Alassoud, Bahaa Ahmed I. (2022) *Understanding palliative care in advanced heart failure: a qualitative descriptive study of cultural impact.* PhD thesis.

https://theses.gla.ac.uk/83167/

Understanding palliative care in advanced heart failure: a qualitative descriptive study of cultural impact

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Thesis submitted in fulfilment of the requirement for the degree of Doctor of Philosophy

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September 2022

Abstract

Background: Heart failure is a complex clinical syndrome that affects more than 65 million people worldwide. Over the next ten years, as the foremost cause of morbidity, mortality, and disability, heart failure could overwhelm the global health infrastructure. Palliative care is intended to relieve symptoms, reduce the burden of severe illness, and improve the quality of life for patients and their families. However, the complexity of palliative care in heart failure is compounded by contextual factors and the often neglected role of culture on peoples' experiences and understanding. Understanding patients' situational and contextual circumstances is implicit in any application of effective palliative care, this thesis explores the impact of culture on palliative care for people with advanced heart failure from diverse backgrounds by focusing on individual understandings.

Methods: A two-step qualitative descriptive design was used, consisting of a mixed-methods systematic review (Phase 1) and a qualitative descriptive study (Phase 2). Phase 1 incorporated a systematic review of quantitative and qualitative data from scientific and grey literature databases. In total, 13 articles were identified as eligible and thematically analysed, synthesised, and presented. In Phase 2, focus group discussions were utilised to explore the understanding of palliative care in heart failure among people from diverse backgrounds as situated in cultural contexts. Data were purposively collected from seven one-off focus groups, consisting of 55 adult participants. Group discussions were audio-recorded, transcribed, and analysed using reflexive thematic analysis. The project was underpinned by critical realism philosophy, conceptually followed the development phase of the Medical Research Council (MRC) Framework and was theoretically guided by the PEN-3 cultural model.

Findings:

Phase 1. The findings indicated that the influences of the culture on the HF understanding was seen as iterative and ongoing evident by the three overlapping themes, namely lay knowledge and beliefs, understanding and reporting symptoms, and understanding of self-care. Patients' understanding of and response to symptoms were strongly linked to their cultural beliefs. Patients from Eastern and

Middle Eastern countries somatised their symptoms to a greater extent, whereas patients from Western cultures reported higher symptom distress scores. People's cultural beliefs about health and disease inform lay knowledge of the diagnosis, causes, treatment, and self-care of heart failure and can thus determine people's healthcare decisions and behaviours, and their access to and utilisation of healthcare services.

Phase 2. Three themes were constructed: (1) culturally embedded understanding of heart failure, in which participants interpreted the illness in terms of a combination of their worldviews and experiences; (2) understanding of palliative care for patients with heart failure, in which context is crucial to unravelling the interpretations and mechanisms by which the process of palliative care is understood; (3) preferences for care, which broadly reflect values indicating which choices are influenced but not controlled by the interplay of illness and cultural understandings. In combination, these three themes highlight the complexity of people's choices and preferences at the end of life, as contextual responses inform decisions that are made in response to changing health circumstances and care experiences.

Conclusion: The results show that people's understanding of heart failure drives the utilisation of palliative care services, and a lack of understanding is one reason for service failures. People's cultural background and life experiences underpin their care preferences and decisions during palliative care for heart failure; therefore cultural knowledge is critical to understanding behaviours. The complexity of the context and the uniformity of findings with regard to the cultural understanding of heart failure can both help and hinder access to palliative and end-of-life care services. To enable people from diverse backgrounds to access palliative care, it is necessary to develop a language for talking about heart failure, images, visuals or models, that transcends cultural interpretations and enhances optimal understanding for people from diverse backgrounds. An understanding of cultural beliefs, values, and preferences, together with effective cross-cultural encounters, must become embedded in the development and delivery of culturally aware palliative care interventions.

Lay Summary

Background: Heart failure is an illness in which the heart cannot function properly to support the body's various organs and functions. Patients with heart failure often experience breathing difficulties and reduced ability to do their daily chores such as housework or perform the duties of their jobs. This life-changing illness has no cure. Therefore, palliative care has become an essential aspect of treatment. Palliative care manages the symptoms rather than the illness itself. It ensures that the patient is comfortable and helps them to adapt to a new lifestyle that is less taxing. Unfortunately, there is little agreement in the medical professions as to how the needs of heart failure patients are best met. Palliative care promotes cooperation between medical professionals, patients, carers, and relatives to provide the best possible care and support for the patient. However, some factors may adversely impact the potential benefits intended by using palliative care. One of these is the lack of attention given to cultural factors, which can significantly impact the effectiveness or appropriateness of palliative care, depending on whether treatment is aligned with religious beliefs.

The study has focused on individuals' understandings of heart failure to explore the impact of different cultural and religious beliefs and values on the delivery of effective palliative care. It has also sought to identify the challenges and needs to be overcome or accommodated when designing care programmes for patients with advanced heart failure and the family members who care for them.

This study was conducted in two stages. It was clear that the researcher has conducted extensive work trying to understand previous research on the subject of palliative care in a broader context and palliative care that focused on heart failure patients. This preparatory work has put the field work with volunteers on a solid foundation that gave the researchers the confidence they needed when planning the areas they wanted to explore further. The researcher then arranged a number of working sessions with a number of groups, including heart failure sufferers and people directly involved in their care. Each group discussion focused on one of the diverse cultural groups to gain insight into how they view and understand palliative care and its benefits for patients with heart failure.

The group sessions generated three main findings. Firstly, participants understood their illness in terms of their own or others' experiences of heart failure. Secondly, their understanding of available care was based on personal experience and interpretations. Thirdly, their preferences for care broadly reflected values indicating choices that were influenced but not controlled by the interplay of illness and cultural understandings. When examined together, these three themes highlight the complexities of people's choices and preferences at the end of life, as contextual responses inform the decisions made in response to changing health conditions and care experiences.

Conclusion: The findings suggest that an optimal understanding of heart failure results in people seeking help from palliative care services. On the other hand, the lack of understanding is one reason for the underuse of these services. People's cultural backgrounds and life experiences determine their healthcare, treatment preferences and decisions. Therefore, the services must be modified so as to incorporate cultural beliefs, knowledge, and understanding. To facilitate and increase access to palliative care services for people from diverse backgrounds, developing a language for talking about heart failure that goes beyond the different cultural interpretations is necessary. A tool that enhances optimal understanding of heart failure, the limitations of cures, and how palliative care can help manage the symptoms, reduce pain, and help the patients and their carers better deal with the impact of heart failure on their lives and after death.

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Publications:

- Alassoud, B., B. Johnston and K. Hogg (2020). Culture and the Understanding of Advanced Heart Failure: A Mixed-Methods Systematic Review. *Collegian* 27, 459-470.
- Alassoud, B., Johnston, B., Stewart S., and Hogg, K., (submitted). Palliative Heart failure care: A realist qualitative exploration of patients' understanding and construction of meaning. *Journal of Clinical Nursing*.

Conference presentations and posters:

Oral Presentations:

- Alassoud, B. (2021). Palliative care for people living with heart failure: The impact of cultural context. The University of Glasgow Three-Minute Thesis competition, Glasgow, UK. Available online at: https://youtu.be/VJAkhH7VZLo

- Alassoud, B. (2021). Palliative heart failure care: A realist exploration of the cultural understanding and meanings. The University of Glasgow - SoMDN Postgraduate Research Day 2021, Glasgow, UK.

- Alassoud, B. (2021). Informing the development of a culturally neutral intervention, guided by the UK Medical Research Council (MRC) Framework. Vilniaus kolegija / University of Applied Sciences (VIKO) - International Teaching Week (IW) 2021 March 1-5, Vilnius, Lithuania.

- Alassoud, B. (2020). Heart Failure and Palliative care: The influence of culture on the understanding of disease and services. The University of Glasgow Three-Minute Thesis competition, Glasgow, UK. Available online at: https://youtu.be/WvkSWF73LqA

- Alassoud, B. (2019). The impact of contextual heart failure understanding on adherence to heart failure self-care: Mapping findings to the situation-specific theory of heart failure self-care. Oral Pecha Kucha style Presentation at The European Academy of Nursing Science – Winter Summit 2019 January 24-25, 2019, University of Birmingham, United Kingdom.

- Alassoud, B. (2019). Palliative care and Advanced Heart Failure: The influence of cultural beliefs on the Utilisation of Services. The University of Glasgow Three-Minute Thesis competition, Glasgow, UK. Available online at: https://youtu.be/_2lEH3PPxjo

Poster Presentations:

- Alassoud, B., Johnston, B. and Hogg, K., (2021). A Critical Realist study of the Understanding of Palliative Heart Failure Care. Poster Presentation at The European Academy of Nursing Science (EANS) in cooperation with the German Society of Nursing Science (DGP) – Summer Conferences [online]; 2021, Koln, Germany. Available online at:
- https://www.egms.de/de/meetings/dgp2021

- Alassoud, B., Johnston, B. and Hogg, K., (2020). The impact of culture on the understanding of advanced heart failure: a mixed-method systematic review of patients' and family members' experiences. Palliative Medicine. Poster presented at The 11th EAPC care World Research Congress Online; 2020 Oct 7-10; Available online at: https://journals.sagepub.com/doi/full/10.1177/0269216320958098

- Alassoud, B., Johnston, B. and Hogg, K., 2020. Cultural implications for the development of palliative care cardiology interventions: preliminary results. Palliative Medicine. Poster presented at: The 11th EAPC World Research Congress [Online]; 2020 Oct 7-10; Available online at:

  https://journals.sagepub.com/doi/full/10.1177/0269216320958098

Acknowledgement

In the name of Allah, the Most Gracious, Most Merciful. All praise and glory to Allah, the Almighty who made it possible for this small work to be accomplished. This work would also not have been possible without the help, assistance, support, and encouragement of many people whom I would like to thank.

First, I am indebted to my academic supervisors Professor Bridget Johnston and Dr Karen Hogg. It was Bridget who gave me the opportunity to come to Scotland, and throughout my PhD studies she has been unfailingly approachable and supportive, offering her professional expertise and guidance throughout the course of this work. I am also extremely grateful to Karen, the busiest clinician I ever knew, for her critical eye, succinct but informative scientific advice, and steadfast encouragement, and for sharing her expertise and enthusiasm about the subject.

I wish to thank my sponsor, the University of Glasgow, for turning my dream of acquiring expertise in nursing research into a reality, and to my co-funder, the British Council Palestine, and particularly Merna Kassis, Scholarships/Higher Education Coordinator, for being so supportive of my aspirations.

I also want to thank all those individuals who participated in the study and so generously and openly shared their views, understanding, and experience of heart failure. Special thanks are due to my patient and public advisers, both for believing in me and for their constant feedback and guidance. In addition, I am deeply grateful to all the patients who agreed to participate in the study, and to the participating community centres and religious organisations that allowed me access to the site and facilitated recruitment and the running of the study.

I am indebted to the Graduate School of the College of Medical, Veterinary & Life Sciences, University of Glasgow, for their world-class training and guidance. I consider myself fortunate indeed to have had this learning experience here in Scotland. Last, but not least, I thank my father and mother, Ahmed and Ghalia, and my brothers, Dia, Alaa, Anas, Safaa, and Walaa, for all their support, prayers, and understanding during the years when I was working for my PhD. And finally, I am indebted to my wife Manar and my heroes, Dia, Abdulrahman, and Hamza, for their endless love, support, and encouragement. May Allah bless you all!

Dedication

This thesis is dedicated, with love, to the state of Palestine and its people who have existed and have resisted for over 74 years.

Author's declaration

I hereby declare, that except where explicit reference is made to the contribution of others, this PhD thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institutions.

Printed name: *Bahaa Alassoud*

List of abbreviations

Abbreviation	Description
ACP	Anticipatory Care Planning
BAME	Black, Asian and minority ethnic
BHF	British Heart Foundation
CASA	The Collaborative Care to Alleviate Symptoms and Adjust to Illness
COPD	Chronic Obstructive Pulmonary Disease
CR	Critical Realism
ENABLE-CHF	Educate, Nurture, Advise Before Life Ends Comprehensive Heartcare for Patients and Caregivers
ESC	European Society of Cardiology
GPRD	General Practice Research Database
HF	Heart Failure
MRC	Medical Research Council
NIS	National Inpatient Sample
NYHA	New York Heart Association
PAL-HF	Palliative Care in Heart Failure
SWAP-HF	Social Worker-Aided Palliative Care Intervention in High-risk Patients with Heart Failure
WISDOM	Working to Improve Discussions about Defibrillator Management
PEN-3	Perceptions, Enablers, and Nurturers (relationship and expectation); Person, Extended Family, Neighbourhood (Cultural Identity); Positive, Existential and Negative (Cultural Empowerment)
PPI	Patient and Public Involvement
WHO	World Health Organization
IAHPC	International Association for Hospice and Palliative Care
PRISMA	Preferred Reporting Items for Systematic Reviews

Chapter 1 Introduction

This chapter begins with a general introduction to the thesis by presenting the current updates about (advanced) heart failure, the definitions and diagnosis, its sign and symptoms, its aetiology and risk factors and the demographic and clinical profiles of HF, including global burden, prevalence, incidence, and hospitalisations, as well as treatment strategies. Following an overview of palliative care, the literature concerning palliative care in advanced heart failure is reviewed. Then, disparities and barriers in service utilisation are presented with more reliance on qualitative data to help understand what is known, the current practice and context and why the service is still suboptimally utilised by patients and their families. Next, the concept of culture is introduced, including the view of culture in healthcare research, its main approaches, and a discussion around the intersection between palliative care and culture. Finally, the chapter ends by outlining the context of this research project and providing insights into the significance of and rationale for, as well as the motivation for this research. The chapter concludes by highlighting the research aims and objectives and outlining the structure of the thesis.

1.1 Heart failure syndrome

Definitions are essential where an understanding of heart failure forms the basis for timely diagnosis and treatment. This thesis primarily utilises the definition and classifications of heart failure described by the European Society of Cardiology (ESC), though it also uses the American Heart Association (AHA) and American College of Cardiology (ACC) definitions of the different stages, classes, and profiles of heart failure. The ESC defines heart failure as a clinical syndrome in which patients suffer typical symptoms (breathlessness and fatigue) and signs (oedema and elevated jugular venous pressure) that arise from an abnormal structure and/or function of the heart (Ponikowski et al., 2016). Although heart failure is treatable, there is no treatment that can cure or reverse the structural damage that has already occurred. Failure to pump the oxygenated blood to the body tissues at the required rate leads to significant compensatory elevated left ventricular filling pressures, which cause the cardinal symptoms of heart failure (McMurray et al., 2012). The heart's inability to meet the demands of the tissues and/or elevated intracardiac pressures results in a multitude of clinical signs and symptoms, and may contribute to the progression of this disabling syndrome (Crespo-Leiro. et al., 2018). All cardinal signs and symptoms are non-specific, multifactorial, and are often observed during exertion in early or mild disease, and at rest in severe disease. Multiple comorbidities worsen the symptoms and may significantly increase the severity and morbidity of heart failure and thereby limiting the therapeutic response to treatment.

1.1.1 Clinical signs and symptoms

Symptoms are defined as multidimensional and subjective constructs that reflect individuals' perceptions and affect activities of daily living (Wilkie and Ezenwa, 2012). Patients with advanced heart failure frequently experience a group of typical and less typical signs and symptoms. Major cardiology and heart failure societies now acknowledge that patients experience as many as nine typical and eight atypical symptoms (Bozkurt et al., 2021). The typical symptoms include breathlessness and fatigue on exertion, swelling (particularly of the ankles), exercise and activity intolerance, and other types of dyspnoea, including orthopnoea, bendopnoea, and paroxysmal nocturnal dyspnoea (Bozkurt et al., 2021, Ponikowski et al., 2016, Thibodeau et al., 2014). Less typical symptoms include depression, satiety and loss of appetite, weight gain, nocturnal cough, bloating, wheezing, palpitations, dizziness, and syncope (Bozkurt et al., 2021, Ponikowski et al., 2016).

As the syndrome progresses, symptoms such as dyspnoea and fatigue occur at rest or on minimal exertion. At this stage, when the pulmonary congestion persists, patients may develop fluid retention, high-intensity pain, and forms of systemic, peripheral, or pulmonary congestion (orthopnoea, bendopnoea, or paroxysmal nocturnal dyspnoea), pain, or cardiac cachexia. These symptoms are often a part of daily life for people living with heart failure, emerging simultaneously in clusters rather than in isolation, and impairing patients' understanding of and ability to monitor and self-manage them (Bozkurt et al., 2021, Ponikowski et al., 2016).

As a result, these restrictive symptoms limit patients' physical capacity and render them vulnerable to dependence and frailty, which are prevalent among patients with advanced heart failure. This complex state affects not only the physical health of the patient, but also their quality of life, including its psychological and sociocultural aspects. However, these aspects and other contextual determinants have not been adequately studied. The most important research aim is to identify the relationships between symptoms and individuals' or groups' perceptions, expectations, and behaviours. In addition, it is important to determine how these relationships differ by the sociocultural context (including values, beliefs, and goals) in which they occur. Cultural understanding is vital to interpreting subjective experience of symptoms and planning self-care strategies (Riegel et al., 2016). However, there has been little empirical research that captures the context of heart failure from different lay perspectives (Quinn et al., 2020, Vellone et al., 2021).

The trajectory of heart failure is based not only on symptoms, but on clinical signs and prognostic markers (Greene et al., 2020, Hogg and Jenkins, 2012). Traditionally, both specific and non-specific signs of heart failure have been the hallmark of clinical assessment of this complex syndrome (McMurray et al., 2012). However, a new consensus-based proposal for a universal definition of heart failure has been provided by Bozkurt et al. (2021). The specific signs of heart failure are elevated jugular venous pressure, extra heart sounds (S3 and S4), rarely with a summation gallop, hepatojugular reflux, cardiomegaly, a laterally displaced apical beat, and nocturnal Cheyne-Stokes respiration in the advanced stages (Bozkurt et al., 2021, Crespo-Leiro et al., 2018, Ponikowski et al., 2016). There are numerous less specific signs, including peripheral oedema (sacral, scrotal, and ankle), unintentional weight gain (more than 2 kg per week) due to fluid retention, the presence of basal lung crepitations, reduced air entry and dullness to percussion at the lung bases (pleural effusion) with or without crackles, tachypnoea, cardiac murmurs, tachyarrhythmias, ascites, hepatosplenomegaly, oliguria, muscle wasting and cachexia, and weight loss, primarily in advanced heart failure (Bozkurt et al., 2021, Crespo-Leiro et al., 2018, Ponikowski et al., 2016). These signs also reflect the degree of structural and functional impairment. When positive signs are few and symptoms are nonspecific, more objective imaging, haemodynamic and biomarkers assessment are recommended to characterise the heart failure progression (Fang et al., 2015).

1.1.2 Current updates: definitions and diagnosis

Heart failure is considered to be a clinically unstable and progressive syndrome, the specific stages of which are set out in the international literature and guidelines. Therefore the use of patient-specific multimodal treatment plans is recommended in order to improve prognostic outcomes and reduce morbidity, hospitalisations, and mortality. However, when it progresses to the advanced stages, heart failure may have a significant impact on clinical management. In the cardiology literature, the most frequently used alternative names for advanced heart failure are *end-stage*, *terminal*, and *refractory* heart failure (Crespo-Leiro. et al., 2018). Throughout this thesis, these terms are considered synonymous and used interchangeably. Advanced heart failure refers to a patient profile characterized by a persistent symptom burden and reduction in quality of life due to recurrent decompensation and rehospitalisation, despite optimal guideline-directed medical therapy (Bjork et al., 2016, Crespo-Leiro. et al., 2018). It is diagnosed based on the patient's symptoms, prognostic markers, and the presence of irreversible organ failure (Metra et al., 2019). At this stage, the characteristic refractory symptoms are dyspnoea and fatigue at rest or with minimal exertion. Standard treatment, by definition, is insufficient, and further interventions must be considered (Crespo-Leiro. et al., 2018, Metra et al., 2019). Episodes of fluid retention are mainly related to non-compliance with self-care strategies, but also indicate further progression of cardiac dysfunction. Until recently, a left ventricular ejection fraction (LVEF) of less than 30% was considered to be another criterion for diagnosis of advanced heart failure. However, according to the latest international guidelines and consensus report, LVEF is no longer considered an independent prognostic factor for the diagnosis of advanced heart failure (Crespo-Leiro. et al., 2018). Even though this chapter focuses on those with reduced ejection fraction (HFrEF), the term advanced heart failure can also be applied to patients with other heart failure subgroups, including HF with preserved ejection fraction (HFpEF). For instance, Dunlay et al. (2021) noticed that nearly 58% of patients with advanced HF had either HFmrEF or HFpEF per the diagnostic criteria suggested by the European Society of Cardiology (2018). According to Cleland et al. (2020), HFpEF (EF≥40%) comprises patients with a mid-range (HFmrEF), normal (HFnEF) and supra-normal (HFsnEF). Patients with HFrEF were initially believed to have the most severe form of HF and lower survival rates than patients with other subgroups. However, several pieces of evidence found similar or even higher mortality rates (Shah et al., 2017, Wehner et al., 2019). To date, and compared to the other HF phenotype, the prognosis and treatment of HFpEF have no convincing improvement, with even worse access to specialist services, including palliative care (Feder et al., 2022).

In view of the major implications of advanced heart failure classification, the leading heart failure societies have proposed several precise definitions. The recent updates in the definitions and guidelines by Crespo-Leiro. et al. (2018), Fang et al. (2015), and Yancy et al. (2017) are essential to an understanding of the present-day burden of heart failure, and for keeping abreast of advances in therapies and management, and thereby enabling clinicians to better understand the rapidly changing patterns of heart failure and integrate them into care for these patients. The definition of advanced heart failure has also evolved and contributed toward a better understanding of the disease process, resulting in improved diagnosis. For example, in 2007 the ESC defined advanced heart failure with an emphasis on patients who are severely symptomatic despite optimal guideline-directed management, regardless of their LVEF (Metra et al., 2007). In addition, the definition included patients with advanced heart failure who remain ambulatory but are essentially categorised as class IV by the New York Heart Association (NYHA) (Metra et al., 2007, Yancy et al., 2013). However, the standard classification systems, such as those of the NYHA and the ACC/AHA, do not take into account the patient's symptom status, prognosis, organ damage, and therapy goals, are based solely on ejection fraction, and do not distinguish between the different stages of heart failure.

1.1.3 Aetiology and risk factors of heart failure

Heart failure is the end-stage phenotype of events that occur in multiple (mainly cardiac) diseases, resulting in functional failure. Therefore, achieving a true consensus definition and identifying aetiologies have posed significant challenges. When studying the causes of heart failure, it is essential to recognise that this condition may develop as a result of multiple aetiologies that may coexist and interact with each other (Groenewegen et al., 2020). Some of these coincide with the risk factors for developing heart failure, and precede this condition. Indeed, patients with heart failure are a highly multimorbid population, and these comorbidities are more likely to share similar risk factors. Conrad et al. (2018) studied the comorbid status of 4 million patients between 2002 and 2014. They observed a 20% increase in the number of patients who developed multimorbidity with three or more chronic conditions. When adjusted for the survival rate of newly hospitalised patients, comorbidity was found to exacerbate the severity of symptoms, diminish the quality of life, and have a poor prognosis (Baldi et al., 2017). Despite its impact on patient outcomes, comorbidities are not yet considered in heart failure classifications.

According to the Global Burden of Disease Study in 2020, a wide range of heterogeneous conditions cause heart failure (see Figure 1.1), most of which result in left ventricular systolic dysfunction and reduced ejection fraction (Feldman et al., 2019). This is consistent with a recent ESC report on heart failure which indicates that more than 75% of all cases can be attributed to just three chronic conditions, namely ischaemic heart disease (26.5%), hypertensive heart disease (26.2%), and chronic obstructive pulmonary disease (COPD) (23.4%) (Bragazzi et al., 2021).

The aetiology of heart failure varies considerably by region and context (Dokainish et al., 2015, Virani et al., 2021, Ziaeian and Fonarow, 2016). Ischaemic heart disease (IHD) and COPD appear to be the most common aetiology in developed countries, particularly where heart failure is predominantly due to left ventricular dysfunction (myocardial infarction-induced LVD) and exacerbated by hypertension and diabetes mellitus (Ziaeian and Fonarow, 2016). On the other hand, low- to middle-income developing countries are primarily affected by hypertensive heart disease, rheumatic heart disease, cardiomyopathy, and myocarditis (Bragazzi et al., 2021, Virani et al., 2021, Ziaeian and Fonarow, 2016). The prevalence of hypertension is strongly associated with heart failure across all regions. Whereas the prevalence of IHD in heart failure is highest in European and North American countries, the prevalence of valvular and rheumatic heart disease is highest in Asian countries (Virani et al., 2021).

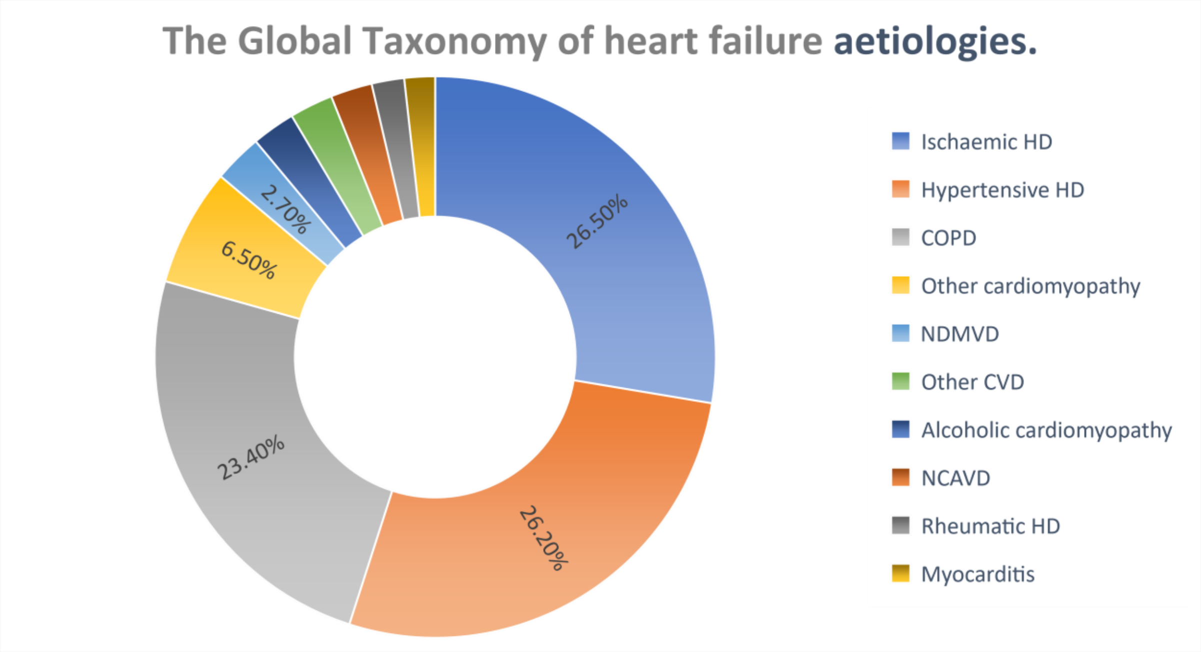

Figure 1.1: The heart failure global taxonomy of aetiologies

1.1.4 Demographic and clinical profiles of heart failure

The burden of heart failure is substantial, and this clinical syndrome is now the foremost cause of morbidity and mortality worldwide, and threatens to overwhelm global healthcare systems in the next 10 years (Benjamin et al., 2019). This clinical syndrome is expected to expand due to primarily population ageing, the presence of predisposing cardiovascular risk factors, inflammation, low socioeconomic status, and comorbidities (Conrad et al., 2018, Groenewegen et al., 2020). Lesyuk et al. (2018), confirmed the economic burden of HF and predicted the trend for rising costs to grow dramatically, based on cost-of-illness assessments between 2004 and 2016. Although heart failure survival rates have increased and then plateaued over the last decade, the overall patient prognosis remains poor, with over half of patients still dying within 5 years of heart failure diagnosis (Jhund et al., 2009, Taylor et al., 2019). More importantly, the incidence rate showed increasing incidence of HFpEF (Tsao et al., 2018). The point raised by Tsao and co-authors prompts the importance of studying HF phenotyping among diverse populations in order to gain a deeper understanding of HF demographic and clinical profiles.

Furthermore, years of life lost to heart failure are significantly higher than for the most common forms of cancer. Conrad et al. (2018) confirmed that non-cardiovascular causes of mortality reduce the rate of improvement in heart failure survival and mortality. For instance, cancer only was reported to cause 15% of deaths among people diagnosed with heart failure within 1 year, which is more likely to increase when patients progress to advanced stages (Conrad et al., 2018, Stewart et al., 2010). This will in turn put a strain on healthcare systems and lead to disproportionate morbidity and mortality, impaired quality of life, higher treatment costs, and limited treatment options, which is further explained in section 1.1.4.3 .

1.1.4.1 Prevalence of heart failure

Data from the Global Burden of Disease Study and other large-scale epidemiological studies show that the global epidemic is affecting more than 64 million people worldwide. Worryingly, all age groups are affected, with the prevalence increasing as the population ages. This rapidly growing healthcare problem affects approximately 2% of the population worldwide, rising to 13% in those over 80 years of age (GBD, 2018, Groenewegen et al., 2020, Virani et al., 2021, Virani et al., 2020). Several epidemiological studies have projected increases in the prevalence of heart failure. For example, in 2012, projections suggested a 46% rise in the prevalence of this condition between 2012 and 2030 (Heidenreich et al., 2013). However, most epidemiological studies have been conducted in European or North American countries, which represent only 15–20% of the global population and cardiovascular disease burden (Sliwa and Stewart, 2015, Yusuf et al., 2014).For instance, there are no population studies assessing HF prevalence and incidence in Northern Africa for any meaningful comparison. However, a growing body of literature supports the upward trends in cardiovascular-related mortality and morbidity, which are indicative of increasing HF prevalence and incidence (Guo et al., 2016, Gupta et al., 2016). Therefore, our understanding of heart failure burden is based on minority populations and high-income groups and the scarce literature published elsewhere (Groenewegen et al., 2020). Given the significant sociocultural and economic differences, the lack of studies in some low- and middle-income countries is a cause for concern.

The prevalence of heart failure varies considerably between studies. This can be partially explained by variation in heart failure definitions and diagnostic criteria, study designs and populations, and age groups, as well as the emergence of newly identified subgroups of heart failure, such as heart failure with preserved EF (HFpEF) and heart failure with mid-range ejection fraction (HFmrEF) (Bauersachs, 2021, Feldman et al., 2019, Groenewegen et al., 2020). For example, for the statistical year 2018–2019, heart failure had a prevalence of 0.9%, which corresponded to approximately 658,944 people in the UK (British Heart Foundation, 2020). However, in a population study of 4 million people in the UK, Conrad et al. (2018) found that the prevalence was 1.5%, whereas the British Heart Foundation (BHF) reported a prevalence of 0.7–0.8% over a relatively similar period (British Heart Foundation). Compared with the BHF data, the figures reported by other large-scale studies were up to twofold higher, confirming that there is widespread under-diagnosis of heart failure and underestimation of its true prevalence.

A limited number of community-based studies have described changes over time in the clinical epidemiology and outcomes of patients hospitalised with heart failure in the UK. For example, the MONICA study by McDonagh et al. (1997), which was the first prevalence study of heart failure, showed that 2.9% of patients had left ventricular systolic dysfunction. Davies et al. (2001) reported a similar figure, namely 2.3%, and Redfield et al. (2003) found a heart failure prevalence of 2.6%. In contrast, Bleumink et al. (2004) reported a prevalence in the range of 6–7%. The higher average age of this study population explained this finding, as those aged 85 years or above had a 17.4% prevalence rate, whereas the prevalence among the 55-64 years age group was 0.9%.

The high HF prevalence is highly economically significant, as reflected in the high associated healthcare costs, with a global economic burden for heart failure of around 108 billion US dollars annually. Of the global expenditures, more than two-thirds account for the cost of direct patient care (Lesyuk et al., 2018).

1.1.4.2 Incidence of heart failure

The incidence of heart failure, which is comparable with the prevalence, has been estimated from national registries and hospital records using number of episodes of hospitalisation, first and/or subsequent admission, and whether hospitalisation was primary or secondary to heart failure. (Jhund et al., 2009) analysed the heart failure data for 5.1 million people in Scotland during the period 1986–2003. Between 1986 and 1994, for men, the age-adjusted hospitalisation rate per 100,000 people increased from 124 to 162, and then gradually decreased in the second half of the study. However, the methodology utilised in this study had limitations, especially in relation to its diagnostic and coding criteria for heart failure. Nevertheless, the frequency and complexity of the hospitalisation data and the multiple changes that occurred within a short time period made it challenging to evaluate using other methods (Cowie et al., 2002). In the same vein, research conducted on other national registries, such as those in England (Blackledge et al., 2003), Sweden (Schaufelberger et al., 2004, Stewart et al., 2010), the Netherlands (Mosterd and Hoes, 2007), and the USA (Chen et al., 2011), reported a similar trend towards a decline in incidence rates. However, after scrutinising the dataset used by Chen et al. (2011), Dharmarajan et al. (2013) pointed out that 25% of the 1.3 million patients were readmitted to the hospital within 30 days, with only one third of admissions related primarily to heart failure.

Patient age is one of the main risk factors for developing heart failure. This observation has led to heart failure being overwhelmingly described as a syndrome of the elderly. Using the UK General Practice Research Database, a total of 20,528 individuals with an average age of 77 years were identified as having heart failure (29% definitive and 71% possible cases). The incidence was reported to be 9.3 per 1000 per year, to increase with age, and to be higher in men than in women (de Giuli et al., 2005). Data from the Continuous Morbidity Recording (CMR) database support the previous conclusions, but also detected a higher incidence in men aged 85 years or above, up to 22 per 1000 per year (Murphy et al., 2004). It is worth mentioning that the observed decline in heart failure incidence in recent decades can be largely attributed to advances in therapeutic management and a decline in the number of case fatalities, as reported by Smolina et al. (2012). However, the opposite situation was reported in a more recent UK-based population study, which found a 12% increase in newly diagnosed cases (Conrad et al., 2018).

While studies such as that by Gerber et al. (2015) demonstrated a substantial decline in heart failure incidence over a 10-year period (from 3.2 to 2.2 per 1000 person-years), others showed a slightly reduced but still high incidence, due to the sample consisting mainly of older adults. A study from Rotterdam recorded an incidence ranging from 1.4 per 1000 person-years up to 47.4 per 1000 person-years in individuals over 90 years of age (Bleumink et al., 2004). Similar trends were observed among a younger age population. Hillingdon Epidemiology study showed a much lower incidence, ranging from 0.02 per 1000 person-years in those aged 25–34 years to 11.6 per 1000 person-years in those aged over 85 years (Cowie et al., 1999).

Another comparison was made in two American population studies, namely the Framingham Heart Study by Levy et al. (2002) and the Rochester Epidemiology Project by Roger et al. (2004), which recorded incidence rates at different time points in order to capture any variation in incidence over time. The former study examined the results obtained during four separate periods that spanned a total period of 50 years, and found that the incidence rates remained steady in men, whereas there appeared to be a reduction of up to 40% in women (Levy et al., 2002). However, the Rochester Epidemiology Project in Minnesota reported a significant difference after 20 years of observation, with incidence rates 25% higher in men than in women, at 378 and 289 per 100,000 persons, respectively (Roger et al., 2004).

The higher incidence rate among adults aged 65 years or over was consistent with the above hypothesis. However, even though the heart failure burden primarily affects older adults, the syndrome is not solely restricted to older people. Recent reports have demonstrated links between obesity, heart failure, and cardiomyopathy among younger people (Andersson and Vasan, 2018, Basic et al., 2020). Furthermore, evidence from Sweden and Denmark shows a diverging trend with regard to the onset and incidence of heart failure, particularly among younger people (Barasa et al., 2013, Christiansen et al., 2017, Rosengren et al., 2016). For example, Barasa et al. (2013) explored the Swedish nationwide registries and identified ischaemic heart disease, cardiomyopathy, idiopathic heart failure, and congenital and valvular heart disease, with an incidence ranging from 5% to 18%, among patients aged 18–34 years with heart failure.

In summary, diverging trends in incidence are not uncommon. Therefore a change in the diagnostic criteria and demographic profile for heart failure will be warranted in order to keep pace with the observed increase among young populations. Even though the incidence of heart failure may stabilise globally, with decreases in high-income developed countries, it is increasing in lower- and middle-income countries. In North America and Europe, the rates are in the range of 1–9 cases per 1000 person-years (Groenewegen et al., 2020). However, these figures are affected by the study type (community or population based), the population investigated, and the criteria used to define and diagnose heart failure.

1.1.4.3 Morbidity (hospitalisations)

A significant consequence of heart failure syndrome is hospitalisation. Heart failure has become the most common diagnosis among inpatients aged over 65 years, and is associated with approximately 1–2% of the healthcare budget in most developed countries (Feldman et al., 2019). Symptoms and symptom exacerbations are the single most frequent cause of hospitalisation (Virani et al., 2021). As suggested by a systematic review of cost-of-illness studies, hospital admission is responsible for 44 to 96% of the overall direct costs for HF. Heart failure exacerbations are often followed by readmissions that require special care and management, both inpatient and outpatient (Lesyuk et al., 2018, Virani et al., 2021). The ultimate management goal is to prevent heart failure progression and rehospitalisation while reducing morbidity and mortality (Benjamin et al., 2019, Ponikowski et al., 2016). Similarly, the UK National Health Service (NHS) spends an estimated 2% of its total expenditure on heart failure management (Braunschweig et al., 2011, Donkor et al., 2016). More than two-thirds of this relates to the costs of frequent, prolonged, and repeat hospitalisations (Braunschweig et al., 2011, Donkor et al., 2016, Stewart et al., 2002). The British Heart Foundation’s Compendium of Statistics in 2020 reported that heart failure resulted in 101,938 hospital admissions and roughly 250,000 inpatient episodes related to heart failure in NHS hospitals, accounting for 12% of all episodes for patients with heart and circulatory disease (British Heart Foundation, 2020).

Analysis of the epidemiological data is crucial to better understanding this syndrome and decreasing the burden associated with it, as prevalence, incidence, and hospitalisations are interlinked. A knowledge of the incidence trends is essential if one is to predict, explain, and project hospitalisations of patients with heart failure. The above-mentioned study by Jhund et al. (2009) showed an increase in first hospitalisations for heart failure between 1986 and 1994, and then declined in parallel with advances in modern drug treatment for this condition. Relatively similar trends were observed across each geographic region examined, including the Netherlands (Mosterd et al., 2002), the USA (Chen et al., 2011), Sweden (Barasa et al., 2013), and Italy (Lorenzoni et al., 2018).

In contrast to the heart-failure-related hospitalisation trend, an increase in non-heart-failure-related events has been evident across regions. A substantial number of studies have identified clinical and sociodemographic factors associated with an increase in rehospitalisation of heart failure patients, including socioeconomic status, age, and comorbidities. Stewart et al. (2003) used the General Register Office for Scotland data to project heart failure burden, and concluded that heart-failure-associated admissions are projected to increase in the next two decades due to the ageing population and higher survival rates after myocardial infarction. Blackledge et al. (2003) confirmed that readmission rates per annum (both short and long term) surged after the age of 60 years. For the same reasons, the National Guideline Centre (2018) projected that these figures would rise by about 50% in the next 25 years.

In a large nationwide study conducted in the USA from 2005 to 2010, the Get With The Guidelines®-Heart Failure (GWTGHF) programme analysed 110,621 patients with heart failure from 275 hospitals. Heart failure was associated with a 6% increase in hospitalisation (from 33 to 39%) due to comorbidities, the most common of which were hypertension, kidney disease, coronary artery disease, and diabetes mellitus (Steinberg et al., 2012). Similarly, the Olmsted County study reported that two-thirds of rehospitalisations were non-cardiovascular related, and that the cardiovascular-related causes were linked primarily to increased numbers of patients with hypertension, atrial fibrillation, and diabetes (Gerber et al., 2015). This was clearly demonstrated in the ESC Pilot HF Survey, where the higher risk of mortality and hospitalisations was associated with diagnoses of diabetes, chronic kidney disease, and anaemia, as well as with the number of comorbidities. One conclusion that can be drawn from the heart failure incidence data is that even though the number of first hospitalisations with heart failure was falling, a rise in the number of readmissions was evident. Such a reduction in the number of patients with a primary diagnosis of heart failure in western countries does not necessarily reflect an actual decline in the heart failure burden. However, readmission rates appear to increase in patients with a secondary diagnosis of heart failure, which could reflect an ageing population with many non-cardiac comorbidities and disabilities.

With regard to hospital readmissions, Dunlay et al. (2009) assessed the hospitalisation frequency, causes, and risk factors for patients with heart failure. They found that virtually all patients were hospitalised once or more, and 43% were hospitalised four times. Non-cardiovascular events were responsible for more than half of the admissions during the study period. These findings are consistent with the results of more recent studies by Dharmarajan et al. (2013), Cheng et al. (2014), and Nichols et al. (2015), who reported that the vast majority of patients had at least one rehospitalisation in the year following diagnosis. All of these studies also pointed to admissions being comorbidity driven and often unrelated to heart failure. Patients with heart failure syndrome are reported to have the highest 30-day readmission rates of any diagnosis (20–25%), with at least 20% of patients or more being readmitted once within at least 30 days of discharge (Cheng et al., 2014, Jencks et al., 2009, Patil et al., 2019). It was noted that 44% and 62% of adverse events occurred within 6 months and 12 months, respectively, and that they were not primarily related to heart failure. Other studies went a step further and showed that not only age and comorbidities but also gender, race, and ethnicity have a specific association with rehospitalisation (Blackledge et al., 2003, Jencks et al., 2009, O’Connor et al., 2016, Patil et al., 2019). These factors have remained linked to a relatively higher risk of rehospitalisation in heart failure patients when adjusting for confounding factors. The relationship between gender and rehospitalisation rates in heart failure has been further debated in the literature. Some studies have shown no significant association (Giamouzis et al., 2011), while others have reported that female patients are more frequently hospitalised (Palazzuoli et al., 2019). Lawson et al. (2020) recently investigated 108,638 heart failure incidents in the UK using the General Practice Research Database (GPRD) linked to hospitalisations between 1998 and 2017. Age-adjusted rates were reported to be 28% higher in the first year in women regardless of the cause of admission. When readmitted, women were more likely to present with advanced heart failure, and had a higher comorbidity burden than men. Sociocultural and economic deprivation are associated with a greater risk of all-cause hospitalisation (Callender et al., 2014, Lawson et al., 2020). The 20-year population-based study used the English Index of Multiple Deprivation to measure patients' socioeconomic status. At baseline, the most deprived patients presented with heart failure at a mean age of 75 years, whereas the most affluent individuals presented at a mean age of 79 years. The most affluent individuals had slightly fewer comorbidities while the deprived groups showed an increase in comorbidity and in demand for healthcare resources, which remained valid after controlling for the year of diagnosis, ethnicity, and gender. The onset of heart failure was strongly associated with ethnic background, occurring nearly 7 years earlier in South Asian and black groups than in their white counterparts. In the UK, Gadoud et al. (2020) published a retrospective analysis for the period 2009–2014, which indicated an increase in the need for palliative care among patients with non-cancer conditions in primary care. However, throughout the study period, patients who lived in the most deprived areas tended to have more medical records than those from the least deprived areas (Gadoud et al., 2020). A US-based prospective observational multinational study (ASIAN-HF) found that 30-day rehospitalisation showed a strong positive association with low levels of language acculturation and foreign-born status among Asian patients with symptomatic heart failure living in the USA (Lam et al., 2013).

Overall, differences in the above-mentioned clinical and sociodemographic factors may at least partially explain the global discrepancies in heart failure epidemiology. Recent studies of the epidemiology and global burden of heart failure suggest a growing prevalence of aetiologies (e.g. hypertensive heart disease) due to population growth and ageing (Bragazzi et al., 2021, Roth et al., 2020). Unravelling the mechanism underlying this association remains challenging. First, such variables are not usually included in clinical trials or collected in heart failure registries. Second, the underlying mechanism is likely to be confounded by many personal and community-level factors. Third, previous empirical studies of sociocultural minorities (both indigenous and immigrant communities) ignored the effects of the broader context – that is, they emphasised the reductionist definition of culture in order to focus on ethnic identity or shared racial heritage. Consequently, efforts to identify these unmeasured factors and address these needs may provide insights that have the potential to greatly enhance outcomes such as survival, quality of life, and symptom burden in a diverse range of patients with heart failure.

1.1.5 Management strategies

Treatment strategies for heart failure have developed exponentially over recent years, and consist of evidence-based, multidisciplinary, patient-centred therapies that are tailored to the different subtypes of heart failure. Heart failure with reduced ejection fraction has the most well-proven therapeutic prospects. In this thesis, the therapeutic options for heart failure are discussed briefly, focusing on patients who progress to the advanced stages of the condition. Although advanced heart failure is incurable, individualised treatments are available that aim to optimise health, functionality, and quality of life, reduce exacerbations, delay disease progression, and address comorbidities and complications. In 2018 the ESC issued a position statement in which it revised and updated the definition of and criteria for diagnosis and treatment of advanced heart failure (Crespo-Leiro. et al., 2018).

Although some of the guideline-directed approaches and pharmacological management have proved to be effective in relieving symptoms and improving the course of heart failure, some patients may still benefit from palliative care management programmes, or from approaches such as mechanical circulatory support (MCS). However, determining the best therapeutic strategy for patients with advanced heart failure remains challenging, and carries the risk of being ineffective or causing high-risk adverse events. The MCS in the form of left ventricular assist device (LVAD) therapy has been shown to be safe, extends survival, and has a positive impact on health-related quality of life (HRQOL) for patients with advanced heart failure if their condition is associated with left ventricular systolic dysfunction or failure (Ponikowski et al., 2016). However, the presence of comorbidities, such as severe right ventricular dysfunction, limits its use (Gustafsson and Rogers, 2017). A prospective observational study showed improvement in the 1-year survival rate, the 6-minute walk test (6MWT), and functional capacity, and a decrease in rehospitalisations and adverse events (Estep et al., 2015). Analysis of the REVIVAL registry suggested that non-cardiac comorbidities other than depression did not prevent gains in health-related quality of life from LVAD support (Cascino et al., 2020). Recent reports indicate that MCS therapy prolongs survival in patients with advanced heart failure. However, current evidence of the morbidity and mortality associated with these devices (including bleeding, the risk of stroke, and infectious complications) remains a concern both for patients and for healthcare providers (Jefferson et al., 2021). Determining the best therapeutic strategy for individual patients with advanced heart failure remains challenging. The use of MCS is associated with a high risk of adverse events, including device failure, infections, and thromboembolic and haemorrhagic events, and our understanding of the reasons for this association are still incomplete (Mehra et al., 2018, Mehra et al., 2016). Moreover, it cannot be assumed that earlier LVAD implantation will improve survival compared with continued medical therapy with the option of LVAD implantation when clinical deterioration occurs (Jefferson et al., 2021, Stehlik et al., 2020). Heart transplantation remains the optimum treatment for refractory cardiac failure. However, the clinical applicability of transplantation is limited by the fact that it is costly, relies on the availability of donors, and excludes poor candidates, given their comorbidities (Metra et al., 2019).

1.1.6 Palliative and end-of-life care

As noted previously, conventional treatments, including device and pharmacological therapies, are not effective as stand-alone options for alleviating the refractory symptoms and perhaps improving the clinical course of patients during the advanced stages of heart failure (Metra et al., 2019). These two challenges remain obstacles to better quality of life for patients with advanced heart failure. Palliative care remains the only appropriate form of care for addressing these challenges. Therefore the early initiation and integration of palliative care throughout heart failure, and not merely as an alternative option in the event of treatment failure, is of vital importance (Campbell et al., 2018, Crespo-Leiro. et al., 2018).

Palliative care must be introduced as early as possible, before patients reach the end of the heart failure pathway, as deciding whether a patient is at the end stage of this condition can be challenging (Sahlollbey et al., 2020, Sobanski et al., 2019). It is essential to rule out all reversible causes of heart failure in these patients, and to ensure that medical therapy has been optimised and any alternative treatment options have been explored. Care planning should be introduced as early as possible, before or as part of the palliative care referral. It is well established that advance care planning can improve both quality of life and patient satisfaction with end-of-life care (Schichtel et al., 2020). Palliative care enhances end-of-life care planning by addressing the management of symptoms and the supportive needs of patients and their families. A clear and shared understanding of the treatment goals necessitates effective communication between the patient, family members, and healthcare professionals. Effective palliative care typically requires multidisciplinary involvement, including cardiologists, heart failure nurses, palliative care physicians and palliative care nurses, and general practitioners (McIlvennan and Allen, 2016). The benefits of palliative care for heart failure patients are well established, yet the provision of palliative care is often suboptimal (Sahlollbey et al., 2020).

Over the past decade, there has been a significant increase in the number of patients with advanced heart failure. Improvements in medical management, procedural interventions, and life expectancy may have lowered the risk of death and improved survival rates. As a result, there is a growing need for end-of-life care for patients with advanced heart failure (Rogers et al., 2017). There has been a clear shift in the treatment paradigm from improving survival outcomes to optimising symptoms and quality of life, with the incorporation of discussions of goals of care and patients' assessment of their needs alongside conventional management (Diamant et al., 2020, Maciver and Ross, 2018). There is mounting evidence of considerable gains in symptom control and quality of life when such approaches are adopted. Therefore it is crucial to ensure that patients, their family members, and healthcare providers are made fully aware of these options (Steinberg et al., 2017). Such knowledge may allow navigation of the collaborative paradigm of care between cardiology and palliative care when treating patients with advanced heart failure. Advance care planning (ACP) is a valuable aspect of palliative care which ensures that the patient's future care is consistent with agreed care goals and values. Recently, several systematic reviews and meta-analyses of ACP studies and trials in patients with heart failure found that ACP was associated with improvement in quality of life, relief of burdensome symptoms, a reduction in the frequency of hospitalisation, and improvement in palliative care referral and access, care preferences and communication at the end of life (Kernick et al., 2018, Nishikawa et al., 2020, Schichtel et al., 2020, Williams et al., 2020). However, some authors have argued that patients' knowledge and awareness of care options, and healthcare providers' responsiveness to patient preferences and values, are unlikely to result in an increased understanding of heart failure or better engagement with end-of-life discussions unless the context, such as the consequences of taking part in ACP, are taken into account (Im et al., 2019).

1.2 Palliative care

The definition of palliative care evolved from the hospice movement and has now become an essential component of optimal healthcare that should be integrated into routine care as early as possible. Cicely Saunders was the first to orient healthcare practice towards the need to address suffering and palliation of symptoms with specific solutions in terminal and end-of-life settings. This approach was subsequently advocated by many national and international organisations and policies, including the World Health Organization (WHO) (Saunders et al., 1995, World Health Organisation, 2002).

1.2.1 What is palliative care?

The World Health Organisation (1990) has defined palliative care and its guiding principles as 'active total care' that targets patients who are 'irresponsive to curative treatment' and their families, aiming for the best possible quality of life. However, the Lancet Commission on Global Access to Palliative Care and Pain Relief suggested that the current definition should be updated to reflect contemporary clinical and scientific evidence and also be relevant to low-income and resource-limited countries (Knaul et al., 2018). Later, the WHO revised its definition to emphasise the now most widely endorsed team-oriented approach (see Table 1.1) (World Health Organisation, 2002). The definition of the target population was also broadened, and the emphasis on patients who did not respond to curative treatment was replaced with a focus on problems 'associated with life-threatening illness.' These changes highlight the importance of early involvement of palliative care, both to prevent and relieve patients' suffering, and they indicate a growing recognition of the advantages of palliative care in life-limiting illnesses.

Over the past decades, palliative care has gained international momentum and broader support. It has been declared a fundamental human right and essential care provision by international organisations, including the World Health Organization, the Worldwide Palliative Care Alliance (WPCA), and Human Rights Watch (World Health Organization, 2014). Some clarifications were necessary to make the revised definitions understandable and operational (Gwyther and Krakauer, 2009, Gwyther and Krakauer, 2013). As a result, experts have questioned the intended meaning for which the definition is applicable across geopolitical, cultural, and economic settings. The emphasis was on the multiple cultures and norms enshrined in local communities that affect the delivery of palliative care, rather than on the possibility that patients' cultural and social contexts, including their beliefs and values, could present obstacles in different settings. It is suggested that healthcare professionals need to be aware of these factors in order to avoid causing distress to the patients who are receiving care, or their families.

Although the WHO definition had been widely accepted, they described it as lacking in clarity, and they concluded that its ambiguity could generate more confusion and uncertainty among clinicians with regard to identifying patients with palliative care needs. However, these reviewers did not suggest how this challenge might be overcome in terms of practice, policy, or research. The critiques continued to highlight the uncertainty of the definition, and how this was an obstacle to the implementation and integration of palliative care interventions (Ferrell et al., 2017).

