provides an understanding of the research being conducted, including background information and a detailed account of the literature search process. The relevant articles are critically appraised, and this detail will be used at the discussion level.

Part 1: Development of the research question

In developed countries, CHF constitutes 1-2% of the adult population and is one of the most frequent sources of hospitalisation due to cardiovascular conditions (Obieglo et al., 2016). According to Xuereb (2018), as cited by Grech (2018), around 700 individuals attend the nurse-led heart failure clinic locally. CHF is associated with negative emotions and self-limiting beliefs, leading to problems in social, mental, and physical functioning, resulting in limitations in activities of daily living. For this reason and due to the increasing incidence of CHF, QoL deserves particular attention among individuals affected by CHF. In addition, the ECS guidelines suggest that improving QoL should be the primary objective of CHF treatment (ECS, 2021).

Multiple studies show a relationship between illness perception and QoL among various conditions. Some of these conditions include patients with contact dermatitis (Benyamini et al., [2012]), breast cancer (Iskandarsyah et al., [2012]), prostate cancer (Mickeviciene et al., [2013]), patients who underwent a coronary artery bypass graft (CABG) (Yaraghchi et al., [2012]) and multiple sclerosis (Spain et al., [2007]. However, no local studies have addressed this correlation among individuals with CHF. This study could be beneficial as it would help in gaining a better understanding of the effects of CHF on QoL, allowing the healthcare system to address barriers to healing and enhance disease management. Therefore, this topic was selected for this dissertation, and the development of the following research question:

Among individuals with chronic heart failure, what is the correlation between illness perceptions and quality of life?

Part 2: Literature search

2.2.1 Searching the literature

A thorough literature search was conducted electronically to obtain existing literature on this topic. This intensive search would allow the identification of related studies and the exploration of gaps in the literature (Lewins, 1992, as cited by White, 2017). This electronic search was carried out after developing the research question by identifying key terms and developing alternative terms respectively, to obtain as many related electronic papers as possible. The electronic databases used for this research are EBSCO and Scopus; both databases are widely known in the health and medical fields.

EBSCO was selected as it searches through multiple databases selected by the researcher. This electronic platform also offers various helping tools to conduct a more focused and productive search, including Boolean operators, truncation, wildcards, and limiters, which were used throughout the search according to the need. Scopus is Elsevier's abstract and citation database; it was deemed appropriate for this search as it offers a vast range of scientific and medical peer-reviewed journals. It allowed the use of Boolean operators, truncation, wildcards, and limiters, making the search more specific and dynamic.

2.2.2 Key terms and alternative terms

Key terms were identified to emphasize the crucial elements of the research question (Table 1). This is an essential step, as these key terms will generate alternative words and phrases for the electronic search.

Table 1

Key terms

Chronic heart failure	Illness perception	Quality of life

In addition, alternative terms were generated from the key terms of the research question, which were identified using a thesaurus and the medical subject headings (MeSH) terms database on PubMed. These alternative terms include abbreviations and words or small phrases with the same meaning as the keywords. In addition, variations using truncation, wildcards and Boolean operators were also used, according to the database being researched (Table 2).

Table 2

Alternative terms

	Key term 1	Key term 2	Key term 3
Key concept	chronic heart failure	Illness perception	Quality of life
Alternative term	"CHF" OR "heart failure" OR "HF" OR "cardiac failure" OR "heart decompensation" OR "myocardial failure"	"Perception of illness" OR "health belief*" OR "illness understanding" OR "illness appraisal" OR "illness thoughts" OR "disease expectations" OR "Illness perception*"	"standard of living" OR "QoL" OR "QOL" OR "life quality" OR "living standards" OR "quality of living" OR "level of well?being" OR "quality of well?being" OR "life condition" OR "HRQOL"

2.2.3 Electronic searches

As previously stated, the databases Scopus and EBSCO were used. Both these databases support Boolean syntax, wildcards, and truncations. The first database search was carried out on Scopus; in the first search, only the key terms were used and were searched within all the fields. In addition, no limiters were applied; this was done to understand what type of results would be generated to apply limiters and changes in the following searches accordingly. This first search yielded 238 hits; upon skimming through the titles of these hits, it was noted that topics related to various diseases other than CHF were generated; this probably occurred as only the key terms were searched, giving the search a broad indication.

Therefore, to obtain as many articles related to the topic as possible, the alternative terms previously identified were included in the second search. This search was conducted through all the fields, and no limiters were used; the search increased to 721 hits. To minimise the number of hits, the third search was conducted by keeping the same keyword combination and changing the field searched to ‘*titles, abstract and keywords*. This search narrowed the number of hits to 25, out of which eight were deemed relevant (Table 3).

Table 3

Search conducted on Scopus database

Search no.	Keyword combination	Limiters applied	Field search	Changes implemented	No. of hits	No. of relevant hits
1	"CHRONIC HEART FAILURE" AND "ILLNESS PERCEPTION" AND "QUALITY OF LIFE"	None	All fields	N/A	238	
2	"CHF" OR "CHRONIC HEART FAILURE" OR "HF" OR "CARDIAC FAILURE" OR "HEART DECOMPENSATION" OR "MYOCARDIAL FAILURE" AND "ILLNESS PERCEPTION*" OR "PERCEPTION OF ILLNESS" OR "HEALTH BELIEF*" OR "ILLNESS UNDERSTANDING" OR "ILLNESS APPRAISAL" OR "ILLNESS THOUGHTS" OR "DISEASE EXPECTATIONS" AND "STANDARD OF LIVING" OR "QUALITY OF LIFE" OR "QOL" OR "QOL" OR "LIFE QUALITY" OR "LIVING STANDARDS" OR "QUALITY OF LIVING" OR "LEVEL OF WELL?BEING" OR "QUALITY OF WELL?BEING" OR "LIFE CONDITION" OR "HRQOL"	None	All fields	Alternative terms were introduced	721	
3	TITLE-ABS-KEY ("CHF" OR "CHRONIC HEART FAILURE" OR "HF" OR "CARDIAC FAILURE" OR "HEART DECOMPENSATION" OR "MYOCARDIAL FAILURE" AND "ILLNESS PERCEPTION*" OR "PERCEPTION OF ILLNESS" OR "HEALTH BELIEF*" OR "ILLNESS UNDERSTANDING" OR "ILLNESS APPRAISAL" OR "ILLNESS THOUGHTS" OR "DISEASE EXPECTATIONS" AND "STANDARD OF LIVING" OR "QUALITY OF LIFE" OR "QOL" OR "QOL" OR "LIFE QUALITY" OR "LIVING STANDARDS" OR "QUALITY OF LIVING" OR "LEVEL OF WELL?BEING" OR "QUALITY OF WELL?BEING" OR "LIFE CONDITION" OR "HRQOL" AND NOT "CANCER" OR "CHRONIC OBSTRUCTIVE PULMONARY DISORDER")	None	Title, abstract, and keywords	Field changed from all fields to title, abstract, and keywords	25	8

This second electronic search was conducted on EBSCO. This database allows the researcher to search multiple host databases within one search; for this electronic search, eight host databases were deemed appropriate (Table 4).

Table 4

Host databases selected in the search conducted on EBSCO

Database	Host databases
EBSCO	Academic search ultimate
	AgeLine, CINAHL Complete
	Cochrane Central Register of Controlled Trials
	Cochrane Clinical Answers
	Cochrane Database of Systematic Reviews
	Cochrane Methodology Register
	MEDLINE complete
	APAPsychInfo.

The first search was carried out using the key terms of the research question, with no limiters, and searched within all the fields, which generated 713 results. Upon skimming through the hits, it was noted that multiple studies were related to heart disease in paediatrics. Therefore, the following search was limited to adults since this study will not be including paediatric participants; this search decreased the number of hits to 96. In the third search, all alternative terms were introduced while leaving the same limiters; this yielded 367 hits. To narrow down the search, the last search was limited to abstract, generating 26 hits, which were screened; six of these hits were deemed relevant. In addition, duplicates were automatically deleted (Table 5).

Table 5

Search conducted on EBSCO

Search no.	Keyword combination	Limiters applied	Field search	Changes implemented	No. of hits	No. of relevant hits
1	"CONGESTIVE HEART FAILURE" AND "ILLNESS PERCEPTION" AND "QUALITY OF LIFE"	None	All fields	N/A	713	
2	"CONGESTIVE HEART FAILURE" AND "ILLNESS PERCEPTION" AND "QUALITY OF LIFE"	Limited to adults	All fields	Limited to adults as previous search yielded studies on paediatric patients	96	
3	"CHF" OR "CONGESTIVE HEART FAILURE" OR "HF" OR "CARDIAC FAILURE" OR "HEART DECOMPENSATION" OR "MYOCARDIAL FAILURE" AND "ILLNESS PERCEPTION*" OR "PERCEPTION OF ILLNESS" OR "HEALTH BELIEF*" OR "ILLNESS UNDERSTANDING" OR "ILLNESS APPRAISAL" OR "ILLNESS THOUGHTS" OR "DISEASE EXPECTATIONS" AND "STANDARD OF LIVING" OR "QUALITY OF LIFE" OR "QOL" OR "QOL" OR "LIFE QUALITY" OR "LIVING STANDARDS" OR "QUALITY OF LIVING" OR "LEVEL OF WELL?BEING" OR "QUALITY OF WELL?BEING" OR "LIFE CONDITION" OR "HRQOL"	All adult (19+ years)	All fields	The alternative terms introduced	367	
4	"CHF" OR "CONGESTIVE HEART FAILURE" OR "HF" OR "CARDIAC FAILURE" OR "HEART DECOMPENSATION" OR "MYOCARDIAL FAILURE" AND "ILLNESS PERCEPTION*" OR "PERCEPTION OF ILLNESS" OR "HEALTH BELIEF*" OR "ILLNESS UNDERSTANDING" OR "ILLNESS APPRAISAL" OR "ILLNESS THOUGHTS" OR "DISEASE EXPECTATIONS" AND "STANDARD OF LIVING" OR "QUALITY OF LIFE" OR "QOL" OR "QOL" OR "LIFE QUALITY" OR "LIVING STANDARDS" OR "QUALITY OF LIVING" OR "LEVEL OF WELL?BEING" OR "QUALITY OF WELL?BEING" OR "LIFE CONDITION" OR "HRQOL"	All adults (19+ years)	Abstract	Limited to abstract	26	6

2.2.4 Study selection

The two electronic searches generated 25 and 26 hits, respectively, amounting to 51 hits. Nine articles were eliminated before screening as they were duplicates. Leaving 42 articles, which were screened through the title and abstract. 32 were then eliminated as they were unrelated to the research topic, leaving 10 articles. The 10 articles were screened for relevance by reading them in full text; six were excluded for reasons mentioned in Table 6, leaving a total of three articles. To further exhaust the literature, another search was carried out by searching through the reference lists of the three identified studies, of which five were sought for retrieval and three were eliminated for reasons mentioned in Table 6. Leaving another two articles. This amounted to a total of six relevant articles. A summary using the PRISMA 2020 flow diagram for systematic reviews can be found below (Figure 1).

Figure 1

PRISMA 2020 flow diagram for systematic reviews

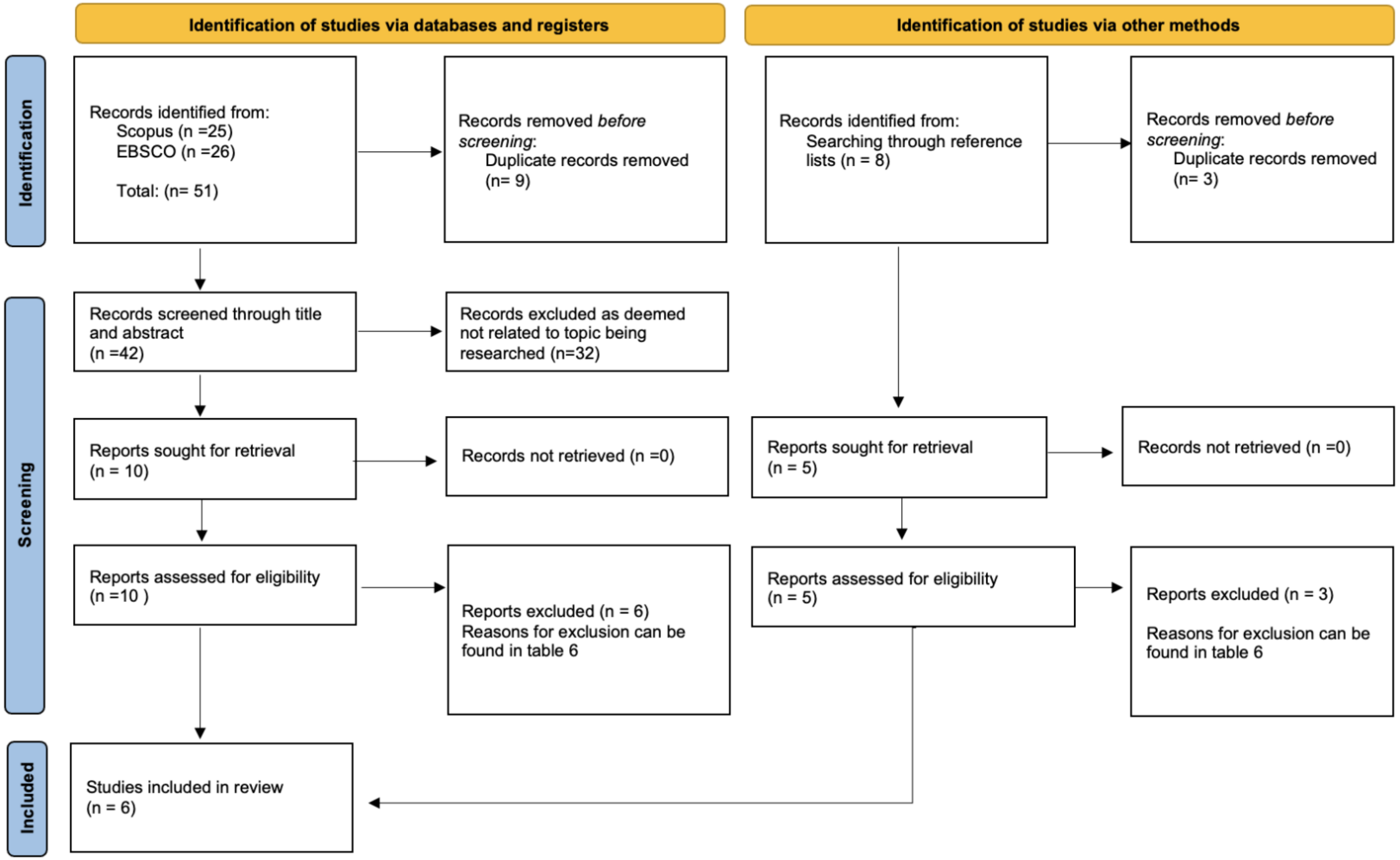


Table 6

Reasons for exclusion

	Reasons for exclusion	Number of articles excluded
Studies identified via database searching	- Did not address QoL	3
	- Did not address illness perception	1
	- Based on care givers perception	2
Studies identified via other methods	- Not specific to CHF	1
	- Did not address illness perceptions	2

2.2.5 Inclusion and exclusion criteria

Formation of inclusion and exclusion criteria is crucial and required practice when conducting research, as this gives the study structure by targeting the study criteria and key components. Inclusion criteria include clinical, demographic, and geographic characteristics. In contrast, exclusion criteria are set to exclude characteristics that might interfere with the study unfavourably (Pneumol, 2008). The full eligibility criteria can be seen in Table 7.

Inclusion criteria encompassed individuals clinically diagnosed with CHF, specifying the diagnostic measurements and parameters, for example, by specifying the left ventricular ejection fraction (LVEF). In addition, studies that included participants under the age of 18 were excluded. Subjects with other co-morbidities and with pacemakers were included in the study. Lastly, eligible articles sought to explore the relationship between illness perception and QoL. Therefore, studies that explored QoL or illness perception only were excluded.

Table 7

Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
- Adult participants 18 years of age of above	- Individuals below the age of 18
- Individuals clinically diagnosed with CHF	- Individuals without a medical diagnosis of CHF
- Individuals with pacemakers (including defibrillator pacemakers)	/
- Patients with other co morbidities other than CHF	/
- Articles exploring the relationship between illness perception and QoL	- Articles looking into QoL only or illness perception only.

2.2.6 Characteristics of key studies

A total of six studies were deemed relevant to the topic being researched. These six key studies include two longitudinal studies and three quantitative cross-sectional studies and one qualitative cross-sectional study. A summary of these key articles can be found in Tables 8.a and 8.b. Furthermore, in the following section, the articles will be critically appraised.

The two longitudinal studies both examined how illness perception affect QoL and mood. Furthermore, both studies sought to examine these changes over time. However, this part is irrelevant to the topic being researched, as this study will not be looking at the changes over time but rather at the relationship between the two variables. Both studies recruited participants from multiple hospitals. Both Mulligan et al. (2010) and Goodman et al. (2012) used validated questionnaires as data collection instruments to measure illness perceptions and QoL. These two studies have recruited a similar cohort; both specified that participants should understand the English Language, have a stable cognitive state, and be adults.

However, Mulligan et al. (2010) also specified that the subjects recruited should be diagnosed according to the European Society of Cardiology Criteria (Tables 8.1 & 8.2).

The four cross-sectional studies all sought to examine the correlation between illness perception and QoL. Hallas et al. (2009) and Carels (2004) examined depression in addition to the relationship between the two variables and Bosworth et al., (2004), examined psychological outcomes. These outcomes will not be used in this study since they are not relevant to the topic being researched. All cross-sectional studies included in this review assessed participants at one point in time. In addition, all four studies used adult subjects. All four cross-sectional studies recruited patients with a CHF diagnosis. Sample sizes varied among the studies, ranging from 228 participants (Clark et al., 2003) to 15 participants (Carels, 2004). Hallas et al., (2009), Carels (2004) and Bosworth et al. (2004), all recruited participants from clinics, whereas Clark et al. (2003) recruited participants from another study by Wishward Health Services (WHS) assessing medication adherence. Hallas et al. (2009) and Clark et al. (2003) used questionnaires to assess illness perception and QoL in their studies. Carels (2004) used a questionnaire to measure illness perception and self-reporting diaries over 2 weeks to assess QoL. Lastly, Bosworth et al. (2004) used semi-structured open-ended protocols to assess both variables (Table 8.2).

Table 8.1

Characteristics of the key studies

Author	Title	Aim	Study design
Goodman et al., (2012)	Illness perception, self-care behaviour and quality of life of heart failure patients: A longitudinal questionnaire survey.	To study the relationship between illness perceptions, self-care behaviour and QoL in patients admitted with a primary CHF diagnosis, and the changes after 2-and 6- months.	Longitudinal questionnaire-based study
Mulligan et al., (2010)	Newly diagnosed heart failure- change in quality of life, mood and illness beliefs in the first six months after diagnosis.	To study how patients' mood and QoL change during the early high risk period post diagnosis of CHF and identify dynamics that may impact changes, after 2 weeks of initial diagnoses and after 6 months.	Longitudinal study
Hallas et al., (2009)	Depression and perception about heart failure predict quality of life in patients with advanced heart failure.	To identify psychological and clinical variables, which predict QoL and mood among people with CHF.	Cross-sectional cohort study
Bosworth et al., (2004)	Congestive heart failure patients' perceptions of quality of life: the integration of physical and psychological factors.	To study the components of illness perception and QoL as understood by the patients living with CHF.	Cross-sectional qualitative with focus groups
Carels (2004)	The association between disease severity, functional status, depression, and quality of life in congestive heart failure patients.	To examine the influence of functional status, disease severity, level of depression on daily QoL among patients with CHF for 2 weeks.	Cross-sectional quantitative study
Clark et al., (2003)	Correlates of health-related quality of life among lower-income, urban adults with congestive heart failure.	To examine the correlation of health-related quality of life and illness representation and characteristics among patients with CHF.	Cross-sectional qualitative study

Table 8.2

Characteristics of key studies

Author and year of publication	Type of study	Time of data collection	Population characteristics	Sample size	Sampling technique	Recruitment	Illness perception measurement	QoL measurement
Goodman et al., (2012)	Longitudinal questionnaire-based study	Questionnaires were completed before discharge from hospital, and 2 and 6 months after discharge.	> 18 years of age, able to understand English, and with the cognitive ability to complete the questionnaires	88 (70% male)	Convenience sampling	Three London hospitals with specialist heart failure services	The Revised Illness Perception Questionnaire (R-IPQ)and the Hospital Anxiety and Depression scale (HADS)	The Self-Care Heart Failure Index (SCHFI) and the Minnesota Living with Heart Failure (MLHF)
Mulligan et al., (2010)	Longitudinal	4 weeks after diagnoses and 6 months later	Diagnosed according to the European Society of Cardiology Criteria, Cognitively stable, English speaking, and considered well.	166	Not specified	The Hillingdon Hospital, West London and The Conquest Hospital, East Sussex.	The illness perception questionnaire (IPQ), Treatment Representations Inventory (TRI), and Hospital Anxiety and Depression Scale (HADS)	The Minnesota Living with Heart Failure Questionnaire (MLHF)
Hallas et al., (2009	Cross-sectional cohort study	Not specified	> 18 years of age	146	Not specified	Outpatient tertiary cardiothoracic hospital clinic	The revised illness perception questionnaire	COPE; World Health Organisation QoL brief assessment ;

						in the United Kingdom	and the Hospital Anxiety and Depression scale (HADS)	And Minnesota living with heart failure questionnaire
Bosworth et al., (2004)	Cross-sectional qualitative with focus groups	Not specified	LVEF <40% Ages ranged from 47-82	15	Stratified	General medicine clinic of the Durham VAMC	Semi-structured open-ended protocols	
Carels (2004)	Cross-sectional quantitative study	2 weeks	Aged 35-92 Documented diagnosis of CHF with an LVEF ≤ 50%	58 (33 men; 25 women)	Not specified	Heart Failure Clinic at a tertiary-care hospital in Northwest Ohio	The Beck's Depression Inventory	Participants completed a QoL diary every day for 2-weeks before going to bed
Clark et al., (2003)	Cross-sectional study	Enrolled during the first seven months of a medication adherence study	English-speaking, 50 years of age or older, CHF diagnoses by a physician	228 (68% female; 47% were not Caucasian)		Wishard Health Services (WHS) in Indianapolis	Health belief scale (HBS)	Kansas City cardiomyopathy questionnaire (KCCQ) And Chronic heart failure questionnaire (CHQ)

Part 3: Risk of bias within the key studies

The risk of bias among the key studies was assessed using critical appraisal tools, according to the study design. The risk of bias within the longitudinal studies was assessed using the critical appraisal skills program (CASP) cohort checklist (CASP, 2018); the risk of bias within the cross-sectional studies was assessed using the Joanna Briggs Institute (JBI) Critical Appraisal tool for cross-sectional studies, (JBI, 2020); and the risk of bias within the cross-sectional qualitative was assessed using the CASP tool for qualitative studies.

2.3.1 Critical appraisal of the longitudinal studies

In this literature review, two longitudinal studies have been selected among the key studies. Mulligan et al. (2010) described their study as being a within-subjects repeated-measures design. Whereas Goodman et al. (2012) identified the study design as being a longitudinal questionnaire survey. To critically appraise these studies the CASP cohort checklist (2018) was used as a guide.

Longitudinal studies monitor the same group of participants over time, comparing outcomes according to exposure to the suspected risk; this type of study also allows the researcher to look at multiple outcomes at one time. These are usually observational in nature (Caruana, 2015).

Both studies addressed their issues; Goodman et al. (2012) sought to examine the correlation of illness perception, QoL, and self-care behaviour among patients with a primary diagnosis of CHF and the changes after 2- and 6-months post-discharge. Mulligan et al. (2010) aimed to examine patients' illness perceptions and QoL changes after being diagnosed with CHF and identify factors that may influence changes. The assessment was carried out when given the diagnoses, after 4 weeks and 6 months. However, for this review, the changes over time would not be assessed, as it is irrelevant to the topic being researched. Therefore, the baseline assessment will be considered for this review.

Both studies recruited participants in a reliable way. Goodman et al. (2012) used the relevant national NICE (2010) guidelines and the international guidelines by McMurray et al. (2012) as diagnostic tools for CHF. Mulligan et al. (2010) used the ESC Criteria by Remme & Swedberg, (2002). Goodman et al. (2012) recruited participants from three different hospitals in the UK, all of which have a heart failure multidisciplinary team and manage patients using the same guidelines. In addition, Mulligan et al. (2010) recruited subjects from two general hospitals in the UK. Both studies were conducted among participants residing in the UK, limiting the study cohort. Retrieval of informed consent is mentioned in both studies.

The sample size of the study conducted by Goodman et al. (2012) was rather small, as it amounted to 88 participants, whereas Mulligan et al. (2010) recruited 166 participants. A smaller sample size may not offer as accurate results as the ideal sample size, as it increases the chance of assuming as true a false premise (Faber & Fonseca, 2014). Goodman et al. (2012) expressed difficulty in recruiting patients due to the nature of the disease; in addition, the dropout rate was quite high due to death.

To calculate the sample size, Goodman et al. (2012) based estimates of a previous study. 139 patients would be needed to achieve 80% power, testing at a 5% significant level, allowing expected mortality of 20% and drop out at another 20% at six months. Therefore, it was calculated that 190 patients would be needed. However, during recruitment, they found difficulties in recruiting more than 88, as some patients with CHF were deemed too sick to participate. Making the study longer would create variations in the treatment of participants who took part at the beginning of the study and participants who took part in later stages. Therefore, a sample of 88 subjects was recruited. By the time of the 6-month follow-up, 21 subjects (24%) passed away, and 17 (19%) did not return for the follow-up questionaries despite the reminders. No statistically significant differences were seen in baseline characteristics between those who completed the follow-up and those who did not.

Mulligan et al. (2010) initially recruited 210 participants who completed the questionaries at baseline; 17 of these participants died before the follow-up questionnaires. Mulligan et al. (2010) claim that the rest of the study subjects (166 participants) completed the follow-up questionnaires. A discrepancy of 27 participants was noted; these were not mentioned in the study. In addition, baseline values of QoL and illness perceptions were compared between those who completed the follow-up and those who died. No significant differences were detected.

For measuring the outcomes Goodman et al. (2012) used two validated questionaries to assess illness perception, the revised version of the IPQ (IPQ-R) and the hospital anxiety and depression scale (HADS), and two validated questionnaires to assess for QoL, the self-care heart failure index and the Minnesota living with heart failure (MLHF). Mulligan et al. (2010) used the IPQ, treatment representations inventory (TRI), and the HADS to assess illness representations. The IPQ shows satisfactory internal consistency and test-retest reliability and can differentiate between illness conditions (Weinman et al., 1996). The TRI also shows satisfactory internal consistency and can be adapted to cardiac patients (Hirani et al., 2008). Furthermore, Herrmann (1997) claims that the HADS is widely used and has been validated for cardiac patients.

In addition, to assess QoL, the MLHF was used. This scale represents a total score and two subscales: emotional and physical QoL domains. According to Garin et al. (2009), the MLHF shows satisfactory internal consistency: Cronbach‘s alpha 0.94 (95% Confidence Interval: 0.91–0.95) and test-retest reliability (Interclass correlation = 0.84). An echocardiogram was also carried out to assess for systolic function and the presence of comorbid illness. The New York Heart Association (NYHA) classification was used at both points in time.

Mulligan et al. (2010) used the original version of the IPQ. This was later revised by Moss-Morris et al. (2002), which extended the original dimensions and added assessments of emotional representations and illness coherence, which might have enhanced findings. The self-regulation model (Leventhal et al., 1998) claims that illness representations induce coping responses, which impacts health outcomes. Mulligan et al. (2010), failed to address this concept, this contribution might have added good value to the study.

Both studies attained ethical approval. Goodman et al. (2012) got approval from the Royal Brompton and Harefield & NHLI Ethics Committee (Ref. 07/Q0404/2). In addition, the study registered with the research and development department in each hospital. Furthermore, Mulligan et al. (2010) confirm that the investigation aligned with the principles outlined in the Declaration of Helsinki; additionally, the study received approval from the hospitals' ethics committees.

Goodman et al. (2012) mentioned that convenient sampling was used. Convenient sampling is a method that relies on the availability of the population for data collection. This is usually opted for as it simplifies the sampling process. It is the cheapest sampling method and can be facilitated in a short time. However, this method may lack credibility as it invites a high level of sampling error and is vulnerable to selection bias, (Dudovskiy, 2018). In addition, Mulligan et al. (2010) did not mention the sampling methods used.

A confounding factor is an influencing factor that can potentially affect the result of the study, which is not the thing being studied (MRC/CSO Social and Public Health Sciences Unit, 2022). The type of analysis used controlled for co-founders. The study conducted by

Goodman et al. (2012) shows that 70% of the study population were males, which shows a discrepancy in the sex recruited for the study which causes an imbalance (Aronson et al., (2018). Whereas 66% of the participants included in the study conducted by Mulligan et al. (2010) were males. Furthermore, both studies included participants from 18 years of age onwards. This might have an impact on results, as those of a younger age range might have a better QoL than those of an older age range.

In the study conducted by Goodman et al. (2012), the three hospitals used for recruitment have heart failure speciality services. Therefore, their results might not be applicable for general hospital settings. This is because the hospital offers extensive educational programs and support related to heart failure. Contrarily, Mulligan et al (2010) recruited participants from three hospitals which do not have heart failure speciality programs. Both studies initially recruited participants during their hospital admission, and results may differ among patients who were not hospitalised.

The self-regulatory model indicates that adapting to chronic conditions is a dynamic process in which many factors influence one another. Therefore, a change in QoL may affect an individual’s view about their disease. In contrast, a person’s views may affect their QoL. A summary of the two longitudinal studies can be found in Table 9.

Table 9

Summary of the risk of bias in the longitudinal studies

Author and publication year of study	Study subjects and setting clearly defined	Acceptable recruitment method	Sample size	Valid and reliable exposure measure	Objective standard criteria used for measurement of condition	Confounding factors identified	Strategies dealing with confounding factors addressed	Valid and reliable outcome measures	Appropriate statistical analysis
Mulligan et al., (2010)	✓	✓	✓	✓	✓	✓	✕	✓	✓
Goodman et al., (2012)	✓	✓	✕	✓	✓	✓	✕	✓	✓

2.3.2 Critical appraisal of the cross-sectional quantitative studies

Three key studies were identified as being cross-sectional quantitative studies. To critically appraise these studies, the JBI critical appraisal tool for cross-sectional studies was used as a guide. Cross-sectional studies are observational studies carried out to analyse data at one point in time. They are usually opted to measure the prevalence of health outcomes, describe features in a specific population, and understand determinants of health, (Weng & Cheng et al., 2020). Hallas et al. (2009), Carels (2004) and Clark et al. (2003), described their studies as being cross-sectional studies.

Eligibility criteria were clearly defined in all three cross-sectional studies. Carels (2004), Hallas et al. (2009) and Clark et al. (2003) included adults of all genders and only those who provided consent. In addition, an official CHF diagnosis was part of the eligibility criteria across all three cross-sectional studies. All studies limited their study to participants who spoke or understood English. Table 10 consists of the eligibility criteria set in the three cross-sectional studies.

All three cross-sectional studies recruited participants in a similar way. Hallas et al. (2009) recruited participants from a tertiary cardiothoracic outpatients' clinic in the UK; however, the recruitment method was not specified. The authors mentioned that 284 participants were identified and deemed eligible to participate in the study, of which only 146 gave their informed consent and handed back the questionnaire, which were included in the study. Similarly, Carels (2004) recruited participants from the Heart Failure Clinic at a tertiary-care hospital in Northwest Ohio, failing to mention how they were recruited. They recruited 58 subjects, with ages ranging from 35-92. In addition, Clark et al. (2003) recruited 212 participants from Wishard Health Services (WHS) in Indianapolis, Indiana, who met the eligibility criteria.

Hallas et al. (2009) and Clark et al. (2003) used similar methods for data collection. They both distributed validated questionnaires at one point in time. To measure illness perception, Hallas et al. (2009) used the R-IPQ and the HADS; Clark et al. (2003) used the health belief scale (HBS). For measuring QoL, Hallas et al. (2009) used the coping orientation for problems experienced (COPE) scale, the WHO QoL brief assessment and the MLHF questionnaire; Clark et al. (2003) used the KCCQ and the chronic heart failure questionnaire (CHQ). In addition, Hallas et al. (2009) used clinical databases and medical records to assess the severity of the condition and functional capacity of the participants. This included looking at echocardiographs, gated acquisition scans, and cardiopulmonary exercise treadmill tests, which were routinely done at the outpatients' clinic. Examinations closest to the study were used (not greater than eight weeks). This was used to further understand the significance of current function.

Similarly, Carels (2004) used the Beck's depression inventory (BDI) questionnaire to assess illness perceptions, which is widely used to evaluate representations of illness among patients with chronic cardiac disease (Carels, 2004). Conversely, to assess QoL, the participants were asked to complete a QoL diary every day for two weeks; sub-scales from well-validated self-reported instruments were selected and unaltered for the QoL diary. This included physical and emotional QoL, social support, positive and negative moods, and coping. This strengthened the study as it gives a less biased measurement than single administration questionaries.

Sample size varied between the studies; Hallas et al. (2009) recruited 146 participants, Carels (2004) recruited 158 participants, and Clark et al. (2003) recruited 228. All three cross-sectional studies provided an account of the participants' demographic data. Furthermore, all three key studies were set in one region and recruited participants from only one clinic, making it difficult to adapt it to the local population. Hallas et al. (2009) obtained written consent, and Carels (2004) only mentioned that consent was required, however, did not specify the type of consent. Therefore, this shows that none of the studies practised anonymity. In addition, they did not specify how the data collection instruments were distributed and none of the studies mentioned sampling methods.

Hallas et al. (2009) and Carels (2004) both used the Statistical Package for Social Sciences (SPSS) to perform statistical analyses. Hallas et al. (2009) used the Pearson correlations to determine a significant relationship between illness perceptions and QoL. Identification of significant variables in the analysis were recognised through correlational analyses and entered into 3 blocks relating to their association with the self-regulatory model. Carels (2004) used the Pearson correlation between mean and standard deviation (SD) to perform QoL indices to rule out the likelihood that a greater mean in QoL variables was not due to greater variability in these variables.

Clark et al. (2003) used estimated bivariate associations between each biological and demographic measures and the CHQ, the KCCQ, and perceived health. A multivariate model was also used with biological and demographic measures as the independent variables and perceived health and the KCCQ as the dependent variables. The cognitive characteristics and environmental resource measures were incorporated into the model to estimate the indirect effects of the biological and demographic measures through social-cognitive factors and environmental resources and the direct effect of environmental resources and social-cognitive factors. None of the studies investigated other chronic conditions (such as asthma) that could compromise the participants' physical symptoms and QoL. In addition, when applying this study to other populations, a discrepancy may be seen as all three studies include mainly Caucasian participants. A summary of the risk of bias in cross-sectional studies can be found in Table 11.

Table 10

Eligibility criteria of the cross-sectional studies

	Inclusion	Exclusions
Carels (2004)	- All genders - >18 years of age - ≤ 50% LVEF.	- Participants with cardiac-related symptoms such as uncontrolled hypertension within 3 months of enrolment - Gestating participants - Participants with pacemakers - Participants who abused of substances and drugs within 12 months of enrolment.
Hallas et al., (2009)		- Individuals who did not comprehend English - Individuals <18 of age - Individuals who did not provide consent.
Clark et al., (2003)	- Participants who took part in the WHS study for adherence medication - English Speaking - ≥50 years of age - Had a CHF diagnoses by a physician	

Table 11

Summary of the risk of bias in the cross-sectional studies

Author and publication year of study	Clearly defined inclusion criteria	Study subjects and setting clearly defined	Valid and reliable exposure measure	Objective standard criteria used for measurement of condition	Confounding factors identified	Strategies dealing with confounding factors addressed	Valid and reliable outcome measures	Appropriate statistical analysis
Hallas et al., (2009)	✓	✓	✓	✓	Can’t tell	N/A	✓	✓
Clark et al., (2003)	✓	✓	✓	✓	Can’t tell	N/A	✓	✓
Carels (2004)	✓	✓	✓	✓	Can’t tell	N/A	✓	✓

2.2.3 Critical appraisal of the cross-sectional qualitative study

One of the identified key articles was described as a cross-sectional qualitative study. In this section, this study, conducted by Bosworth et al., (2004) was critically appraised. The critical appraisal was carried out using the CASP critical appraisal tool for quantitative studies as a guide.

Eligibility criteria were clearly defined; the study included adult males only, with a LVEF of ≤40%, and patients who visited the Durham VAMC clinic at least once. Consent was obtained verbally over the telephone. In addition, the study was limited to participants who spoke or understood English.

Bosworth et al. (2004) recruited participants from the general medicine clinic of Durham (VAMC) and conveyed three focus groups made up of 15 male patients with a CHF diagnosis. Potential subjects were chosen using a centralised database. The most common diagnostic test was an echocardiogram to determine the LVEF and an angiogram. Eligible subjects were contacted by telephone. Then, focus groups were organised and stratified according to the NYHA stage; five participants were classified with NYHA stage III/IV, and 10 with NHYA stage I/II. Ages ranged from 47 to 82. Focus groups were taped, transcribed, and reviewed using the constant comparisons method.

Bosworth et al. (2004) explain that focus groups were used to collect data. Three focus groups were organised with five subjects in each group. Discussions were led by a psychologist; the average time of the discussion was 90 minutes. The discussion construction was of a semi-structured, open-ended nature. Participants were asked to discuss what was important to them when dealing with a chronic illness and the meaning of QoL and its components. When something was not clear the subjects were asked to clarify.

The sample size was a total of 15 participants. Since this was a qualitative study, the sample size is not considered small. Furthermore, an account of the subjects' demographic data was provided. A limiter noted was that all participants recruited were from the same region, of which most were Caucasian, making it harder to apply to different populations; another contributor to this limiter is that all participants were males.

Bosworth et al. (2004) audiotaped and transcribed the interviews conducted in the focus groups; this data was entered in a software called NUDIST. A grounded theory approach was taken with a constant comparison method. Two investigators transcribed and analysed the data independently. The first coder organised the analysis using NUDIST, permitting identification and coding of exemplars of attributes related to QoL, the second coder reviewed this. The investigators developed additional conceptual domains while axial coding by describing comparisons between themes. More than 30 attributes were identified, which were then collapsed into five broad domains.

Bosworth et al. (2004) did not investigate whether participants had other chronic conditions (such as asthma), which could affect the outcome concerning the subjects' physical symptoms and QoL. In addition, this study was carried out mainly among Caucasian subjects, which restricts its application among other populations. A summary of the risk of bias across the cross-sectional qualitative study can be found in Table 12.

Table 12

Summary of the risk of bias in the qualitative cross-sectional study

Author and publication year of study	✓
Clearly defined inclusion criteria	✓
Study subjects and setting clearly defined	✓
Valid and reliable exposure measure	✓
Objective standard criteria used for measurement of condition	✕
Confounding factors identified	Can’t tell
Strategies dealing with confounding factors addressed	N/A
Valid and reliable outcome measures	✓
Appropriate analysis and reporting of results	✓

Part 4: Results

2.4.1 Results of the longitudinal study

This section represents the results of the two longitudinal studies retrieved for this literature review. However, only the baseline results are presented, as the longitudinal changes are irrelevant to the research topic. The studies were conducted by Goodman et al. (2012) and Mulligan et al. (2012), respectively.

In the study conducted by Goodman et al. (2012), the univariate analysis shows a strong association between emotional representation on the R-IPQ and the MLHF emotional score (Adj $R^2 = 0.52$, $P < 0.0001$). A robust connection was seen between subjects with a strong emotional perception and self-care confidence, suggesting that subjects who were more emotionally affected by their illness had an inferior confidence in their capability to self-care ($P < 0.0001$ Adj $R^2 = 0.36$). Contrarily, participants who had the ability to make sense of their illness, showed less emotional symptoms (Illness Coherence on IPQR negatively associated with MLHF emotional score Adj $R^2 = 0.20$, $P = 0.01$) and with HADS anxiety score and depression score [$R^2 = 0.24$ and 0.30, respectively, both $P < 0.0001$]).

Furthermore, self-care confidence was positively related to illness coherence (Adj $R^2 = 0.22$, $P = 0.001$). No difference was noted in self-care maintenance and self-care management by the HADS categories in either depression or anxiety. Minor evidence was noted with self-care confidence. The majority of the participants in the study conducted by Goodman et al. (2012) expressed that the causes of their CHF were not in their control. The highest two causes for their illness were aging (64%) and by chance (45%) (Table 13).

In the study by Mulligan et al. (2012), 37% of the participants scored within the ‘possible’ clinical anxiety range, of which 12% scored within the ‘probable’ clinical anxiety range. Mulligan et al. (2010) claim that at baseline, participants generally had positive beliefs for controlling CHF. A variation was seen in beliefs regarding consequences and duration. Satisfaction concerning treatment decisions was also seen among the participants. Participants' perceptions of their chronicity of the disease showed a mean of 19.8 ± 4.2 at baseline (p= <0.001). A better perception was seen in QoL scores among subjects who did not have chronic obstructive pulmonary disease (COPD), those with an improved NYHA and a greater reduction in self-reported symptoms (IPQ ‘identity’), percieved consequences of the illness and depression (Table 14).

In both longitudual studies, not all domains were investigated at baseline, as some were only examined over time at the two additional longitudinal points.

Table 13

Results of the study conducted by Goodman et al., (2012). One-way ANOVAs comparing IPQ and Self Care data with HADS diagnostic groups: anxiety – mean (SD) and depression – mean (SD).

	Normal	**Border line**	**Case (anxious)**	**Normal**	**Border line**	**Case (depressed)**
Identity	4.73 (2.37)	5.88 (2.23)	7.25 (1.92)***	5.16 (2.40)	5.42 (2.61)	7.00 (1.95)
Consequences	18.85 (3.65)	21.08 (4.28)	22.35 (2.59)***	19.34 (3.76)	19.75 (3.98)	23.10 (2.83)***
Illness coherence	17.47 (4.58)	16.42 (4.77)	16.60(3.47)	17.82 (4.57)	14.91 (3.73)	15.75 (3.61)
Treatment control				17.70 (2.70)	17.38 (3.80)	16.80 (2.95)
Emotional representation	15.09 (4.62)*	18.63 (4.62)**	22.45 (4.35)***	14.96 (4.14)*	21.33 (3.03)	23.16 (3.98)***
Self-care maintenance	52.44 (13.47)	55.63 (10.56)	56.50 (10.43)	53.30 (12.84)	52.5 (10.16)	58.88 (10.71)
Self-care management	56.10 (19.65)	61.33 (18.09)	59.92 (19.22)	58.07 (19.61)	56.30 (14.06)	60.79 (20.77)
Self-care confidence	63.97 (19.91)	55.43 (14.68)	59.84 (16.36)	61.66 (18.25)	58.03 (17.19)	59.63 (18.50)

The level of significance is <0.05

* Significant difference between normal and borderline cases in relation to the IPQ and SC category

** Significant difference between borderline and depressed/anxious cases

*** Significant difference between normal/depressed cases

Table 14

Results of the study conducted by Mulligan et al., (2010)

	At baseline	
Variable	**Mean**	**SD**
Mood		
Depression	6.16	4.02
Anxiety	4.69	3.18
QoL		
Physical	20.57	11.31
Emotional	9.03	6.86
Total score	41.16	22.77
Illness belief		
Identity	9.14	4.21
Consequences	3.08	.59
Cure/control	3.67	.58
Timeline	3.20	.88
Treatment beliefs		
Treatment value	4.17	.52
Concerns	2.66	.76
Cure	3.13	.84
Decision satisfaction	4.06	.55

2.4.2 Results of the qualitative cross-sectional studies

Carels (2004) shows that a greater negative mood was significantly related to higher rates of depression, *t*(54) = 4.63, p=≤0.01, and lower LVEF, *t*(54) = 3.62, p= 0.05. In addition, the more severe the depression, the more it was associated with greater social conflict, *t*(54) = 3.68, p=≤0.01; lower positive moods *t*(54) =2.58, p=≤ 0.01; and lower perceived social support *t*(54) = 1.95, p=0.05. Therefore, greater variability in negative perceptions was associated with higher depression, *t*(54) = 3.42, p=≤0.01, and greater variability in social conflicts were associated with lower functional impairment, *t*(54) = 1.97, p= 0.05. Carels (2004) states that depressive symptoms are associated with diminished emotional and physical QoL. Therefore, CHF patients with depressive symptoms report more CHF-related physical symptoms and more variability in their pattern of physical symptoms. Similarly, they endorsed statements indicating a diminished emotional QoL, such as feeling out of control and feeling like a burden to family members. These findings are consistent with the other key studies, which suggest that depression can significantly decrease QoL in CHF patients. Coping behaviours were a common factor between the studies. Carels (2004) found that greater acceptance was significantly associated with lower depression, *t*(54)= 2.10, p=≤ 0.05. However, with greater functional impairment, *t*(54) = 1.95, p=≤0.05. This was also associated with greater symptom-focused coping, *t*(54) = 1.98, p= 0.05. Lastly, higher LVEF was associated with greater variability in distraction coping *t*(54) = 2.41, p=≤0.02. Hallas et al. (2009) show that depressed and anxious subjects exhibited more negative coping styles such as denial, behavioural and emotional disengagement and venting of emotions (Table 15).

Hallas et al. (2019) claim that 32% of the participants reported clinical depression, 25% reported ‘borderline’ clinical depression and 30% reported clinical anxiety. It was noted that patients with reported depression held more negative illness perceptions than those in non-depressive patients. These negative perceptions were related to their symptoms, the controllability of the illness, and the consequences of CHF. Similarly, this was also seen among participants with anxiety, who perceived greater uncertainty regarding the fluctuation and timeline of CHF and demonstrated less disease coherence. Illness representations independently anticipated the variance in depression scores, and by consequences of beliefs attributed to CHF. Depression showed the greatest significance in predicting negative QoL outcomes in the models used in the study conducted by Hallas et al. (2009) in the WHOQOL and the MLHF (Table 16).

Clark et al. (2003) noticed that age and gender were associated with some health related QoL measures. However, an indicator variable for Caucasian individuals had the most consistent association among the CHF related QoL measures. Despite the variable associations in the study, there was no clear path showing a significant association between participant characteristics and environmental variables. Associations of illness perception with health related QoL measures were apparent, however, modest. This may indicate opportunities for improving this with the possibility of improving CHF related QoL. LVEF and comorbidity were not linked with any QoL measures. Clark et al. (2003) argue that it is possible that a LVEF is not a good measure when measuring the severity of CHF, as most of the participants had a an LVEF of >40%. For this reason, Clark et al. (2003) split participants into two groups, group one containing a LVEF of 35% or less and group two containing a LVEF of 35% or greater. The LVEF and QoL correlations were estimated. In addition, the severity of CHF may be better represented through the NYHA classification. However, Clark et al. (2003) did not include this analysis in their assessment since it was based on participants’ perceptions (Table 17).

Table 15

Results of the cross-sectional study conducted by Carels (2004). Multiple regression with mean level QoL and illness perception

Variable	R^2	**β**	**Standard Error**	**Standard β,**
QoL physical	0.41			
Ejection fraction		0.23	0.21	0.28
Functional class		11.33	2.13	0.59*
Depression		0.46	0.19	0.27*
QoL emotions	0.45			
Ejection fraction		0.03	0.04	0.08
Functional class		0.05	0.73	0.01
Depression		0.40	0.06	0.66*
Negative emotions	0.34			
Ejection fraction		-0.08	0.04	-0.23*
Functional class		0.39	0.78	0.06
Depression		0.31	0.07	0.53*
Positive emotion	0.12			
Ejection fraction		-0.02	0.03	-0.08
Functional class		-0.09	0.49	0-.03
Depression		-0.11	0.04	-0.34*

* $p \leq 0.05$

Table 16

Results of the study conducted by Hallas et al., (2009)- Pearson corelations between QoL measures and other variables

	HADA	HADD	ID	TLC	TLAC	CONS	PC	TC	IC	ER	ESS	VENT	DEN	BDIS
PQOL	-.514**	-.638**	-.450**	-.294**	-.130	-.372**	.361**	.124	.133	-.374**	-.039	-.241*	-.107	-.416**
PSQOL	-.579**	-.716**	-.260**	-.164*	-.008	-.322**	.353**	.191*	.246**	-.523**	-.041	-.291**	-.161	-.492**
SQOL	-.358**	-.433**	-.0.95	-.101	-.035	-.238**	.185*	.164*	.088	-.230**	.239*	-.260**	-.204*	-.222*
EQOL	-.356**	-.591**	-.322**	-.325**	-.116	-.397**	.357**	.222**	.361**	-.428**	-.157	-.299**	-.210*	-.465**
MLHF	.575**	.647**	.494**	.361**	.041	.481**	.215**	-.081	-.102	.490**	.042	.263**	.114	.320**

IPQ-R scales: ID=identity; TLC= timeline-cyclical; TLAC=timeline-acute/chronic; PC= personal control; TC=treatment control; IC= illness coherence; ER= emotional representations.

HADS scales: HADA= hospital anxiety subscale; HADD= hospital depression subscale.

WHOQOL scales: PQOL= physical QoL; PSQOL= psychological QoL; SQOL= social QoL; EQOL= emotional QoL; MHLF= Minnesota living with heart failure questionnaire.

Table 17

Results by Clark et al., (2003)- Ordinary least squares regression models of perceived health, KCCQ, CHQ.

	Perceived health		KCCQ Functional status		CHQ Emotional	
	Model 1 (SD)	Model 2 (SD)	Model 1 (SD)	Model 2 (SD)	Model 1	Model 2
Age	0.003***(0.01)	0.003***(0.01)	0.36* (0.18)	0.18 (0.18)	0.32*** (0.08)	0.25** (0.07)
Male	0.00 (0.11)	0.09 (0.11)	1.54 (3.40)	5.11 (3.30)	2.72 (1.43)	4.12** (1.33)
White	-0.14 (0.10)	-0.15 (0.11)	-11.35*** (3.08)	-10.06** (3.1)	-4.43*** (1.29)	-4.03*** (1.24)
Comorbidity	-0.01 (0.01)	-0.01 (0.02)	-1.25 (0.74)	-1.17 (0.68)	0.25 (0.31)	0.19 (0.27)
Ejection fraction	0.22 (0.31)	-0.23 (0.31)	7.71 (9.8)	7.02 (9.05)	-0.05 (4.10)	0.45 (3.65)
Education		0.01 (0.01)		0.55 (0.55)		-0.03 (0.22)
Income		0.01 (0.10)		7.00* (3.01)		4.96*** (1.22)
Health beliefs		0.01*** (0.00)		0.22** (0.08)		0.05 (0.03)
Patient communication		-0.00 (0.00)		-0.16** (0.53)		-0.05* (0.02)
Social support		-0.00 (0.00)		0.10 (0.07)		0.11*** (0.03)
Adequate literacy		0.14 (0.12)		5.58 (3.60)		3.70* (1.44)
Adjusted R-squared	0.12	0.14	0.09	0.25	0.14	0.33

KCCQ- Kansas City cardiomyopathy questionnaire; CHQ- Chronic Heart failure clinic

* P<0.05

**P<0.01

***P<0.001

2.4.3 Results of the qualitative cross-sectional study

In the study by Bosworth et al. (2004), a negative influence was seen of physical symptoms on participants' QoL. Participants also showed concern for future management of symptoms. In the focus groups, participants showed negative effects on cognitive symptoms related to CHF, such as confusion and memory loss. In addition, a concern for the impact of their symptoms on their family members was also seen.

Bosworth et al. (2004) noted that during the focus groups, participants spoke with frustration about losses related to ability, taking away some of their independence, influencing their QoL. In addition, since this study included male participants only, the impact of CHF on their masculine role was also affected in household roles and due to loss of sexual intimacy. Loss of work and income were also two factors that strongly impacted their QoL. Bosworth et al. (2004) mentioned that participants admitted that in times of low mood, low self-worth, and depression, a link between their physical QoL and role limitations was noted. Therefore, limiting beliefs were linked with limiting their ADLs.

Bosworth et al. (2004) mentioned how the participants in the focus group revealed finding alternatives to previous leisurable activities or adopting more spiritual beliefs. Interestingly, strengthening of spiritual beliefs was seen more in patients with higher stages of CHF.

Part 5

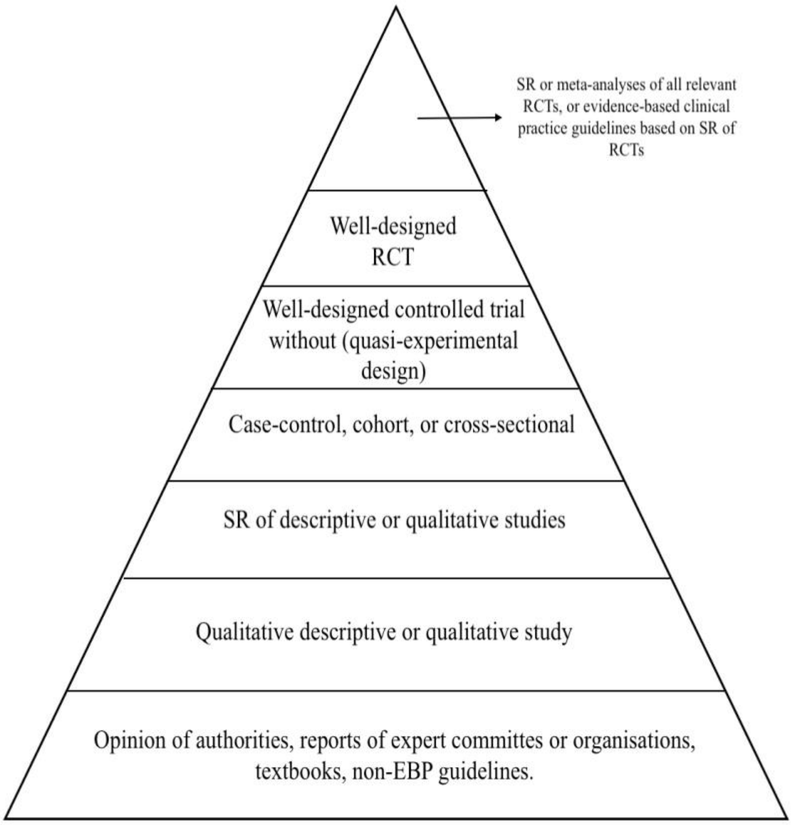
2.5.1 Overview of the literature review

This review was carried out by examining reliable studies related to the topic being researched in an evidence-based way. The studies retrieved in this literature review consist of two longitudinal and three quantitative cross-sectional studies and one qualitative cross-sectional study. According to Ingham-Broomfield (2016), understanding the hierarchy of evidence is one of the main components in recognising the most rigorous studies to apply them in healthcare. The Hierarchy of Evidence Pyramid provides a visual demonstration of different research designs and their level of reliability (Figure 2).

Figure 2 gives a detailed representation of the hierarchy of evidence in pyramid form. The top of the pyramid represents the most reliable study designs; while the pyramid decreases, so does the reliability (Walden University, 2018). Systematic reviews (SR) and meta-analyses are found at the apex of the pyramid, deeming them the most reliable. Both study designs included in this review, longitudinal and cross-sectional studies, can be found in the fourth row in the below pyramid. Cross-sectional and longitudinal studies encompass a low level of aetiology hierarchy. However, the information gathered from these studies may be the starting point that provides the incentive to carry out a study of better quality (McNair & Lewis, 2012).

Figure 2

Hierarchy of evidence- Adapted from Melnyk & Fineout-Overhault, 2005



2.2 Conclusion

In conclusion, this chapter gave an overview of the topic being researched while providing evidence-based literature relevant to the topic by giving a step-by-step process of how this was achieved. Critical analyses of the articles retrieved, and their respective results were provided. The next chapter encompasses the methodology used to retrieve data for this research study.

Chapter 3: Research Methodology

3.1 Introduction

This chapter presents the aims and objectives of this research study, describes the methods used to carry out this research project and why they were chosen and explains data collection and analysis methods. It also presents limitations in the study design and how they were minimised. It explores reliability and validity issues and finally discusses ethical considerations.

3.2 Research outline

3.2.1 Problem statement

It is natural to formulate illness perceptions attributed to one's chronic disease. These attributions may impact the individual's psychological well-being, affecting disease control and QoL (Smith et al., 2015). As Holmes (1989) stated, healthcare professionals (HCPs) should aim to improve QoL to achieve other therapeutic goals. Therefore, it is suggested that HCPs formulate QoL evaluations and address QoL issues in conjunction with other treatment. Hence, this study is being carried out to investigate the association of these illness perceptions with QoL, particularly among patients with CHF.

3.2.2 Aim and objectives of the study

The principal aim of this dissertation was to investigate the relationship between illness perceptions and QoL among patients diagnosed with CHF.

<u>The specific objectives of the study are:</u>

- Assessment of illness perception among individuals with CHF
- Assessment of QoL among individuals with CHF
- Assessing the association between participants' demographic and clinical characteristics with illness perception and QoL

- Analyzing the correlation between illness perception and QoL among individuals with CHF

3.3 Research design

3.3.1 The chosen research design

Research design is the approach taken towards collecting data and analysing the data set to address the aim of the research study. Appropriate research design implementation affects the study's credibility (Scholtz et al., 2020).

A quantitative approach was taken to carry out this study. Quantitative research is defined by Sukamolson (2007) as a representation of numerical data and observations to explain and describe a phenomena. This approach was chosen as this study aims to better understand situations that affect individuals by testing relationships, discovering patterns and generalising results to a wider population. A cross-sectional design was chosen as it allows the researcher to measure the variables of the study simultaneously at one point in time. In addition, cross-sectional designs allow the researcher to assess the association between different variables (Setia, 2016).

The researcher assumes that illness perceptions and QoL may correlate, which may be helpful when developing proactive policies in healthcare by identifying high-risk patients and planning for psychological interventions in conjunction with medical interventions (Yaraghchi et al., 2012). This was seen in other diseases, including contact dermatitis (Benyamini et al., 2012), prostate cancer (Mickeviciene et al., 2018), patients who underwent a CABG (Yaraghchi et al., 2012) and patients with multiple sclerosis (Spain, 2007), among others. Therefore, this hypothesis will be tested in this dissertation through a cross-sectional research design, aimed to assess a large sample of participants diagnosed with CHF at one point in time.

3.3.2 Research tools and data collection

Data collection took place by distributing questionnaires among patients diagnosed with CHF at the Heart Failure Clinic at a general hospital in Malta. The questionnaires included three sections: collection of (1) demographic and clinical characteristics, (2) data related to illness perceptions, and (3) data collection related to QoL. The collection of data was carried out from June to October 2022. No personal data was collected to maintain anonymity. Therefore, individuals who participated in this study are non-identifiable.

The research tools used for the collection of data are two validated questionnaires. The brief illness perception questionnaire (B-IPQ) (Weinman et al., 1996) (Appendix A) was used to collect data related to illness perception. Whereas the brief Kansas City cardiomyopathy questionnaire (KCCQ-12) (Spertus 2012) (Appendix B) was used to gather information related to QoL. Permission was obtained to use both the B-IPQ (Appendix C) and the KCCQ-12 (Appendix D). In addition, 10 additional questions were included to gather information on the participants demographic data and clinical status (Appendix E).

The B-IPQ is derived from the original IPQ developed by Weinman et al. (1996) and later revised by Moss-Moris et al. (2002). The B-IPQ is a 9-item scale which assesses emotional and cognitive illness representations (Broadbent et al., 2006). It encompasses a single-item scale approach for assessing perceptions on a continuous linear scale, providing a concise assessment of illness representations, which can be adapted to large-scale studies (Broadbent et al., 2006).

The KCCQ-12 is a 12-item self-administered questionnaire developed by John Spertus (2012); it is a shorter version of the original Kansas City Cardiomyopathy

Questionnaire (KCCQ-23), consisting of 23 questions. The KCCQ-12 addresses the social, physical, and emotional domains of QoL among individuals with CHF (Spertus, 2020).

These questionnaires were chosen as they are both widely used. In addition, they were both tested for reliability and validity by their respective authors. This is discussed in more detail in imminent sections.

These questionnaires were distributed via an intermediary person at the nurse-led heart failure outpatient clinic. The intermediary person works at the heart failure clinic and has access to the patients who attend their appointments. The role of the intermediary person was to give brief information on the study and its purpose to potential participants while highlighting its importance to healthcare. In addition, should they wish to participate voluntarily, they may do so by filling in the questionnaire and putting it in an enclosed designated box in the outpatients' waiting area. An invitation letter explaining the role of the intermediary was given to the intermediary person and signed (Appendix F).

3.3.3 Target population and eligibility criteria

The target population is the group of people that the researcher is interested in researching and examining (Whaley, 2022). According to Patino and Ferreira (2018), to conduct a high-quality research study, forming eligibility criteria is a required practice. Eligibility criteria outline key features included in the study termed *inclusion criteria*, whereas features that may hinder the study's success or pose a risk for unfavourable outcomes are termed *exclusion criteria*. The target population for this study included participants 18 years of age or older who are medically diagnosed with CHF. In addition, no restrictions on gender, ethnicity and race were put in place (Table 18).

Table 18

Eligibility criteria

	Inclusion criteria	Exclusion criteria
Demographic	Adults >18 years of age; All genders	Individuals <18 years of age
Clinical	Medically diagnosed with CHF	Individuals not diagnosed with CHF
Geographic	No restriction on ethnicity and race; Individuals who understand either English or Maltese	Individuals who do not understand either English or Maltese

3.3.4 Sample size and Sampling

The sample size was determined by using an online sample size calculator (https://www.surveysystem.com/sscalc.htm). A sample of 248 participants was needed to allow a margin of error of +/- 5% with a confidence interval (CI) of 95%.

The sampling technique used in this research study is convenient sampling. Convenient sampling is a method that recruits all eligible participants willing to participate in the study. This method is time-efficient, inexpensive and readily available, making it uncomplicated to conduct (QuestionPro, 2022). Limitations of this type of sampling include bias; collected samples may not represent the population of interest. Convenience sampling may introduce selection and sampling bias. This issue might lead to less credibility of the research findings (Simkus, 2022).

3.3.5 Translation of the instruments

The target population mainly included Maltese citizens; therefore, the data collection instruments were translated from their original language, English, to Maltese. The WHODAS 2.0 translation package (version 1.0) guided the translation process (Appendix G). The translation was done on the demographic and clinical data questionnaire (Appendix H), on the B-IPQ (Appendix I) and on the KCCQ-12 (Appendix J).

This process was done by having an independent professional translator translate the data collection instruments from English to Maltese while highlighting phrases and terms that posed problems for further linguistic evaluation. However, since the questionnaires were concise and straightforward, linguistic evaluation was not needed. Another translator back-translated the questionnaires to their original language, English. Lastly, a group discussion between the translator and the back-translator was held to formulate the final version in the Maltese language. The discrepancy identified was the translation of the term CHF, which was translated to 'insufiċjenza tal-qalb' in some questions and to 'falliment tal-qalb' in other questions. It was decided that 'insufiċjenza tal-qalb' was more appropriate. Therefore, this was used to translate the term CHF among the questionnaires to keep consistency. In addition, the translated questionnaires were tested for consistency before starting the actual data collection. This will be further explained in the pilot study section (3.5).

3.4 Reliability and validiity

Reliability and validity are notions used to assess the quality of the research. They indicate how well a technique, method, or test measures something. Reliability evaluates consistency, and validity evaluates the accuracy of a measure (Middleton, 2021).

3.4.1 Reliability

Reliability refers to how consistent a method that measures something is. It measures the extent to which results may be replicated if the research is repeated under the same circumstances. This is carried out by testing the consistency of the results amongst different observers, through time and across parts of the test itself. If the same results are achieved, it is considered reliable. A reliable measurement is not always valid; although results may be reproducible, it does not indicate accuracy (Middleton, 2021).

There are different methods to assess Reliability. Test re-test examines the consistency of a measure across time, therefore assessing whether the same results would be obtained if the measurement is repeated. The interrater measures the uniformity of a measure across observers. Therefore, whether the same results would be obtained if different researchers carried out the same study. Internal consistency refers to the uniformity of the measurement itself, whether the same results would be obtained from different parts of the test designed to assess the same measurement. Reliability ought to be considered when data collection takes place. It is imperative to use data collection instruments which are stable, precise and reproducible (Middleton, 2021).

3.4.1.1 Reliability testing of the B-IPQ

In the B-IPQ, Karatas et al. (2017) used Cronbach’s Alpha internal consistency coefficient to determine if each item measures the characteristics they aim to measure. The Cronbach’s alpha was 0.85, cognitive illness representation was 0.80 and emotional illness representation was 0.83. These findings show high-reliability scales. Table 19 shows the total item correlations and Cronbach’s Alpha coefficients for emotional and cognitive illness representations (Karatas et al., 2017).

Table 19

Total item correlation and Cronbach's alpha reliability coefficients (brief-IPQ)

Factors and Items	Mean	SD	Total-item correlation	Cronbach's alpha coefficient without the item
Emotional illness representations (Cronbach's alpha: 0.83)				
Item 1 (consequences)	6.73	2.49	0.572	0.815
Item 4 (illness identity)	5.42	2.53	0.607	0.800
Item 5 (Concern)	4.85	2.95	0.678	0.769
Item 7 (emotions)	6.00	2.99	0.762	0.726
Cognitive illness representations (Cronbach's alpha 0.80)				
Item 2 (personal control)	5.11	2.94	0.702	0.667
Item 3 (treatment control)	4.15	3.15	0.621	0.760
Item 6 (coherence)	4.57	2.68	0.624	0.753

3.4.1.2 Reliabilty testing of the KCCQ-12

Pettersen et al. (2005) assessed the KCCQ for reliability and internal consistency. This was done using Crobach's alpha, which ranged from 0.66 to 0.95 (Table 20). According to Tavakol and Dennick (2011), the acceptable values of alpha range from 0.70- 0.95; results with a low alpha value could be due to a low number of questions and poor inter-relatedness between heterogeneous constructs and items. In the test re-test, interclass correlation coefficients on various KCCQ scales were physical limitation 0.79, symptoms 0.78, symptom stability 0.60, social limitation 0.73, self-efficacy 0.41, KCCQ functional status 0.83 and KCCQ clinical summary 0.83 (Pettersen et al., (2005).

Reproducibility, also referred to as test-retest reliability, examines the changes in the scores among patients whose clinical status has not changed (Spertus & Jones, 2016). Spertus & Jones (2016) explained that the reproducibility of the KCCQ-12 was assessed by comparing baseline and 6-week changes among the Heart Failure Clinic patients who showed no clinical changes based on physician and patient global health assessments and who did not participate in clinical events. The mean and SD of 6-week change scores and interclass correlations were calculated. The interclass correlation indicates the proportion of variability among scores due to ‘between-patient’ differences (versus within-patient). Interclass correlations >0.4, 0.6 and 0.8 indicate moderate, significant and excellent reproducibility.

Table 20

KCCQ scales (0-100) scores and internal consistency (KCCQ-12)

	n	Number of items	Mean (SD)	% Floor	% Celling	Internal consistency reliability
Physical limitation	380	6	81 (24)	1	28	0.91
Symptoms	399	7	82 (21)	0	28	0.86
Symptom in stability	384	1	52 (12)	1	4	(Not provided)
Social limitation	366	4	75 (29)	2	36	0.90
Self-efficacy	397	2	75 (24)	1	22	0.66
Quality of life	394	3	78 (23)	1	30	0.84
KCCQ functional status	399	13	81 (21)	0	19	0.93
KCCQ clinical summary	403	20	79 (21)	0	13	0.95

3.4.2 Validity

Validity refers to the accuracy of a measurement tool. Therefore, it assesses the extent to which results measure what they are supposed to measure. If a tool has high validity, it shows that results correspond to real characteristics, properties, and variations. This is assessed by examining how well results link to recognised theories and other trials of the same concept (Middleton, 2021).

Validity can be estimated based on three main types of evidence. Each type can be assessed through statistical methods or expert judgement. These three types of evidence are:

- construct, which assesses the adherence of a measure to the existing knowledge and theories of the concept being measured;
- content, which assesses the degree to which the measurement covers all features of the concept being measured;
- criterion, assesses the extent to which a measure's result parallels other valid measures of the same concept (Middleton, 2021).

Internal and external validity should also be considered when assessing the cause-and-effect relationship. Internal validity refers to the degree of confidence that other factors or variables do not affect the cause-and-effect relationship being tested (Bhandari, 2022). External validity refers to the degree to which results from the study can be generalised to other groups, events or situations. (Streefkerk, 2021).

3.4.2.1 Validity of the B-IPQ

According to Karatas et al. (2017), the authors used exploratory factor analysis (EFA), which determined the factor structure of the B-IPQ. This showed that emotional illness representations comprised item 1, item 4, item 5, and 7. The loadings of the items in this factor ranged from 0.697 to 0.844. In addition, this shows a total variance of 52.609%. Cognitive illness representations compromised of item 2, item 3 and item 6; the loadings of the items in this factor ranged from 0.694 to 0.885.

Moreover, this shows 14.516% of the total variance. The level of acceptance for the factor loading values was limited to 0.40. Table 21 represents the factor, factor loadings and the variances obtained from the EFA.

Table 21

The factor, factor loads and variances (B-IPQ)

Items	Factor loads	Eigenvalues	Variance	Cumulative variance
Emotional illness representations				
Item 7 (emotions)	0.844	4.209	52.609	52.609
Item 1 (consequences)	0.789			
Item 5 (concern)	0.750			
Item 4 (illness identity)	0.697			
Cognitive illness representations				
Item 6 (coherence)	0.885	1.161	14.516	67.125
Item 2 (personal control)	0.812			
Item 3 (treatment control)	0.694			

Table 22 represents the correlation coefficients between the emotional and cognitive illness representations. The data obtained shows a moderately significant correlation between the two factors ($p < 0.01$) (Karatas et al., 2017).

Table 22

Coefficients of the correlations (B-IPQ)

Sub dimensions	Emotional illness representations	Cognitive illness representations
Emotional illness representations	1.00	0.542
Cognitive illness representations	0.542	1.00

3.4.2.2 Validity of the KCCQ-12

Validation was tested across three clinical settings using a series of analyses by evaluating construct validity, responsiveness and detection of minimal clinically significant differences. Parallel analyses of these studies were conducted for comparison. For evaluation of construct validity, the scores of each domain of the KCCQ-12 were compared with their corresponding score of the original, full questionnaire version, the KCCQ-23. Means and SD of the scores and the differences and concordance coefficients were calculated and reported. Moreover, the KCCQ overall summary scores were calculated using the NYHA class I to IV, and the association was estimated using Kendall's τ-b rank correlation coefficients (Spertus & Jones, 2016).

According to Frey (2018), predictive validity refers to the degree to which assessment scores are related to performance on a criterion which is administered in the future. Spertus & Jones (2016) explain that the KCCQ scores were used to predict the outcome of cardiovascular hospitalisation among patients with stable CHF or of 6-month death (EPHESUS Month 6 data) and the outcome of patients recovering from acute CHF hospitalisation (EVEREST Week 1 data). Kaplan- Meier methods within predefined score categories (0 - <25- poor; 25- <50- fair; 50-<75 – good; 75-100 excellent) were used to calculate cumulative 6-month incidence.

Responsiveness examines the sensitivity of the measure to clinical change. Responsiveness of the KCCQ-12 to clinical change was measured by the changes from baseline to 1 week after hospitalisation for acute CHF. The mean and SD of the change and the standardised response mean were calculated. Standardised response means > 0.5, and 0.8 shows moderate and robust responsiveness (Spertus & Jones, 2016).

Minimal clinically important difference defines the extent to how clinically meaningful the change is. In the KCCQ interpretability study, physicians were asked to complete a global evaluation of patients with clinical changes at baseline and follow-up visits by completing a 15-point scale: -7 (indicates high limitations) and +7 (indicates low limitations). Three assessments were implemented; the ROC analyses predicted significant improvement (global assessment rating of ≥2) and significant deterioration (global assessment rating of ≥-2) in the 6-week change in the KCCQ scores. The optimal KCCQ cut point was chosen at the point maximising Youden’s Index for each endpoint, which weighs specificity and sensitivity equally. Cut point confidence intervals were derivative of bootstrap methods. According to previous reports, the mean group differences in KCCQ scores ≥5 points show clinical importance. The specificity and sensitivity of intraindividual changes in patient scores of these scales being clinically significant were reported. Analyses were conducted on the entire KCCQ Interpretability Study population to fully use all available data (Spertus & Jones, 2016). A summary of this can be found in Table 23.

Table 23

Analysis for Validity conducted on the KCCQ

	Study 1: Stable HF (n=673)		Study 2: HF Clinic visit (n=273)		Study 3: Acute HF Recovery (n=853)	
	Mean±SD*	Missing (%)	Mean±SD*	Missing (%)	Mean±SD*	Missing (%)
Physical limitation						
Low intensity						
1a. Dressing yourself	4.6±0.9	4	4.4±0.9	1	4.0±1.1	2
1.b. showering/bathing	4.6±0.9	4	4.4±1.0	0	3.9±1.2	2
Moderate intensity						
1.c. walking 1 block	4.2±1.2	5	3.6±1.4	2	3.4±1.3	4
1.d. Yard work/housework	3.8±1.3	8	3.1±1.4	3	2.7±1.3	11
High intensity						
1.e. climbing stairs	3.8±1.3	7	3.0±1.5	3	2.7±1.3	7
1.f. Hurrying/jogging	3.0±1.5	15	2.1±1.4	7	1.9±1.1	12
Symptom frequency						
3. Swelling frequency	4.6±1.0	2	4.0±1.4	1	3.6±1.4	1
5. Fatigue frequency	5.3±1.8	1	4.1±2.0	1	3.8±1.9	1
6. Dyspnoea frequency	5.6±1.8	1	4.4±2.1	1	4.1±2.0	1
9. Dyspnoea- sleeping upright	4.6±1.0	1	4.0±1.4	0	4.0±1.4	1
Quality of life						
12. Enjoyment of life	4.0±1.1	1	3.3±1.3	0	3.1±1.2	1

13. Rest of life as is now	3.5±1.2	1	2.9±1.3	0	2.6±1.2	0
14. Discouraged or down	4.0±1.1	1	3.5±1.1	1	3.4±1.2	1
Social limitation						
15.a. Hobbies/ recreation	3.8±1.3	9	3.0±1.4	8	2.9±1.3	15
15.b. Working/ chores	3.9±1.4	25	3.0±1.3	5	2.9±1.3	10
15.c. Visiting family/ friends	4.2±1.1	7	3.8±1.2	8	3.1±1.4	12
15.d. Intimate relationships	3.8±1.3	9	3.0±1.5	22	2.7±1.5	37

3.5 Pilot study

A pilot study is a small-scale, preliminary study conducted before starting large-scale quantitative research to evaluate the feasibility, cost, practicality, and the needed time and resources. Therefore, it evaluates the potential for a future project by identifying design issues which may be problematic (Simkus, 2022). Since the questionaries were translated into the Maltese language, part of the pilot study was dedicated to testing the translated questionaries for reliability through a test re-test procedure.

The pilot study was conducted between April and May 2022. After the translation process of the data collection instruments, the questionnaires were tested for stability to ensure that the translated versions to Maltese were consistent with the original English versions. This was done by distributing the English version of questionnaires at the Heart Failure Clinic whilst also giving the participants another questionnaire in the Maltese version, enclosed in an envelope addressed to the heart failure clinic. The intermediary person distributed the questionnaires and made sure that the participants taking part in the test-retest were knowledgeable in both Maltese and English. In addition, participants were also instructed that should they be willing to participate in this language validation process, they may fill in the copy provided in the envelope after two weeks and send it by post. According to Park et al. (2017), 14 days is an ideal time between intervals. Therefore, the interval between one questionnaire and the other was set to two weeks. In addition, a total of 50 questionnaires were distributed, of which 26 were collected back.

Test-retest reliability was carried out on the B-IPQ and the KCCQ-12. Kendall’s tau-B test on SPSS was used to test the reliability of both questionnaires, as they measure outcomes through an ordinal scale. Kendall’s tau-B is a non-parametric measure assessing the relationship between two variables. This method was chosen because Kendall’s tau-B test is suitable for quantitative, ordinal variables present in both questionnaires. Therefore, this test will indicate how strongly the two variables correlate (Van Den Berg, 2022). Kendall’s tau-B correlation coefficient gives a value of 0 to 1, where 0 indicates no relationship between the two variables and 1 indicates a perfect correlation (Van Den Berg, 2022).

The B-IPQ encompasses eight questions, assessing the participants’ illness perception through an 11-point scale ranging from 0-10. The results all showed a strong association between the variables, with statistical significance (Table 24).