All this uncertainty led the leading palliative care organisations to recognise the need to develop unambiguous evidence- and consensus-based definitions that would improve quality of care. The International Association for Hospice and Palliative Care (IAHPC) developed a global definition (IAHPC, 2018) based upon the Lancet Commission's recommendation in 2018 for potential endorsement by the WHO (Knaul et al., 2018). The IAHPC surveyed members from 88 countries in order to identify how palliative care is defined (active, holistic care rather than an approach to care), and when, where, for whom and by whom care should be provided. The resulting global definition described palliative care as active, holistic care provided for people with health-related severe suffering because of severe illness, particularly towards the end of the illness pathway. This new definition aimed to improve quality of life and relieve the suffering of patients, their families, and their carers by triggering a more timely referral of all patients who need care, regardless of their age, diagnosis, prognosis, country/region, or income (IAHPC, 2018, Radbruch et al., 2020). Furthermore, generalists can provide palliative care. This includes any clinician involved in managing life-limiting illness who has basic training, or palliative care specialists within a multidisciplinary team, depending on the complexity of the patient's needs. The needs of patients with a progressive disease such as heart failure, and their families, should be addressed from the early stages right up until death, and during bereavement. The WHO and IAHPC care definitions are compared in Table 1.1.

Table 1.1: Palliative care definitions: WHO (2002) vs IAHPC (2018).

	WHO definition proposed in 2002	**IAHPC definition proposed in 2018**
What is palliative care?	An approach to improving quality of life.	Active, holistic care.
Who is eligible for palliative care?	Patients and their families facing the problems associated with a life-threatening illness.	Individuals across all ages with serious health-related suffering due to severe illness, especially those near the end of life, their families, and caregivers.
What are the aims of palliative care?	Prevention and relief of pain, suffering, distressing symptoms, and other physical, psychosocial, and spiritual problems.	Prevention, early identification, and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress, and social needs.
How does palliative care see the trajectory towards death?	It will enhance quality of life and may positively affect the course of illness. It affirms life and regards dying as a normal process. It intends neither to hasten nor to postpone death.	It will enhance quality of life and may positively influence the course of illness. It intends neither to hasten nor to postpone death, it affirms life, and it recognises dying as a natural process.
How are the aims of palliative care achieved?	By means of prevention, early detection and impeccable assessment and treatment of suffering. It integrates the psychological and spiritual aspects of patient care. It offers a support system to help patients live as actively as possible until death, and families	Through the prevention and relief of suffering by means of early identification, comprehensive assessment, care planning, and management of holistic needs. It provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families to determine the goals of care.

	to cope during the patient's illness and in their own bereavement.	It provides support to the family and the caregivers during the patient's illness, and in their own bereavement.
When is palliative care offered?	Early in the course of illness, in conjunction with other therapies that are intended to prolong life. When investigations are needed to better understand and manage distressing clinical complications.	Throughout the course of an illness, according to the patient's needs. It is provided in conjunction with disease-modifying therapies whenever needed. It is delivered recognising and respecting the cultural values and beliefs of the patient and their family.
Who provides palliative care?	It uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated.	It depends on the complexity of cases. It can be provided by generalists (HCP with basic palliative care training). Specialist palliative care involving a multidisciplinary team is required for referral of complex cases.
Where is palliative care provided?		It is applicable throughout all healthcare settings (whether in the patient's place of residence or in institutions) and at all levels (primary, secondary, and tertiary).

WHO, World Health Organization; IAHPC: International Association for Hospice and Palliative Care.

Based on the IAHPC definition, palliative care can be provided across all settings (inpatient, outpatient, and community services) and care levels (primary, secondary, and tertiary). It is also appropriate throughout the illness trajectory, solely or in conjunction with disease-modifying treatment based on the patient's needs, values, and preferences, and is interdisciplinary to ensure optimal holistic and individualised care (Radbruch et al., 2020). This definition clearly distinguishes palliative care from hospice and end-of-life care. Hospice care, defined as caring for and treating people with distressing symptoms near the end of life with end-of-life care, represents a small subset of palliative care. However, another viewpoint is that the terms *palliative care* and *hospice* differ remarkably in the US (Chapman and Bass, 2000). While the terms are often used interchangeably across Europe, the term *hospice* means a hospital in some Latin languages or an inpatient unit, the US-based model refers to *hospice* as a home care programme and *palliative care* as a hospital-based service (Higginson, 2018, Remington and Wakim, 2010). Beyond variations in terminology, differences also exist concerning the provision of service. In the United States, hospice care services are separate to palliative care, primarily provided at home, exclusive for terminally ill people with less than six months of life expectancy and have financial implications (Chapman and Bass, 2000, Remington and Wakim, 2010).

Even the consensus-based IAHPC definition has failed to gain support from some of the palliative care organisations. Some organisations decided not to endorse the revised definition, despite their criticisms of the WHO definition (Bauersachs, 2021, Macauley, 2019, Ryan et al., 2020). They opposed the suggestion that the term 'life-limiting' should be replaced by a broader one and considered that alternative terms such as 'severe' were too negative in their meaning and denoted unpleasant emotions.

Due to the existence of multiple definitions, there has been considerable confusion about the meaning of palliative care among healthcare professionals, patients, and families. From a service provider's point of view, despite the repeated references to needs assessment in the clinical guidelines, there is no consensus about which criteria need to be comprehensively assessed. Thus, for example, the need for assessment of cultural needs is identified by some but not all definitions, which could explain why patients who are receiving palliative care report higher rates of unmet needs (Anderson et al., 2018, Goni-Fuste et al., 2021). Again from the service user's point of view, a practical approach to good-quality palliative care demands that all definitions use terms that are understandable. The public understanding and readiness to receive palliative care are valid methods for identifying palliative care patients and needs.

1.2.2 Palliative care in advanced heart failure

Over the past decade, palliative care has extended beyond cancer and has been integrated into routine care for patients with other life-limiting conditions, including heart failure (Klinedinst et al., 2019). Despite recent advances in cardiac treatment, heart failure outcomes remain poor. Following a heart failure diagnosis, 1–10% of patients progress to the advanced stages of heart failure, and of these individuals, around 80% die within less than five years (Bjork et al., 2016). End-stage or advanced heart failure is prevalent among older adults and typically results in lower quality of life, a severe symptom burden, frequent hospitalisations, and a high mortality risk (Sobanski et al., 2019).

Heart failure has an unpredictable and variable trajectory with acute episodes of exacerbation (Sobanski et al., 2019). The uncertain prognosis of heart failure is often complex and more challenging than for patients with other life-limiting illnesses (McIlvennan and Allen, 2016). Stewart et al. (2001) described heart failure as 'more malignant than cancer' given the poor prognosis and survival rates, which are often worse than those for cancer. Mounting evidence and numerous clinical guidelines highlight the fact that patients with heart failure and their families can benefit from a palliative approach to their care (Bekelman and Allen, 2018, Hill et al., 2020, Kavalieratos et al., 2017, Riley and Beattie, 2017, Rogers et al., 2017, Sahlollbey et al., 2020, Sobanski et al., 2019). However, there is little empirical evidence available with regard to the implementation of palliative care in cardiology. Clinical guidelines and consensus papers published by the ESC, AHA, and EAPC advise the inclusion of palliative care alongside specialist-level, life-prolonging management of heart failure (Hill et al., 2020, Jaarsma et al., 2009, Sobanski et al., 2019, Yancy et al., 2017). However, best practice for integrating palliative care into heart failure management in parallel with standard medical treatment has not been thoroughly investigated (Kavalieratos et al., 2017). To date, rather than evidence, expert opinion-based consensus in the form of position statements and recommendations has been presented. Some authors, such as Hill et al. (2020), have attempted to guide the integration of palliative care into heart failure care by a synthesis of the currently available evidence. The review-based ESC position paper is well presented, but does not indicate how the review was performed or on which data it was based. It would also be helpful to know whether the quality of the evidence was checked.

In 2009, the Heart Failure Association of the ESC outlined the first position statement on palliative care for patients with heart failure (Jaarsma et al., 2009). This was a definite step towards integrating palliative care into the mainstream care of patients with advanced heart failure even when death is not imminent. Palliative care has been included in the ESC guidelines on heart failure ever since. However, despite the recommendations, only a handful of countries across Europe have designated heart failure units according to the *EAPC Atlas of Palliative Care in Europe 2019* (Arias-Casais et al., 2019), and just eight European countries have successfully integrated palliative care with conventional, life-prolonging cardiology services (Seferović et al., 2020). On the other hand, fewer patients with heart failure access the service globally, both within the UK and across Europe.

1.2.2.1 Systematic reviews and meta-analysis of the literature

A recent systematic review of RCTs by Sahlollbey et al. (2020) demonstrated a considerable reduction in hospital readmissions and a modest but significant improvement in symptoms and quality of life for patients receiving a palliative care intervention compared with those receiving usual care. However, the impact of these interventions was found to vary in terms of content, intensity, and intervention provider. The study was criticised for its lack of clarity about survival rates, quality of life, and symptom burden, and its findings were discouraging from the patient’s point of view (Jaarsma et al., 2020). Diop et al. (2017) published a systematic review and meta-analysis to identify the palliative care interventions available to patients with advanced heart failure. Of the 15 studies that were reviewed, eight were RCTs, two were prospective cohort studies, and five were retrospective controlled studies. The sample consisted predominantly of outpatients who were living at home with caregivers, and the review concluded that home-based palliative care interventions in conjunction with heart failure management improved patient-centred care outcomes. Patient quality of life, satisfaction, and symptoms showed a notable improvement, with more patients documenting their care preferences. A meta-analysis of three studies reported a 42% reduction in rehospitalisation risk for patients with heart failure (Diop et al., 2016, Diop et al., 2017). However, that study has serious methodological drawbacks that limit the reproducibility and interpretation of its findings. For instance, critical decisions were neither described nor justified, and the use of operational palliative care definitions compromises the rigour of a systematic review. The authors did not describe their population and inclusion criteria in detail and failed to provide structured criteria to support their inclusion decisions (NYHA class) and ensure comparability between studies. The search strategy for this review was string-based and was applied only on PubMed, which is likely to compromise the search sensitivity and increase the risk of a biased outcome that may not accurately represent the available literature (Tacconelli, 2010). The lack of formal methodological quality assessment limits the significance of the findings. Therefore the findings should not challenge the substantial evidence supporting the benefits of palliative care in heart failure. However, the evidence relating to rehospitalisation risk reduction should be further investigated in a real population of patients with advanced heart failure.

Datla et al. (2019) analysed the literature for the period from 1995 to 2017 and reached a similar conclusion regarding the trend towards improved patient-reported outcomes, and a reduction in the numbers of hospitalisations and readmissions. They attempted to address palliative care benefits in heart failure through a systematic review. This review demonstrated the effectiveness of the combined approach to research, namely multidisciplinary palliative care interventions with usual heart failure management. A meta-analysis was not feasible due to the heterogeneity among the studies, and the review findings were also inconsistent due to the methodological and clinical heterogeneity among studies. The review included 23 articles, and the authors pointed out that it was not designed to capture all of the relevant literature on palliative care in advanced heart failure. The RCT studies accounted for eight of the 23 primary studies, with some suffering from contamination of the control group, low intervention dose, or early discontinuation, and patients ‘crossed over’ to receive the intervention. In addition, 70% of the studies were US based, which limits the generalisability of the findings. Finally, Zhou and Mao (2019) performed a systematic review and meta-analysis of seven RCTs published between 2008 and 2017. Their review analysed the physical and psychological sequelae of a heart failure diagnosis and the usefulness of palliative care in mixed-stage heart failure trials. The primary outcome was mortality. Compared with the control group, palliative care was significantly associated with better quality-of-life scores and less severe depression. In contrast, mortality and rehospitalisation rates differed among the patients in both groups.

1.2.2.2 Randomised controlled trials of palliative care for heart failure

A handful of randomised control studies (RCTs) have trialled the use of palliative care in patients with advanced heart failure. They include Palliative Care in Heart Failure (PAL-HF), Collaborative Care to Alleviate Symptoms and Adjust to Illness in Chronic Heart Failure (CASA), Social Worker-Aided Palliative Care Intervention in High-Risk Patients with Heart Failure (SWAP-HF), Working to Improve diScussions about DefibrillatOr Management (WISDOM), and Educate, Nurture, Advise, Before Life Ends Comprehensive Heartcare for Patients and Caregivers (ENABLE-CHF-PC). These trials reported that structured palliative care interventions could improve quality of life, depression, anxiety, understanding of prognosis, and wellbeing in patients with heart failure. However, there is no evidence of a reduction in mortality and hospitalisation risk in patients with advanced heart failure.

The PAL-HF trial was a randomised, unblinded, single-centre trial involving 150 patients with adequate sample size and gender representation. The trial by showed that participants who received an multidisciplinary nurse-led intervention, 6 months of palliative care, and optimal cardiological treatment exhibited significant improvements in heart-failure-related and overall HRQOL, anxiety, depression, and overall wellbeing, based on well-established and validated patient outcome measures (Rogers et al., 2017). Even though the trial by Rogers et al. (2017) is deemed to be the most rigorous and clinically relevant with low-moderate risk of bias, the trial was criticised for the concealing the age range of the patient group, high attrition and loss to follow-up, and selection bias, as participants were recruited from the established HF program.

In the SWAP-HF trial an experienced social worker initiated structured discussions about the goals of care. Despite the fact the study started in hospital and ended in the outpatient setting, there were twice as many documented advance care preferences and better prognostic understanding at six months among the participants in the intervention group compared with those in the control group. Most patients who survived beyond six months better understood their prognosis but no improvements were observed in quality of life scores, depression, or anxiety (O'Donnell et al., 2018). The trial was criticised for the small sample size, unclear diagnostic criteria, and the exclusion of potentially eligible participants. For example, patients referred to hospice or for cardiac transplantation. Additionally, participants age range and duration of follow-up were not reported for either arm of the trial, but the mean age was mentioned.

The CASA trial was a multisite RCT investigated the impact of focused symptom and psychosocial interventions on the outcome of patients living with advanced heart failure. Bekelman et al. (2018) utilised a collaborative intervention that included a combination of support, telephone calls, and visits. Patients in the intervention group were jointly managed by a multidisciplinary team, a nurse, a cardiologist, a specialist in palliative care, a general practitioner, and a social worker. It was found that patients in the intervention arm of the trial had significantly reduced symptoms of depression, pain, fatigue, and better adaptation to HF. However, heart-failure-related health status and quality of life were similar between groups (Bekelman et al., 2018). Compared to the PAL-HF trial, CASA trial participants were not gender balanced as only 21.3% were female and the HF-specific health status was lower in the control group which may indicate that the trial was underpowered to detect any difference. Another limitation was that the duration for CASA interventions was not explicitly stated.

In 2019, Goldstein et al. conducted a six-centre, cluster-randomised, controlled, blinded trial. The WISDOM trial demonstrated the benefits of a clinician-based multicomponent communication training intervention. The training session on advance care planning improved engagement in discussions about the goals of care and implantable cardioverter defibrillator (ICD) deactivation for patients who were ineligible for advanced therapies. However, there was no detectable increase in deactivation decisions (Goldstein et al., 2019). Indeed, these findings do not suggest that the interventions fail to preclude hospital admissions or death, but rather they highlight potential pitfalls that future researchers need to avoid. These pitfalls and the intervention effects may be confounded by the small sample size, above-average attrition rate, remarkable gender imbalance and single-centred nature of the study. In addition to the limited generalisability of the results, heart failure phenotypes such as end-stage diastolic heart failure, for which there are few proven therapeutic options, may confound the outcome.

The ENABLE-CHF-PC trial is a nurse-led, telehealth psychoeducational intervention. To date, this is the largest and most racially diverse RCT. Participants in the two arms of the trial did not show differences in quality of life or mood. However, the secondary outcomes, such as pain intensity and interference showed improvement in the intervention arm over a period of 16 weeks (Bakitas et al., 2020). The study sample, which predominantly consisted of patients with advanced heart failure (99.5%), may explain these inconclusive findings. The proportion of people with advanced heart failure was 75% in PAL-HF and 47% in CASA. The high baseline scores in the ENABLE-CHF-PC trial reflect a fairly good quality of life (KCCQ score of 52.6) and high functional status (FACIT-Pal score of 36.4), which could also have contributed to the findings. It is worth mentioning that baseline quality of life scores were also higher than in the PAL-HF and CASA trials, for which the KCCQ scores were 33.7 and 47, respectively. However, a clear and meaningful benefit was observed after sensitivity analysis for patients with relatively poor quality of life. The authors suggested that this lack of intervention effect was a possible ‘ceiling effect’ in the light of previous ENABLE trials conducted with cancer patients. They argued that the high non-completion rates and non-compliance among participants (only 50% could attend palliative care consultations) made it more difficult to demonstrate positive outcomes. However, another explanation may be the unique obstacles that are encountered, and conflicting cultural values and preferences, as reported in earlier work by Rhodes et al. (2015).

Dionne-Odom et al. (2020) offered the same explanation to account for the lack of positive outcomes in their ENABLE-CHF-PC trial aimed at family caregivers of patients living with advanced heart failure. These authors speculated that the observed family caregivers were not distressed and had good quality of life, so there was no scope for the telehealth programme to improve the score further. However, the trial group did not attend to the contextual and situational differences when aimed at a diverse and symptomatic population aged 50 years or over. Sociocultural understanding and knowledge of heart failure syndrome, cultural perspectives when reporting symptoms, and the perception of 'non-traditional' health technology and contextual aspects of the delivery of their telehealth programme were not considered. Since they explained their inconclusive results in terms of either ceiling or ground effects, it is strongly recommended that the trial applies participant stratification techniques to identify and then target the groups with most complex needs, who might benefit more from the palliative care intervention. Indeed, the acceptability, feasibility, and effectiveness of any culturally based palliative care intervention need to be tested rigorously in order to identify research gaps.

1.2.3 Disparities in access to palliative care for heart failure

Despite the available recommendations and guidelines for integrating palliative care into mainstream care for patients with heart failure, the proportion of patients with heart failure who access palliative care services is repeatedly reported to be low. In Scotland, a retrospective review of nine GP practices analysed the data for all patients who died during a one-year period (Zheng et al., 2013). Only 19% of patients with organ failure were referred for palliative care, and less than 50% were referred to specialist palliative care. In comparison, patients with cancer represented 75% of general referrals and 69% of specialist referrals (Zheng et al., 2013). The result was consistent with the findings of a previous study, which reported that less than 20% of the patients on the palliative care register had non-cancerous conditions. The authors concluded that the current palliative care framework is not applicable to other conditions (Harrison et al., 2012).

In 2014, Gadoud et al. led an initiative to review the largest primary care database, the Clinical Practice Research Datalink (CPRD). The group evaluated the English registry looking for disparities in palliative care for heart failure compared with cancer. Patients with heart failure represented only 7% of the registry, compared with 48% of oncology patients at the end of life. During the last week of life, patients with heart failure and cancer had their palliative care needs recognised by 30% and 8%, respectively. In contrast to the situation for patients with heart failure, the findings suggest that providers are more willing to refer oncology patients. By using the primary care registry database, Gadoud and colleagues had access to an impressively large sample of 27,689 patients with either cancer or heart failure, who died in 2009. There is no doubt that their findings provide meaningful insights, but these data sources are not without limitations. The data are over 10 years old and represent only a tiny proportion of general practices in the UK, making it challenging to draw conclusions and modify services accordingly.

The UK's National Heart Failure Audit data for the period from 2013 to 2014 also demonstrated that heart failure was the reason for around 43,000 hospital admissions. The patients were mainly symptomatic (79% were NYHA category III/IV), with a median age of 80 years. Overall, these patients were a high-risk group, with a 30-day mortality risk of 15% and a 1-year mortality risk of 25%. However, despite their high-risk profiles, only 4% of patients were referred to palliative care services (Cleland et al., 2015). Similar referral rates were reported in the USA using the National Inpatient Sample (NIS) database. Patel et al. (2019) identified 621,947 episodes of hospitalisation for patients with a primary diagnosis of acute heart failure between 2010 and 2014. The results showed that only 3.6% of eligible heart failure cases were referred to palliative care services, with an upward trend from 2.0% to 3.6% during the study period. However, using the same NIS database, Alqahtani et al. (2019) reported that 939,680 patients with heart failure were hospitalised over a 12-year period (2003-2014). The authors confirmed the upward trend in access rates, from 0.12% in 2003 to 3.6% in 2014. This trend still increased over time after adjusting for baseline demographics and comorbidities. The data suggested that increasing access to palliative care services was associated with a longer duration of stay and higher hospitalisation costs than was the case for patients who did not access these services. For similar reasons, Khan et al. (2021) published their study of an extended NIS cohort (2002–2017), looking for palliative care consultation trends for patients admitted to hospital with decompensated heart failure. They investigated whether factors such as race and gender have an impact on engagement with palliative care services. The study confirmed an upward trend to around 6.2% in 2017, and demonstrated low utilisation rates among racial and ethnic minorities.

Mandawat et al. (2016) conducted a cross-sectional analysis of data from the Veteran Affairs External Peer Review Program (2007–2013). This study identified 4474 patients with advanced heart failure, and is considered to be one of the largest studies of this kind to assess palliative care access 1 year after hospitalisation due to heart failure. During the 7-year period, 7.6% of the patients had their palliative needs recognised, at a mean age of 83.6 years, with an in-hospital mortality rate of 72.8%. Similar rates were observed for patients with COPD and heart failure, but all of these rates were lower than for cancer patients. However, these results are not generalisable, as the study sample consisted predominantly of male US veterans. It is worth noting that the US findings represent selective and late access to palliative care, resulting in more sudden deaths and more in-hospital deaths. While the reported rate of palliative care utilisation increased, it remains low compared with the UK and some other high-income countries.

In the UK, The National Confidential Enquiry into Patient Outcome and Death (2018) recently identified a disparity in access for patients who died during hospitalisation for acute decompensated heart failure in 2016, 12% of whom had previously accessed palliative care. Another UK population-based retrospective cohort study using the CPRD and hospital episodes statistics for the period 2009–2014 was conducted by Gadoud et al. (2020), looking for potential changes in palliative care provision for non-cancer conditions, including heart failure. These records represent 7% of the entire population of the UK (Herrett et al., 2015). During the time period covered by the study, the estimated UK population was on average 63.5 million; therefore the database includes half a million citizens (Office for National Statistics, 2021). In total, 47,473 adult deaths were recorded and included in the analysis by Gadoud et al. (2020). Compared with the earlier work by the same team, there appears to have been an increase in recognition of palliative care needs in heart failure, enabling higher levels of access in an efficient and timely manner. The proportion of palliative care recordings in heart failure increased from 12.6% in the first study year to 15%

in the second year and 21.2% in the final year, but remained substantially lower than the corresponding figures for cancer (57.6%, 60.6%, and 61.9%, respectively). The median course of palliative care treatment has considerably improved for patients with dementia and COPD, but not for those with heart failure. Compared with the median days in year one (168.5), the duration shortened by 32% (104 days) in year two and 9% (153 days) in the final year.

1.2.4 Barriers to palliative care utilisation in heart failure

In the UK, the year 2000 represented crucial reforms in heart failure, particularly in relation to the advanced stages of the condition (Department of Health, 2000). The NHS recognised heart failure patients' palliative care needs and published the National Service Framework for Coronary Heart Disease. This policy described as a radical shift in UK health policies away from the traditional paradigm and towards the availability of palliative services for all, regardless of the diagnosis, and based on each patient's needs and conditions (Addington-Hall and Gibbs, 2000). In 2004, the National Institute for Health and Clinical Excellence (NICE) issued guidelines to standardise the palliative and supportive care, and advised that there was a need for high-level communication skills and strategies to support patients and their families (NICE, 2004). There was no standardised and independent strategy for palliative care in heart failure until the NHS introduced a strategy for end-of-life care, which was referred to as the 'End of Life Care Pathway' (Department of Health, 2008). This strategy is regarded as an essential milestone in progress towards enhanced access to palliative care and expanding specialist services. Since then, there has been an expansion in palliative care literature demonstrating better recognition of palliative care needs and access for patients with heart failure for example, Stewart and McMurray (2002) and Rogers et al. (2017).

Despite the benefits of palliative care in advanced heart failure, looking at the history reveals several potential challenges. The new 'Pathway' is based on guidance and experience from palliative care services for cancer patients. The lack of practical heart-failure-specific strategies may itself be a barrier to patients accessing services. The current practice for palliative care referral is predominantly based on cancer prognosis, given the fact that advanced HF has a fluctuating trajectory. In addition, it is noticeable that the transition from guidelines to implementation is challenging and encounters difficulties in delivery and barriers to access.

1.2.4.1 The disparity stems from the fluctuating trajectory

Numerous barriers have been identified that hinder access to palliative care for patients with advanced heart failure. A literature search has highlighted the multifactorial nature of the problem. Barriers to palliative care access are related to the syndrome, the patient and their family, the provider, and the system (Klinedinst et al., 2019). The trajectory in heart failure is highly unpredictable and uncertain, and has been termed 'prognostic paralysis' (Stewart and McMurray, 2002). Prognostication in heart failure is the most commonly cited barrier to offering palliative care to patients with heart failure. It is also often a reason for referring patients to palliative care services during the refractory stages of heart failure, when survival rates are very low, and its effectiveness may be limited (Rogers et al., 2017). This unpredictability and prognostic uncertainty continues into the advanced stages of heart failure, when palliative care needs are a vital component of overall management (Gadoud et al., 2013, Hogg and Jenkins, 2012). A recent narrative review of palliative care access in heart failure identified poor prognosis as another barrier to early utilisation of care. The author suggested that the current unreliable criteria for prognostication and the lack of clinically validated models are reasons for the current failure to integrate palliative care into mainstream heart failure care (Romano, 2020). In addition, identifying patients in the final year of life has become a routine clinical service (Haga et al., 2012). The Gold Standards Framework Prognostic Indicator Guide (Haga et al., 2012) and the Supportive and Palliative Care Indicators Tool (SPICT) were developed to overcome such challenges (Highet et al., 2014). SPICT is a tool developed as an initiative by the Scottish government in 2012 to address barriers to palliative care access. A collaborative project aims to augment clinical judgement and provide insights on eligibility for specialist palliative care. Despite the recommendations, the use of these tools to identify patients in their last year of life is still problematic, given the fact that the appropriateness of the use of prognostication tools in heart failure is still disputed, with no evidence for either their accuracy or a strong correlation with palliative care needs (Haga et al., 2012, Hogg and Jenkins, 2012). Most of these tools were developed in limited ambulatory populations and lacked validity and generalisability.

Improved palliative care and early referral are associated with enhanced symptom control, a better quality of life, more engagement in future care planning, less reported caregiver burden, and reduced healthcare costs (Datla et al., 2019). However, there is a need to identify when and how this can be achieved, to enable short- and long-term planning. Gadoud et al. (2013) pointed out that if it is to be successful, the palliative care approach should be initiated early on and offered simultaneously with standard treatment. When patients are managed in a multidisciplinary or integrated model of care based on needs, they have fewer hospital admissions and better engagement with care conversions near the end of life. Campbell et al. (2018) defined the need for specialised palliative care and the clinical characteristics of patients who require specialist palliative care using patient-reported outcome measures (PROMs). PROMs evaluate quality of life, symptoms, and mood at baseline and every 4 months thereafter. Patients with any persistent or severe deterioration in PROM for two or more consecutive visits with no improvement were eligible for specialised palliative care . Equally, if patients score 29 out of 100 or less on the Kansas City Cardiomyopathy Questionnaire (KCCQ), they are considered to have specialist palliative care needs, and this is commonly used as a potential ‘trigger’ to refer patients for palliative care (Campbell et al., 2018). Therefore Campbell et al. (2018) recommended that the referral process should consider needs and predict deteriorations, rather than solely focusing on predicting mortality or survival, and that it should involve triggering holistic assessment and making a proactive palliative care plan. Based on the newly emerging evidence, some guidelines recommended that referral to palliative care should occur concurrently with disease-directed care, and that it should be based on needs, not prognosis. The ESC and other international guidelines have advocated the integration of supportive and palliative care into cardiology early in the course of heart failure, and intensively in advanced heart failure (Crespo-Leiro. et al., 2018, Hill et al., 2020). In 2020, the expert statement from the EAPC emphasised that support and referrals to palliative care should be based on the needs of the patient and their family, rather than on time-based prognostication criteria (Sobanski et al., 2019).

1.2.4.2 The critical literature on barriers and challenges

A UK study described the use of a telephone survey with 20 healthcare professionals representing hospital, hospice, and community settings and covering challenges related to the syndrome, the patient, cardiology, palliative care, and the system (Selman et al., 2007). The main concern was limited knowledge and experience of heart failure or palliative care. This was exacerbated by stigma and misconceptions about palliative care equating to euthanasia or assisted dying. Professionally, uncertainties about prognosis and survival led to low referral and access rates. Another extensive qualitative study interviewed 30 patients with advanced heart failure, 20 family caregivers, and 65 healthcare providers in order to investigate the disparity in access to palliative care services in Scotland (Browne et al., 2014). The findings echo those of Selman (2007) in many respects, such as poor understanding of heart failure, prognostic uncertainty, misperceptions of palliative care, poor communication, and fragmentation of care. The poor understanding translated into lack of self-care, and family members being unnecessarily burdened by fragmented and poorly coordinated care, but this did not explain the lack of coordination. Patients with advanced heart failure often have significant comorbidities, so various disciplines are involved in their care across settings. Care fragmentation, poor communication, and lack of coordination between disciplines can lead to uncertainty about whose responsibility it is to introduce palliative care (Jaarsma et al., 2009, Trivedi et al., 2019). The barriers perceived by generalists and specialist providers were also explored (Kavalieratos et al., 2014). Even though the interviewees were positive about integrating palliation into routine cardiology care, they lacked an understanding of palliative care, its benefits in heart failure, and how it can be integrated. The majority regarded palliation as care triggered by prognosis, and believed that it mandates discontinuation of life-preserving interventions.

A study of a similar sample in Australia cited complex multi-level challenges to accessing palliative care services in the context of advanced heart failure (Singh et al., 2020). At the patient level, these included a misunderstanding of heart failure and its unique and unpredictable trajectories. At the provider level, they included conflicted approaches to care (e.g. referral decisions) and the need to improve palliative care knowledge and skills. At the system level, they included resource limitations and the need to improve the current model of care. Romanò (2020), in a narrative review, found comparable findings but added staff shortages and stigmatising referrals to the list. The author also highlighted the disparity in the meanings assigned to palliative care terms as a product of culture. Therefore a new model that factored in culture and values along with the early integration of specialists in palliative care was introduced.

Qualitative studies focused on patients' experience and understanding of heart failure in order to uncover the generative causation by analysing multiple data sources. Klindtworth et al. (2015) investigated the association between understanding of heart failure, needs, and engagement in palliative care through a series of qualitative longitudinal interviews conducted at 3-month intervals. The participants had a limited understanding of heart failure and did not regard it as a life-limiting illness, but instead had attributed their symptoms to ageing. During the advanced stages, heart failure patients have been found to trivialise their illness and downplay its burden, resulting in avoidance of palliative care consultations (Klindtworth et al., 2015). Similar findings related to patients' limited understanding of heart failure have since been reported in a study of 13 patients and nine family carers (Stocker et al., 2017). In addition, participants were found to conflate palliative care with hospice care. Some other inaccuracies were cited as hindering access to palliative care, including the view that heart failure is acute, curable, or survivable, and only requires routine management.

Namukwaya et al. (2017) reported 40 interviews with patients with advanced heart failure and their family caregivers from Uganda. The interview narratives revealed that patients had a distorted understanding of heart failure, and did not link their symptoms to heart failure unless the condition resulted in severe functional limitation. The authors suggested that such lack of understanding might prevent patients from seeking healthcare and adhering to treatment. Metzger et al. (2013) also noted that although some patients were aware of their poor prognosis, their poor understanding of heart failure led 50% of the participants to dispute the prognosis given by the clinician. In addition, patients were often sceptical about palliative care, equated it with death, overestimated their life expectancy, and preferred to seek curative care.

1.2.5 Public perceptions about palliative care: lessons learned

Whilst relatively few studies have addressed this area in the context of the advanced stages of heart failure and its impact on palliative care utilization and possible solutions (Im et al., 2019), there is significant literature on the limited public awareness and misperceptions about palliative care and it is consequences in other fields such as oncology. The literature indicates that certain trends and demographic variables, including age, gender, income, education, and ethnicity, were associated with better awareness and attitudes but not with better access to palliative care. Compared to males, especially if more educated or in their middle age, females are most likely to have better awareness and a more positive attitude towards palliative care (Adjei Boakye et al., 2020, Koffman et al., 2007) or to be more knowledgeable on the topic (Kozlov et al., 2018, Shalev et al., 2018). Members of the public who knew someone who accessed palliative care scored higher scores in terms of knowledge. For instance, Patel and Lyons (2020) found that young adults <40-65 years old) and females were most highly correlated with better knowledge and/or awareness levels of palliative care.

Consistently Kozlov et al. (2018) showed that more than 50% of those taken part in their study reported that they had never heard of palliative care. This study also demonstrated that higher Palliative Care Knowledge Scale (PaCKS) scores were significantly related to better knowledge and personal experience. Some prior studies reported mixed results for age, gender, and ethnic disparity in palliative care knowledge. For example, Huo et al. (2019) reported that adults (>50 years old) were more aware of palliative care than young adults (18 to 49 years old), while others reported that men were more knowledgeable than women (Barwise et al., 2019). However, the findings by Huo et al. (2019), who used the chi-square test and multivariable logistic regression to examine the association between categorical variables, demographic characteristics and palliative care knowledge for 3194 participants, confirmed the previous findings that women had a better knowledge of palliative care. In addition, they found that more than two-thirds (71%) did not know about palliative care, and 84.5% of Hispanic respondents had no knowledge of palliative care. Higher knowledge of palliative care was also associated with other demographic characteristics, including higher education and income, current employment, being married, having health insurance, and having a history of cancer. The findings of ethnic and racial disparities in knowledge about palliative care were consistent across different cohorts (Chuang et al., 2017, Dionne-Odom et al., 2019, Faigle et al., 2017, Matsuyama et al., 2011). Hence, the previous literature has consistently reported significant evidence of ethnic and racial disparities in knowledge, awareness and access to palliative care and its designated services.

Furthermore, even though a small proportion of participants in the above studies had self-reported adequate knowledge of palliative care, common misconceptions still exist, such as the belief that this care type is only available during end-of-life care and for dying patients or cancer diagnoses (Benini et al., 2011, MacLeod et al., 2012, McIlfatrick et al., 2013, McIlfatrick et al., 2014, Shalev et al., 2018, Wallace, 2003, Westerlund et al., 2018). Dionne-Odom and co-authors (2019), in a survey of family caregivers using the National Cancer Institute Health Information National Trends, indicated that approximately half of caregiver participants who self-report adequate palliative care knowledge thought hospice care was the same as palliative care and death.

There is evidence that this widespread misperception and lack of knowledge and understanding about palliative care amongst the members of the public could be explained by different factors. First, having no experience as a patient or a caregiver for a family member who received or was referred to palliative care. Patel and Lyons (2020) demonstrated that people with previous palliative care experiences with a family member or friend had higher awareness and knowledge levels than those without experience (Patel et al., 2019). Secondly, the observed public lack of awareness and knowledge may be justified by the broader societal stigma and taboos of openly discussing life-threatening illnesses and death. Similarly, the term *palliative care* is often equated by members of the public with death and dying (Patel et al., 2019) and confused with euthanasia. Zimmermann et al. (2016) found that patients and their caregivers avoid telling their social network that they are receiving palliative care to avoid upsetting them. They were conscious that the term would be perceived as dying, thus creating stigma. Members of the public would be hesitant to engage or share their experiences and, therefore, the real meaning and purpose of palliative care through their life experiences. This reluctance may factor in this pervasive awareness or knowledge gap if continued. As a result, enhancing public education, including that palliative care does not equate to death, may serve as a proper function in raising awareness and facilitating discussions more openly and honestly and improving recognition of what palliative care truly entails (McIlfatrick et al., 2014). Lastly, palliative care service unavailability, insufficient referrals and resource limitations were also mentioned as contributing factors to the low levels of awareness, knowledge and perception of palliative care (Abu-Odah et al., 2020). Limited knowledge usually coexists with limited awareness and misconceptions, and both constitute barriers to accessing service, as they relate to negative attitudes toward this care approach (Klinger et al., 2014, Patel and Lyons, 2020).

As mentioned earlier, there is much discussion in the literature on barriers and enablers to accessing palliative care, but the role played by culture is rarely discussed. Essentially, developing a clear understanding of how culture affects people's understanding of their illness can enhance the ability of healthcare professionals to fulfil their roles.

1.3 Culture

1.3.1 What is culture?

Culture is an abstract, complex, and multifaceted concept. Despite efforts to reach a consensus, the concept of culture remained on the table for debate by anthropologists until the late 1990s (Jahoda, 2012). Some anthropologists based their definitions on the standard view of culture, and others invented more specialised ones, many of which were conflicting and challenging to implement. Location was the main point of disagreement; idealists believe that culture is intangibly located only in mind, whereas behaviourists locate it tangibly in the material world (Biehl et al., 2019, Hwang, 2019). Rigorous scientists insisted on viewing culture as a variable that can be measured (Mcdougall et al., 2017), whereas others opposed such a position and asserted that culture could be examined by studying a spectrum of interconnected elements interwoven into a cultural phenomenon (Biehl et al., 2019). Alfred Lang summarised a century-long struggle by concluding that ‘attempts at defining culture in a definite way are futile’ (Lang, 1997). The diversity of intentions, meanings, and contexts explain why there is no single accurate and universally accepted definition of culture. Nevertheless, even though the concept has been defined and evolved in various ways over the last decades, there is agreement among scholars about the importance of studying culture in order to gain a better understanding of human behaviours.

1.3.2 How has the concept evolved?

In the mid-twentieth century, Kroeber and Kluckhohn (1952) attempted to define culture by reviewing 164 different definitions systematically. However, the resulting definition was too comprehensive and cumbersome, limiting its applicability and usefulness. As stated by Adler (1997), it emphasised culture as ‘the ideational side of social action’ that goes beyond ‘tangible to intangibles, including implicit tactics, meanings, and intuitive understandings’, with cultural studies viewed as ‘the interpretative study of human behaviours.’ This was a call for anthropologists’ to define and views of culture more inclusively including what people prefer or see good or bad.

Robert Redfield, an American anthropologist, defined culture simply and elegantly as ‘conventional understandings manifest in act and artifact’ (Redfield, 1941). This definition focuses on the shared understandings that make sense of people’s beliefs and values in their resulting practices, and in beliefs based on those understandings. Redfield’s definition recognises that culture is not always seen and overtly expressed, but its impact can be everywhere. Many medical anthropologists endorsed the definition because it recognises the importance and uniqueness of each individual and their needs while acknowledging the implicit culture of healthcare systems and institutions (Napier et al., 2014). Redfield (1941) assumes that not all members in a given ‘cultural group’ automatically share values, ideas, or acts.

Émile Durkheim, the classic social theorist who believed in social relativism, defined culture by separating what can be observed (empirical reality) from the held beliefs even if unchallenged (social facts) (Durkheim, 1982). He believed in the importance of what is taken for granted as the grounds for people's existence, despite their limited awareness (Durkheim, 1982). For Durkheim, the comparative perspectives of people and their awareness of their culture are limited until they experience something different. Durkheim's work is one of the most notable attempts to define culture by applying a social relativist understanding and presenting it as both objective and subjective.

The classical definition advocated by Edward Tylor, an English anthropologist, addresses culture as a complex whole, including elements that are shared by a group with similar characteristics, such as customs and language (Avruch, 1998, Tylor, 1871). The definition has been widely used as a reference point by the United Nations Educational Scientific and Cultural Organization (2001). An outstanding review by the Lancet Commission on Culture and Health (Napier et al., 2014) expanded the definition of culture, drawing on the work of anthropologists such as Redfield, Durkheim, and Tylor. Napier et al. (2014) attempted to understand the effects of the broader dimensions of culture on health. Health, well-being, and illness are all sociocultural constructs, and improvement of health outcomes requires an understanding of how cultural values and beliefs influence health and healthcare delivery.

1.3.3 The postmodern view of culture and healthcare

In an attempt to define culture in healthcare, increasingly complex definitions have been proposed in the literature, and increasingly sophisticated views and methods have been adopted. The postmodern view of culture goes beyond understanding it as a single, measurable factor, and instead views it as an entity associated with many factors, such as gender, age, and ethnicity (Ahmad, 1996, Baker and Beagan, 2014, Kleinman and Benson, 2006). All of these factors influence the way in which people experience, comprehend, and react. Therefore different cultural groups do not hold similar understandings, and the way to understand culture is primarily based on the patient's unique experience. As Ahmad (1996) and Luna and Cameron (1989) have argued, the ultimate way to account for people's culture and its impact on healthcare is to view culture as a context, which is shaping and being shaped by social and contextual powers. They propose that culture provides the most comprehensive and holistic approach to understanding health-related beliefs, values, meanings, and behaviours.

In the healthcare context, anthropologists Arthur Kleinman and Peter Benson were the first to study culture. Their publication *Anthropology in the Clinic: Cultural Competency and How to Fix It* summarised what clinicians need to know in the clinical encounter, and what matters for patients and their families (Kleinman and Benson, 2006). The definition focuses on care as a dynamic and multidimensional concept that spans cultural, moral, and emotional dimensions and culture as a fluid, evolving, and non-homogeneous entity with no clear boundaries that differentiate one group from another. The proposal that culture can be reduced to a technical skill for the benefit of patients – for instance, by training clinicians – made Kleinman's work the position of contemporary anthropologists from 2006 onwards.

Based on the wide-ranging definitions of culture relevant to this research, and on self-reflection, the authors realised the extent to which people's understandings and behaviours are embedded in their culture by nature. This means that people's cultural backgrounds will influence their healthcare decision making about what to do, how to think, what is a priority, and how to access care and engage with treatment (Evans et al., 2012, Helman, 2007). More recently, numerous studies have emphasised the fluid nature of culture, whereby meanings, beliefs, values, and behaviours, along with changing circumstances, contexts and contextual power, shape the 'elusive concept' and the 'complex and … constantly evolving … process through which ordinary activities and conditions take on an emotional tone and moral meaning for participants' (Chan et al., 2009). Thus the high degree of dynamicity and the potential interactional understanding are compatible with the orientation, including the philosophical grounds of this thesis, and fit well with its design. Therefore, to a large extent, this thesis is in agreement with the definitions proposed by the medical anthropologist Cecil Helman and by Chan et al. (2009). However, because it considered the literature on cultural features, the latter's postmodern view of culture was assumed to be particularly relevant to this thesis, and to embrace the depth and breadth of the research described here. Furthermore, the definition in the box below is a composite drawn from many sources which acknowledge that culture is neither static nor straightforward. The definition was deemed necessary given the study's explanatory nature and the need for a practice-focused definition of culture.

Culture is a fluid and multifaceted construct that incorporates the concepts of race, ethnicity, social class, ancestry, language, religion, and a common place of origin, and provides a medium or lens through which people's beliefs, values, norms, and behaviours, along with changing contexts, create their perception and worldview. Thus culture is a part of the context, both shaping and being shaped by other social and structural powers, and it provides a holistic outlook that enables the understanding of health-related beliefs, values, meanings, and behaviours.

Textbox 1.1 Composite definition based on postmodern sources.

1.3.4 Approaches to culture in healthcare

Approaches to cultural care developed in response to evidence of disparity in care access and patient outcomes (Betancourt et al., 2005). All of the approaches are underpinned by the assumption that people from diverse cultures have unique needs, dissimilar value systems, different priorities, and diverse perceptions. Healthcare professionals must therefore provide appropriate care for people of any culture, and consider how cultural background might influence patients' understandings, decisions, and behaviours (Betancourt et al., 2016). In the past century, Madeleine Leininger, a nursing theorist, established cultural competency in transcultural nursing (Leininger et al., 1987) and encouraged others who came under the same influence to expand on cultural competencies. This has resulted, for example, in the work by Green (1995), Campinha-Bacote (1999), and Purnell (2005). However, it is increasingly concerning that some approaches portray culture as static, or define cultural groups as homogeneous, which runs the risk of reinforcing stereotypes and racism. Hence, using these descriptions only to enhance clinicians' awareness of cultural nuances when engaging in cross-cultural encounters remains critical. Studies that discuss cross-cultural care use several common phrases and concepts related to culture that include, but are not limited to, 'cultural competence', 'cultural safety', 'cultural humility', and 'cultural awareness.' All concepts overlap in philosophy, but vary in scope and implementation. A summary of the main concepts and how they have been used in the literature will now be presented.

Cultural awareness refers to the degree of self-awareness and cultural identity, including beliefs, values, norms, and importance to self and others. This approach is the most commonly used concept in cross-cultural education, with little attention paid to cross-cultural interaction (Holland, 2019, Shepherd, 2019). Nevertheless, it demonstrates that the awareness of different cultural values and practices is essential for avoiding ethnocentrism. It was criticised for not being able to enhance healthcare outcomes or tackle the health disparities (Shepherd, 2019). Cultural competence was developed in response to calls to improve care for minority groups. It aims to expand cross-cultural knowledge at individual and system levels, with the goal of achieving cultural proficiency (Cross, 1989). It is a continuous, dynamic and evolving process that emphasises learning about the culture of the patient, personal attitudes, communication, and organisational policies. Furthermore, by understanding the cultural background, characteristics, context and the belief system of patients, clinicians are well positioned to avoid providing care that is not considerate to their beliefs and expectations, given that the expectation of culturally competent care is a basic patient right (Alizadeh and Chavan, 2016, Shao et al., 2018, Shen, 2015). Cultural competency has proved necessary but insufficient, and it lacks focus on organisations, policy, and capacity to support healthcare professionals (Shepherd, 2019). Despite its comprehensive philosophy, this approach is still endpoint oriented, focused on providers' self-reflexivity. Others have presented a modern view, highlighting its fluidity and focusing on accepting cultural differences and understanding that communication is the way to achieve compassionate care and tackling disparity (Kumagai and Lypson, 2009, Taylor, 2003). Due to these limitations, other prototype approaches, such as cultural safety, sensitivity, and humility, have originated from cultural competency (Curtis et al., 2019). The rapid growth of these approaches, accompanied by a change in terminology and theoretical positioning, led to confusion in their clinical application and a lack of understanding of their scope and philosophy. In a review of 59 articles, Jones et al. (2019) compared various culturally focused care approaches and highlighted the need to prioritise being culturally safe rather than ‘competent’ in others’ health belief systems, by investing in ways to address self-bias. Cultural safety seeks to give patients the power to access services and interact in clinical encounters (Laverty et al., 2017).

In contrast with cultural competency, cultural safety seeks to eliminate ethnocultural disparities and to ensure that services are appropriate and equitable by addressing these issues at the institution, clinician, and patient level, rather than at the provider level alone (Kumagai and Lypson, 2009, Papps and Ramsden, 1996, Shepherd, 2019). Ramsden (2002), who pioneered the concept of cultural centredness, identified the following steps for achieving cultural safety in nursing practice. From cultural awareness to cultural sensitivity and cultural safety, clinicians are urged not only to self-reflect on their own cultural beliefs, but also to reflect on the culture and norms of their institution and services. Some experts such as Tilki and co-authors (2004) and Betancourt et al. (2016) argued that these cultural approaches are necessary competencies and/or tools that enhance the health providers’ capacity to provide care considerate of people’s culture and promotes their opportunity to succeed in a diverse workplace.

Due to increasing population diversity, a greater emphasis on appropriate person-centred care, incorporating cultural aspects, is needed in present-day healthcare systems. However, lack of clarity and applicability may reduce the potential for healthier, safer, and better-quality cross-cultural clinical encounters. Another approach to cultural competency in healthcare is cultural congruence (Schim and Doorenbos, 2010). Cultural congruence aims to achieve high-quality and high-value patient-centred care across all population groups through understanding, appreciating, and responding to the patient’s cultural preferences, maintaining individualised care and avoiding prejudice attitudes (Leininger et al., 1987, Shen, 2015). The three-dimensional figures comprises the provider level and the following four components: cultural diversity, awareness, sensitivity and competence behaviours. Then, patient or client level that consist of patient, family, and community attitudes, beliefs, and behaviours. Lastly, the outcomes layer of a culturally congruent care which represent a well matching relationship and interaction between the patient and provider (DeWilde and Burton, 2017).

1.3.5 Cultural Distress Theory

Moving from evidence to practice, culturally congruent care, the ever-evolving extension of cultural competence, emphasises the idea of a tailored “fit” between a patient’s culture and care expectations and decisions and actions as a pre-requisite for effective and dynamic relationship between the patient and provider. As culture gives meaning and sets the context in which people experience care, incongruent cultural care is often associated with distressing experiences. Ignoring patients’ cultural values and beliefs in their approach to patients, whether intentional or otherwise, may lead to imbalanced relationships, mismatches or cultural incongruence care, which can adversely affect physiological, emotional, and overall health by triggering causing cultural pain and distress (DeWilde and Burton, 2017, McFarland and Wehbe-Alamah, 2018). The consequences of this widely reported conflict that patients experience when care is incongruent with their values and beliefs may include healthcare services underutilisation, treatment noncompliance, impaired recovery and widened power gap between the provider and patient (DeWilde and Burton, 2017, McFarland and Wehbe-Alamah, 2018, Purnell and Fenkl, 2019, Shen, 2015)

Moreover, DeWilde and Burton (2017) offer a framework for understanding this distress, drawing on two theories, the cultural care theory of Leininger’s (1988) and the foundation and definition of ‘Othering of Canales’ (2010), specifically related to structural stress. They defined cultural distress as an unpleasant response or state rooted in a culture when facing interpersonal conflicts and a lack of control over the surrounding environment that often impairs the patient-providers ability to cope with day-to-day encounters.

Nevertheless, cultural distress can also manifest with the parallel experiences of being ill, and being culturally different to what is familiar within society, particularly when receiving care from a mono-cultural health service that ignores their cultural belief (DeWilde et al., 2019). The cultural distress theory addresses three related and interrelated concepts: othering, structural stress and allostatic load (DeWilde and Burton, 2017). Firstly, the concept of othering is defined as the experience of feeling or being marginalised or a minority group being essentially different from the majority group based on tangible differences such as language or skin colour (Canales, 2010, Jensen, 2011). Secondly, a phenomenon known as structural stress means further susceptibility to disempowered and sustained otherness when living under specific socioeconomic and social structures (DeWilde et al., 2019, Jensen, 2011, Kagawa-Singer et al., 2015). Canales (2010) and Kagawa-Singer et al. (2015) hypothesised that the experiences of stress related to social structure increase vulnerability for marginalisation and othering. Lastly, the allostatic load. Allostasis is the concept of "stability through change" in which human bodies maintain homeostasis by making physiological and behavioural adjustments in response to stressors (DeWilde et al., 2019, McEwen, 2017, Sterling, 1988). However, with repeated exposure there many physiological, endocrine, and neural, responses to stress (Karatsoreos and McEwen, 2011, Seeman et al., 2004). In simple terms, allostasis is the mechanism; the allostatic load is the deterioration that accumulates due to the recurrent activation of these mechanisms and homeostasis, or excess stress mediators, is the end product.

1.3.6 Culture and palliative care

The fields of culture and palliative care intersect at two important points, namely patient worldviews and explanatory models. Patient worldviews refer to how patients perceive the world and shape realities, and what life means to them (Palos, 2015). In emergencies or severe illness, people’s understanding of and attitudes toward illness and the meaning of suffering are influenced by their worldviews and belief systems, which are rooted in their cultural identity. Hence patients’ responses, decisions, and actions with regard to palliative and end-of-life care are inevitably guided by their cultural worldviews. Patients’ communication is based on their worldviews acquired through lived experiences and cultural identity in terms of values and beliefs. Agom et al. (2019) confirmed that patients’ cultural worldviews are integral to decision-making processes for palliative care. The same principle applies to healthcare professionals, whose race, biases, and cultural identity may also shape their worldviews, which in turn influence their views, understanding, and explanations about palliative care, given that worldview is the lens through which health, illness, death, and dying are defined (Palos, 2015, Purnell and Fenkl, 2019).

Cultural worldviews shape how people understand and respond to information, including the way they understand illnesses, describe their cause, and set expectations based primarily on the other field of intersection, the illness explanatory model. It is in fluid, subjective, and culturally based ways that people construct or give meaning to experiences (such as illness and health) and change over time in response to situational changes (Kleinman, 1980, Kleinman et al., 1978). As with worldviews, there is evidence to show that these models can influence patients' and families' perceptions of illness and domains of palliative care, including goal setting, decision making, communication, future care planning, and health behaviours (Agom et al., 2019, Kleinman et al., 1978, Namukwaya et al., 2017, Palos, 2015).

Central to this intersection is the notion of variant characteristics of culture or defining attributes, including race, ethnicity, gender, age, ancestry, language, religion, educational and socioeconomic status, shared place of origin, and immigration history, among others (Purnell and Fenkl, 2019). Not all cultural attributes have equal health-related influences, and their impact has not been well researched (Purnell and Fenkl, 2019). Socioeconomic status and gender predominate, and are considered by Ruiz et al. (2012) and Gurung (2019) to be the most well-studied attributes to date. Gurung (2019) studied cultural influences on health-related factors. He found that during crises, people's culture plays a crucial role in the way that they manifest, report, and respond to symptoms, cope with challenges, and seek and accept treatment. Gurung concluded that the influence of culture is visible in two dimensions, namely its impact on health, and its impact on people's approach to health. Therefore, in order to account for the culture of patients and their families, we need to understand their approaches to care and the underpinning values and paradigms. Six et al. (2020) declared that palliative care was born in a Western context and is predominantly affected by its standards and values, such as dignity, autonomy, and quality of life, among other things.