Table 24

B-IPQ Kendall's tau-B results

	Kendall's Tau-B (τ_b)	P Value
Question 1	0.968	P=<0.001
Question 2	0.707	P=<0.001
Question 3	0.941	P=<0.001
Question 4	0.834	P=<0.001
Question 5	0.824	P<0.001
Question 6	0.727	P=0.001
Question 7	0.584	P=0.004
Question 8	0.614	P=0.002

The KCCQ-12 encompasses 12 ordinally scaled questions, where participants were instructed to mark the most appropriate answer on the scales provided within each question. Similarly, Kendall's tau-B was also used to assess the correlation between the two phases of the questionnaire. Kendall's tau-B test results on the KCCQ-12 show strong stability among all the questions. However, the P value of the first question did not show statistical significance. In this question, participants were asked how much they feel they have been limited due to CHF when showering/bathing; they were asked to rate their response on a 5-point scale ranging from *'extremely limited'* to *'not at all limited'*. In addition, an option *'limited for other reasons/ does not do this activity'* was also provided. The p-value might have varied as one of the participants marked *'quite a bit limited'* in the first questionnaire and *'limited for other reasons/does not do this activity'* in the second questionnaire. All other questions show strong stability. These values can be found in Table 25.

Table 25

KCCQ-12 Kendall's tau-B results

Question no.	Kendall's tau-B (τ_b)	P value
1.a	0.583	(P=0.134)
1.b	1.000	(P= <0.001)
1.c	0.839	(P= <0.001)
2	0.910	(P= <0.001)
3	0.848	(P=<0.001)
4	0.897	(P=0.001)
5	0.772	(P=0.007)
6	0.663	(P=<0.001)
7	0.817	(P=0.001)
8.a	0.792	(P=<0.001)
8.b	0.730	(P=0.001)
8.c	0.953	(P=<0.001)

In light of the test re-test reliability, no amendments were made in both questionnaires. In addition, no other problematic issues related to the study design and approach were identified in the pilot study.

3.6 Ethical consideration

Ethical clearance was granted by the Faculty of Health Sciences Research Ethical Committee (FREC); Ethical clearance code: FHS-2021-00032 (Appendix K). This is a primary task in protecting research participants. This was required prior to the distribution of the research instruments as to ensure that the research aims to attain good, that expected benefits will outweigh any probable risks and that human subjects will not be harmed (Tangwa, 2009). This section provides discussions related to the ethical principles adopted in this dissertation.

3.6.1 Permissions and gaining access

In addition to ethical clearance by the FREC, several other permissions were required to carry out this research study. These include:

- Departmental permissions, including permission from the Chairman of Cardiology, all cardiology consultants who have patients attending the Heart Failure Clinic (Appendix L) and from the nursing officer of the Heart Failure Clinic who acted as the intermediary person for this study (Appendix F).
- Institutional permissions from the Chief Executive Officer (CEO) of Materdei Hospital (Appendix M) and the Data Protection Officer (DPO) (Appendix N)
- Permission to use the brief-IPQ (Appendix C) and the KCCQ-12 (Appendix D)
- Ethical permission to carry out this research was granted by the FREC (Appendix K).

3.6.2 Beneficence and non-maleficence

Beneficence is defined as the principle of doing good by promoting the well-being of others. Moreover, non-maleficence refers to the intention to avoid needless harm or injury to others (Sher, 2011). In healthcare research ethics, beneficence and non-maleficence translate into maximising the benefits and minimising the harms, especially to the participants (Tangwa, 2009).

According to Hinson (2012), weighing risks with benefits is crucial when conducting a study. Potential harm in observational studies is commonly less than in experimental studies. This depends on whether the observational study collects information from previously collected information or whether new information is being collected. Potential harm in observational studies is breaching of confidentiality. However, this will not be an issue in this study as data was collected anonymously, and therefore, breaching confidentiality will not be possible.

Since this study sought to examine how illness perception and QoL are linked among participants with CHF, the findings may be beneficial in the healthcare setting by providing benefits and improving the delivery of care among patients with CHF, possibly integrating the findings with the care already being given (Hinson, 2012). A strategy to prevent harm to participants during the data collection process was providing support offered by Kellimni.com at no financial costs (Appendix O).

3.6.3 Anonymity

Anonymity in research is defined as data that does not contain information identifying individuals (Keio University, 2021). Anonymity was maintained throughout the study, as the study participants were blinded from the researcher at all times, making them unidentifiable. This was done via an intermediary person, who was identified to distribute the questionnaires among the participants at the Heart Failure Clinic, making them anonymous from the researcher. Subjects were instructed by the intermediary not to write their name on the research instrument. Information regarding anonymity was given to the participants' in the information letter attached with the data collection tools. In addition, data gathered for this dissertation was only accessible by the researcher, dissertation supervisor and co-supervisor for research purposes.

3.6.4 Informed consent

Informed consent is a legal and ethical requirement in research involving human subjects. It is the process of informing participants about all the benefits and risks of the intervention, which leads them to deciding whether they wish to participate in the study. This involves informing the participants about the purpose of the study, their rights, the potential risks and benefits, what their role entails, the duration of the intervention and the extent of confidentiality, so their participation is entirely voluntary (Nijhawan et al., 2013).

According to Wagner (2020), informed consent encompasses four principles: the ability or capacity to decide, the disclosing of information by the researcher, the competency to understand relevant information and the documentation of consent. To keep participants anonymous, a consent form was not distributed. However, an information letter was attached to the research instruments. The information letter encompassed a brief overview of the purpose of the study, an explanation of how data collection will take place and informing potential participants that their participation is entirely voluntary. In addition, the information letter also provides an account of how the data gathered will be stored and that all questionaries will be destroyed upon completion of the study. Lastly, the information letter clearly states that by completing and handing in the questionnaire, implied consent is given. The information letter was given both with the English version (Appendix P) and the Maltese version (Appendix Q) of the data collection instruments. Furthermore, the intermediary person gave a brief explanation to all potential participants so that individuals who are uninterested in participating would not be given the information letter and the questionnaires.

3.7 Data analyses

Data analyses was carried out using SPSS version 28.0.0.0. Prior to starting the analyses of the research study various tests were carried out as to ensure accurate data entry. Test-retest reliability was carried out in the pilot study on the B-IPQ and the KCCQ-12 to ensure consistency between the original English version and the translated Maltese version. The test-retest reliability was carried out using the Kendall’s tau B test. This test was chosen as it assesses quantitative variables through an ordinal scale, which is present in both questionnaires, (Van Den Berg, 2022). Additionally, testing for normality was carried out to minimise the chances of inaccurate and unreliable conclusions. This will be further explained in the next chapter (Section 4.5.1).

To analyse the data collected and carry out this research study various statistical tests were used, depending on what was being tested and the distribution of normality. This will be further explained in the next chapter (Section 4.5.2).

3.8 Conclusion

In conclusion, this chapter encompassed a brief overview of the issue being researched, outlining the aim and objectives of the research study. In addition, decisions regarding research design and methods were explained and justified; reliability and validity testing of the research instruments was enlightened; ethical considerations and potential ethical issues arising from the study were discussed. Methods of data analysis are also presented. The next chapter comprehends the results retrieved from this study and gives more detail of the data analysis procedures which were used.

Chapter 4: Results

4.1 Introduction

This chapter gives a detailed account of the results of the study. It starts by presenting the participants' socio-demographic data and clinical information. After this, results related to this study's four aims and objectives will be given. Objective one encompassed the assessment of illness perceptions, objective two encompassed the assessment of QoL, objective three encompassed the testing for association between participants' demographic and clinical information with illness perception and QoL, and objective four encompassed the correlation between illness perception and QoL.

4.2 Socio-demographic characteristics and clinical information of the participants

A total of 248 individuals with heart failure were conveniently recruited in this study through the Heart Failure Clinic in a general hospital in Malta. A sample of 248 was needed for the study to allow a margin of error of +/- 5% with a CI of 95%. Once 248 questionnaires were obtained, data collection was stopped.

Eligible participants needed to be 18 years of age and above. Recruited participants were mainly between the ages of 70-85 (44%, *n*=109) and males (64.9%, *n*=161). The commonest level of education achieved was secondary-level education, amounting to 116 (46.8%). 14.1% (*n*=35) achieved a post-secondary level of education, and 6.5% (*n* =16) achieved a tertiary level of education. Furthermore, most participants were married 54.8% (*n*=136). Before being diagnosed with CHF, the majority of the participants lived with family members (67.7%, *n*=168). In addition, it was observed that the number of individuals living in a community home increased by 7.7% (*n*= 19) after being diagnosed with CHF.

Participants were also asked whether they felt supported by their family/social contacts and the health care system. The majority of the participants (81%, *n*=201) reported feeling supported by their family and social contacts, and 94.4% (*n*=234) claimed to feel supported by the healthcare system. A summary of the participants' socio-demographic data is shown in Table 26.

Table 26

Socio-demographic data of the study participants (n= 248)

		Frequency (N=248)	Percentage (%)
Age	18-29 years	3	1.2
	30-49 years	25	10.1
	50-69 years	84	33.9
	70-85 years	109	44
		27	10.9
	86+ years		
Gender	Male	161	64.9
	Female	87	35.1
	Other	0	
Level of education	NIL	11	4.4
	Primary	70	28.2
	Secondary	116	46.8
	Post-secondary	35	14.1
	Tertiary	16	6.5
Marital status	Single	32	12.9
	Married	136	54.8
	Widowed/separated/divorced	75	30.2
	Others	4	1.6
State of living before being diagnosed with heart failure	Living alone	54	21.8
	Living with family members	168	67.7
	Living in a community/elderly home	19	7.7
	Other	7	2.8
State of living after being diagnosed with heart failure	Living alone	44	17.7
	Living with family members	1672	67.3
	Living in a community/elderly home	27	10.9
	Other	6	2.4

Support from social contacts	Yes	201	81
	No	47	19
Support from the healthcare system	Yes	234	94.4
	No	13	5.2

In addition, in order to measure the participants' clinical status, they were asked about their frequency of past hospital admissions and whether they had other medical problems. The majority of the participants reported being hospitalised once or twice, which amounted to 38.3% (*n*= 96). In addition, 133 participants (53.6%) reported having other medical conditions in addition to CHF. A total of 248 medical conditions were mentioned among the 133 participants. A summary of the clinical information of the participants can be found in Table 27.

Table 27

Clinical information of the study participants (n= 248)

		Frequency (N=248)	Percentage (%)
Past hospital admissions	Never	56	22.6
	Once or twice	95	38.3
	Three or four times	56	22.6
	More than four times	38	15.3
Other medical problems	Yes	133	53.6
	No	114	46

Further to the question enquiring about medical problems, participants who indicated that they had other medical conditions (53.6%, *n*=133) were asked to specify the other conditions, some mentioned multiple conditions. Total conditions mentioned amounted to (*n*=203). The majority mentioned that they were diagnosed with diabetes mellitus (DM), amounting to 31% of all the mentioned conditions. A list of the medical conditions mentioned, and their respective frequencies can be found in Table 28.

Table 28

Frequencies of other reported medical conditions (n=203)

Other medical conditions	Frequency (*n*=203)	Percentage (%)
DM	63	31
Hypertension	26	12.8
COPD	13	6.4
CKD	10	4.9
AF	9	4.4
Mobility problems	5	2.5
Depression	5	2.5
CVA	5	2.5
PVD	4	2
Hypercholesterolemia	3	1.5
Ischemic heart disease	2	1
Valvular problems	2	1
Heart block	2	1
Other health conditions	54	26.6

4.3 Objective 1: Assessment of illness perceptions among individuals with CHF

Assessment of illness perception was carried out using the B-IPQ questionnaire, which consists of nine questions (items). Eight questions scoring on a scale of 0-10, and an additional open-ended question which asked participants what they thought their causal factors were. The eight items assessed were (Item 1) consequences, (item 2) timeline, (item 3) personal control, (item 4) treatment control, (item 5) symptom occurrence, (item 6) concern, (item 7) understanding and (item 8) emotional response.

To assess the overall score of illness perception, representing the degree to which their illness was perceived as threatening or nonthreatening, reverse coding was done on items 3, 4 and 7 and added to items 1, 2, 5, 6, and 8. A higher score indicates a more threatening view of their illness (Broadbent et al., 2006). Therefore, higher scores indicate that the participants perceive their illness to have greater consequences (*item 1*), a more chronic timeline (*item 2*), less personal control (*item 3*), that the treatment is less effective in managing their illness (*item 4*), that the illness is causing the participants to experience many symptoms (*item 5*), a greater level of preoccupation (*item 6*), a lower degree of understanding their illness *(item 7*) and a greater degree of emotional disturbance (*item 8*).

Scores were assessed using means; a mean within the range 0-3.33 encompassed a low score, indicating low threat, 3.34-6.66 indicated moderate threat and 6.67-10 indicated high threat. The highest score was seen among timeline (item 2), with a mean of 8.39 *(SD= 2.146),* suggesting that participants viewed their illness as being chronic. This was followed by the domain assessing concern (item 6) about their illness, which showed a mean score of 6.90 (*SD*= 2.381). Despite this, emotional response (item 8) suggests moderate scores with a mean of 6.63 (*SD= 2.567)*. When participants were asked whether CHF affected their lives (item 1), results showed moderate scores with a mean of 6.21 (*SD= 2.966)*. Personal control (item 3) showed moderate scores with a mean of 5.36 (*SD=2.925)*. Symptom occurrence (item 5) showed moderate score with a mean of 5.39 *(SD=2.848).* Understanding the illness (item 7) showed moderate scoring with a mean of 5.02 (*SD=2.574).* Lastly, low scoring was only seen in the domain assessing treatment control (item 4), showing a mean of 2.64 (*SD=2.477),* indicating that participants perceived their treatment as being very effective. Two domains reported high scoring (timeline and concern), five reported moderate scoring (consequences, personal control, symptom occurrence, understanding and emotional response) and one reported low scoring (treatment).

The total mean score of illness perception ranged from 0-80. Therefore, a score from 0-26.66 indicates low impact on illness perception, 26.67- 53.33 indicates moderate impact on illness perception, and 53.34- 80 indicates high impact on illness perception. The total mean score was 45.98 (*SD= 13.177, MDN = 46.00),* indicating that participants perceived their illness as moderate threat. A summary of these values can be found in Table 29 and table graph (Figure 3), below.

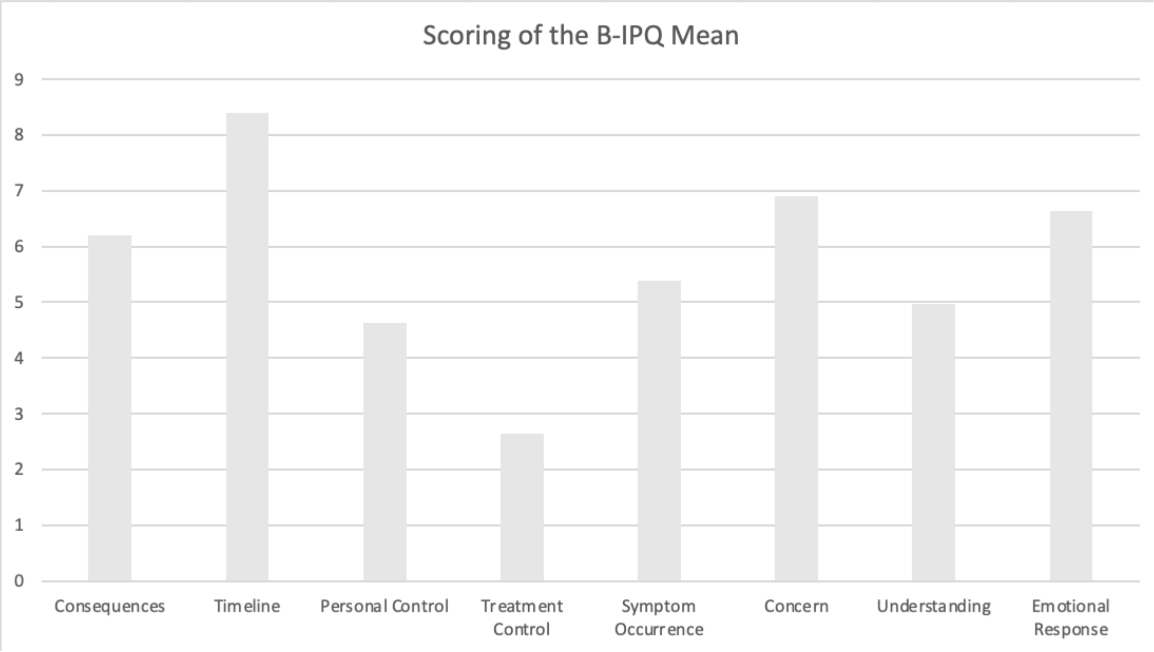
Table 29

Scoring of the B-IPQ

Item	(*n*)	Mean		Median	SD	Variance
			Std. error			
1. Consequences	248	6.21	.188	7	2.966	8.796
2. Timeline	241	8.39	.138	9	2.146	4.606
3. Personal control	247	4.64	.186	5	2.925	8.557
4. Treatment control	247	2.64	.158	8	2.477	6.135
5. Symptom occurrence	247	5.39	.181	6	2.848	8.108
6. Concern	247	6.90	.151	7	2.381	5.626
7. Understanding	247	4.98	.164	5	2.574	6.626
8. Emotional response	248	6.63	.163	7	2.567	6.590
Total (overall mean score of illness perception)	236	45.98	.858	46.00	13.177	173.629

Figure 3

Table graph: scoring of the B-IPQ



4.3.1 Perceived casual factors

Through an open-ended question, participants were also asked to list the factors that they thought caused their CHF. From the total sample, 136 participants mentioned causal factors; an additional nine claimed that they did not know what caused their CHF. Among the 136 who mentioned what caused their illness, smoking was the most common, which amounted to 24.6% (*n*=56), followed by cardiomyopathy with 16.7% (*n*=38). Different aetiologies were mentioned, including myocardial infarction, ischemia, and obesity. These were followed by family history (16.2%, *n*=37), lifestyle (15.8%, *n*=36), excessive alcohol use (10.5%, *n*=24), stress (6.1%, *n*=14), age (4.4%, *n*=10), medication (3.1%, *n*=7) and the least mentioned with 1.3% (*n*=3) respectively, were work and others. A summary of the perceived causal factors can be found in Table 30.

Table 30

Casual factors mentioned (n=136)

Casual factor	Frequency (*n*=136)	Percentage (%)
Smoking	56	24.6
Cardiomyopathy	38	16.7
Hereditary	37	16.2
Lifestyle	36	15.8
Alcohol	24	10.5
Stress	14	6.1
Age	10	4.4
Medication	7	3.1
Work	3	1.3
Other	3	1.3

4.4 Objective 2: Assessing the QoL among individuals with CHF

The KCCQ-12 is a questionnaire designed to assess QoL among individuals with CHF. This questionnaire encompassed 12 questions, all with a Likert scale. Some questions had a 5-point scale (questions 1, 2, 5, 6, 7, 8), while others had a 7-point scale (questions 3 and 4). In addition, questions 1 (a, b, and c) and 8 (a, b and c), which investigated the participants' limitations in certain activities, ranging from '*extremely limited'* to '*not at all limited'*, had a sixth option which did not form part of the scale *'limited for other reasons or did not do the activity'*. Since this did not form part of the scale, statistical analysis was done on the 5-point scale, and the results for the sixth option were analysed separately.

The questions encompassing a 5-point scale (0-5), mean scores between 0-1.66 indicated a high level of limitation in QoL, a score between 0.67- 3.32 indicated moderate level of limitation, and scores between 3.33-5 indicated low levels of limitation. Furthermore, the questions encompassing a 7-point scale (0-7), mean scores between 0-2.33 indicated high levels of limitation, a score between 2.34-4.66 indicated moderate level of limitation, and a score between 4.67-7 indicated low level of limitation. Lower scoring suggests higher limitations in QoL.

The limitations for showering and bathing resulted in a mean score of 3.70 out of a total score of 5 (SD 1.347), indicating low limitation scores, similar to walking one block on level ground, with a mean of 3.44 (SD 1.897). However, jogging or hurrying was experienced at a moderate level of limitation with a mean of 2.26 (SD 1.409). The mean for experiencing swelling of the feet, ankles or legs in the past two weeks was 3.47 (SD 1.459), indicating a low score. Likewise, the mean score of having to sleep propped up on at least three pillows due to shortness of breath (SOB) was 3.63 (SD1.451), indicating a low score. However, when assessed for how much participants felt that CHF limited their enjoyment in life, a mean score of 3.04 (SD 1.437) indicated moderate limitation in enjoyment. In the question assessing the satisfaction rate if they had to live with CHF for the rest of their lives, the mean score (2.53, SD 1.147) show they would be moderately satisfied. Limitations for carrying out hobbies and recreational activities showed a mean of 3.11 (SD 1.437), indicating moderate limitation; the limitation for working or carrying out household chores shows a mean of 2.98

(SD 1.432), making it a more limiting factor than hobbies however still within the moderate limitation range. Visiting family and friends out of their homes resulted in moderate limitation, with a mean score of 3.14 (SD 1.503).

Among the questions encompassing a 7-point scale (0-7), (questions 3 and 4) scoring ranges were distributed as previously mentioned. In the questions assessing how much participants experienced fatigue in the past two weeks, scores indicate moderate limitation with a mean of 4.27 (SD 2.039), whilst when asked how many times they experienced SOB in the past two weeks, mean scores indicate a moderate response with a mean of 4.46 (SD 1.929). The total mean score of QoL ranged from 0-64. Therefore, a score from 0-21.33 indicated low QoL, 21.34- 42.66 indicates moderate QoL, and 42.67-64 indicates high QoL. The total mean score of QoL was 36.50 (*SD=14.453*), indicating moderate limitations in QoL (Table 31).

Table 31

Scoring of the KCCQ-12

Item	Total (*n*)	No. who answered 6th option	Remaining total				
			(*n*)	Mean	Median	SD	Variance
Question 1*							
(a) Showering/ bathing	248	4	244	3.70	4.00	1.347	1.815
(b) Walking 1 block on level ground	248	7	241	3.44	4.00	1.377	1.897
(c) Jogging or hurrying	248	8	240	2.26	2.00	1.409	1.985
Question 2 * Swelling of feet, ankles and legs	248			3.47	4.00	1.459	2.129
Question 3 ** Fatigue	248			4.27	5.00	2.039	4.156
Question 4 ** Shortness of breath (SOB)	248			4.46	5.00	1.929	3.723
Question 5 * Sleep upright due to SOB	248			3.63	4.00	1.451	2.106
Question 6 * Limited enjoyment of life	246			3.04	3.00	1.437	2.064
Question 7 * Satisfaction rate	247			2.53	2.00	1.147	1.315
Question 8 *							
(a) Hobbies/ recreation activities	248	11	237	3.11	3.00	1.437	2.064
(b) Working/ household chores	248	13	235	2.98	3.00	1.432	2.051

(c) Visiting social contacts	248	4 (1 missing)	243	3.14	3.00	1.503	2.258
Total QoL scores	226			36.50	36.00	14.453	208.900

* 5-point scales: 0-1.66 =high scores, 1.67-3.32= moderate scores, 3.33-5 low scores

** 7-point scales 0-2.33= high scores, 2.34-4.66=moderate scores, 4.77- 7= low scores

4.5 Objective 3: Assessing the relationship between the participants' characteristics with illness perception and QoL

4.5.1 Normality testing

Normality testing was carried out to assess the distribution of continuous data and the assumption of normality. This testing is done to compare the scores in a sample to a normally distributed set of scores. The null hypothesis is that the sample is distributed normally. If the distribution is not normal, the test will be statistically significant (Ghasemi & Zahediasl, 2012). This is done before conducting statistical analysis to minimise the chances of inaccurate and inconsistent conclusions (Rani Das, 2016).

For this dissertation, the Kolmogorov-Smirnov test and the Shapiro-Wilk test were used. The Kolmogorov-Smirnov test compares the data with a known distribution, thus allowing the researcher to identify whether they have the same distribution (Zhang & Wu, 2001). The Shapiro-Wilk test is constructed on the correlation between the data and the corresponding normal scores (Ghasemi & Zahediasl, 2012). A P-value of <0.05 indicates that the data does not follow the normal distribution, therefore rejecting the null hypothesis. Once these tests are carried out, the researcher can identify which correlation tests can be used to analyse the data. A parametric test will be used for normally distributed data, whereas for skewed data, a non-parametric test will be used.

The results for the illness perception score of the Kolmogorov-Smirnov show a P-value of 0.200, and the Shapiro-Wilk test shows a P-value of 0.226, indicating that the scores were normally distributed; therefore, a parametric test was used. Whereas, for the QoL score, both the Kolmogorov-Smirnov and the Shapiro-Wilk tests scored a P-value of <0.001, indicating that the scores were not distributed according to the normality of the assumption; therefore, a non-parametric test was used. A summary of these values can be found in Table 32.

Table 32

Normality testing of the dependent variables

Dependent variable	Kolmogorov-Smirnov test			Shapiro-Wilk test		
	Statistic	df	P- value	Statistic	df	P-value
Illness perception score	0.48	236	0.200	0.992	236	0.226
KCCQ-12 score	0.107	226	<0.001	0.938	226	<0.001

df= degree of freedom

4.5.2 Statistical testing used

All statistical testing was carried out on IBM SPSS statistics (version 28.0.0.0). Different tests were carried out according to what was being tested and according to the distribution of normality. To measure the correlation between illness perception and age, the Pearson correlation was used; this test measures the strength of a linear relationship of continuous data among normally distributed data. In addition, since data in QoL was not distributed normally, the Spearman Correlation sufficient was used to measure the relationship between QoL and age.

The independent sample t-tests and the Mann-Whitney U test both compare mean scores between two groups; therefore, this test was used to test gender, participants' other medical conditions, whether they feel supported by their family and social contacts and by the healthcare system. When asked to specify their gender, three options were provided: '*males'*, '*females'* or '*other*. Since none of the participants chose the option '*other'* it was eliminated when testing was carried out. To test the groups of these variables with illness perception, the independent sample t-test was used as data for illness perception was distributed normally. Whereas, to test the groups of these variables with QoL, the Mann-Whitney U test was used as the data was skewed.

The one-way ANOVA and Kruskal Wallis H test are used to compare the means of three or more groups. Therefore, to assess the relationship of level of education, marital status, living arrangements before and after being diagnosed with CHF and past hospital admission with illness perception, the one-way ANOVA test was used as it is a parametric test and therefore used on normally distributed data. In addition, to test these variables with QoL, the Kruskal Wallis H test was used as data in QoL was not distributed normally. A summary of the statistical analysis used for this study and the reasons for choosing them can be found in Table 33.

Table 33

Statistical analysis of each demographic subgroup and reasons for choosing them

Variable	Association	Normality result	Test	Reason for choosing test
Age	Illness perception	Parametric	Pearson correlation	To investigate the relationship between two continuous variables
	Quality of life	Non-parametric	Spearman Correlation	
Gender	Illness perception	Parametric	Independent sample t-test	To compare mean scores between two related samples
	Quality of life	Non-parametric	Mann -Whitney U test	
Education level	Illness perception	Parametric	One-way ANOVA	To compare mean scores between three or more independent groups
	Quality of life	Non-parametric	Kruskal-Wallis H	
Marital status	Illness perception	Parametric	One-way ANOVA	To compare mean scores between three or more independent groups
	Quality of life	Non-parametric	Kruskal-Wallis H	
State of living before being diagnosed with CHF	Illness perception	Parametric	One-way ANOVA	To compare mean scores between three or more independent groups
	Quality of life	Non-parametric	Kruskal-Wallis H	
State of living after being diagnosed with CHF	Illness perception	Parametric	One-way ANOVA	To compare mean scores between three or more independent groups
	Quality of life	Non-parametric	Kruskal-Wallis H	
Past hospital admission	Illness perception	Parametric	One-way ANOVA	To compare mean scores between three or more independent groups
	Quality of life	Non-parametric	Kruskal-Wallis H	

Other comorbidities	Illness perception	Parametric	Independent sample t-test	To compare mean scores between two related samples
	Quality of life	Non-parametric	Mann-Whitney U test	
Support from relatives and social contacts	Illness perception	Parametric	Independent sample t-test	To compare mean scores between two related samples
	Quality of life	Non-parametric	Mann-Whitney U test	
Support from the healthcare system	Illness perception	Parametric	Independent sample t-test	To compare mean scores between two related samples
	Quality of life	Non-parametric	Mann-Whitney U test	

4.5.3 Age

The Pearson correlation (r) showed that all p-values indicate that the results were statistically significant. There was a positive correlation between age and illness perception in the total score ($r = 0.337$; $p = <0.001$), indicating that the two variables are moving in the same direction. Therefore, this suggests that as age increased, illness perception scores increased as well. Lower illness perception scores indicate more positive illness perceptions, so older individuals had more negative illness perceptions than their younger counterparts (Table 34.1).

Table 34.1

Correlation between age and illness perceptions using the Pearson correlation

Domains	*n*	*r*	P-value (2-tailed)
Consequences	248	0.267	<0.001**
Timeline	241	0.367	<0.001**
Personal control	247	0.421	<0.001**
Treatment control	247	0.234	<0.001**
Symptom occurrence	247	0.703	<0.001**
Concern	247	0.479	<0.001**
Understanding	247	0.127	0.046*
Emotional response	248	0.470	<0.001**
Total illness perception score	236	0.337	<0.001

* Correlation is statistically significant at the level 0.05 level

** Correlation is statistically significant at the level 0.001 level

The Spearman correlation test shows that all p-values indicate statistical significance. A negative correlation is seen between the total QoL score and age (-0.398; *p*= <0.001), indicating that as age increased, QoL decreased (Table 34.2).

Table 34.2

Correlation between QoL with age using the Spearman Correlation (2-tailed)

	Age		
	n	*r*	*P*-value
Showering	248	-0.482	<0.001
Walking 1 block	248	-0.379	<0.001
Jogging/hurrying	248	-0.351	<0.001
Swelling of feet, legs, and ankles	248	-0.345	<0.001
Fatigue	248	-0.343	<0.001
SOB	248	-0.278	<0.001
Sleeps upright due to SOB	248	-0.260	<0.001
Enjoyment of life	246	-0.350	<0.001
Satisfaction rate	247	-0.315	<0.001
Hobbies/ recreational activity	248	-0.273	<0.001

Working/ household chores	248	-0.300	<0.001
Visiting social contacts	248	-0.382	<0.001
Total QoL score	226	-0.398	<0.001

2.5.4 Gender

Negative t-test results indicate that the mean of males is lower than that of females. Conversely, positive t-test results indicate that the mean of females is lower than that of males. Since the p-value between gender and illness perception (p= 0.149) was greater than the level of significance, there is not enough evidence to suggest that a correlation exists between the two groups. Therefore, we accept the null hypothesis (Table 35.1).

Table 35.1

The relationship between gender and illness perception using the independent sample t-test

	t-test for equality of means				
	T	df	p-value	Mean difference	Standard error mean
Consequences	-1.945	246	0.26	-0.763	0.392
Timeline	2.181	239	0.15	0.625	0.286
Personal control	1.523	245	0.65	0.592	0.389
Treatment control	1.423	245	0.78	0.470	0.330
Symptom occurrence	-1.699	245	0.45	-0.642	0.378
Concern	-0.488	245	0.313	-0.155	0.318
Understanding	-0.653	245	0.257	-0.225	0.344
Emotional response	-1.033	256	0.151	-0.353	0.342
Total illness perception score	-0.449	234	0.149	-2.957	1.792

The Mann-Whitney U test showed that the total score of QoL and gender exceeds the level of significance (p= 0.062). Therefore, this indicates that the evidence of the relationship between the variables is not strong enough (Table 35.2)

Table 35.2

The relationship between gender and QoL using the Mann-Whitney U

	Ranks			Test statistics			
	Gender	*n*	Mean rank	Mann-Whitney U test	Wilcoxon W	Z	P-value
Showering/bathing	Male	161	126.20	6729.500	10557.500	-0.530	0.596
	Female	87	121.35				
Walking 1 block	Male	161	128.01	6438.500	10266.500	-1.076	0.282
	Female	87	118.01				
Jogging/ hurrying	Male	161	131.45	5884.500	9712.500	-2.177	0.029
	Female	87	111.64				
Swelling of the feet, legs, and ankles	Male	161	124.96	6929.500	10757.500	-0.142	0.887
	Female	87	123.65				
Fatigue	Male	161	126.98	6604.000	10432.000	-0.751	0.453
	Female	87	119.91				
SOB	Male	161	130.92	5970.000	9798.000	-1.944	0.052
	Female	87	112.62				
Sleeps upright due to SOB	Male	161	131.09	5942.000	9770.000	-2067	0.039
	Female	87	112.30				
Enjoyment of life	Male	160	131.41	5615.000	9356.000	-2.430	0.015
	Female	86	108.79				
Satisfaction	Male	160	127.08	6466.500	10294.500	-0.951	0.342
	Female	87	118.33				
Hobbies/ recreational activities	Male	161	131.35	5900.500	9728.500	-2.084	0.037
	Female	87	111.82				
Working/ household chores	Male	161	129.95	6126.000	9954.000	-1.656	0.098
	Female	87	114.41				

Visiting social contact	Male	161	131.31	5906.500	9734.500	-2.084	0.037
	Female	87	111.89				
Total QoL score	Male	147	119.44	4933.000	8093.000	-1.865	0.062
	Female	79	102.44				

4.5.5 Level of education

The one-way ANOVA showed a p-value higher than the significance level (p= 0.224) in the total score of illness perception and level of education. This suggests that there is not enough evidence that level of education affects illness perception (Table 36.1).

Table 36.1

The relationship between level of education and illness perception using one-way ANOVA

Illness perception domain	Level of education	*n*	Mean rank	SD	P-value
Consequences	NIL	11	8.27	1.555	<0.053
	Primary	70	6.07	3.205	
	Secondary	116	5.84	3.026	
	Post-secondary	35	6.91	2.490	
	Tertiary	16	6.44	2.502	
Timeline	NIL	11	9.45	1.036	0.365
	Primary	67	8.31	2.451	
	Secondary	112	8.21	2.162	
	Post-secondary	35	8.60	1.769	
	Tertiary	16	8.75	1.880	
Personal control	NIL	11	4.27	1.902	0.098
	Primary	69	5.33	2.919	
	Secondary	116	4.49	3.077	
	Post-secondary	35	3.74	2.737	
	Tertiary	16	4.94	2.294	
Treatment control	NIL	11	3.73	1.902	0.285
	Primary	70	2.99	2.784	
	Secondary	115	2.42	2.384	
	Post-secondary	35	2.51	2.454	
	Tertiary	16	2.19	1.905	
Symptom occurrence	NIL	11	8.09	1.375	0.006
	Primary	69	5.78	3.082	
	Secondary	116	4.99	2.808	
	Post-secondary	35	5.03	2.479	
	Tertiary	16	5.50	2.582	
Concern	NIL	11	7.18	2.483	0.150
	Primary	70	6.57	2.790	

	Secondary	115	6.79	2.311	
	Post-secondary	35	7.80	1.729	
	Tertiary	16	6.94	1.769	
Understanding	NIL	11	4.45	2.067	<0.001
	Primary	70	5.76	2.499	
	Secondary	116	5.30	2.561	
	Post-secondary	34	3.29	2.140	
	Tertiary	16	3.25	1.807	
Emotional response	NIL	11	7.82	1.662	0.314
	Primary	70	6.64	2.998	
	Secondary	116	6.36	2.524	
	Post-secondary	35	7.09	2.331	
	Tertiary	16	6.75	1.438	
Total illness perception score	NIL	11	53.27	6.084	0.224
	Primary	65	47.63	15.625	
	Secondary	110	44.71	13.112	
	Post-secondary	34	45.15	10.563	
	Tertiary	16	44.75	9.657	

The Kruskal-Wallis H test was used to assess the relationship between QoL and level of education. The total QoL score shows statistical significance (p=0.001). The Kruskal-Wallis H test shows that the lowest mean scores in QoL were seen among individuals without education, which increased with the education level. This suggests that as the level of education increases, QoL increases as well (table 36.2).

Table 36.2

The relationship between level of education with QoL using the Kruskal-Wallis H

QoL domain	Level of education	*n*	Mean rank	Kruskal-Wallis H	df	P-value
Showering	NIL	11	33.77	26.720	4	<0.001
	Primary	70	111.71			
	Secondary	116	137.85			
	Post-secondary	35	127.67			
	Tertiary	16	139.06			
Walking 1 block	NIL	11	45.05	17.851	4	<0.001
	Primary	70	117.04			
	Secondary	116	133.34			
	Post-secondary	35	136.13			
	Tertiary	16	122.28			
Jogging/hurrying	NIL	11	69.41	12.365	4	<0.015
	Primary	70	113.11			
	Secondary	116	131.30			
	Post-secondary	35	141.39			
	Tertiary	16	125.97			
Swelling of the feet, legs, and ankles	NIL	11	59.05	20.779	4	<0.001
	Primary	70	111.69			
	Secondary	116	141.18			
	Post-secondary	35	110.04			
	Tertiary	16	136.25			
Fatigue	NIL	11	65.41	19.562	4	<0.001
	Primary	70	111.45			
	Secondary	116	142.42			
	Post-secondary	35	107.57			
	Tertiary	16	129.31			
SOB	NIL	11	61.55	13.934	4	0.008

	Primary	70	118.12			
	Secondary	116	136.47			
	Post-secondary	35	112.60			
	Tertiary	16	134.94			
Sleeps upright due to SOB	NIL	11	63.27	12.322	4	0.015
	Primary	70	121.39			
	Secondary	116	134.92			
	Post-secondary	35	115.17			
	Tertiary	16	125.09			
Enjoyment of life	NIL	10	76.80	12.807	4	0.012
	Primary	70	107.87			
	Secondary	115	137.47			
	Post-secondary	35	124.96			
	Tertiary	16	117.44			
Satisfaction	NIL	11	56.09	13.487	4	0.009
	Primary	70	117.74			
	Secondary	115	130.10			
	Post-secondary	35	137.80			
	Tertiary	16	124.03			
Hobbies/ recreational activities	NIL	11	38.32	22.378	4	<0.001
	Primary	70	124.01			
	Secondary	116	137.71			
	Post-secondary	35	108.47			
	Tertiary	16	125.16			
Working/ household chores	NIL	11	59.14	13.606	4	0.009
	Primary	70	122.00			
	Secondary	116	136.04			
	Post-secondary	35	113.04			
	Tertiary	16	121.75			

Visiting social contacts	NIL	11	56.45	18.57	4	<0.001
	Primary	70	109.29			
	Secondary	116	138.16			
	Post-secondary	35	125.50			
	Tertiary	16	136.63			
Total QoL score	NIL	10	47.60	18.335	4	0.001
	Primary	60	99.18			
	Secondary	109	27.65			
	Post-secondary	31	110.15			
	Tertiary	16	118.50			

4.5.6 Marital status

The one-way ANOVA was carried out to compare mean scores of illness perception and marital status. The total illness perception score was statistically significant (p= <0.001). The lowest mean scores were seen among married individuals (M= 41.79), indicating that illness perceptions were less negative amongst married participants (Table 37.1).