On the other hand, Heggestad et al. (2020) found it challenging when the pre-defined palliative care context conflicted with patients' sociocultural context. For instance, Dewar et al. (2015) studied dying with dignity in the context of Hindu beliefs and values in the USA. The authors found that adherence to cultural customs, values, and religious beliefs, as well as family unity, can challenge the concept of autonomy that is so highly valued in palliative care. Moreover, such adherence could lead a patient to express a different set of end-of-life care preferences. It is noteworthy that the sense of obligation experienced by family members may result in their feeling isolated and burdened by such caregiving obligations.

The western model of palliative care assumes a specific and characteristic view of dealing with death, including death as a normal part of life, and it should not be hastened or postponed. However, several studies have challenged this view by mentioning the manifestation or view on cultural differences (Six et al., 2020). For example, others argued that the public's attitudes towards death vary across cultures depending on their worldview and what constitutes a good death (Dewar et al., 2015, Rahemi and Williams, 2020). This matter is perhaps best summarised by looking at Selin and Rakoff's 2019 citation, *Death across Cultures* (Selin and Rakoff, 2019). The authors stressed the importance of studying culture and cultural attitudes towards death and provided various cultural experiences on death and dying. As part of their final message, Selin and Rakoff made a compelling argument, suggesting that death and attitudes to death are neither homogenous across cultures nor within a culture. Instead, death still reflects lived situational and contextual experiences across cultures. This work perhaps best explains these fundamentally different attitudes towards death and dying by different social and demographic profiles and family systems of those nearing death. Another explanation may be found in the diversity of each culture's religious and societal norms and traditions. Part of the suggested explanation for these attitudes may be the immigration of people from eastern countries to the west and the construction of a more hybrid attitude towards death, most probably due to acculturation. Echoing what was mentioned by Kellehear (1984), the twentieth-century crisis and the growing individualisation of death are often used as an explanation for the same phenomenon (Kellehear, 1984, Selin and Rakoff, 2019)

However, the degree of emphasis on such values and their meanings may differ across populations and settings. Thus it provides one means by which patients can decide their palliative care preferences. In a migrant community, limited access to support is often attributed to lack of financial resources as well as to lack of familiarity with the types of formal care available to patients and their families, as they may well be unfamiliar with their host country's cultural beliefs with regard to caregiving (Six et al., 2020). There is clear evidence that palliative care does improve quality of life and reduce the cost of care. However, studies have shown that among different racial and ethnic groups there is significant variation in the acceptability of, satisfaction with, and perceptions of the current palliative care system (Cain et al., 2018, Evans et al., 2012, May et al., 2016, Payne, 2016). As mentioned earlier, several studies have looked at the influence of culture on palliative care and highlighted the fact that the values adopted in the modern Western palliative care model are not universally shared (Cain et al., 2018, Rahemi and Williams, 2020). Furthermore, the people who typically need palliative care are elderly, which may lead to generation-related cultural differences. Another barrier to receiving palliative care in some cultures is an inability to accept that the patient's illness is incurable. Such acceptance is a fundamental aspect of being placed on a palliative care programme, and therefore a lack of acceptance can be a barrier to accessing palliative care services.

1.4 Setting the scene

This study explores the influence of culture on the ways in which patients and their family members understand advanced heart failure and palliative care. In addition, it explores whether the palliative care cardiology services remain underutilised by culturally diverse groups, whose language and life experiences differ from those of the predominant population, due to cultural understanding and/or misconceptions.

The concept for this PhD stemmed from my Palestinian origins, my cardiac nursing practice values, and my emerging interest in cultural factors and understanding of palliative care. As an individual, I have been personally affected by heart failure. As a son, I witnessed the massive impact of heart failure with reduced ejection fraction on my father. Professionally, as a cardiac nurse, I have cared for patients during the critical stages of heart failure and helped their families to cope with the impact of the illness, and I have always endeavoured to prioritise the patient’s individual needs, while considering a broader holistic perspective. In doing so, I have striven to address the challenges presented by the disruptive nature of heart failure, and simultaneously to encourage each patient to consider the options available to them in terms of cure, care, and support. I also engaged with each patient to explain what was happening, the reasons for this, and the importance of following treatment and healthcare recommendations in order to improve symptom identification and quality of life.

Even while I was employed as an acute care nurse, before I started working as a nurse in the heart failure unit, I had an interest in the subject of heart failure. I began to consider the future of patients who were discharged from hospital having been given a diagnosis of heart failure. I firmly believe that this syndrome requires long-term management and considerable support both from healthcare professionals and from the patient’s family. Based on my own perspective and observations, only a few patients and family members understood their new situation, whereas the majority were very anxious and seemed overwhelmed by the amount of information that they needed to assimilate, and by its complexity. Others appeared to be in denial and could not cope with either the situation or the information, but were merely passively waiting for someone (a doctor or nurse) or something (a miracle) to rescue them. Most of the patients were older adults with a cluster of symptoms, including hypertension, heart failure, diabetes, or chronic obstructive pulmonary disease (COPD). As a result, they were unable to cope successfully in a community setting, and were frequently re-hospitalised.

During the same period, I worked as a nurse educator and at a university nursing faculty, which further stimulated my interest in heart failure. Moreover, I have always been struck by the number of patients who are living with this syndrome, and I wanted to understand how nurses can improve the situation for these patients. On one particular shift I had been delegated the night supervisor’s duties, and this led me to initiate informal conversations with many patients and accompanying family members in the cardiac care unit. It was clear that we permitted family caregivers to stay overnight in a closed unit, and that, as clinicians, we allowed the family to comfort the patient and keep them company in order to reduce feelings of stress and anxiety I also spoke to cardiac nurses, resident physicians, and colleagues in the education setting. What I found most significant was the similarity between the responses of professionals and patients, expressed in phrases such as There is nothing that can be done or We can do nothing but pray, or wait, or try …. The unexpectedness of the medical professionals' and patients' shared understanding and mindsets further stimulated my interest in heart failure, particularly during the terminal stages. I began to suspect that such a mindset might have arisen as a result of the nurses, doctors, and other healthcare professionals becoming increasingly insensitive to the patients' struggles over time.

My PhD journey began when I started to read about palliative care. Palliative care was not included in our nursing education or training in Palestine. After months of researching and reading, I realised that such care must be customised to society's needs, preferences, goals, and, in the case of Palestine, very minimal resources. The total value of Palestinian imports is very low, and does not meet the minimum needs for healthcare, as a result of which it has been impossible for healthcare professionals to keep up with all the latest advances in healthcare. I wanted to find other ways of caring for patients that would be adaptable and achievable, but as palliative care was not included in our training, it was hard to know where to begin. It was at this point that Professor Bridget Johnston at the University of Glasgow offered me the opportunity to study for a PhD and explore the palliative care options that can be adapted to improve quality of life for patients with advanced heart failure. The focus of the thesis was shaped by three months of scoping and discussions with supervisors and colleagues. Throughout my PhD, the focus and direction were influenced by my working experience in cardiac care and by the significant experience of my supervisory team, Professor Bridget Johnston and Consultant Cardiologist Karen Hogg, in palliative care and heart failure research and practice.

1.5 The research problem.

Although the standard of healthcare has improved greatly in recent years, healthcare disparities are still a major problem, extending to the worldwide provision of palliative care services for patients with life-limiting illnesses. In the context of heart failure, access to and utilisation of palliative care services, particularly among diverse and multicultural populations, remains limited, highlighting the need for further research on palliative care in cardiology (Sahlollbey et al., 2020). Over the last two decades, several evidence-based guidelines on heart failure have been published to help clinicians to integrate palliative care into routine heart failure care (Braun et al., 2016, Hill et al., 2020). These guidelines include advice on a coordinated approach at a sufficiently early stage of heart failure to influence the prognosis, positively impact symptoms and QOL, and minimise hospitalisations, risk of death, and healthcare costs (Sahlollbey et al., 2020). However, the provision of palliative care for those affected by heart failure is still suboptimal and underutilised by patients and caregivers (Sobanski et al., 2019). Research spanning years, if not decades, indicates that data on contemporary palliative care access are still lacking (Riley and Beattie, 2017). The proportion of patients with heart failure who access palliative care services is repeatedly cited as low, and palliative care is underutilised by patients and caregivers at all stages in the heart failure trajectory, despite the escalating numbers of patients with advanced heart failure, and the associated need for palliative care (Gadoud et al., 2014, Gadoud et al., 2020).

1.6 Research focus: significance, rationale and contribution

As palliative care provision for those affected by HF is still suboptimal and underutilised, research studies on palliative care in cardiology research must seek the reasons for this and examine the disparities, which are present on multiple levels. These disparities are mediated by a range of factors, including understanding of illness and cultural issues, that either promote or hinder palliative care and treatment. Patients' cultural understanding and perceptions may depend on a number of different contextual and situational variables that influence their behaviours, decision making, and belief systems, especially in emergency situations or severe life-limiting illnesses such as heart failure. The extent to which individuals' understanding is influenced by culture depends on contextual factors such as the variant characteristics of the culture. Several studies, including that by Gelfman et al. (2017) on behalf of the IMPACT-HF project, have identified a number of research and practice priorities for improving the integration and utilisation of palliative care for patients with heart failure. They suggested that palliative care disparities can be reversed by an improved understanding of patients, their symptoms, and the needs of patients with heart failure and their families. To achieve this, they urged clinicians and researchers to explore the patient's understanding of heart failure, the syndrome trajectory, persistent symptoms, and the benefits of palliative care as a way to address this complex problem. Clinicians would then be able to determine the best models of palliative care based on patients' understandings and needs.

In addition, the scarcity of published studies of the impact of cultural factors on patients' and family carers' understanding of heart failure may exacerbate this disparity (Worster et al., 2018). As palliative care continues to evolve, the various aspects of culture in this field of care are becoming a priority, and cross-cultural communication is proving to be an essential part of successful patient–family-provider encounters (Etkind et al., 2017, Semlali et al., 2020). Quality of life and experience of symptoms, as crucial elements of palliative care, are multidimensional and subjective constructs that reflect individuals' perceptions and the context in which they are experienced. People's values and beliefs also need to be considered, and culture is a vital and influential aspect of context that shapes these perceptions. Although these concepts have been widely explored, there has been little empirical research on heart failure that has captured the cultural context from different lay perspectives (Quinn et al., 2020). There is much discussion in the literature on factors that promote or hinder access to palliative care, but the role played by cultural background in accessing palliative care services has rarely been considered (Allen et al., 2012, Hill et al., 2020). This problem is aggravated by a lack of formal recognition and support. A systematic review of 139 published studies found the existing palliative care evidence and guidelines to be patchy and lacking in cultural sensitivity (Ahluwalia et al., 2018).

1.7 Personal circumstances; reflections

I grew up in Palestine where young people could not pursue postgraduate education in nursing. However, I strongly believe in the power of education to create opportunities and transform societies, and I wanted to pursue a doctoral degree. As a result, my family and I were the first in our region to go to a university abroad. During my studies at the University of Glasgow, I have been privileged to work alongside experts in the field of palliative care in cardiology, and to have very supportive colleagues. However, I have encountered many personal difficulties and setbacks. Having my third corneal graft rejected during the first year of my PhD was the toughest. At that time, I even wondered whether I could continue with the severe visual disability. Fortunately, I had swift corneal transplant surgery. A few months later I had two corneal rejections. Both had responded to treatment but required lifelong immunosuppression to prevent rejection of the new graft, not to mention the side effects and the risk of chronic infections associated with the drug. Nevertheless, I always have faith that things will turn out positively.

In September 2019, I had to suspend my studies for 3 months due to this illness. After I resumed my studies, the country went into complete lockdown for months, the university was closed, and the ‘stay at home’ message was enforced. During the pandemic, when it was necessary for me to shield due to being at high risk, I had to adopt a new style of working in order to reduce the impact on my research project. In the midst of the pandemic I was also juggling an illness, a PhD, and parenting, but despite these challenges I felt well supported by my supervisors, family, and friends.

My supervisors and I agreed on a flexible mitigation plan. This involved minimising the impact of the lockdown by modifying my thesis timetable to make it compatible with the real-time situation while allowing me to remain productive. The mitigation strategies included writing for publications, disseminating my findings, preparing a thesis plan, and writing up the initial chapters.

In the belief that heart failure clinicians are critical stakeholders with regard to gaining a complete understanding of the topic, we aimed to assemble a panel in which experts could discuss their perspectives, and revisit and validate our findings.

As a result, progress was made in developing a third Delphi consensus study aimed at the clinician and service level. By doing this virtually, it would have been possible for me to continue to collect data from the panellists and ask them to verify my findings using a short online survey, as shown in Appendix IV. However, this plan ceased to be viable when all research activities were suspended due to the global crisis and the impact of to COVID-19 on heart failure clinicians.

1.8 The research aims and questions

This PhD study was designed to investigate how people's culture affects their understanding of palliative care services for heart failure in one of the most culturally diverse communities in the UK. In addition, it aimed to determine whether these services remain underutilised by minority ethnic groups, whose language and life experiences differ from those of the predominant population, due to cultural understanding or misconceptions. The qualitative descriptive design was appropriate to the study aim as it enables investigators to describe the participants' understandings and experiences (Doyle et al., 2020, Sandelowski, 2000). The descriptive data therefore helped to elucidate the actual process and mechanism of meaning-making (Creswell and Creswell, 2018).

1.8.1 Research aims

This PhD aimed to investigate the impact of culture on palliative care services for patients with heart failure from diverse backgrounds by focusing on individual understandings. In addition, the study aimed to identify cultural implications and challenges that need to be considered when developing and implementing interventions to support palliative care in advanced heart failure.

1.8.2 Research Questions

The first step of this research was to define a systematic review question with which to search the published literature on the influence of cultural factors in patients with heart failure, and to use the following questions to identify the current gaps in the literature, and to guide subsequent studies.

- What is the impact of culture on people's understanding of advanced heart failure?

Given the scarcity of empirical evidence, the subsequent research questions must be broad enough both to provide an explanatory entry point to the ways in which people describe, experience, and interpret heart failure and palliative care, and to identify the extent to which their narratives and understandings are influenced by culture, and the underlying mechanisms that are contributing to the current understanding or lack of it. Having considered the philosophical foundations and literature, the following research questions emerged and guided the main qualitative study:

- What cultural beliefs / attitudes may be involved in how patients construct their understanding of palliative care for heart failure?
- How do patients with heart failure from diverse cultural backgrounds perceive how palliative care is received and delivered?

1.9 Structure of the thesis

The thesis consists of seven main chapters, which describe a consecutive series of steps, each of which contributes significantly to advancing our understanding of the cultural impact on understandings of heart failure and palliative care as well as potential ways in which the current practice could be improved so as to support the provision of palliative care for people with advanced heart failure. This thesis builds on the existing literature, empirical research findings, current practice, and patient and public input, specifically pertaining to cultural factors. The content of each chapter is summarised briefly below:

Chapter 1 provides an overview of the research evidence on heart failure, palliative care, and cultural factors both in the UK and internationally, emphasising the role that culture plays as a contextual power. It also highlights the influence of patients' and family members' understanding of these concepts on access to palliative care services. Lack of access to palliative care services is a particular problem for patients with heart failure, who are less likely to be offered a palliative care referral than patients with cancer, despite the large burden of suffering associated with heart failure. Access difficulties are related to poorer health outcomes and are especially pronounced in cultural groups. Stakeholders' perspectives on the concept of culture in an advanced heart failure context are explored, in order to provide a more comprehensive overview.The chapter provides an introduction to the study and an overview of the thesis, including the main research concepts, context, purpose, and aims. The rationale and background to the study, its significance, and its implications for theory, research, and practice are also discussed.

Chapter 2 describes the first study, namely a systematic review of the current evidence on the impact of cultural factors on the understanding of advanced heart failure. A systematic search strategy and a mixed-methods synthesis focus on exploring how culture influences the understanding of advanced heart failure for patients and their family members, and how culture influences the adoption of healthy behaviours.

Chapter 3 presents the theoretical and methodological approach and rationale for the studies included in this thesis, and the methods used in each study. The thesis was posited as an exploratory piece of work, aimed at increasing our understanding of the processes and complexities involved in the role of culture in understanding palliative care and heart failure. As this has to date been an under-theorised area, with little evidence of successful application of nursing and anthropological models, it fitted neatly into a combination of the PEN-3 cultural model and the Medical Research Council (MRC) Framework for the development of complex interventions. The chapter also provides an overview of the strengths of the MRC Framework in this project, given the various complex and interacting components that are involved. Finally, the rationale and methods used in each study, adopting a theoretical and philosophical approach from a critical realist standpoint, are presented.

Chapter 4 describes in detail the methods and procedures that were used during the project, including locations, access, sampling, eligibility criteria, data collection methods, data analysis, and ethical considerations. The chapter concludes by presenting details of a series of Patient and Public Involvement (PPI) and regular research advisory meetings that aimed to inform each stage of the process.

Chapter 5 presents the findings from qualitative focus groups conducted with members of the public, including patients and carer participants. These focus groups explored the contextual power of culture and ingrained beliefs and values that support multiple interpretations of heart failure, palliative care, and experiences of providing and seeking help. Reflexive thematic analysis was used to analyse the focus group findings. Finally, the chapter describes how the hypothetical patient scenario was designed to explore participants' understanding of heart failure and palliative care as situated in the sociocultural context.

Chapter 6 discusses the findings from the focus group discussions with seven groups, whereby it begins by reflecting on the impact of culture on how patients construct their understanding of palliative care for heart failure, followed by examining the findings concerning their perceptions of how it is received and delivered.

Chapter 7 outlines the study's principal findings, bringing together the results obtained from the systematic review, the exploratory qualitative study, relevant empirical research, and the literature. This is followed by a summary of how the research aims were achieved, and a discussion of the contributions that the research project has made to knowledge and theory, and its clinical implications. The chapter also includes a brief assessment of the strengths and weaknesses of the thesis. Finally, the relevance of the study to clinical practice and future research are evaluated.

1.10 Chapter summary

This chapter has summarised the research evidence on heart failure – the global epidemic that threatens to overwhelm global healthcare systems in the near future. It has also described the current management strategies for patients and family caregivers. Although research studies have demonstrated the benefits of palliative care interventions in terms of improving quality of life, specific symptoms, understanding of the prognosis, and patient well-being, the provision of palliative care for heart failure patients is still suboptimal. Culture is one of the areas that merits further empirical investigation.

Chapter 2 Culture and the Understanding of Advanced Heart Failure: A Mixed-Methods Systematic Review

This chapter has been published in *Collegian*, by Elsevier, on behalf of the Australian Royal College of Nursing. As the author of this Elsevier article, I retain the right to include it in my PhD thesis.

Alassoud, B., B. Johnston and K. Hogg (2020). Culture and the understanding of advanced heart failure: a mixed-methods systematic review. *Collegian*, 27(4), 459–470.

2.1 Introduction

This chapter is a published mixed-methods systematic review that summarises and draws upon the broad evidence on how influential culture is shaping the understanding of advanced heart failure (see Appendix II-A). In addition, this review informs the remaining chapters of the thesis. The literature presented was obtained through seven scientific databases and multiple grey literature sources. The searches for the systematic review were conducted in 2020 and updated in September 2021. The searches were run across the same seven databases and retrieved 374 articles. The title and abstract screening of the newly published literature identified eight articles as potentially eligible. However, the full-text screening revealed that none of the articles had met all the requirements for inclusion.

2.2 Background and aims

Heart failure affects 1–2% of the population (Piotr et al., 2014), with over 26 million patients affected globally (Bui et al., 2011, Piotr et al., 2014). The prevalence increases steadily up to 10–13% with advancing age (Conrad et al., 2018). In the UK, 1–2% of National Health Service (NHS) expenditure is spent on heart failure management (Cowie, 2017), and 60–70% of this is on patient hospitalisation costs. Around 10% of people with heart failure will progress to advanced/end-stage heart failure (Deng et al., 2002, Fang et al., 2015, Xanthakis et al., 2016). Advanced heart failure is defined as 'a primary diagnosis of chronic heart failure under optimal therapy with persistent symptoms or NYHA Class III–IV symptoms with frequent hospitalisation during the previous 12 months' (Abouezzeddine and Redfield, 2011). Patients who reach this stage often have burdensome refractory symptoms and poorer quality of life, requiring collaboration between cardiology and palliative care (Sobanski et al., 2019). Palliative care (IAHPC, 2018) benefits patients with advanced heart failure (Conrad et al., 2018, Crespo-Leiro et al., 2018, Jaarsma et al., 2009) by relieving suffering and enhancing the quality of life both of patients and of their families (McIlvennan and Allen, 2016). Increased mobility of global populations has created its own Western and Eastern cross-cultural challenges, particularly when attempting to provide culturally appropriate health and palliative care services for multi-ethnic minority groups within mainstream Western health systems. Culture is known to affect people's health and health-related outcomes (Kagawa-Singer, 2011, Kwabi-Addo, 2017, Suurmond et al., 2015), but little is known about the influence of culture on chronic disease and disease understanding. Research is needed into how the understanding of advanced heart failure affects patients' and family members' heart failure beliefs, treatment preferences, expectations about the disease, and help-seeking behaviours at crucial points during the treatment process for heart failure. The purpose of this review is to explore how culture influences both the understanding of advanced heart failure for patients and their family members, and the adoption of healthy behaviours. This research is vital for the development of culturally appropriate interventions to improve healthcare provision.

2.3 Methods

A mixed-methods systematic review design was used, incorporating approaches for data extraction, analysis, and synthesis. The mixed-methods approach was deemed suitable due to the heterogeneity of the primary research on culture and heart failure. The review was conducted in accordance with the PRISMA checklist (Liberati et al., 2009). The protocol was registered and published on PROSPERO (CRD42018084612) (see Appendix II-B).

2.3.1 Search strategy and study selection

The review question was developed using an adapted tool from the PICO (Cooke et al., 2012) and SPICE (Booth, 2006) frameworks. To ensure rigorous search strings, a combination of text words and medical subheadings was used, where applicable, for each search string. Following the recommendations of Brunton et al. (2017), four search strings were iteratively tailored and refined to aid the adapted tool from SPICE and PICO frameworks to address the review question (see Table 2.1). Due to the scarcity of evidence on the role of culture in shaping different HF understandings, we piloted our search using broad search terms on MEDLINE through Ovid (see Appendix II-C). Thereafter, the established syntax was extended to EMBASE, CENTRAL, CINAHL, PsycINFO, Web of Science, Scopus and grey literature databases (Appendix II-D) in January 2018 with no date restrictions.

Table 2.1: The search strategy nested within the hybrid framework.

	Searching string (MESH or Keyword)
Disease of interest Heart Failure	MeSH: Heart Failure/ Cardiomyopathy, Dilated/ Shock, Cardiogenic/ exp Ventricular Dysfunction/Cardiac Output, Low/ Keywords: Heart Failure.tw. ((heart or cardiac or myocard*) adj2 (fail* or insufficien* or decomp*)).tw. ((dilated or congestive) adj2 cardiomyopath*).tw. ((ventricular or ventricle*) adj2 (failure or insufficien* or dysfunction*)).tw. cardiogenic shock.tw. (DCM or heart failure or CHF or LVSD or HFrEF or HFpEF or HFmEF or RVD or RVDD).tw.
Population of interest Patients, family members and clinicians.	MeSH: Patients/Family/Health Personnel Keywords: (patient* or inpatient* or outpatient* or parent* or relative* or famil* or carer* or caregiver* or care-giver* or spous* or husband* or wife* or wive* or partner* or sibling* or daughter* or son* or clinician* or physician* or doctor* or nurs* or GP* or ((Health or healthcare or health care) adj2 (practitioner* or profession* or provider*))).tw.
Phenomena of interest Understanding of Advanced Heart Failure.	MeSH: Comprehension/Knowledge/Communication/Health Literacy/Attitude to Health/ Keywords:(mean* or define* or comprehen* or experience* or belief* or thought* or view* or opinion* or perception* or perspective* or attitud* or know* or understand* or aware* or compl* implement* or operational* or philosoph* or appl* or conceptual* or interpret* translat* or value* or behavio*).tw. (health and (literate or literacy or numeracy)).tw.
Output/Impact The impact of culture.	MeSH: Culture/Anthropology, Cultural/Continental Population Groups/Ethnic Groups/ Keywords: (cultur* or multicultural or multi-cultural* or intercultural* or inter-cultural* or transcultural or trans-cultural* or cross-cultural* or crosscultural* or multiethnic or bicultural* or bi-cultural* or ethnic*).tw.

2.3.2 Eligibility

All published and unpublished qualitative, quantitative, and mixed-methods studies that focused on at least one of the outcomes of interest were eligible for inclusion. In addition, studies that used primary or secondary data were eligible if they provided more information or reported different results. As can be seen from Table 2.2, studies published in English that identified participants as adults (> 18 years) with advanced heart failure, family members of patient with advanced heart failure, or healthcare professionals who had provided care for a person with advanced heart failure were included.

Table 2.2: The eligibility criteria for screening potential articles

Population of interest - Perspective	**Patients** Adult patients aged 18 years or over and diagnosed with advanced heart failure, according to a combination of three definitions from leading professional bodies with regard to heart failure – the European Society of Cardiology (ESC), the American Heart Association/American College of Cardiology (AHA/ACC), and the Heart Failure Society of America (HFSA). Other evidence included being in the advanced stage of heart failure regardless of aetiology, life expectancy, and other prognostic indicators. This by default excludes all studies focusing on acute heart failure and mixed heart failure populations. Studies of mixed disease populations are eligible for inclusion if the number of patients with heart failure and any outcomes pertaining to them are specifically described.
	Patients’ family members and/or caregivers Formal or informal, paid or unpaid carers who are ≥ 18 years years of age Caregivers of patients (aged ≥ 18 years) with a documented history of heart failure for more than 3 months. They have cared for patients with advanced heart failure, reflecting how culture could affect patients’ understanding and hence their subsequent treatment choices.
	Healthcare professionals Healthcare personnel in particular (nurses and physicians) who dealt, cared or treated patients with advanced heart failure.

Design of interest	All published and unpublished studies that report about participants' understanding of advanced heart failure either qualitatively (e.g. by interviews or focus groups), quantitatively (by instrument), or using a mixed approach were included and given careful consideration for inclusion. Theoretical papers, opinion pieces, editorials, essays, and newspaper articles were excluded. Studies published only as conference abstracts or posters were also excluded if the full versions were not accessible or available.
Output/ Impact of interest	Any study that focuses on the impact of the cultural contexts on individuals' understanding either directly (i.e. certain values conflict with the understanding, treatment, and viability of these options) or indirectly (i.e. low levels of health literacy and poor knowledge about culture and its influences on self-care). Studies were included in this review if they addressed how different cultural contexts suggest different ways of conceptualising the understanding of advanced heart failure. Primarily, the conceptual understanding of causes, symptoms, management, and treatment choices/decisions with regard to heart failure (heart transplant and LVAD), in addition to any technical outcomes on how culture is enacting lifestyle and environmental changes, performing rehabilitation exercises, and following treatment plans (i.e. medication, or assistive devices or technologies).

2.3.3 Theoretical framework

Health and illness are culture specific, and culture is a critical determinant of human health outcomes and shapes health behaviours. The PEN-3 model situates culture at the forefront of health determinants and healthcare interventions (Airhihenbuwa, 1990, 1995, 2007; Airhihenbuwa & Webster, 2004). Figure 2.1 presents the three interrelated PEN-3 domains of inquiry. Each domain has three subcomponents assembled to form the three PEN acronyms, and is assumed to represent the overall impact of culture on that domain. We used two components of the PEN-3 model, namely the relationships and expectations domain and the cultural empowerment domain (Figure 2.1), to guide our search strategy and data synthesis. Themes were constructed solely based on the extracted data without reference to the PEN-3 model constructs. The two constructs were used as a guide to identify and assess all forms of cultural impacts in each study. The cultural impact themes were further evaluated using the concepts of perceptions (beliefs and values), enablers (this subdomain also includes barriers), and nurturers (the role of social support) in the relationships and expectations domain. We then categorised the data under the constructs that reflect the form of impact (positive, existential, or negative).

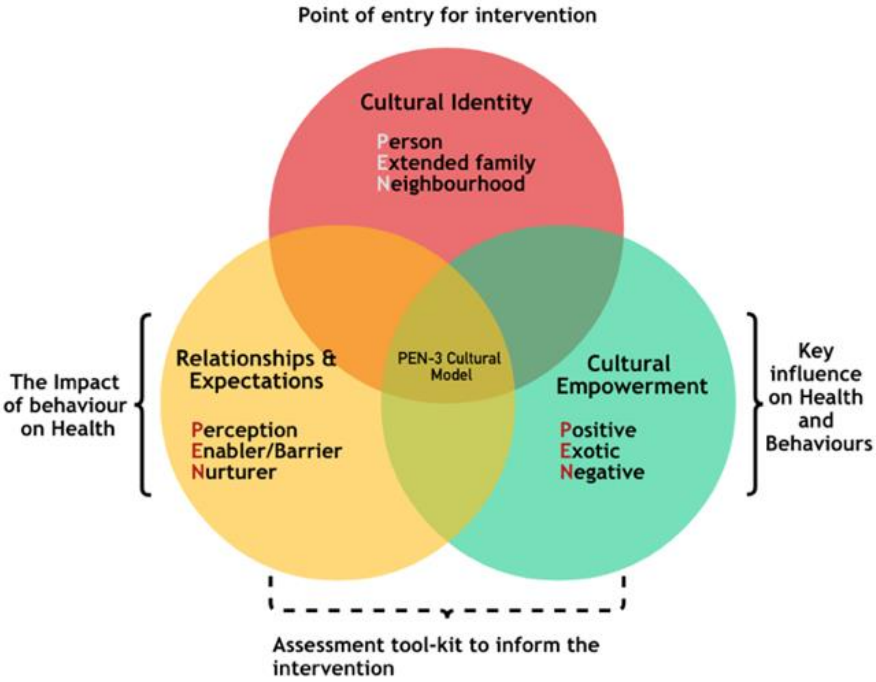

Figure 2.1: PEN-3 cultural model (Airhihenbuwa, 1989).

2.3.4 Data extraction

We developed our own data extraction form to best match the review aims in accordance with robust systematic review guidance (Higgins, 2011). The form was piloted for feasibility by the two authors (BA and BJ). Data extraction, which was performed by BA and confirmed subsequently by two reviewers (BJ and KH), took place in two stages. First, we extracted data on study authors and year, methodology, methods of data collection, sample and population characteristics, and heart failure severity and the impact of culture (see Table 2.3). Second, data related to the cultural impact were subsequently summarised (see Table 2.4). The use of assessment properties of the PEN-3 model resulted in the cultural findings being framed and organised to centralise culture at the core of intervention development. Table 2.5 shows the findings of additional analysis undertaken by cross-tabulated themes with components and subcomponents of the PEN-3 model.

Table 2.3: Selected articles in this systematic review

Article	Author (date); Country	Methodology	Data collection methods	Sampling	Sample no. (male/female ratio)	NHYA class	MMAT
1	Artinian et al. (2002); USA	Descriptive correlational	Investigator-designed questionnaire for sociodemographic data, a 4-point self-rated NYHA scale for severity and a 5-point self-perceived health scale, plus a 15-item heart failure knowledge test.	Non-probability (quota)	123 Pts (89/32)	The total means 2.57±1.25 equal to class III.	Moderate
2	Barg et al. (2017); USA	Grounded theory	Open-ended, semi-structured telephone interviews with a sample from a previous study. Process not adequately described. Modified grounded theory analysis was employed	Purposive	39 patients (32/7) 42 caregivers (9/33)	III and IV; 100%	Moderate
3	Dickson et al. (2013); USA	Mixed methods	Concurrent nested design using semi-structured guided interviews, standardised instrument and self-report surveys for sociodemographic data. Qualitative data have more weight than quantitative data; both types of data were collected simultaneously	Purposive	30 patients (18/12)	III; 67%	Moderate
4	Etemadifar et al. (2015); Iran	Descriptive, exploratory, qualitative	Semi-structured interviews were utilised and conducted according to patients' preferences. Field notes were documented based on researchers' observations. The study adopted an inductive approach and data collection	Purposive	21 caregivers (5/16)	NS	Moderate

			continued until full saturation, when no new threads emerged.				
5	Jiang et al. (2013); Taiwan	Phenomenological	Semi-structured in-depth interviews were conducted by the team in a cardiac ward/post-discharge unit. Caregivers were interviewed when possible; however, in the case of disagreement, patients' words were preferred	Purposive	12 patients (8/4)	NS* (frequent rehospitalisation and advised fluid restrictions)	Low
6	Lip et al. (2004); UK	Cross-sectional	Questionnaire-based interviews conducted after initial pilot. Three researchers interviewed patients in English, Urdu, Punjabi, and Hindi. Interviews were conducted in a standardised way, as far as possible.	Consecutive	103 patients (66/37)	III and IV; 62.2%	Moderate
7	Mau et al. (2017); Hawaii	Randomised controlled trial	Three health behaviour questionnaires were used at baseline and at 12-month follow-up: 23-item Kansas City Cardiomyopathy Questionnaire, 10-item Centre for Epidemiological Studies of Depression Scale; 12-item Health Survey.	Randomised	150 patients (103/47)	III; 11%, IV; 48%	High
8	McCarthy et al. (2015); USA	Mixed methods	Sequential transformative design study. Quantitative data collected first using the Self-Care Heart Failure Index, Duke Activity Status Index, Patient Health Questionnaire and a standardised survey to estimate heart failure severity. Data were collected qualitatively through, semi-structured interviews	Convenience sample as part of Dickson et al. (2013)	30 patients 18/12)	III; 65%	Moderate

9	Moser et al. (2014); USA,China,Taiwan,Netherlands, and Sweden	Observational	Interviews to obtain sociodemographic data; clinical data collected from medical records; symptoms identified using the Minnesota Living with Heart Failure Questionnaire.	Purposive	720 patients (455/265)	III and IV; 69.9%	Moderate
10	Namukwaya et al. (2017); Uganda	Constructivist grounded theory	Serial qualitative in-depth interviews conducted three times at 3-month intervals; interview consisted of 9 open-ended questions with multiple prompts**	Purposive	21 patients (6/13)	III and IV; 100%	Moderate
11	Parkand Johantgen (2016); USA vs. China and Taiwan	Cross-sectional, observational	All participants who had completed all symptom inventories in terms of symptom reporting and clusters were included in the study***	Secondary analysis of Moser et al. (2014).	480 patients (308/172)	III; 48.5% IV; 23.5%	Moderate
12	Pattenden et al. (2007); UK	Phenomenological qualitative study	Semi-structured interviews were conducted in patients' homes by a qualified, bilingual researcher; 60% were interviewed with caregivers. Patients and caregivers had separate sets of questions. Interview notes were taken during and after each interview. An interpreter attended one interview	Purposive	36 patients (23/13) 20 caregivers (2/18)	III; 36% IV; 22%	High
13	Rong et al. (2016); China	Descriptive qualitative study	Semi-structured interviews were conducted for 30–60 minutes until full saturation. All sessions took place in an accessible room in the cardiac ward	Purposive	15 patients (9/6)	III; 40% IV; 20%	Moderate

Table 2.4: Data extraction summary of the cultural impact outcomes.

Author (date); country	Population focus	The impact of culture
Artinian et al. (2002); USA	African American communities	Culture and related sociodemographic factors inform patients' lay heart failure self-care knowledge and adherence
Barg et al. (2017); USA	LVAD-DT community (European American, Native American, and African American)	This cultural appreciation of the use of technology in healthcare affects patients' perceived control over treatment preferences and decisions
Dickson et al. (2013); USA	African American community	The culture endorses supernatural assumptions as a cause of heart failure, which limit perceived control over health and motivation to engage in healthy self-care practices
Etemadifar et al. (2015); Iran	Iranian caregivers' community	Carers lack a clear understanding of heart failure and rely on lay cultural beliefs. They believe that religion and culture are the main source of knowledge, due to perceived role ambiguity
Jiang et al. (2013)/;Taiwan	Older Chinese/Taiwanese community	Patients are bound more to cultural beliefs about food, medicinal products, exercise intolerance, and the importance of family, than to the health recommendations provided. Culture also creates barriers to asking clinicians questions or interacting with them
Lip et al. (2004); UK	Multi-ethnic, multicultural communities (including white European, Indo-Asian, and Afro-Caribbean)	Ethnic, cultural, and religious beliefs guide patients' perceptions of heart failure and its treatments. As a result, the majority of patients lack a clear understanding of the disease, including its symptoms, perceived control over the condition, and adherence to treatment

Mau et al. (2017); Hawaii	NHOPI communities	Health education programmes have a positive impact on the understanding of heart failure morbidity and mortality when they are consistent with cultural beliefs and provided by trained staff in a sensitive manner
McCarthy et al. (2015); USA	African American community	Exercise was defined based on patients' cultural context, which led the majority of patients to refuse to take part in cardiac rehabilitation programmes, particularly those living in low socioeconomic groups
Moser et al. (2014); USA, China, Taiwan, The Netherlands, and Sweden	Western (USA and Europe) vs. Eastern (Asian) communities	Understanding of symptoms, symptom experience, symptom reporting, and clustering were consistent across different cultures
Namukwaya et al. (2017); Uganda	Kampala Communities, Uganda	Cultural context informs health beliefs, decisions, and behaviours
Park and Johantgen (2016); USA vs. China and Taiwan	Western vs. Eastern communities	Eastern patients have a similar order of distressing symptoms to their Western counterparts. However, they show delayed symptom reporting, are less able to recognise the change in psychological symptoms, and underestimate the severity of disease compared with patients from Western backgrounds
Pattenden et al. (2007); UK	Patients and caregivers of South Asian origin living in rural and urban Scottish and Irish communities	Culture is responsible for the formation of most health beliefs and behaviours. This also applies to people who have migrated from Eastern to Western cultures
Rong et al. (2016); China	Older Chinese communities	Chinese patients are unable to adhere to dietary and fluid restrictions due to the conflict of these with their innate cultural beliefs and religion. Culturally influenced beliefs should not be ignored, particularly among older generations living in low socioeconomic groups.

LVAD-DT, left ventricular assisted device-destination therapy; NHOPI, Native Hawaiian and Other Pacific Islanders.

Table 2.5: Modified PEN-3 Model crosstabulation analysis

Second domain (Relationships and expectations)	**Theme**	**Third domain (Cultural empowerment)**		
		Positive	Existential	Negative
Perceptions (cultural values and beliefs held by people about their heart failure affecting the knowledge and understanding of it).	The understanding of symptoms, and reporting and clustering	Physical symptoms are top priority. Symptoms that develop quickly and intensely should be reported, as they indicate heart failure exacerbation	The ranking orders of physical symptoms	Eastern patients had significantly lower perceived severity of disease and sensitivity to psychological symptoms. Subjective understanding of symptoms and their severity. The reported symptoms need to be confirmed and consistent with being severe as defined by the community.
	Lay knowledge and beliefs about heart failure	Common understanding was relatively uninformed within each culture	Lack of knowledge	Cultural non-biomedical understanding of heart failure definition, its causes and treatment. Poor health literacy. Experience-based knowledge, including self-care. Misconceptions about heart failure and new treatments. Perceived role of supernatural power in developing diseases, low perceived control over their condition, and the perceived superiority of traditional healers, food, and medicine. Role ambiguity and caregiver uncertainty when providing care. Perceived family burden if they follow dietary advice.
	Understanding of heart failure self-care	Accepting illness and positive attitudes towards treatment if consistent with the cultural definition of disease.	The history of having a healthy and active lifestyle	Patients do not comply with the treatment regimen (i.e. they skip their medication if they have no symptoms). Misconceptions about self-care practices (i.e. exercise is believed to worsen the symptoms of heart failure).

		The family is responsible for the health, well-being, and follow-up of its members		Misunderstanding of the benefits of a cardiac diet, and a preference for traditional unhealthy food.
		Positive	Existential	Negative
Enablers/barriers (the impact of systems-level factors,which could facilitate or impede any change i.e. help seeking behaviour)	Relationship between cultures and adopting healthy behaviour such as help seeking	The availability of resources (i.e. a range of healthy food and medicines, westernised as well as traditional) Social support and kinship Healthcare system when responsive to patients' unique cultural needs		Low socioeconomic status, costly healthy food and health checks. Emphasis on the importance of family and social kinship and social gatherings more than on health. Lack of a system that combines Western with traditional medicine. No regular health checks and follow-ups unless the patient is seriously ill. Healthcare advice that is culturally incompetent.
Nurturer (the impact of social support and its role in changing health behaviour)		Positive		Negative
		The embeddedness of the caring role Family and friends support the patient's health and well-being Family and friends' understanding of heart failure and the importance of balanced food and a healthy lifestyle during the course of illnesses Friends as a good resource for valuable advice		Food etiquette and family members being burdened by the need to prepare different meals for patients. Suboptimal understanding of family and friends about heart failure and self-care. A healthcare system that is inconsiderate to family members and their needs, and lacks culturally appropriate information, mainly about patients' self-care.

Table 2.5 sets out the findings of additional analysis we have undertaken by cross-tabulation of themes with components and subcomponents of the PEN-3 model. The cross-tabulation of PEN-3 subconstructs contributes towards the first and second aims of the review, since it provides a brief overview of the impact of cultural beliefs on knowledge and understanding of heart failure, systems-level enablers or barriers (help-seeking behaviour), and the nurturer role of social and family support.

2.3.5 Quality assessment

This literature synthesis included quantitative, qualitative, and mixed-methods research papers; we used one quality assessment tool to fit all study typologies. To ensure consistency, we adopted the Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2009) for use with the most common types of empirical studies. One of the reviewers (BA) independently evaluated the 13 studies that were included. The other two authors (BJ and KH) reviewed and assessed each paper for quality assurance purposes. All of the studies were ranked according to the score achieved and the number of criteria fulfilled. Studies were classified as being of low, moderate, or high quality based on the MMAT criteria, along with the quality of reporting and reviewers' critiques based on results. The quality levels are presented in Table **2.3**. These scores informed the data synthesis process.

2.3.6 Synthesis of results

The hybrid design to synthesise results (Sandelowski et al., 2006, Whittemore and Knafl, 2005) allowed the grouping of data into findings by domain rather than by different research methodologies (Sandelowski et al. 2006), as shown in Figure 2.2. Descriptive thematic analysis was utilised for qualitative and quantitative data. We analysed the data and then synthesised the findings according to the five stages of the integrative synthesis proposed by Whittemore and Knafl (2005). First, line-by-line data coding and grouping were performed according to the domain. Second, these codes were evaluated and compared within each domain. Third, qualitative and quantitative data were combined using the integrated design of mixed-methods synthesis. (Sandelowski et al., 2006). The integrated design was appropriate as it allowed the synthesis and assimilation of quantitative and qualitative data together to explore the type, size, and consistency of the cultural impact. Fourth, data comparison involved coding and summarising data related to aspects of the influenced domain about the understanding of advanced heart failure. Data were also compared within similar data sets. The conclusion and verification stage involved classifying themes according to their relationships with the understanding of heart failure. All of the authors have independently analysed the data and then verified them collectively. Three themes were constructed independently of the model constructs, and solely by scrutinising the information from the primary resources constructed themes were then mapped on to the model.

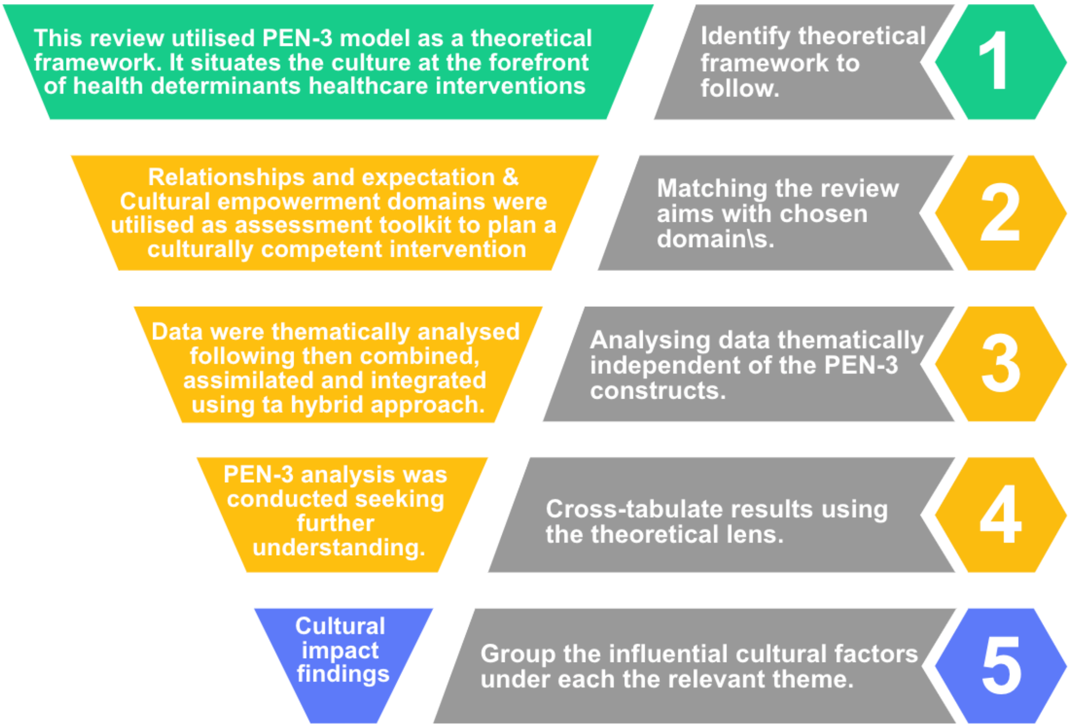

Figure 2.2: Data analysis and synthesis steps

Using the PEN-3 model, we examined participants’ cultural values and beliefs that affected their understanding of heart failure, which ranging from positive to negative, as illustrated in Table 2.5. This achieved the first aim. The other two subconstructs were employed to achieve the second aim. Themes were cross-checked with the included studies by the review team to ensure coherence and consistency of the issues related to the cultural impact across the analysis phase, so as to enhance the credibility and reliability of the review findings.

2.4 Results

2.4.1 Study selection

The scientific and grey database searches retrieved 5977 citations; titles and abstracts were screened using Covidence systematic review software (www.covidence.org). To avoid selection bias, BA, BJ, and KH independently reviewed these articles. In total, 11 articles met all the inclusion criteria for our study, and an additional two papers were identified through citation chaining and electronic hand searching of the *European Journal of Cardiovascular Nursing* and the *European Journal of Heart Failure* from January 2015 to March 2018. The screening process is illustrated in Figure 2.3.

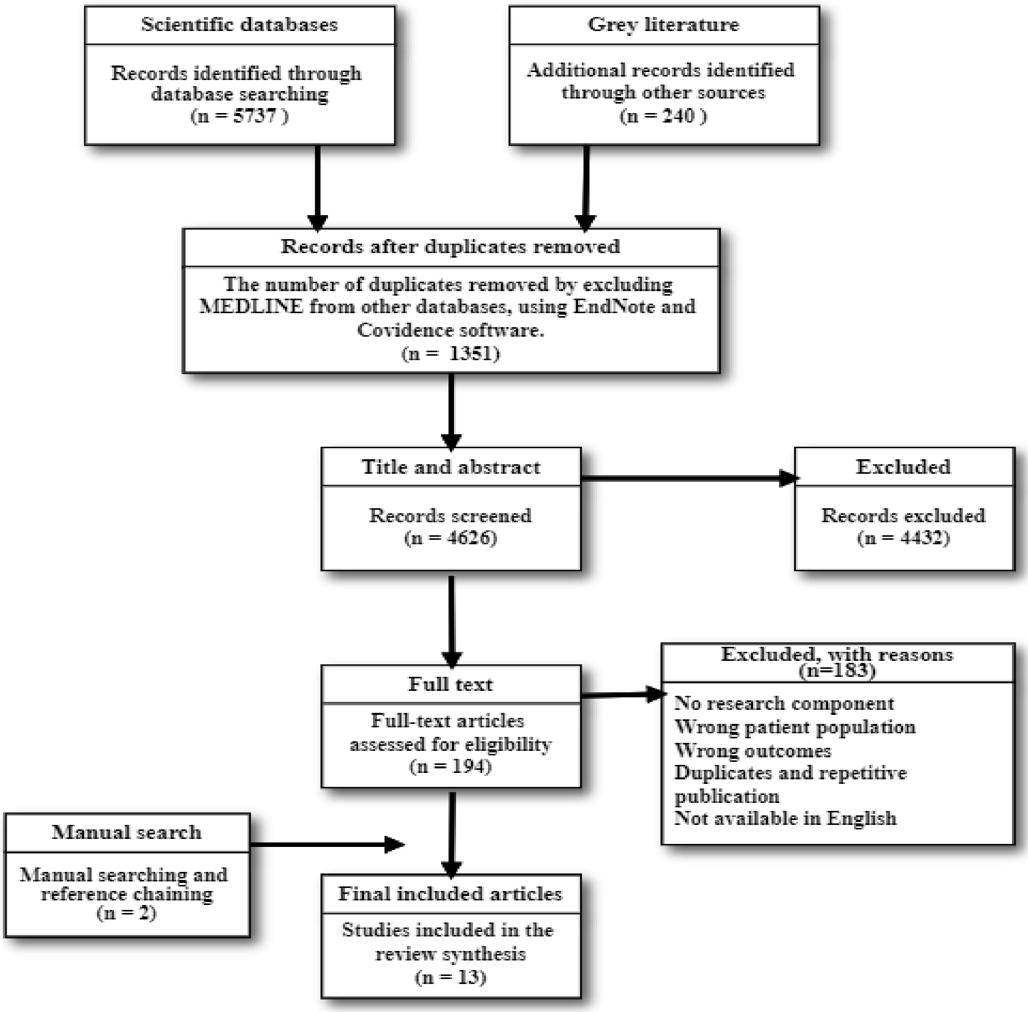

Figure 2.3: PRISMA flowchart through the review process

2.4.2 Study characteristics

A total of 13 articles published between 2002 and 2017 were reviewed. Table 2.5 lists these numbered articles. There were six qualitative studies (Articles 2, 4, 5, 10, 12, and 13), five quantitative studies (Articles 1, 6, 7, 9, and 11), and two mixed-methods studies (Articles 3 and 8). Most of the studies were conducted in Western countries (n = 7) (Articles 1, 2, 3, 6, 7, 8, and 12). The majority of the studies considered patients only (n = 10), two studies included caregivers with patients, and there was only one study of caregivers (Article 4). There were dyads of patients and their caregivers in four studies (Articles 2, 5, 10, and 12). None of the studies considered the clinicians' perspective. In total, 11 studies collected data fully or partially in hospital settings (Articles 1, 3, 4, 5, 6, 7, 8, 9, 10, 11, and 13).

Many included studies were methodologically limited, with significant variation and flaws. There was often limited detail about the strategies used to enhance the trustworthiness and rigour in the primary studies, affecting the interpretation and synthesis process. See Appendix II,(G) for the assessment of each included study. The methodological limitations were considered when interpreting the findings and the scores informed the data synthesis process. However, given the limited number of evidence, none of the studies were excluded based on quality scores.

2.4.3 Review domains

The constructed themes can be integrated into a layered onion model (Figure 2.4). This diagrammatic model depicts the multi-layered interrelationships between cultural beliefs and values and the understanding of advanced heart failure at different levels or layers. At the centre of the onion, the coloured tiles are the main themes, which have an impact on all the other layers. First, there is the influence of culture on lay knowledge and understanding of all aspects of heart failure. Second, culture is emphasised as a major component of how advanced heart failure symptoms are perceived and grouped. Third, cultural norms and values could be negatively or positively associated with self-management behaviours. The middle layer represents the way in which patients conceptualise the collectively agreed values and beliefs of the community. Therefore a deeper understanding of this layer would guide and, to a certain extent, provide explanations for the ways in which multiple cultural milieus, along with other factors, interact to produce unique health decisions and behaviours. The outer layer shows the explicit influences of the culture on the understanding of heart failure. Cultural influences on understanding were seen to be iterative and ongoing. The three constructed themes all overlapped. Inconsistencies between patients' own beliefs and health recommendations limit the understanding of syndrome and the adoption of certain healthy behaviours.

Figure 2.4: Cultural impact on the understanding of advanced heart failure

2.4.3.1 Lay knowledge, beliefs and perceptions about heart failure

Several studies have shown that most patients lack a clear understanding of what heart failure is (Articles 1, 4, 6, 10, and 12), why they developed heart failure (Articles 10 and 12), and the implications of a heart failure diagnosis (Articles 1, 6, 10, and 12) (Table 3.1). For instance, one-third of the enrolled subjects and almost two-thirds of Asian patients were unaware of their heart failure diagnosis (Article 6). Furthermore, patients and their families appear to refer to heart failure and define its meaning differently across cultures; none of these even approximated to biomedical explanations (Articles 3, 6, 8, 10, and 12). Finally, the research evidence demonstrated that most non-Western patients consider families, friends, and traditional healers to be their main sources of knowledge about heart failure. Conversely, and interestingly, they considered healthcare professionals to be their main sources of information during the advanced stages of disease (Articles 1, 3, 4, 6, 7, 10, and 12).