Table 37.1

The relationship of marital status and illness perception using the one-way ANOVA

Illness perception domain	Marital status	*n*	Mean rank	SD	P-value
Consequences	Single	32	6.59	0.490	0.004
	Married	136	5.64	0.257	
	Widowed/separated/divorced	75	6.91	0.330	
	Other	4	9.00	0.000	
Timeline	Single	30	8.87	0.295	0.088
	Married	135	8.10	0.199	
	Widowed/separated/divorced	72	8.64	0.235	
	Other	3	10.00	0.000	
Personal control	Single	32	6.06	0.577	<0.001
	Married	136	3.83	0.227	
	Widowed/separated/divorced	74	5.45	0.339	
	Other	4	6.00	0.577	
Treatment control	Single	32	3.31	0.480	<0.001
	Married	135	2.16	0.176	
	Widowed/separated/divorced	75	3.36	0.330	
	Other	4	0.00	0.000	
Symptom occurrence	Single	32	5.19	0.478	<0.001
	Married	135	4.70	0.243	
	Widowed/separated/divorced	75	6.48	0.297	
	Other	4	9.00	0.000	
Concern	Single	32	7.28	0.331	0.150
	Married	135	6.58	0.213	
	Widowed/separated/divorced	75	7.27	0.277	
	Other	4	7.50	0.866	
Understanding	Single	32	5.66	0.423	<0.001
	Married	135	4.39	0.210	
	Widowed/separated/divorced	75	5.72	0.299	
	Other	4	6.75	1.601	

Emotional response	Single	32	7.19	0.459	0.009
	Married	136	6.13	0.222	
	Widowed/separated/divorced	75	7.23	0.279	
	Other	4	7.75	0.479	
Total illness perception score	Single	30	51.17	14.667	<0.001
	Married	131	41.79	12.022	
	Widowed/separated/divorced	71	51.15	12.231	
	Other	3	54.00	6.928	

Total QoL scores were significantly higher in married individuals (M= 130.81; p= <0.001). Higher mean scores indicate better QoL, whereas lower mean scores indicate lower QoL (Table 37.2).

Table 37.2

Relationship of marital status with QoL using the Kruskal-Wallis H

QoL domain	Marital status	*n*	Mean rank	Kruskal-Wallis H	df	P-value
Showering	Single	32	117.64	17.946	3	<0.001
	Married	136	139.89			
	Widowed/separated/divorced	75	99.30			
	Other	4	97.75			
Walking 1 block	Single	32	120.27	19.061	3	<0.001
	Married	136	139.53			
	Widowed/separated/divorced	75	101.22			
	Other	4	53.00			
Jogging/hurrying	Single	32	119.02	20.073	3	<0.001
	Married	136	139.76			
	Widowed/separated/divorced	75	101.33			
	Other	4	53.00			
Swelling of the feet, legs, and ankles	Single	32	133.02	9.553	3	0.023
	Married	136	131.83			

	Widowed/separated/divorced	75	109.68			
	Other	4	54.25			
Fatigue	Single	32	114.47	16.415	3	<0.001
	Married	136	139.94			
	Widowed/separated/divorced	75	100.78			
	Other	4	93.75			
SOB	Single	32	119.59	28.788	3	<0.001
	Married	136	144.13			
	Widowed/separated/divorced	75	92.26			
	Other	4	70.00			
Sleeps upright due to SOB	Single	32	109.33	8.172	3	0.043
	Married	136	134.75			
	Widowed/separated/divorced	75	112.79			
	Other	4	86.00			
Enjoyment of life	Single	32	103.63	19.624	3	<0.001
	Married	135	141.16			
	Widowed/separated/divorced	75	100.33			
	Other	4	121.00			
Satisfaction	Single	32	99.38	16.971	3	<0.001
	Married	135	139.69			
	Widowed/separated/divorced	75	106.47			
	Other	4	89.50			
Hobbies/ recreational activities	Single	32	103.08	20.863	3	<0.001
	Married	136	141.22			
	Widowed/separated/divorced	75	99.88			
	Other	4	158.00			
Working/ household chores	Single	32	112.44	22.011	3	<0.001
	Married	136	142.30			
	Widowed/separated/divorced	75	96.07			
	Other	4	118.00			
Visiting social contacts	Single	32	108.97	20.545	3	<0.001
	Married	136	141.91			

	Widowed/separated/divorced	75	98.55			
	Other	4	112.75			
Total QoL score	Single	29	104.19	20.588	3	<0.001
	Married	124	130.81			
	Widowed/separated/divorced	69	87.86			
	Other	4	86.63			

4.5.7 State of living before being diagnosed with CHF

According to the one-way ANOVA test, the total illness perception score was significantly higher among participants living in a community home (M= 58.84; p= <0.001), indicating that illness perception affected them the most (Table 38.1).

Table 38.1

Living arrangement before being diagnosed with CHF and illness perception using the one-way ANOVA

Illness perception domain	Living arrangement before being diagnosed with CHF	*n*	Mean rank	SD	P-value
Consequences	Living alone	54	6.13	2.921	<0.001
	Living with family members	168	5.77	2.936	
	Living in a community home	19	9.16	1.015	
	Other	7	9.14	0.900	
Timeline	Living alone	50	8.70	1.753	0.006
	Living with family members	166	8.11	2.312	
	Living in a community home	19	9.68	0.820	
	Other	6	9.50	0.837	
Personal control	Living alone	54	6.11	3.069	<0.001
	Living with family members	167	3.94	2.634	
	Living in a community home	19	6.11	2.622	
	Other	7	6.00	3.606	
Treatment control	Living alone	54	3.41	2.617	0.007
	Living with family members	167	2.31	2.289	
	Living in a community home	19	3.63	3.077	
	Other	7	1.86	2.340	
Symptom occurrence	Living alone	54	5.74	2.816	<0.001
	Living with family members	167	4.92	2.817	

	Living in a community home	19	7.84	1.642	
	Other	7	7.29	2.059	
Concern	Living alone	54	7.00	2.457	0.291
	Living with family members	167	6.74	2.374	
	Living in a community home	19	7.63	2.266	
	Other	7	7.86	2.035	
Understanding	Living alone	54	5.69	2.330	0.002
	Living with family members	167	4.57	2.547	
	Living in a community home	19	5.89	2.331	
	Other	7	6.86	3.485	
Emotional response	Living alone	54	6.78	2.689	<0.001
	Living with family members	168	6.31	2.533	
	Living in a community home	19	8.89	1.243	
	Other	7	7.14	2.116	
Total illness perception score	Living alone	50	49.90	13.033	<0.001
	Living with family members	161	42.92	12.349	
	Living in a community home	19	58.84	7.981	
	Other	6	54.7	14.583	

The Kruskal-Wallis H test shows that the best QoL was seen among individuals living with family members (M= 127.68; p= <0.001); the higher the score indicates a better QoL (Table 38.2).

Table 38.2

The relationship of QoL with the living arrangement <u>before</u> being diagnosed with CHF using the Kruskal Wallis H

QoL domain	Living arrangement before being diagnosed with CHF	*n*	Mean rank	Kruskal-Wallis H	df	P-value
Showering	Living alone	54	120.72	35.665	3	<0.001
	Living with family members	168	137.12			
	Living in a community home	19	52.05			
	Other	7	47.50			
Walking 1 block	Living alone	54	126.89	38.115	3	<0.001
	Living with family members	168	135.76			
	Living in a community home	19	57.08			
	Other	7	18.79			
Jogging/hurrying	Living alone	54	111.07	24.195	3	<0.001
	Living with family members	168	137.07			
	Living in a community home	19	77.68			
	Other	7	53.30			
Swelling of the feet, legs, and ankles	Living alone	54	128.33	20.421	3	<0.001
	Living with family members	168	131.42			
	Living in a community home	19	55.97			
	Other	7	114.93			
Fatigue	Living alone	54	106.91	38.184	3	<0.001
	Living with family members	168	140.80			
	Living in a community home	19	45.79			
	Other	7	82.71			
SOB	Living alone	54	111.76	34.361	3	<0.001
	Living with family members	168	139.09			
	Living in a community home	19	46.11			
	Other	7	85.36			
Sleeps upright due to SOB	Living alone	54	119.16	24.370	3	<0.001
	Living with family members	168	134.51			
	Living in a community home	19	53.74			
	Other	7	117.64			

Enjoyment of life	Living alone	54	110.85	30.650	3	<0.001
	Living with family members	166	137.59			
	Living in a community home	19	55.39			
	Other	7	71.79			
Satisfaction	Living alone	54	106.84	23.531	3	<0.001
	Living with family members	167	137.26			
	Living in a community home	19	67.63			
	Other	7	92.93			
Hobbies/ recreational activities	Living alone	54	104.28	26.829	3	<0.001
	Living with family members	168	139.27			
	Living in a community home	19	72.32			
	Other	7	67.71			
Working/ household chores	Living alone	54	104.31	23.859	3	<0.001
	Living with family members	168	138.61			
	Living in a community home	19	76.66			
	Other	7	71.57			
Visiting social contacts	Living alone	54	111.07	26.326	3	<0.001
	Living with family members	168	137.89			
	Living in a community home	19	65.34			
	Other	7	67.36			
Total QoL score	Living alone	53	103.86	37.253	3	<0.001
	Living with family members	151	127.68			
	Living in a community home	15	31.50			
	Other	7	56.29			

4.5.8 State of living after being diagnosed with CHF

The one-way ANOVA test was used to assess the correlation between the state of living after being diagnosed with CHF and illness perception. The lowest total illness perception score was seen among individuals living with family members (M= 43.34; p=0.001); low scores indicate better illness perceptions (Table 39.1).

Table 39.1

The relationship between living arrangement after being diagnosed with CHF and illness perception using the one-way ANOVA

Illness perception domain	Living arrangement before being diagnosed with CHF	*n*	Mean rank	SD	P-value
Consequences	Living alone	44	6.30	2.733	<0.001
	Living with family members	167	5.83	2.968	
	Living in a community home	27	8.04	2.682	
	Other	6	9.00	0.894	
Timeline	Living alone	40	8.53	1.894	0.008
	Living with family members	165	8.10	2.310	
	Living in a community home	17	9.52	0.935	
	Other	5	9.40	0.894	
Personal control	Living alone	44	5.91	2.956	<0.001
	Living with family members	166	4.04	2.659	
	Living in a community home	27	6.70	2.658	
	Other	6	5.33	3.445	
Treatment control	Living alone	44	2.95	2.401	0.003
	Living with family members	166	2.40	2.325	
	Living in a community home	27	4.15	3.060	
	Other	6	1.33	2.066	
Symptom occurrence	Living alone	44	5.41	2.389	<0.001
	Living with family members	166	4.96	2.839	
	Living in a community home	27	7.81	1.665	
	Other	6	6.83	1.835	
Concern	Living alone	44	7.34	2.034	0.434
	Living with family members	166	6.77	2.384	
	Living in a community home	27	7.15	2.670	
	Other	6	7.50	1.975	
Understanding	Living alone	44	5.50	2.052	0.009
	Living with family members	166	4.62	2.593	
	Living in a community home	27	6.04	2.591	
	Other	6	6.33	3.502	

Emotional response	Living alone	44	6.59	2.609	<0.001
	Living with family members	167	6.35	2.546	
	Living in a community home	27	8.74	1.375	
	Other	6	6.67	1.862	
Total illness perception score	Living alone	40	48.88	13.054	<0.001
	Living with family members	160	43.34	12.688	
	Living in a community home	27	58.15	8.151	
	Other	5	50.60	11.908	

The Kruskal-Wallis H test assessed the correlation between QoL and living arrangements after being diagnosed with CHF. The highest scores were seen among individuals living with family members (M=123.87; <0.001); this indicated that those individuals living with family members after being diagnosed with CHF had better QoL (Table 39.2).

Table 39.2

The relationship of QoL with the living arrangement after being diagnosed with CHF using the Kruskal Wallis H

QoL domain	Living arrangement after being diagnosed with CHF	*n*	Mean rank	Kruskal-Wallis H	df	P-value
Showering	Living alone	44	132.43	44.701	3	<0.001
	Living with family members	167	134.34			
	Living in a community home	27	48.57			
	Other	6	52.67			
Walking 1 block	Living alone	44	138.11	42.486	3	<0.001
	Living with family members	167	132.43			
	Living in a community home	27	58.52			
	Other	6	19.58			
Jogging/hurrying	Living alone	44	120.16	27.684	3	<0.001

	Living with family members	167	134.05			
	Living in a community home	27	70.22			
	Other	6	53.50			
Swelling of the feet, legs, and ankles	Living alone	44	143.42	31.636	3	<0.001
	Living with family members	167	127.93			
	Living in a community home	27	54.80			
	Other	6	122.58			
Fatigue	Living alone	44	120.56	40.891	3	<0.001
	Living with family members	167	136.52			
	Living in a community home	27	45.58			
	Other	6	93.17			
SOB	Living alone	44	121.77	38.444	3	<0.001
	Living with family members	167	135.85			
	Living in a community home	27	47.61			
	Other	6	93.25			
Sleeps upright due to SOB	Living alone	44	130.36	29.110	3	<0.001
	Living with family members	167	130.69			
	Living in a community home	27	56.57			
	Other	6	133.50			
Enjoyment of life	Living alone	44	119.84	31.498	3	<0.001
	Living with family members	165	133.97			
		27	57.28			
		6	79.67			

	Living in a community home					
	Other					
Satisfaction	Living alone	44	116.48	26.544	3	<0.001
	Living with family members	166	133.83			
	Living in a community home	27	62.35			
	Other	6	103.58			
Hobbies/ recreational activities	Living alone	44	113.88	26.443	3	<0.001
	Living with family members	167	135.41			
	Living in a community home	27	67.30			
	Other	6	74.92			
Working/ household chores	Living alone	44	116.28	27.231	3	<0.001
	Living with family members	167	135.11			
	Living in a community home	27	64.33			
	Other	6	78.92			
Visiting social contacts	Living alone	44	122.73	28.725	3	<0.001
	Living with family members	167	134.03			
	Living in a community home	27	61.44			
	Other	6	74.67			
Total QoL score	Living alone	43	116.21	42.293	3	<0.001
	Living with family members	150	123.87			
	Living in a community home	23	34.30			
	Other	6	64.42			

4.5.9 Past hospital admissions

The one-way ANOVA assessed the relationship between illness perceptions and past hospital admission rates. The highest scores were seen among individuals who were hospitalised more than four times (M= 55.71; p=<0.001). Higher scores indicate a more negative illness perception (Table 40.1).

Table 40.1

The relationship between past hospital admission rate and illness perception using the one-way ANOVA

Illness perception domain	Past hospital admissions	*n*	Mean rank	SD	P-value
Consequences	Never	56	3.84	2.788	<0.001
	Once or twice	95	6.46	2.600	
	Three or four times	56	6.79	2.521	
	More than four times	38	8.03	2.736	
Timeline	Never	54	7.70	2.470	<0.001
	Once or twice	92	8.10	2.239	
	Three or four times	54	9.13	1.505	
	More than four times	38	8.97	1.823	
Personal control	Never	56	3.13	2.615	<0.001
	Once or twice	95	4.55	2.496	
	Three or four times	55	5.18	2.789	
	More than four times	38	6.29	3.416	
Treatment control	Never	56	1.59	1.797	<0.001
	Once or twice	94	2.17	2.227	
	Three or four times	56	3.34	2.596	
	More than four times	38	4.34	2.704	
Symptom occurrence	Never	56	2.98	2.562	<0.001
	Once or twice	94	5.61	2.587	
	Three or four times	56	6.00	2.382	
	More than four times	38	7.34	2.233	
Concern	Never	56	6.29	2.484	0.167
	Once or twice	94	7.11	2.207	
	Three or four times	56	7.02	2.300	
	More than four times	38	7.18	2.740	

Understanding	Never	55	4.36	2.563	0.038
	Once or twice	95	4.79	2.283	
	Three or four times	56	5.52	2.642	
	More than four times	38	5.61	2.973	
Emotional response	Never	56	5.36	2.526	<0.001
	Once or twice	95	6.89	2.447	
	Three or four times	56	6.68	2.398	
	More than four times	38	7.95	2.313	
Total illness perception score	Never	53	35.58	10.136	<0.001
	Once or twice	89	46.01	11.462	
	Three or four times	53	49.28	11.484	
	More than four times	38	55.71	13.505	

`The Kruskal-Wallis H was used to assess the correlation between past hospital admission rates and QoL. The highest scores were seen among participants who were never hospitalised (M=168.38; p=<0.001). High scores indicate a better QoL (Table 40.2).

Table 40.2

The relationship between QoL with past hospital admission rate using the Kruskal Wallis H

QoL domain	Past hospital admissions	*n*	Mean rank	Kruskal-Wallis H	df	P-value
Showering	Never	56	171.13	64.371	3	<0.001
	Once or twice	95	130.38			
	Three or four times	56	103.63			
	More than four times	38	62.17			
Walking 1 block	Never	56	165.83	43.581	3	<0.001
	Once or twice	95	127.31			
	Three or four times	56	104.92			
	More than four times	38	75.76			
Jogging/hurrying	Never	56	166.04	39.086	3	<0.001
	Once or twice	95	122.86			
	Three or four times	56	107.48			
	More than four times	38	82.48			
Swelling of the feet, legs, and ankles	Never	56	174.53	58.689	3	<0.001
	Once or twice	95	127.66			
	Three or four times	56	95.33			
	More than four times	38	76.20			

Fatigue	Never	56	173.63	53.578	3	<0.001
	Once or twice	95	124.73			
	Three or four times	56	103.79			
	More than four times	38	72.38			
SOB	Never	56	176.74	59.858	3	<0.001
	Once or twice	95	119.29			
	Three or four times	56	114.52			
	More than four times	38	65.57			
Sleeps upright due to SOB	Never	56	167.01	54.275	3	<0.001
	Once or twice	95	125.80			
	Three or four times	56	114.54			
	More than four times	38	63.61			
Enjoyment of life	Never	56	175.99	66.902	3	<0.001
	Once or twice	95	122.06			
	Three or four times	54	109.26			
	More than four times	38	60.39			
Satisfaction	Never	55	177.64	67.342	3	<0.001
	Once or twice	95	120.56			
	Three or four times	56	113.02			
	More than four times	38	61.51			
Hobbies/ recreational activities	Never	56	170.73	57.880	3	<0.001
	Once or twice	95	125.02			
	Three or four times	56	114.15			
	More than four times	38	60.66			
Working/ household chores	Never	56	170.13	54.177	3	<0.001
	Once or twice	95	128.64			
	Three or four times	56	103.46			
	More than four times	38	68.25			
Visiting social contacts	Never	56	180.23	70.463	3	<0.001
	Once or twice	95	123.06			
	Three or four times	56	106.71			
	More than four times	38	62.50			
Total QoL score	Never	52	168.38	73.470	3	<0.001
	Once or twice	86	113.70			
	Three or four times	48	96.82			
	More than four times	38	53.13			

4.5.10 Other co-morbidities

To assess the correlation between illness perception and the presence of other comorbidities, the independent samples t-test was used. The independent t-test indicates that participants with other comorbidities scored higher than those without comorbidities, indicating that the latter had more positive perceptions. Positive t-test results indicate that participants with comorbidities are affected more negatively (p= 0.002) (Table 41.1).

Table 41.1

The relationship between illness perceptions and co-morbidities using the independent sample t-test

		t-test for equality of means		95% CI of the difference	
	T	df	P-value (2-tailed)	Mean difference	Standard error mean
Consequences	3.362	245	<0.001	1.244	0.370
Timeline	3.422	238	<0.001	0.931	0.272
Personal control	0.369	244	0.713	0.138	0.374
Treatment control	1.347	244	0.167	0.426	0.316
Symptom occurrence	3.827	244	<0.001	1.355	0.354
Concern	2.300	244	0.022	0.696	0.303
Understanding	1.122	244	0.263	0.369	0.329
Emotional response	1.667	245	0.097	0.545	0.327
Total illness perception score	3.128	233	0.002	5.293	1.692

The Mann-Whitney U test was used to test the correlation between the presence of other comorbidities and QoL. Results showed that participants without comorbidities had higher QoL (M=126.90; p=0.002) than those with comorbidities (M=99.94; p= 0.002). A higher score indicates better QoL (Table 41.2).

Table 41.2

The relationship between QoL and multiple co-morbidities using the Mann Whitney U test

	Ranks			Test statistics			
	Other co-morbidities	*n*	Mean rank	Mann-Whitney U test	Wilcoxon W	Z	P-value
Showering	Yes	133	105.45	5113.500	14024.500	-4.595	<0.001
	No	114	145.64				
Walking 1 block	Yes	133	110.05	5725.500	14636.500	-3.401	<0.001
	No	114	140.28				
Jogging/ hurrying	Yes	133	114.99	6383.000	15294.000	-2.246	0.025
	No	114	134.51				
Swelling of the feet, legs, and ankles	Yes	133	108.42	5509.500	14420.500	-3.817	<0.001
	No	114	142.17				
Fatigue	Yes	133	107.81	5428.000	14339.000	-3.898	<0.001
	No	114	142.89				
SOB	Yes	133	108.90	5572.500	14483.500	-3.637	<0.001
	No	114	141.62				
Sleeps upright due to SOB	Yes	133	117.62	6732.500	15643.500	-1.590	0.112
	No	114	131.44				
Enjoyment of life	Yes	132	114.76	6370.500	15148.500	-2.011	0.044
	No	113	132.62				
Satisfaction	Yes	133	118.74	6881.000	15729.000	-1.178	0.239
	No	113	129.11				
Hobbies/ recreational activities	Yes	133	118.13	6800.000	15711.000	-1.421	0.155
	No	144	130.85				
Working/ household chores	Yes	133	120.67	7137.500	16048.500	-0.806	0.420
	No	114	127.89				

Visiting social contact	Yes	133	114.58	6328.000	15239.000	-2.292	0.022
	No	114	134.99				
Total QoL score	Yes	116	99.94	4806.500	11592.500	-3.107	0.002
	No	109	126.90				

4.5.11 Perceived support from relatives and social contacts

To assess the correlation between illness perception and perceived support from relatives and social contacts, the independent samples t-test was used. The independent t-test indicates that participants who felt supported by their relatives and social contacts had significantly better illness perception scores than those without support (p= <0.001). Negative t-test results indicate that participants who felt supported scored lower than those who did not feel supported (Table 42.1).

Table 42.1

The relationship between illness perceptions and social/familial support using the independent sample t-test

		t-test for equality of means		95% CI of the difference	
	T	df	P-value (2-tailed)	Mean difference	Standard error mean
Consequences	-3.550	75.715	<0.001	-1.558	0.439
Timeline	-1.465	62.688	0.148	-0.508	0.347
Personal control	-5.662	69.591	<0.001	-2.521	0.445
Treatment control	-2.238	61.488	0.029	-1.002	0.448
Symptom occurrence	-3.726	77.370	<0.001	-1.543	0.414
Concern	-2.994	71.792	0.004	-1.086	.363
Understanding	-4.287	65.797	<0.001	-1.807	0.421
Emotional response	-4.684	246	<0.001	-1.870	0.399
Total illness perception score	-5.817	234	<0.001	-12.335	2.121

The Mann-Whitney U test was used to assess the correlation between QoL and perceived support from family and social contacts. Results show that the total scores of participants who felt supported scored higher in QoL scores (M=120.36; p=0.001). Higher scores indicate better QoL (Table 42.2).

Table 42.2

QoL and social/familial support using the Mann-Whitney U test

	Ranks			Test statistics			
	Perceived social support	*n*	Mean rank	Mann-Whitney U test	Wilcoxon W	Z	P-value
Showering	Yes	201	131.38	3341.000	4469.000	-3.257	0.001
	No	47	95.09				
Walking 1 block	Yes	201	130.88	3442.000	4570.000	-2.971	0.003
	No	47	97.23				
Jogging/ hurrying	Yes	201	129.55	3709.000	4837.000	-2.403	0.016
	No	47	102.91				
Swelling of the feet, legs, and ankles	Yes	201	128.37	3946.000	5074.500	-1.811	0.070
	No	47	107.97				
Fatigue	Yes	201	130.62	3493.000	4621.000	-2.817	0.005
	No	47	98.32				
SOB	Yes	201	131.42	3333.000	4461.00	-3.184	0.001
	No	47	94.91				
Sleeps upright due to SOB	Yes	201	128.56	3908.000	5036.000	-1.933	0.053
	No	47	107.15				
Enjoyment of life	Yes	199	130.85	3214.500	4342.500	-3.407	<0.001
	No	47	92.39				

Satisfaction	Yes	200	133.43	3214.500	3942.500	-4.422	<0.001
	No	47	83.88				
Hobbies/ recreational activities	Yes	201	131.20	3376.000	4504.000	-3.100	0.002
	No	47	95.83				
Working/ household chores	Yes	201	130.39	3540.500	4668.500	-2.719	0.007
	No	47	99.33				
Visiting social contact	Yes	201	133.04	3006.500	4134.500	-3.971	<0.001
	No	47	87.97				
Total QoL score	Yes	182	120.36	2756.000	3746.000	-3.208	0.001
	No	44	85.14				

4.5.12 Perceived support from the healthcare system

To assess the correlation between perceived support and illness perception, the independent samples t-test was used. Results showed that illness perceptions of participants who did not feel supported by the health care system were affected more negatively. Negative scores indicate that those who felt supported scored lower on the illness perception questionnaire, meaning that illness perceptions were more positive (Table 43.1).

Table 43.1

Illness perceptions and perceived support from the healthcare system using the independent sample t-test.

		t-test for equality of means		95% CI of the difference	
	T	df	P-value (2-tailed)	Mean difference	Standard error mean
Consequences	-0.408	245	0.683	-0.347	0.848
Timeline	-0.867	238	0.387	-0.553	0.637
Personal control	-2.939	244	0.004	-2.417	0.822
Treatment control	-2.561	12.489	0.024	-2.750	1.074
Symptom occurrence	-2.724	244	0.007	-2.187	0.803
Concern	-0.032	244	0.975	-0.022	0.681
Understanding	-2.585	244	0.010	-1.877	0.726
Emotional response	-2.917	15.357	0.010	-1.449	0.497
Total illness perception score	-2.854	233	0.005	-11.000	3.855

The Mann-Whitney U test was used to assess the correlation between perceived support from the healthcare system and QoL. Since the significance level (p= 0.060) was higher than the significance level, the evidence was not deemed strong enough to suggest an effect between the variables exists (Table 43.2).

Table 43.2

QoL and perceived support from the healthcare system using the Mann-Whitney U test

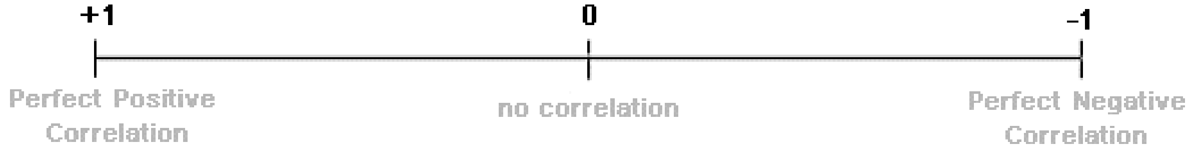
	Ranks			Test statistics			
	Perceived social support	*n*	Mean rank	Mann-Whitney U test	Wilcoxon W	Z	P-value
Showering	Yes	201	131.38	3341.000	4469.000	-3.257	0.001
	No	47	95.09				
Walking 1 block	Yes	201	130.88	3442.000	4570.000	-2.971	0.003
	No	47	97.23				
Jogging/ hurrying	Yes	201	129.55	3709.000	4837.000	-2.403	0.016
	No	47	102.91				
Swelling of the feet, legs, and ankles	Yes	201	128.37	3946.500	5074.000	-1.811	0.070
	No	47	107.97				
Fatigue	Yes	201	130.62	3493.000	4621.000	-2.817	0.005
	No	47	98.32				
SOB	Yes	201	131.42	3333.000	4461.000	-3.184	0.001
	No	47	94.91				
Sleeps upright due to SOB	Yes	201	128.56	3908.000	5036.000	-1.933	0.053
	No	47	107.15				
Enjoyment of life	Yes	199	130.85	3214.500	4342.500	-3.407	<0.001
	No	47	92.39				
Satisfaction	Yes	200	133.43	2814.500	3942.500	-4.422	<0.001
	No	47	83.88				
Hobbies/ recreational activities	Yes	201	131.20	3376.000	4505.000	-3.100	0.002
	No	47	95.83				
Working/ household chores	Yes	201	130.39	3540.000	4668.500	-2.719	0.007
	No	47	99.33				
Visiting social contact	Yes	201	133.04	3006.000	4134.500	-3.971	<0.001
	No	47	87.97				
Total QoL score	Yes	212	115.02	950.500	1041.500	-1.878	0.060
	No	13	80.12				

4.6 Objective 4: The relationship of illness perception and QoL among individuals with CHF

The Spearman correlation coefficient was used to assess the correlation between illness perception and QoL. This test was deemed appropriate since one of the questionnaires violated the normality assumption. Moreover, the Spearman correlation coefficient measures the strength of the relationship between two continuous variables, which ranges from -1 to 1. A correlation coefficient close to 1 indicates a strong positive relationship between the two variables; a correlation coefficient close to -1 indicates a strong negative relationship between the two variables, while a correlation coefficient close to 0 indicates no relationship between the two variables (Figure 4).

Figure 4

Spearman coefficient correlation scale



The Spearman correlation test investigates whether a relationship between two variables is significant. The null hypothesis specifies that there is no relationship between the two variables and is accepted if the p-value exceeds the 0.05 level of significance. The alternative hypothesis specifies that there is a significance between the two variables and is accepted if the p-value is less than the 0.05 criterion.

Table 19 presents the results of the Spearman correlation test. Since the Spearman correlation coefficient is negative (-0.757; p=<0.001) and close to -1, it indicates that a strong negative relationship is found between quality of life and illness perception. A negative correlation suggests that as one variable increases, the other variable decreases. This means that as illness perceptions scored higher (were more negative), they were associated with lower QoL. This can also be seen in Figure 5.

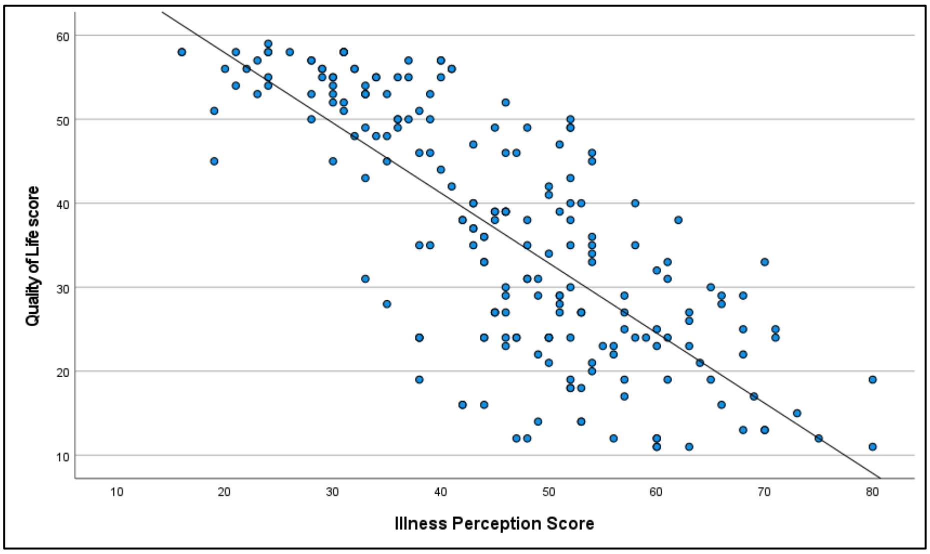
Table 44

Spearman correlation test between the B-IPQ and the KCCQ-12

		Total KCCQ-12 score
Total B-IPQ	Correlation coefficient	-0.757
	p-value	<0.001

Figure 5

Q-Q plot presenting the correlation between QoL and illness perception



4.6.1 The correlation of QoL and illness perception with the participants' demographic and clinical characteristics

All the demographic and clinical characteristics of the participants showed a statistically negative correlation between illness perception and QoL. This means that as one variable increased the other decreased. Therefore, as illness perception increased (become more negative) QoL worsened. These can be seen in the following Q-Q plots (Figures 6 - 15).

A negative correlation can be seen among all age groups, however among the age group ‘86+’ the negative correlation is weak, (Figure 6). Among both males and females, a negative correlation can be seen, (Figure 7). A negative correlation can be seen among all levels of education, (Figure 8). A negative correlation can be seen among ‘single’, ‘married’ and ‘widowed/separated/divorced’ subgroups. The subgroup ‘other’ was eliminated as only four participants chose this option, making it too weak to be indicative of a population, (Figure 9). A negative correlation was seen among all living arrangements before being diagnosed with CHF, with a weaker negative correlation among participants living in an elderly home. In addition, the option ‘other’ was eliminated as only seven participants chose this option, which does not make it strong enough to indicate a correlation, (Figure 10). The same was reported for living arrangements after being diagnosed with CHF, (Figure 11). A negative correlation can be seen among both individuals who felt supported and those who did not feel supported, by their social contacts, (Figure 12). The same was reported for perceived support from the health care system (Figure 13). A negative correlation was seen among all reported frequencies of hospital admissions (Figure 14). Among individuals with and without other medical a negative correlation was seen, (Figure 15).