Patients with advanced heart failure and their families acknowledged that cultural beliefs had shaped how they managed their chronic illness (Articles 4, 5, 8, 10, 12, and 13). This cultural appreciation also has a marked effect on perceived control over the patient's condition (Article 6), self-care knowledge (Articles 3, 5, 8, 10, 12, and 13), treatment preferences and decisions (Articles 2, 5, 8, 10, 12, and 13), and family caregiving roles during the advanced, end-of-life stage (Article 4) (Table 3.1). People frequently ascribed patient struggles with having a 'bad heart' to supernatural assumptions such as 'God's will' (Article 12), stressors (Article 3), and devil spells or bewitching (Article 10). This cultural misconception led patients to continue worshipping, accepting distressing symptoms, or practising stress reduction techniques, although these behaviours were not regarded as self-care but as their normal cultural practice (Articles 3, 4, 5, 6, 8, 10, 12, and 13). This highlights another distinct understanding of the disease that is directly linked to cultural health beliefs.

In addition, lay cultural knowledge was found to affect the acceptance of treatment. One of the studies (Article 2) proposed that the cultural milieu influenced decisions, behaviours, and therefore post-treatment experience with left ventricular assist devices (LVADs). This effect on beliefs about treatment decisions was seen to be particularly important for those in low socio-economic groups (Articles 1, 3, 8, 10, 12, and 13).

Our synthesis demonstrates that lack of understanding led family caregivers to rely on cultural norms when caring for their loved ones (Articles 2, 4, and 5). It was clear that being ignored by the healthcare system and other family members further aggravated the role ambiguity and state of uncertainty (Articles 2 and 4). Caregivers were found to be assisting other family members rather than carrying out 'caregiving responsibilities' (Articles 4 and 5). For example, in Article 4, the caregiver's role was attributed to cultural and religious beliefs (i.e. Allah-centred caring). This culturally bounded understanding of caregiving confirms the results presented by Article 12 eight years previously in a similar culture.

2.4.3.2 Understanding symptoms, reporting and clustering

The studies suggested that patients' understanding of symptoms and the ways in which they responded to them were strongly linked to their own cultural and personal beliefs (Articles 3, 5, 6, 9, 10, and 11). For patients with heart failure, symptoms were subjectively understood, reported, and derived from their cultural milieu (Articles 3, 6, 9, 10, and 11). The more advanced the heart failure, the more likely it is that the patient will have serious symptoms. However, patients were reluctant to report symptoms, as they needed to be legitimised and consistent with the culture-specific definition of severe symptoms. For instance, some African cultures legitimise abdominal swelling and leg swelling as serious symptoms that may prevent people from working, or may require the seeking of help (Articles 3 and 10).

Understanding of symptoms and how they cluster across cultures was reported in two studies, which yielded conflicting findings (Articles 9 and 11). It was clear that each culture had a tendency to report similar types, patterns, and clusters of symptoms. However, contradictions were found when Eastern and Western cultures were compared. With regard to physical symptoms, the ranking orders of physical symptoms were relatively similar across different cultures but not symptom severity scores. However, psychological symptoms were perceived differently and subjectively across cultures (Articles 9 and 11). Patients from Eastern cultures may have delayed symptom reporting, been less able to recognise changes in psychological symptoms, and underestimated the severity of disease compared with patients from Western backgrounds (Articles 6, 9, and 11).

In Article 9, symptoms were identified and labelled according to type, and demonstrated that the physical and emotional clusters were mainly consistent across cultures. However, Article 11 describes some differences triggered by cultural beliefs and values, in which symptom labelling was based on symptom intensity. For instance, patients from Western cultures reported a higher symptom distress score for 75% of symptoms compared with those from Eastern cultures. The symptom clusters in the Eastern cultures differed in terms of the number of classes and their composition. The influence of culture on understandings of psychological symptoms, such as depression, was more evident in Western cultures than in Eastern ones. Eastern cultures were also more likely to ignore psychological symptoms and to perceive physical symptoms as less severe. Unsurprisingly, as symptom order was not different across cultures (Articles 9 and 11), the findings confirm that culture shapes the decisions of patients with advanced heart failure when monitoring, identifying, evaluating, and linking symptoms to heart failure and how they respond to them.

2.4.3.3 The understanding of self-care for heart failure

Culturally coined beliefs about self-care for heart failure were a major determinant of the ability of patients from non-Western cultures to adhere to self-care practices. Our results demonstrate the fundamental role of the understandings of the patient’s family and friends, and therefore support the need to enhance heart failure self-care among traditional cultures (Articles 3 and 8). However, the understanding of self-care is defined by culture, and adherence to and performance of self-care are moulded by other co-impacting interdependent factors such as age, ethnicity, religion, socioeconomic status, and linguistic factors in traditional societies. Furthermore, these factors have the potential to modify culturally influenced beliefs about self-care. The problem with self-care is twofold. Patients are not only failing to adhere to self-management of their disease, but are also developing a blasé attitude toward change, even if this is followed by worsening symptoms or rehospitalisation (Articles 1, 3, and 5). This was also found in patients with advanced heart failure (Article 13). For instance, cultural dietary habits, especially for people on low incomes, were problematic; patients found it difficult to reconcile switching to a cardiac diet or monitoring their salt and fluid intake (Articles 3 and 5).

In terms of self-care, cultural impacts were viewed to be explicit as enablers and implicit as barriers to self-care practices. Despite the positive responses with regard to exercise, most participants were neither exercising nor aware of the importance of exercise in heart failure rehabilitation (McCarthy et al., 2015).

Similarly, a sense of contradiction was noted within certain cultures regarding adherence to prescribed medications, particularly when patients expressed admiration and gratitude that was not necessarily reflected in their behaviours (Artinian et al., 2002, Dickson et al., 2013, Jiang et al., 2013, Lip et al., 2004, McCarthy et al., 2015, Namukwaya et al., 2017, Pattenden et al., 2007, Rong et al., 2017). For example, in African American culture, even lifelong adherence to medication was considered an essential step for living. More than two-thirds of participants from the same culture had not correctly answered the questions testing their heart failure knowledge about their medications (Artinian et al., 2002). Furthermore, the longer heart failure symptoms persist, the less likely patients are to trust medications, particularly when biomedical treatment is no longer sufficient to relieve suffering during the advanced stages (Jiang et al., 2013, Namukwaya et al., 2017, Rong et al., 2017).

Most cultures appreciate the importance of family and extended kinship bonds in enhancing the understanding and performance of self-care (Articles 3 and 8). When people understood their disease with a high level of health literacy, family members played a positive role in enhancing positive self-care behaviours. These included adherence to medication, dietary and fluid restrictions, and help-seeking behaviours (Articles 3 and 8). Conversely, family members' poor understanding of self-care practices was influenced by culture (Articles 5 and 13). In these cultures, self-management programmes are viewed as stepping away from the norm and could lead to social isolation (Article 3); becoming a burden on one's family is perceived as the inevitable result of such adherence (Article 5).

Our results also suggest that knowledge of heart failure symptoms and medications was given highest priority on patients' lists of 'unmet needs' (Articles 1, 3, and 12), mainly due to their direct and clear correlation with poor functionality and quality of life. Patients' self-management decisions and actions were consequently based on changes in symptom severity. However, their ability to recognise and evaluate changes in symptoms was often poor, due to subjective monitoring of symptoms (Article 3) – for example, reporting dyspnoea as 'too much pressure' or 'losing breath.' This subjective monitoring was affected by cultural factors and led to unwise actions, such as delayed help-seeking behaviours.

Help-seeking decisions are also based on patients' unique experiences and knowledge, and are easier to make and adhere to if they are consistent with cultural beliefs (Articles 3, 5, 8, 12, and 13). Most studies have suggested the need to identify more culturally appropriate interventions to increase knowledge (Articles 1, 2, 6, and 10), to reduce readmissions and cardiovascular deaths (Article 7), to facilitate self-care and enhance compliance (Articles 1, 3, 5, 8, 11, and 13) and to achieve better dyadic emotional, psychological, and coping support (Articles 2, 4, 6, 7, and 12). Our finding suggests that interventions were tailored to Western culture (Articles 5, 10, and 13) and implemented worldwide. These interventions need to be culturally customised before they can be implemented for cultural groups residing in Western countries. Although these groups do to a certain extent adapt to their host cultures, decisions regarding self-care are often driven by their original cultural beliefs (Article 1, 2, 3, 6, 7, 8, and 12). There is reasonable evidence that interventions in which appropriate cultural modifications are applied produce better health outcomes. For instance, Article 7 provided evidence of the effectiveness of programmes that fitted with cultural beliefs and were provided by trained registered nurses to patients and family members using interactive teaching techniques.

2.5 Discussion

This mixed-methods review has identified three constructed themes relating to the influence of culture on the understanding of advanced heart failure. These themes were examined through a theoretical lens. The PEN-3 model was utilised and served as a tool to assess, analyse, and synthesise the cultural impacts according to patients' and family members' understanding of heart failure across different cultures (see Table 2.5). This study was challenging, as our broad search strategy retrieved only 13 relevant articles, none of which directly addressed the cultural understanding of heart failure directly.

However, all of the studies investigated the effects of cultural beliefs on patients' and/or family members' understanding of heart failure, although none of them explicitly explored the understanding of healthcare professionals. These cultural insights could be critical for developing complex interventions to overcome obstacles triggered by cultural misconceptions. Furthermore, there was a lack of consistency in methodological rigour across many studies. This included tool utilisation, data analysis methods, and even the definition of culture, as a universal consensus on this definition is not available at the time of writing.

We found that people from non-Western cultures, whether living in a Western country or their original country, are more likely to have a distorted understanding of heart failure because of the cultural ideas and beliefs that have been passed down from one generation to the next. People living in modern or Western cultures who adopt biomedical ideologies are also more likely to thrive on change (Ibeneme et al., 2017, Lip et al., 2004, Pattenden et al., 2007). Often, traditional cultures believe that faith, religion, and culture are integrated and intertwined, and culture and technology have always been interconnected. Patients therefore tended to accept their fate because of their inherent cultural faith in healthcare (Truitt and Verdial, 2017).

Our findings suggest that lay knowledge about the diagnosis, causes, treatment, and self-management of heart failure is predominantly influenced by cultural context. From a qualitative perspective, the impact of culture on lay knowledge was cumulative, starting early and occurring at every stage of the heart failure trajectory up to its advanced stages. Each culture shares a specific set of interwoven values, beliefs, and behaviours that influence patients' and families' understanding of advanced heart failure. Patients from non-Western cultures were keen to control their condition and to engage with healthcare services when necessary if this was compatible with their beliefs. However, due to the absence of culturally competent services, they were compelled to seek help from their system of cultural health beliefs. Some of these beliefs limited their perceived control over their condition, leading to further problems with managing healthy behaviours (i.e. help seeking). In summary, neither patients nor their families were adequately prepared for the advanced stage of their illness and for end-of-life care. This problem was noted across all studies, irrespective of study design, country, setting, or date.

Understanding heart failure is a prerequisite for better management across the trajectory of the condition (Sobanski et al., 2019). Despite the recent universal focus on heart failure, people still rely on culturally informed lay knowledge and understanding of the synrome. This review found little empirical evidence of such lay knowledge, and none of the articles considered the correlation between lay knowledge and culture. However, researchers have investigated lay knowledge in an attempt to understand the non-compliant behaviours exhibited by people when they are ill (Popay and Williams, 1996, Rosenstock, 1974), and more recently there has been a growing recognition of the concept of lay knowledge within research (Rabeharisoa et al., 2014), especially in medical sociology.

This review contradicts, in principle, the claim made by Namukwaya et al. (2017) that lay knowledge of heart failure definitions, symptoms, and the use of folk medicine are derived from patient cultural contexts. Our findings are broadly in line with the evidence from the heart failure 'initiative' campaign, where misconceptions and cultural misbeliefs led most people to ignore symptoms or perceive them as age related (Störk et al., 2016). A similar conclusion was reached by others who asserted that cultural health beliefs, from caregivers' perspectives, not only influence lay knowledge and understanding of heart failure but also create it (Fang et al., 2016). Nevertheless, family caregiving is seen as an embedded norm in life and culture in many non-Western cultures (Fang et al., 2016, Grant and

Graven, 2018). Our synthesis is consistent with a previous meta-analysis and reviews which explored the influences of cultural and familial beliefs on heart failure self-care (Attaallah et al., 2016, De Geest et al., 2004, Horne et al., 2013, Sebern and Riegel, 2009, Shahin et al., 2019). Culturally sensitive clinical management depends on clinicians' level of understanding of patients' cultural beliefs and values (McQuaid and Landier, 2018).

Cultural beliefs and norms may influence the understanding and manifestation of symptoms. This view is consistent with previous findings (Zhou et al., 2016). However, our results contradict the conclusions reported by Moser et al. (2014) and Park and Johantgen (2017) about symptom clustering. This may be due to the use of a more advanced analysis technique and symptom intensity-based labelling in these studies. Both of them utilised a customised set of subscales of the original Minnesota Living with Heart Failure Questionnaire (MLHFQ) tool. This may have compromised the validity of the tool and the reliability of the findings, as omitted symptoms could be equally important to some patients, despite the assumed higher readability of the new reduced tool. In addition, the removal of items such as 'difficulty walking or climbing' was not discussed or justified. It remains unclear to what extent symptom clustering is attributed to cultural, ethnic, or societal factors. In parallel with DeVon et al. (2017), we believe that more attention should be paid to understanding how symptoms cluster cross-culturally.

Another significant finding from our review relates to heart failure self-care. When discussing patients' understanding of heart failure self-care in different cultural contexts, it is imperative to understand their unique lifestyle, dietary patterns, and traditions. The data indicate that many cultures were neither motivated nor provided with the necessary skills and knowledge for self-care. Although the majority believed that some of their cultural beliefs led to their poor self-management of their health, they did not agree that a westernised lifestyle was the solution. This gap would be best addressed by culturally competent heart failure interventions that could enhance understanding of self-care and related behaviours, increase service satisfaction, and ultimately improve health-related outcomes. In addition, lay beliefs about heart failure were misleading in terms of symptom recognition, so it is not realistic to expect proper engagement in self-care.

The narratives of poor adherence to self-care (e.g. medication) may be due to communication problems and can be attributed to cultural differences. Therefore a disparity between the person's cultural understanding and the biomedical understanding held by clinicians may lead them to neglect medications or other healthcare recommendations. In addition, there may be a failure to empower family members or keep them in the loop of treatment or conversation. There is a global consensus on the vital role of specialist palliative care services in deploying these approaches and adequately addressing the needs of the patient and their family members (Sobanski et al., 2019, WHO, 2016). Patients from non-Western cultures seek healthcare consultations for more serious or life-threatening illnesses when their traditional treatment fails or their symptoms worsen (Jiang et al., 2013, Namukwaya et al., 2017, Rong et al., 2017). Therefore, if they are to bridge the gap effectively, cultural considerations when developing an intervention should include the patient's language, the social context and role of the family, and patient values and beliefs about the disease.

2.5.1 Limitations

A few limitations were identified during this synthesis. The review was predominantly qualitative, which reflects the recent but growing interest in this subject globally. Qualitative investigations are beneficial as a starting point for exploring a new phenomenon, but the subjective nature of this type of inquiry also carries a risk of bias, and may compromise the transferability of the findings. Moreover, most of the data were collected in hospitals and so may not be representative of the general population. The small sample sizes of the primary studies may also reduce the generalisability of the results.

In addition, the searches were limited to English-language articles, which will exclude some of the literature from non-Western, non-English-speaking cultures, especially from countries across Asia and South America. Finally, research in this field is complex, as the impact of culture is hard to measure, making definitive recommendations for better cultural care provision based solely on these reports problematic. Nevertheless, this area warranting further detailed study.

2.6 Chapter summary

The purpose of this review was to explore how culture influences both the understanding of advanced heart failure among patients and their family members, and the adoption of healthy behaviours. It is apparent that there is much complexity surrounding the effect of culture on the understanding of advanced heart failure, and therefore heart failure-related decisions and behaviours. Particularly among non-Western patients, the role of culture is crucial to the understanding of heart failure and its management. Patients' perception of the severity of their heart failure is primarily based on the severity of the symptoms. Patients act when their symptoms become severe or worsen based on their perceived intensity and cultural interpretations. Patients with heart failure who hold non-Western cultural beliefs are more likely to avoid or delay seeking healthcare services, for reasons that include their lay knowledge and understanding of heart failure diagnosis, causation, symptoms and treatment, coupled with other socioeconomic barriers. Cultural competency is central to patient-centred care, and could be achieved by developing and implementing interventions to support healthcare providers to provide safe and high-quality care for diverse patient groups and their families in a culturally sensitive fashion. These interventions should be tailored to the lay understanding of heart failure so as to maximise the benefit and cultural relevance of health messages, and thus their impact on knowledge and behaviours. The findings with regard to the cultural impact on understanding of advanced heart failure go some way toward explaining both the delayed presentation of patients with heart failure and the underuse of palliative care cardiology services.

Chapter 3 Literature pertaining to the selected methods.

3.1 Introduction

This chapter aims to provide an overview of the literature pertaining to the selected methods, and to discuss the evolution of the chosen research methods and designs. It begins with the philosophical underpinnings of modern nursing research, which are listed in Table 3.1. There follows an explanation of why the chosen paradigm 'critical realism' is helpful for this study.

paradigm	Critical realism
The ontological position	I believe that there is one objective but stratified reality that exists independently of one's own perceptions. People construct understandings about advanced heart failure as a life-limiting illness from the social world around them.
The epistemological position	Our knowledge of *advanced heart failure* is more likely to be fallible and incomprehensive. As we are social beings in a unique context, I believe that this knowledge is mediated by subjective beliefs, perceptions, and interpretations tempered by *our lived experience* and cultural assumptions. *Knowing this is only achievable by accessing people's inner world, through interpretivist thoughts and perception.*
The chosen methodology	In line with my epistemology, qualitative descriptive methods and approaches help to explain how influential the culture has been on participants' understanding and the generative mechanisms that determined their heart failure understanding and help-seeking practices.
Conceptual and theoretical underpinnings	The MRC Framework guided this thesis to inform the development of a palliative care intervention. The PEN-3 cultural model was used as a theoretical underpinning.
Methods	Systematic review Focus group discussions Purposive and snowball sampling Reflexive thematic analysis

Table 3.1:An outline of the literature pertaining to this thesis

A full description of the philosophical, conceptual, and theoretical positions is then given. The chapter also discusses the augmented Medical Research Council (MRC) Framework for developing and evaluating complex interventions, the framework's enhanced and optimised development phase, and the rationale and application of the MRC Framework in this thesis. The final section of the chapter provides an overview of the rationale for deploying open qualitative descriptive epistemology, including the approaches to data collection, analysis, and interpretation that were used.

3.2 Philosophy in research

As new knowledge is obtained through the application of research methodology, the philosophy underpinning research summarises the researcher's beliefs and assumptions, which guide the interpretation of their findings (Creswell, 2013, Denzin and Lincoln, 2011). These underlying assumptions and philosophies upon which the research is based are termed a *paradigm*, which is defined as a 'set of beliefs, concepts, values, and methods that deals with first or ultimate principles' (Guba and Lincoln, 1994). Within each philosophy, some embedded beliefs and assumptions define principles to address, the nature of reality (ontology), the nature of knowledge (epistemology), how values influence the research (axiology), and the methodological underpinnings of the research process (Creswell, 2013, Denzin and Lincoln, 2011). **Error! Reference source not found.** shows the overlap between the v arious ideas and links between the ontology, epistemology, and philosophical perspective and the research application.

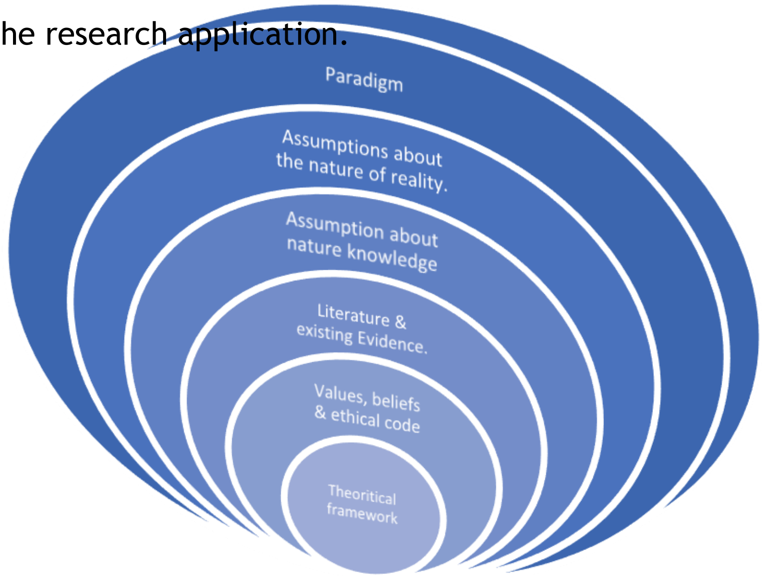

Figure 3.1: The overlapping factors influencing paradigm choice.

3.2.1 Research paradigms in nursing research

Research paradigms have been similarly defined in nursing literature to denote the conceptual grounds where the quest for meaning, knowledge, and realities is rooted (Weaver and Olson, 2006). However, here there is more focus on the impact of a particular paradigm on the research problems and structure of inquiry, and how it guides the choice of methodology: 'paradigms are patterns of beliefs and practices that regulate inquiry within a discipline by providing lenses, frames and processes through which investigation is accomplished' (Weaver and Olson, 2006).While paradigm was perceived as a nexus between aims and methods, this new knowledge helped understand the research problem and refine the process accordingly. Consciously or otherwise, this understanding would enhance the quality and relevance of nursing research through making informed and evidence-based methodological decisions (Ryan, 2018, Weaver and Olson, 2006). So, researchers are called to be clear about the philosophical underpinning their work in order to make explicit methodological choices that answer their research question and guide their choices, data handling and determine the entire research approach before beginning the research (Creswell and Creswell, 2018, Davies and Fisher, 2018, Mills et al., 2006, Ryan, 2018).

3.2.2 Exploring Key paradigms in nursing

a Denzin and Lincoln (2011) recognised six major paradigms in nursing research: positivism, post-positivism, interpretivism, critical theory, constructivism, and participatory action frameworks. However, Weaver and Olson (2006) noted that positivist, post-positivist, pragmatism, interpretive, and critical social theory mainly used paradigms in nursing research. The two dominant paradigms are interpretivism (or subjectivism) at one end of the spectrum and positivism (or objectivism) at the other, and most of the discussions on ontology and epistemology in healthcare research are based on these (Barbour, 2018, Flick, 2014, Polit and Beck, 2018). This research is situated in the nursing and anthropological domains where various research approaches are used, each with different philosophical assumptions. Before considering the methodology described in this thesis, it is important to briefly summarise the main research paradigms in nursing. This chapter focuses on 'critical realism' as the research paradigm that guided this PhD study.

3.2.2.1 Positivism

According to the positivist ontology, the world is 'real', ordered, and regular, and that fact is driven by immutable natural laws and mechanisms (Corry et al., 2019, Denzin and Lincoln, 1994). Positivists are seen as reductionist and deterministic, and they generally believe in objectivity and follow a hypothetico-deductive testing model to emphasise it (Welford et al., 2011, Young, 2008). Tight control over the context is needed to assume generalisations and enrich researcher credibility (Athens, 2015, Guba and Lincoln, 1994, Lincoln, 2007, Young, 2008). Epistemologically, positivists are wedded to a character vision of the world, wherein the reality is absolutely fixed, and people are assumed to have personal beliefs and act according to them (Reason and Bradbury, 2008). Therefore, positivists believe in distinguishing between people who experience reality and those who study it (dualism). Axiologically, the researcher must maintain scientific neutrality and not allow their own beliefs and values to cloud the facts (Ryan, 2018, Weaver and Olson, 2006). Consequently, their investigations tend to use scientific methodology, and the methods utilised commonly include experiments and surveys (Polit and Beck, 2013).

3.2.2.2 Post-positivism

The paradigm is empirical, orthodox, scientific, and experimental, with an objective epistemic position (Creswell, 2013, Creswell, 2014). It is considered to be a ‘softer’ type of positivism that follows the same principles but specialises in falsifying hypotheses (Creswell, 2013, Lincoln, 2007). However, the previous claim of the absolute truth of knowledge is contested, and the researcher is separated from the participants or study data (Phillips et al., 2000, Tanlaka et al., 2019, Welford et al., 2012). In postpositivist views, realities are neither absolutely certain nor fully understood, and knowledge is iteratively developed through repetition (Weaver and Olson, 2006). Their philosophy offers nursing research a better mechanism for developing appropriate knowledge and addressing complex human phenomena.

Post-positivists do not emphasise strategies and methods as much as the positivists do. Instead, they advocate methodological pluralism and allow multiple perspectives (Denzin and Lincoln, 2011, Guba and Lincoln, 1994, van der Poll et al., 2019). Nevertheless, they remain more quantitatively oriented (Scotland, 2012). This position led to the paradigm being viewed as an extension of positivism (Creswell, 2013, van der Poll et al., 2019), and critiqued for its failure to address the whole person, while other scientists refuted the claims because post-positivism values all methods and attempts to address holism (Schumacher and Gortner, 1992).

3.2.2.3 Interpretivism

Interpretivists pay particular attention to comprehending the meaning that individuals ascribes to their own actions and others' reactions (Ryan, 2018, Weaver and Olson, 2006). Interpretivism, which incorporates an anti-positivist position, assumes more than one situated reality and therefore adopts a relativist ontology (Creswell, 2013, Denzin and Lincoln, 2017, Weaver and Olson, 2006). A hypothesis is formulated to generate and test a theory inductively (Morse and Field, 2013, Ryan, 2018). Reality is viewed as complex, multifactorial, context dependent, culturally and historically situated, and impossible to identify objectively (Creswell, 2013, Monti and Tingen, 1999). Since the focus is on drawing understandings from multiple sources and interpreting human behaviours and lived experiences. Interpretivists believe in developing objective outcomes from a subjective perspective. This philosophy, which only appears to be a paradox, makes it possible to reconcile objectivism and subjectivism, which is the power of interpretivism in nursing (Denzin and Lincoln, 2017, Weaver and Olson, 2006, Welford et al., 2011).The understandings that researchers and participants develop are essential for the accurate interpretation of reality and phenomena that are analysed through the eyes of people involved, using their experiences and conditions (Ritchie et al., 2013, Welford et al., 2011). However, researchers must acknowledge and take into account the influence of their values and experiences on their work (Creswell, 2014). Methodologically, approaches can be chosen to capture subjective experiences, display multiple perspectives (such as observations and interviews), and combine qualitative and quantitative approaches.

3.2.2.4 Pragmatism

Pragmatism is a movement that advocates a combination of qualitative and quantitative methods and the inclusion of interpretivism and positivism to aid understanding of the effects of ideas and actions (Creswell, 2014, Kelly et al., 2017, Polit and Beck, 2013). Pragmatic ideology is relational (adopting a 'middle position') and rejects the dichotomy between objectivists and subjectivists, preferring moderate common-sense forms of what works best based on how the methodology resolves the research question from the researcher's perspective (Kankam, 2019, Maarouf, 2019, Morgan, 2007). Pragmatism could also have been considered as a research paradigm for this study. However, it would be argued, firstly, that pragmatisms principal purpose is to claim knowledge derived from experience and real situations for practical application and solution, and not to generate interest-based knowledge (Creswell, 2014, Maarouf, 2019). Secondly, the ontological position of pragmatism is neither realist, nor interpretivist, but experientialist, and is not committed to any specific system of reality. This does not work well with the ontological basis of this study, which asserts that the truth is objectively real, and but cannot be fully accessed. Given the dynamic nature of culture, people act and interact based on how they understand things, and therefore, there is an implication of multiple interpretations and meanings that can only be addressed through a relativist epistemological position. Hence, when investigating cultured understanding, our social history and cultural background may inform our understanding of this objective reality. (Creswell and Creswell, 2018, Kelly et al., 2017). Although the initial plan was to conduct mixed methods research, including an e-Delphi survey and a qualitative descriptive study, the current study is qualitative descriptive one with greater emphasis placed on the focus group data and the reflexive thematic analysis informed by the systematic review. The choice of paradigm occurred as part of an iterative process, as well as the interplay between my personal beliefs and assumptions. I needed methods to answer "knowledge-oriented" research resulting in critical realism as the paradigm choice for this thesis.

3.2.2.5 Critical and other Meta-Theories.

Critical theory is one of the meta-theories, which are characterised by their broad perspectives and beliefs that structure navigates and guides human actions (Bronner, 2011, Ryan, 2018). Accordingly, critical theory places a strong emphasis on the influence of sociocultural circumstances, which often inform the process of data analysis (Allana and Clark, 2018). Theorists believe that truth exists as 'taken-for-granted' reality, and that the surrounding factors shape reality over time (Guba and Lincoln, 1994). Like positivist and postpositivist theories, these theories are ontologically realist but epistemologically different. Specifically, the view of one objective and value-neutral reality exists outside the human mind and perception. There are two systems of contrasting philosophies within realism, namely empirical realism and critical realism. Empirical realism assumes that reality can be accurately comprehended by our senses. On the other hand, critical realism (established by Roy Bhasker during the 1970s and 1980s) states that the world image received through the senses might be neither accurate nor true. Both claim that knowledge comes from human experiences and interactions, but differ in their view of how this knowledge can be used to understand reality, as relying on one's senses to know and interpret realities may lead to false conclusions (Bhaskar, 2013).

Critical theory is to a certain extent similar to the critical realists' beliefs about the nature of reality, and it acknowledges the researcher's influence on the researched phenomenon (Guba and Lincoln, 1994, Ryan, 2018). Nevertheless, critical realism has a broader scope as it does not exclusively emphasise structure or context. As a middle-ground position, critical realism grew out of the 'paradigm wars' between the contradictory positions – positivism and interpretivism – and developed beyond its polarity (Clark et al., 2008). Others have further discussed, clarified, and elaborated on the resulting conclusions (Bhaskar, 2013, Clark et al., 2008, Denzin and Lincoln, 2011, Fletcher, 2017). For example, Maxwell (2012) defined critical realism as shown in **Error! Reference source not found.**.

Critical realism combines realist ontology (the belief that there is a real world that exists independently of our beliefs and constructions) with a constructivist epistemology (the belief that our knowledge of this world is inevitably our own construction, created from a specific vantage point).

Textbox 3.1: The definition of critical realism by Maxwell (2012, p.180)

3.3 Critical Realism

Critical realism draws insights from the agency, structure, and their own powers to understand and explain causal relationships and important contextual influences (Bhaskar, 2013). The context is a multilayered construct that includes issues related to systems, situations, and people (La Roche, 2012). Knowing how individual and context factors interact to inform outcomes and influence actions causally in everyday practice, causation represents the experienced outcomes generated in complex interactions. The diversity of methods permitted helped to explain the interplay between agency, structural, and related power and various generative mechanisms that produce the current influenced outcome (Fletcher, 2017, Maxwell, 2012). It was argued that qualitative descriptive research, not only theory-bound techniques, are ideal for this position due to substantial differences in how each engages with existing theory (Doyle et al., 2020).

The epistemological processes of critical realism for examining 'how to know and uncover the assumed reality' are abduction and retroduction. The aim of abduction is not to develop a new theory but rather to identify the best framework that fits and demystifies the phenomena under investigation by updating, merging, combining, or adjusting an existing theory to explain the research phenomena. The other procedure concerning critical realism epistemology is retroduction. It focuses on finding the necessary context that triggered the causal mechanism to produce the observed results. In contrast to abduction, during retroduction the critical realists constantly return to empirical data and ask additional questions to identify the mechanisms responsible for particular events. The resulting patterns or tendencies – or, in critical realist terms, demi-regularities – were used to reveal the underlying generative cultural mechanisms of understanding. Distinct from other critical reasoning approaches, they permit more profound interpretations and patterns and expand knowledge beyond the surface-level empirically observable reality (Fletcher, 2017, Maxwell, 2012).

3.3.1 Justification, scope and relevance of critical realism

Critical realists believe that the observed and non-observed outcomes exist or arise due to an interplay between individual-related factors (personal beliefs, values, and attitudes) and context-related factors (social and cultural norms). Critical realism seems a natural fit with health service research, in which researchers are engaged in informing, developing, and evaluating interventions for the interdependent aims of improving health outcomes and the efficiency of service delivery. Similarly, evidence of a causal relationship between the intervention and improvement in health outcomes in the light of the cultural context could be obtained without the need for a randomised trial. However, it would be not achievable without using qualitative methods (Allana and Clark, 2018, Pawson and Tilley, 2001). This is because intervention should be tested in an open system, as closed-system trials assume the context to be controlled or irrelevant to the testing process (Allana and Clark, 2018, Fletcher, 2017). In addition, critical realism has been deemed suitable for explaining social or cultural behaviour through reference to these causal mechanisms and their effects throughout the three-layered 'lily-pond' metaphor for reality (Schiller, 2016) (see Figure 3.2). It is therefore the fundamental principle of choice to underpin our research by the critical realist paradigm.

Throughout this project, I was searching for knowledge about the influence of culture on understanding of heart failure and palliative care. As can be seen in Table 3.1, my philosophical position can be described as critical realist, ontologically realist, and epistemologically interpretivist. The current position implies that the collected data do not lead to direct access to reality, as the reality, in part, remains beneath the observed surface, but the participants' perceptions, interpretations, and beliefs affect their understanding of reality. Along with our philosophy for research methodology, the MRC Framework for Complex Interventions was used as a methodological guide (Craig et al., 2008, Craig et al., 2013, Skivington et al., 2021).

3.3.2 One objective but stratified ontology

Critical realism posits reality via a stratified, three-layered, interconnected but distinct ontology – the empirical level, the actual level, and the realms of the real level (Schein, 2017, Schiller, 2016). Stratified ontology assumes reality to be shaped by social, political, cultural, economic, and ethnic factors that become reified into a series of structures. The stratified ontology is simplified using the lily-pond metaphor to replace the well-known, overrated, and hyped iceberg metaphor. The outstanding intellectual contribution of the lily-pond metaphor lies in its presentation of multiple levels of culture. Edgar Schein’s model has overridden the assumption of ‘static’ culture in favour of a dynamic, ever-changing, and constantly evolving ecosystem, which has enhanced the contemporary understanding of human behaviours.

Firstly, the realm of the empirical level – the seen, experienced, and perceived part of reality – can be measured empirically and is often understood through human interpretations and perceived through 'common sense.' This level of reality is equivalent to objects seen above the water surface (see Figure 3.2), where context implies meanings, ideas, and decisions. However, humans can only observe the empirical scene, which is insufficient for understanding the whole system. Thus any knowledge claim is fallible and can never be certain (Clark et al., 2008). The middle level is the actual domain, where another part of the reality is experienced or interpreted by humans and occurs irrespective of human perception. However, events within this level are true happenings, nurturing and often different from the observed empirical level of reality (Schein, 2017, Schiller, 2016). Finally, the real level pertains to the causal structures or powers. These structures generate all the observable or unobservable events in the actual domain and those empirical events. According to the founder of critical realism, Roy Bhaskar, the deepest level of reality represents the absolute powers that can explain the real-world events, behaviours, or outcomes independent of human understanding and awareness (Bhaskar, 2013)

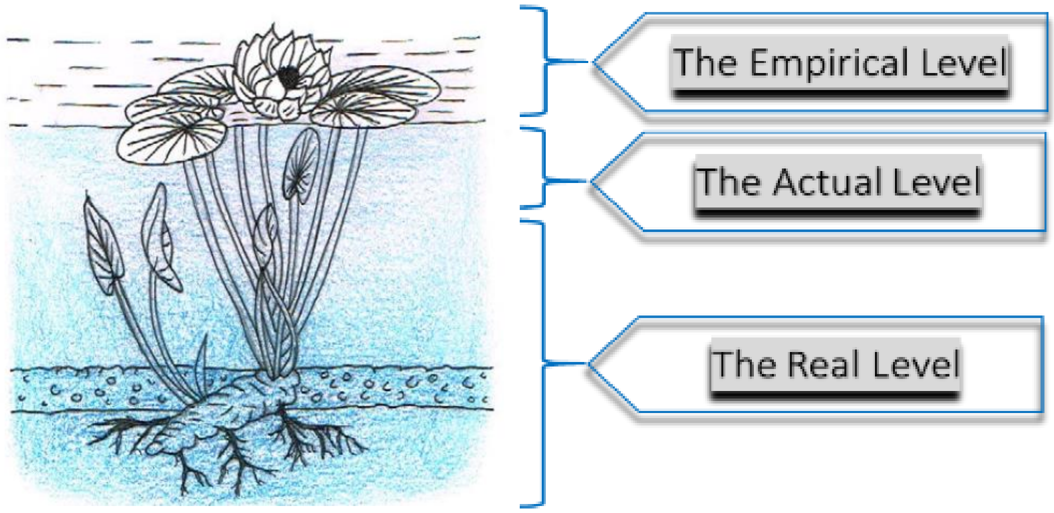

Figure 3.2: The 'Lily Pond' metaphor of reality (The stratified ontology)

3.3.3 Interpretive (Constructivist) Epistemology

This PhD project utilised a critical realist philosophy of science, which is a position between positivism and natural interpretivism. The combined philosophy adopts a realist ontology and an interpretivist epistemology with qualitative descriptive methodology (Fletcher, 2017). A critical realist approach suggests the presence of one objective reality that can be constructed and interpreted differently. To understand the relationship between people's experiences and the underlying mechanisms, critical realists favour and intend to mix different methodologies to answer the research questions accurately (Allana and Clark, 2018). This approach also facilitates the use of components from different research paradigms – positivism and interpretivism – to promote understanding of the complexity of reality but not to try to translate it (Fletcher, 2017). This sound philosophical basis rationalises the methodological pluralism that enables a rich understanding of the subject matter and facilitates exploration of the phenomenon through multiple dimensions before developing complex health interventions (Chiang-Hanisko et al., 2016, Polit and Beck, 2017). The primacy of context, the underlying mechanisms, the explanatory ontology, and the exploratory design make the study methodology remarkably coherent and congruent with the assumed premises, mainly in exploring the stratified reality of each layer, both the tangible events and the intangible mechanisms (Bhaskar, 2013, Zhang and Creswell, 2013). Thus the interpretivist epistemology of the qualitative description is rightly pragmatically oriented and practice focused, allowing patients' or families' perspectives to be appropriately addressed (Grove and Gray, 2018). It complements how that phenomenon is experienced and interpreted instead of emphasising it with perspectives beyond those obtained by the more methodologically rigid approaches (Jolley, 2020, Polit and Beck, 2017, Schiller, 2016). The triangulation of methods and findings confirms those findings (McEvoy and Richards, 2006), ensures their comprehensiveness, explores inferences retroductively, and therefore can validate and generate explanations for effective intervention development (Allana and Clark, 2018, Maxwell and Mittapalli, 2010). In this research, the qualitative descriptive approach allowed a better understanding of the complex nature of the cultural influences and provided multiple insightful perspectives. Typically, this congruent philosophy and methodology reject the longstanding, qualitative or quantitative dichotomy and somehow combine them. In other words, the value here stems from bringing together the objective and subjective knowledge and interpretations of data by observing the same single reality and multiple interpretations while also positioning these perspectives within the sociocultural, political, and historical contexts to provide more robust answers to research questions.

3.4 Theoretical and Conceptual Frameworks

The project conceptually followed the development phase of the Medical Research Council (MRC) Framework and was theoretically guided by the PEN-3 cultural model.

3.4.1 PEN-3 cultural model: theoretical framework

This cultural model consists of three interrelated domains of inquiry, namely relationships and expectations, cultural appropriateness/empowerment, and cultural identity. As shown in Figure 3.3, each domain consists of three subcomponents which are assembled to form the three PEN acronyms and are assumed to represent the overall impact of culture on that particular domain. The relationships and expectations domain is used to identify and foster perceptions, enablers/barriers, and nurturers to enhance or hinder healthy behaviours. The cultural appropriateness/empowerment domain identifies positive values, beliefs, and norms regarding the behaviour of interest, to embrace and encourage it (Airhihenbuwa, 2010, Iwelunmor et al., 2014). In addition, it attempts to recognise and modify existential or negative behaviours for better health outcomes. Finally, cultural identity is formed through the interactions between a person, their extended family, and their neighbourhood. The first two domains, namely relationships and expectations and cultural empowerment /appropriateness, serve as the assessment set to inform the planning and development of the intervention, whereas the last domain, namely cultural identity, determines the entry points for the developed intervention (Iwelunmor et al., 2014).

There are five reasons for using the PEN-3 model. First, unlike other theories, it highlights the impact of culture on health research and practice by prioritising the positive impact of culture without problematising people's values and beliefs (Airhihenbuwa, 2010). It emphasises the person's context as a whole, portraying the impact as positive, unique, and negative attributes; in this way it has enabled researchers to develop culturally competent interventions that relate to culture as an asset rather than a barrier (Iwelunmor et al., 2014). Second, unlike other cultural models, the PEN-3 model focuses on the person, family members, and community as factors that inform the understanding and adoption of health behaviours (Airhihenbuwa, 1995, Airhihenbuwa, 2007, Holland, 2019). Even though the model is influenced by three schools of thought concerning health behaviour change, namely the *theory of reasoned* action, the *PRECEDE framework*, and the *health belief model*, it assumes that the broader social–cultural contexts shape understanding and behaviours (Airhihenbuwa, 2010, Glanz et al., 2008, Green and Kreuter, 2005, Iwelunmor et al., 2014). Third, the work by Airhihenbuwa (2010) is consistent with the critical realist approach that stands in between the mind-dependent (subjective) and the mind-independent (objective) reality. Fourth, the model shifts away from an exclusive focus on individuals (agency) toward the broader context (structure), and emphasises the power and the causation relationships and expectations of individuals within their cultural contexts. Fifth, a methodologically sound model has been validated and widely utilised to plan, develop, and implement healthcare interventions to reduce health inequalities and ensure cultural components. In addition, it provides a platform to assess and analyse primary and secondary data under the main domains and subcomponents of the PEN-

3 model (see Figure 3.3) using a variety of techniques, such as categorising and cross-tabulating data.

However, the model is not without drawbacks. For example, the omission or ignorance of the (variant) characteristics of the culture and their impact, such as socioeconomic status, might obscure reality and present a misleading, false-positive impact of culture during intervention development. Another limitation is the limited transferability or applicability of this model to different contexts. The lack of a precise evaluation or feedback process to determine the success of applying the PEN-3 model also restricts its transferability. However, this study does not claim to have transferability. Additional challenges encountered while planning the empirical phase include the absence of guidance on applying the model across (or within) amulticultural society, and the incompatibility with quantitative analysis.

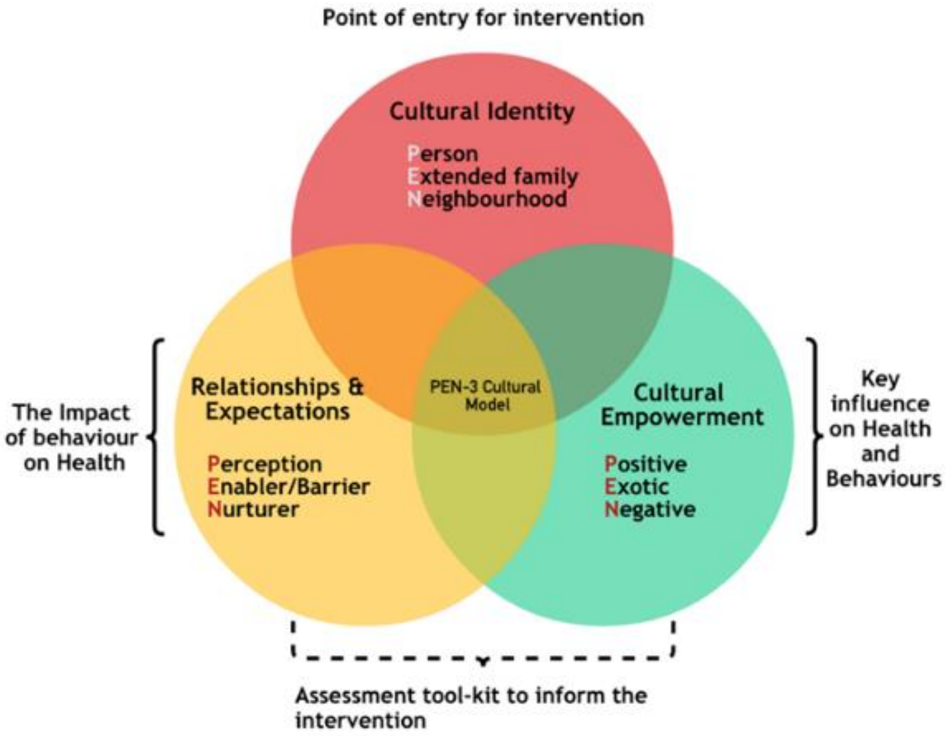

Figure 3.3: The PEN-3 Cultural Model: domains and usability

3.4.2 The Medical Research Council (MRC) Framework

The Medical Research Council (MRC) Framework has been widely employed in complex intervention developments in healthcare as a practical and methodological guide (Bleijenberg et al., 2018). Its fundamental strength is that it lessens the likelihood of inconclusive and futile trials by paying attention to developing, designing, and testing interventions in the early stages (Craig et al., 2008, Skivington et al., 2021). The MRC Framework has four phases: development, feasibility/piloting, evaluation, and implementation (see Figure 3.4).

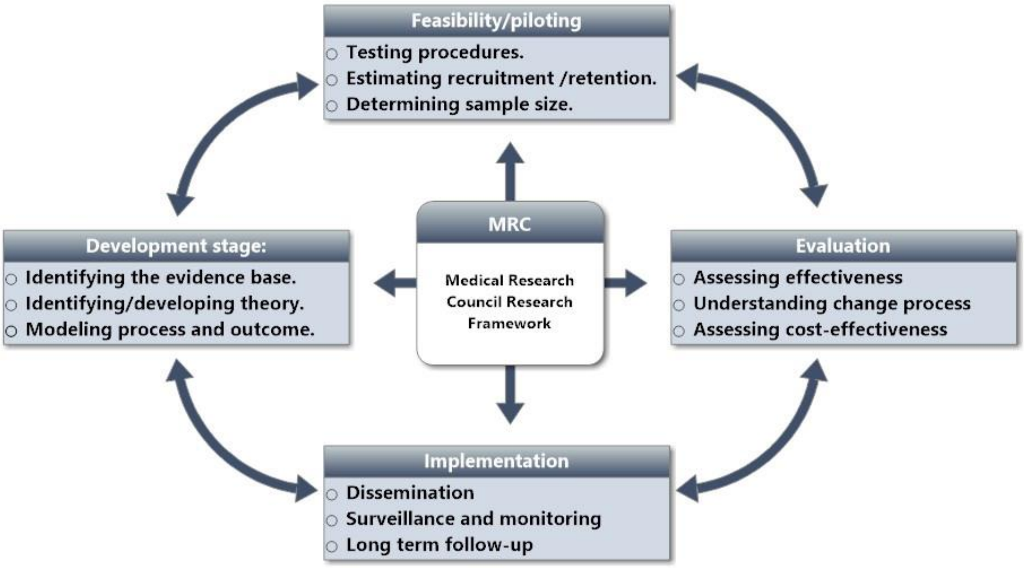

Figure 3.4: The Medical Research Council (MRC) Framework (2008).

The MRC revised guidelines consist of three steps, namely identifying the existing evidence, identifying and developing a theory, and modelling the process and outcomes (Senn et al., 2013). As pointed out by the guidelines, these stages are not linear, as is demonstrated by the bidirectional arrows that denote interactions between the different phases (Bleijenberg et al., 2018, Senn et al., 2013).

3.4.2.1 The enhanced and optimised development phase of the MRC Framework

Recently, the MRC Framework was introduced to nursing research to enhance intervention development and feasibility (Richards and Hallberg, 2015). However, compelling evidence indicates that there is a real need to improve the current framework to focus on patients' and caregivers' needs during the intervention development (Levati et al., 2016). Furthermore, it is vital to involve relevant stakeholders who are receiving or delivering the intervention. Craig et al. (2013) have responded to these calls by revising the MRC guidance documents to help researchers to make appropriate methodological and practical decisions. For example, Ettema et al. (2014) have enhanced the MRC development process, adding a 'face validity' step by seeking consultations on the content and the clinical applicability of their interventions (Ettema et al., 2014). Bleijenberg and colleagues have further enhanced and enriched the development stage by adding new elements such as identifying the problem, determining recipients' and providers' needs, and examining the current practice and context. Thus the addition of these elements has strengthened the internal and external validity of the intervention, and maximised the chances of intervention success (see Figure 3.5) (Bleijenberg et al., 2018)

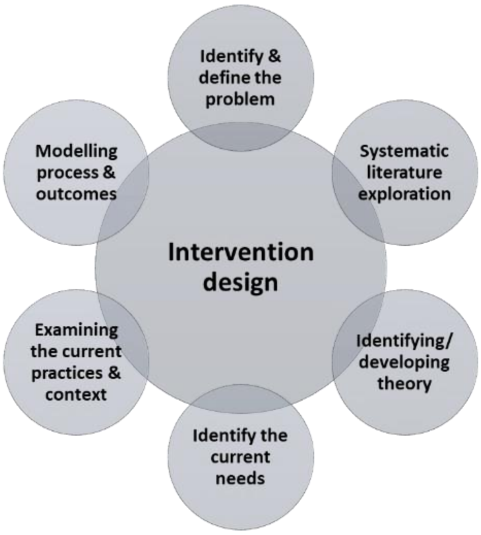

Figure 3.5: Revised MRC development phase (Bleijenberg et al. 2018)

3.4.3 *The rationale for the application of the MRC Framework in this thesis*

The aim of this project is to increase our understanding of the complexities and processes associated with the influences of culture on the understanding of heart failure syndrome, and hence of the underused palliative care services in the context of heart failure. The topic under investigation has several components that interact at different levels. The complex nature of the research topic requires a complex, sophisticated, and transparent framework to guide the research process. MRC guidance provides a systematic, flexible, less linear approach to the steps necessary to solve the problem, with greater attention to the early development phase. As is shown in Figure 3.6, adding the critical realist perspective to the MRC Framework has increased fitness for context and relevance to clinical practice, thereby enhancing the value of nursing research and reducing research waste. The MRC Framework guided this thesis to develop palliative care interventions using the dynamic and sequential six-step model suggested by Bleijenberg et al. (2018).

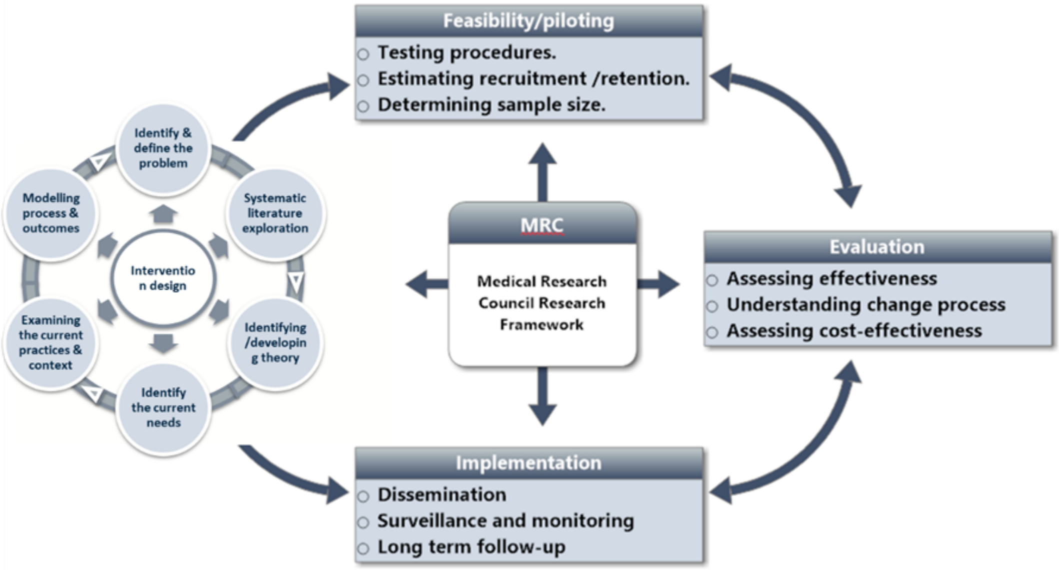

Figure 3.6: The Revised MRC Framework (Bleijenberg et al., 2018)

Step 1: Identifying and defining the problem

Due to the continued infiltration of the East by Western culture, and ongoing migration toward the West, more significant challenges are expected when providing palliative care services in ethnic minorities or multi-ethnic, multi-lingual, multi-religious, and multicultural societies. There is compelling evidence that integrating palliative care into standard cardiology management is beneficial for patients with advanced heart failure and their families at many levels (Allen et al., 2012, Aspromonte et al., 2017, Braun et al., 2016, Higginson et al., 2014, Higginson et al., 2003, Michelle S. Diop et al., 2017, Yancy et al., 2013). However, this evidence and the guidelines associated with it have proved limited and lacked the domain of culture (Ahluwalia et al., 2018). To date, there has been a lack of empirical evidence to address this domain, despite the importance of this component in examining the feasibility of interventions (Ahluwalia et al., 2018, Alizadeh and Chavan, 2016, Handtke et al., 2019, Jirwe et al., 2009, Michelle S. Diop et al., 2017). As society in the UK becomes increasingly diverse, the integration of culture into healthcare service delivery has been identified as a priority. As was discussed in **Error! Reference source not found.** and **Error! Reference source not found.**, research is encouraged to examine heart failure disparities, which are known to be present at multiple levels and to be mediated by many factors, including understanding of illness and cultural issues. Problem identification requires a deep insight into the nature of practitioners', patients' and family members' understanding of advanced heart failure and how culture affects these understandings, and hence help-seeking behaviours. Therefore a systematic review of the published evidence was conducted in order to better understand the problems in their unique context.