Figure 6

Q-Q plot presenting the correlation between QoL and illness perception according to the participants' ages

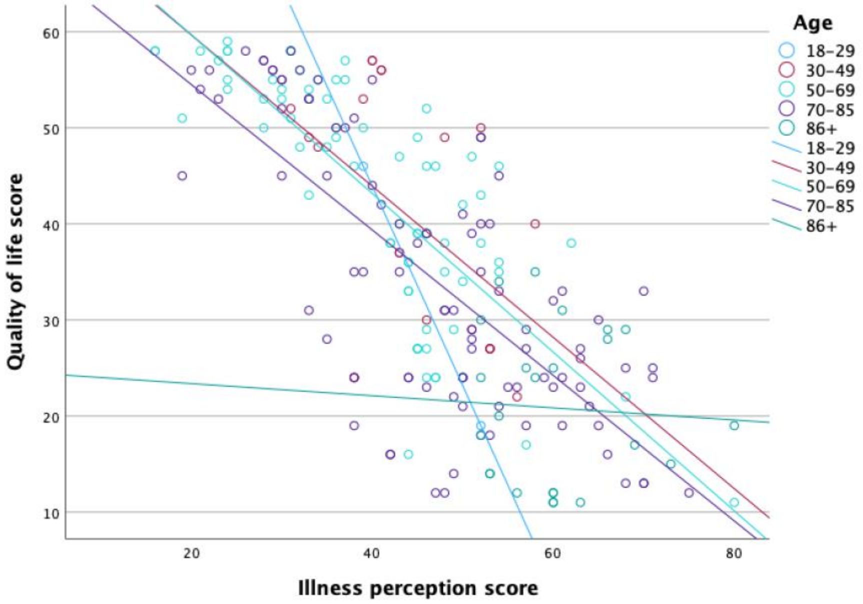


Figure 7

Q-Q plot presenting the correlation between QoL and illness perception according to the participants' gender

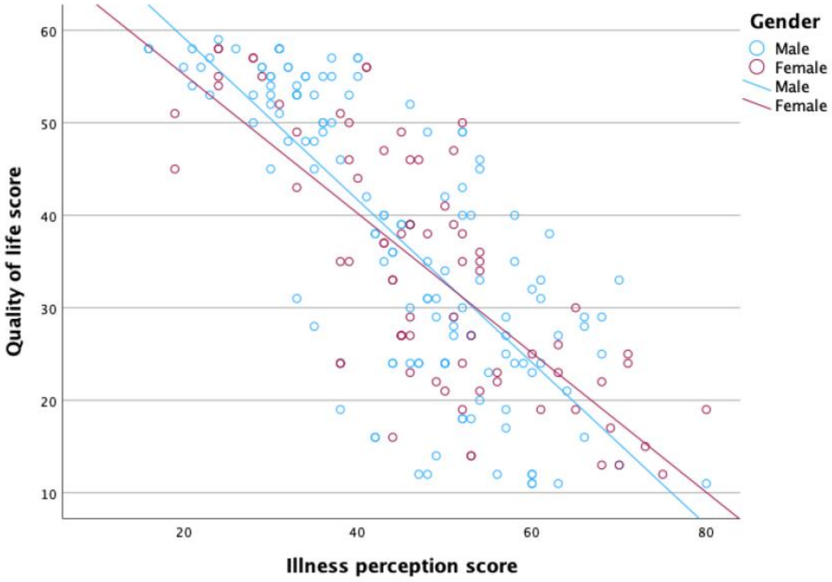


Figure 8

Q-Q plot presenting the correlation between QoL and illness perception according to the participants' level of education

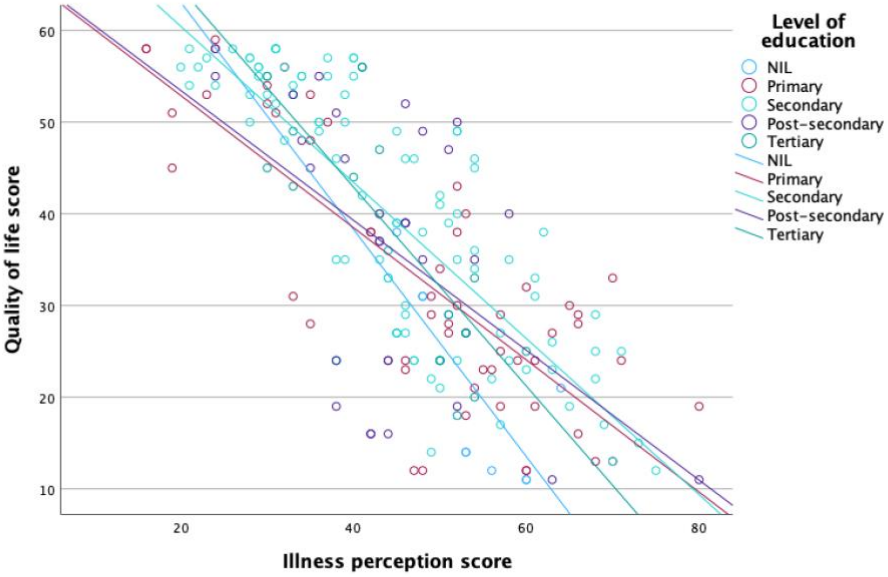


Figure 9

Q-Q plot presenting the correlation between QoL and illness perception according to the participants' marital status

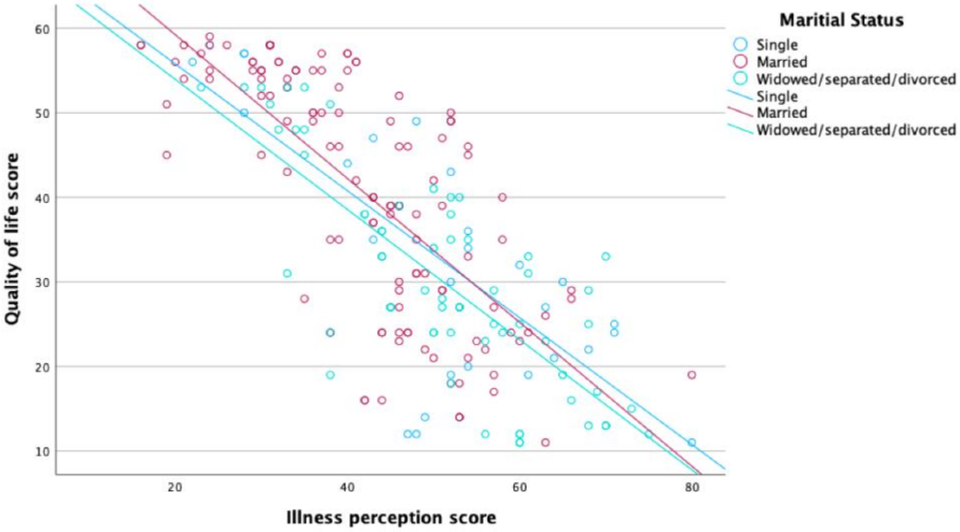


Figure 10

Q-Q plot presenting the correlation between QoL and illness perception according to the participants' living arrangement before being diagnosed with CHF

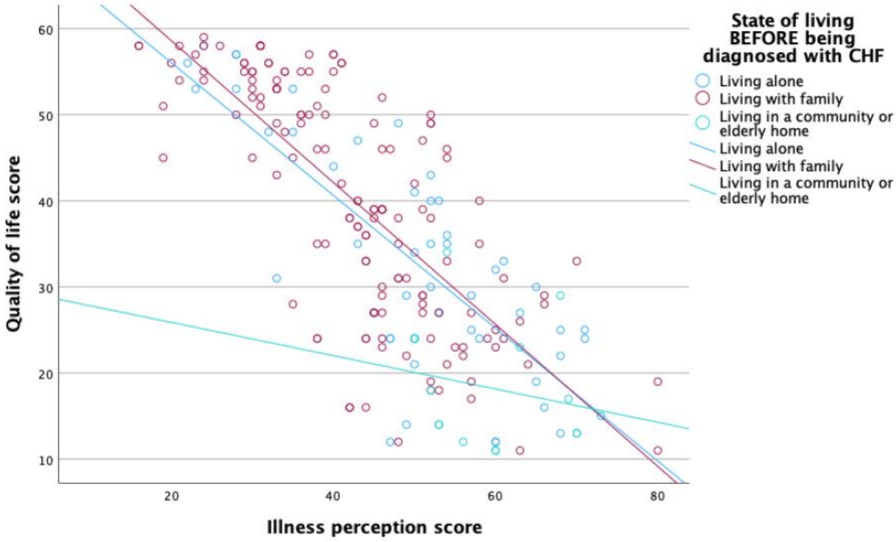


Figure 11

Q-Q plot presenting the correlation between QoL and illness perception according to the participants' living arrangement after being diagnosed with CHF

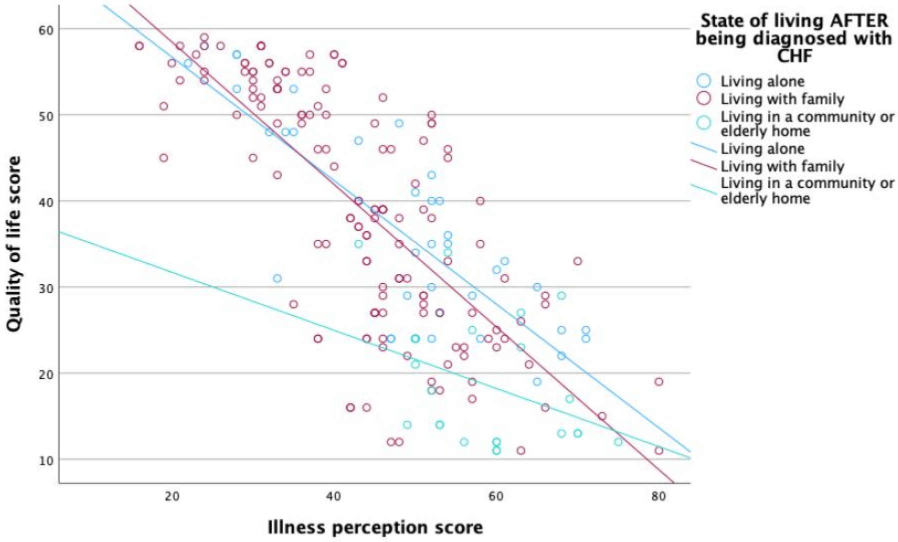


Figure 12

Q-Q plot presenting the correlation between QoL and illness perception according to the participants' perceived family and social support

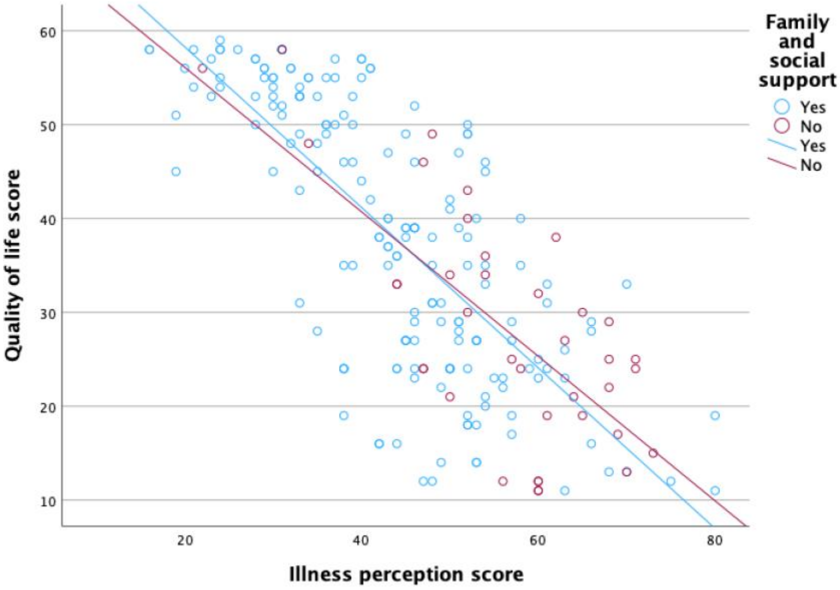


Figure 13

Q-Q plot presenting the correlation between QoL and illness perception according to the participants' perceived support from the healthcare system

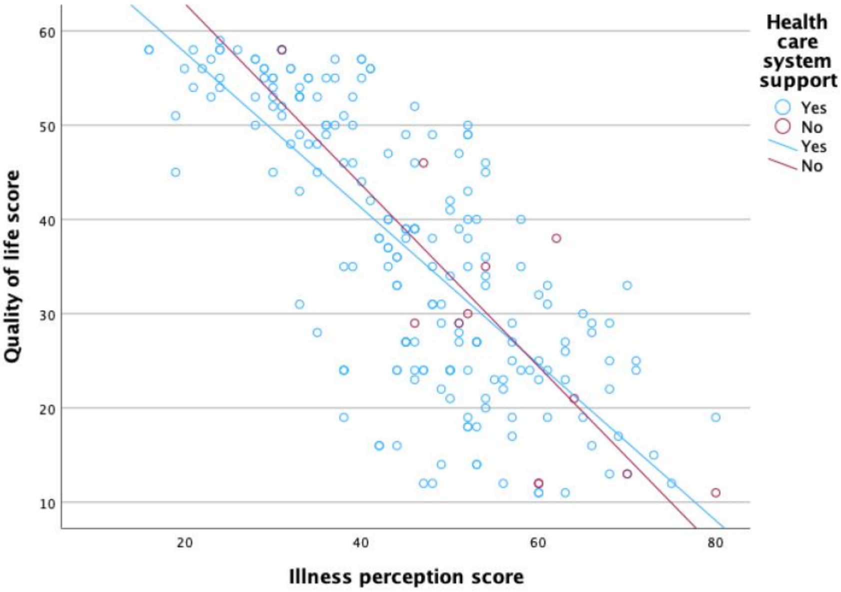


Figure 14

Q-Q plot presenting the correlation between QoL and illness perception according to the participants' frequency of past hospital admissions

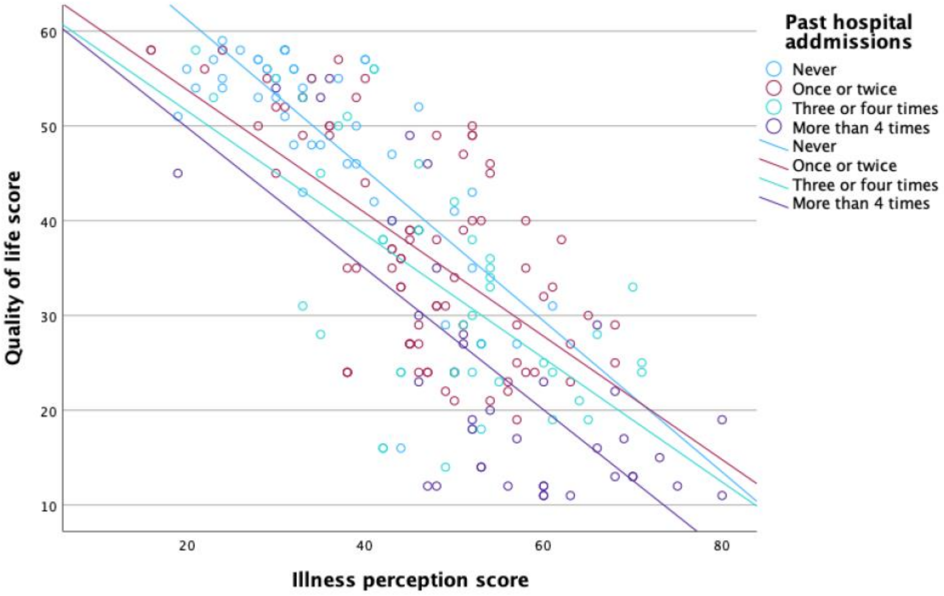
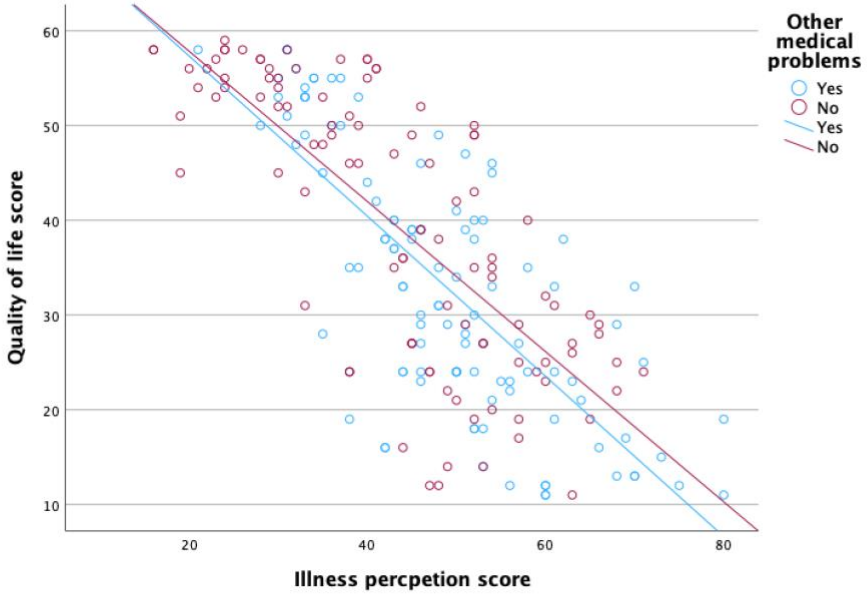


Figure 15

Q-Q plot presenting the correlation between QoL and illness perception according to whether the participants' had other medical conditions



4.7 Conclusion

This chapter presented the results obtained from the data collection, and the study's objectives were addressed. Total illness perception scores indicate that participants viewed their illness as a moderate threat. Negative illness perception was observed in two domains: in how chronic they perceived their illness to be, and in how concerned they were for their illness. Suggesting that participants viewed their illness as being highly chronic, and that they were very concerned about their illness. The most positive illness perception was regarding treatment control, suggesting that participants viewed their treatment choices to be very effective. Smoking, cardiomyopathy and genetics were the most frequently mentioned casual factors according to the study participants.

Total QoL scores indicate that participants reported having moderate limitations. High limitations were not reported in any QoL domains investigated. However, the highest limitations in QoL are when jogging or hurrying.

Assessment of the relationship of QoL and illness perception among the different demographic and clinical information subgroups; age showed that as it increased, illness perception was more negative. As the level of education increased, QoL increased as well. Illness perception was more positive among married participants and who lived with family members both before and after being diagnosed with CHF. Furthermore, the lowest QoL was seen among individuals living in a community home. The more frequent hospital admission rates, the more negative their illness perceptions were. In addition, as hospital admission rate increased, QoL decreased. Participants with other medical problems in conjunction with CHF had more negative perceptions and lower QoL than participants without other medical problems. Participants who reported feeling supported by their relatives showed more positive illness perceptions; the same was observed among individuals who felt supported by the health care system. In addition, participants who felt supported by their relatives reported better QoL. There was not enough evidence to suggest that a relationship exists between illness perception and gender, QoL and gender, illness perception and level of education, and perceived support from the healthcare system and QoL, as the p-values were greater than the level of significance.

When assessing the correlation between illness perception and QoL among the participants' demographic data and clinical information, a negative correlation was seen among all the subgroups, that is the more positive the illness perceptions were, the better the QoL. The next chapter aims to discuss the main findings of the research study and compare them with the reported literature findings.

Chapter 5: Discussion

5.1 Introduction

This chapter presents a detailed discussion of the main findings of this study. It provides an account of the participants' socio demographic characteristics and clinical information. It then addresses the objectives of this study by referring to the related study results and comparing these with those of the key studies identified in the literature review (Chapter 2). Additionally, since literature on this topic is still scarce, literature related to other diseases will also be referred to. Lastly, the strengths and limitations of this study will be discussed.

5.2 Participants' socio demographic characteristics and clinical information

A total of 248 individuals living with CHF were conveniently recruited through the Heart Failure Clinic in a general hospital in Malta. The most common age range was 70-85 years (44%, n= 109), closely followed by 50-69 years (33.9%, n=84); this was similar to the key studies conducted by Goodman et al., 2012; Mulligan et al., 2010 and Carels 2004. The majority of the participants were males (64.9%, n= 161), this is comparable with most of the literature (Carels 20014; Goodman et al., 2012; Mulligan et al., 2010; Hallas et al., 2009), furthermore, one of the studies recruited only males (Bosworth et al., 2004). This supports the literature showing that males are more likely to develop CHF than females, suggesting that CHF is most common among males, (Giagulli et al., 2013).

The most common level of education was secondary level (46.8%, n= 116), only two key studies collected information about the participants' level of education, (Carels, 2004; Bosworth et al., 2004). The fact that secondary level of education is compulsory in Malta might have influenced the data collected, (Bezzina, 2013). The majority of the participants reported that they were married (54.8%, n=136). Three key studies collected information regarding marital status; all the three studies reported that the majority were married, (Hallas et al., 2009; Goodman et al., 2012; Bosworth et al., 2004). Most common state of living of the participants was living with family members, both before (67.7%, n=168) and after (67.3%, n= 167) being diagnosed with CHF. This trend was expected since most of the participants reported being married.

Most participants reported feeling supported both from their social contacts (81%, n=201) and from the health care system (94.4%, n=234). This trend was expected as most participants were married and lived with family members which might contribute to feeling supported. In addition, since data collection was carried out at the Heart Failure clinic, which supports and follows up patients regularly even via telephone, participants are more likely to feel supported. Positive support eases stress associated with disease, (Bosworth et al., 2004). The most common admission rate was once or twice (38.3%, n=95), this was not consistent with the literature which shows that CHF is one of the most common reasons for repeated hospital admissions, (Goodman et al., 2012). This might have been influenced by the fact that data collection was carried out in an outpatients department, therefore targeting participants who were most likely mobile and independent, therefore patients who are not at end-stage or patients who have their CHF under control. However, the presence of other medical problems were more common (53.6, n=53.5). The most disease apart from CHF among the participants was diabetes (31%, n=63), this was expected since both CHF and diabetes are associated with comparable risk factors.

5.3 Objective 1: Illness perception of individuals with CHF

The first objective of this study was to assess the illness perception of individuals with CHF. Research on illness perception emerged from the common-sense model of self-regulation by Leventhal et al., (1980). Individuals were asked to reflect on the influence of the illness on their lives, through their personal experiences, (Hagger et al., 2017). This approach was adapted in this study by using the B-IPQ to collect data on illness perception among the study participants.

According to responses obtained from the illness perception questionnaire, the participants of this study perceived CHF as having moderate overall impact on their lives. This may have been influenced by various external factors, including familial support, healthcare support, independency level and level of QoL. Bosworth et al., (2004), stated that support improves the individual's way of coping with the disease. In this study, 81% of the participants reported having familial support and 94.4% reported having support from the healthcare system, this might have positively influenced the participants' overall illness perception. Another factor which might have influenced this result is level of independency. Participants reported low limitation with showering/bathing and walking 1 block on ground level, whereas, jogging/hurrying, carrying out hobbies/recreational activities, working/ doing household chores and visiting their social contacts revealed moderate limitation. These factors might have influenced the result of the overall illness perception among the participants. In addition, overall moderate limitations were reported when assessing QoL, this result might also have influenced the overall illness perception, since a link between illness perception and QoL was reported in this and other studies. This will be explored further when assessing objective 4 (5.6).

CHF is one of the most common illness responsible for frequent hospital admission, (Khan et al., 2021). However, most of the participants in this study reported being hospitalised only once or twice, suggesting that their CHF was quite under control. Since recruitment was carried out through an outpatient's department (Heart Failure Clinic), where patients were being continuously educated on how to live with CHF and how to deal with symptoms which may arise, this may have led to decreased hospitalisations. This can also be observed in the longitudinal study by Goodman et al., (2012), who states that a participative person-centred approach, tailoring an illness management program addressing the patients' illness perceptions and assisting patients in identifying barriers, helps to increase management and self-care confidence.

There were very minor changes in living arrangements before and after being diagnosed with CHF, with the majority still living with their family members; participants who started living in an elderly home after being diagnosed with CHF only increased by 3.2%. This was expected as the participants reported CHF to have moderate consequences on their lives.

Participants perceived CHF to have a chronic timeline, this might be influenced by the fact that medications given for CHF are normally given indefinitely. Research shows that once the sequence of fluid retention, hospitalisation and subacute congestion begins for CHF patients, the cycle typically repeats itself until death, (Riegel et al., 2018). However, participants still perceived treatment of CHF to be very helpful, even more than personal control. This might suggest that personal interventions such as restricting fluid, restricting sodium intake and weighing themselves regularly was hard to maintain. Moreover, treatment was reported successful in alleviating symptoms of CHF. Nevertheless, symptom occurrence was scored moderate among the study participants. This might also be indicative of the low hospital readmission rate among the participants. This is consistent with the literature as both longitudinal studies, carried out by Goodman et al. (2012) and Mulligan et al. (2010), reported that treatment satisfaction was high.

In this study participants reported high concern for their illness. During the focus group of the study conducted by Bosworth et al. (2004), participants mentioned concerns about symptom occurrence and symptom management for the future, even when symptoms were not yet present. Additionally cognitive symptoms were also mentioned while discussing concerns which include confusion and memory loss. The study by Mulligan et al. (2012) also reported that participants showed concern for their illness.

Understanding of their illness scored moderate among the participants. Bosworth et al. (2004), Goodman et al. (2012) and Hallas et al. (2009) reported low understanding of the participants' illness. However, Bosworth et al. (2004) reported that participants expressed that even their family and close connections fail to understand the extent of the disease. Bosworth et al., (2004) argues that a strong support system from the family and close connections would enhance the understanding of the patient and its way of coping with CHF. Familial support was reported very high in this study; therefore, this might have influenced the results to be higher than that of the key studies. Goodman et al. (2012) reported poor understanding among their study participants, however, they suggested that if healthcare systems empower individuals with CHF to learn and understand their illness, they would improve management of the disease and self-care measures. This might explain why moderate scoring was seen among the participants of this study, as participants were recruited from the Heart Failure clinic, therefore disease management was likely to be given to the participants. In fact, participants reported very high scores of support from the healthcare system.

Emotional response to illness scored moderate among the participants of this study. Hallas et al., (2009), reported that anxious and depressed patients had worse coping styles when compared with patients without anxiety and depression. It was also reported in their study that individuals with advanced CHF show higher emotional distress. Furthermore, Bosworth et al., (2004) reported that depression, anxiety, fear, low self-worth, and guilt were common emotions among the group, many times these emotions were linked with physical limitations. Emotional response was expected to score lower since only 2.5% of the participants reported suffering from depression, however according to Uniyal (2022), many mental health issues are commonly undiagnosed, including depression and anxiety.

Various causes of CHF were identified by the participants which they perceived to be the causes of their illness. The most common causal factors were smoking, cardiomyopathy and hereditary causes. Smoking is highly associated with CHF incidence, due to its association with higher left ventricular mass and lower left ventricular strain, (Kamimura et al., 2018). In addition, smoking is one of the most modifiable risk factors of CHF, (Son & Lee, 2020). Cardiomyopathy can also be a cause for CHF as it may result in any disorder that damages the ventricular ejection of blood, (Malik et al., 2022). CHF can also be transmitted from a biological generation to another, making it hereditary, (Schiller, 2021). This shows that the three most common perceived causal factors among the participants are all possible. Since participants' understanding of their illness scored moderate, a good level of comprehension of causal factors was expected.

5.4 Objective 2: QoL of individuals with CHF

The second objective was to assess the QoL of individuals with CHF. This was done using the KCCQ-12. The overall score of QoL showed moderate limitations among the study participants. This was expected since participants were recruited through an outpatients department, so participants were more likely to have some level of their independence since they have to attend for their appointments regularly.

When assessing everyday physical activities showering/bathing and walking 1 block on level ground showed low limitations, whereas jogging or hurrying showed moderate limitations. It was expected that jogging/hurrying would be more challenging, due to the limitations CHF symptoms present, such as dyspnoea and swelling of the feet. Bosworth et al., (2004) reported that physical activity is more likely to be impaired with the presence of chronic conditions. However, Hance et al., (1996) argues that having a strong support system helps maintain QoL, which might have played a role in the results, since the participants reported good support both from family and the healthcare.

Participants were assessed on how much they experience CHF-related symptoms daily. Swelling of the feet scored low occurrence, fatigue and SOB scored moderate occurrence. However, the need to sleep upright during the night due to SOB was low. This might indicate that the participants recruited had either their condition under control or were in their early stages, as swelling of the feet usually indicates worsening of the disease, whereas fatigue and SOB are early signs of CHF. Since sleeping upright scored low occurrence, this shows that paroxysmal nocturnal dyspnoea was not an issue among most of the participants, (John Hopkins Medicine, 2022). This was consistent with the participants' perception of symptom occurrence, which scored moderate in the B-IPQ. Since participants' perception of treatment control scored high this might also suggest that their illness was under control due to treatment satisfaction.

The participants in this study showed moderate scores in how much CHF limited their enjoyment in life and their satisfaction if they had to live with CHF for the rest of their lives. Hallas et al., (2009), reported that in their study negative perceptions about consequential outcomes were related to non-adherence to treatment, impaired recovery, and decreased satisfaction. This might be another reason why overall illness perception and QoL scored moderate.

Carrying out hobbies and recreational activities, doing household chores and visiting relatives outside of their home all showed moderate limitations among the study participants. CHF patients are known to have difficulties in their social lives due to symptom occurrence, impairments, and physical limitations, (Mullian et al., 2010). In addition, Bosworth et al., (2004), explained that their participants reported feeling frustrated due to role loss, which included household chores and social roles. Additionally, many of their participants limited themselves to activities in fear of symptom exacerbation. Carels (2004) stated that greater functional impairment was associated with reduced QoL.

5.5 Objective 3: Assessing the relationship between participants' characteristics with illness perception and QoL

In this section the relationship between the participants' demographic and clinical data with illness perceptions and QoL will be discussed. As age increased, illness perception worsened. Old age may lead to health problems, which results in poorer perceived health and mortality, (Stewart et al., 2012). In addition, as age increased QoL decreased as well; according to the Stereotype Embodiment Theory (Levy 2009), as one grows older, individuals internalise society's negative perceptions of ageing and apply them to their own ageing. These perceptions may become self-fulfilling prophecies, affecting their health, functioning and longevity, through health behaviours, (Westerhof and Wurm, 2015). From the key studies identified in previous chapters, only Clark et al., (2003) assessed the relationship between age with illness perception and QoL; their results were consistent with this research as their findings show that as age increased QoL was negatively affected, especially in the emotional and fatigue domains, which in turn negatively affected their illness perception.

The analyses between gender with illness perception and QoL shows that no significant correlation exists. In addition, none of the key studies mentioned an association between these variables. In a study which assessed the relationship between illness perception and QoL among patients with colorectal cancer, women had worse illness perception than men, in addition the relationship between illness perception and QoL was significantly stronger among men than among women, (Gemert, 2017).

The analyses between level of education with illness perception shows that no significant correlation exists. However, when assessed with QoL, among higher levels of education QoL was better. This could be that participants with a higher education were more likely to understand and articulate their illness and what it entails, giving them a better understanding of their disease and how to cope with it. According to Zhan et al., (2022), education reduces income inequality and poverty which affects human wellbeing and happiness. This life success may impact QoL. Furthermore, higher education is associated with higher income, which is positively related with better QoL. Individuals with secondary education reported the highest levels of enjoyment of their life and satisfaction of living with CHF was highest among participants with post-secondary education.

When assessing marital status with illness perception and QoL, married individuals held the most positive perceptions with regards to their illness and reported the best QoL among the subgroups. According to Kim et al., (2018), married adults show better health outcomes than non-married individuals; marriage generates advantages in economic resources, health behaviour, and social and psychological support. Additionally, martial termination potentially puts a strain on an individual's life, which might alter hormonal and neural control, and cause immunological changes among divorced, separated, or widowed individuals, making them more susceptible to poor health. Furthermore, Gutiérrez-Vega, (2017), explains that marital status is also associated with better QoL due to its effects on psychological, physical, and social aspects in life. None of the key studies explored this correlation.

Illness perceptions and QoL yielded better results among participants living with family members, whereas participants living in elderly/community homes held the most negative illness perceptions and lower QoL. These results were similar among the participants both before and after being diagnosed with CHF. From the key studies, Hallas et al., (2009), Clark et al., (2003) and Goodman et al., (2012), all reported that individuals with social support had more positive health beliefs, which led to better self-management QoL and health outcomes. Conversely, Carels (2004) argued that participants who had social and familial support often felt like a burden on their social contacts.

It was observed that as hospital admissions increased illness perceptions became more negative and QoL decreased. These findings were expected as frequent hospital admissions contribute to physical, mental, social and spiritual deprivation, (Huang et al., 2020). In the key study conducted by Goodman et al., (2012), it was observed that after their first admission participants were confused and lacked confidence, then after six months these participants claimed to have improved their confidence, however self-management still did not improve. Therefore, this might suggest that although individuals might get accustomed with their illness, disease management is still a struggle leading to low QoL and low illness perceptions.

Participants with other comorbidities, other than CHF, had more negative illness perceptions and less QoL than those who did not have other medical problems. Clark et al., (2003) reports similar findings, stating that the sicker the individual is the lower the QoL they will have. The presence of other comorbidities could contribute to an increase in symptoms and physical restrictions, which would promote negative illness perceptions and low QoL, (Carels 2004). The results in the study by Mulligan et al., (2010) are also consistent, reporting that QoL, perceptions and moods are all affected when other comorbidities are present. Conversely, Hallas et al., (2009) observes that no differences were reported, among those with other comorbidities and those without, in anxiety and depression.

Participants who perceived support from their social contacts held better illness perceptions and scored higher in QoL. This was expected as from the six key studies four yielded similar results. Carels (2004) mentioned that depression and negative mood was associated with lower social support. Furthermore, Hallas et al., (2009) states that depression, anxiety and stress promotes a decline in health whereas social support promotes better health, which mediates biological processes. In addition, social support is one of the coping factors used to help patients gain greater health belief and self-management efficacy. Clark et al., (2003) supports this by stating that social support is an important component of treatment and outcomes of CHF. On the other hand, Bosworth et al., (2004) argues that although the influence of social support is beneficial, it may also contribute to feelings of guilt of being a burden on their families, therefore argues that their social network can simultaneously be a benefit and also a burden.

In addition to social support, participants were assessed on their perceived support from the health care system. Support from the healthcare system was more common than support from their relatives and social contacts. Illness perception was better among participants who reported feeling supported by the healthcare system, however the analysis of perceived support from the healthcare system and QoL does not show that a corelation exists. According to Clark et al., (2003), development of assessment tools for self-management of CHF include social support, provider-patient communication and health beliefs. Interventions to employ these factors within the care of CHF patients have shown improved health outcomes. Bosworth et al., (2004) explains that having a support system protects against risk of morbidity and mortality. The results of this study might have been influenced by the fact that data collection was carried out at the Heart Failure Clinic, which makes patients feel supported by the health care system.

5.6 Objective 4: Assessing the correlation between illness perception and QoL

The findings of this study suggests that a relationship between illness perception and QoL exists. Results suggest that a negative correlation is present; this means that as one variable increases the other decreases. Therefore, as illness perception scores lowered (became more positive) QoL was reported better; likewise, as QoL declined, illness perception scores were higher (became more negative).

These findings were consistent with the literature identified in previous chapters. Goodman et al., (2012), reported similar findings explaining that illness perception and emotional representations affected the participants ability of self-care, therefore QoL was positively associated with illness coherence. Bosworth et al., (2004), reported that illness perceptions are built on feelings of self-efficacy and independence, as physical function plays a major role in the individual's perception of their QoL. Carels (2004) reported that negative illness perceptions increase the risk of depression which in turn decreases QoL in patients with CHF. Hallas et al., (2009) were consistent in their results reporting that anxious and depressed individuals have more negative beliefs about CHF, advancing to negative coping styles and a decline in QoL. In addition, changing negative beliefs improves psychological well-being and QoL, irrespective of the severity of their illness. Clark et al., (2003). Mulligan et al., (2010) concluded their study by stating that addressing illness perceptions would improve QoL in patients with CHF.

The findings of this study related to a positive correlation between illness perceptions and QoL. The results of this objective were the most consistent among the different domains assessed in the questionnaires and among the different demographic characteristics. Additionally, they were also consistent with the findings of the key studies, which all reported that such a corelation exits (Goodman et al., 2012; Mulligan et al., 2010; Bosworth et al., 2004; Carels, 2004; Hallas et al., 2009; Clark et al., 2003).

Furthermore, the positive relationship between illness perception and QoL was also seen in studies among other diseases, including breast cancer (Ośmiałowska et al., 2022), epilepsy (Tu et al., 2022), intermittent claudication (Striberger et al., 2022), cancer (Vatvani et al., 2017) and also advanced cancer (Jabbarian et al., 2021), among others. It was seen that individuals with higher levels of acceptance and positive illness perception function better in ADLs, and experience less disease-related symptoms, the opposite was seen among participants with a negative disposition, (Ośmiałowska et al., 2022). However, since this association has been researched by cross-sectional studies, one cannot conclude as to the direction of association, that whether QoL is affected by illness perception or the other way around.

5.7 Strengths and limitations of the study

5.7.1 Strengths

The main strength of this study is that it addresses the research question extensively, which offers an insight into the nature of illness perception and QoL, as well as the relationship between the attributes and associations with other demographic and clinical variables. The cross-sectional study design, which was of quantitative nature allowed the collection of data from a large pool of participants, making the results more generalisable. In addition, a cross-sectional design uncovers trends in socio-demographic variables allowing the understanding of which subgroups are most affected in specific domains.

The questionnaire chosen for data collection of QoL (KCCQ-12), was disease specific, this is an advantage as it was designed to measure specific QoL domains among individuals with cardiomyopathy. Additionally, although the questionnaire measuring illness perception (B-IPQ) was not disease specific, it is validated and widely applied to various populations and conditions. These questionnaires used were both shorter versions of original questionnaires, the use of shorter versions keeps participants engaged and collects higher quality data, (Taylor, 2021). The questionnaires were available in both Maltese and English therefore, this reached a wider population and minimised selection bias.

5.7.2 Limitations

The study design, although associated with various strengths as previously identified, also had some limitations. Since the study design was cross-sectional, data collection took place at one point in time, therefore, casualty cannot be determined. Therefore, there is no way to identify the direction of associations, (Cornell, 2023). This limitation could have been eliminated by carrying out a longitudinal study instead, however, this was not possible due to time constraints. Another limitation related to the study methods was the use of self-reported questionnaires. Participants may not be aware of their habits, or may underestimate or overestimate frequencies of their responses, such as symptoms occurrence.

Participant recruitment was carried out from only one clinic, and although this specialized clinic may reach the majority of individuals with CHF, this method excluded those who attend other clinics or those who do not attend follow up clinics at all. In addition, this study might be only generalisable among individuals who are not in the end-stage of their disease, if data collection took place among in-patients, different results might be yielded. Furthermore, the convenience sampling used gives rise to further sampling bias as compared to random sampling methods.

A measure of coping was not included in the study, as the self-regulation model by Leventhal et al., (1998) proposes. Illness beliefs generate coping responses, which affects health outcomes, (Mulligan et al., 2010). Coping assessment may have helped to obtain a better understanding of the relationship between changes in illness perceptions and QoL in individuals with CHF.

5.8 Conclusion

This chapter presented the participants’ socio demographic and clinical data, to give the reader a better understanding of the participants. Additionally, these were compared to demographic data obtained in the identified key studies. The results of this study were comparable to those of other studies, however, not all the demographics and patient information were addressed in the key studies.

The first objective assessed the illness perception of individuals with CHF. This showed moderate impact, which was similar to the findings of the key studies. However, these varied among some of the domains. The second objective assessed the QoL among individuals with CHF, which showed moderate limitations in QoL. This was also comparable to the key studies which addressed these domains. Objective 3 assessed the association between participants' demographic and clinical data with illness perception and QoL. It was observed that a correlation exits among most of the assessed demographics, except between gender and illness perception; gender and QoL; and level of education and illness perception. Objective 4 assessed the relationship between illness perception and QoL. These results showed a positive correlation, as illness perception got more positive, QoL increased. This was comparable to other studies. In the domains which were not addressed in the key studies, other literature was applied. Lastly, the strengths and limitations of the study were addressed.

The next chapter entails the conclusion of the research study, by giving a summary of the findings of this research study. Additionally, recommendations for further research, education and practice will be given.

Chapter 6

6.1 Introduction

This chapter aims to conclude this dissertation by summarising the research project, its aims, methods, and findings. This is followed by recommendations for future research and practice.

6.2 Summary of the findings

This study aimed to assess the illness perception and QoL of individuals with CHF, the relationship between the participants' characteristics with illness perceptions and QoL, and the correlation between illness perception and QoL. This was done by collecting data from self-administered questionnaires given to individuals attending the Heart Failure clinic in an acute general hospital in Malta. Numerical data were extracted, and various statistical tests were carried out according to what was being analysed.

The findings in this study suggest that illness perception had a moderate effect among individuals with CHF, However, some domains showed more threat than others. The highest threats were seen in how chronic participants perceived their illness to be and how concerned they were for their illness. Moderate threat was perceived with other variables, while treatment control showed low threat, meaning that the participants found their treatment choices beneficial, even more than personal control. This indicates that treatment was found to be more effective than lifestyle modifications. The three highest perceived causal factors were smoking, cardiomyopathy and genetics.

Overall, QoL showed moderate limitations among the study participants. Low limitations among the participants were seen when showering/bathing and walking one block on ground level. Most of the other factors including those related to physical activity, social activities, fatigue, SOB and enjoyment of life showed moderate limitations. When assessed on the occurrence of other symptoms related to CHF, swelling of the lower limbs, and having to sleep propped up on at least three pillows due to SOB showed low limitations among the participants. None of the assessed domains showed high limitations.

It was observed that some of the participants' demographic and clinical data influenced their illness perception and QoL. These included age, level of education, marital status, level of education and perceived level of support. State of living both before and after being diagnosed with CHF, frequency of hospital admissions and having other medical problems were also influential.

To answer the research question, the findings of this study suggest that a correlation between illness perception and QoL exists among individuals with CHF. A positive correlation was seen. The more negative their illness perception was, the lower their QoL was and vice versa. Moreover, these trends were also observed among the participants' demographic and clinical characteristics as well.

6.3 Recommendations

Recommendation 1: Conducting further research using different research methods

Conducting a qualitative study may help achieve a more in-depth understanding of the individual's perceptions of their illness and how it influences or is influenced by their QoL. This is achieved by analysing feelings, behaviours and thoughts. This was seen in one of the key studies identified during the literature review conducted by Bosworth et al. (2004). This would better explain how illness perception and QoL are interlinked.

Conducting a longitudinal study may also be beneficial as it explores the changes in illness perception and QoL at more than one point in time. This may help identify unforeseen trends when conducting a study at one point in time.

Recommendation 2: Conducting further research among participants from a different setting

Future research can be conducted on participants with CHF in an in-patient setting. This may yield different results than those obtained from this study from an outpatient setting. In addition, a comparison study between the two different settings can also be carried out.

Recommendation 3: Extending education provided by the Heart Failure Clinic to the community

It was noted in this study that only 10.9% of the participants resided in a community/elderly home. In addition, individuals residing in community/elderly homes had lower QoL and more negative illness perceptions. The Heart Failure Clinic's service can be extended to the community, where HCPs can visit these individuals at residential care homes.

Recommendation 4: Providing more psychosocial support

Part of the care plan provided to CHF patients may include more emphasis on psychosocial care. It was observed throughout the study that those lacking support have lower QoL and more negative illness perceptions. Understanding emotional and social representations when tailoring the individuals' plan may help achieve better health outcomes. Additionally, involving the affected individuals' relatives and primary caregivers in their care plan, would enhance the care being delivered when at home. This would help relatives and caregivers to understanding the needs of the individual with CHF and help them to identify barriers hindering their wellbeing.

6.4 Conclusion

This chapter gave a summary of the findings of this study concerning its main objectives. These objectives encompassed the assessment of illness perceptions among individuals with CHF, the QoL of individuals with CHF, the relationship between the participants’ demographic data with illness perception and QoL, and the correlation between illness perception and QoL. The findings of this study suggest that individuals with CHF in Malta experience a moderate level of QoL and moderate perceived impact of CHF on their wellbeing. This study also identified a positive relationship between illness perceptions and QoL and that various demographic characteristics may affect these two variables. Through these findings, recommendations for future research, education and practice were given.

Appendices

Appendix A: The Brief- illness perception questionnaire

The Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views:

How much does your illness affect your life?

0	1	2	3	4	5	6	7	8	9	10
no affect at all										severely affects my life

How long do you think your illness will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

How much control do you feel you have over your illness?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control										extreme amount of control

How much do you think your treatment can help your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely helpful

How much do you experience symptoms from your illness?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all										many severe symptoms

How concerned are you about your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned										extremely concerned

How well do you feel you understand your illness?

0	1	2	3	4	5	6	7	8	9	10
don't understand at all										understand very clearly

How much does your illness 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

Please list in rank-order the three most important factors that you believe caused <u>your illness</u>. *The most important causes for me:-*

1. ________________________________

2. ________________________________

3. ________________________________

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By filling in and returning the questionnaire you are implying consent.

Appendix B: The Cardiomyopathy questionnaire (Kansas City) (KCCQ-12)

Cardiomyopathy Questionnaire (Kansas City) (KCCQ-12)

The following questions refer to your **heart failure** and how it may affect your life. Please read and complete the following questions. There are no right or wrong answers. Please mark the answer that best applies to you.

1. **Heart failure** affects different people in different ways. Some may mainly feel shortness of breath while others mainly fatigue. Please indicate how much you have been limited by **heart failure** (for example, shortness of breath or fatigue) in your ability to do the following activities <u>over the past 2 weeks</u>.

Please place an **X** in one box on each line

Activity	**Extremely** limited	**Quite a bit** limited	**Moderately** limited	**Slightly** limited	**Not at all** limited	**Limited for other reasons or did not do the activity**
Showering/Bathing	☐	☐	☐	☐	☐	☐
Walking 1 block on level ground	☐	☐	☐	☐	☐	☐
Jogging or hurrying (as if to catch a bus)	☐	☐	☐	☐	☐	☐

2. Over the <u>past 2 weeks</u>, how many times did you have **swelling** in your feet, ankles or legs when you woke up in the morning?

Every morning	3 or more times a week, but not every day	1-2 times a week	Less than once a week	Never over the past 2 weeks
☐	☐	☐	☐	☐

3. Over the <u>past 2 weeks</u>, on average, how many times has **fatigue** limited your ability to do what you wanted?

All of the time	Several times a day	At least once a day	3 or more times a week but not every day	1-2 times a week	Less than once a week	Never over the past 2 weeks
☐	☐	☐	☐	☐	☐	☐

4. Over the <u>past 2 weeks</u>, on average, how many times has **shortness of breath** limited your ability to do what you wanted?

All of the time	Several times a day	At least once a day	3 or more times a week but not every day	1-2 times a week	Less than once a week	Never over the past 2 weeks
☐	☐	☐	☐	☐	☐	☐

KCCQ-12 – Australia/English

5. Over the past 2 weeks, on average, how many times have you been forced to sleep sitting up in a chair or with at least 3 pillows to prop you up because of **shortness of breath**?

Every night	3 or more times a week, but not every night	1-2 times a week	Less than once a week	Never over the past 2 weeks
☐	☐	☐	☐	☐

6. Over the past 2 weeks, how much has your **heart failure** limited your enjoyment of life?

It has **extremely** limited my enjoyment of life	It has limited my enjoyment of life **quite a bit**	It has **moderately** limited my enjoyment of life	It has **slightly** limited my enjoyment of life	It has **not limited** my enjoyment of life at all
☐	☐	☐	☐	☐

7. If you had to spend the rest of your life with your **heart failure** the way it is right now, how would you feel about this?

Completely dissatisfied	Mostly dissatisfied	Fairly satisfied	Mostly satisfied	Completely satisfied
☐	☐	☐	☐	☐

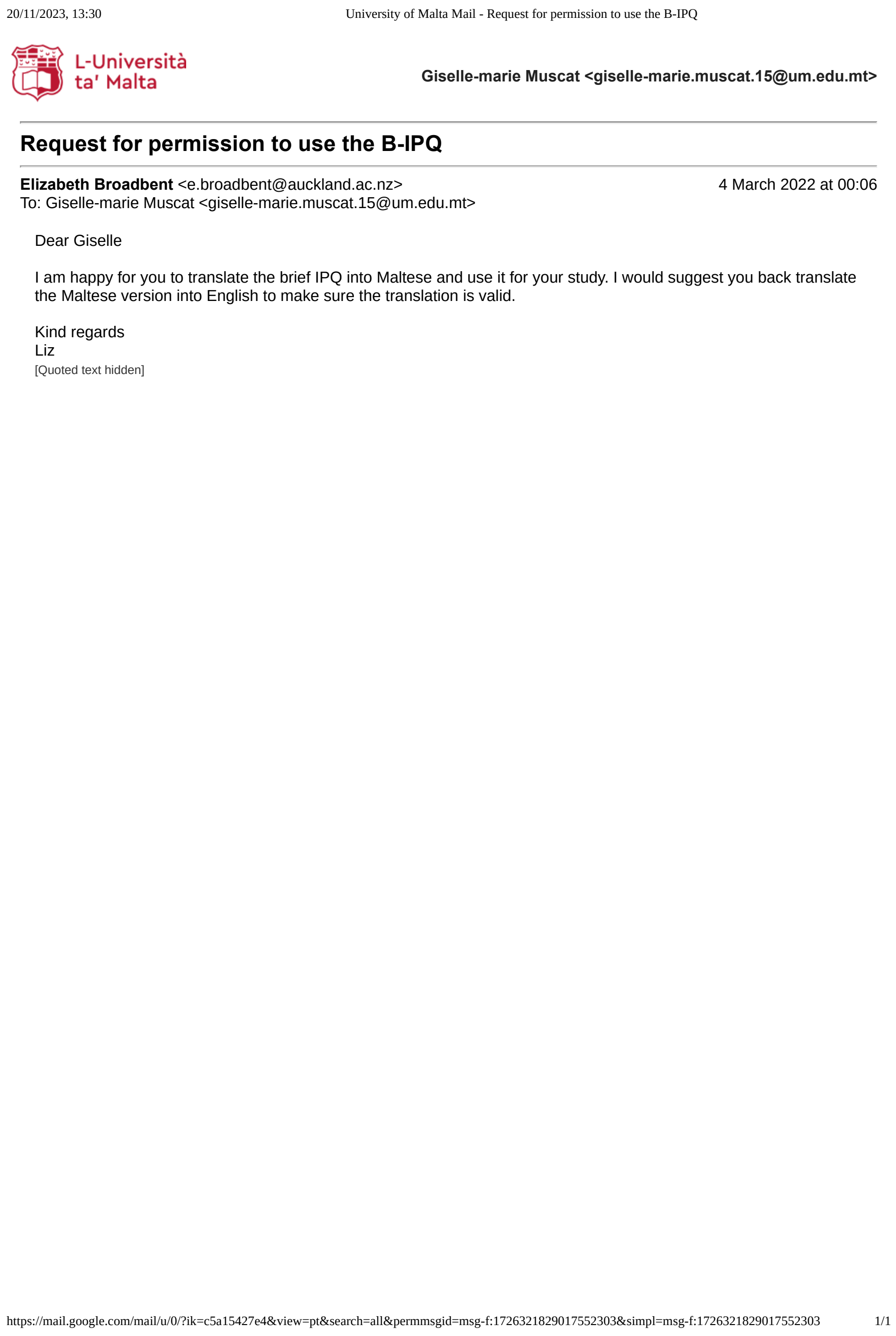
8. How much does your **heart failure** affect your lifestyle? Please indicate how your **heart failure** may have limited your participation in the following activities over the past 2 weeks.

Please place an **X** in one box on each line

Activity	**Extremely** limited	**Quite a bit** limited	**Moderately** limited	**Slightly** limited	**Not at all** limited	**Limited for other reasons or did not do the activity**
Hobbies, recreational activities	☐	☐	☐	☐	☐	☐
Working or doing household chores	☐	☐	☐	☐	☐	☐
Visiting family or friends out of your home	☐	☐	☐	☐	☐	☐

By filling in and returning the questionnaire you are implying consent.

Appendix C: Permission to use the B-IPQ and translate it to Maltese



20/11/2023, 13:30 University of Malta Mail - Request for permission to use the B-IPQ

L-Università ta' Malta

Giselle-marie Muscat <giselle-marie.muscat.15@um.edu.mt>

Request for permission to use the B-IPQ

Elizabeth Broadbent <e.broadbent@auckland.ac.nz> 4 March 2022 at 00:06
To: Giselle-marie Muscat <giselle-marie.muscat.15@um.edu.mt>

Dear Giselle

I am happy for you to translate the brief IPQ into Maltese and use it for your study. I would suggest you back translate the Maltese version into English to make sure the translation is valid.

Kind regards
Liz
[Quoted text hidden]

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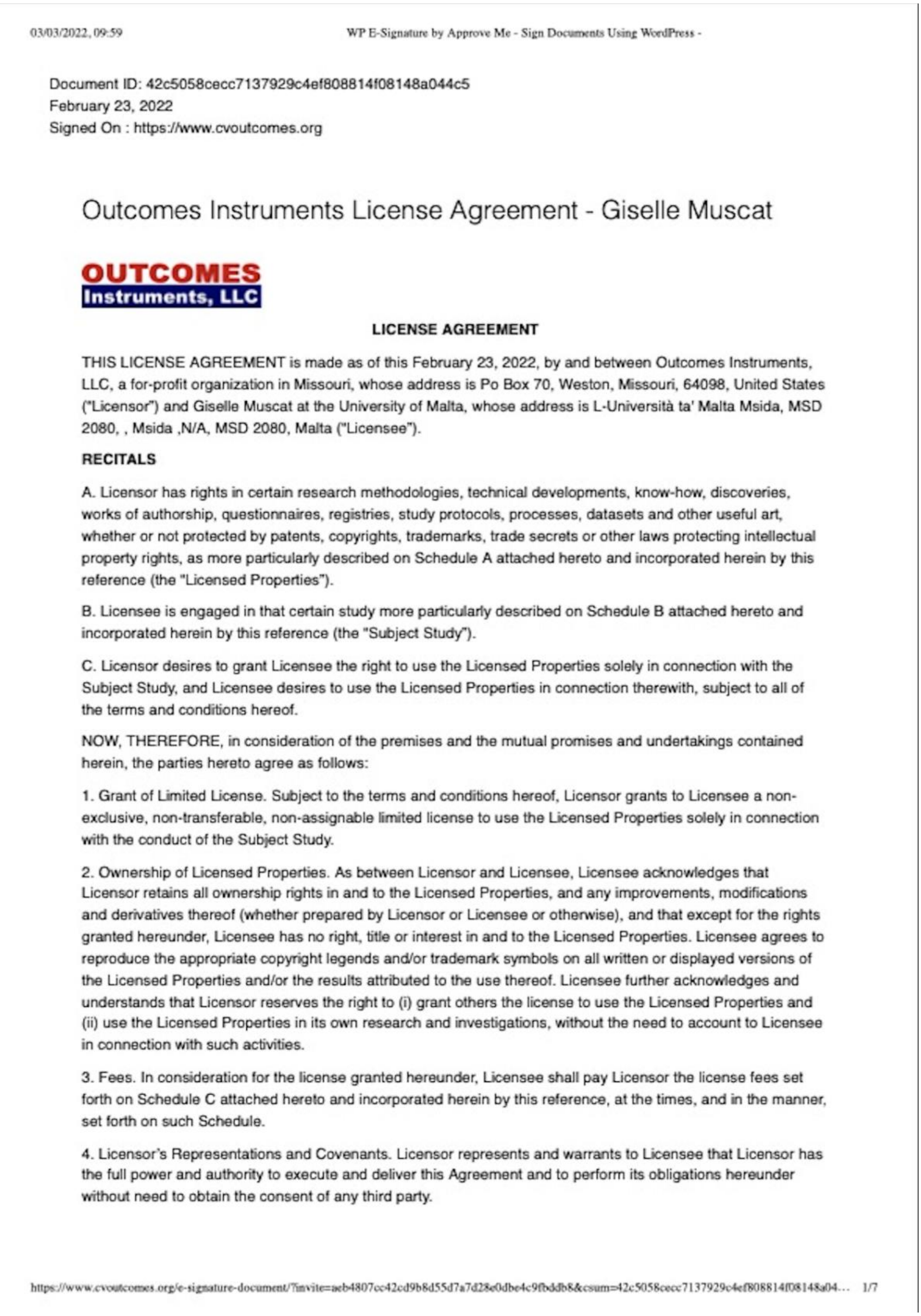
Appendix D: Permission to use the KCCQ-12 and translate it to Maltese



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February 23, 2022
Signed On : https://www.cvoutcomes.org

Outcomes Instruments License Agreement - Giselle Muscat

OUTCOMES
Instruments, LLC

LICENSE AGREEMENT

THIS LICENSE AGREEMENT is made as of this February 23, 2022, by and between Outcomes Instruments, LLC, a for-profit organization in Missouri, whose address is Po Box 70, Weston, Missouri, 64098, United States ("Licensor") and Giselle Muscat at the University of Malta, whose address is L-Università ta' Malta Msida, MSD 2080, , Msida ,N/A, MSD 2080, Malta ("Licensee").

RECITALS

A. Licensor has rights in certain research methodologies, technical developments, know-how, discoveries, works of authorship, questionnaires, registries, study protocols, processes, datasets and other useful art, whether or not protected by patents, copyrights, trademarks, trade secrets or other laws protecting intellectual property rights, as more particularly described on Schedule A attached hereto and incorporated herein by this reference (the "Licensed Properties").

B. Licensee is engaged in that certain study more particularly described on Schedule B attached hereto and incorporated herein by this reference (the "Subject Study").

C. Licensor desires to grant Licensee the right to use the Licensed Properties solely in connection with the Subject Study, and Licensee desires to use the Licensed Properties in connection therewith, subject to all of the terms and conditions hereof.

NOW, THEREFORE, in consideration of the premises and the mutual promises and undertakings contained herein, the parties hereto agree as follows:

1. Grant of Limited License. Subject to the terms and conditions hereof, Licensor grants to Licensee a non-exclusive, non-transferable, non-assignable limited license to use the Licensed Properties solely in connection with the conduct of the Subject Study.

2. Ownership of Licensed Properties. As between Licensor and Licensee, Licensee acknowledges that Licensor retains all ownership rights in and to the Licensed Properties, and any improvements, modifications and derivatives thereof (whether prepared by Licensor or Licensee or otherwise), and that except for the rights granted hereunder, Licensee has no right, title or interest in and to the Licensed Properties. Licensee agrees to reproduce the appropriate copyright legends and/or trademark symbols on all written or displayed versions of the Licensed Properties and/or the results attributed to the use thereof. Licensee further acknowledges and understands that Licensor reserves the right to (i) grant others the license to use the Licensed Properties and (ii) use the Licensed Properties in its own research and investigations, without the need to account to Licensee in connection with such activities.

3. Fees. In consideration for the license granted hereunder, Licensee shall pay Licensor the license fees set forth on Schedule C attached hereto and incorporated herein by this reference, at the times, and in the manner, set forth on such Schedule.

4. Licensor's Representations and Covenants. Licensor represents and warrants to Licensee that Licensor has the full power and authority to execute and deliver this Agreement and to perform its obligations hereunder without need to obtain the consent of any third party.

https://www.cvoutcomes.org/e-signature-document/?invite=aeb4807cc42cd9b8d55d7a7d28e0dbe4c9fbddb8&csum=42c5058cecc7137929c4ef808814f08148a04… 1/7

5. Site Visits. Licensor shall have the right to inspect and observe from time to time through such agents or representatives as Licensor may designate, on Licensee's site, the activities conducted by or for Licensee with respect to the Licensed Properties to determine whether Licensee is using the Licensed Properties in a proper fashion as provided hereunder. To the extent Licensor is granted access to a patient's "protected health information" ("PHI"), as such term is defined in the Health Insurance Portability and Accountability Act of 1996 and the regulations promulgated thereunder, the parties agree to negotiate and execute a Business Associates Agreement containing customary covenants regarding the confidentiality and limited use of such PHI.

6. Reports. Licensee shall keep and maintain comprehensive and accurate records pertaining to its use of the Licensed Properties, and the status and progress of the Subject Study. Such reports shall be available for examination by Licensor and its agents or representatives at any time upon reasonable advance notice.

7. Licensee's Conduct. Licensee agrees that it shall use the Licensed Properties only as permitted hereunder and further agrees to refrain from modifying, altering or amending the Licensed Properties or taking any action which could adversely affect the validity, goodwill and reputation thereof. Upon the termination or expiration of this Agreement, Licensee shall immediately discontinue all use of the Licensed Properties.

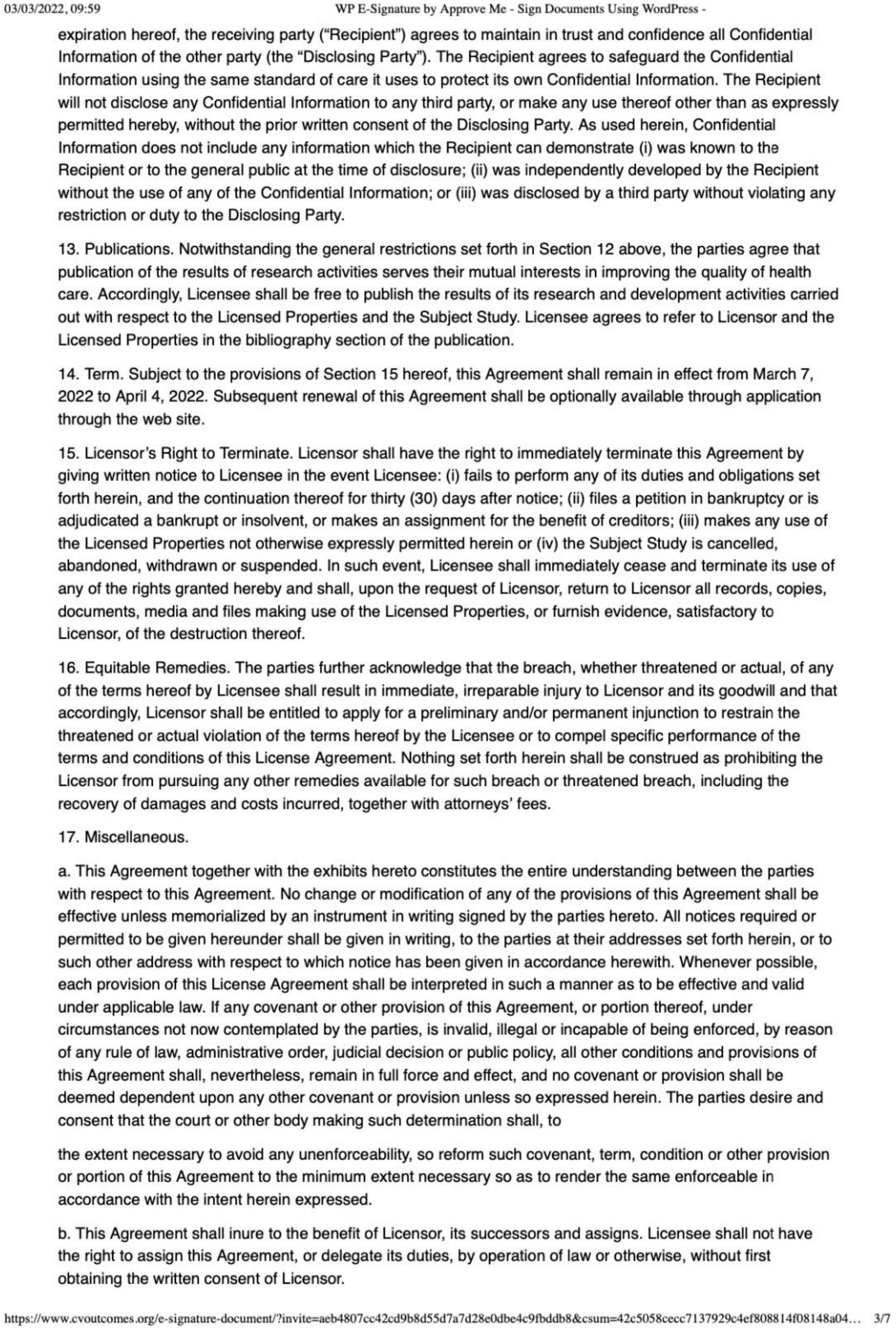
8. Litigation. As between Licensor and Licensee, only the Licensor shall have the right to commence or prosecute any claims or litigation to protect or enforce its rights in and to the Licensed Properties. Licensee agrees that it will immediately provide notice to Licensor upon learning of any litigation, whether actual or threatened, against Licensee in connection with Licensee's use of the Licensed Properties. Licensee further agrees that it will cooperate fully with Licensor by providing any information requested by Licensor in any litigation arising in connection with Licensee's use of the Licensed Properties.

9. Disclaimers; Limitations of Liability. LICENSEE ACKNOWLEDGES THAT THE LICENSED PROPERTIES ARE LICENSED "AS IS", WITH ALL FAULTS. LICENSOR HAS MADE NO REPRESENTATION OR WARRANTY THAT THE LICENSED PROPERTIES ARE SUITABLE FOR LICENSEE'S USE IN CONNECTION WITH THE SUBJECT STUDY. LICENSEE SHALL RELY ON ITS OWN JUDGMENT IN EVALUATING ITS USE OF THE LICENSED PROPERTIES AND ANY OUTCOMES ATTRIBUTABLE THERETO, WITHOUT RELYING ON ANY MATERIAL OR INFORMATION PROVIDED BY LICENSOR. LICENSOR DISCLAIMS ANY REPRESENTATIONS OR WARRANTIES, EXPRESS OR IMPLIED, INCLUDING WITHOUT LIMITATION ANY REPRESENTATIONS OR WARRANTIES AS TO THE LICENSED PROPERTIES' MERCHANTABILITY OR FITNESS FOR A PARTICULAR PURPOSE. IN NO EVENT SHALL LICENSOR BE LIABLE FOR SPECIAL, CONSEQUENTIAL, EXEMPLARY OR PUNITIVE DAMAGES. LICENSOR'S LIABILITY HEREUNDER SHALL BE LIMITED TO LICENSEE'S DIRECT DAMAGES RESULTING FROM LICENSOR'S BREACH OF ANY OF ITS OBLIGATIONS HEREUNDER WHICH CONTINUES UNREMEDIED FOR THIRTY DAYS AFTER WRITTEN NOTICE BUT SHALL IN NO EVENT EXCEED THE AMOUNT OF THE FEES ACTUALLY PAID BY LICENSEE TO LICENSOR HEREUNDER.

10. Indemnification of Licensor. Licensee hereby agrees to hold Licensor harmless of and from and indemnifies it against any and all losses, liabilities, claims, damages and expenses (including attorneys' fees and expenses) which Licensor may incur or be obligated to pay, or for which it may become liable or be compelled to pay in any action, claim or proceeding for or by reason of any acts, whether of omission or commission, that may be claimed to be or are actually committed or suffered by Licensee arising out of Licensee's use of the Licensed Properties. The provisions of this paragraph and Licensee's obligations hereunder shall survive the expiration or termination of this Agreement.

11. Indemnification of Licensee. Subject to Section 9 hereof, Licensor hereby agrees to hold Licensee harmless of and from and indemnifies it against any and all losses, liabilities, claims, damages and expenses (including attorneys' fees and expenses) which Licensee may incur or be obligated to pay, or for which it may become liable or compelled to pay in any action, claim or proceeding for or by reason of any breach of any representation, warranty or agreement on the part of Licensor under this Agreement.

12. Nondisclosure. During the term of this Agreement, the parties may have access to trade secrets, proprietary information, or other sensitive materials belonging to the other which are not generally known to the public ("Confidential Information"). During the term of this Agreement and for a period of five (5) years after termination or



expiration hereof, the receiving party ("Recipient") agrees to maintain in trust and confidence all Confidential Information of the other party (the "Disclosing Party"). The Recipient agrees to safeguard the Confidential Information using the same standard of care it uses to protect its own Confidential Information. The Recipient will not disclose any Confidential Information to any third party, or make any use thereof other than as expressly permitted hereby, without the prior written consent of the Disclosing Party. As used herein, Confidential Information does not include any information which the Recipient can demonstrate (i) was known to the Recipient or to the general public at the time of disclosure; (ii) was independently developed by the Recipient without the use of any of the Confidential Information; or (iii) was disclosed by a third party without violating any restriction or duty to the Disclosing Party.

13. Publications. Notwithstanding the general restrictions set forth in Section 12 above, the parties agree that publication of the results of research activities serves their mutual interests in improving the quality of health care. Accordingly, Licensee shall be free to publish the results of its research and development activities carried out with respect to the Licensed Properties and the Subject Study. Licensee agrees to refer to Licensor and the Licensed Properties in the bibliography section of the publication.

14. Term. Subject to the provisions of Section 15 hereof, this Agreement shall remain in effect from March 7, 2022 to April 4, 2022. Subsequent renewal of this Agreement shall be optionally available through application through the web site.

15. Licensor's Right to Terminate. Licensor shall have the right to immediately terminate this Agreement by giving written notice to Licensee in the event Licensee: (i) fails to perform any of its duties and obligations set forth herein, and the continuation thereof for thirty (30) days after notice; (ii) files a petition in bankruptcy or is adjudicated a bankrupt or insolvent, or makes an assignment for the benefit of creditors; (iii) makes any use of the Licensed Properties not otherwise expressly permitted herein or (iv) the Subject Study is cancelled, abandoned, withdrawn or suspended. In such event, Licensee shall immediately cease and terminate its use of any of the rights granted hereby and shall, upon the request of Licensor, return to Licensor all records, copies, documents, media and files making use of the Licensed Properties, or furnish evidence, satisfactory to Licensor, of the destruction thereof.

16. Equitable Remedies. The parties further acknowledge that the breach, whether threatened or actual, of any of the terms hereof by Licensee shall result in immediate, irreparable injury to Licensor and its goodwill and that accordingly, Licensor shall be entitled to apply for a preliminary and/or permanent injunction to restrain the threatened or actual violation of the terms hereof by the Licensee or to compel specific performance of the terms and conditions of this License Agreement. Nothing set forth herein shall be construed as prohibiting the Licensor from pursuing any other remedies available for such breach or threatened breach, including the recovery of damages and costs incurred, together with attorneys' fees.

17. Miscellaneous.

a. This Agreement together with the exhibits hereto constitutes the entire understanding between the parties with respect to this Agreement. No change or modification of any of the provisions of this Agreement shall be effective unless memorialized by an instrument in writing signed by the parties hereto. All notices required or permitted to be given hereunder shall be given in writing, to the parties at their addresses set forth herein, or to such other address with respect to which notice has been given in accordance herewith. Whenever possible, each provision of this License Agreement shall be interpreted in such a manner as to be effective and valid under applicable law. If any covenant or other provision of this Agreement, or portion thereof, under circumstances not now contemplated by the parties, is invalid, illegal or incapable of being enforced, by reason of any rule of law, administrative order, judicial decision or public policy, all other conditions and provisions of this Agreement shall, nevertheless, remain in full force and effect, and no covenant or provision shall be deemed dependent upon any other covenant or provision unless so expressed herein. The parties desire and consent that the court or other body making such determination shall, to

the extent necessary to avoid any unenforceability, so reform such covenant, term, condition or other provision or portion of this Agreement to the minimum extent necessary so as to render the same enforceable in accordance with the intent herein expressed.

b. This Agreement shall inure to the benefit of Licensor, its successors and assigns. Licensee shall not have the right to assign this Agreement, or delegate its duties, by operation of law or otherwise, without first obtaining the written consent of Licensor.

c. This Agreement shall be governed by and construed in accordance with the laws of the Missouri.

SCHEDULE A: LICENSED PROPERTIES

KCCQ-12 Instrument For Trainees / Students

KCCQ-12 - English (UK)

SCHEDULE B: DESCRIPTION OF STUDY

Project Name

Illness perception and quality of life among patients with congestive heart failure.

Project ID

10417

Project Type

Cross-sectional analysis

Project Dates

Start: March 7, 2022

End: April 4, 2022

Enrollment

Total enrollment: approximately 200

Schedule of Use

Will be administered to participants at the heart failure clinic at one point in time.

Total uses per subject: 1

Total uses: NaN

Sponsor Name

Giselle Muscat at the University of Malta

Sponsor Type

Nursing

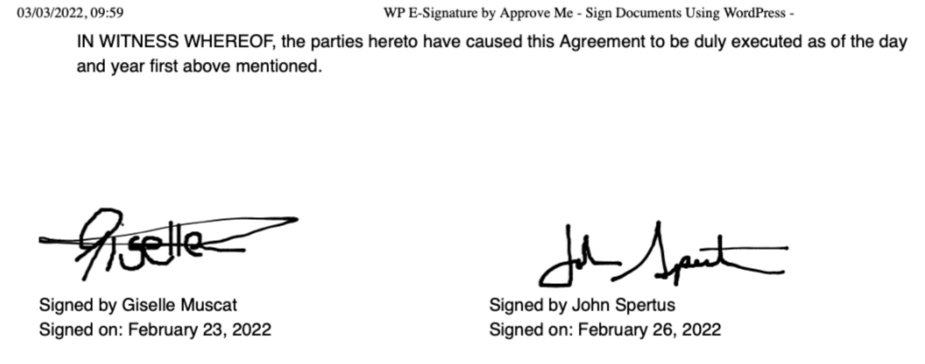
SCHEDULE C: LICENSE FEES & PAYMENT TERMS

Payment Terms

Payable on Receipt

Total License Fee Including Additional Scoring Codes

$100.00

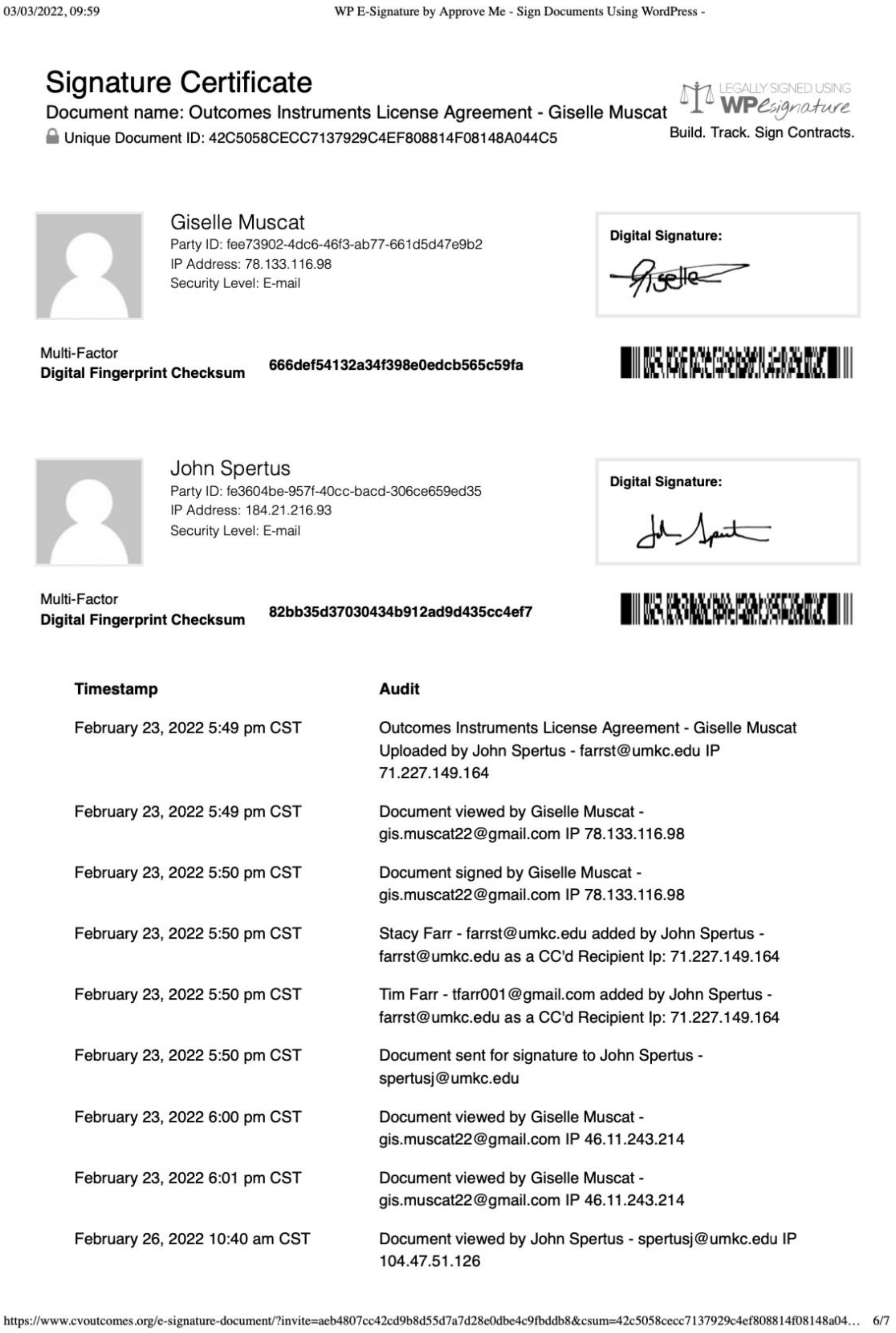


IN WITNESS WHEREOF, the parties hereto have caused this Agreement to be duly executed as of the day and year first above mentioned.

Giselle

Signed by Giselle Muscat
Signed on: February 23, 2022

Signed by John Spertus
Signed on: February 26, 2022



Signature Certificate

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Giselle Muscat
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IP Address: 78.133.116.98
Security Level: E-mail

Digital Signature:
Giselle

Multi-Factor
Digital Fingerprint Checksum **666def54132a34f398e0edcb565c59fa**

John Spertus
Party ID: fe3604be-957f-40cc-bacd-306ce659ed35
IP Address: 184.21.216.93
Security Level: E-mail

Digital Signature:

Multi-Factor
Digital Fingerprint Checksum **82bb35d37030434b912ad9d435cc4ef7**

Timestamp	Audit
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February 23, 2022 5:50 pm CST	Document signed by Giselle Muscat - gis.muscat22@gmail.com IP 78.133.116.98
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February 23, 2022 5:50 pm CST	Tim Farr - tfarr001@gmail.com added by John Spertus - farrst@umkc.edu as a CC'd Recipient Ip: 71.227.149.164
February 23, 2022 5:50 pm CST	Document sent for signature to John Spertus - spertusj@umkc.edu
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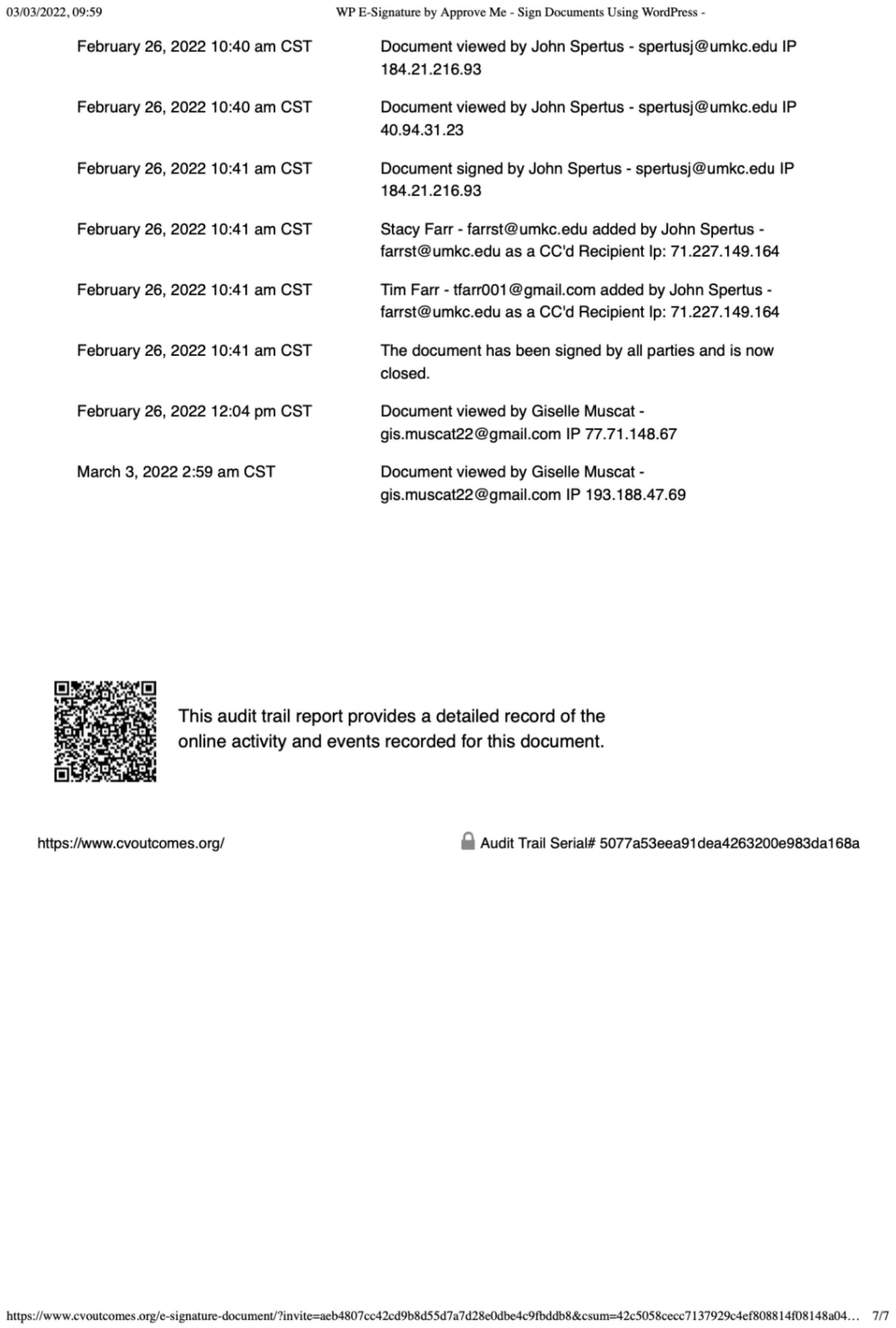
February 23, 2022 6:01 pm CST	Document viewed by Giselle Muscat - gis.muscat22@gmail.com IP 46.11.243.214
February 26, 2022 10:40 am CST	Document viewed by John Spertus - spertusj@umkc.edu IP 104.47.51.126



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February 26, 2022 10:41 am CST	Document signed by John Spertus - spertusj@umkc.edu IP 184.21.216.93
February 26, 2022 10:41 am CST	Stacy Farr - farrst@umkc.edu added by John Spertus - farrst@umkc.edu as a CC'd Recipient Ip: 71.227.149.164
February 26, 2022 10:41 am CST	Tim Farr - tfarr001@gmail.com added by John Spertus - farrst@umkc.edu as a CC'd Recipient Ip: 71.227.149.164
February 26, 2022 10:41 am CST	The document has been signed by all parties and is now closed.
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March 3, 2022 2:59 am CST	Document viewed by Giselle Muscat - gis.muscat22@gmail.com IP 193.188.47.69

This audit trail report provides a detailed record of the online activity and events recorded for this document.