Step 2: Identifying the evidence base

Following the MRC guidance, the second step of the development process was to conduct a systematic review to identify the existing relevant evidence base (Bleijenberg et al., 2018). It is sometimes possible to find a recently completed appropriate systematic review that is appropriate to the needs of the intended development work (Craig et al., 2013). However, preliminary searches did not yield any high-quality systematic reviews that matched the identified problem for this thesis. The reviews focused on identifying and exploring how culture influences the understanding of advanced heart failure from the perspectives of patients and their family members, and how this may determine help-seeking behaviours. The review approach to evidence combined a systematic literature search with a theory-driven approach to synthesis. The findings of the systematic review (Section 2.4) highlighted the influential role of culture in assimilating the understanding of advanced heart failure and how central culture is to heart failure management. Lay heart failure knowledge of heart failure, symptom reporting and clustering, and heart failure self-management were the themes constructed. The literature synthesis shows a substantial gap and little empirical work on heart failure capturing the cultural context from a different lay perspective. As culture deserves more attention in the developmental phase of complex interventions, this study acted as a baseline for the next steps in the data collection process to empirically assess needs and analyse current practice and context.

Step 3: Identifying and developing theory

The literature was reviewed to find an appropriate nursing theory or model to address the above-mentioned problem and underpin intervention development. Cultural understanding in nursing, including transcultural theories, has been deployed in recent decades to meet people's cultural needs (Değer, 2018, Ryan and Twibell, 2002). However, most of these theories or models failed to account for culture in service development, and no one transcultural model was deemed to be more appropriate than the others (Holland, 2019). Furthermore, although many nursing theories have been proposed and widely used to promote and deliver high-quality, safe, culturally competent healthcare, few of them have focused on patients, and none have focused on patients belonging to a diverse cultural group (Holland, 2019, Seaton, 2010). Holland (2019) cited a critical analysis study conducted by Seaton (2010), who assessed the literature on transcultural nursing theories. Both authors have highlighted the urgent need to reform these ineffective and even unsafe nursing theories. Figure 3.7 shows a word cloud representing the pitfalls of nursing theories developed to enhance cultural competency practice.

Due to a lack of focus on patients' cultural aspects concerning the core tenets, constructs, or philosophical foundations of these theories, this thesis departs from the traditional orthodoxy of transcultural nursing. Instead, following the situation discussed above, this work focuses on culture and understanding heart failure and palliative care by mapping it to a culturally centred approach, namely the PEN-3 cultural model.The model was proposed and updated by Professor Airhihenbuwa in response to the omission of culture when explaining health outcomes and placing culture at the centre of development of health interventions.

Figure 3.7: Critique of transcultural theories (Holland, 2019)

In Phase 1, the study utilises ‘relationships and expectations’ and ‘cultural empowerment’ domains as an assessment and analytical toolkit, as seen in Theoretical framework 2.3.3. The relevant component and entries were cross-tabulated for each theme, as depicted in Table 2.5. In Phase 2, the PEN-3 model was used as a theoretical framework to design the focus group topic guide and facilitate group discussions (see **Error! Reference source not found.**-F). Questions were primarily mapped to the relationships and expectations, including perception, enablers and barriers, and nurturers. This dimension was employed to uncover the individual and contextual factors that led to the current participants’ understanding. In addition, it provided a tool with which to scrutinise the implicit, cultural meanings, which are often ethnic and culture-specific.

Step 4: Determining the needs

In line with the MRC Framework, this stage aimed to gain detailed insights into participants' needs, understandings, and preferences, and incorporate them into the development process (Bleijenberg et al., 2018, Craig et al., 2013, Skivington et al., 2021). As culture may imply different and unique understandings of heart failure and palliative care, it is vital to collaborate with patients and their families to effectively identify and meet their needs within the context in which they occur. The involvement of patients and families in this process allows the content and delivery of the intervention to be tailored to their needs, including cultural issues. This means that the intervention is more likely to be accepted and adopted (Bleijenberg et al., 2018). A qualitative descriptive study explored the understanding, needs, perceptions, and preferences of potential future recipients of the intended intervention. Qualitative methods, mainly consisting of focus groups with stakeholders, are well suited to identifying individual needs and barriers to those needs. Participants interact with the group and build on their ideas and understandings, which in turn help to identify their needs. Further details of the study results are presented in Chapter 6.

Step 5: Examining current practice.

To further develop culturally appropriate palliative care interventions, the guidance recommends both exploring the current practice and context in which the intervention will be delivered, and exploring understanding, needs, and preferences. The qualitative descriptive study constitutes Phase 4, in which needs, experiences, and preferences are determined, and then moves towards Phase 5 of the project, by examining these within the context in which they occurred. During the group discussion, the interaction between participants enriches the data, allows them to speak openly, and is more likely to yield genuine responses. This is very useful both for examining current practice and context, and for understanding barriers and facilitators so as to be able to implement and tailor the intervention according to the resulting research knowledge. However, the lack of understanding of palliative care and heart failure and the heterogeneity and dynamic nature of care needs and preferences represent the complexity of developing palliative care intervention to target a culturally diverse population.

In this step, patient and public input was used to provide another perspective on examining the context. In addition, the advisory group, particularly those who have experienced heart failure at first hand, were consulted to assist in interpreting and contextualising the findings at this stage. In addition to the study's public involvement strategy, every effort was made to include other stakeholders, and specifically healthcare professionals, to assist in examining the current practice, and planning and designing appropriately. However, due to the national lockdown and restrictions enforced during the pandemic, the research team was unable to commence studies or obtain ethical approval.

Step 6: Modelling process and outcomes

Modelling the processes and outcomes of an intervention is the third stage in the original complex intervention development process. This step involves modelling the active intervention components by synthesising the knowledge gathered from the earlier elements of the development phase. The previous five stages and the consultations carried out with the patient and public involvement advisers identified the current problem and defined its context. Thus they provide fruitful insights into the gaps in current practice, and whether these gaps can be bridged. At this stage, neither economic evaluation nor formal modelling was performed. However, as stated above, the research questions address many aspects of the cited guidance recommendations. The study identifies the known barriers and facilitators. The focus groups that we conducted were very fruitful in identifying different values and their deep-rooted influence on understandings of heart failure among the various groups. This methodology facilitated the aim of exploring ‘what works, for whom, in what circumstances, and why’ to inform a suitable and feasible intervention. This stage aimed to refine and prioritise the components of the intervention by balancing the 'best fit' with the nature of the syndrome, busy practice, and the context (Bleijenberg et al., 2018, Richards and Hallberg, 2015).

3.5 Rationale and Methods for both studies in this thesis

3.5.1 The systematic review and mixed methods synthesis

The systematic review is a robust and comprehensive literature examination that helps to address an aim similar to that of the empirical studies (Aveyard, 2019, Whittemore and Knafl, 2005). Systematic reviews are becoming increasingly popular in nursing and health-related sciences (Aveyard and Bradbury-Jones, 2019, Sutton et al., 2019). Various approaches have been described, but they all involve identifying a comprehensive and systematic answer to the review question (Aveyard et al., 2016). A search of the existing literature was carried out as recommended by Aveyard et al. (2016), followed by analysis and synthesis of the best available evidence from scientific studies to investigate a specific clinical question. This analysis and synthesis of the relevant evidence can include published peer-reviewed articles as well as other evidence (i.e. unpublished and grey literature) to guide the intervention development (Aveyard et al., 2016). This methodology includes intensive and critical processes that set it apart from literature reviews. However, this does not necessarily imply that systematic reviews are always good quality or bias-free. The keys to quality systematic reviews are a minimisation of bias through comprehensive, transparent and reproducible methods (Gough et al., 2017). Systematic reviews are prone to bias associated with data identification and retrieval, including publication, language, selective reporting, and reporting biases. Other types of bias that may be encountered while designing and conducting reviews such as those related to the included studies selection, performance, detection and attrition bias. These flaws can be mitigated by formulating true and important review questions, an adequate literature search inclusive of non-English language studies, searching both published and unpublished studies, addressing quality of reporting and methodological quality of the included papers and publishing all outcomes, whether positive or negative. Furthermore, an explicit methodology, a pre-defined protocol and a appropriate study methods and tools reduce biases and enhances transparency.

As stated in the previous section, the MRC guidance (Bleijenberg et al., 2018, Craig et al., 2013) advocates systematically reviewing the relevant existing evidence during the preliminary phase of developing an intervention. Reviews are encouraged to scrutinise the identified problem and its key dimensions, particularly in the absence of high-quality evidence. As no previous systematic review has been conducted in this area, the purpose of the present review was to identify, evaluate, and synthesise all of the relevant evidence without applying any limits.

Meta-analysis and qualitative synthesis were unsuitable for this review due to the heterogeneity of the primary research on culture and heart failure (Deeks et al., 2008, Higgins and Green, 2008), so I adopted a mixed-methods systematic review design. The mixed-methods synthesis is particularly relevant when asking a complex review question, in this case 'What is the impact of culture on the understanding of advanced heart failure?', and when seeking to understand the underlying mechanisms of this impact, which is challenging to measure. The mixed-methods synthesis combined qualitative and quantitative evidence to unite perspectives using various data extraction, analysis, and synthesis approaches. The hybrid design for synthesis of the results (Sandelowski et al., 2006, Whittemore and Knafl, 2005) allowed data grouping into findings by domain rather than by different research methodologies. The mixed-methods synthesis, in which quantitative and qualitative data complement one another, aligns with the initial plan to conduct a mixed-methods thesis on critical realism as a middle-ground philosophy. As discussed earlier, the whole thesis, including this review, acknowledges an objective reality and maintains subjective knowledge. 1.4 presents a detailed account of the systematic review.

A key question would be why a realist review and evaluation were not employed. Realist synthesis is perhaps the most widespread application of realist methodology that has a firm root in philosophy and social sciences. It is neither a method nor a formula but a theory-driven logic and a flexible approach to enquiry that embraces both qualitative and quantitative questions (Pawson, 2013, Wong et al., 2012). Realist synthesis draws on a wide range of research studies and uses the most conceptual and critical ones. It is appropriate for analysing complex systems involving diverse people from different backgrounds and locations (Aveyard et al., 2016). However, their engagements and experiential understanding as fallible experts should be documented, formalised and tested (Pawson, 2013, Wong et al., 2012). Technically speaking, the limitation of realist synthesis is that this approach to a systematic review focuses on realist evaluation and examination mechanisms of how an intervention works, it is underlying mechanisms and under what circumstances, known as context-mechanism-outcome (CMO) configurations (Aveyard et al., 2016, Pawson, 2013). Focusing on gathering data to build, refine or clarify an underlying theory of interventions and the causal relationships between the CMO concepts was beyond the scope of this study. In our case, the synthesis addresses questions about the influence that culture may have on understanding. The focus is, therefore, on the mechanisms rather than on how each group behave.

Another 'What works' review which we considered but rejected is the Critical Interpretive Synthesis (CIS) by Dixon-Woods et al. (2006). Critical interpretive synthesis is derived from and carries some principles of meta-ethnography designs and grounded theory analysis. Therefore, it is based on qualitative tradition and aims to generate a theory grounded in both qualitative and quantitative studies (Dixon-Woods et al., 2006, Flemming, 2010). In addition, CIS, apart from quantitative and qualitative studies, synthesises large and diverse literature that includes a variety of document types like theoretical work and policy documents, which are indeed excluded in our review (Flemming, 2010). In our case, it can be argued that CIS could help to understand how culture as part of context influences understanding. However, as we are interested in the process of influence, not the theoretical orientation itself, as well as synthesising findings in the form of a coherent theoretical framework, a critical interpretive synthesis was not appropriate.

3.5.2 The qualitative descriptive study.

The philosophical and theoretical foundation of this thesis, augmented by the MRC Framework, provides directions and assists in laying down what data need to be collected and how to organise and analyse them as per the purpose of the study. As mentioned earlier, critical realism has a realist (objective) ontology but an interpretivist (subjective) epistemology. The systematic review found that cultural factors shaped the patients' understanding of heart failure and their family caregivers' objective (empirical) reality. However, our knowledge of this reality is limited. We can only see part of this reality indirectly through the lived experience, interpretations and reflections of patients and their family caregivers (see Figure 3.2). Since every individual has a different experience and subjective interpretations, qualitative methodologies were naturally fit for this purpose.

3.5.2.1 Traditional qualitative methodologies

Within qualitative methodology, various designs are available to aid in navigating and understanding the study topic, including ethnography, phenomenology, grounded theory, narrative enquires. Each design often selects a specific set of methods and is driven by a theory (Neergaard et al., 2009). Although qualitative descriptive might be described as the least theory-driven, it maintains goal congruence and avoids 'method slurring' despite its broad methods strategy (Neergaard et al., 2009, Polit and Beck, 2017).

Despite their well-defined protocols, distinctive philosophies, and established procedures and methods, the above-described qualitative designs were not appropriate for this study (Aspers and Corte, 2019). Although culture was clearly a core dimension in this study, ethnography as an observation-based method was not suitable for capturing how participants perceive and interpret the studied phenomena. Also, since the study was not focused solely on establishing an in-depth essence of direct and immediate individual experience and understanding, phenomenology was not pursued (Aspers and Corte, 2019, Polit and Beck, 2017). Grounded theory as a theory-generating design that adheres ontologically to the belief that there are multiple realities was not also suitable for this exploratory and descriptive nature of the topic (Creswell and Poth, 2016). Finally, critical realism does not align with the 'never absolute' ontological and 'hard' epistemological position held by the traditional designs (Doyle et al., 2020).

Such poorly understood phenomena prioritise the detailed accounts of and insights into participants' experiences and perceptions rather than total commitment to a framework.

3.5.2.2 The qualitative descriptive study.

Instead, an emerging methodology, namely a qualitative descriptive (exploratory) design, which is becoming increasingly popular in nursing and healthcare research, was chosen (Bradshaw et al., 2017, Sandelowski, 2000, Sandelowski, 2010). The design was first described by Sandelowski (2000) and Stebbin (2001). Despite being different to the underpinning theories and approaches, both agreed on the qualitative descriptive design to be used when 'little is known about a subject' (Holloway and Galvin, 2016, Holloway and Wheeler, 2010). Polit and Beck (2020) advocate for this design to uncover the real nature of the 'little-understood phenomenon,' which is the case for this study. To rationalise an empirical exploration, both camps emphasised the need to demonstrate that little or no work had previously been done. Chapter 2 highlights the scarcity of literature on culture and palliative care in heart failure. Chapter 3, a systematic review of the literature, confirmed the earlier findings. This lack of literature necessitates a broader qualitative inquiry to produce a novel description and capture all of the relevant data on the study subject (Sandelowski, 2000).

This design is ideal for clinical research, particularly in nursing and midwifery, where the intended research outcome is to provide comprehensive accounts and gain insights from participants regarding 'who, what, and where' for the phenomenon in question within its unique context by acknowledging the influence of researchers' perceptions, experiences, and beliefs about these descriptions (Doyle et al., 2020, Sandelowski, 2010, Schneider et al., 2016). Furthermore, it provides nursing researchers with the freedom to decide on methodological procedures appropriate for addressing nursing research questions without the need to adhere to the methodological and philosophical dictates, especially if the traditional methods are not appropriate for the aim and specific objectives of the research. Nevertheless, the fact that the technique is known to have a degree of flexibility and does not require pre-selection of variables or preconceived ideas about the topic has attracted the attention of some (Grove and Gray, 2018, Sandelowski, 2010). It has also attracted criticism from others concerned with methodological quality in qualitative research. Sandelowski (2010) attributed the misinterpretations of the simplicity, flexibility, and utility of the qualitative descriptive design in her earlier work to the use of phrases such as ‘straight descriptions of phenomena are desired’ or ‘least theoretical and philosophical approach’ (Sandelowski, 2000). The design was criticised for lacking a guiding theoretical framework and conceptual focus. It was deemed to be an overly dependent design involving minimal or no data analysis or interpretation (Barbour, 2003, Caelli et al., 2003, Hunter et al., 2019). However, Sandelowski argued that the main advantage of this design is that it is highly flexible and has no theoretical assumptions or pre-existing constraints. Thus the choice of method for sampling, data collection, and analysis is left to the researcher’s discretion, which justifies her view that it is a distinctive approach which is reinvented every time it is used. A response echoed the earlier position articulated by Neergaard et al. (2009), that prioritising participants’ accounts and allowing the collection of rich data from a relatively small sample instead of relying on rigid methodological perspectives proposed by others were the main strengths of this design. Qualitative descriptive studies came to the fore in support of ‘free form’ data collection and analysis as a departure from the constraints of traditional qualitative methods (Schneider et al., 2016). Some of the critics have argued that the rigour of this qualitative design can be enhanced by addressing four interrelated areas, namely the researchers’ theoretical positioning, utilising methods congruent with their methodology, employing strategies to establish trustworthiness and rigour, and engaging more analytically with the data (Caelli et al., 2003, Hunter et al., 2019). In response, the current study, the phenomenon of interest, is investigating the understanding of heart failure and palliative care and the role of culture in forming such an understanding. Hence a qualitative descriptive design was supported by clear theoretical, conceptual, and philosophical foundations to enhance the methodological rigour and trustworthiness of the findings.

3.5.3 Qualitative descriptive design Methods

In a recent review, Hunter et al. (2019) acknowledged that the literature is divided into two camps, represented by Sandelowski (2000) and Stebbins (2001), respectively, and concluded with a conceptual framework combining both methods to guide the method selection and the implementation process, including data collection and analysis. Purposive sampling, focus groups, and thematic analysis were the most commonly used methods for descriptive qualitative research (Hennink et al., 2020, Hunter et al., 2019, Sandelowski, 2010).

In this context, an appropriate sampling technique is essential for achieving optimum results and ensuring that best-fit participants are approached and invited to participate in the study. Sandelowski (2000) and Stebbins (2001) recommend purposive sampling in order to obtain the most information-rich participants with knowledge and experience of the phenomenon of interest (Hunter et al., 2019, Ritchie et al., 2013). Purposive, judgmental, or eligibility-based sampling is a sampling strategy in which participants are chosen deliberately to best contribute to the study and meet the study needs (Palinkas et al., 2015, Polit and Beck, 2018). Participants are included because they have particular characteristics that enable detailed exploration of the issues under investigation (Doyle et al., 2020, Moule, 2018). Kim et al. (2017) emphasised that this sampling often demands more time and resources to recruit people who best share their own experiences. A purposive (purposeful) sample is complex, as it relies extensively on the researcher's judgement and knowledge of the population under study and who will be most informative for the research question (Palinkas et al., 2015, Polit and Beck, 2018). However, purposive sampling can be very advantageous when the researcher intends to reach a particular sample that cannot easily be accessed via any other strategies. Creswell and Creswell (2018) and Barbour (2018) argued that the focus of purposive sampling is to reflect the diversity and value in collecting rich data, which outweigh achieving representation for generalisation.

Snowball or network sampling is being considered as an adjunctive technique by qualitative descriptive researchers (Doyle et al., 2020). Snowballing effectively targets a hidden or inaccessible group (Polit and Beck, 2018), and is based on the notion that people with similar characteristics group together by asking participants in the study to make referrals or nominations. However, this approach is also considered weak as the final sample heavily relies on participants' referrals, their level of trust, and whether or not they are willing to cooperate with the researcher (Creswell and Creswell, 2018).

As qualitative research focuses on the richness of the data, the term 'saturation' appears inappropriate in qualitative studies such as this thesis. Instead, the sample size is to be determined by 'Information saturation' or 'information power' (Malterud et al., 2016). The information power indicates that the more relevant and informative the sample is, the smaller sample size is required and represented by five dimensions related to the aim of the study aim, specificity of the sample, theoretical background, quality of the discussion, and the research approach to data analysis (Malterud et al., 2016). A review of 220 focus group studies underscored the pitfall that several papers were not transparent in reporting saturation or failed to do that correctly. Carlsen and Glenton (2011) also revealed that half of the primary studies did not report on a maximum or a minimum number of participants showing significant concerns for the quality and rigour of their work. Regarding the number of discussions, it was suggested that four focus groups are sufficient to reach code saturation. In order to achieve meaningful saturation, or to fully understand the issues identified in codes, five or more group discussions are required (Braun and Clarke, 2021, Hennink et al., 2019).

3.5.4 Focus group discussions.

Even qualitative descriptive research uses diverse methods for data collection. Interviews (both individual and group) are considered to be superior in terms of their ability to gain in-depth, rich descriptions and allow the researcher flexibility in exploring data and attending to non-verbal clues or emotions (Hunter et al., 2019, Krueger, 2014). Kim et al. (2017) found that data collected through individual interviews and focus groups with a semi-structured nature were the most common.

Focus group discussions originated as a tool for listening to people and learning from what they said (Morgan, 1996). They were then refined as a technique for better understanding how a group of participants is recruited and invited to discuss their thoughts and ideas, and comment on a research topic based on their personal experience through a facilitated discussion (Krueger, 2014). Several detailed methodological textbooks about the focus group as a data collection method are available (Barbour, 2008, Hennink, 2007, Krueger, 2014, Morgan, 1996). However, Barbour (2018) and Barbour and Morgan (2017) went beyond describing the actual conduct of focus groups or the 'how to' approach, to cover planning, conducting the groups, analysing the results, and reporting advice.

Focus group discussions have many advantages, such as exploring participants' inner worlds, subjective experiences, and understanding of the topic under discussion (O. Nyumba et al., 2018). These group conversations can be a stand-alone method for data collection that offers an appealing experience for participants and facilitators (Jolley, 2020), despite being criticised on multiple grounds, some of which have been addressed, while others require the researchers’ consideration. The perceived informality of focus groups encourages participants to interact with the facilitator and other members and describe frankly and honestly the experiences, perceptions, and beliefs that are necessary to them as groups or individuals (Barbour and Morgan, 2017, O.Nyumba et al., 2018). However, others have argued that this approach does not facilitate a complete understanding or in-depth personal narratives of these experiences (Kitzinger, 2005, Krueger, 2014). Therefore researchers must carefully weigh the advantages and disadvantages of the different types of focus groups in the light of their study field and aims.

Group discussions facilitate faster data collection and shorter time commitment than individual interviews. However, this has raised the question of how such a ‘quick and easy’ tool can collect data from large numbers of people (Lambert and Loiselle, 2008). Researchers admitted that this is particularly important if focus group transcripts deal with multiple individual interviews and ignore the group interaction during analysis (Barbour and Barbour (2018), (Harding, 2018, Kitzinger, 2005, Onwuegbuzie et al., 2009, Wilkinson, 2011). The interactive and dynamic nature of focus groups where one participant comments or prompts another has been demonstrated to be helpful in reflective thinking and experience sharing along with articulating new ideas and understandings (Barbour, 2018, Morgan, 1996). Thus this method would allow participants to navigate and put forward issues that are not usually discussed or addressed (Dawson, 2019, Moule, 2018). As Creswell and Poth (2016) have emphasised, it is possible to obtain good-quality information in a limited time and on a sensitive topic via focus groups if the participants are cooperative and share similar interests or experiences. In cross-cultural studies, it was suggested that selecting candidate groups based on common sociocultural characteristics maximised group interactions and discussion of shared experiences (Barbour and Morgan, 2017).

In addition to observing participants' interactions in their natural environment, the group facilitator can simultaneously attend to the non-verbal communication (Krueger, 2014, Ritchie et al., 2013). In the case of multiple discussions, the group harmony enhances participants' interactions, reduces researcher bias, and enable researchers to capture patterns of meaning across the datasets (Barbour and Morgan, 2017). As the participants in each group must either have had personal or second-hand experience of heart failure, this method provides valuable insights into their understanding, attitudes, and beliefs that are also gleaned from intragroup interactions.

The use of focus group discussions as a data collection tool in cross-cultural health research is becoming increasingly popular (Barbour, 2018, Kitzinger, 2013). For example, Hennink (2017) reported that it identifies different kinds of personal meanings and their relationships, and uncovers the common themes, echoing a previous claim that focus groups allow participants to construct their own views of their experiences (Lehoux et al., 2006). Therefore focus groups help to elicit broader, shared cultural and community understandings and contextual interpretation. Since the basic methodological principles of focus groups remain unchanged, no significant methodological changes were required. However, researchers must bear in mind that applying focus groups in cross-cultural contexts require a flexible, well-planned, and sensitively mediated approach that also has methodological rigour (Harding, 2018, Hennink, 2017).

There is evidence that hard-to-reach groups, such as minority and marginalised groups, are less likely to discuss sociocultural matters or engage in planning end-of-life care, and therefore are less likely to receive care that is sensitive to their culture (Barbour, 2018). Consequently, focus groups are increasingly favoured for accessing these under-researched populations and approaching sensitive topics such as sociocultural matters in end-of-life care (Barbour and Barbour, 2018, Shrank et al., 2005). However, the literature argues that focus groups have less potential, applicability, and usability for gathering data on sensitive topics from hard-to-reach populations (Barbour, 2008). Individual interviews are another powerful means of understanding people and exploring their thoughts and experiences (Creswell and Poth, 2016, Hennink et al., 2020). It was anticipated that even though interviewing people on a one-to-one basis would enable open discussion about a potentially sensitive topic, it can cause more recruitment challenges, especially when targeting a particular disempowered population (Barbour and Morgan, 2017). It was also noted that some groups, such as women of cultural or religious groups, would prefer individual rather than group interviews, due to concerns about confidentiality (Creswell and Poth, 2016). (Purnell and Fenkl, 2019) argue that they may also be reluctant to share their thoughts with outsiders or researchers due to the ingrained cultural values and social norms. Sometimes dividing focus group discussion according to certain characteristics such as gender may be an option. Gender-segregated discussions creates a comfortable environment for male or female participants to share their views more freely and confidently rather than in a mixed group (Krueger, 2014).

Although that is debatable in some instances, as such research is often conducted on sensitive topics, our critical realist position assumes that these specific areas and their level of sensitivity will differ from one culture to another, given that this is a sociocultural constructed reality (Allana and Clark, 2018, Morgan, 2018).

However, the reliability of using focus groups in cross-cultural research depends primarily on the interviewer’s skills and experience, and the nature of the research topic (Barbour, 2018, O. Nyumba et al., 2018). For example, this approach requires skill in asking questions and the ability to help participants feel comfortable and speak openly while keeping on topic and stopping break-away conversations. In addition, the interviewer may unintentionally trigger social desirability bias, such as specific answers, by providing hints or unconscious signals (Creswell and Creswell, 2018). Therefore the researcher must balance the need to be flexible, culturally sensitive, and safe, and the need to maintain methodological rigour.

The choice of focus groups was underpinned by drawing on the participants' attitudes, feelings, thoughts, beliefs, and experiences to trigger fruitful interactions between the study participants, rather than initiating participant-facilitator interaction (Barbour, 2018, O. Nyumba et al., 2018). Unlike other methods, therefore, focus groups can generate a detailed understanding and a wide range of perspectives on the topic being discussed (Barbour, 2008, Barbour, 2018).

This study used focus group discussions to investigate the cultural influences on understandings of heart failure and palliative care among multi-ethnic and multicultural communities in Glasgow, Scotland. This approach facilitated the exchange of thoughts and ideas in order to explore shared cultural understandings and determine the real impact of culture on participants from the same culture. For the data gathered in the focus groups to enhance understanding of the topic, it must be adequately analysed. A proper understanding of the method of data analysis can maximise the insights and benefits that can be gained from the data (Dale and Mason, 2011, Krueger, 2014). Only reliable and rigorous results can enhance the contribution to the existing knowledge base on the topic (Harding, 2018), and enable the development of a culturally competent healthcare intervention.

3.5.5 Qualitative data analysis

Numerous data analysis strategies are discussed in the literature on qualitative data analysis methodology. According to Dawson (2019) and Harding (2018), the main options are thematic, comparative, content, and discourse analysis. In the present study, the advantage of using a qualitative descriptive design is that it enables much broader data analysis without being limited by or confined to pre-existing philosophical or theoretical constraints (Doyle et al., 2020). For this reason, content and thematic analyses are the most commonly used data analysis techniques in qualitative descriptive research (Bradshaw et al., 2017, Schneider et al., 2016). These approaches are defined as systematic coding and categorising, respectively, and they aim to examine and break transcripts into smaller meaning units and go through them in a descriptive and interpretative manner to identify common patterns and themes.

However, content analysis entails qualifying and quantifying data to explore large datasets by counting and looking for word trends, codes, and patterns, as well as searching their frequency and relationships. With regard to content analysis, Kim et al. (2017) concluded that in qualitative literature it had proved helpful as a low-inference data analysis technique for domain summaries. In other words, this technique simply tries to summarise and reflect on a dataset and provide a sample description (Jolley, 2020). Thematic analysis, on the other hand, provides more versatile and complex data, necessitating an advanced interpretation that ranges from data driven (semantic) to researcher developed (latent) to identify recurring themes and uncover mechanisms and contextual meanings (Braun et al., 2019, Vaismoradi and Snelgrove, 2019). Although Sandelowski (2000) favoured content analysis over other analytical tools in the context of descriptive studies, recent evidence suggests that the poorly understood nature and the lack of adequate guidance led researchers to confuse and conflate them (Doyle et al., 2020, Vaismoradi and Snelgrove, 2019, Vaismoradi et al., 2013). It is argued that the research aims, the questions, and the researchers' epistemological position must determine the decision to favour one method (or a combination of methods) over another, given that the 'free-form' design is mostly explorative and inductive in nature (Kim et al., 2017, Ritchie et al., 2013). As the aim of the research was to answer questions concerned with what people understand, how they perceive or experience a phenomenon, and how they interpret it and construct their understanding, thematic analysis is the most suitable approach (Colorafi and Evans, 2016, Kim et al., 2017). In addition, unlike content analysis, which hovers between paradigms, thematic analysis is flexible and can be conducted within the realist paradigm to contextualise participants' accounts (Braun and Clarke, 2006, Braun et al., 2019, Dawson, 2019).

Discourse analysis lends itself to and is considered to be an alternative to the thematic analysis used to analyse the focus group data. Even though discourse analysis emanates from the in-group discursive interactions, its foundation lies exclusively in linguistics and communication that is very distant from clinical practice (Onwuegbuzie et al., 2009). This analysis involves how language and text are analysed to communicate perceptions, and it reveals embedded ontology and epistemology beliefs (Krueger, 2014). However, the focus on understanding means that discourse analysis would not be appropriate for this study, as the aim is to identify and interpret patterns to generate themes (Harding, 2018). Discourse analysis is practicable when researching and assuming multiple realities and how they are produced, negotiated, and stimulated in everyday conversation and texts. However, this fits with the relativist ontology and contradicts the critical realist position of this thesis (Crotty, 2020). Nevertheless, it can contribute to the field of palliative care and heart failure, if the intention is to deconstruct meanings and construct words to examine the current attitude and expected behaviours concerning sensitive topics such as sensitive communication near the end of life, or a good death, in a particular community.

3.5.5.1 The scope of qualitative analysis

Qualitative research is primarily exploratory and open-ended research that aims to understand and explain data in order to make claims about a truth (Braun and Clarke, 2013, Richards, 2020). Compared with quantitative methods, qualitative approaches offer participants more choice and the freedom to express their views and beliefs in their own words (Aspers and Corte, 2019, Creswell and Creswell, 2018). The scope of qualitative analysis is broad in the real sense, and ranges from being *descriptive* and *exploratory* in nature to a more probing *interpretative* analysis (Braun and Clarke, 2013, Harding, 2018). This scope determines the analysis type, depending on the research aims and the researcher's dataset. Reicher (2000) and Ritchie et al. (2013) drew attention to the fact that participants' words could be used in two ways, which they described as 'experiential' or `discursive.' Subsequently, Braun and Clarke substituted the terms *'experiential' and 'critical' (Braun and Clarke, 2006, Braun and Clarke, 2013)*. The *descriptive* analysis aims to describe the main features/results and express opinions, thoughts, views, or perspectives on the topic of interest in the data, mainly when little is known about the topic (Braun et al., 2017).

This type of analysis commonly takes an *experiential* perspective on the expressed meaning of participants' views, experiences, and understandings as reported by participants in the dataset straightforwardly (Braun and Clarke, 2013). This method simply focuses on and prioritises the interpretations of participants' words, rather than using the analysed data to further explore other arguments in depth (Braun and Clarke, 2013, Braun et al., 2017). Language is the way to unearth participants' inner thoughts and meanings. When a surface-based interpretation output is followed, participants' meanings and experiences and the role of experiential researchers is bound strictly to data collection, organisation, and reporting (Braun and Clarke, 2013, Braun et al., 2017). The more extreme method, at the other end of the analysis spectrum, is called the interpretative method. Compared with the descriptive approach, the interpretative analysis attempts to gain a more thorough and deep understanding of the participants' words. It tries to add a conceptual dimension to the data collected, and to understand why and how these results were generated (Braun et al., 2017).

In contrast to descriptivists, interpretivists draw from the critical qualitative analysis perspectives. This approach is characterised by interrogating the expressed words in the data in order to explore other phenomena (Braun and Clarke, 2013). Critical qualitative research focuses on what the meaning represents, based on researchers' interpretations of the data rather than taking their meaning at face value. This research explores culture as an influential factor and its impact on the meanings and understandings of disease and service expressed in the dataset. Due to participants' unique ways of understanding within their sociocultural contexts by prioritising critical sociocultural interpretation instead of the psychological aspects, this project can be categorised as critical qualitative research.

3.5.5.2 Analysing focus group data

Several methods and techniques are available for analysing qualitative data. However, group data analysis, including discussions and interactions, is quite different from analysis of data from individual interviews (Harding, 2018). The unique characteristics of group data analysis have been debated and divided the research community into two camps. Due to the significance of this argument, as it is fundamentally shifting the data analysis to a new arena, this topic has been further debated and discussed by others (Harding, 2018). The first camp believes that the methodological difference between focus groups and individual interviews is related to data collection, not data analysis. Hence the data analysis is similar regardless of whether the data were gathered from a group or an individual (Barbour, 2008, Barbour, 2018, Wilkinson, 2011). The second camp has claimed the opposite, and called for specific methods of data analysis to exploit the richness of the focus group data to the full (Duggleby, 2005, Morgan and Krueger, 1998, Onwuegbuzie et al., 2009).

Given the lack of clear evidence as to whether or not the analysis of focus groups has to be essentially different from the ordinary interviews, this focus group study will take a position that is halfway between the two camps and analyse the group data, considering the salient features of focus group discussions when necessary. This middle-course analysis will consider the inter- and intra-group dialogues and interactions, focusing the analysis on how participants reached the conclusions rather than what the discussion was about. The adopted analysis techniques will also be adapted and further developed to address the unique opportunities that focus groups present and provide an opportunity to perform a thematic analysis, looking for mutual needs and concerns among groups to facilitate the development of culturally appropriate services.

3.5.5.3 Braun and Clarke have trademarked thematic analysis

Thematic analysis was developed in the 1970s by Gerald Holton, a physicist and scientific historian. At that time it was seen as merely a tool for translating and interpreting transcript data (Holton, 1988). Several scholars have until recently opposed thematic analysis as an independent method, arguing that it is a subjective tool that can compromise the reliability of findings and that it must be used adjunctively with other methods, such as the grounded theory (Boyatzis, 1998, Bryman, 2016, Ryan, 2010, Ryan and Bernard, 2000). These critiques stemmed from controversy over how thematic analysis ought to be viewed and applied, and what constitutes a theme (Bryman, 2016). As a result of this lack of guidance, authors still understand and apply it differently. However, with more detailed information, clearly outlined step-by-step guidance and directing researchers to the best available analytical approach, Braun and Clarke have advocated the simplest version of data analysis yet (Braun and Clarke, 2013, Braun et al., 2017, Bryman, 2016, Ritchie et al., 2013, Ryan and Bernard, 2003). They defined thematic analysis as 'a method for identifying, analysing and reporting themes within a certain dataset' (Braun and Clarke, 2006). The definition was further enhanced to include 'interpretation of themes' instead of 'reporting themes'. They also focused on how the analysis process should be performed to answer the research questions and fulfil research aims but not examine a predetermined hypothesis (Braun and Clarke, 2013).

3.5.5.4 Reflexive thematic analysis.

The The term 'thematic analysis' is often used as an umbrella term to denote various approaches encompassing two broad categories and three approaches to data. First, the traditional positivist, also known as 'small q', focuses on accuracy, reliability bias avoidance, and generalisability of coding. This approach stems from a 'scientific' quantitative research orientation (Braun and Clarke, 2019, Terry et al., 2017). Coding reliability and codebook approaches to thematic analysis are examples of this category. Both are deductive and involve multiple coders to ensure accuracy or reliability of coding. They also utilise a codebook/coding framework and conceptualise themes as domain summaries that developed early, in or prior to the analysis. Secondly, the qualitative, 'Big Q', in the opposite direction, is more focused on generating rich insights into individual perceptions and experiences from a relatively small sample (Terry et al., 2017). A reflexive approach to data analysis is firmly positioned within the second category (Braun and Clarke, 2019). While the standard approach in qualitative data analysis aims to reproduce consensus from the datasets (Harding, 2018), the reflexive analysis embraces the subjectivity of the analysis processes as it is centralised and significantly dependent on the researcher's unique and subjective understanding of the data meanings (Braun et al., 2019).

Notwithstanding the latter consideration, the analysis is primarily based on credible insights from participants' accounts (Braun and Clarke, 2013, Harding, 2018). Sharing expert perspectives on the data inform or modify how the researcher comprehends these meanings (Braun et al., 2019). Unlike coding reliability and codebook, themes are constructed by the reflexive researchers as the output of their understanding of the data codes, categorisation, and meaning patterns (Braun and Clarke, 2013, Braun et al., 2017). The categorisation process involves a detailed examination of the outputs, what patterns they demonstrate, and how they relate to the overall dataset (Braun et al., 2019). Accordingly, the outputs are coded as the data is analysed, and more information becomes available to the researcher rather than fixing the framework before starting the analysis process (Barbour, 2018, Braun et al., 2017). In critical realist terms, these patterns of ‘demi-regularities’ provide the flexibility to enhance the analysis outputs and better inform the decision-making process by utilising the researcher’s knowledge, background, and understanding (Braun and Clarke, 2013, Braun et al., 2019).

This iterative, organic and interpretive approach allowed the researcher to understand the coding outcomes and adapt them as necessary. Adding, combining, dividing, or removing codes has occurred throughout the analysis process and as the understanding of the results evolved (Braun et al., 2019). Unlike commonly used techniques that define the analysis process as a ‘phase’, this approach does not have a specific starting point for the analysis process (Braun and Clarke, 2013, Harding, 2018). Themes could evolve throughout the research life cycle and include the previously read, identified, and synthesised literature (Braun et al., 2019). At a certain point, the collected dataset and the analysis method could impact the researcher’s coding and theme decisions throughout the research life cycle (Miles et al., 1994). Consequently, data coding and the coding framework could probably start before the transcription stage, which is considered a vital and influential part of the analysis process (Harding, 2018). It is essential to work on transcription and data collection simultaneously, to help to identify themes as and when they materialise. In most cases, the interview included follow-up questions related to the interviewees. It is recommended that researchers avoid limiting the discussion to the topic guide, or using it as a coding framework for data analysis (Barbour, 2018). As an overlap between the researcher’s interests and the interview guide is anticipated, it is imperative to be mindful of the possible risk of limiting the scope of the analysis (Braun et al., 2019). Harding et al. (2018) and Barbour (2018) suggested naming themes, giving themes descriptions, or coding decisions using participants’ words in order to mitigate this risk and remain focused on what they were saying (Barbour, 2018, Braun et al., 2019, Harding, 2018).

3.5.5.5 Methodological quality.

Such an approach may need to be treated with scepticism, as the technique is supposed to allow participants to have their say, rather than merely conveying the impression of giving them a voice. However, care must be taken to distinguish between a genuine desire to represent the participants’ views, and the researcher’s ability to provide that platform. Embedding participants' voices in the analysis strengthens this research approach (Harding, 2018). Reflective thematic analysis uses several techniques that encourage the researcher to play the role of a storyteller using the various participants’ narratives (Braun et al., 2019), simultaneously boosting the trustworthiness and reliability of the analysis process and answering the earlier criticisms of thematic analysis (Braun and Clarke, 2013).

Despite the subjective nature and lack of rigour of qualitative research and data analysis, the reflexive approach emphasises the need to apply quality frameworks and constructs to demonstrate trustworthiness and rigour (Braun and Clarke, 2013, Doyle et al., 2020). The researcher is well positioned to ensure quality, trustworthiness, and rigour of the qualitative research output through methodological completeness, soundness, and adequacy. There is an ongoing debate in the literature regarding the terminology that best describes rigour and subsequent quality measures in qualitative research (Polit and Beck, 2017). While positivist methodologies focus on reliability, objectivity, internal and external validity, and generalisability, the qualitative investigations replace these principles with credibility, transferability, dependability, confirmability, and authenticity (Denzin and Lincoln, 2011, Guba and Lincoln, 1994, Polit and Beck, 2017). Details of the various criteria for trustworthiness and rigour and how they were established for this study are summarised in Table 4.1 and detailed in Appendix V-A. The help and support of the patient and public involvement advisers in data analysis also entrenched participants' voices in the research outputs and enhanced the research value. This emphasises its analysis principles that enable the researcher to benefit from the participants' extensive lived experiences evident in their told accounts, and combines these benefits with the researcher's ability to interpret the experiences in the analysis.

3.5.6 Patient and Public Involvement (PPI)

In recent years, and in the UK specifically, there have been growing calls to provide patients with life-limiting conditions and their family members with better assistance in terms of modifying existing services or planning new ones (Brett et al., 2014, Mockford et al., 2011, NIHR-CED, 2020). Stakeholder involvement in healthcare practice exists through several engagement-related concepts, such as patient and person-centred care, Patient and Public Involvement (PPI), shared decision making (SDM) and co-production in which patient voices are amplified and thus guaranteed to be heard (Barry and Edgman-Levitan, 2012, Batalden et al., 2016, Ekman et al., 2011, Hudon et al., 2012, Locock et al., 2017, Mockford et al., 2011). For example, PPI is a way to explore the patient's side of the story – the perspective of lived experience – and provide them with an opportunity to guide a research process that is capable of identifying and meeting the needs of their counterparts (Greenhalgh, 2009). Such a process operates through an embodied engagement that adds value to the existing evidence by addressing a real gap in knowledge, answering essential and relevant questions, yielding findings that align with patients' and caregivers' needs and preferences, and tailoring the intervention to those needs and preferences (Brett et al., 2014, Crowe et al., 2015).In addition, the involvement of patients, family members, and healthcare stakeholders in planning how to analyse, report, and disseminate the research findings increases the study's potential to meet its aims, change current practice, and improve health care and outcomes (Ramakrishnan and Miller, 2021). However, Greenhalgh et al. (2019), who reviewed the existing frameworks to support PPI in research, and found that over 50% of PPI frameworks were founded in the UK, confirmed that a 'one-size-fits-nobody' approach is the right one. They praised this approach for having sufficient rigour without imposing needless restrictions and running the risk of failure. Therefore researchers are encouraged to select, adapt, customise, and then implement an existing framework to meet the end users' needs and the research aims while at the same time paying attention to the context.

3.6 Chapter summary

This chapter has presented the literature pertaining to methods and described the philosophical, methodological, and theoretical foundations of this project. It began by discussing why paradigms are so important in nursing research. Then, as the study addresses the role of culture in shaping individual understandings, it was determined that this would be best achieved by providing a critical realist view. The chapter then discussed in detail the ontology and epistemological orientation of the whole thesis and how they informed the method that was chosen. It also described how the research questions were answered based on the underpinning assumptions, and why. The chapter then addressed the way in which the aims were mapped on to the MRC Framework recommendations, and why, and it considered how and why the collected answers were analysed according to reflexive thematic methods. Finally, it described how the chosen methods enhanced the study’s methodological quality, increased the rigour of the data analysis, and improved the reliability of the findings.

Chapter 4 Methods

4.1 Introduction

This PhD aimed to investigate the impact of culture on palliative care services for patients with heart failure from diverse backgrounds by focusing on individual understandings. In addition, the study aimed to identify cultural implications and challenges that need to be considered when developing and implementing interventions to support palliative care in advanced heart failure.

This qualitative study was guided by the following research questions:

- What cultural beliefs/attitudes may be involved in how patients construct their understanding of palliative care for heart failure?
- How do patients with heart failure from diverse cultural backgrounds perceive how palliative care is received and delivered?

4.2 Study design

The study employed a qualitative descriptive design as no similar research was found prior to this study. The recruitment centres were purposively selected, while potential participants were recruited via convenience and snowball sampling. Members of the public who were living with or providing care for someone with, or who had previously had, heart failure, heart disease, and/or other long-term conditions and who were willing to discuss their understanding of illness and culture were eligible. Data were collected through one-off semi-structured group discussions with each cultural group using a hypothetical patient scenario. The focus group data were analysed by reflexive thematic analysis using Nvivo 12 software. The study was conducted between October 2017 and January 2020.

4.3 Patient and Public Involvement (PPI)

4.3.1 Recruitment of Advisors

All advisers were recruited through a local network of contacts from cultural and social events, cafés, libraries, and other public places. None of the study advisers was recruited by online advertising, professional organisations, or personal contacts. As the impact of PPI in research is societally, ethically, and scientifically beneficial to enhancing nursing research and reducing waste, PPI has become mandatory for all PhD students in the Palliative and End of Life Care Patient and Public Involvement (PPI) research group at the University of Glasgow. In addition, as a national test-bed in the NIHR INVOLVE project, Professor Bridget Johnston has shared our real-life experience with PPI in a booklet of Implementation Stories (UK Standards for Public Involvement, 2020).

Our criteria for finding a suitable adviser were that they should contribute substantially to the project but also represent one of the targeted cultural groups. The decision about a PPI adviser was made in consultation with the PhD supervisors. Given that the current doctoral project was undertaken to investigate participants' cultural diversity and its influences on their understanding, efforts were directed towards primarily recruiting PPI advisers to reflect a wide diversity of contexts, perspectives, and geographical locations, and to bring together various cultural experiences and backgrounds. The four volunteers who accepted the invitation to become involved were all male and were aged between 39 and 70 years at the time of recruitment. A brief synopsis is provided in

Appendix III-B &C.

The four advisers were recruited for different reasons. Cameron, Muhammad and Allan were recruited because of their personal experience of living with heart failure. However, Wael was recruited because of his experience of providing care for his mother, and for his mother-in-law, who had chronic heart diseases. One adviser, Allan, was offered and utilised specialist palliative care services and treatments. The selected PPI representatives were also culturally diverse. Cameron and Allan were both white Irish and Scottish, whereas Muhammad and Wael were of South Asian and Middle Eastern origin, respectively. In addition, all of the advisers were noted to possess forms of experiential knowledge. None of this knowledge was research related, but rather it was closely related to knowledge sharing and transfer between peers who have similar symptoms and complaints and who share the same sociocultural background.

Given the voluntary nature of the contribution, some advisers were involved in parts of this doctoral research. Cameron solely supports the project for one year (during the systematic review synthesis and reporting). Some advisers had agreed to participate but ended their involvement mainly because of deteriorating heart failure and mental health problems during the pandemic. Other reasons such as cultural conflicts, work demands, or emerging life stresses or events were also mentioned. Mohammad ended his involvement for family reasons during the pandemic.

4.3.2 Patient and Public Involvement arrangements

In total, more than 100 hours of investigator–adviser interaction were recorded, and were regarded as the most critical data sources. The study PPI contributors have sacrificed time, effort and money by travelling for a meeting or catch-ups, allocating time (and other resources) to ensure that their voice is heard, which was the primary motivation for their involvement. In recognition of this, the investigator used to travel to their local area to limit travel costs, and they were offered shopping vouchers (to the value of £20 each time) as a gesture of thanks when they contributed to the study by reading, advising, or providing feedback on the ideas, steps, or concepts.

Aiming for meaningful involvement, it was essential to develop an open and honest relationship in which advisors were encouraged to challenge and comment on ideas, clarify any assumptions, and critique the rationales behind each decision initially proposed by the research team. Periodic meetings were held during their involvement in supporting this project. In-person face-to-face meetings were the preferred and most frequently used method of contact. Some volunteers preferred email contact when written material was circulated or feedback was sought, whereas others preferred the material to be printed or verbally discussed. During the lockdown, face-to-face meetings were supplemented with online meetings using Zoom or WhatsApp.

A formal PPI advisory group was not created because of the nature of this PhD project, which was an underfunded study with limited time and resources. On the other hand, involving independent PPI advisers rather than establishing an advisory group has established one-to-one focused and friendly relationships and fostered a good rapport and open dialogue. Such friendship has been instrumental in enabling the completion of this project, designing its steps, and ensuring continued involvement throughout this research.

4.3.3 Advisors’ contribution to this project

To ground this thesis in reality and relevant experience, it was decided that PPI representatives would be recruited to join and contribute to the research from the beginning of the research process. Members were invited to act as independent PPI advisers rather than to join an advisory group. Even though the advisers were not included in writing the doctoral proposal that started before any advisor was recruited, they consulted on various issues. The PPI representatives advised on research priorities, study design, recruitment, and data collection and analysis. They also raised ethical concerns and disseminated studies from the University of Glasgow to the broader society.

4.3.3.1 Contribution to the Systematic review

After advisors responded positively to the invitation to support the study, they were briefed about its process, procedure, and goals. They were involved in examining the systematic review synthesis to ensure its credibility. Themes and sub-themes of the literature synthesis were explored and explained with a detailed description for each of them. The discussion refined the themes (i.e. language and hierarchy) and confirmed that the findings reflected an aspect of his experience. For instance, the recommendation to combine narratives concerning heart failure diagnosis, aetiology, and treatment under the heading 'Lay heart failure beliefs and knowledge.' This was justified from the PPI representatives' experiences as these conceptions were drawn from lay beliefs and knowledge gained from their own experience or the similar experience of someone else. It was also mentioned that the diverse contexts and cultures underline the importance of doing so, as lay beliefs and knowledge are the main determinants of help-seeking behaviour. This exercise also identified new aspects that did not exist in the systematic review, and it was recommended that they should be explored and included as part of the subsequent empirical study. On a personal level, the involvement of Cameron as a psychologist had a positive impact on the investigators' self-esteem and reduced feelings of isolation. He was consulted five times during the reporting and discussion of the results, including recommendations and dissemination. With regard to dissemination, the PPI adviser collaborated and distributed some visualisations that summarised the systematic review findings across his network in an informally organised meeting

4.3.3.2 Contribution to the focus group study

PPI advisers have provided advice and support throughout the data collection process, particularly when planning the focus groups with the cultural group. Their cultural brokering role was evident in bridging the gap between individuals or groups from their cultural backgrounds. For instance, Muhammad served as a translator to bridge the communication gap between the researcher and the community and facilitated a mutual understanding despite the language barriers and various assumptions and values. Thus, the involvement of PPI advisers resulted in better recruitment strategies in terms of participant numbers and group cohesion. The research team developed the topic guides for the focus groups, and the guides were reviewed by the PPI advisers. The study planned to use the same topic guide but to customise it for five or more focus group. The data obtained was limited, superficial, and simply indicated a possible failure to address our research questions; therefore the approach was modified. The issue was discussed with the study and PPI advisers. Both recognised the former's limited contribution and suggested approaching people less directly using a scenario-based approach. The study advisers were involved in resolving problems in gaining access to centres and starting recruitment. At certain sites, recruitment of participants was complicated, with many potential participants abstaining or opting out. The PPI liaison group support made the access process relatively easy because of their connections and lack of administrative barriers.

Their involvement in this research has made them more active and confident in the research process. Ideally, the PPI members would be willing to have their say, be involved in a study, and speak about their experiences. However, instead, their engagement led them to cooperate in planning, designing, and implementing the study. In addition, one adviser, whose experience of quantitative analysis was substantial, was keen to know about data analysis, particularly reflexive analysis. On the other hand, Allan began to reflect on additional PPI contributions to the research process, moving from involvement to co-production.

4.3.4 Researcher reflections on their involvement

Involving PPI advisers in planning, executing, analysing, and reporting findings has challenged the perspectives and beliefs of the researcher. Having a PPI adviser on board demonstrates how different it is for a researcher to see the world from patients' and public points of view while embedded in this process. Commonly, researchers or clinicians see the world through their practice and data, through a 'professional' lens. The predominant influences from disciplines, such as researchers' worldviews and theories, are inseparable from the data-handling process as part of socially and culturally constructed realities. Although qualitative research allows the researcher to study individual experiences, meanings, and interpretations quite effectively, what matters to them in terms of their goals is frequently lost. Unfortunately, the debate over these methods' lack of rigour and reliability has led to a failure to respect them. The nature of the qualitative research process led researchers to focus more on improving the accuracy and quality of findings, while forgetting what is of most importance to them. As a result, participants' voices are lost. They become a part of a theory and are called participants, which results in care that lacks integral elements such as compassion, cultural sensitivity, or professionalism, and causes unnecessary suffering. It is clear that researchers are more likely to lose participants' voices during data analysis. Cameron, the first recruited PPI adviser, confirmed that while reflecting upon the offer to join the research team, he described the clinical research as overprocessed food, which looks very tempting but sometimes tastes terrible.