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Appendix E: Demographic data and clinical status questionnaire (English version)

Demographic data questionnaire

The purpose of this section is to gather information on participants' demographic and clinical characteristics, which are relevant to this study.

Please mark the most appropriate box:

1.	Age	18-29 years	
		30-49 years	
		50-69 years	
		70-85 years	
		86+ years	

2.	Gender	Male	
		Female	
		Others	

3.	Level of education	NIL	
		Primary	
		Secondary	
		Post-secondary	
		Tertiary	

4.	Marital status	Single	
		Married	
		Widowed/separated/divorce	
		Other	

5.	State of living before being diagnosed with heart failure	Living alone	
		Living with family members	
		Living in a community or elderly home	
		Other	

6.		Living alone	

	State of living after being diagnosed with heart failure	Living with family members	
		Living in a community or elderly home	
		Other	

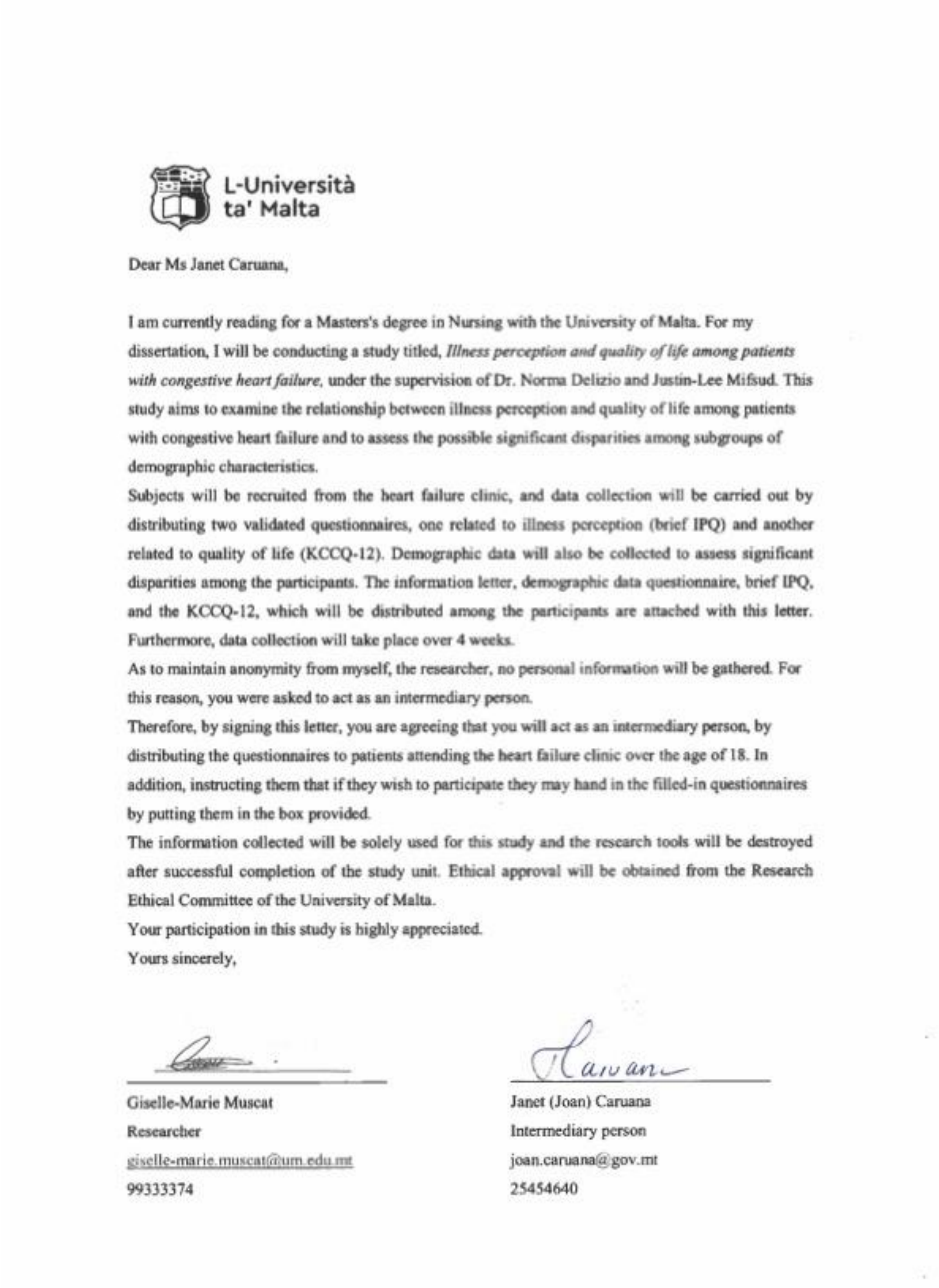
7.	Past hospital admissions	Never	
		Once or twice	
		Three or four times	
		More than four times	

8.	Do you have other medical problems?	Yes	
		No	
	If you answered ‘yes’, please specify? ____		

9.	Do you feel supported by your family or social contacts?	Yes	
		No	

10.	Do you feel supported by the health care system?	Yes	
		No	

Appendix F: Signed invitation letter explaining the role of the intermediary



L-Università
ta' Malta

Dear Ms Janet Caruana,

I am currently reading for a Masters's degree in Nursing with the University of Malta. For my dissertation, I will be conducting a study titled, *Illness perception and quality of life among patients with congestive heart failure*, under the supervision of Dr. Norma Delizio and Justin-Lee Mifsud. This study aims to examine the relationship between illness perception and quality of life among patients with congestive heart failure and to assess the possible significant disparities among subgroups of demographic characteristics.

Subjects will be recruited from the heart failure clinic, and data collection will be carried out by distributing two validated questionnaires, one related to illness perception (brief IPQ) and another related to quality of life (KCCQ-12). Demographic data will also be collected to assess significant disparities among the participants. The information letter, demographic data questionnaire, brief IPQ, and the KCCQ-12, which will be distributed among the participants are attached with this letter. Furthermore, data collection will take place over 4 weeks.

As to maintain anonymity from myself, the researcher, no personal information will be gathered. For this reason, you were asked to act as an intermediary person.

Therefore, by signing this letter, you are agreeing that you will act as an intermediary person, by distributing the questionnaires to patients attending the heart failure clinic over the age of 18. In addition, instructing them that if they wish to participate they may hand in the filled-in questionnaires by putting them in the box provided.

The information collected will be solely used for this study and the research tools will be destroyed after successful completion of the study unit. Ethical approval will be obtained from the Research Ethical Committee of the University of Malta.

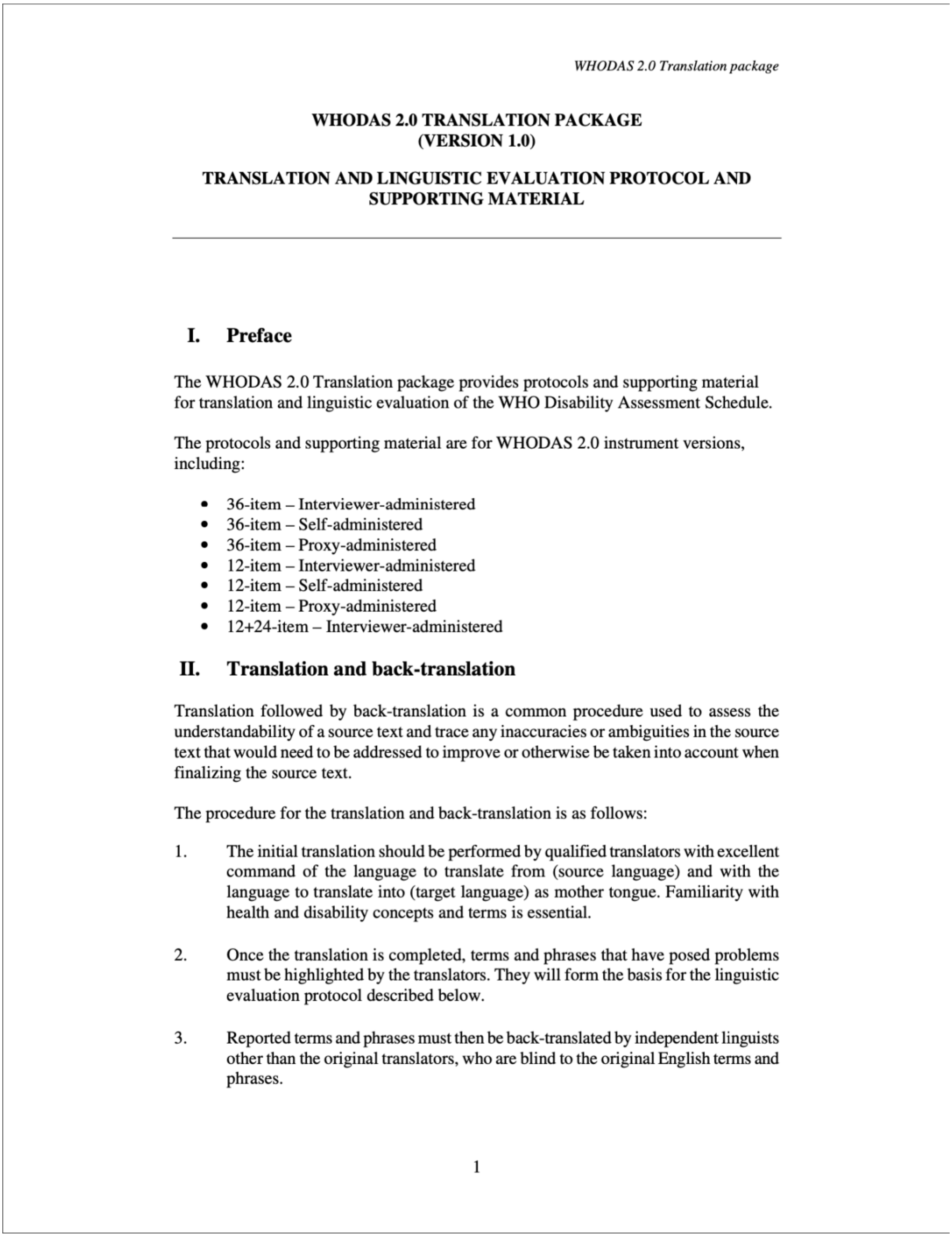
Your participation in this study is highly appreciated.

Yours sincerely,

Giselle-Marie Muscat
Researcher
giselle-marie.muscat@um.edu.mt
99333374

Janet (Joan) Caruana
Intermediary person
joan.caruana@gov.mt
25454640

Appendix G: The WHODAS 2.0 translation package



WHODAS 2.0 TRANSLATION PACKAGE
(VERSION 1.0)

TRANSLATION AND LINGUISTIC EVALUATION PROTOCOL AND SUPPORTING MATERIAL

I. Preface

The WHODAS 2.0 Translation package provides protocols and supporting material for translation and linguistic evaluation of the WHO Disability Assessment Schedule.

The protocols and supporting material are for WHODAS 2.0 instrument versions, including:

- 36-item – Interviewer-administered
- 36-item – Self-administered
- 36-item – Proxy-administered
- 12-item – Interviewer-administered
- 12-item – Self-administered
- 12-item – Proxy-administered
- 12+24-item – Interviewer-administered

II. Translation and back-translation

Translation followed by back-translation is a common procedure used to assess the understandability of a source text and trace any inaccuracies or ambiguities in the source text that would need to be addressed to improve or otherwise be taken into account when finalizing the source text.

The procedure for the translation and back-translation is as follows:

1. The initial translation should be performed by qualified translators with excellent command of the language to translate from (source language) and with the language to translate into (target language) as mother tongue. Familiarity with health and disability concepts and terms is essential.

2. Once the translation is completed, terms and phrases that have posed problems must be highlighted by the translators. They will form the basis for the linguistic evaluation protocol described below.

3. Reported terms and phrases must then be back-translated by independent linguists other than the original translators, who are blind to the original English terms and phrases.

4. A group discussion between translators, back-translators and a group of subject field specialists should be held to ensure that the meaning of the original text is clarified and that translation is satisfactory. All differences should be resolved to arrive at a final translation.

This information should be presented in a report and sent to WHO Geneva for review prior to the publication of the WHODAS 2.0 translation.

Key recommendations to translators

1. Always aim for a translation that captures the conceptual equivalent of the source language (typically English), not a word-by-word translation or etymological equivalent. Think about the concept behind the term and try to render the concept using target language terms in a manner that is most relevant to your setting.
2. Always strive to be simple, clear and concise.
3. The translation in the target language should be directed at the widest possible audience. Avoid addressing only medical, legal or any other specialized group.
4. Avoid jargon. In particular do not use:
    a. technical terms that cannot be understood clearly (with the exception of technical medical terms which may be unavoidable);
    b. colloquialisms, idioms and vernacular terms that cannot be understood by most people in everyday life.
5. Think about gender and age applicability: is the term applicable to both genders and across the age span? Is it offensive or objectionable?

More detailed guidelines for the translation are enclosed in Appendix 1.

II. Linguistic Evaluation

Linguistic differences caused by changes in the meaning of words between dialects, translation difficulties, as well as difference that arise when applying a concept across cultures, are some of the primary cross-cultural problems in translation. Linguistic evaluation should be done by a group of subject field specialists which might be experts or field workers who have a good understanding of how respondents react to terms.

The steps in completing the data collection and recording for this objective are:

A. Translate the questionnaire, following the translation guidelines, including the back-translation for those items which have been provided.

B. Add terms and phrases which may have posed problems to the initial list of terms and complete the attached **Linguistic Evaluation Data Sheet** (Appendix 2). This may be done alone or in consultation with the translator, back-translator, or other linguist.

C. Send back the completed Linguistic Evaluation Data Sheets to WHO, Geneva.

During the linguistic evaluation process, several possible problems may be encountered:

1. The source language (e.g. English) term has a different or modified meaning in the local version of the same language (e.g. American English). The differences in meaning are sufficient to change the way in which the term should be used in the English version of the questionnaire used for disability question set testing .

   Example: Differences in usage of the English language

   The word "notes" in British English is used in the sense of currency notes to refer to paper money. However, for this to be understood in the same way in the United States it will have to be replaced by "bills".

2. The term cannot be translated into the target language, or translation is very difficult, because there is no exact equivalent idiom or term to express the concept in the target language.

   Example: Difficulty in translation

   The term "responsiveness" does not have an equivalent or parallel term in a least two major languages in India, Hindi and Telugu. It will need to be explained using a phrase to get the concept across.

3. The meaning of the original term is modified during translation because:
   a) only part of the meaning of the source language term is present in the target language term. Part of the original connotations are lost. This makes the term too narrow in meaning.

   Conversely,

   b) the meaning of the source language term is expanded in the target language term. The target language term has more (or different) connotations than the original. This makes the translated term too broad in meaning.

   Example: narrower term

   In Dutch, the term "community" is difficult to translate because it normally denotes a group of people, but does not denote the sense of belonging that is present in the English term.

The word "distress" has a different meaning depending on the culture. It may either mean "pain", "anguish", "stress" or "difficult/dangerous situations".

Example: broader term

The word "interference" has 10 different, separate, meanings in Arabic, making translation of the more generic English term difficult.

4. Two or more terms (describing as many different concepts) translate in the target language into one single term. The distinctions between the original terms are lost.

   Example: merging

   The terms for "community" and "society" cannot be distinguished in some Indian languages.

5. The term can be translated, but there are cultural applicability issues with the definition or the examples given. These issues can include a lack of correspondence between the local resources or environment and the definition or examples; or a condition that makes the item or definition irrelevant in the local culture.

   Example: Cultural applicability

   Learning a new task or engaging in household work: In different cultures, the kinds of new tasks one is required to learn from time to time or the kind of work all persons do around the house, irrespective of one's gender, varies considerably. In such cases appropriate examples will have to be provided to convey the intent of the questions.

   Example: Local resource or environment differences

   Use of devices such as hearing aids, wheelchairs or the presence of ramps in buildings: The availability of devices and the presence of such modifications to buildings may vary considerably from country to country and explanations may be required to convey to respondents the nature of these devices or modifications.

   Example: Irrelevancy of item or definition

   Putting on clothes over the head: in a country where clothing is either only wrap around or buttoned down the front this item may not be applicable.

   Example: Problem with technical jargon

   Vitiligo: skin discoloration could be used instead.

APPENDIX 1

Guidelines for Translation WHODAS 2.0

Introduction

There is an increasing need to have uniform and standard application of health and disability related classifications and linked assessment instruments across the world. This makes it necessary for these to be available in equivalent versions and formats that can be used in a wide variety of settings and languages. In the past, most of the classifications and measurement instruments were developed in one language and then translated into other languages. The process of translation was often not standardised, hence the applicability of the translated versions was uncertain. Recent experience from a number of studies conducted by the WHO has made it possible to ensure a high level of cross-cultural and cross-language applicability in this area.

Equivalence

Since the source and the target language versions of the instruments are expected to serve the same purpose, equivalence between them is crucial. The word "equivalence" itself has been used in a variety of ways, but the single most essential feature of the source and target language versions is that they should convey the same concepts

The actual meaning of terms used to denote the concepts may differ from language to language; this may affect the level of detail required to be covered in the instrument. For example, if the item refers to the house where one lives, a reasonable translation in most languages could easily be made. But, if the details of the individual rooms or furniture in the house are being envisaged, a conceptual translation becomes more difficult, but all the same more necessary, since a simple translation may be inappropriate and indeed misleading. Conceptual equivalence can be arrived at only by involving in the translation, individuals who have a good understanding of the concept being asked in the source instrument and who also know the target language and culture well e.g. health experts, field workers etc.

The translation process

Translation of the source language instrument into the target language, back-translation into the source language by an independent translator and comparison of the back-translation with the original has been the commonly used method for a long time. However, the success of this method was uneven, depending on the extent of care exercised during the process. Over years of work by the WHO and its collaborating centres, the following methods have been developed for translation of instruments.

The standard WHO method

The present section outlines the translation process and assessment for adequacy of translation using the standard complete back-translation method.

a) Establishment of a group of translators, supported by bilingual experts from the various relevant disciplines corresponding to the subject field covered by the instrument to be translated. They should know both the source language and the target language and should be familiar with the way the target language is spoken by the majority of people in the study population.

b) The bilingual group should be completely familiar with the overall form of the instrument and the manner of its application. It should also be familiar with the instrument being translated, including its underlying concept, objectives, procedures and rules.

c) Identification of a monolingual group that would be representative of the population and whose members speak only the target language.

d) Translation of the instrument from source into target language. This should be done by the translators in consultation with and under the direct supervision of the experts. The initial translation should be done by individuals who are familiar with the concepts and, therefore, know what concept is to be conveyed.

e) Detailed review of the translation by the bilingual group to identify areas of possible difficulty and issues for exploration in the monolingual group.

f) Review and discussion of the translation by the monolingual group moderated by a representative from the bilingual group. Understandability, acceptability and cultural applicability of the questions, appropriateness of format, wording and phrasing, possible obstacles to question response and any other anticipated problems should be discussed. Specific solutions to the problems should be sought through discussion.

g) Discussion of the results of monolingual group consultation in the bilingual group. Problem items and sections of the translated version should be analysed and reformulated. The redrafted items and sections should again be discussed with the monolingual group. Amendments, if any, in the source text should be suggested.

h) Independent back-translation into the original source language of the full, revised, translated version. Professional translators should be used for this work in an independent manner, i.e. they should not have been exposed to the original instrument or involved in the earlier translation of the instrument.

i) Comparison of the back-translation with the original version for conceptual equivalence. Issues related to linguistic equivalence should also be discussed to ensure that the concepts are conveyed satisfactorily. Problem sections should be revised, rechecked with the monolingual group and back-translated again. This process of checking the translated version should be repeated until satisfactory equivalence is achieved.

j) Final recommendations for amendments to the instruments, based on the translation/back-translation exercise should be made.

k) Issues related to formatting, style of presentation and document design should be finalised. These should be kept as close to the original as possible, though it is recognised that different languages and cultures may need some changes. For example, Urdu is written from right to left and in some languages a larger font size is used conventionally.

Some do's and don'ts

- Aim at the conceptual equivalent, not a word-by-word translation or etymological equivalent. Think about the definition of the original term (within the system of concepts of the instrument) and try to translate the term in the most relevant manner applicable to the target setting.
- Be simple, clear and concise.
- The translation in the target language should aim at the most common audience. Avoid addressing medical, legal or any other specialised group unless the instrument is to be used only by such a special group.
- Do not use technical terms, unless the instrument is for use only by technical users.
- Do not use colloquialisms.
- Think about gender and age applicability. Match it with the aims and the applicability of the original, as far as possible.
- If the term is embarrassing or offensive in the target language, think about how essential it is to the instrument. If it is essential, use the phrase that is conceptually nearest to the source language phrase, but at the same time, the least offensive or embarrassing in the target language.

APPENDIX 2

LINGUISTIC EVALUATION DATA SHEET

Site: _________________ Local Language: _______________ Date _______

I. Item from List of Terms for Linguistic Evaluation: __________________________

a. *Provide translation of the item (from translated WHO questionnaire)* _________________
b. *Provide back-translation of your translation*_____________________________________

II. Which of the following conditions apply to the linguistic problems for this item?
Please place a check mark beside all of the appropriate responses. Explain if necessary.

____ 1. *The item has a different meaning in the local usage of English than is intended in the WHO English version.*

Please explain:

____ 2. *The item is difficult or impossible to translate because there is no target language idiomatic equivalent, or no equivalent term.*

____ 3. *The item, when translated, has a meaning that is narrower than the original term. Only part of the connotations of the original term carry over into the target language.*

_____4. *The item, when translated, has a meaning that is broader than the meaning in the original. The translated items has additional meanings that would change the interpretation of the item.*

_____ 5. *The item can be translated, but there is a cultural applicability problem with the item, or with the definition, or with the examples used for the item.*

Please explain the problem in cultural applicability _________________________________

____ 6. *Other problem:* ____

Please give your suggestions for overcoming the difficulty with this item.

____

Appendix H: The translated version of the demographic data (Maltese version)

Kwestjonarju tad-dejta demografika

L-iskop ta' din it-taqsima huwa li tiġbor informazzjoni dwar il-karatteristiċi demografiċi u kliniċi tal-parteċipanti, li huma rilevanti għal dan l-istudju.

Jekk jogħġbok immarka l-aktar tweġiba xierqa:

1.	Eta'	18-29	
		30-49	
		50-69	
		70-85	
		86+	

2.	Sess	Ragel	
		Mara	
		Oħrajn	

3.	Livell ta edukazzjoni	Xejn	
		Primarja	
		Sekondarja	
		Post-sekondarja	
		Terzjarja	

4.	Stat ta ħajja	Xebba/Ġuvni	
		Miżżewweġ/Miżżewġa	
		ArmelArmla/ Separat/a /divorzjat/a	
		Oħrajn	

5.	Ma min kont tgħix qabel ma gejt dijanjostikat/a b' insufiċjenza tal-qalb konġestiva?	Ngħix waħdi	
		Ngħix mal-familja	
		Ngħix f'dar ta komunita jew ta l-anzjani	
		Oħrajn	

6.	Ma min qed tgħix bħalissa ?	Ngħix waħdi	
		Ngħix mal-familja	
		Ngħix f'dar ta komunita jew ta l-anzjani	
		Oħrajn	

7.	Kemm 'il darba tħalt l-isptar kawża ta' l-insufiċjenza tal-qalb konġestiva?	Qatt	
		Darba jew darbtejn	
		Tlett darbiet jew erbgha darbiet	
		Izjed min erbgha darbiet	

8.	Għandek problem tas-saħħa oħrajn?	Iva	
		Le	
	Jekk għażilt 'Iva', speċifika x'inhuma? ____		

9.	Tħoss li għandek għajnuna minn nies ta' madwarek ?	Iva	
		Le	

10.	Tħoss li għandek għajnuna mis servizzi tas-saħħa ?	Iva	
		Le	

Appendix I: The translated version of the brief illness perception questionnaire (Maltese version)

Il-Kwestjonarju Qasir dwar il-Perċezzjoni tal-Mard

Għall-mistoqsijiet li ġejjin, jekk jogħġbok immarka b'ċirku n-numru li jikkorrispondi l-aħjar għall-fehmiet tiegħek:

Kemm taffettwalek ħajtek il-marda tiegħek?

0	1	2	3	4	5	6	7	8	9	10
ma taffettwani xejn										taffettwali ħajti b'mod sever

Kemm taħseb li l-marda tiegħek se tkompli?

0	1	2	3	4	5	6	7	8	9	10
żmien qasir ħafna										għal dejjem

Kemm għandek kontroll fuq il-marda tiegħek?

0	1	2	3	4	5	6	7	8	9	10
assolutament l-ebda kontroll										ammont kbir ta' kontroll

Kemm taħseb li t-trattament tiegħek jista' jgħin lill-marda tiegħek?

0	1	2	3	4	5	6	7	8	9	10
l-ebda għajnuna										ta' għajnuna kbira

Kemm tesperjenza sintomi mill-marda tiegħek?

0	1	2	3	4	5	6	7	8	9	10
l-ebda sintomu										ħafna sintomi severi

Kemm inti imħasseb/imħassba dwar il-marda tiegħek?

0	1	2	3	4	5	6	7	8	9	10
l-ebda tħassib										imħasseb/imħassba ħafna

Kemm tħoss li tifhem il-marda tiegħek?

0	1	2	3	4	5	6	7	8	9	10
ma nifhem xejn										nifhem b'mod ċar ħafna

Kemm taffettwak emozzjonalment il-marda tiegħek? (eż. tagħmlek irrabjat/a, imbeżżgħa, imdejjaq/imdejqa jew depress/a?

0	1	2	3	4	5	6	7	8	9	10
ma taffetwani xejn emozzjonalment										taffettwani ħafna emozzjonalment

Jekk jogħġbok niżżel fl-ordni tal-klassifika t-tliet fatturi l-aktar importanti li temmen li kkawżaw <u>il-marda tiegħek</u> . *L-aktar kawżi importanti għalija:-*

1. ________________________________

2. ________________________________

3. ________________________________

♥ Drittijiet tal-Awtur. Għal permess biex tintuża l-iskala, jekk jogħġbok ikkuntattja: lizbroadbent@clear.net.nz

Billi timla u tirritorna dan il-kwestjonarju inti tkun qiegħed/qiegħda tagħti kunsens biex jiġi uzat fl-istudju.

Appendix J: The translated version of the Cardiomyopathy questionnaire (Kansas City) (KCCQ-12)

mistoqsijiet li ġejjin jirreferu għall **insuffiċjenza tal qalb tiegħek** u kif din tista' taffettwalek ħajtek. Jekk jogħġbok aqra u imla l mistoqsijiet li ġejjin. Ma hemm l ebda tweġiba tajba jew ħażina. Jekk jogħġbok tweġiba li tapplika l aħjar għalik.

insuffiċjenza tal taffettwa lil persuni differenti b'modi differenti. Xi wħud jistgħu fil biċċa l kbira jħossu qtugħ ta' nifs filwaqt li oħrajn aktar taħkimhom għeja. Jekk jogħġbok indika kemm kont **insuffiċjenza tal** (pereżempju, qtugħ ta' nifs jew għeja) fil kapaċità tiegħek li tagħmel l tivitajiet li ġejjin aħħar ġimagħtejn

Jekk jogħġbok poġġi f'kaxxa waħda fuq kull linja

						Limitat għal raġunijiet oħra jew ma nagħmilx
Tieħu shower/Banju	☐	☐	☐	☐	☐	☐
Timxi blokka waħda fuq art ċatta	☐	☐	☐	☐	☐	☐
Tiġġoggja jew timxi b'pass mgħaġġel (qisek trid t	☐	☐	☐	☐	☐	☐

aħħar ġimagħtejn **kellek nefħa** f'saqajk, fl għekiesi jew f'riġlejk meta qomt filgħodu?

filgħodu	f'ġimgħa, iżda mhux	ġimgħa	ġimgħa	aħħar ġimagħtejn
☐	☐	☐	☐	☐

aħħar ġimagħtejn, bħala medja, kemm **għeja** kapaċità tiegħek li tagħmel dak li xtaqt?

ħin			ġimgħa iżda	ġimgħa	ġimgħa	aħħar ġimagħtejn
☐	☐	☐	☐	☐	☐	☐

4. Matul l-aħħar ġimagħtejn, bħala medja, kemm-il darba **il-qtugħ ta' nifs** illimita l-kapaċità tiegħek li tagħmel dak li xtaqt?

Il-ħin kollu	Diversi drabi kuljum	Mill-inqas darba kuljum	3 darbiet jew aktar fil-ġimgħa iżda mhux kuljum	Darba jew darbtejn fil-ġimgħa	Inqas minn darba fil-ġimgħa	Qatt fl-aħħar ġimagħtejn
☐	☐	☐	☐	☐	☐	☐

5. Matul dawn l-aħħar ġimagħtejn, bħala medja, kemm-il darba ġejt sfurzat/a biex torqod bilqiegħda fuq siġġu jew allinqas bi 3 imħaded biex jerfgħuk minħabba **il-qtugħ ta' nifs**?

Kull lejl	3 darbiet jew aktar f'ġimgħa, iżda mhux kull lejl	Darba jew darbtejn fil-ġimgħa	Inqas minn darba fil-ġimgħa	Qatt matul l-aħħar ġimagħtejn
☐	☐	☐	☐	☐

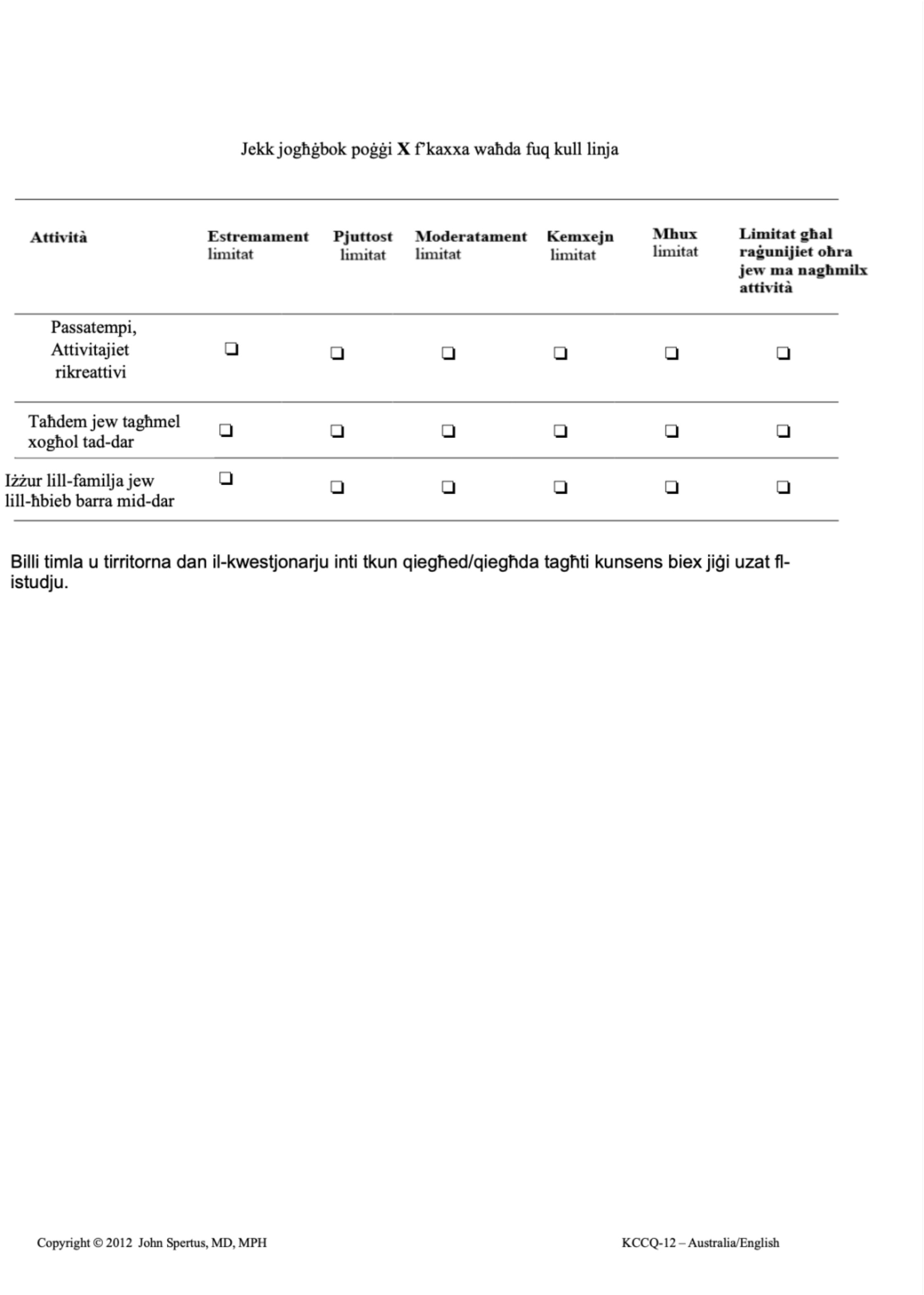
6. Matul dawn l-aħħar ġimagħtejn, kemm limitatlek it-tgawdija tal-ħajja tiegħek il-**falliment tal-qalb** tiegħek?

Illimitatli **ħafna** t-tgawdija tal-ħajja tiegħi.	Illimitatli **mhux ħażin** it-tgawdija tal-ħajja tiegħi.	Illimitatli **b'mod moderat** it-tgawdija tal-ħajja tiegħi.	Illimitatli **ftit** it-tgawdija tal-ħajja tiegħi.	Ma llimitatli **xejn** it-tgawdija tal-ħajja tiegħi
☐	☐	☐	☐	☐

7. Jekk kellek tqatta' l-bqija ta' ħajtek bil-**falliment tal-qalb** tiegħek il-mod kif inhi bħalissa, kif tħossok dwar dan?

Kompletament mhux issodisfat	Fil-biċċa l-kbira mhux issodisfat	Ftit issodisfat	Pjuttost issodisfat	Kompletament issodisfat
☐	☐	☐	☐	☐

8. Kemm taffettwalek l-istil ta' ħajja tiegħek l-**insuffiċjenza tal-qalb** tiegħek? Jekk jogħġbok indika kif il-**falliment tal-qalb** tiegħek jista' jkun li llimita il-parteċipazzjoni tiegħek fl-attivitajiet li ġejjin matul l-aħħar ġimagħtejn.