The PPI in data analysis has challenged researcher assumptions about current practice, and the notion of 'good' or 'desired' outcomes. Encountering different worldviews and opposing questions about the researcher's axiological position, such as 'what is reasonable, what is desired and what is appropriate', led to examination of personally held assumptions, beliefs, and values. Thus an opportunity can lead to intellectual growth and reflexive practice, reinforce ethical conduct, and increase responsibility and reliability.

While generating initial codes focused on medical terminologies and capturing clinical or theoretical connections and interactions, Wael has drawn attention to the patients' and caregivers' lack of knowledge and misperceptions, and their reliance on their experience of heart disease in the clinical setting. Several cross-cutting themes were constructed by discussing these two perspectives, such as 'Palliative care in heart failure: a lily-pond concept.' This theme represents the stratified understanding by combining the philosophical, PPI representative, the investigator and participant perspectives, observed and simplified using a three-layer lily-pond metaphor. Such a theme would not have been constructed as strongly as this in the final analysis without PPI involvement and their support in understanding the patients' and family members' perspectives. The frequent talking through of data and findings helped to develop a mutual understanding of the data and common grounds. Codes, categories, and themes were articulated clearly without the need to use jargon. The above open unambiguous coding introduced greater rigour and reliability into the study.

4.3.4.1 Areas for improvement

Despite the positive impact of the PPI advisers on research quality and results, it is sometimes impossible to remain focused and avoid going off topic. This is understandable and is repeatedly cited as a challenge to their involvement. However, the nature of the topic made it even more challenging. Firstly, the long-standing assumptions, value conflict, and uncertainty around palliative care caused advisers to experience difficulty when invited to talk about their personal stories at the start. Secondly, despite the existence of various PPI models, there is considerable confusion and a lack of guidance on interacting with individuals or groups from diverse cultures and backgrounds.

Moreover, it is often complicated by advisers' limited experience and bound by the strict time and financial constraints for doctoral researchers. It was acknowledged that participants came from different places of understanding that determine how and what they share about their experience. This necessitates calling for new ethically sound and culturally valid PPI methodologies to invest in and foster community collaborations to deliver the best research output with impact.

4.4 Study settings

Scotland has a diverse, complex, multicultural society and has been experiencing exponential growth of cultural diversity within its population (Smith and Simpson, 2015, Walsh et al., 2019). However, in general, but particularly in Glasgow, it has poorer health outcomes and higher mortality rates than the rest of the UK, even when areas with similar levels of deprivation are compared. It has been observed that no single factor is responsible for this, but rather a complex interaction between multiple factors. The 'Glasgow effect' is a term coined by researchers to refer to this health phenomenon that cannot be explained by deprivation alone, given the expanding cultural diversification of Glasgow's population (Cowley et al., 2016). All empirical work in this thesis was carried out in the Greater Glasgow and

Clyde area, which is the most densely populated region in Scotland. It is divided into six local authorities: Glasgow City, Renfrewshire, East Dunbartonshire, East Renfrewshire, West Dunbartonshire, and Inverclyde (for further details, see **Error! Reference source not found.**-A).

Given the impossibility of covering the full range of cultures in Glasgow, a unique sociocultural strategy was proposed to overcome such limitations. First, Scotland's 2011 Census and forward projections data were used and examined to select the target groups which reflect Glasgow's social and cultural diversity underpinned by the size and geographical spread. Then, the recruitment sites were purposely selected to reflect the diverse cultural groups and chosen to cover the localities and geographical distribution of the targeted groups in Glasgow. The target sites consisted of community centres, charities, and religious organisations. The research team, including Patient and Public Involvement (PPI) volunteers, selected a total of 14 community-based organisations and community centres.

4.4.1 Initial contacts

An introductory email containing an overview of the study and contact details was sent to all cultural and religious community organisations, such as churches and mosques, that could potentially be included in the study. Reminder emails were subsequently sent, but only one response was received. Text messaging and phone calls were also used to contact community members, but secured only one appointment. Therefore it was decided that these groups could only be accessed by visiting them and participating in their events in person. Each site was visited up to three times before the initial contact was made. These visits to potential recruitment sites and networking with potential contacts enabled the key organisations that catered for different cultural groups in Glasgow to be identified. The other main objectives of the visits were to gain access to community members, to get to know the group by meeting individuals and groups, to introduce and generate interest in the study, and to identify a person from each target group who would be willing to help to establish communication links and liaise with other members within their group.

4.4.2 Gaining access

Gaining access to and establishing communication channels with centres in a foreign country presented practical challenges. In the initial stages it was difficult to establish a rapport and gain the trust of the staff of each organisation. However, the research team's familiarity with the diversity of Glasgow allowed a relationship of trust to be nurtured and developed. Moreover, the early practical challenges provided useful insights into the complexities of these relationships, especially those of a study-sensitive nature. Even though the initial plan was to recruit a sample covering a wide range of cultures from Glasgow's diverse community, the response to the first contact was much lower than expected. In total, eight out of fourteen centres gave consent for the research team to access the site and provided details of their planned events and activities, as seen in Figure 4.1. These eight centres were included in the application that was submitted to the relevant university ethics committee for approval. Although permission for physical access to each of the centres had already been granted by the College of Medicine, Veterinary & Life Sciences (MVLS) ethics committee and by the centres' boards, social access required seeking out liaisons and leaders to identify the potential participants.

Many leaders and liaisons had both positive and negative views about heart failure and palliative care. However, their views and opinions were not always expressed in black and white. In some cases, positive views, attitudes, or experiences translated into access being granted easily, and the investigator's task was facilitated by leaders who shared an interest in the subject and understood its value. However, gaining social access to other sites, where leaders were reluctant to participate or unsure about the outcome of the study, required much time and effort. Those leaders' negative attitudes far outweighed their perceptions of the potential benefits of the study. These views and experiences also provide essential context in terms of understanding and depth when interpreting culture-related investigations.

4.4.3 On-site study liaisons and coordinators.

The coordinators were often sceptical about the research, and reluctant or even frightened to discuss the topic openly with the researcher, whom they had not known before the study. However, involving a PPI volunteer or a key person from within the targeted group, who recognised the value of the research, helped to create bridges between the research team and the candidate centres. These bridges eased recruitment by playing a pivotal role in disseminating information about the study to potential participants, referring them to the interviews, accommodating their needs, and developing a rapport with the staff.

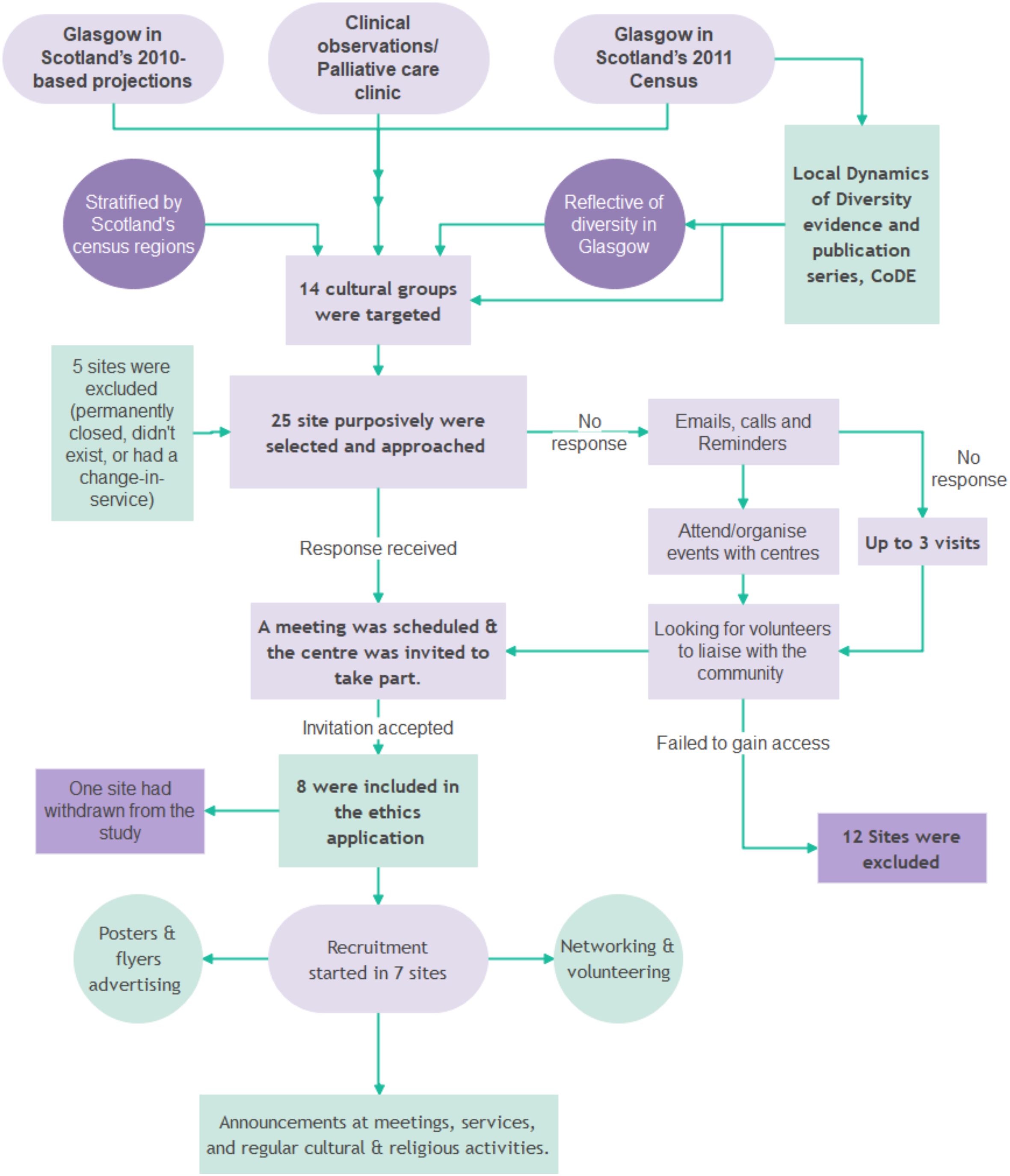

Figure 4.1 Recruitment flowchart

Finding a door opener was the key to establishing a good rapport and a relationship of trust, both of which are essential for success. In addition to allowing access, this strategy also helped to reduce the amount of time spent searching for interviewees and solve any problems encountered while conducting the study. However, developing trust and gaining access to some centres sometimes required undertaking certain management activities and meetings, such as a workshop. Access was also sometimes challenged, or conditional upon avoiding certain subjects, such as death. In the latter case, the leaders had a significant influence on the perspectives of the groups.

4.5 Study sites

4.5.1 Socio-demographic Profile of study sites

Six sites were located within the Glasgow City Council region and one was located within the East Dunbartonshire Council region. However, participants recruited at these sites were living in Glasgow City, and in East and West Dunbartonshire. According to the Scottish Index of Multiple Deprivation (SIMD), the three councils' shares of 20% of the most deprived neighbourhoods are 45.4%, 3.8% and 39.7%, respectively. As shown in Figure 4.2, most of the participants who were interviewed at Sites *B* and *G* were from data zones in the 5% most deprived areas in Scotland, namely Springburn, Gorbals, Govanhill, and Pollock. Participants who were interviewed at Site *A* were from data zones ranked from the 5% and 10% most deprived areas, namely Cowcaddens, Woodside, and Maryhill. Participants interviewed at Sites *C* and *F* were from data zones in the least deprived areas of Scotland, namely Bearsden, Milngavie, Bishopbriggs, and Finnieston. Most of the participants who were interviewed at Site *D* were spread between Govan, Drumchapel, and Clydebank. These data zones are ranked among the 5–20% most deprived neighbourhoods in Scotland. It is noteworthy that the participants were residing in areas that ranged from the most deprived areas (SIMD 1) to the least deprived ones (SIMD 5). However, the majority were from the most deprived neighbourhoods, which could be explained by the fact that a significant proportion of ethnic-minority communities were residing in these areas. This association is not new in this context, as the deprivation levels in these areas have recently been linked to various problems, including health, education, and access to services (Walsh, 2017, 2019). When linked to demographic characteristics of the participants and their accounts, this gradient can provide a unique context and diverse perspective on the topic not yet considered, particularly when exploring the understanding of an illness and, subsequently, its impact on help-seeking decisions and behaviours. The inclusion of this social gradient has increased the richness of the data. In order to provide a detailed picture of the study sites, each of the areas will now be discussed in turn.

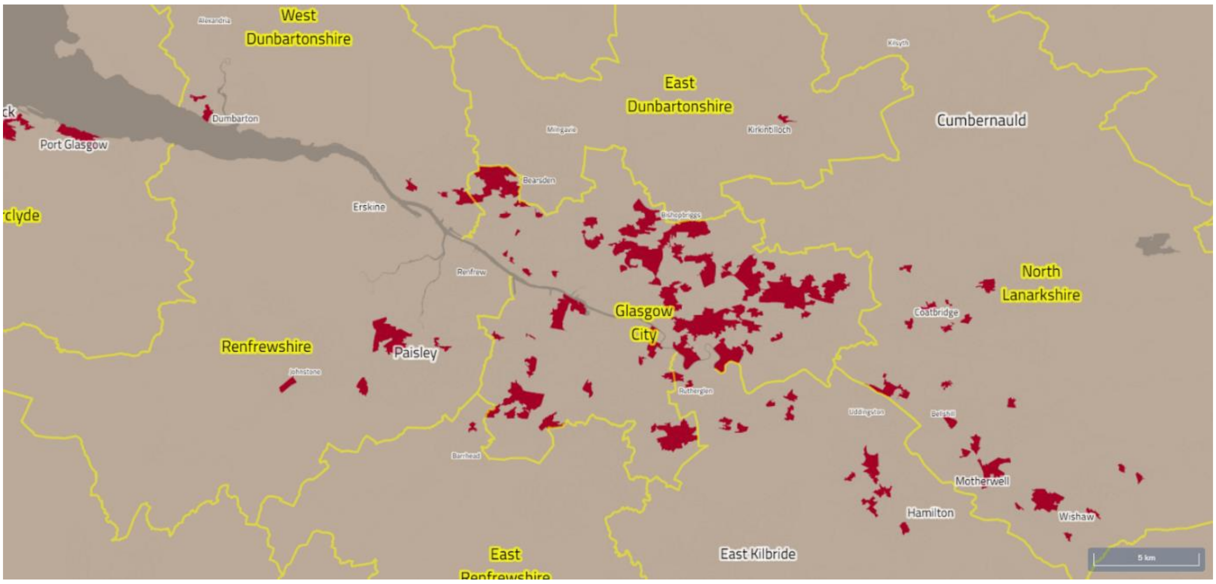

Figure 4.2: Authorities share of 5% most deprived area (Source: SIMD, 2020)

4.5.2 Profile of study sites

Site A

Site A is a Scottish charity and community centre that serves as a contact point for supporting and educating members of the public, particularly the Chinese community, with regard to their culture, health, and well-being. The centre is an intermediary between the Chinese community and the local authorities, and facilitates integration into Scottish society. It also serves as a hub that allows members to preserve their Chinese culture and maintain social ties. The organisation’s main themes are improving members’ quality of life, promoting cultural exchange, increasing racial harmony, and supporting the Chinese community, including asylum seekers.

Site B

Site B is an Islamic centre and mosque located in central Glasgow. It is the home of the earliest Muslims who migrated from India and Pakistan to Glasgow. The centre is now a place of worship for the largest Muslim congregation in Scotland, and a multifunctional place of assembly, law, education, and promotion of health and social cohesion for the community. Usually mosques serve a large geographical area and are open for anyone to visit, and as a place of worship for all Muslims. Therefore their populations can be very ethnically and culturally diverse. However, in Scotland, mosques are segregated into ethnic-philosophical schools. Site B has a predominantly Pakistani-led Muslim congregation, followed by other South Asian minority groups. As a result, the site attendants were from one ethnocultural group who spoke the same language. This focus group discussion took place in an elderly day-care facility attached to the site.

Site C

Site C is a hub of the Scottish faith community, in particular Sikhs. It is a place where congregation members can worship, hear religious teachings, and learn about mainstream, Sikh, and Indian cultures. More recently, the site has been involved in health education, promotion, and research. However, as its members had received little information about the new approach, some of them challenged the research team, suggesting that the centre is more about social life and culture than about health and research. In addition, the investigators were told that they were 'swimming against the stream' with regard to issues that go against Sikh religious doctrine, such as abandonment of care.

Site D

Site D is part of a UK-wide organisation that is committed to promoting better understanding, engagement, and harmony between communities. It serves the Muslim community of Glasgow by providing a place for worship and spiritual teachings, and while remaining true to Islamic principles, the centre aspires to support charitable work and cultural activities, promote health awareness, and support healthcare research. Much like Site B, the centre is primarily used by Middle Eastern and North African Muslims. Their shared culture and traditions, including one language, Arabic, allow an even higher level of resource sharing and cultural understanding.

Site E

This Scottish charity and multicultural centre supports asylum seekers, refugees, black and ethnic minorities, and migrant workers settling in Glasgow and integrating into its broader community. The services provided by the Integration Network include cultural activities, Q&A drop-in sessions, information sharing, women's groups, a mothers and children group, and language support. In addition, the centre plays an essential role in providing health information, including registration for and access to healthcare and non-healthcare organisations, community groups, and individuals.

Site F

This village church has a relatively small congregation, and is situated about 5 miles northwest of Glasgow. The study was advertised by local community centres and religious organisations within the village. Participants were recruited primarily through one church community group and liaison. The church holds a number of services during the week, including Sung Eucharist on Sundays, an Ecumenical prayer group on Tuesdays, and a mid-week service on Thursdays. In addition, the church offers various social activities, including craft activities. Seeking access to some centres to discuss palliative care for heart failure was challenging. However, the nine participants at this church in northwest Glasgow had notably higher levels of education and health literacy. The small congregation may not be representative of what the wider population of white Scottish people and Christians believe, but this is unlikely to have distorted the results, given the nature of the study question and conversations.

Site G

This Scotland-wide community organisation based in northeast Glasgow aims to understand black, Asian, and minority ethnic (BAME) communities better, and to facilitate social acceptance and build thriving, engaged, and integrated communities. This organisation also supports its members' development and welfare needs. In addition to improving education, relieving poverty, and promoting cultural links between African and Scottish populations, the centre has a role in improving health education and well-being for the wider public.

4.6 Sampling and eligibility

The study sites were based in Greater Glasgow and were selected to represent the diversity of Glasgow's population, as per the predefined strategy. From the sample of seven sites, participants were conveniently selected. Members of the public in Glasgow who were living with or providing care for someone who has or had heart failure, heart disease, and/or other long-term conditions and who were willing to discuss their understanding of illness and culture in a single group discussion were invited to participate. Participants who met the inclusion criteria (see Figure 4.3) were not required or assumed to have prior expert knowledge. However, a general understanding was desirable, to help to ensure engagement with and success of each session.

Eligible participants must:

- Be aged 18 years or older
- Have resided in Greater Glasgow for 12 months or longer
- Be able to communicate in English, to speak and understand.
- Be able and willing to give informed consent
- Be able to provide a written privacy notice
- Be wlling to devote 60 minutes of their time to one-off group discussions
- Be willing to undergo audiotaped discussions
- Belong to one of the target groups

Excluded if

- Unable or unwilling to meet any of the inclusion criteria

Figure 4.3: The eligibility criteria for participating in the study.

The study did not rely on a pre-set sample size to determine when to terminate recruitment. Instead, an estimation approach was used based on the research teams' knowledge and expertise, and informed by the depth and appropriateness of data gathered. The initial plan was to conduct at least five focus groups with different cultural groups for meaning saturation, with an anticipated 6–12 participants per group. This would give a total sample size of 30–50 participants. However, the sampling process proved challenging, so it was decided to keep sampling until the study groups and data were sufficient to achieve the aims and address the questions of the study.

Non-probability, purposive sampling was adopted for the study population using inclusion criteria, aligning with the study design and philosophical position. It utilised a purposeful sampling technique with a maximum variation strategy between groups – the method used to select participants based on their sociodemographic characteristics so as to maximise sample diversity. At the same time, selection of candidate members within each group, who were found to be eligible, was based on common sociocultural characteristics in order to maximise group interactions and allow discussion of shared experiences.In addition to purposive sampling, snowball sampling was used to reach new participants from the purposively selected one. Snowball sampling was also utilised when any participant stated that they knew someone from the same culture group whom they thought might be willing to participate and volunteered to tell them about the study.

4.7 Recruitment Procedure

The selection of potential sites and obtaining their initial consent was carried out prior to ethical approval through word-of-mouth advertising. Ethical approval was granted for conducting the focus group interviews (see Appendix IV-A). Upon approval from the site representatives, the potential participants were approached at each site during routine visits or prayer times. Posters and flyers advertising the research were also displayed and distributed at all sites. The local centres assisted with the recruitment by community networking and by making announcements at meetings, services, and regular cultural activities.

The study information package containing the study information sheet, flyer, and an overview of the study plan (see Appendix IV) was handed to eligible participants. People who expressed their willingness to participate were then asked to contact the principal researcher directly via phone or email or indirectly by expressing their interest to their group liaison, who was then contacted by the principal researcher within an agreed timeframe. This timeframe would allow the individuals to get their questions answered and carefully consider whether or not they wished to participate. If they agreed to participate in the study, they would then be asked to provide their contact details, including a preferred method of communication by which they could be notified of the location, date, and time of the group meeting. Participants were then given the informed consent form and privacy notice (see Appendix IV- D and E) to read and sign in the presence of the facilitator or co-facilitator. Following this, the recruitment process continued until the target sample size for each group was achieved, and there were no more participating sites to recruit. Finally, eligible participating volunteers who demonstrated an interest in discussing their perspectives on culture and heart failure received the relevant information, and groups were formed, where possible, based on their cultural background in order to capture different perspectives. Hence exploring various beliefs, values, and symbols may drive the understanding of the different interpretations of heart failure and may capture the culture-coined understanding of palliation in heart failure.

Unfortunately, some site coordinators withdrew their assistance almost immediately after the recruitment process, as they lacked information on members' health status. Despite all of these efforts, recruitment was very slow. The most common reasons for non-participation were lack of response to emails or phone calls, or the contact being too busy or overrun with research requests. Logistical constraints such as centre closures, changes in role, lack of interest in face-to-face recruitment, issues with consent forms and recording, and the centres' competing priorities were the most commonly cited reasons. Therefore the investigator had to seek alternative recruitment methods for participation, or sometimes coordinate events and workshops to introduce the study to eligible members of the public informally. Consequently, the top-down recruitment strategy changed to a bottom-up one. As a result, the 6-week period for collecting data had to be extended to ensure that there were sufficient participants.

4.8 Data collection process

The qualitative research used focus group discussions to collect data. All sessions were conducted in Glasgow between April and September 2019. Seven sites were used as the final recruitment locations – four community centres or charities, and three religious organisations. The participating sites also provided a space for the group interviews.

4.8.1 Focus group preparation

The selection of venues considered the choice of a liaison person and the convenience of the participants. The locations for each focus group were selected to ensure that they were well ventilated, bright, and comfortable, with adequate seating. If disabled access was required for any participant, this was made a priority. Before the participants' arrival, the seating arrangement took the form of a round-table setting, with chairs arranged around the table facing each other. Study-related forms and relevant health information booklets, guides, and leaflets such as the British Heart Foundation's *Living with Heart Failure*, *Reducing Your Blood Cholesterol*, and *Blood Pressure* were displayed at group meetings, and participants were invited on several occasions to take away copies. It was perhaps not surprising that most of the participants ignored the health information leaflets, despite these invitations. It was noticed that the majority of the participants considered these materials unhelpful. The 'one-size-fits-all approach' of these materials was maybe due to the varying needs of patients. Some groups regarded them as inappropriate or not fit for purpose. For example, most of the participants in the second session were unable to read them due to literacy problems. The participants at Site A also considered that the materials lacked cultural appropriateness, particularly in relation to food and exercise.

On arrival, the investigators welcomed the participants and thanked them for their participation. Since it was not uncommon to see new respondents on the day of the discussion, participants were asked to introduce themselves and their roles. All of the participants were then briefed about the study and allowed questions. Once everyone was settled, each participant received two copies of the consent form and privacy notice to read and sign. They could retain one copy and return the other to the facilitator. Every meeting started with greeting people and introducing the research team. The facilitator also gave a short explanation of the purpose of the focus group, confidentiality issues, ground rules, and the right to withdraw. The audio recording began with the participants' names or nicknames. They were also asked to say that name every time they spoke, to facilitate mapping out where everyone was sitting, assist with note taking, and make the transcriptions easier to perform.

4.8.2 Piloting testing

Before the actual group sessions, a pilot session was conducted with five participants. The pilot session aimed to adjust the topic of the discussion and questions to be context-specific, unbiased, and meaningful for the informants. The data collected during this session were not included in the analysis. Even though the pilot discussion was highly nerve-racking and the interview outcome was not as planned, it helped to identify unanticipated issues with the focus group guide that could be rectified for future sessions. The pilot interview also allowed the researcher to practice facilitating and moderating the discussions.

Issues related to the duration of the session, the topic guide language, questions, and prompts were all highlighted by the pilot interview. Feedback and advice from supervisors, PPI advisors and liaisons were sought and taken into consideration during this trial phase. The outcome was used as a guide to improve the data collection tool and evaluate the effectiveness of the focus group design. This included shortening the interview duration to 60 minutes, including 10–15 minutes for debriefing, and developing a generic topic guide, simplified and customised for each session (the questions required reframing with regard to language, mode of administration, and validity). The interview guides can be found in Appendix IV-F

4.8.3 Reflection on the first two focus groups

The purpose of these multicultural discussions was to explore the influence of culture as context on the understanding of heart failure and palliative care. The first two actual focus groups have provided further insights into the data collection techniques and procedures. However, the reflection showed dissatisfaction and a real need for change. In addition, some ambiguities were discovered in the study topic guide, which must be resolved to ensure optimal understanding of all the questions. Knowing how the discussion worked best and asking more indirect questions to gather detailed information aligned with the research aims.

The sensitive nature of discussions about the cultural dimensions of illness and care with multicultural participants required the research team to step aside from the traditional method to seek further clarification by conducting real-life discussions using a hypothetical patient scenario. Thus a hypothetical vignette was developed through an iterative process by the research team. A previous systematic review informed the hypothetical scenario (Alassoud et al., 2020). This was reviewed by a Patient and Public Involvement (PPI) adviser and guided by the clinical experiences of the research team in nursing, palliative care, and cardiology to encourage the type of information that was desired.

Reflection after the execution of all focus groups showed that the vignette approach was superior to the old strategy, especially with ethnic-minority elders, in providing realistic scenarios in which their attitudes could be assessed and exploring sensitive issues related to the topic objectively without being bound up in personal problems. It facilitated the discussions in contexts with a high degree of uncertainty, particularly in cross-cultural communication, and was suitable for and accessible to participants with a range of literacy levels. In addition, the case straightforwardly assisted the comprehension of abstract concepts and reduced any sensitivity. Therefore enabling a quick, open, and honest response triggered and delved into their logic and emotional side.

4.8.4 The hypothetical scenario

Participants within each focus group were presented with a customised scenario from their community and culture. Multiple amended versions were adapted and tailored to best suit and capture each cultural context. For instance, the names of the hypothetical patients were chosen to reflect the essence of the studied culture.

Inderjit, Amu, and James referred to the hypothetical patients belonging to south Asian, African, and Western cultures, respectively. As Figure 4.4 illustrates, each scenario consisted of a short description of a clinical situation with a reasonable number of questions. Four overarching storylines were constructed to gain cultural insights into the perspectives of having heart failure and being offered palliative care around the end of life. A person who was dying of incurable advanced heart failure had a history of heart disease, leading to poor quality of life and the burden of refractory symptoms. The cardiologist had to refer this patient to palliative care services for better symptom management, as conventional treatment alone could no longer relieve the patient's suffering. During the terminal stage of the illness he was brought to an emergency room, where he later died. In the scenario, the patient was resuscitated, catheterised, and shocked many times. Like thousands of people in this country, he did not have the opportunity to discuss and plan his future support, care, and wishes. Thus care was not tailored to him individually, and the staff could not meet the unique needs of this patient and his family.

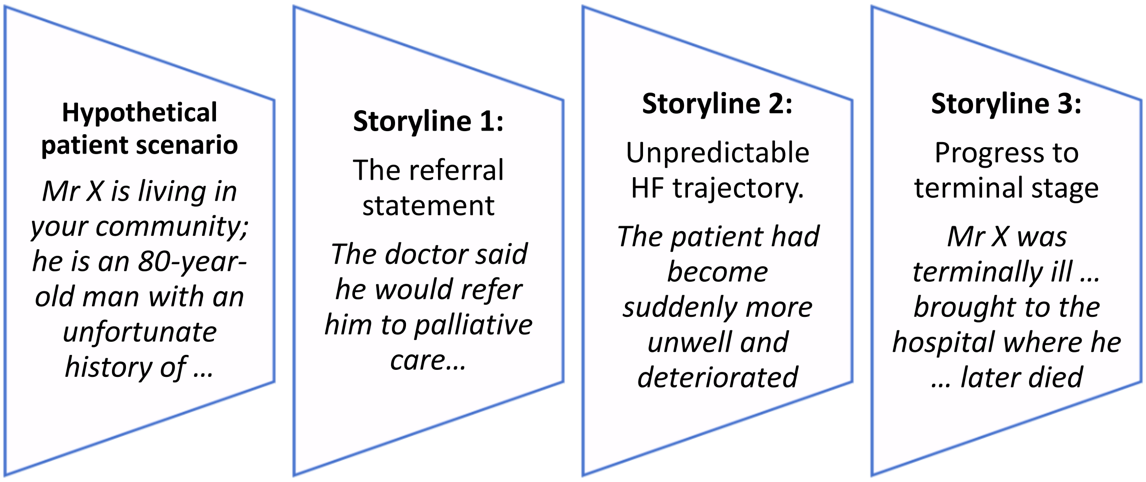

Figure 4.4: The hypothetical clinical vignette was used to elicit discussion.

The scenario was pilot tested with the Patient and Public Involvement advisers to demonstrate face validity and clarity. The study utilised a flexible age specification for the hypothetical patient between 50-80 years. Specifying the patient's age was suggested as a proxy for comorbidity and frailty and an essential factor in decision making in critical situations. Hence, it would trigger more thoughts and extract additional information during the group discussions. As can be seen in Figure 4.5, the open-ended questions and prompts were developed to cover the following main domains; participants’ perceptions, experiences, preferences, cultural help seeking, and decision-making styles. Although respondents were asked similar questions, sometimes the semi-structured conversation – particularly the follow-up questions – allowed the investigator to delve deeper into their opinions and worlds, which took the discussion in an unexpected but productive direction.

- What do you think the community understands by the term Heart failure/palliative care?
- Where would you like this person to be cared for? home? Hospital or at the hospice? (Personally)
- Do think in general people in your community would prefer him to be treated at home? or would prefer him to come to the hospital?
- What happens when this person becomes suddenly more unwell?
- As an X community do you think general the culture would /not prefer these words to be used or these discussions to happen?
- Do you think we have to have these conversations? To tailor the care according to what the patient wants and what is important to him?
- How else could we know what matters the most to you?

Figure 4.5: An example of the central questions of the scenario

4.9 Ethical and quality considerations

4.9.1 Ethical and regularity considerations

It is crucial to consider and address ethical issues when designing research. As this research includes direct contact with human participants, the ethical issues that could arise include the consent process, confidentiality, the risk to participants, and data management. These issues were carefully considered in order to maximise the benefits gained and minimise risk and discomfort to participants. Four months before the study was expected to commence, the ethics application was submitted to the relevant bodies at the University of Glasgow. The university has an online Research Ethics System to facilitate the preparation and submission of non-clinical ethics applications. The College of Medical, Veterinary, and Life Sciences has a robust and independent ethical review process and requires its researchers to uphold the highest ethical standards. Its policy document describes the need to 'respect the autonomy, rights and welfare of participants; minimise risk to participants and researchers; respect participants' rights to withdraw from the research at any time; appropriately manage personal data.' The MVLS College Ethics Committee approved the application on 28 March 2019. This study adhered strictly to Glasgow University's ethical policy (2019), code of practice (2014), the General Data Protection Regulation (GDPR), and the Data Protection Act 2018.

All of the organisations have been approached in an ethically correct manner. During the recruitment phase and consent procedures, the research team adhered to the principles of honesty, truthfulness, transparency, justice, benevolence, non-malevolence, and respect for participant autonomy. The recruitment process was coordinated through a liaison person, although no pressure was put on participants. Volunteers who were 18 years or older and who were willing to give their informed consent were considered eligible as per the criteria listed above. Potential participants then discussed the study with the group liaison before contacting the researcher. The Participant Information Sheet (PIS) was designed to fully inform participants about the research, why they had been asked to participate in the study, and the possible advantages and disadvantages of taking part (see Appendix IV-C). The PIS also informed participants that they need only participate if they wished to do so, and it set out their right to withdraw at any time with no explanation required. The recruited PPI adviser contributed to the content and language of all the study documentation. Participants were encouraged to read an information sheet and the focus study plan, which summarise the procedure and the purpose of the study, before the agreed day and then provide written informed consent on that day. Permission to audio-record the focus group discussion was obtained before the commencement of the discussion, though participants were informed about it in the Privacy Notice (PN) and the informed consent form (ICF) (see Appendix IV-D and E).

The study was conducted as per ethical approval and liaison recommendations that demographic questionnaires should not be used. Instead, a piece of general demographic information was obtained verbally. In the interests of confidentiality and anonymity, all names remained anonymous and would not be identifiable in this or any future report. However, participants who were extremely concerned about security and privacy when discussing understandings of culture and illness were invited to choose a nickname or a pseudonym. Additionally, compliant with privacy laws and to further protect participants' confidentiality and anonymity, all recordings were deleted upon completion of the data analysis. The data collected were kept confidential and securely stored on a password-protected computer (Glasgow University drive). The data were then anonymised, and an ID number was used to identify participants. All participants details, including names and contact details, were removed. Focus group transcripts were stored in encrypted files in a password-protected computer in line with the new data protection act at the University of Glasgow. Every precaution was taken to ensure that participant confidentiality and anonymity were not compromised during and after the group discussion. The fact that the group meetings were conducted in the participants' preferred location also added value to the confidentiality of data and the anonymity of participants.

4.9.2 Methodological quality, rigour, and reliability

In this qualitative inquiry, the researcher is the data collection instrument, analysis, and construction of findings. The study followed criteria and an accompanying strategy to ensure its methodological strength and foster confidence in its findings. This qualitative investigation focuses on credibility, transferability, dependability, confirmability, authenticity, and reflexivity (Denzin and Lincoln, 2011, Guba and Lincoln, 1994, Polit and Beck, 2017). Details of the various criteria for reliability and rigour and how rigour they were established for this study are summarised in Table 4.1 and detailed in Appendix V-A.

Table 4.1: Steps to ensure the methodological quality

Criterion	Technique	Description
Credibility	Member checking and triangulation	Credibility was ensured using member checking and triangulation in analysis. In addition, the multiple perspectives within the research team further enhanced the credibility
	Peer checking	Two co-investigators (BJ and KH) back-checked and cross-checked codes to ensure the robustness of the analytical process, to examine all of the data reflected in the coding, and to confirm themes being grounded in the datasets
	Prolonged engagement and observation	The research team engaged with the topic throughout the study's 1-year duration, including the 4-month period of data collection; prolonged engagement was applied. Unfortunately, the persistent observation was not possible due to the nature of the study (one-off focus group). However, the scenario was reviewed and modified to focus on the relevant issues in the following groups.
	Authenticity	Findings were reported to capture the diverse perceptions of all participants. These findings are supported by several quotations, enabling readers to easily understand the influence of culture
Transferability	Reflexive practice	Detailed information on methods (data collection, analysis, and interpretation), the context, situation, and phenomena with enough quotes were provided to improve transferability. Also we aimed to understand the context within which our work falls
	Adequate sampling	The sample was recruited from seven different cultural and religious organisations, and amounted to 55 in total. This is higher than the median, as reported by O.Nyumba et al. (2018). Understanding the subject from an adequate and diverse ethnocultural perspective is perceived to encourage more reflexivity and improve the authenticity and transferability of the data

Dependability	Audit trail	A complete account of all relevant documents collected throughout the study has been saved securely on a shared drive and is available upon request (hypothetical scenario, reflective accounts, field notes, topic guide, transcripts, and data analysis backups). All sensitive and critical decisions made throughout the study are also documented and justified in detail. Dependability was evidenced by prolonged and persistent engagement, member and peer checking, triangulation, and reflexive practice
Confirmability	Triangulation	Triangulation, both investigator and disciplinary, of participants' diverse perspectives ensured the confirmability of the findings
	Member checking	The PPI study advisers have been engaged throughout the study, and reviewed the results before publication
	Bracketing	BA and the co-facilitator have declared their roles as facilitators; neither of them have specific opinions or are experts on the topic. Thus the team tried to bracket off their professional part and focused on the purpose of the study. Being aware of their disposition, preconceptions, and impact on the interpretation – but not the way in which the study was conducted – facilitated bracketing (Braun and Clarke, 2013). The audio recording increased the confirmability of the results and ensured their dependability. Finally, the transferability of the findings was improved through the recruitment of diverse cultures and settings

4.9.3 Reflexivity

The lead author is a PhD nursing researcher, nursing instructor and practitioner, with little experience in qualitative research. From the beginning, the investigator aimed to be reflexive throughout this thesis, an example is shown in Appendix V-F. Throughout the research process, the lead investigator addressed reflexivity by identifying the experiences, background, values, and ontological and epistemological positions and describing how they have shaped this project and inquiry formation (Bradshaw et al., 2017). The principal supervisor first suggested reflective practice in the first PhD year. A primary reason for this was to encourage the development of writing and critical thinking skills and the ability to understand and engage with the literature and critically evaluate it. He is being reflective on the process of reflexivity concerning what went well and what went less well, why this was so, what should be done better next time, and what else can be done to improve this. At the start of the study, a reflexive diary was maintained to elicit the pre-understandings, beliefs, and biases towards the topic area, and to record and assess how their prejudices and pre-understandings influenced this research (Colorafi and Evans, 2016). The research design is outlined, and an attempt was to rationalise the decisions made about the methodological approaches under challenging circumstances and time constraints. A clear explanation of how centres were targeted, how the sample was selected, how participants were recruited, and how subsequent data were collected, including strengths and limitations, was also provided. Despite the reflexivity, prolonged engagement with the data and the thick description of the reflexive analysis, it has been acknowledged that accounts cannot be considered objective. The investigator created the adopted protocol and could be limited in terms of understanding, application, and degree of self-awareness.

4.10 Data analysis

Group discussions were digitally recorded and transcribed verbatim. The researcher or a professional service has transcribed the focus groups and translated them into English when necessary, see Appendix V-B. Transcripts were annotated with field notes, including non-verbal expressions using the NVivo software package (QSR International, 2020). Each transcript was converted into an audio file using the Read&Write Gold version 11.0, this text-to-speech software that supported the author’s reduced visual acuity in both eyes. The software helped to reduce screen time, which had been a real obstacle to analysing the data. In addition, the translated data was read many times and checked by the PPI adviser to ensure high translation quality.

As outlined previously, reflexive thematic analysis (TA) was chosen as an analytical tool to explore understandings of heart failure and palliative care and how culture or underlying culturally related factors may influence this understanding. Rather than attempting to achieve a unifying agreement, as may be desired in other approaches to qualitative data analysis, it was decided that a reflexive approach would be taken. Based on Braun and Clarke (2006), Braun et al. (2019), the reflexive approach can be utilised through six thematic analysis phases: data familiarisation, code generation, theme construction, theme review, and theme identification and labelling, and report production and writing up.

4.10.1 Familiarisation

This phase is primarily about familiarisation with the datasets, which started during the transcription process. Audio transcribing and translation have helped to give a general idea about the content and how group members answered the questions. The author kept listening to the audio-recorded data during the execution phase, and time was taken to capture any initial thoughts, notes, or observations. Then, the author immersed himself in repeated reading to identify meanings and patterns for each group and across groups, which later informed the generating of codes. The audio and written transcripts were checked against the actual recording to confirm their accuracy by BJ. Finally, brief notes about patterns observed, points of interest, and potential codes were captured across the entire dataset.

4.10.2 Generating initial codes

Similar patterns clustered around specific meanings, and prevalent accounts relevant to the research question were tagged and identified as initial, first-order codes. Initial coding from transcripts and field notes was carried out in two sub-steps; each session was analysed individually and then compared collectively with sessions by a cross-cutting analysis. The strategy was used to understand inter- and intragroup differences and similarities and to develop a reflexive interpretation present in the participants’ accounts beyond spoken words. The coding process was initially data-driven to reflect the semantic account of data, and developed over time with proximity to latent, or researcher-developed coding where implicit and explicit accounts were contextually interpreted. Hence coding was done at both levels, latent and semantic, which facilitated an in-depth understanding of the data and how codes could best capture the patterns across the datasets. This step was performed by BA and confirmed subsequently by two supervisors (BJ and KH).

4.10.3 Constructing themes

Transcripts were condensed into text summaries, grouped according to the case storylines, and broken down into meaningful chunks, see Appendix V-C. Next, the data review extended to broadly incorporate as many potential codes as possible by (BA) and ensure that all potentially relevant accounts were adequately considered and exhaustively coded. This early review stage, by supervisors (BJ and KH), resulted in a significant shift in the nodes' hierarchical relationships, whereby codes identified as not capturing the required pattern were discarded. Once the initial codes were exhausted, they were collated into a list. As a result, a total of 163 nodes were created across the dataset. Categories were determined based on the frequency or intensity, which was later assessed for overlap and broader connections. While nodes with overlapping meanings were merged, codes with similar meanings were grouped as parent, child, and grandchild nodes in NVivo software.

4.10.4 Reviewing themes

The codes were then sorted into themes by searching for ways to answer the research questions. The reflexive notes and discussion summaries aided the process of finding connections and links during theme construction. The search for themes was done by the author (BA) inductively and abductively and did not rely on a theory or previous findings; instead, it was situated in the contextualistic epistemic position. This position was beneficial as it retains the ultimate interest in the ‘realities or truths’ in the datasets, but explores the multifaceted reality constructed from diverse contexts with acknowledgement of my culture, understanding, and active role within this process. As ever, the study approach to data analysis began as ‘experiential’, prioritising respondents’ perceptions, and experiences. Then, it progressed into a more interpretative form, which was advantageous in uncovering implicit meanings. The recursive process of Clarke and Braun's thematic analysis allowed the researcher to review themes and go back and forth between stages and elements of the dataset. As a result, the process allowed making sense of the hierarchical relationships of the themes at three primary levels. First, the overarching themes solely organise and structure the analysis. This level is expected to capture encapsulated ideas without participants' data or accounts. Second, the principal and central concepts or themes that capture various patterns in the data and sub-themes reflect each theme's specific aspects. Third, themes were reviewed by the research team (BA, BJ and KH) throughout the process and refined to confirm that all content devised a clear pattern.

4.10.5 Revisiting themes

Themes were checked against the coded transcripts to ensure consistency and validity before revising and labelling themes. The resultant themes were further reviewed and reorganised – for example, by combining or splitting themes –to seek clarity and a better understanding of the data. Finally, the themes were iteratively developed into a thematic map, and the themes and thematic map were compared against the dataset to check their representation and completeness, see Appendix V-D. Once themes were felt to capture the 'coherent story' within the data, the review was complete. The author defined and labelled themes by producing names and definitions that captured the essence of the dataset contained within each theme. The candidate themes and labels and the relationships identified up to this point were provisional until supervisors reviewed and reached consensus, as seen in Appendix V-E.

4.10.6 Report production

Lastly, writing up the themes and conveying meanings in a comprehensive and representative way. All notes and observations documented in the notebook were further collated and reflected upon throughout the analysis. As a result, the continuous refinement of themes may differ slightly between the report for publication and the full report. The final report was produced by the author and revised critically by supervisors.

4.11 Chapter summary

This chapter has summarised in detail the methods used to answer the research questions and aims. It has provided support for the use of a qualitative descriptive design, and has described the process of sampling, recruitment, and data collection. In addition, it has described the ethical considerations before summarising and reflecting on the methods selected to ensure methodological quality, reliability, and reflexivity. It has discussed in detail the study approach to data analysis and the steps followed for the examination of the dataset. Finally, it has detailed the process of recruiting, consulting, and corresponding with the PPI volunteers, and has described their contribution to this thesis.

Chapter 5 Findings

A similar edited version of this chapter is submitted for publication as

Alassoud, B., Johnston, B., and Hogg, K., (Submitted). Palliative Heart failure care: A realists' qualitative exploration of patients' understanding and construction of meaning. *The Journal of Advanced Nursing.*

5.1 Introduction

Chapter 6 presents the focus group findings, and explores understandings and responses in the context of palliative care and heart failure. The first section offers the relevant sociodemographic characteristics of groups and participants. The second section presents the qualitative findings from the group discussions. Finally, the results are presented, and themes are constructed as per the participants' accounts rather than the research questions or objectives. Multiple quotations from the key informants express the participants' mutual values, beliefs, thoughts, and opinions. All who participated in any focus group sessions were assured of anonymity. Each participant was assigned labelling criteria using participant details (cultural group, age, sex, role) for illustration, **Chinese, 60s, Male, Retired Nurse**. The labels provide brief information on the participants' location and cultural and religious backgrounds.

5.1.1 Participant and group characteristics

A total of 77 people were identified as potential participants. After their eligibility had been confirmed, 55 individuals participated. The findings show common and distinct characteristics among the seven groups. However, notable diversity exists among and within each of the broader cultural groups. **Error! Reference source not f**

ound. shows that the sampling strategy was geographically inclusive, catering to diverse backgrounds within Greater Glasgow.

Although the study did not collect detailed sociodemographic data on the participants, the so-called variant characteristics of cultural groups relevant to the aim of this project were collected for each focus group, and are presented in Table 5.2. These characteristics, or defining attributes, were necessary to determine the cultural affiliations and worldviews held by participants and the degree to which they align with or diverge from the predominant practices, understandings, and perspectives within that group. As is shown in Table 5.2, the diversity was driven by the characteristics of the sites, participants, and cultures. Besides the fact that the context uniquely frames each group, the related power interactions and relationships enhanced the diversity among and within the groups. Seven focus groups with participants from various cultures and contexts in Scotland were conducted in four community centres and three religious or faith-based organisations. Participating members of the public belonged to white Scottish, South Asian, Chinese, African, Middle Eastern and North African (MENA), and mixed Asian (asylum seekers) ethnocultural groups. Six sites were located in the Glasgow City Council region and one was located in the East Dunbartonshire Council region. However, participants recruited at these sites were living in Glasgow City, and in East Dunbartonshire and West Dunbartonshire. It is noteworthy that participants resided in areas that ranged from the most deprived (1st decile) to those in the least deprived areas (9th and 10th deciles). However, the majority were from the most deprived neighbourhoods, which could be explained by the fact that a significant proportion of ethnic-minority communities were residing in these areas. As shown Table 5.2, most of the participants at sites B and G are from data zones ranked among the 5% most deprived areas in Scotland, namely Springburn, Gorbals, Govanhill, and Royston. Participants interviewed at site A are from data zones ranked among the 5–10% most deprived areas, namely Cowcaddens, Woodside, and Maryhill. Participants at sites C and F are from data zones ranked among the least deprived areas in Scotland, namely Bearsden, Milngavie, Bishopbriggs, Finnieston, Jordanhill, and Pollokshields. Most of the participants interviewed at site D were spread between Govan, Drumchapel, and Clydebank. These data zones are ranked among the 5–20% most deprived neighbourhoods in Scotland.

Table 5.1: Sample distribution

Site	A	B	C	D	E	F	G
Number of Participants	9	12	8	6	5	9	6
Duration in minutes	45	40	50	40	30	40	55

As the table illustrates, all group discussions lasted, on average, 42 minutes, ranging between 30-50 minutes. All interviews were conducted in English except for one, which started in English and continued in Arabic. Changing the discussion language was requested by a participant, and nobody objected. Participants explained that they understood the scenario and the questions. However, due to the sensitive nature of the discussion, they preferred Arabic to express their thoughts. BA and a bilingual PPI advisor performed a forward and backward translation. Both are native in Arabic, fluent in English, and familiar with the study terms and processes. In addition, an expert language professional verified the Arabic-translated version.

Table 5.2: The demographic profile of the key informants

Site/group characteristics				**Participant characteristics**			**Cultural attributes**			
Label	**Location**	**Type**	***n***	**Type**	**Gender**	**Age (years)**	**Ethnicity/ ancestry**	**Religion**	**Immigration status**	**SIMD health domain**
FG 1, site A	Glasgow City, North	Community centres	9	4 patients 3 carers 2 not stated	7 female 2 male	(1) < 50 (1) 50-59 (6) 60-69 (1) 70-79	Chinese	Not stated	First and second generation	1st decile
FG 2, site B	Glasgow City, Southside	Community centres	12	8 patients 3 carers 3 not stated	0 female 12 male	(1) 50-59 (4) 60-69 (7) 70-79	South Asian; Pakistani	Muslim	First generation	1st decile
FG 3, site C	Glasgow City, West.	Religious organisations	8	2 patients 5 carers 1 not stated	1 female 7 male	(1) 50-59 (5) 60-69 (2) 70-79	South Asian; Indian	Sikh	First and second generation	7th decile or higher
FG 4, site D	Glasgow City, North	Religious organisations	6	1 patient 5 carers	0 female 6 male	(2) < 50 (2) 50-59 (2) 60-69	Arab and Kurd; MENA	Muslim	First and second generation	1st and 2nd decile
FG 5, site E	Glasgow City, Central	Community centres	5	3 patients 2 carers	3 female 2 male	(2) < 50 (3) 50-59	Mixed Asian	Mixed	Asylum seekers	Highly deprived areas
FG 6, site F	East Dunbartonshire	Religious organisations	9	2 patients 4 carers 3 not stated	6 female 3 male	(1) 50-59 (2) 60-69 (6) 70-79	Scottish	Christian	Native/local	8th decile or higher
FG 7, site G	Glasgow City, North East	Community centres	6	2 patients 4 carers	0 female 6 male	(3) < 50 (2) 50-59 (1) 60-69	Western and Central African	Christian	First and second generation	1st decile
Total			55	22 patients 23 carers 10 not stated	16 female 38 male	(8) < 50 (11) 50-59 (20) 60-69 (16) 70-79				

In total, 55 participants participated in a one-off focus group discussion from April to September 2019. One discussion was conducted for each cultural group, with a mean number of eight participants per session. Research participants were members of the public living with direct or indirect experience of heart failure and/or heart diseases. Of the 55 participants, 22 individuals self-identified as patients, 23 self-identified as carers or family members, and the remaining 10 individuals had non-stated status. The majority of these participants were recruited using a passive snowballing technique. As a result, even though they answered ‘yes’ to the eligibility questions, they did not give details when they were asked. For example, at site B, the person who runs the elderly care service had brought three participants on the day of the discussion and told the investigators, ‘They fit both’, meaning that they self-identified both as patients and as carers. Approximately two-thirds of respondents (65%, *n* = 36) were in their sixties and seventies. Only 14.5 % of the sample were under 51 years of age. There were more men (69%, *n* = 38) than women (31%, *n* = 17). Furthermore, three sessions had male-only participants despite some effort to recruit more gender-balanced samples (see Figure 5.1). The higher prevalence of heart failure among men than women (1.8% vs 1.1%) can, we believe, be attributed to cultural and religious reasons. The majority of the participants came from a faith background – Christian (37%), Muslim (35%), or Sikh (15%). Most of the respondents (81%) described themselves as patients or family members of someone with ‘heart failure/heart disease.’

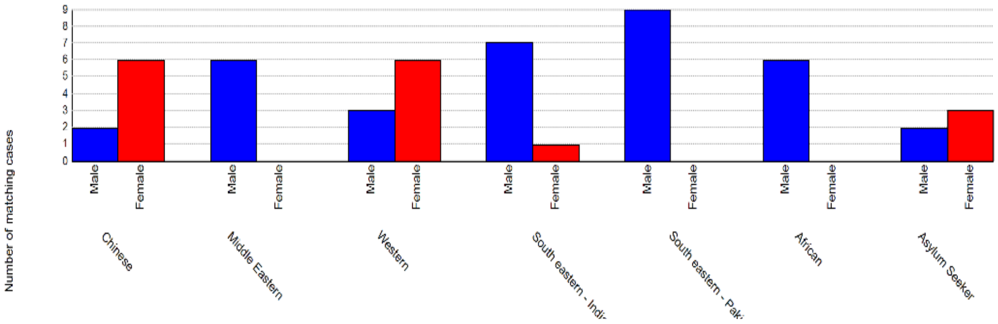

Figure 5.1: Participant gender versus cultural group

Following the plan to record the most prominent, visible, and accessible minority ethnic and cultural groups in Glasgow (see Table 5.1 and Figure 5.2), 36% of our key informants were of South Asian origin (people with ancestral origins in Pakistan, India, and Bangladesh, and others who came from South Asian countries and cultures), 20% were of Middle Eastern and North African (MENA) origin, 16.3% were affiliated with Western culture, 14.5% were affiliated with Chinese culture, and 13% were affiliated with mixed African cultures.

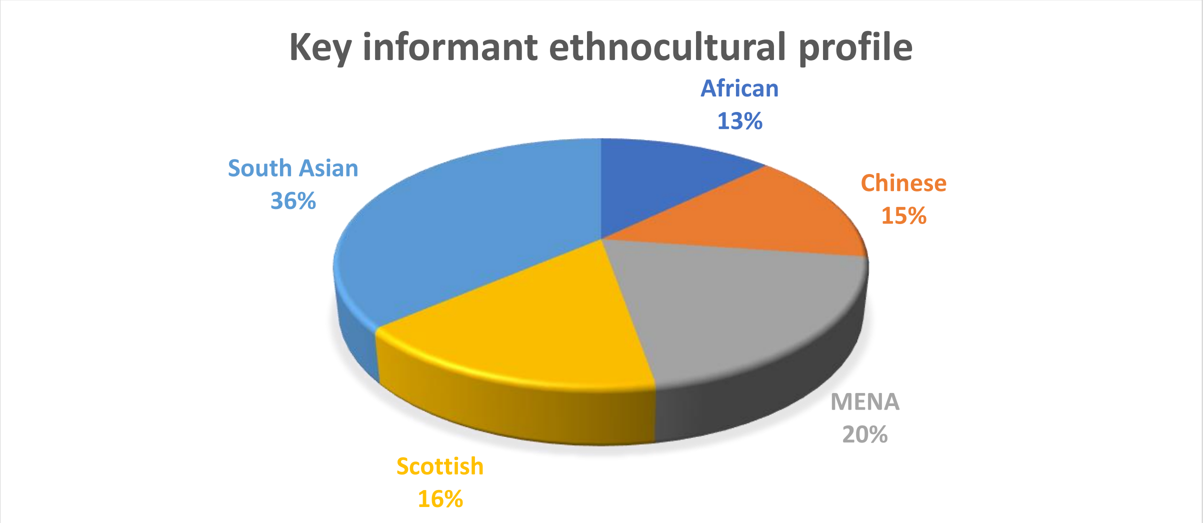

Figure 5.2: The ethnocultural profile of key informants.

5.1.2 Constructed themes

Respondents were asked to imagine a hypothetical scenario in which a patient living with heart failure reached the advanced stage of illness, when conventional biomedical treatments were no longer effective, curative, or stand-alone options. The patient and his wife had been told that they would be referred to palliative care cardiology services to help to manage the symptom burden. Being referred to palliative care may uncover their understanding and the impact that cultural factors may have on this understanding. Three main themes were constructed from the data through the reflexive thematic analysis.

Table 5.3: Themes and subthemes

Theme 1	Theme 2	Theme 3
Culturally embedded understanding	**Palliative care in heart failure**	**Palliative care preferences**
6.2.1. Confusion or lack of understanding	6.3.1. Care for dying … or seriously ill. (misunderstanding palliative care)	6.4.1. Preferred place of care
6.2.2. If my heart fails … I go (making sense of heart failure)	6.3.2. Does it just mean … nothing can be done? (constructing meaning and literal understanding)	6.4.2. Challenging family involvement
6.2.3. Preconceptions and cultural worldviews	6.3.3. An appointment for all to keep anyway (assumptions)	6.4.3. End-of-life-care conversations 6.4.4. Preferences reflect values

5.2 Culturally embedded understanding

The central theme describes how culture creates assumptions and shapes personal worldviews about heart failure as a life-limiting illness, given the confusion or lack of understanding (subtheme 1). The syndrome is seen, defined, and interpreted through personal and cultural lenses, which determine how participants create meanings and make sense of terms used by health professionals to talk about a condition (subtheme 2). When lacking an understanding of heart failure, and when faced with an event outside of their personal worldview, participants resort to a broader system of inherent knowledge or experience related to heart failure, heart conditions, or similar life-limiting illnesses to establish their respective meanings within that belief system (subtheme 3).

5.2.1 Confused/lack of understanding

After delivering the hypothetical scenario, participants were asked real-life questions grounded in their personal and cultural understandings, which were believed to be well captured by the questions ‘Do you know someone with heart failure? or ‘Have you ever heard of heart failure?’, to explore their knowledge and understanding of the disease. The vast majority of answers indicated that they had never heard this term. However, a consensus was reached on its seriousness, and on heart disease being the biggest killer globally. This metonymic understanding, linked to the heart as an organ that symbolises life and outweighs other organs, was not based on knowledge but rather on symbolic connotations.

> *“I believe heart fail… well, heart disease is the biggest killer, not just in Scotland, but all over the world.”*
>
> ***Chinese, 60s, Female, Project Manager***

> *“The majority of people in our community they never heard that before”*
>
> ***African, 40s, Male, Charity Manager***

Participants often referred to the syndrome using plain and informal language during the discussions. However, none of them had previously used the term ‘heart failure’ or suggested any first-hand or second-hand familiarity with it. The following were the most frequent terms:

> *Heart problem, the heart is not working, heart condition, heart muscle working at 10%, heart trouble, clogged arteries.*

This unfamiliarity was mainly caused by the respondents’ limited health awareness and literacy. As a result, all heart failure narratives emerged from their cultural understandings and were reproduced and reinforced through personal experiences. The confusion stemmed from their preconceived notion that heart disease, including heart failure, is acute and similar to a heart attack. As the excerpts below show, participants built on the knowledge and insights gained from their experience and confused heart failure with heart attack and other acute heart diseases.

> *“I have seen heart failure… my sister’s husband, he had heart failure a while bac…three or four years ago, and he survived... whenever he was going for a walk and especially going over the hill he used to get breathless … a quite a bit of sharp pain …the doctor sent him right away to the hospital and they detected the heart failure.”*

Pakistani, 70s, Male, Patient

> *"I suppose it's somebody that had what used to be called a heart attack decades ago. Presumably that's heart failure?"*

Scottish, 70s, Male, Caregiver

> *"I don't think anybody distinguishes between the various types of heart failures and other heart problems."*

Arab, 60s, Male, Caregiver

Few respondents tried to construct new contextual meanings for the syndrome that the vignette embodies, which indicated that they were still in an ongoing process of assimilating new understandings with previously held information and experiences.

> *"I suppose 'it's somebody that had what used to be called a heart attack decades ago. So presumably that's HF?"*

Scottish, 70s, Male, Caregiver

When defining what is meant by heart failure, respondents were even more confused. They were challenged by the pre-understanding of the concept of life, health, and illness. This was illustrated on several occasions when life-limiting illness was interpreted in a pure curative sense.

> *"That means there is no cure for anything and you're just passing the time. That is the understanding at the moment."*

Indian, 70s, Male, Retired GP

> *"one man with 80 years with a problem … he's going unwell day by day. For the people …that can do some transplantation and looking after another heart, that's going to be one possibility."*

African, 40s, Male, Caregiver

A similar observation was noted in the non-homogeneous 'asylum seekers' group, where participants did not know about heart failure or what is meant by chronic or life-limiting illness. Instead, they expected a speedy cure based on the notion that the NHS is one of the best healthcare systems globally.

> *"Not a problem at all as long as the doctor knows this is the best for him to go to.*
> *The most important thing is his health so wherever is best …no problem as long as he is treated and his life is prolonged."*
>
> ***Asylum Seeker, 50s, Female1&5***

Lending justification to their 'locus' of understanding, participants from black, Asian, and minority ethnic (BAME) communities asserted the role of related cultural artefacts, including language, in the co-construction of meaning.

> *"If you are telling them all in English … then its a waste of time … because that person will not understand anything."*
>
> ***Indian, 50s, Male, Caregiver***

This point was also reinforced by the absence of equivalent terms in participants' first languages. Some languages do not contain words that accurately capture the nuances of the term 'heart failure'. For example, participants whose first language was Arabic used the term 'heart trouble' and avoided using the term 'heart failure' because the latter's literal translation was seen as inhuman, suggesting that 'the heart cannot pump or fill with blood at all.'

Another participant stated that her mother died of heart when asked to elaborate, she understandably confused heart failure with heart attack, which stemmed from the immediate, intermediate, or underlying cause of death reported in the death certificate.

> *"My father died of a heart problem. Well, his death certificate was a myocardia infection. And my mother died of a heart failure."*
>
> ***Chinese, 60s, Female, Project Manager***

Only three participants had reported some understanding of heart failure - a retired GP, a retired nurse, and the caregiver for a patient currently living with heart failure. Even when they conceptualised heart failure within the biomedical framework, the meanings were rooted in and filtered by their personal experiences and cultural worldviews.

> *"Heart failure … the heart is not working fully … that means there is no cure … you are just passing the time."*
>
> ***Indian, 70s, Male, Retired Gp***

In the light of the healthcare providers' traditional use of technical language, the participants' subjective interpretations may perpetuate stereotypical portrayals and communication deficits around heart failure. At this point, patients may be left unable to understand heart failure, report symptoms, or communicate their needs. Failure to do so may result in a confused understanding and missed opportunities to receive appropriate treatments to tackle the progression of heart failure.

5.2.2 If my heart fails … I go

A notable discrepancy was observed in understanding what is implied by the term 'heart failure.' Participants making sense of heart failure within each group was a complex issue that individual participants responded to differently. The subtheme reflects compelling and less compelling arguments about how the term is portrayed and how this may influence public opinion and thus healthcare decisions and actions. In general, heart failure was made sense of as a single disease instead of a complex syndrome that involves a cascade of events and a cluster of signs and symptoms. This is perhaps why heart failure was perceived to be less progressive and its consequences limited to the heart itself in the sense of cure and recovery.

> *"Cancer is like a ghost, but heart trouble is becoming more widely accepted and not seen as dangerous as cancer. HF may have specific treatment … so as not to worry"*
>
> ***Arab, 50s, Male, Caregiver***

Therefore considerable difficulty was encountered in attempting to find appropriate labels for heart failure symptoms. Many patient informants described the symptoms they experienced using very vivid and often subjective descriptions.

> *"I would say tightness, breathless, sickness. I wouldn't say tired, but you couldn't move."*
>
> ***Pakistani, 70s, Male, Patient3***

Before defining terms, participants conceptualised the term ‘heart failure’ in relation to their experiences. In making sense of these experiences, participants engaged in three processes associated with their worldviews, namely criticising the term for being bizarre and horrifying, refusing or denying its existence, and suggesting a change of term. For example, the meaning of the word ‘failure’ elicited fear and uncertainty among participants. In addition, the use of the word ‘failure’ in relation to the heart was interpreted in terms of imminent death and gave a sense of hopelessness. Thus some participants were reluctant to make sense of heart failure, as was evident in the following conversation.

A paired conversation shows participants' reluctance and fears

- *Well, I think HF, from where I am coming from, everybody knows that when your heart fails, then you are dead! that needs to be revived. So even in the hospital when your heart fails then you need a machine to get the heart back to working again*
- *To me if they said heart fail, it’s like the end of life, because if they say my heart fails I go, oh my God, it might be…I won’t be able to…*
- *yeah, African people ...they will be maybe their first time .. they will be very afraid, you know, failure, when you hear..heart failure, it’s like it’s already in action.*

African, 40s & 50s, Male1-3

Sometimes the fear and panic seemed to translate into a refusal to use the term or failure to recognise its existence. However, the more health-literate participants sometimes controlled this. The more health literate participants were, the more likely they were to accept the term and make sense of the concept accordingly.

> *“Maybe that term hadn’t been used. Would that be standard, to say you’ve got HF?”*

Scottish, 70s, Male, Caregiver

Some respondents treated the term with caution and suspicion, which led to ignorance. Therefore all kept silent, looking at each other.

> *"GF 1 What do you think the community understands by the term Heart failure?*
>
> *All participants simultaneously said this is the first time they hear of it [Agreement].*
>
> - *Have you heard of this before!*
> - *No, no, ever.*
> - *No at all."*

Asylum Seeker, 50s, Female1-3

However, they arrived at two overlapping positions after the term was explained and clarified in plain and straightforward language. The majority doubted that the term was informative, and felt that it had no connection to ordinary life experiences. However, they shed light on its use being confined to professionals only and urged a term change to make it more meaningful to patients and carers. Some questioned the accuracy of the term and also attributed participants' lack of understanding to the medical language or jargon used during consultations. For instance, like many other participants, a retired physician believed that it would be better to describe it using a functionality percentage.

> *"They understand probably better if you tell them what is it that your heart is working 40%, 30% or 60%."*

Indian, 70s, Male, Retired Gp

Generally, members of the public believed that their communities shared the same attitude and understanding. However, they believed that the situation was changing as the next generation was educated, spoke the country's language, and became more culturally adapted.

> "Because of my father … had this. Therefore, its getting closer, and closer, there is knowledge."

Chinese, 60s, Female, Patient

> "Generally, in the community, I think the younger people will understand more than the older generation."

Indian, 50s, Female, Caregiver

The above accounts show an apparent reliance on experience-based knowledge among the participants interviewed when they lacked knowledge or contextual awareness and literacy. As a result, heart failure prognosis and its unpredictable nature were neither recognised nor understood.

5.2.3 Preconceptions and cultural worldviews

Participants across cultural groups who came together to engage in deep conversations about heart failure had not attributed any of the symptoms described in the vignette to heart failure. For instance, they believed that dyspnoea does not correlate well with heart failure unless it occurs with chest pain.

> *"My 'wife's brother... had heart failure a while back...a quite a bit of sharp pain …the doctor sent him right away to hospital, they detected the heart failure and he survived."*
>
> ***Pakistani, 70s, Male, Patient***

Even though participants were observed referring to their cultural teachings to identify the disease aetiology, the Western biomedical views of disease causation were accepted by most interviewees. Participants used several explanatory models for heart failure in line with the naturalistic disease theory system by attributing heart failure to disruptive behaviours that break the body-environment balance. For example, family history or being genetically predisposed may lead to heart failure and conditions such as high blood pressure, diabetes, and high cholesterol, which were thought to increase the risk of developing heart failure.

> *"I think so, yes. Because if you keep on a bad diet, you can make yourself worse and worse, deteriorating, you know."*
>
> ***Chinese, 60s, Female, Patient***

> *"I had triple by-pass … the cause was hard work, overwork I should say, not taking the food at the same time, stress from the family."*
>
> ***Pakistani, 70s, Male, Patient***

> *"Can having other illnesses bring on heart failure?"*
>
> ***Scottish, 70s, Male, Retired Teacher***

The above excerpts uncovered the informal, experiential means whereby participants co-constructed their knowledge about the causes of heart failure in both personal and systematic terms. It is important to note that certain health beliefs, such as those about consuming certain meals at bedtime and about stress, point toward the dominance of cultural explanatory models of illness. Participants' responses did not always align with the biomedical models, but were not exclusively focused on physical health.

In another example of informal and experiential construction, a woman participant narrated a story in this regard. She shared her experience of caring for her frail father and answered the question 'What do you believe is the cause of heart failure?' as if it was 'Why did your dad have heart failure?'.

> *"Number one, diet, or genetic… Number two, diabetes. Number three, high blood pressure. then you have, lifestyle. And then, you have, I remember something, cholesterol comes last."*
>
> ***CHINESE, 60S, FEMALE, Retired Teacher, Caregiver***

Despite this agreement, we found that terms such as 'healthy lifestyle',' 'diet', and' 'behaviour' were understood in a veil of ambiguity. Furthermore, understanding of these symbolic concepts differed among participants, with significant differences in meaning, practice behaviours, and regularities of practice. For instance, some groups limited the meaning of exercise to walking, while others understood exercise as a regular sporting activity. The following excerpt illustrates how important it is to make education patient centred and culturally tailored by asking contextually pertinent questions.

> *"I think it depends on the culture of someone. It's like the Western culture doesn't apply to our culture. Therefore, whatever they advise, I never eat that stuff, so its not good to tell me."*
>
> ***Chinese, 60s, Female, Patient***

This symbolic concept was also different with regard to the type of practice or behaviours, and how often. For example, some groups had limited the meaning of exercise recommendation to walking when possible, while others understood exercise regularly as a professional sporting activity. Therefore the context gives sense to the terms 'lifestyle' and 'exercise.' It was also noted that participants' socioeconomic status shapes the shared meaning of this construct. The following two examples demonstrate how the context would shape the meaning when participants were prompted about exercise.

> *"They don't make them walk. Maybe walking is good for him. We don't know. When we have a heart attack, we say don't make them walk."*
>
> ***Arab, 60s, Male, Caregiver***

> *"I think it's the food we consume, because most people are working and we only have a big good meal in the evening and obviously after that you are supposed to sleep and you don't do any exercise and you don't do any walking. And apart from that I think, I can't, unless it's in the gene."*
>
> ***Pakistani, 70s, Male, Patient***

The same applies to dietary habits, as we have observed that culture, in particular Eastern culture, plays an influential role in nutritional choices. Some patients mentioned that the cause could be related to the quality of their cultural food, which was described as dense and containing high numbers of calories, and the time they usually eat their main meal.

> *"we are not doing exercise. We are looking at our food, what we are eating; too much greasy and all of that, we just…specially timing our.. nearly bedtime … and then go to sleep and the artery close."*
>
> ***Pakistani, 70s, Male, Patient***

Other participants also perceived that heart failure could arise from other comorbidities, such as high blood pressure and diabetes, attributed to genetics and family history, and that the disease was inevitable and running in families.

> *"No, I'm not healthy. I'm not healthy…Quite a lot, high blood pressure, diabetes…"*
>
> ***Chinese, 60s, Female, Patient***

> *"Yeah, family history; and my father, my grandfather, my mother their blood pressure and their heart problem they are from it."*

Pakistani, 70s, Male, Patient

The following two excerpts illustrate how consideration and understanding of patients' sociocultural background is crucial to addressing their unique needs by making questions more contextually suitable for Chinese people, and thus producing effective patient-centred and culturally tailored education that may change diet-related behaviours.

> *GF: So, do you think advice should be .. like…what kind of food do you eat, that's what you mean?*
>
> *P7: You mean, what advice the doctors should give …[Exclaiming]*
>
> *P1: I think it depends on the culture of someone. It's like, the western culture doesn't apply to our culture. So, whatever they advise, I never eat that stuff, so it's not good to tell me."*
>
> *GF: Well, that's what I'm trying to say, checking out what you normally eat.*
>
> *P4: Well, at least nowadays…the GPs do, what is your diet like?*
>
> *GF: Yeah, but do they in hospital?*
>
> *P4: I'm not sure.*
>
> *P7: in Hong Kong, the doctor usually asks … not that much. in restaurant, cooking is really, tend to use a lot of oil, and MSG [Monosodium glutamate]. … you don't know how much,, it's much higher than salt."*
>
> *GF: Oh, I see, so that's another really big point. Because the western conception would be related to the restaurant, yeah.*
>
> *P7 & 2: Yeah.. MSG, yeah.*
>
> *P2: Yeah, that's true. But as I say, even in the western world, the western way of eating, you get us over here, Europe, here, and on the continent, they eat a lot more salads, more veg, and more olive oil, and tomatoes.*
>
> *GF: Yeah, absolutely, that's a really, really good point.*

Chinese, 50S-70s, 1,2,4&7

Even though none of the participants had personalised the interpretations of disease causation, the references to South Asian cultures being more genetically susceptible to heart disease were seen as an unconscious attempt to align with their perceived limited control over health. The inevitability of heart disease was interpreted through cultural and religious meaning-making. Combining cultural and religious meaning-making has affected their response to this phenomenon, which is endured with patience, obedience, compliance, and contentment.

> *"I think …you don't do any exercise and you don't do any walking. And apart from that I think, I can't, unless it's in the gene…because of this disease, but I've been told by our consultant in the Asians and in the Scottish that's the biggest issue... that's what they say is the two major factor like diabetic and the heart."*
>
> ***Pakistani, 70s, Male, Patient***

> *"Sometimes it is running in your family if you are coming from genes and if your father or grandfather with a heart problem, running from very bad from my family…my father, my grandfather, my mother their blood pressure and their heart problem they are from it."*
>
> ***Pakistani, 70s, Male, Patient***

Using the lay explanatory model to construct knowledge about the causes of heart failure was considered problematic, as it is entirely based on the shared culturally specific explanations of heart failure. Furthermore, these shared cultural explanations and patterns are more likely to guide their prognosis, treatment options, and decisions following the same 'cultural sense or logic.'

5.3 Palliative care in heart failure

Our results emphasise the lack of clarity about palliative care (subtheme 1) and its role and benefits in heart failure (subtheme 2). Participants bring their cultural meanings into care as a resource to redefine and renegotiate meaning, and as a coping mechanism during the critical stages of illness. We found that the contextual understanding of heart failure (theme 1) challenges and forms part of palliative care understanding. The complex meanings are not fixed but dynamic and continually evolving, mirroring the participants' multilayered and multidimensional contexts rather than independent and self-governing ones.

5.3.1 Care for dying… Or seriously ill.

Respondents were requested to imagine the hypothetical scenario in which a patient was referred to palliative care services for better symptom management. They were then asked to consider whether they knew what it meant to them to explore how each context/storyline might affect their understanding. Participants were first asked if they had heard of palliative care or used the word ‘palliative’ before. Some participants said that they had, and the rest said that they had not.

> *“This is the first time that I hear of this type of medicine or treatment.”*
>
> ***Arab, 30s, Male, Software Engineer***

> *[All participants simultaneously said] “this is the first time they hear of such a care system”*
>
> ***Asylum Seeker,1-5***

Those who had never heard of the term felt pessimistic about trying to avoid the subject. During the discussion, and later, when the rest of the scenario was discussed, views changed several times with some evidence of changes in attitude. The following excerpts illustrate the response to the palliative care referral statements.

> *“Pardon? I do not understand. What is that? …I do not think has anybody heard about it [palliative care].”*
>
> ***Pakistani, 70s, Male,Shop keeper, Patient***

> *“What is palliative?”*
>
> ***Pakistani, 60s, Male, Patient***

A handful of participants had heard of the term and were prompted to tell more about it. Most of them spoke about their second-hand experience of terminal cancer. Nevertheless, those participants did not have any better knowledge or understanding in practical terms than their counterparts.

> *“It is the care of people who are dying … or seriously ill.”*
>
> ***Chinese, 60s, Female***

In addition to patients with cancer, they thought that older patients, and patients with HIV, stroke, and drug addiction should be entitled to this care. None of them had anticipated that heart failure would be on the eligibility list for palliative care. Even when explicitly prompted, their most frequent responses were either 'No idea' or no response at all. Nevertheless, some interviewees had persistent belief that palliative care fits cancer-only.

> *"Maybe palliative care is the one that the doctor was saying is…in the Indian community they relate it to cancer more than the heart. If somebody said palliative care, I would just think of terminal cancer. I wouldn't associate it with heart. But I didn't know that you got palliative care with heart conditions as well.."*
>
> ***Indian, 70s, Male, Retired GP***

None of the interviewees reported any form of education by healthcare providers. Instead, they had little awareness and wealth of second-hand experiential knowledge to make sense of the scenario. For instance, participants believed that palliative care was predominantly given at hospices, and were unaware of its home or hospital provision or of its benefit for families. Sometimes little or no understanding of palliative care may be due to the unavailability of palliative care in the countries of origin of the participants and/or lack of culturally and linguistically appropriate education and information about these concepts.

> *P 2 "my opinion anyone, like [the hypothetical patient], who has been to hospital with heart failure should have his companion given a course on .. palliative care that he/she needs after leaving hospital."*
>
> *P 2 "However, do we have such a care system within our culture?"*
>
> *P 4 "Not in our country nor in our culture, no. We have none of this."*
>
> *P 6 "Still, the culture is based on what we used to do back home."*
>
> ***Arab, 30s-60s, Males***

Having no access to sufficient quality of intelligible information was seen to provide room for misconceptions and may reduce the visibility of and benefits of this type of care. Hence participants were unwilling to seek or engage in palliative care due to false beliefs and misconceptions. For example, two participants, who were leading their communities, whispered:

> *"Palliative care, there are misgivings about it. Quite a lot … and a lot of people think that it is terminal care when you are given palliative care."*
>
> ***Indian, 70s, Male, Retired GP***

> *"Our understanding of things [Palliative care] based on what happened to my grandfather ten or thirteen years ago … things could be different now…in term of treatment may not be seen good now or even still practiced. because we haven't developed our knowledge on the advancement of treatment we still have cultural understanding."*
>
> ***Arab, 60s, Male, Caregiver***

While misinformed, participants spoke a great deal about palliative care but did not acknowledge the importance of getting the correct information from suitable sources. Sharing experiences – even if these were based on misconceptions – was the main stem leading to the shared meanings and coping strategies. These experiences are easily endorsed and become facts. Unless the misconceptions are cleared up, this position is liminal, particularly if the experience was negative. Participants also perceived palliative care as end-of-life care based on their experience with an older relative or friend with a terminal diagnosis.

> *"Is its end-of-life care, is it?... Heart failure. You just said it, heart failure, could you say, is the end of life."*
>
> ***African, 40s, Male, Social Worker***

> *"I have an experience, palliative care was terrible for my mother, she was always drowsy, could not speak to her."*
>
> ***Indian, 50s, Male, Caregiver***

In another example, palliative care was perceived as being available just for the very last days of life, and the participant was shocked when they were told that a person might access palliative care for several years. This pluralistic uncertainty was observed across all groups. It was not exclusively seen among people living with the disease or providing care for them, but was also the case for participants who identified themselves as retired health professionals.

> *"So, you can have palliative care for several years, can you?"*
>
> ***Scottish, 70s, Male, Caregiver***

> *"People will be 30 years, you can be under care?"*
>
> ***African, 40s, Male2***

There was some indication that responses depended primarily on experience (contextual and intersectional) – in other words, taking into account that the participant's interpretations were often influenced by their context and did intersect with religion, literacy, education, age, immigration, and other characteristics of a culture. Despite the participants' common cultural bonds, beliefs, and practices, there was great diversity among and between groups. Considering their cultural attributes of culture would help to understand how the context has affected these experiences, inform their understanding, and direct their actions.

5.3.2 Does it just mean … nothing can be done?

Even when palliative care was clarified as care dedicated to managing symptoms and discomfort, focusing on enhancing the quality of life, participants were uncertain and preconditioned by a matrix of cultural milieus and lived experiences. Defining palliative care unexpectedly challenged participants' ideology of treatment, and traditional and non-traditional cultural groups appeared to recognise palliative care as being of no benefit due to their embedded recovery-focused worldviews.

> *"A lot of people think that it is terminal care when you are given palliative care. That means there is no cure for anything, and you're just passing the time."*
>
> ***Indian, 50s, Male, Caregiver***

The repeated reference to palliative care as 'nothing can be done' and the use of the expression 'just passing the time' confirmed the cure-focused philosophy as a dominant goal of care. It was also illustrated by regarding palliative care as a stage where patients are literally at death's door, which was clear across groups. Thus people succumb to death's grip, and families start the countdown to this grip as soon as they have heard the word 'palliative.' The following excerpt shows how the same respondent made a quick U-turn in response to the transition from cure to palliation after the referral statements.

> *"Does it just mean that there can be nothing done for it? Does it just mean … nothing can be done?... You'd have great empathy with him, with anyone who was in a terminal state or palliative care."*
>
> ***Scottish, 70s, Female, housewife***

Of interest is that denoting palliative care as a 'stage of illness' resulted in a palliative care image equating to the abandonment of care, which is equivalent to the abandonment of significant value, such as the filial obligation. Therefore palliative care was perceived by some participants and endorsed by many others, including clinicians, as 'no other options' care. This attitude was expressed in particular by family members to justify care that was not consistent with their beliefs when approaching death. However, among participants who self-identified as having heart failure or other forms of heart disease, most patients valued comfort-based care and would prefer a home-like setting rather than a hospital-like one.

> *"The most important thing is his health so wherever is best …no problem as long as he is treated and his life is prolonged. For me…I believe, patient themselves, when they're terminal, they would like to stay at home… I prefer to spend my last days at away from hospital no pain and to feel comfortable."*
>
> ***Asylum Seeker, 50s, Female***

Besides the divergent views about care needs and outcomes, there was another reason for the vague understanding and negative portrayal of palliative heart failure care. The care is being offered only when patients are terminally ill and palliative referrals characterised the end of a curative treatment pathway, which was perceived to pose a challenge. For example, one participant who was an active caregiver commented on the abrupt way in which his mother's treatment had ended.

He used a death euphemism that means ‘to die from it’ not just to deny and resist death, but to communicate that what is important to the caregiver (their goal of care) is to keep their loved one alive.

> *“That means there is no cure for anything and you're just passing the time.”*
>
> ***Indian, 70s, Male, Retired GP***

> *“If there is no cure, we’ll have to live with it.”*
>
> ***Arab, 60s, Male, Patient***

Introducing palliative care earlier in the disease trajectory would help to change this, would encourage people to be less apprehensive and fearful, and would make palliative care a less appalling and more appealing service.

> *“[From the beginning]...when the family knows that “end-of-life care’ is planned and customised... To take care of the pain that the patient suffers… to feel comfortable, I think the attitude will change”*
>
> ***Arab, 60s, Male, Caregiver***

Participants with a migration history, who had by their own account struggled to integrate modern and traditional healthcare ideologies, were found to deny the inevitability of this one-directional disease journey. For example, asylum seekers preferred to seek help from non-biomedical sources and exhaust all of the alternatives before accepting the palliative care referral.

> *“In our country... people can have the heart... Like this … we have another way to treat our people, African medicine, sometimes it works, sometimes it does not work.”*
>
> ***African, 40s, Male***

5.3.3 An appointment for all to keep anyway

The findings that will be presented in this section complement those in the previous two sections and are situated in the same context within the overarching theme. This subtheme stemmed from discussions literally around a ‘heart that is failing and care that does nothing.’ Death and its understanding were explored by considering the participants' responses and interpretations of the given scenario. These interpretations and assumptions reside in and subconsciously influence the taken-for-granted way the members understand heart failure in palliative care. The following subtheme has some compelling findings which are discussed while continuing to highlight the interplay between culture and its characteristics with regard to the understanding of death.

The words ‘death’ or ‘dying’ were not mentioned by any of the participants in three focus groups, and were mentioned only ten times in all of the other transcripts. The taboo around discussing death necessitates the use of euphemisms to refer to death. These alternative terms were a cultural phenomenon that echoes the longstanding death-denying culture. For example, Chinese participants used the word ‘dying’ when referring to people generally: *‘So, it is the care of people, care for people who are dying.’* However, when discussing the death of someone in their community: *‘you know who to contact if somebody has passed away, someone in the community, you know.’* In a similar case, African respondents claimed their culture is open to words like death and dying but preferred *‘about to go’* and ‘*is passing away*’.

Notably, several religious expressions discussed death and dying among faith groups. These faith-guided expressions were used to make sense of death and dying in their spiritual and religious lives.

> *“My cousin and his wife, who were very keen Christians, he was a retired minister and he was dying of cancer and he was very near the end, and he was reluctant to let go but she said to him, Jesus is holding out his hand to you, grasp it. And that was her permission to him to go, as it were.”*
>
> ***Scottish, 70s, Female, Caregiver***

While religion and spirituality were seen as necessary as the wheel to run the coping vehicle, similar expressions came into the discussion, such as religious euphuisms to replace the word ‘death'.

> *"The doctor can decide to put it to the patient in a less direct or blunt way. In the case of the 70-year-old Ahmed, the doctor could say something like "we have done all we can for you, it is now in God's hands."*
>
> ***Arab, 50s, Male, Caregiver***
>
> *"Various participants confirmed that the term is there but other terms as more prominent such as "may God have be kind to him", "may God ease his suffering", "may god have mercy on him". We don't want to say he is dead or dying."*
>
> ***Asylum Seeker, 30s, Male, Student***

While death was perceived as an existential life event, participants' attitudes toward death and dying discussions were diverse, as they hinged on some misconceptions described earlier, in Section 5.3.2, and how they were interpreted and manifested. For example, those who understood heart failure predominantly through their cultural worldview were found to accept pain and suffering, which disproves the characteristic view of a good death as being pain free.

> *"A patient may be strong in his belief in God and be able to accept the illness as something that God has given to him and therefore accept God's gift to him or her. We should accept the illness as a guest and treat it well and when we treat it well it goes easy on us just like the guess who respects his/her host."*
>
> ***Arab, 50s, Male, Caregiver***

Some informants' viewpoints cast doubt on the direct relationship between heart failure and death. They developed a sense of unrealistic hope which was misguided by limited health literacy. Hence a non-interventionist approach to death, such as withdrawal of treatments, was often refused.

> *“We believe your time is fixed, when you’re going...apart from that [Heart failure].”*
>
> ***Indian, 50s, Male, Charity board***
>
> *“We strongly believe that God has the ultimate decision on whether we live or die…I think we keep on hoping until the last minute.”*
>
> ***Arab, 50s, Male, Caregiver***

In contrast, higher levels of health, religious, and cultural literacy would reflect more confidence about discussing needs and interventions within the palliative care facilities. Furthermore, they treated ‘death’ with acceptance as an inevitable life event and a gateway to a better afterlife. Interestingly, even though culture, spirituality, and religion are bound inextricably together, the participants showed that these deeply held views were highly individualised, and that they were interpreted and manifested differently.

> *“I think it’s an appointment for all to keep anyway…We know that death isn’t the end.”*
>
> ***Stottish, 60s, Female***
>
> *“A lot of Christians quite struggle with it as well. Like it’s going to be oh well don’t worry, I’ve got another life to go to, I’ll be fine.*
> *The difficulty is we’re all individuals and it’s our individuality that is the most important [agreement].”*
>
> ***Stottish, 50s, Female, Church Minister***

Another contextualisation of death revealed how a good death was defined. For example, some groups were seen as pro-life quantitively, based on the number of years lived – for example, ‘*My father … had a good life … a good 84 years*.’ This attitude was seen among those who viewed heart failure through a religious lens; they rarely accepted that heart failure was fatal ‘*It’s written [religious reference]. So we cannot really give up*’. Others understood it qualitatively, based on life qualities and the patient’s age at that point, regardless of religion.

It was clear that some constituents of a good death were similar across cultures while others were culture-specific. The discussion revealed that peaceful death or minimal suffering were just as important and critically the same as quality of life, as will be seen below. However, in practical terms, the two quotes are subtly different. The former meant that a good death is a suffering-free end-of-life experience, whereas when the latter was put in context it referred to the non-interventionist palliative and end-of-life-care approach, and it goes against a good death.

> *"Nowadays, the medication is too good, they prolong their life, but, That the life is prolonged, but the quality isn't so good."*
>
> ***Chinese, 60s, Female, Caregiver***
>
> *"Yeah, a good life. You do not want to be living if it is a miserable life. If you have a good life, more important…"*
>
> ***Indian, 50s, Male, Charity Board***

On the other hand, some of the current principles of a good death among traditional cultures contradict the philosophy of palliative care. For instance, in some Eastern cultures, dying in a hospice or a care home is stigmatised and perceived as a bad death or taboo. Their understanding of what constitutes a good death was underpinned by the perceived lack of family willing to provide care, which goes against their cultural definition of a dignified and honoured death for families. Relevant findings will be presented under the next theme. Informants across all groups confused 'euthanasia', 'don't resuscitate' (DNR/DNAR), and suicide, and reported them as forms of a bad death that comes as a result of individual action rather than action by God.

> *"I think it [the orders] is seen as a form of suicide which is not allowed like saying to someone I am going to get in the water because I want to drown so please do not try to save me… I don't think that our culture take that into account and we feel that we are the decision makers and we should do all we can to safe the patient's life [Agreement]"*
>
> ***Arab, 60s, Male, Project Manager***

Although the participants were speaking from their cultural background, they consistently expressed the view that beliefs, values, and traditions were not necessarily the same among all members of their cultural group. However, it is more likely for beliefs and values among people from the same culture to be shared if they belong to the same generation, socioeconomic status group, and faith group. In addition, all of the participants felt that if healthcare professionals could take the time to understand the individual, this would be the most respectful way to provide a dignified death.

5.4 Palliative care preferences

The results show that place of care (subtheme 1), family involvement (subtheme 2), communication and end-of-life-care preferences are not homogeneous but rather they are culturally diverse. However, some care experiences and preferences were common across different cultures and ethnic groups, mainly due to shared values (subtheme 4). This highlights the complexity of predicting patients' preferences, and the need for effective future care conversations and planning to identify and meet preferences while fostering respect for cultural differences.

5.4.1 Preferred place of care

Participants preferred the imaginary elder to be cared for at 'home' after the advanced heart failure diagnosis and palliative care referral. It is important to note that conversations about the place of care were rarely initiated. The meaning of 'home' was symbolic and went beyond the physical site and formed part of the negotiated context, as shown inTable 5.4A. Generally, people said they would prefer to be treated and prepared for death at home, emphasising the role played by the family in defining and meeting this preference. For example, participants assumed that arranging for senior members of an ethnic community to die in their place of birth, is what the patient wants. Alternatively, if not applicable, they would prefer the traditional healers/doctors and medicine back home to deal with illness rather than going to the hospital in the UK when a patient was terminally ill.

The participants personally thought that patients still want to be cared for at home if possible. However, if they cannot cope with the situation and cannot get enough daycare support at home, the decision as to whether to seek help from alternative settings would be made by family members consistent with their cultural assumptions and religious beliefs. Sometimes, the caring culture at home was just a resilient attitude in response to the limited choices available, despite its apparent futility, see Table 5.4, B&G. Diverse participants across groups claimed that these inherited assumptions reflected the patient's preference. However, younger generations disputed this and demonstrated a need to turn off and tune away from these assumptions. As the paired conversation captures in Table 5.4C, the primary reason for opting out is an objection to the lack of patient-centredness. In our view, cultural structures put preference in the form of rules that are merely arbitrary perceptions. For example, breaking cultural rules, the value of filial piety is often perceived as taboo, culturally alienating behaviour, and dishonouring to family members (see quote 5D).

In contrast to a tattoo, preferences were dynamic and could be easily changed to adapt to the patient's context, health status, and changing needs. Perhaps the credit given to hospices by most user groups, particularly minorities, as a specialised palliation and support service is an example of the dynamic nature of these preferences (see Table 5.4E).

Table 5.4: Participants quotes for home as a place of care preferences

A. The symbolic meaning of home
- *“Why would not you take him to the resolution centre, back to home”* - *“We would prefer, if we talk about someone having heart failure, will prefer to have them looked after properly in the house, maybe to cook some proper African food, looking for bath the patient with our relative, toileting in the morning, making sure he is clean, changing their clothes, looking after them, talking to them in our language, making them to talk also to people back home, maybe that will be very helpful.”* African, 30s-50s, Males
B. Situational decisions
- *“It depends how his wife is and how supportive.... and family... Some people are better at coping.... Some can turn hands on nursing care in a way that perhaps others can’t.”* Scottish, 70s, Male
C. Death-oriented decisions
- *“You said he is 80 years old...Hospital is not suitable for those things [dying protocols].”* African, 40s, Male
D. Observing rules and values
- *“I cared for my mother-in-law [at home]. As I felt obliged culturally to help her and look after her.”* Arab, 50s, Male, Caregiver
E. Preferences are dynamic
- *“Probably it will be better to be treated. At hospice the patient is not feeling very painful and can feel who’s there.”* Indian, 50s, Male, Caregiver
F. Financial implications for decisions
- *“There’s certain establishments I could possibly go to with a huge financial implication... not knowing if it’s free or there’s going to be a charge; what’s going to happen to my pension.”* Scottish, 70s, Male, Caregiver
G. limited health awareness and literacy
- *“You either put him in hospice and hospice is just like a parking lot for people waiting to die, or you tell it is no care to be provided for them.”* *Arab, 60s, Male, Caregiver*

Participants were prompted about aspects of who should be deciding on this matter. The prompts added another dimension to the discussion, elicited the sample's heterogeneity and intergenerational differences, and triggered a couple of intragroup paired conversations. One of the paired conversations took place between four participants from two different generations seated on opposite sides of the table, facing each other. One participant was in his late twenties, and the other three were in their fifties. The participants were divided into two camps on the subject of who decides on end-of-life care, including limited professional care when the hypothetical patient became unwell. As the following excerpt illustrates, the first group assumed that the man in the hypothetical scenario was dying and required only ordinary care and attention to basic needs, which were best met at home. However, they later capitulated and agreed with the others. Again, this was seen as an example of younger-generation vs. older-generation perspectives.

A paired conversation on ethical and cultural issues on decision making

P 4: House probably, he is old age generally with a…eighty years …hospital is not suitable for all those things

P 3: Why wouldn't you take him to the house? To the solution centre, back to home, take him back home, why?

P 4: What I mean by, because this old person, he can be cared of from the home, so somebody can…medical people can go and look after from home and to go into the hospital and come back, that is a problem.

P 3: No, that is possible with hearts, I don't think so. The question is, if you are unwell, would you want to be at home or in the hospital.

P 4: Hospital. Short term is okay But If he is my father, I don't want to keep him for long in hospital

P 3: Why not? Is it his wish or your own? Is it against his wish or what you want? Is it what he wants or what you want? He will want to get well and go home

P 2: You said 80 years old. Normally the family take care of, is now that age the family take care of it, so normally they take… don't take much decision. So all the family play a role in it.

African, 30-50s, Males

The younger participants challenged the older ones in the opposite conversation on whether these decisions represented the patient's wishes and preferences. The younger generation was more aware of centralising the care around what the patient preferred, emphasising that the patient's autonomy and wishes must be respected as long as he was not incapacitated. The third participant, who was one of the leaders for the African community, explained the rule on the place of care decision making and summarised collectively how the African culture mirrors their current way of life.

> *"In our culture, from Africa, from an ethnic minority, we assume that when we have our relative who is unwell, we assume that the person is in the position where they cannot think properly, then we have to, as a family, take a proper and correct and accurate decision on his behalf."*
>
> ***African, 40s, Male***

Participants from BAME backgrounds had similar views about care preferences. The majority agreed that culture gave individuals the basis for coping with choices, which is necessary for the affected person and is culturally appropriate. It was justified as an originally westernised concept that sometimes contradicted their cultural norms and might cause harm to patients and their families. However, seldom were any of these incongruities or concerns about harm communicated to clinicians.

Although respondents were asked about the preferred place of care, their answers unconsciously referred to the preferred place of death rather than the place of care. These answers resonate with similar understandings in other groups who valued patients' wishes regarding the place of death more than the place of care. The results demonstrate that the place of care and death among all cultural and religious groups was an integral part of a successful end-of-life-care experience.

> *"If they're very, very ill you can't give the same care in the house, even though they would like to stay in the house."*
>
> ***Indian, 50s, Male, Caregiver***

> *“The patients themselves, particularly almost always, they will not want to go to hospital any time. Even when they’re terminal, they would like to stay at home. And be looked after.”*
>
> ***Indian, 70s, Male, Retired GP***

The cultural tendency towards interdependence led to lower preferences to care for loved ones at home and seek institutional healthcare when death is imminent. This attitude was seen in particular by family members and sometimes resulted in institutionalised death. On the other hand, most of those who self-identified as patient participants had acknowledged the significant role that institutionalised care plays in managing their diseases compared with when they used to rely on non-institutionalised care even if patients wanted to die at home. A sense of discordant preference was clear between patients and their families from the previous results.

Some clues suggest that preferences have been previously negotiated between patients and families among participants with higher socioeconomic status. Nevertheless, the individual circumstances and level of care needed often dictate the preferred place of death, despite any previously expressed preferences. The following narratives show how these preferences arose from participants’ understanding, experience, and attitudes.

> *P 2: most people want to be at home Agreement].*
>
> *GF: He is getting more unwell ….. Do you think he still wants to be at home?*
>
> *P4: Yes [Agreement].*
>
> *P 7: If that necessitates getting specialist equipment … I think the feeling would be get to hospital, get what’s required for it to alleviate his symptoms, hopefully for not too long, but to get to the familiar circumstances of home [Agreement].*
>
> ***C6-EP2&7***

> *The condition of the patient determines where he/she is cared for.*
>
> ***Arab, 60s, Male, Patient***

5.4.1.1 Hospice

The answer to the 'place of care' question was often 'home'. If the home option was not feasible, other settings such as hospice or hospital were considered. 'It is much dependent' reflects some of the participants' answers, for example, with a tendency to favour one place over another. Some participants reported previous access to hospice care services. For example, such services were well known to the Chinese, Indian, and Scottish groups but not to the other groups. The hospice experience generally seems to be associated with relatively better knowledge and understanding of palliative care. The service users identified the hospice as a congenial setting and the best alternative to home palliative care.

> *"I think probably it will be better to be treated at a hospice."*
>
> ***Indian, 50s, Male, Caregiver***

> *"if care is not possible at home and if you can't get enough day care coming in at home then the only alternative is to be in…A hospice."*
>
> ***Scottish, 70s, Male, Retired Teacher***

The hospices provide higher-quality and more person-centred care for older people with severe illnesses and their families compared with hospitals. The system was described by service users from minority ethnic groups as being more specialised in palliation and support, balanced use of pain medication, and degree of compromisation.

P 2: At hospice, the patient is not feeling very painful, and also, they can feel who's there.

P 4: People are much happier there when they go there.… My friend's wife was seriously bad, and we asked for a hospice for them, they said there's no place. She suffered in hospital.

P 3: if the same patient is transferred to some other organisation like a hospice, life is much better there for them because the drug which is given to them is much lower and much controlled… People are much happier there when they go there.

P 7: At the hospice, they have a sense of what they are doing, they can feel you, speak to you" "In hospitals, they won't allow you to stay unless your patient

> *is delirious and want to jump out of the bed … all with a long stay at the hospital will feel even more sick”.*
>
> ***Indian, 50s-60s, Males, Caregivers***

Despite their positive experience of palliative care at the hospice, participants referred to some barriers and stress experienced in securing a place there.

> *“But at the last stage, he stayed there, last stage of the illness.”*
>
> ***Chinese, 60s, Female***

> *“I remember trying to arrange my mother-in-law to go into a hospice and I was told no, because they’re only really for people who have got about ten days to live.”*
>
> ***Stottish, 50s, Female, Church Minister***

In addition, informants from BAME groups who had only vague understandings of residential care homes had negative attitudes. These attitudes were shaped by a terrible experience and underpinned by underserved communities, resulting in mistrust in their ability to respect the patient culture and understand their needs at the end of life.

> *“For you to understand people’s understanding of our culture, say, for instance, someone that’s from Africa, if you go to most of the care homes or elderly departmental side you will never see an African doctor or nurse in that department. So if you don’t put people that will understand say like us there, how do you understand what we’re going through.”*
>
> ***African, 40s, Male***

Accurate capturing of place-of-care preferences requires that respondents understand the available options and what each of them actually provides. However, many responses were in the form of questions, as participants were unaware of palliative care provision and hospice or residential care settings.

> *“I used to read it and see the word, but I don’t know what it means. Could you clarify that? Could it be a health centre? How long can you stay in a hospice?”*
>
> ***Asylum Seeker, 50s, Female***

Similarly, certain assumptions based on wrongly interpreted values were seen to deter participants from seeking treatment in these settings.

> *P6: think …we continue to look after the patient at home should the patient be put in a hospice, where people whose time is over or passing?*
> *P1: Ummm…. nursing home or care?*
> *P6: Thats care home.*
>
> ***ARAB, 50S-60S, MALE, CAREGIVER & PROJECT MANAGER***

In addition to cultural determinants, decisions about the preferred place of care and death are influenced by socioeconomic factors. The diversity of responses reflects the complex and overlapping nexus between the patient's and family's socioeconomic status – for instance, social class and financial resources, the patient's and family's level of health literacy and health awareness, and belonging to a deprived or marginalised community and/or having immigration status or experience. These factors all, in turn, inform the patient's care and death preferences. For example, little was known by participants across the groups about the financial burden of hospice care and residential care homes around the end of life.

> *"There are certain establishments that I could possibly go to and there might be a huge financial implication, such as a care home. What about the hospice, is there going to be a financial implication; but the person might not have thought about the hospice, not knowing whether it's going to be free or there's going to be some kind of charge or whatever; what's going to happen to my pension."*
>
> ***Scottish, 70s, Male, Caregiver***

> *"It depends if it is private that charges for the services. If it is they would keep the patient as long as he/she want as long as they pay."*
> *"It's all governmental here, you do not have to pay."*
>
> ***Arab, 50s-60s, Male, Caregivers***

5.4.1.2 Hospital

Most participants felt that the current hospital philosophy and structure contradicted the provision of palliative care. Participants referred to the nationwide shortages of hospital nurses and doctors. Nowadays, time and resource constraints are becoming the norm in hospitals, and the lack of capacity, training, and competence go against this specialised care. This was seen to affect the patient's condition adversely and cause dramatic shifts in how the needs and preferences of patients and their relatives were accommodated. Participants, mainly the service users, commented on hospital palliation as follows: '*Nurses and doctors have no time*', '*They became insensitive to complaints*', '*Deaf ears*', and '*They are overworked and busy*.'

Within these institutional care settings, some participants expressed concern that the financial outlook of the NHS nowadays is inadequate for the provision of hospital palliative care. In addition, other logistical factors such as limited visiting hours, the inability of family members to participate in care, and sometimes premature discharge from the facility were often cited as possible reasons that could intensify this attitude. From the participants' perspective, these disadvantages were the perceived reasons for avoiding staying or dying in a hospital.

Furthermore, community-level factors present further challenges to communication needs, due to limited English proficiency and limited health literacy, or being illiterate. On the other hand, hospital care had improved, and healthcare professionals had become more culturally aware. For example, concerning the cultural preference of Chinese people with regard to cold or ice water, hospitals had recently started to take into consideration their preference for warm drinking water.

> *"Chinese people staying in hospitals would never drink cold water, they always drink warm, or hot water. Now, the hospitals realise that"*
>
> ***Chinese, 60s, Male, Retired Nurse***

It was understandable that most healthcare providers had qualified and trained in Western healthcare systems and were often unaware of these cultural preferences and their impact on people. Simple initiatives, such as those described above, had a positive effect in enabling hospitals to provide more culturally appropriate care.

However, a simple comparison between the two following conversations on Halal food initiatives shows that the current palliative care philosophy of tackling variations in cultural needs and preferences may result in conflicts unless employed along with a rigorous assessment.

Discussion on new culturally considerate initiatives at hospitals

P5: *I think to be honest I've got to say this, they did a wonderful job, all the way. obviously when I'm on machines, nothing I can do and nothing they can do. But eventually when I was fit and could pray, they let me pray, they provide me the room.*

P7 *So, you know, I think they are, they are doing a marvellous job.*

P2: *I've been so many times and so long, four day in a week no complaint, nothing at all.*

P3: *Because family realised day-by-day they try to improve it and I think this and they ask you how you, are you satisfied and if any complaint. they try to get you what you want, they get Halal food there. Like the gentleman says, I pray in the, and they allow you to pray. They give you separate room, they allowed you even with conflict and this happen with never any issue really. And that was, like mis [mis]understanding like some, you know.*

P7: *Well, I think sometimes depending also how the patient answer to them, you know. So, my experience is that they are doing a wonderful job.*

Pakistani, 70s, Males, Patients

Nevertheless, cultural assessment, listening to patients and family members, and communicating effectively were believed to be the ways to nurture a cultural understanding between stakeholders.

Discussion on the ineffectiveness of these initiatives without assessment

P2: I think the local population may understand that to some extent, but the Asian culture is… No. So that cultural need is not being met because they're treating it just like numbers.

P4: And also our people, as she said, don't complain.

P9: They don't complain, no.

P4: What happens is when the food comes, you're a brown colour, automatically you'll get halal. We don't eat halal. So we're forced to eat halal in hospitals.

P4: Yeah.

P2: Well I don't know whether you've gone to hospital. Anybody sitting there, the nurse will come, the one…or a dietitian, oh, you are for halal. They'll just write halal.

P9: They'll just look at the colour and…

Indian, 50s-70s, Males

5.4.2 Challenging family involvement

Cultures strongly emphasise familism as a cultural value and family involvement as a preference. The discussion revealed varying standpoints on this involvement, pointing to the drivers and quality of involvement. However, an unexpected result was the lack of comments about family involvement by patient participants. One explanation is that participants spoke about the family support and presence for the hypothetical patient as taken for granted, so they did not even think to mention it. Another justification could be the pervasive and entrenched nature of this involvement in their culture.

"I am a heart patient and I had triple by-pass by open heart surgery and the cause was …. stress from the families and from …. Others"

Pakistani, 70s, Male, Patient

In view of the extensive family involvement in all aspects of care, the other explanation is the burden of care on family members. One patient participant said:

> *"Yeah. People like me. A health problem…Most people at my age… They're the most suffering."*
>
> ***Indian, 70s, Male, Patient***

Although family participation in the care process was observed to increase the acceptability of palliative care, it was also found to pose challenges. Some participants opposed palliative care as it is highly institutionalised care. Hence, they will not preserve their rights to participate in providing and planning care as mentioned in Section 5.4.1. Another outdated perception equated ageing with ill health, dependency, and incapacity. As a result, family members felt culturally obliged to provide the necessary care.

> *"Because of the age of the patient, fear from the illness …and worries about a deterioration in his condition. The culture of dealing with a 70-year-old patient it is different from … a 20 or 25-year-old patient."*
>
> ***Arab, 20s, Male, Student***

> *"You said 80 years old. Normally the family take care of, is now that age the family take care of it."*
>
> ***African, 40s, Male***

> *"But at his age and his condition, I think they need to involve the family."*
> *"Yes, when you're that age, I don't think they have that understanding."*
>
> ***Indian, 50s, Male, Caregiver***

The data concluded that although many family members from ethnic minorities felt culturally obliged to provide care, this did not mean that they felt willing or prepared to do so. They believed that providing bedside care was the family's responsibility, and the cultural value of filial piety underpinned family involvement.