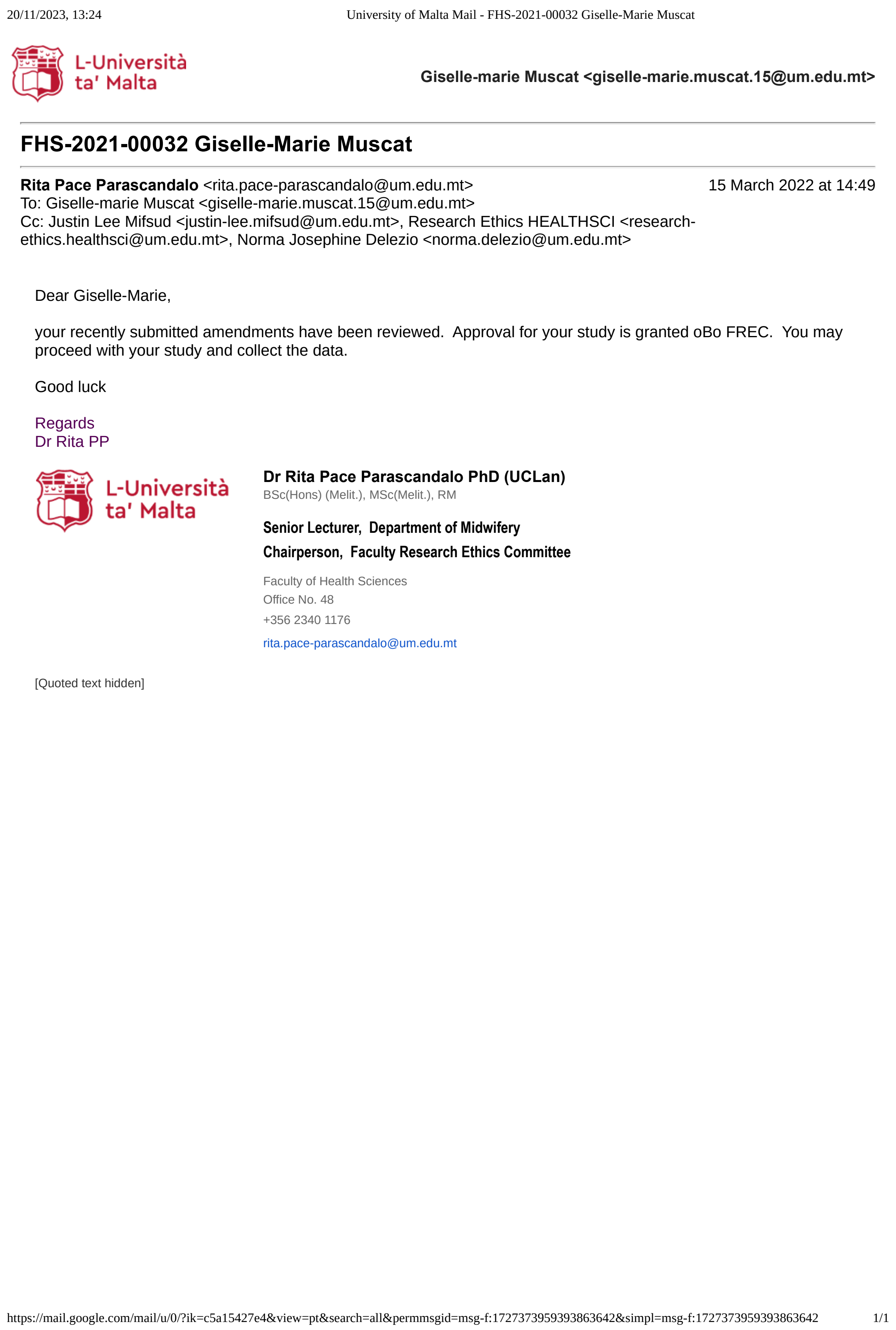


Jekk jogħġbok poġġi **X** f'kaxxa waħda fuq kull linja

Attività	**Estremament** limitat	**Pjuttost** limitat	**Moderatament** limitat	**Kemxejn** limitat	**Mhux** limitat	**Limitat għal raġunijiet oħra jew ma nagħmilx attività**
Passatempi, Attivitajiet rikreattivi	❑	❑	❑	❑	❑	❑
Taħdem jew tagħmel xogħol tad-dar	❑	❑	❑	❑	❑	❑
Iżżur lill-familja jew lill-ħbieb barra mid-dar	❑	❑	❑	❑	❑	❑

Billi timla u tirritorna dan il-kwestjonarju inti tkun qiegħed/qiegħda tagħti kunsens biex jiġi uzat fl-istudju.

Appendix K: Permission from the FREC to carry out the study



20/11/2023, 13:24 University of Malta Mail - FHS-2021-00032 Giselle-Marie Muscat

L-Università ta' Malta

Giselle-marie Muscat <giselle-marie.muscat.15@um.edu.mt>

FHS-2021-00032 Giselle-Marie Muscat

Rita Pace Parascandalo <rita.pace-parascandalo@um.edu.mt> 15 March 2022 at 14:49
To: Giselle-marie Muscat <giselle-marie.muscat.15@um.edu.mt>
Cc: Justin Lee Mifsud <justin-lee.mifsud@um.edu.mt>, Research Ethics HEALTHSCI <research-ethics.healthsci@um.edu.mt>, Norma Josephine Delezio <norma.delezio@um.edu.mt>

Dear Giselle-Marie,

your recently submitted amendments have been reviewed. Approval for your study is granted oBo FREC. You may proceed with your study and collect the data.

Good luck

Regards
Dr Rita PP

L-Università ta' Malta

Dr Rita Pace Parascandalo PhD (UCLan)
BSc(Hons) (Melit.), MSc(Melit.), RM

Senior Lecturer, Department of Midwifery
Chairperson, Faculty Research Ethics Committee

Faculty of Health Sciences
Office No. 48
+356 2340 1176
rita.pace-parascandalo@um.edu.mt

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Appendix L: Persmision from the charmain of cardiology and cardiology consultants who have patients attending the Heart Failure Clinic

L-Università
ta' Malta

Dear Consultant,

I am currently reading for a master's degree in nursing with the University of Malta and am conducting a study entitled **"Illness perception and quality of life among patients with congestive heart failure"** under the supervision of Dr Norma Josephine Delizio and Mr Justin-Lee Mifsud.

The purpose of this study is to examine the relationship between illness perceptions and quality of life among patients with congestive heart failure, and to assess possible significant differences among subgroups of demographic characteristics.

Subjects will be recruited from the heart failure clinic, and data collection will be carried out by distributing two validated questionnaires, one related to illness perception and another related to quality of life. Demographic data will also be collected as to assess significant disparities among the participants. The information letter, demographic data questionnaire, brief illness perception questionnaire and the Kansas City cardiomyopathy questionnaire -12, which will be distributed among the participants are attached with letter. Furthermore, data collection will take place over 4 weeks.

Subjects recruited for this study will remain anonymous from the researcher as no personal information will be collected, and research instruments will be distributed via an intermediary person working at the heart failure clinic. The information collected will be solely used for the purpose of this study and the research tools will be destroyed after successful completion of the study unit. Ethical approval will be obtained from the Research Ethical Committee of the University of Malta.

I would appreciate your approval and support for this research study. Thank you for reading this.

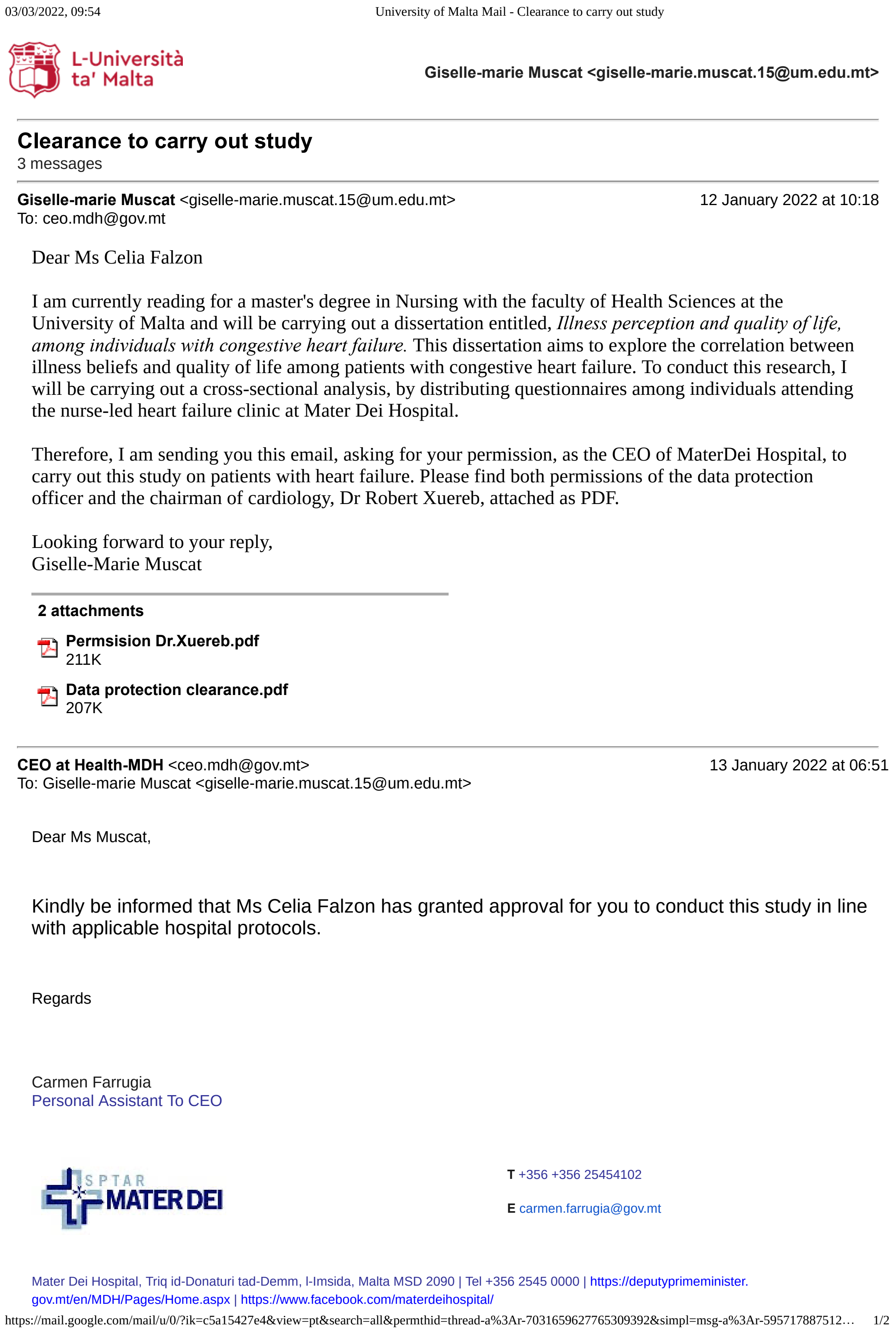
Yours sincerely,
Giselle-Marie Muscat

By signing, I authorise the researcher to carry out this project for the purposes described above and I agree to the requirements of the research study.

Name	**Signature**	**Date**
Dr Caroline Magri		24/2/2022
Dr Tiziana Felice		24.2.2022

Dr Oscar Aquilina	24/2/22
Dr Mark Sammut	24/2/22
Dr Andrew Cassar	24-2-22
Dr Alex Borg	04-03-2022
Dr Andrew J Cassar Maempel	24/2/22
Dr Maryanne Caruana	24/2/22
Dr Daniela Cassar Demarco	24/2/22

Appendix M: Permission to carry out study on patients from the Heart Failure Clinic from the CEO of Mater Dei Hospital



03/03/2022, 09:54 University of Malta Mail - Clearance to carry out study

L-Università ta' Malta

Giselle-marie Muscat <giselle-marie.muscat.15@um.edu.mt>

Clearance to carry out study

3 messages

Giselle-marie Muscat <giselle-marie.muscat.15@um.edu.mt> 12 January 2022 at 10:18
To: ceo.mdh@gov.mt

Dear Ms Celia Falzon

I am currently reading for a master's degree in Nursing with the faculty of Health Sciences at the University of Malta and will be carrying out a dissertation entitled, *Illness perception and quality of life, among individuals with congestive heart failure.* This dissertation aims to explore the correlation between illness beliefs and quality of life among patients with congestive heart failure. To conduct this research, I will be carrying out a cross-sectional analysis, by distributing questionnaires among individuals attending the nurse-led heart failure clinic at Mater Dei Hospital.

Therefore, I am sending you this email, asking for your permission, as the CEO of MaterDei Hospital, to carry out this study on patients with heart failure. Please find both permissions of the data protection officer and the chairman of cardiology, Dr Robert Xuereb, attached as PDF.

Looking forward to your reply,
Giselle-Marie Muscat

2 attachments

Permsision Dr.Xuereb.pdf
211K

Data protection clearance.pdf
207K

CEO at Health-MDH <ceo.mdh@gov.mt> 13 January 2022 at 06:51
To: Giselle-marie Muscat <giselle-marie.muscat.15@um.edu.mt>

Dear Ms Muscat,

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

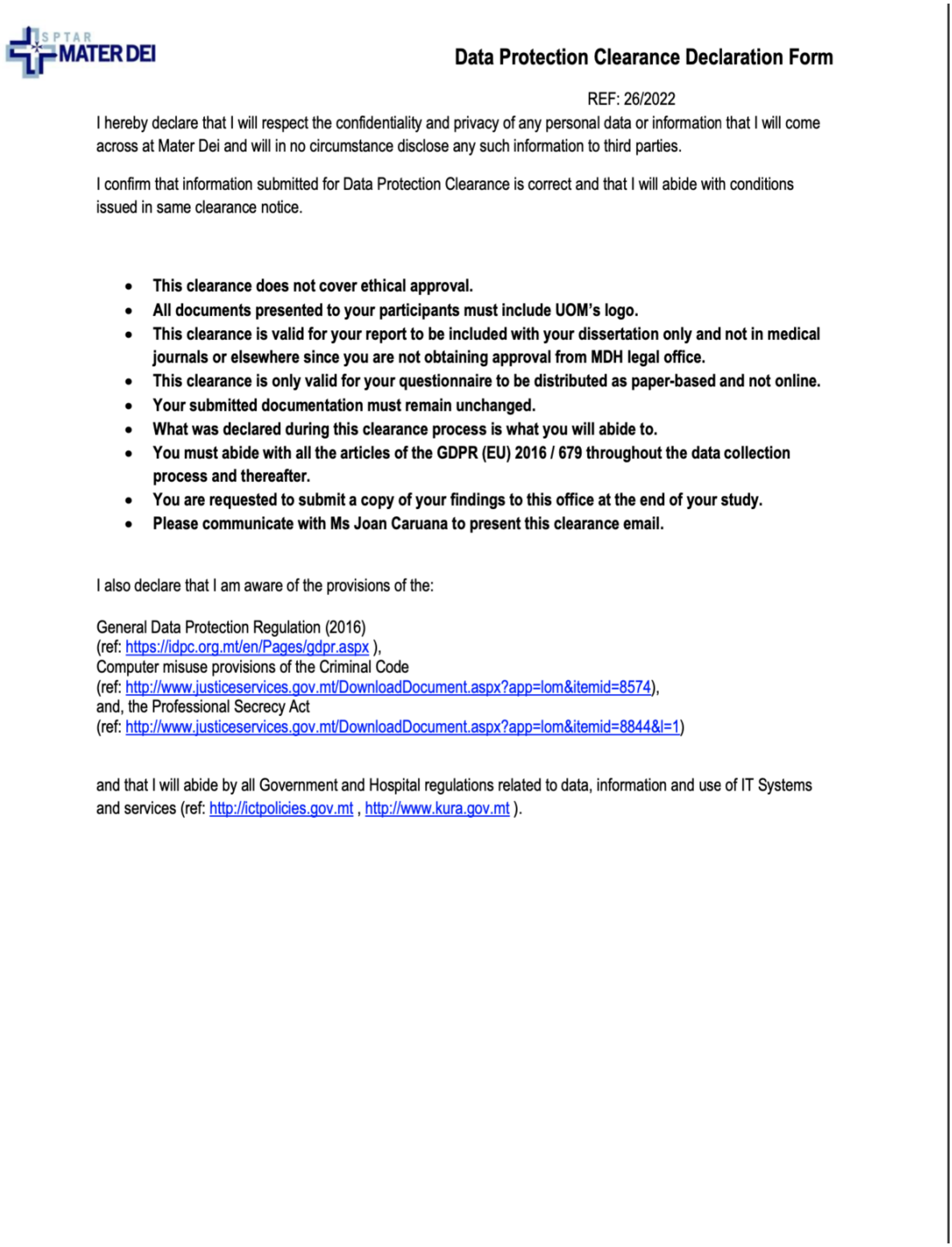
T +356 +356 25454102

E carmen.farrugia@gov.mt

Mater Dei Hospital, Triq id-Donaturi tad-Demm, l-Imsida, Malta MSD 2090 | Tel +356 2545 0000 | https://deputyprimeminister.gov.mt/en/MDH/Pages/Home.aspx | https://www.facebook.com/materdeihospital/

https://mail.google.com/mail/u/0/?ik=c5a15427e4&view=pt&search=all&permthid=thread-a%3Ar-7031659627765309392&simpl=msg-a%3Ar-595717887512… 1/2

Appendix N: Permission to carry out study from the DPO



SPTAR MATER DEI

Data Protection Clearance Declaration Form

REF: 26/2022

I hereby declare that I will respect the confidentiality and privacy of any personal data or information that I will come across at Mater Dei and will in no circumstance disclose any such information to third parties.

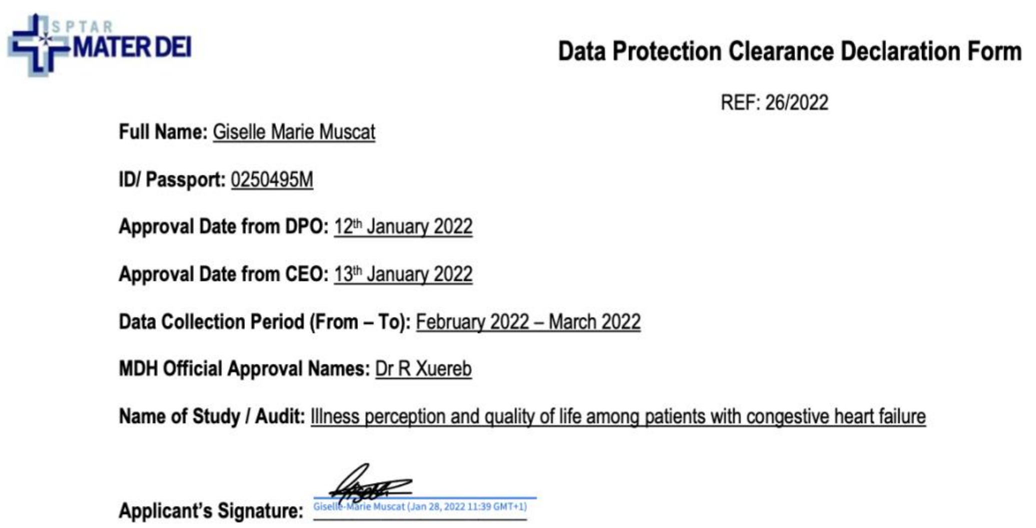
I confirm that information submitted for Data Protection Clearance is correct and that I will abide with conditions issued in same clearance notice.

- **This clearance does not cover ethical approval.**
- **All documents presented to your participants must include UOM's logo.**
- **This clearance is valid for your report to be included with your dissertation only and not in medical journals or elsewhere since you are not obtaining approval from MDH legal office.**
- **This clearance is only valid for your questionnaire to be distributed as paper-based and not online.**
- **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 (EU) 2016 / 679 throughout the data collection process and thereafter.**
- **You are requested to submit a copy of your findings to this office at the end of your study.**
- **Please communicate with Ms Joan Caruana to present this clearance email.**

I also declare that I am aware of the provisions of the:

General Data Protection Regulation (2016)
(ref: https://idpc.org.mt/en/Pages/gdpr.aspx),
Computer misuse provisions of the Criminal Code
(ref: http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8574),
and, the Professional Secrecy Act
(ref: http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8844&l=1)

and that I will abide by all Government and Hospital regulations related to data, information and use of IT Systems and services (ref: http://ictpolicies.gov.mt , http://www.kura.gov.mt).



SPTAR MATER DEI

Data Protection Clearance Declaration Form

REF: 26/2022

Full Name: Giselle Marie Muscat

ID/ Passport: 0250495M

Approval Date from DPO: 12th January 2022

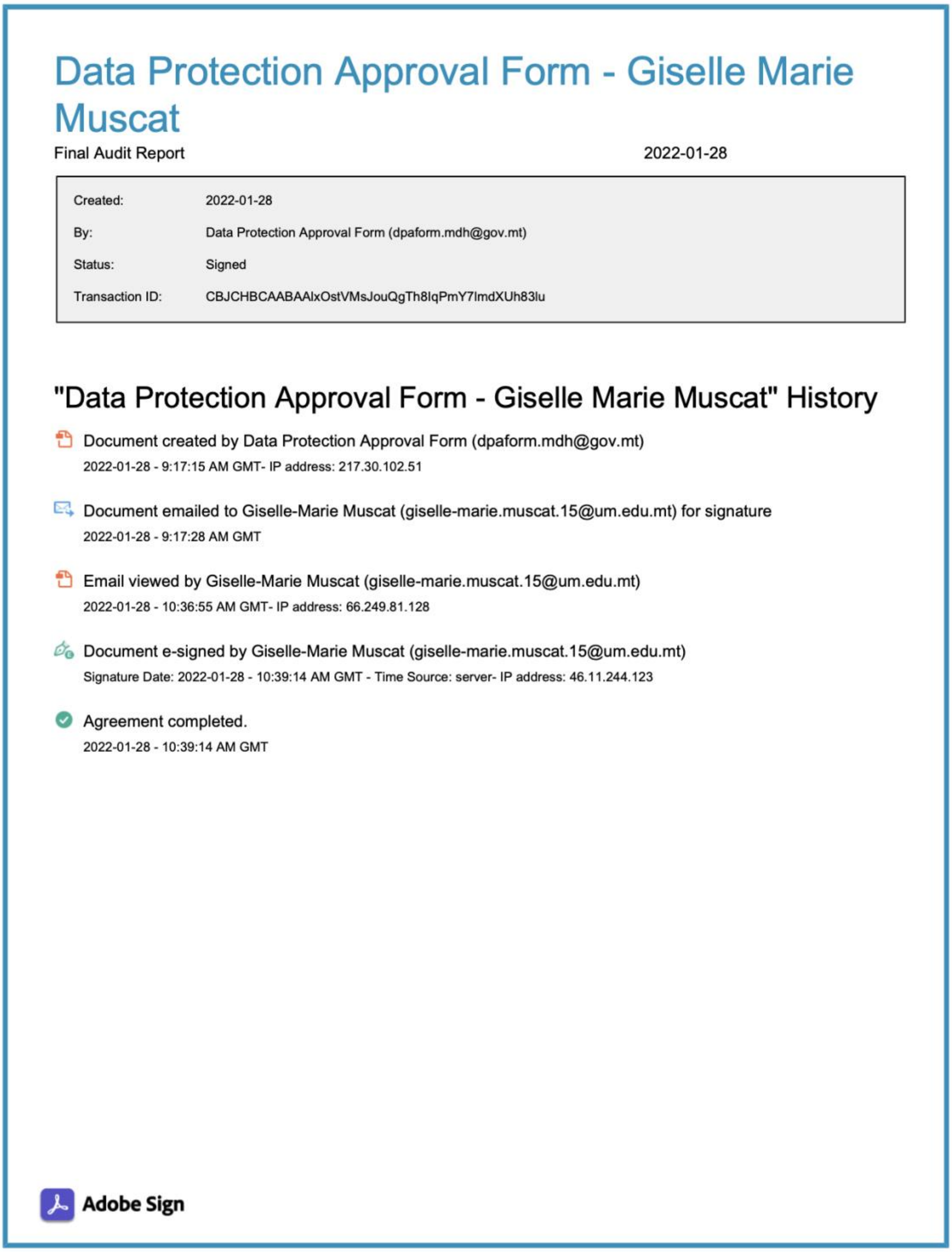
Approval Date from CEO: 13th January 2022

Data Collection Period (From – To): February 2022 – March 2022

MDH Official Approval Names: Dr R Xuereb

Name of Study / Audit: Illness perception and quality of life among patients with congestive heart failure

Applicant's Signature: Giselle-Marie Muscat (Jan 28, 2022 11:39 GMT+1)



Data Protection Approval Form - Giselle Marie Muscat

Final Audit Report 2022-01-28

Created:	2022-01-28
By:	Data Protection Approval Form (dpaform.mdh@gov.mt)
Status:	Signed
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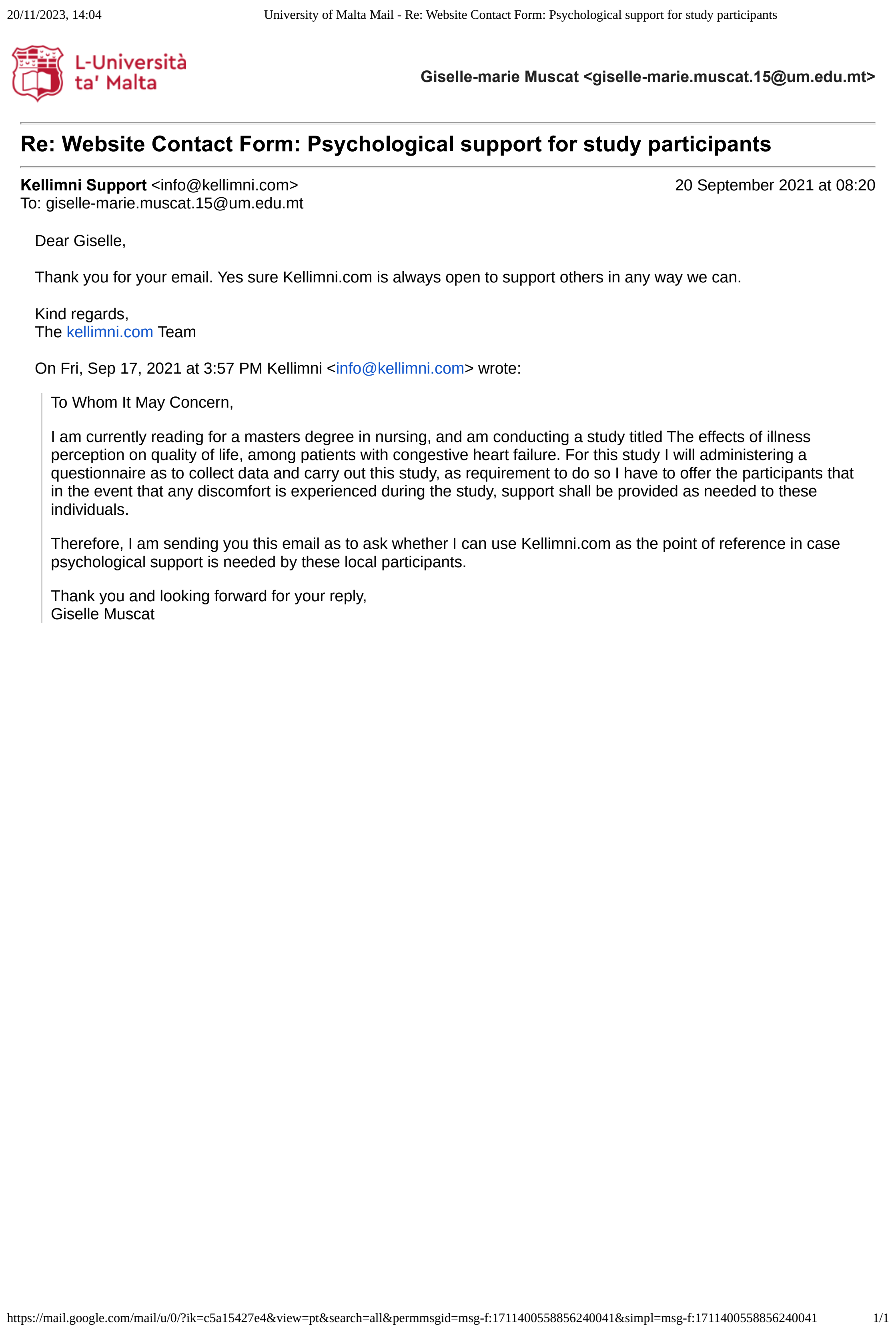
✓ Agreement completed.
2022-01-28 - 10:39:14 AM GMT

Appendix O: Psychological support agreement



20/11/2023, 14:04 University of Malta Mail - Re: Website Contact Form: Psychological support for study participants

L-Università ta' Malta

Giselle-marie Muscat <giselle-marie.muscat.15@um.edu.mt>

Re: Website Contact Form: Psychological support for study participants

Kellimni Support <info@kellimni.com> 20 September 2021 at 08:20
To: giselle-marie.muscat.15@um.edu.mt

Dear Giselle,

Thank you for your email. Yes sure Kellimni.com is always open to support others in any way we can.

Kind regards,
The kellimni.com Team

On Fri, Sep 17, 2021 at 3:57 PM Kellimni <info@kellimni.com> wrote:

> To Whom It May Concern,
>
> I am currently reading for a masters degree in nursing, and am conducting a study titled The effects of illness perception on quality of life, among patients with congestive heart failure. For this study I will administering a questionnaire as to collect data and carry out this study, as requirement to do so I have to offer the participants that in the event that any discomfort is experienced during the study, support shall be provided as needed to these individuals.
>
> Therefore, I am sending you this email as to ask whether I can use Kellimni.com as the point of reference in case psychological support is needed by these local participants.
>
> Thank you and looking forward for your reply,
> Giselle Muscat

https://mail.google.com/mail/u/0/?ik=c5a15427e4&view=pt&search=all&permmsgid=msg-f:1711400558856240041&simpl=msg-f:1711400558856240041 1/1

Appendix P- Information letter given to participants attached to the research instruments (English version)

L-Università
ta' Malta

Participant's information letter

Dear Participant,
My name is Giselle-Marie Muscat, and I am currently reading for a master's degree in Nursing at the University of Malta. As part of my course requirements, I am conducting a research study entitled:

Illness perception and quality of life among patients with congestive heart failure.

This study aims to analyse the association between illness beliefs and quality of life among individuals diagnosed with congestive heart failure. You are being invited to participate in this study; your participation would help us understand the subject area and improving the care of patients with congestive heart failure.

Data collection will occur via two self-administered questionnaires attached to this information letter and these will take approximately 10 minutes to complete. The questionnaires will collect personal information and information about your views on your illness and on your quality of life.

Your participation in this study is entirely voluntary, and you are free to withdraw at any time without the need to provide a reason. However, it is crucial to understand that since data collection will be carried out anonymously, once the questionnaire is completed and handed in, it would be impossible to identify individual questionnaires.

It is your right to keep a copy of this information letter for future reference. Furthermore, all data collected from this research shall be used solely for the purpose of this study, and due to anonymity, participants' identity and personal data will not be gathered. Therefore, your identity cannot be revealed in any reports, presentations of publications arising from this study.

Data gathered from this study will be stored on a password-protected computer in an encrypted format. Due to the nature of the study, upon completion of the survey, the data will be stored anonymously. In addition, only the academic supervisors will have access to coded data. The physical copies of the questionnaires will be destroyed upon successful completion of the study unit.

Since data collection will be gathered in an anonymous manner, no consent form will be given out. However, filling in and returning the questionnaire implies consent. In addition, no loss of benefits or penalties is involved.

If you feel distressed during the participation of this questionnaire, the service of a health care professional through kellimni.com will be available at no financial cost. This can be done through their website kellimni.com, where you will have the option to chat with a professional online, send them an email or talk to them via their downloadable application. It is your right to request the results at the end of the study.

Your participation is beneficial for carrying out this study and is greatly appreciated. I wish to thank you in advance for your time.

Sincerely,

Giselle-Marie Muscat

Giselle-Marie Muscat

Researcher

99333374

giselle-marie.muscat.15@um.edu.mt

Delezio

Norma Delezio

Research Supervisor

99845463

norma.delezio@um.edu.mt

Appendix Q- Information letter given to participants attached to the research instruments (Maltese version)

L-Università
ta' Malta

Ittra ta' informazzjoni tal-parteċipant

Għażiż/a Parteċipant/a,

Jien jisimni Giselle-Marie Muscat, u bħalissa qed nistudja sabiex nikseb il-Lawrja tal-Masters fl-Infermerija fl-Università ta' Malta. Bħala parti mir-rekwiżiti tal-kors tiegħi, qed nagħmel studju ta' riċerka intitolat:

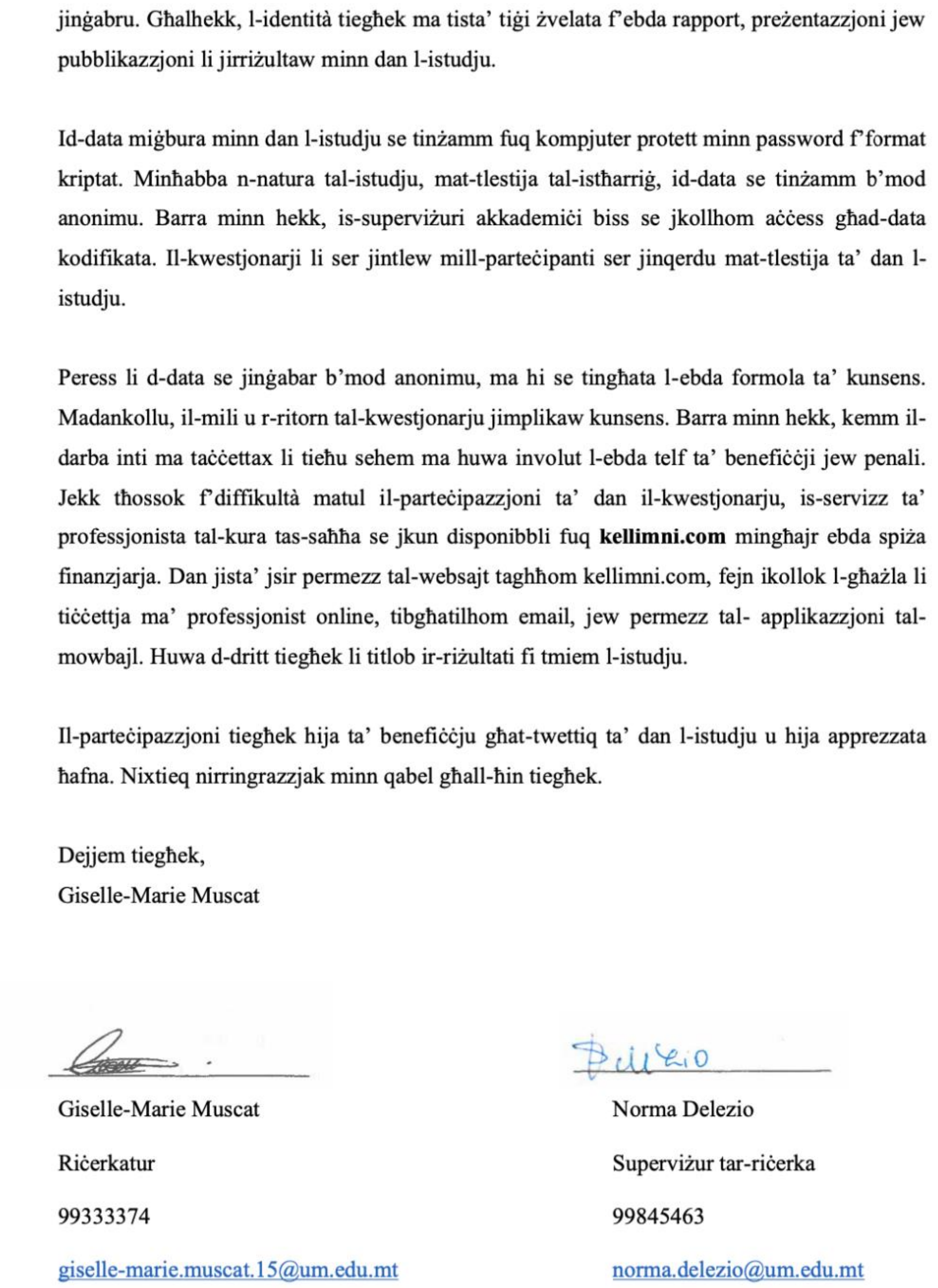
Illness perception and quality of life among patients with congestive heart failure (Il-perċezzjoni tal-mard u l-kwalità tal-ħajja fost pazjenti b'insuffiċjenza tal-qalb konġestiva).

Dan l-istudju għandu l-għan li janalizza kif nies li għandhom insuffiċjenza tal-qalb konġestiva jaħsbuha dwar din il-marda u kif din taffetwa l-kwalità tal-ħajja tagħhom. Qed tiġi mistieden/mistiedna tieħu sehem f'dan l-istudju; il-parteċipazzjoni tiegħek se tgħinna nifhmu s-suġġett u ntejbu l-kura tal-pazjenti b'insuffiċjenza tal-qalb konġestiva.

Il-ġbir tad-data se jseħħ permezz ta' żewġ kwestjonarji mehmuża ma' din l-ittra ta' informazzjoni. Dawn il-kwestjonarji jieħdu madwar 10 minuti biex jitlestew. Il-kwestjonarji se jiġbru informazzjoni personali u informazzjoni dwar il-fehmiet tiegħek dwar il-marda tiegħek u dwar il-kwalità tal-ħajja tiegħek.

Il-parteċipazzjoni tiegħek f'dan l-istudju hija kompletament volontarja, u inti liberu/a li tirtira fi kwalunkwe ħin mingħajr il-ħtieġa li tagħti raġuni. Madankollu, huwa kruċjali li wieħed jifhem li peress li l-ġbir tad-data se jitwettaq b'mod anonimu, ladarba l-kwestjonarju jitlesta u jingħata, ikun impossibbli li jiġu identifikati kwestjonarji individwali.

Huwa d-dritt tiegħek li żżomm kopja ta' din l-ittra ta' informazzjoni għal referenza fil-ġejjieni. Barra minn hekk, id-data kollha miġbura minn din ir-riċerka ser tintuża biss għall-fini ta' dan l-istudju, u minħabba l-anonimità, l-identità tal-parteċipanti u d-data personali mhux se



jinġabru. Għalhekk, l-identità tiegħek ma tista' tiġi żvelata f'ebda rapport, preżentazzjoni jew pubblikazzjoni li jirriżultaw minn dan l-istudju.

Id-data miġbura minn dan l-istudju se tinżamm fuq kompjuter protett minn password f'format kriptat. Minħabba n-natura tal-istudju, mat-tlestija tal-istħarriġ, id-data se tinżamm b'mod anonimu. Barra minn hekk, is-superviżuri akkademiċi biss se jkollhom aċċess għad-data kodifikata. Il-kwestjonarji li ser jintlew mill-parteċipanti ser jinqerdu mat-tlestija ta' dan l-istudju.

Peress li d-data se jinġabar b'mod anonimu, ma hi se tingħata l-ebda formola ta' kunsens. Madankollu, il-mili u r-ritorn tal-kwestjonarju jimplikaw kunsens. Barra minn hekk, kemm il-darba inti ma taċċettax li tieħu sehem ma huwa involut l-ebda telf ta' benefiċċji jew penali. Jekk tħossok f'diffikultà matul il-parteċipazzjoni ta' dan il-kwestjonarju, is-servizz ta' professjonista tal-kura tas-saħħa se jkun disponibbli fuq **kellimni.com** mingħajr ebda spiża finanzjarja. Dan jista' jsir permezz tal-websajt taghħom kellimni.com, fejn ikollok l-għażla li tiċċettja ma' professjonist online, tibgħatilhom email, jew permezz tal- applikazzjoni tal-mowbajl. Huwa d-dritt tiegħek li titlob ir-riżultati fi tmiem l-istudju.

Il-parteċipazzjoni tiegħek hija ta' benefiċċju għat-twettiq ta' dan l-istudju u hija apprezzata ħafna. Nixtieq nirringrazzjak minn qabel għall-ħin tiegħek.

Dejjem tiegħek,
Giselle-Marie Muscat

	Delezio
Giselle-Marie Muscat	Norma Delezio
Riċerkatur	Superviżur tar-riċerka
99333374	99845463
giselle-marie.muscat.15@um.edu.mt	norma.delezio@um.edu.mt

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