For example, within the fourth group, all members had something in common – they all had responsibilities towards people with heart diseases. Apart from their personal motives, cultural expectations and family loyalty were the main drivers for providing care at home, as in other traditional cultures. The approach described above barely considers what the patient wants. Instead, they would rather focus on being congruent to avoid committing any sinful act and relieve the family's stress and fears.

P 3: In the case of terminal illness, I think our culture says we care for our terminal loved ones at home, as we are required and expected to do so. But, still, the culture is based on what we usedto do back home.
P 4 But do we have such care system within our culture?
P 5 Not in our country nor in our culture, no.
P 3 We have none of this.

Arab, 20s-60s, Male, Student, Patient & Caregiver

"we do not push relatives outside the home"

African, 40s, Male, Charity Manager

I cared for my mother-in-law. As a human being and seeing a sick person I felt obliged culturally to help her and look after her. Not because I am… [I can/know] because her own son should have provided her with the care she needed but he didn't. You know what I mean

Arab, 50s, Male, Caregiver

The extent to which family caregivers could provide care had a detrimental impact on their ability to meet the patient's preference for care. Besides norms and values concerning the case discussed, almost all participants have agreed on the importance of knowledge, willingness and ability to cope with caregiving responsibilities, and assessing the patient's needs at the end of the discussion.

Family caregivers' readiness to provide care for a terminally ill patient

"It depends on their own circumstances. Just like, in my case, because the family have someone looking after him… I just have ..the mother is already 90, but she's not going to the care home, my father as well, he also had a cancer, and then he just, he'd prefer to die at home."

Chinese, 60s, Female

"We don't know if people in our culture have the general know-how! home is not always the right place to care for this person"

Arab, 60s, Male, Project Manager

"It depends how his wife is and how supportive. Some people are so much better at coping with this sort of thing than others, through no fault, it's just how they are. Some people can turn their hand to nursing care in a way that perhaps others can't in the same way."

Scottish, 70s, Male, Retired Teacher

"But from my experience our culture… in Africa we don't have care system, we don't have it…Families provide the care system. Both systems will have some issues. The family do not have an idea, but this is really hard problem."

African, 40s, Male, Caregiver

The following discussions revealed a generational shift among participants regarding the importance of balancing cultural values and the care needed. Younger participants held radically different views to the older participants, and questioned the drivers and the quality of care provided at home.

> *“But from my experience our culture what I want to say is, in Africa we don’t have care system, we don’t have it. Families provide the care system. family say we don’t have money to keep this man here and we know he’s not going to survive, we just take him home.”*
>
> ***African, 40s, Male, Caregiver***
>
> *“Culture does certainly influence our knowledge and sometimes our knowledge can be wrong because of cultural beliefs. There are a lot of misconceptions in our culture which lead to our care knowledge and skills shortcomings.”*
>
> ***Arab, 60s, Male, Project Manager***
>
> *“If you tell a 70 year old patient that they are going to die they must say I had a good life and death had to come at some point. Yes, but these are older people. Those who are over 70 or even 60 would not take advice and change easily.”*
>
> ***Arab, 20s, Male, Student***

As noted earlier, family members were overwhelmed by the patient’s condition, and some inaccurate cultural understandings influenced their approach to management. Regardless of its effectiveness, the culture of caring at home was family-driven and culturally coined. Some would stick to this choice even when other participants declared it to be futile, especially at the end of life. Some participants assumed that the norm was created due to the financial consequences of hospitalisation.

> *“the family say we don’t have money to keep this man here and we know he’s not going to survive, we just take him home. There they are better [laughing], you know. So that’s really condition we take people home. But if there’s money I don’t think we do it, I don’t think we do that, no. But because of there is no money to maintain in such places in hospital there, you take him home.”*
>
> ***African, 40s, Male, Caregiver***

Designating a decision-maker was a familial responsibility and a culturally shaped role. The scenario administered involved the patient's wife in every storyline and clues about her involvement and her struggles. People from traditional cultures preferred to leave critical decisions to a senior family member, who was more likely to be male (e.g. the oldest son) and to ignore the wife's presence even when the patient was not incapacitated.

> *"I don't think that our culture takes her [wife] into account … We feel that we [family] are decision-makers and we should do all we can to save the patient's life [agreement]. "*
>
> ***Arab, 60s, Male, Caregiver***

One explanation for this is the belief that a son or daughter would make better decisions as they are more educated and speak the country's language. The other suggested explanation is that there are cultural norms of male domination and culturally shaped thoughts about gender roles or traditional views of women. Only one group was most likely to have a spouse as the alternative decision-maker. This suggests that decision making is based on cultural beliefs and norms and cannot be judged without taking the cultural context into account. Despite the majority implicitly favouring family surrogate decision making, the discussion revealed different viewpoints on the value of tradition behind this involvement. Family involvement, in which cultural norms take precedence over patient needs, would not necessarily enhance patient autonomy or respect the patient's care preferences. It was also evident that families could allow the specialists to make decisions on their behalf in order to avoid being blamed or held responsible for the decision made, particularly if death was imminent or expected.

5.4.3 Communication preferences

There was considerable variation both between and within groups with regard to communication preferences. Some participants wanted to know and communicate directly, honestly, and explicitly, whereas others had a cultural preference for more implicit, subtle, and non-verbal communication. In addition, the findings indicated that some preferred collaborative authority and decision making, whereas others favoured minimum engagement in care communication and decision making. For example, most participants for whom English was not their first language, and who felt that they lacked understanding, preferred clinicians to dominate communication. They believed that this made a huge difference and created genuine trust in the Scottish healthcare system.

> *GF: So, how do you find the overall communication?*
> *P 5: obviously, that is not… an issue … since you have a procedure. Before that, they told me I am sorry, nothing else we can do for you. You have to live with medicine as long as you ..what do you think?*
> *GF: Yeah, well, they need to ask …*
> *P 6: My consultant ... asked me... yesterday and he told me, he says what did you think? I said … what should I think! So you tell me; I need to get it done.*
>
> ***Pakistani, 70s, Males, Patients***

The preferred authoritarian style may reduce participants' readiness and ability to communicate their needs and priorities and engage in treatment decisions, given the perceived power gap. Consequently, a few others viewed the shared authority and patients' decision-making engagement as a sign of lack of knowledge on the service provider's side. Clinicians who communicated collaboratively with the patient and family during the decision-making process often lacked competency or confidence. One participant criticised the discussion of treatment options in textbooks during the consultation instead of communicating their messages assertively and authoritatively.

> *I think one thing that we notice also, I would say it's also competencies, not just communication, not just culture, but competencies. The GP in Africa, there's no need to ask or read a book to do any ....*
> *In Cameron, I've been to the GP many times… they will take a book, read, read, read,... So even what they are giving you they are not very sure. So They would ask you or just .. go and test it. If that is not okay, you come back.*
>
> ***African, 40s, Male, Charity Manager***

Remarkably, each community or culture has its own unique preferences with regard to communication, with some aspects of communication being similar across cultures and others being group-specific. Participants mostly preferred openness and directness in communication, to enhance their knowledge and ability to make informed decisions. However, the discussions revealed some within-group disagreements as to whether information should be shared with the patient. In addition, some respondents expressed doubts about the feasibility of one-on-one communication without the family present, particularly when communicating bad news to a patient.

A paired conversation highlights in-group discrepancies on breaking bad news.

GF: So do you think in general the culture is encouraging doctors and nurses to speak more honest…like to be honest with the patient?

P 4: They should be honest with the patient, yes.

P 2: No, most patients now would like to know about it.

P 4: What's wrong with them. Openly. Rather than keeping it a secret.

P 9: Well it depends. Sometimes if the family's told and it's better not to tell them because if they…sorry to say, would've given up life.

P 4: She would've died early.

P 9: Yeah, she would've died early

P 3: The family first and then…Not the patient….In a terminal case I'm talking…

Indian, 50s-70s, Males

The strong views about prognostic communication near the end of life were justified explicitly in terms of helping the patient due to their lack of proficiency in English, and promoting the family’s pivotal role in care communication. Others based their judgment on the extent to which the patient’s heart failure had progressed, and it might be grounded in the shared misconception that palliative care equates to care in the terminal stages of heart failure. Nevertheless, the implicit message was clear - to oppose the Western approach of truth-telling, which would leave the patient hopeless and helpless. Key informants from collective/BAME cultures expressed the view that breaking bad news to terminally ill patients is odd, eccentric, and culturally inappropriate.

A paired conversation opposes the value of truth-telling in palliative care

P 3: I think that's the clash of cultures. Western culture…telling the patient everything… Upfront. And the Asian culture where the family is more important than the individual. The collective family.

P 2: Yes, I understand that confidentiality in the NHS and other places, they will not …. But when somebody is unwell like that then they need to…

P 4: If ' 'somebody's seriously ill the Asian family would … prefer to be consulted first. Rather than the patient, not the patient …

P 5: NOT the patient [barracking].

Indian, 50s-70s, Males,
Retired Gp, Board Member,& Caregiver

Nearly all of the informants across groups qualified the above responses as wrong but real. However, it was noted that the younger participants from BAME communities, who were already being influenced by modern Western culture, had demonstrated how acculturation was slowly eroding these cultural practices.

An example of different understanding and attitudes driven by acculturation

GF: when there is no cure, or it is awful news, do you still prefer to hear it?

P 4: Yes, it is best to be done face-to-face, which allows the patient to ask questions that he/she may have.

P 1: It has to be done face to face in a professional way.

P 2: Giving all the details to the patient is the right thing to do. But in our culture that does not happen. Our culture has a lot contradiction with respect to how much the patient should be told in the case of a terminal illness.

P 6: doing so you are contributing more for the person to give up. So this is your preference, Ahmed?

P 2: Yes

Arab, 30s-60s, Males

Upon clarifying that disclosing information to family first would breach the law, participants reiterated the barriers in the current approach and philosophy to terminal care. Then, participants were invited to respond to questions relating to communicating care needs and preferences in advance and whether or not they would prefer these discussions to happen. First, regarding the care planning, it was noted that advance care planning was not clearly understood or even known by almost all public members, especially the older ages. None of them has been asked to or already participated in these conversations. Therefore, their responses were not necessarily based on prior personal experience or knowledge but rather on personal attributes and worldviews even before the concept was defined. For example, the vast majority held a pre-understanding of the term to denote imminent death, "*give up*" and "*let go*", while others thought that the consultant had given up on the patient and decided to "*stopping treatment*". Strikingly, advanced care planning was often reduced, among faith groups, to documenting orders like Do Not Resuscitate, Organ Euthanasia, or Organ Donation. As shown below, a community leader denied, at first, these conversations that oppose the worldviews that they may hold.

> *"That special customisation of the care and planning for the care is not available in our culture. It's good to have it but we don't have it."*
>
> ***Arab, 60s, Male, Project Manager***

> *"Is that because they want to cut us up and sell bits off?"*
>
> ***Scottish, 70s, Male***

A few others reacted positively to the conversation and regarded it as essential and highly valued. For instance, a woman who had sought asylum after migrating to the UK alone felt enthusiastic about having the conversations once she had arrived in the host country. She later explained that her decision stemmed from the desire to control her health, and her adherence to cultural norms and faith disciplines.

> *"Would you consider taking part ?"*
> *"Yes definitely, I hope to do that. Why not ..I would say yes. I would not mind…I have a lot of faith in God and I told the doctors that I like life. And I am good now."*
>
> ***Asylum Seeker, 50s, Females***

After having ACP explained to them, key informants admitted that their culturally based understanding and the meaning ascribed to ACP influenced their altitude and ultimately misled their initial choice. In addition, they acknowledged the importance of ACP in guiding decisions concerning the hypothetical case. Nevertheless, one member of the public questioned the timing of ACP conversations and why these conversations are not offered earlier in life, before the patient with an incurable life-limiting illness reaches the advanced stages.

A paired conversation concerning the timing of advanced care planning

EP 9: So, when you're talking about your advanced care plan at what stage is this done? Is this done before someone really is advanced? Or less advanced? Or before you get to the point?

Stottish, 50s, Female, Church Minister

EP 7: I think if you're gasping for breath, it's very difficult to make decisions about anything.

Scottish, 70s, Male

Despite the continuous reiteration of the benefits of ACP, some other participants remained negative and refused to follow the argument. To gain more balanced and informative insights into ACP, we asked the participants to suggest obstacles to the implementation of ACP. Language barriers topped the list, particularly when preparing for cross-cultural ACP, given that language can influence a person's worldview. Thus the participants' first language unconsciously reflects their cultural beliefs, values, and norms. The following narratives demonstrate how language is crucial for communicating culture and for conversations about the goals of care.

> *"Well, you get a lot of people … don't speak the language, they don't speak English, and it's very difficult. By the time you are waiting to get a translator, or whoever it is, it could be, I suppose, people are in pain."*

Chinese, 60s, Male, Retired Nurse

> *"I think at that age if you are telling them all in English and you don't have an interpreter, in Punjabi, then it's a waste of time. Because that person will not understand anything."*

Indian, 50s, Male, Caregiver

In fact, a carer and the daughter of a patient who was receiving palliative care pointed to the need to assess the patient's level of comprehension and language needs, and a family member who can take on that role.

> *"Yeah. The first generation that came, they're the ones that obviously…Yeah. They're not illiterate but they just didn't need to speak, so they didn't learn. Some of them learnt, some of them didn't. I'm not saying…the majority…they don't like to trouble anybody… It'll be just done with the family."*

Indian, 50s, Female, Caregiver

Language-related issues were regarded as inevitable due to the growing number of cultures and languages within Scottish society. A retired Chinese nurse who had worked in Scotland for more than 20 years acknowledged the ongoing challenge of accommodating the diverse language needs compared with past times.

> *"There used to be…when there were just a few languages, in the old days… basically had to have Chinese, Urdu, just a few Asian languages. Now, there is so many languages, it's every language under the sun, it's impossible to have the information translated into every language. Because if you do translate into some and not the others, it would be discrimination."*

Chinese, 60s, Male, Retired Nurse

Interpretation and language assistance was essential to facilitate these sensitive discussions. However, many non-native-speaking participants reported issues related to the NHS interpretation services that forced them to rely on family or community members.

> *P 1: I once had to go to hospital, but the interpreter could not be there, they were telling me about a lump and until now I know nothing about my condition.*
>
> ***Asylum Seekers, 50s, Female***
>
> *P 3: Some are, I mean their interpretation is rubbish.*
>
> ***Asylum Seekers, 50s, Male***
>
> *P 1: Of course. He was playing with his mobile phone, he was on a call to arrange a pick up for his school boy with his wide, he was not with me, I was connected to devices and my heart is … [Exclamation]*
>
> ***Asylum Seekers, 50s, Female***
>
> *"It's (the current interpreting services) pretty poor at the moment."*
>
> ***Indian, 50s, Male, Caregiver***

When family members provided interpretation services, this in particular was found to hinder the establishing of direct non-family-mediated communication and identifying care preferences in a person-centred manner. The following examples illustrate the risks that such communication through family can carry. In fact, healthcare providers are documenting future care plans that reflect family preferences rather than the patient's needs as information is more likely to be withheld from the patient. This is how a retired physician and a carer explained it:

> *P 4: Interpretation will be done by the family rather than…*
>
> ***Indian, 50s, Male, Caregiver***
>
> *P 8: In that case they need to involve the family. … At his age and his condit*
> *I think they need to involve the family. Then go with the 'family's wis*
>
> ***Indian, 50s, Female, Caregiver***

Among the asylum seekers, interpretation was the most significant issue throughout the discussion. Asylum-seeker participants saw interpreters as their window to the healthcare world. In terms of competency, many mentioned the substantial likelihood of poor and unreliable interpretation. Therefore it was suggested that interpreters undergo medical training and education in the concepts and practical communication skills required for dealing with patients, particularly in a palliative care setting. However, as the following paired conversation illustrates, the availability and ability of interpreters may be variable.

Even when English-language support was available and accessed, participants faced challenges with regard to the accuracy of translation and understanding. It was apparent that interpreters' language fluency does not always result in optimal understanding. Most of the asylum-seeker participants believed that even with good interpreters, their dissatisfaction was correlated with poor translation. It appears that there is a need for interpreters to go beyond translation and assist with understanding the healthcare messages.

A paired conversation on ACP using a translator

P 1 it is better to be face-to-face... I don't need a translator; I need somebody to help me understand.

GF: Does this applies to general communication or to conversation to plan future care?

P 4: Yes, I mean…In that context, both parties need a medium or a reliable facilitator, otherwise, it will be messy and might not work.

P 5: Accuracy in the interpretation is the key. I expect the interpreter to also act as a comforter and not just translate the words. They should put you at ease not to stress you more.

P 1: Yes, definitely there is a difference. I am an Iraqi and once had an interpreter who I think was a Sudanese or Somali during my hospital stay. I was asked to press a button on something when I am at home, so I asked which one the green or black button, so he said the black when I know the doctor said "GREEN".

Asylum Seeker

Hiring or seeking assistance from bilingual or bicultural healthcare professionals, bidialectal well-trained medical interpreters who have been engaged in ACP or belong to a similar culture can assist in these discussions. In addition, it may be helpful to engage the community, culture and faith group leaders to introduce or facilitate these discussions as an icebreaker and preparatory steps for initiating and raising awareness around ACP conversations. These measures and actions were considered critical for effective cross-cultural palliative care encounters and enhancing the ACP uptake.

> *I work in a hospital…with different kind of people, palliative care, end of life, all those kinds of things. So, the story we always have from them [patients] every day because the doctors, the GPs, they don't understand them. They don't just care to understand what the patient is going through, they doesn't .. even listening to her. But they only care, oh, we are just doing enough the end of the day, sign this and for you to understand people's … understanding of our culture, say for instance someone that's from Africa, if you go to most of the care homes or elderly departmental you will never see an African doctor or nurse. So, if you don't put people that will understand say like us there, how do you understand what we're going through.*

African, 40s, Male, Social Worker

5.4.4 Preferences reflect values

Discussing resuscitation and planning care and death were critical points that brought the situation to a sharp turnabout where the incongruities between ACP and participants' values and beliefs were unearthed. It was noted that, beyond the availability and awareness of the services, cultural beliefs and values were likely to influence people's preferences considerably. As mentioned previously, participants saw themselves at a liminal state in the ACP scenario between accepting ACP conversation and the 'no-guarantee state' to get what they wanted. Furthermore, many of the respondents' beliefs concerning care planning were fundamentally associated with hastening death. In order to rationalise these beliefs, they spoke of past direct or indirect experiences. Distinct cultural values such as family-centred decision making influenced ACP engagement among ethnic minorities. It was reported that palliative care plans should consider the decision-making process and how cultural differences may affect this process. For example, the immediate and extended family is expected to be consulted and kept informed as they are affected by the outcomes.

A paired conversation report on decision making as a familial value

GF 1: does your culture have anything that makes it easy or difficult for the patient to discuss this in advance?

MB 4 I would say NO.

GF 1: You don't think we would be prepared to discuss it, others?

MB 2: I this case specifically... he would not have given this any thought beforehand... we.. we don't plan, I mean the family would know what to do usually. we want to know all the details and discuss any options for treatment..

MB 4 The family would say NO.

MB 1: There is no such thing as confidential discussions between the patient and the doctor in our culture. So, having treatment in hospital for a long period is not possible, a heart failure patient once they are slightly better after a few days they are sent home and it is not possible to argue that the patient prefers ....

The last quote proves that communication preferences in general also applies to communication near the end of life. However, the communicated choices and decisions stayed modal for mere possibility rather than ability. In simple terms, it is not about what the patient wants but rather what family and culture regard as acceptable and possible at a particular time. Another extract by others who were very privileging the value of interdependence echoes the message that the current approach to future care planning is less culturally appealing and clashes with their collective values.

"But it's the family they have to talk to....When they are planning, because...A bigger family can cope or not."
"Yeah, It depends if their families are able to support them..."

Indian, 50s, Male & Female, Caregiver

Certain sociocultural beliefs and perceptions reinforced being accustomed to the norms, such as the perceived power gap between doctors and public members. In addition, some cultures are likely to have particular communication norms and practices if the patient is terminally ill. For example, when the hypothetical patient deteriorated, the family members would step in and make care decisions on the patient's behalf.

> *Now in our culture, from Africa, from ethnic minority, we assume that when we have our relative who are unwell, we assume that the person is in the position where they cannot think properly, then we have to, as a family, take a proper and correct and accurate decision on its behalf.*
>
> ***African, 40s, Male***

It is noteworthy that the discussions revealed some in-group discrepancies in the participants' belief that this information should be shared with the patient or their family. The quotes suggested that these collective values challenged the heart failure prognostic communication preferences.

Most of the participants viewed communication as a prerequisite for trusting relationships, a shared understanding of heart failure, and successfully participating in care planning. However, the reported communication flaws seemed to cause a lack of confidence or trust in the healthcare system, and therefore present a subtle yet powerful barrier to this collaboration. Another social worker from an African community has stressed the need to pay attention to poor communication as a cultural experience and principle underpinning conversations before they become feasible; he gave the following rich example for illustration.

> *"For instance, this might be a single tree, and you want the tree to be dead, right. You just cut the branches. If you do not cut the roots, the tree will still come up again. So for you to kill the tree, have to start from the bottom, to deal with the roots first, before going out there. So you guys need to deal within yourself and within several care."*
>
> ***African, 40s, Male, Social Worker***

The discussions with those participants have shown that lack of trust influenced their willingness to set care preferences at the end of life. However, it also uncovered promising evidence of people changing their attitudes and accepting these communications if culturally appropriate. For example, a family carer participant living with diabetes and hypertension was invited to comment. His cultural understanding, which was reinforced through personal experience, was applied to this unfamiliar situation.

P 4 Our Arab culture, especially heart patients, would suffer and ignore the recommendation justifying that with a lack of confidence in recommendations. The patient will find it hard to reconcile with their and others' experiences.

P 5 My dad had part of his aftercare therapy in Lebanon and part here. In everyone tried to interfere for the best for him. However, here in Glasgow, there was no issues in treatment and care. They [Nurses and doctors] did everything for him, sometimes even things that we were not able to d. Of course there is a big difference between Lebanon and here.

P 4 Trust is…I think Arabs who live here [UK] trust and rely on locally available services more…, we have learned to trust the professionals.

Arab, 60s, Male, Patient&Caregiv

Care planning conflicts may arise from fundamental conflicts in the underlying palliative care values and participants' beliefs. Nevertheless, these conflicts are often obscured by a contemporary healthcare culture that is individualistic. The autonomy-based discussions were believed to undermine the collectivist and family-centred values held by many participants. However, planning care was more feasible among these cultures if introduced as a broader concept that was beneficial for both patients and families.

For example, there was a sense of appreciation of ACP services that address patients' preferences and assist families in preparing for death, avoiding conflict, and coping with the caregiving burden.

P 5: But these conversations, when the patient sits with the doctor, would be very helpful and would include Ahmed says if i am getting more ill or in my last days I prefer to spend my last days at home away from hospital, I do have that right as patient!

P 1: I do agree [Agreement]

P 6: But, I don't think this concept of discussing whether to resuscitate or not is accepted in our culture. To ask in advance not to be resuscitated I think is seen as a form of suicide.

Arab, 50s-60s, Males, Caregivers & Project Manage

Other interviewees found these complex conversations with the patient to prevent potential conflict over family wishes to resuscitate and the institutional procedure related to DNR orders not to resuscitate based on the expected outcomes.

P 2: ACP is the best solution;

P 3: yes, if it is an individual plan for every patient, that would be appreciated very much by the Asian culture or particularly Sikhs.

P 2: But unfortunately, practically it doesn't happen. And many times, they are ignored when they go to hospitals. And as you say, this is just a moaning or complainer, oh, they can't understand.

Indian, 50S-70s, Males, Caregiver & Retired GP

Nevertheless, using ACP to document orders such as DNR that go against the basic principles of a good death reduced their desire to engage in these conversations. The last participants with high cultural literacy justified from a religious point of view that believers must not accept giving up, and people must keep on hoping until the last minute. Euthanasia, 'Do not Resuscitate' (DNR/DNAR) orders, and suicide wishes were culturally refused and considered taboo topics from a religious point of view. Informants considered them a bad way to die as it comes from individual action rather than God's determination.

"It's written [Religion reference... So we can't really give up. You have to ke trying as long as you've got your last breath, live as long as you can."

Indian, 50s, Female, Caregiver

"But, I don't think this concept of discussing whether to resuscitate or not is accepted in our culture. To ask in advance not to be resuscitated I think is seen as a form of suicide."

Arab, 60s, Male, Project Manager

These initial responses showed the dominance of culture-focused and non-interventionist understandings of palliative care at terminal stages. Participants' attitudes towards ACP were also affected by their longstanding sociocultural meanings and reactions to death that hindered their understanding. Nevertheless, they were convinced that discussing offensive and taboo topics such as death, which is still forbidden in many cultures, would anticipate death and planning future health deterioration would bring it closer.

"Living, and not dying …what matters the most…"
"My aunt had cancer. But to her dying days we didn't tell her she had cancer because I think if she had known she would've given up life, She would've died early."

Indian, 50s, Male, Caregiver

The last storyline of the hypothetical scenario aimed to shift participants' initial attitude towards death and dying discussions. Participants were asked to assume the role of a patient's family member and contemplate how this would alter their perspective and preferences about ACP. Participants' attitudes towards death and dying discussions hinged on different values and how these values were interpreted and manifested. For example, the palliative care team was blamed for keeping the patient drowsy while under the effect of analgesic drugs during the last few days of life. They expected their loved one to stay alert and interact with the family when dying.

> *"palliative care .. hospitals are not properly organised for that. They keep people so much under the influence of drugs, people don't know what's happening, they don't recognise us at this stage. if the same patient is transferred to a hospice, life is much better there for them because the drug which is given is much lower and much controlled.* "
>
> ***Indian, 50s, Male, Caregiver***

Among groups, and regardless of their religious identity, spiritual beliefs played a central role in the decisions about their engagement. The majority believed that God is the ultimate authority over health, illness, and death. However, the way they implemented and conceptualised this belief differed. Participants with low levels of religious literacy translated their beliefs in the higher power of God into loss of control and leaving decisions to those who were perceived to be in a superior position in terms of culture and religion. They believed that God had already decided the outcome despite the work of healthcare professionals. However, participants with higher levels of religious literacy were more likely to benefit from their belief in God and the spiritual afterlife, as it supported their plans and decisions about how they wanted to live, how they wanted to be treated, and where they wanted to prepare for death and die. Interestingly, and despite their strong belief in the afterlife, these deeply held views were disputed by some participants. These participants considered that what matters more is highly individualised and context-dependent

P 7 I think because we think about the issues of life and death more, and we also have the hope of a further life.

P 1 it's an appointment for all to keep anyway…We know that death isn't the end.

P 9 I don't think you can assume all Christians have a defined sense of afterlife. Some Christians actually don't fathom it at all. A lot of Christians quite struggle with it as well. Like it's going to be oh well don't worry, I've got another life to go to, I'll be fine.

P 2: The difficulty is we're all individuals and it's our individuality that is the most important [agreement].

Scottish, 50S-70S, Males & Females

Respondents in agreement see that people are becoming more open to speaking about death and dying, at both personal and public levels, and to bringing their ideas to the forefront. Such discussions, including this focused discussion, perhaps are essential to enhance and encourage the ACP dialogue. The following paired conversation tells the story of people changing their attitude and becoming more open to discussing death:

> *P 2 If they ask the question about whether the community would want to talk about this or whether people would want to talk about this matter a few decades ago, not all that many decades ago either, they would probably say, we don't want to talk about it.*
>
> *P 5 For example.*
>
> *P 2 For example, just an example here, my mother died of cancer and it was stomach cancer, and she never mentioned the word cancer once.*
>
> *P 9 No, my mother was the same.*
>
> *P 2 And she was nursed by my father at home. Now, that was going back over 40 years ago. Nowadays as we know, it's far more open, but then it would have been a very small minority who would have spoken openly about it.*
>
> ***Scottish, 50S-70S, Males & Females***

The inevitability of death has not translated into more open discussions of death. As illustrated here, reluctance to discuss the heart failure prognosis near the end of life is a major challenge and requires great sensitivity when raising the subject of death. The interviewees were asked to continue to imagine the hypothetical scenario and consider whether faith would help to ease the dying moments. They all agreed that strong faith was the way to reach this peaceful moment and alleviate fears, worries, and pain. Thus informants presume that death anxiety and fear (thanatophobia) are not primary issues but the process of dying, the fear and emotional anguish associated with dying.

P 2 For some people it's not so much the death that's the concern. It's the process of dying. Because when we get to that final stage, that last process of dying, it's a relief for the person. [Agreement]. I think that applies too to Christians: some Christians even with strong faith by their very nature, by their very make-up could actually be more worried about themselves than others…It varies among Christian people as well as through people in society.

P 8 probably have a sense of people praying for you and I think that makes a big difference when you're in that situation [dying].

Scottish, 70S, Male & Female

From the discussion, it was clear that some constituents of a good death were similar across cultures, while others were different. Preferences for care that broadly reflect values were regarded as an essential characteristic of a good death. However, each group has its own distinct idea of what constitutes a good death. The above account has shown that the term 'good death' is shaped by the sociocultural context and is continually revised according to personal experiences. Therefore contextual meanings of death have an impact on how the event is viewed and how relevant values must be embodied and fulfilled. For example, some participants perceived good death quantitatively, whereas others within the same cultural group understood it qualitatively.

P 4: My father was sick, he was taken to hospital. Oh, he had a good life, he had a good 84 years. So you don't want him to suffer. They didn't do anything, the doctors because of the age they tend to say, oh no, it's no use [resuscitation]. But it shouldn't…

P 2: What matters the most, stay alive! Yeah, a good life. You don't want to be living if it's a miserable life. If you have a good life, more important…

Indian, 50s, Males, Caregivers

5.5 Chapter summary

In this study, culture and its embedded understanding shaped needs and responses to terminal heart failure at the end of life. Hence it forms a part of patients' means of deciding on their palliative care preference. The underlying culture determines the needs of its community and sets the scene for how and where these needs are considered and met consistently with values and beliefs. Consistent with the theme (1), the results also confirmed in no uncertain terms that the cultural worldview and lay explanatory models regarding care and treatment influence people's understanding of palliative care and, therefore, the need for and when to seek palliative care services. Participants' context, including cultural factors, is likely to influence their preferences and determine, to a considerable extent, whether these preferences will be endorsed or renounced on ethical grounds.

Chapter 6 Discussion of the focus group findings

This chapter begins with discussing the findings of the focus group study and reflecting on cultural beliefs that may be involved in how patients construct their understanding of palliative care for heart failure and their perceptions of how it is received and delivered. Following this, the following chapter summarises the findings, research questions and how I have addressed them. Focus group strengths and limitations are mentioned next chapter, section 7.4.

6.1 Culturally embedded understanding of heart failure and palliative care

In this study, the results go beyond previous reports, showing that understanding, or lack of, has a context-situated meaning. The terminal HF diagnosis carried situational meanings that challenged some core beliefs and violated global meanings. Participants went through meaning-making, wherein situational meanings (lack of or confused understanding) were reframed to align with pre-existing global meanings (curative cultural worldviews). This cognitive processing is employed to weave the new knowledge into integrated beliefs and meanings and assimilate a new understanding. These findings resonate with those of Im et al. (2019), Park (2010) in terms of contextual meanings. Failure to capture these meanings appeared to be a source of confusion about palliative care in heart failure. Similar results were obtained in comparable studies that ruled out any chance for altering global meanings to accommodate the situational meaning (Agom et al., 2019, Ivynian et al., 2019).

From a medical anthropology perspective, these observations were consistent with Kleinman's assumptions, in that people use lay explanatory models (EM) to construct illness meanings and describe experiences within their cultural context (Kleinman, 1980, Kleinman, 2017). In nursing, McSweeney et al. (1997) maintained the definition set out by Kleinman and provided a novel perspective for considering how these subjective interpretations, the one crucial side of reality, are socioculturally situated. Even though participants have defined, constructed and interpreted meanings through their cultural lenses, they, rightly or wrongly, construct HF knowledge according to the naturalistic disease theory system. Our findings disagree to some extent with previous studies in which participants suspected multiple causative factors that were unrelated to actual causes (Agom et al., 2019, Namukwaya et al., 2017). However, they are in line with MacInnes (2014), who referred to culture as the power that drives assumptions, shapes distinct perceptions, directs patients' self-care and determines their importance.

Nevertheless, the lay and the biomedical models were similar in aetiologies, yet they differed in symptom, treatment and care domains. One explanation from the present findings is that participants were initially unaware of their diagnosis, and their narratives were based on generic experiences with other heart diseases. A similar conclusion was reached by Clark et al. (2012) in terms of explanatory models and incomplete HF understanding. This led participants to make sense of HF as a single disease and refer to the syndrome, using plain terms, i.e., heart troubles or a bad heart. However, the various models regarding symptoms could be linked to our previous results in 1.4 1, where symptoms were subjectively understood, derived from and legitimised by the common culture-specific milieus. Furthermore, the findings in this study are similar to other studies where participants did not correlate breathlessness to heart failure but to other perceived ailments, including ageing. These points link to what has been noted by Andersson et al. (2012) and Ivynian et al. (2015), who argued that multi-morbid participants had difficulty understanding HF and tried to normalise symptoms initially as coping mechanisms, which brought further confusion to distinguish HF and non-HF symptoms, leading to delayed treatment (Taylor et al., 2017).

Most interviewees knew very little about palliative care and many struggled with understanding terms and benefits. Prior HF and no HF research provide essential context for this section. Knowledge and awareness were limited among participants in different cultural groups. However, a handful of studies have shown opposite results. For example, Mallon et al. (2021) claimed that young adults had a high level of awareness but insufficient knowledge, but not misperception, about palliative care. However, their awareness did not necessarily translate to an accurate understanding of palliative care (McIlfatrick et al., 2014).

A gap was noticed between what people believe they know and their actual knowledge and did not necessarily translate to an accurate understanding of palliative care (Grant et al., 2020, Zhu and Enguídanos, 2019). In our study, participants familiar with palliative care did not have any better knowledge or understanding in practical terms than their counterparts. Addressing this evidence gap is important because insufficient knowledge is usually associated with misperception and negative attitudes towards palliative care (Adjei Boakye et al., 2020, Cheng et al., 2019, Huo et al., 2019, Klindtworth et al., 2015). For example, Grant et al. (2020) concluded that what is challenging about palliative care is “low awareness/common misconceptions.”

In keeping with evidence from other conditions such as COPD and cancer, the insufficient palliative care knowledge among patients and caregivers despite declining status was cited as a barrier to accessing the service (Enguidanos et al., 2021, Pinnock et al., 2011, Stocker et al., 2017). For example, Enguidanos et al. (2021) Cardenas et al. (2022) argued that the critical challenge to enrolment in palliative care is culture, which ranges from language to beliefs, as well as attitudes and preferences. Others reported even more concerning findings that the same applies to healthcare providers as the cultural background of patients and caregivers influences the behaviours of the treating physician. In the context of HF, it is concluded that the evidence suggests that patients’ limited knowledge and understanding of heart failure and palliative care impact patient outcomes (Stocker et al., 2017). Optimal understanding of heart failure has been identified as a prerequisite for patients recognising palliative care needs and responding to them. Such understanding is also a product of culture and context (Cain et al., 2018, Im et al., 2019, Romanò, 2020, Wittenberg et al., 2015). Therefore, a lack of understanding hinders communication of needs and diminishes willingness to seek help in worsening heart failure (Klindtworth et al., 2015).

One key finding was that participants had minimal familiarity with palliative care heart failure, with the cultural embeddedness of their HF understanding of heart failure challenging and forming part of palliative care understanding. As with HF, palliative care was seen, defined, and interpreted through personal experience. Their experience determined how they understood and made sense of palliative care and, hence, potentially what misconceptions they may hold, which was a common thread in chapter 1. Participants bring their cultural meanings into care as a resource to redefine and renegotiate meaning, and as a coping mechanism during the critical stages of illness. As we noted, participants' interpretations have perpetuated HF misunderstandings but also awakened preconceptions and uncovered misconceptions about palliative care in HF. The most common misconceptions held by participants across groups were that; palliative care is exclusively for terminal cancer during the last six months of life; heart failure is not eligible for palliative care; Palliative care equates to end-of-life care and is predominantly given at hospices, palliative literally means a 'terminal stage of illness' and palliative care is 'no other option' or 'nothing can be done' care. These common misconceptions were mainly supported by previous literature (Browne et al., 2014, Huo et al., 2019, Klindtworth et al., 2015, Kozlov et al., 2018, Namukwaya et al., 2017, Patel and Lyons, 2020, Romano, 2020, Selman et al., 2007, Shalev et al., 2018, Singh et al., 2020, Stocker et al., 2017). However, aspects of culture were rarely addressed. For example, it was evident in our study that even when palliative care was clarified as care dedicated to managing symptoms and discomfort, focusing on enhancing the quality of life, participants were uncertain and preconditioned by a matrix of cultural milieus and lived experiences. Our result corroborates with the previous reports that cultural understanding and religious beliefs are utilised to make sense of their illness and guide care decisions, particularly when treatment fails to cure an illness (Agom et al., 2019).

Due to the longstanding and chronically continued fear and lack of interest in discussing death and how people culturally want to die, the meaning ascribed to death was very scant in this study. Prior evidence confirms that discussing death and dying is not a common practice and is still an avoidable topic in various cultures (Asano et al., 2019), with some data pointing out clear divergences and unveiled grey areas within and across cultures (Tucker Edmonds et al., 2020). In the current study, death and dying discussions were not explicitly declared to be taboo. However, some participants perceived initiating the discussion to bring it closer. Hence, according to McIlfatrick et al. (2021) and as recommended by the Quality of

Death Index, it may be advantageous to accept the emerging situation of ‘death’ in order to improve our understanding of death and confront any related cultural taboos for better engagement in end-of-life care situations (Lang et al., 2022). At the same time, quality of dying and good death concepts are gradually gaining momentum. As a result, people slowly accept death and dying discussions instead of avoiding them. This study has shown that; while death was perceived as an existential life event, the cultural understanding of death and participants’ attitudes towards death and dying discussions were diverse, with each group having its own distinct idea of what constitutes a good death. For instance, all groups agreed upon peaceful death or minimal suffering and attending to care preferences that broadly reflected values and regarded these as essential characteristics of a good death. This concurred with previous literature, which argued that culture, plays a crucial role in shaping the perceptions and attitude towad death. Selin and Rakoff (2019) have stressed that death and attitudes to death are neither homogenous across cultures nor probably within a culture and emphasised the importance of studying culture and cultural attitudes towards death and provided various cultural experiences on death and dying (Lang et al., 2022, Selin and Rakoff, 2019, Tucker Edmonds et al., 2020).

6.2 Palliative and end-of-life care preferences

Palliative and end-of-life care preferences were varied in this study, but shared experiences and responses arose across different groups. The shared cultural practices focused on the home as the preferred place of care, the need to involve families in care and care decisions at this stage, diverse communication preferences and care values at the end of life.

Even though participants agreed on home as the preferred place of care after the referral statement, overt preferences were absent. This is consistent with Gomes et al. (2013) who argued that related preferences conversations were rarely initiated. Instead, we found that situational factors and individual differences influenced the choice made in the negotiated context (see Table 5.4). These findings confirm earlier research in HF (Formiga et al., 2004, Im et al., 2019) and concur well with other findings (Gomes et al., 2013, Martín et al., 2016). However, the word ‘home’ was symbolic and denotes the comfort zone set out by cultural and communal norms, where a person feels safe, surrounded by extended family and friends, and can practice cultural and religious rituals with limited visits to healthcare settings. The similarities with Dittborn et al. (2021) further support the idea that family plays a vital role in palliative and end-of-life care, with a comment that they may be overwhelmed and left alone, especially within the culture of caring at home. For example, arranging for senior members of an ethnic community to die in their place of birth, the resolution centre, is the way to preserve their dignity and fulfil cultural and religious rituals during their preferable last days of life. Our analysis, along with Rahemi and Parker (2021), referred to the unique patients' meanings and preferences as what matters when planning end of life care.

In a comparable sense, statements about the preferred place of care and death were rarely absolutely expressed, as uncertainties tended to favour one place over another, similar to the description in Bellamy and Gott (2013). We suggest that these preferences are purely a reflection of more profound beliefs, values and rules. Consistent with past studies, we found that observing cultural rules were sometimes prioritised over addressing the patients' needs and preferences (Bellamy and Gott, 2013, Shrank et al., 2005, Turner and Flemming, 2019). In this study, many participants seemed to value palliative care but chose to hold onto cultural worldviews which sought security, dignity, unity and avoided cultural taboos. Interestingly, despite that, our findings illustrated that involving family in the care process increased the acceptability of palliative and end of life care across all groups. These findings were noted by others where the triadic consultations facilitate patients' understanding (Laidsaar-Powell et al., 2017, Laidsaar-Powell et al., 2013) and communicating needs (Koren et al., 2018, Mackie et al., 2018) in the cancer context.

Nevertheless, participants saw familism as a core value, and family involvement as a preference. Both of these intertwined made caring for people near the end of life very challenging. This also accords with earlier oncology observations where family involvement impeded the patient-centredness of care (Alassoud et al., 2020, Laidsaar-Powell et al., 2017). From a realist anthropological perspective, family involvement was conceptualised within participants' socio-cultural milieu. It occurred in an open context where multiple mechanisms can co-generate the reality, and therefore, the complexity of family involvement differed in dimensions and degrees within and between groups. Concerning care decisions, family involvement was driven by families' unrealistic expectations, lack of knowledge, grief, and emotional reactions (Harasym et al., 2020). Our study featured the intergenerational cultural differences as younger generations advocated for patient autonomy. As family involvement varies and may carry some paradoxes, this area warrants further investigation with culturally and ethnically diverse stakeholders and researchers.

In this study, some preferences such as the home as the preferred place for care seemed to be an endpoint-oriented preference, dominated by family and underpinned by their taken-for-granted assumption, with subconscious references, that it was the place of death. The caring culture at home was found to structure the preferences in the form of rules that may be merely an arbitrary perception of some values, given that the traditional one-size caring approach, adopted mainly by caregiver participants, undermines the essence of all moral values. As a result, it would backfire and lead to conflicting preferences. Our study extends the previous research where breaking rules and ignoring values of filial piety was considered taboo, a culturally alienating behaviour that dishonoured family members (Six et al., 2019).

In contrast to a taboo subject, treatment and care choices were seen by others as dynamic and quickly changing preferences that adapted to the patient's context, health status and changing needs. Successful palliative care utilisation and positive experiences are proven to change rules or add new ones as knowledge and assumptions develop and become taken for granted. Perhaps, the credit given to hospices by most user groups, particularly ethnic minorities, as being more specialised in palliation and support is an example of the dynamic nature of these preferences (Baik et al., 2020, Russell et al., 2019). Whereas non-user groups, who had no idea about the palliative care setting, apart from the reported misconceptions /experiences, are expected by others to abide by cultural rules. Patients or caregivers may have had a distressing experience with clinicians if responded to these ideas in a culturally insensitive way, a commonly cited cause of cultural pain and distress, that may negatively affect access to care services, as illustrated in Section 1.3.5 (DeWilde and Burton, 2017). Apart from the constraining values and beliefs, care preferences expand beyond culture to other socioeconomic factors, such as limited health literacy and the financial implication of using a service (Cain et al., 2018).

This study confirmed that communication is always cultural, and effective communication is challenging in cross-cultural clinical encounters. Any failure would undermine the patients' and families' ability to communicate needs and concerns and further increase palliative care disparity. The current work found a considerable variation between and within groups in the nature, content, and composition of communications. It is encouraging to compare to, and corroborate with, the ideas of Cain et al. (2018) and Parker et al. (2007). They suggested the strong influence of cultural paradigms and values that affect all aspects of patients' lives, including preferences for care and communication patterns. As communication preferences also varied, driven by their values and cultures, the lenses participants used to understand heart failure, communicate palliative care needs and make decisions, also varied. These findings further support an understanding of how diverse people communicate rather than to make generalisations (Dittborn et al., 2021).

Curative care orientation brought about a sceptical attitude to any clear-cut communication near the end of life and believed that clinicians should not break bad prognostic news to the hypothetical patient. However, for decisions to be successful and an end of life discussion to be conducted, people must have an accurate prognostic understanding of advanced HF (Hogg and Jenkins, 2012). Meyers and Goodlin (2016) pointed out that compromised prognostications led patients with HF to overestimate their life expectancy and possibly underestimate palliative care. Others reported these unrealistic expectations to cause end-of-life care clash (Agom et al., 2019, Klindtworth et al., 2015). Hence, neither communications regarding withdrawing life support (i.e. Do not Resuscitate) nor end of life conversations on future care will be welcomed. The reported reluctance of clinicians to discuss prognosis with the patient and families seemed to also emanate also from situational constraints (Cheang et al., 2015, Schulz et al., 2017).

Our analysis seems to link these potential clashes with cultural communication, high family involvement, limited English and health literacy, and immigration experience to these conflicts. In opposition, assuming communication preferences based on tangible culture may lead to stereotyping and devolution of power away from the patient. When death is imminent, this was believed to challenge the provision of end of life care, interfering with the principles of palliative and patient-centred care, increasing the utilisation of general cardiology services, and enhancing the prevalent culture that prefers life-prolonging treatments (Hutchinson et al., 2020).

Our data shows that most members of the public did not understand or know ACP, especially older people. Opposing Detering et al. (2010), who found ACP acceptable and feasible in migrant communities, we found the service suboptimal among diverse and vulnerable older adults. One reason for these conflicting results could be the minimal attention paid to the cultural and systemic factors and their potential impact on people's ability to initiate discussions on death, dying and care at the end of life, for example, the exclusion of non-English and non-competent patients. It is evident that socio-cultural considerations pose significant challenges to ACP and its process, whereas it would be more promising if these factors were considered in their socio-cultural context (Ali et al., 2021, Chan et al., 2020, Phenwan et al., 2020). Our findings on the cultural influence on ACP discussion, to a limited extent, agree with Schichtel et al. (2020) but disagree with Harshaw-Ellis (2021). The latter said, “Those from ethnic minority groups often prefer more intensive therapies, die in the hospital, and are less likely to engage in end-of-life planning”. Mistaken, inappropriate and stereotypical use of ill-equipped data aimed at clinicians to be aware of these disparities.

Most respondents’ attitudes and beliefs about care planning were generally negative, associated with hastening death and equated to euthanasia. They remained pessimistic but were willing to continue the focus group session. These findings mirror those found when studying care planning in heart failure and other life-limiting conditions (Ali et al., 2021). Participants’ willingness and readiness for ACP characterises the pre-contemplation and contemplation stages of the ACP process, which can be attributed to using a hypothetical scenario that desensitises the topic. The successful outcome of using decision-making aids match those observed in earlier studies (Metzger et al., 2016, Michael et al., 2015).

Participants were asked to elaborate on perceived barriers to participation to gain more balanced and informative insights. Although groups have similar challenges regarding the goal of care discussions, ACP, these findings highlighted some culturally specific and unique challenges. A significant challenge identified and consistent across cultures was the culturally embedded understanding of heart failure and palliative care in heart failure. It was clear that contextual factors such as limited English, health literacy and high perceived religious literacy affected the stakeholders' willingness to participate. On the other hand, the perceived low control over their situation was seen as a preference for clinicians-centred decision-making, attributed to total trust in doctors and self-mistrust. Culturally, they tended to leave critical decisions to the discretions of consultants and therefore were less likely to participate in ACP. Participants iterated the challenges that terminally ill patients and their families face in accessing services, such as the perceived conflict with the current approach and philosophy of palliative versus curative care.

As palliative care is not valueless, the discussion revealed some incongruities with the participants' values and beliefs (Six et al., 2020). Similar to other studies, our findings highlight death-denying values, mistrust, family-centric decision making and communication disparities near the end of life as crucial barriers to ACP conversations (Agom et al., 2019, Chan et al., 2020, Im et al., 2019, Six et al., 2020). However, Six et al. (2020), Heggestad et al. (2020) and Dewar et al. (2015) affirmed that values, such as dignity, autonomy, quality of life, and preparing and discussing death are the core values in palliative care.

This confirmed the findings from several studies that highlighted that the adopted values in the modern Western palliative care model are not universally shared (Cain et al., 2018, Rahemi and Williams, 2020). Notwithstanding, it is essential to note that ACP studies may offer findings predominantly with a mono ethnocultural context. Despite being settled in the UK, BAME participants are still highly influenced by traditional cultural values that inform their attitudes and perspectives, making it hard to differentiate between culturally informed values and myths and misgivings about specific values. In this regard, our findings are somewhat consistent with. However, given the significance and dearth of research, future studies are required to investigate these underpinning values to ACP among seriously ill patients and their family members.

Finally, the lack of HF understanding is usually explained using the superficial reductionist perspectives by individual related factors such as unfamiliarity with the medical language, limited (health) literacy, or system-related factors, including lack of available information provided about HF syndrome, its cause, and treatment (Bakitas et al., 2020, Dionne-Odom et al., 2020). However, similar explanations in the HF literature are merely simple descriptions that do not consider the context, capture the relationships, and how the two elements, understanding and culture, are attached. For instance, Klindtworth et al. (2015) attempted to understand the need and perceptions of patients with advanced HF at the end of life. Unfortunately, those results show poor HF understanding due to poor knowledge and prognostic communication during clinical interactions. Also, it is unsurprising that participants' false optimism had steered them away from end-of-life care conversations. However, the authors have not addressed the sociocultural constructions of this understanding, including the role of culture and cultural attributes, and the possible underlying action mechanisms that were overlooked.

In this study, considering participants' cultural attributes, which are central to this intersection between palliative care and culture, helped to understand how the context has affected these experiences, informed their understanding, and directed their actions, as introduced in 1.3.6. Consistent with HF and non-HF literature, age, ethnicity, and educational attainment were independent predictors of low health literacy. In simpler terms, patients with HF who were older, belonged to Latino or African American ethnicity, and had primary education or below were more likely to have limited health literacy. Similarly, a positive correlation was observed between health literacy and knowledge by which participants with adequate high health literacy had significantly better HF knowledge on cardiac diet and medication adherence. However, the association between health literacy and gender was contradictory (Cajita et al., 2016, Sentell and Braun, 2012). Limited health literacy reduces patients' ability to comprehend and act on health information, communicate needs to clinicians, and access healthcare services (Magnani et al., 2018, Son and Won, 2020). In addition, low health literacy levels have been found to limit health literacy among patients with HF, creating a barrier to achieving an optimal quality of life and attaining knowledge related to self-care (Namukwaya et al., 2017, Peterson et al., 2011).

It is also important to note the relationship between health literacy and socioeconomic status. Lower health literacy is more common amongst populations with lower socioeconomic status. Considerable evidence suggests an association between socioeconomic status, cardiovascular risk profiles, and outcomes. Patients with higher socioeconomic status tend to have a lower risk and better outcomes (Schultz et al., 2018). For example, Lawson et al. (2020) studied patients' socioeconomic status using the English Index of Multiple Deprivation. They found that the most affluent individuals had slightly fewer comorbidities, while the deprived groups showed an increase in comorbidity and demand for healthcare resources, which remained valid after controlling for the year of diagnosis, ethnicity, and gender. The onset of heart failure was strongly associated with ethnic background, occurring nearly seven years earlier in South Asian and black groups than in their white counterparts. In another population-based study, 15.4% of participants had limited health literacy, which was associated with being older, females, non-white and belonging to deprived groups based on income (Anderson et al., 2021). Levels of acculturation, including being foreign-born, immigration history and non-English mother tongue, were associated with limited health literacy after variable adjustment.

Chapter 7 Overall Discussion

This chapter discusses the findings of the thesis and reflects on ways in which the study could contribute to clinical healthcare practice and research. The chapter starts by revisiting the thesis questions and aims, and showcasing the main findings of this PhD. The following section lays out the strengths and weaknesses of this thesis. This PhD study demonstrated how a straightforward approach could add valuable insights and yield a possible explanation for a complex clinical problem. The final section illustrates how relevant the findings are to clinical practice and future research, drawing on Docherty and Smith (1999) criteria.

7.1 General overview of group discussions

This study used focus group discussions with members of the public to facilitate the exchange of thoughts and ideas, to help to explore shared cultural understandings, and to comment on the cultural impact on understandings of heart failure and palliative care. The choices made for the data collection followed an extensive literature scoping of relevant studies among similar cultural groups, and enabled participants to construct meanings and share understandings based on their personal experience, and to integrate these into their existing knowledge and capabilities. All of the participants were willing to speak openly and honestly, and it was apparent that cultural influence was of genuine interest to them. Participants who regularly attended the study site and who already knew other people taking part might increase this openness and honesty. In addition, the recorded conversations were not the first time that the subject matter was discussed, or the first time that they had met the investigator. The focus groups were positive and went extremely well. All of the participants were friendly, open, and willing to participate in the discussion. Conscious that this was the first time the leading investigator had had to lead a focus group with an outsider, the study team was exceptionally challenged, but the sessions were completed successfully. Having a colleague with extensive experience as a co-facilitator made the discussion more manageable, interesting, and productive.

7.2 Revisiting the research questions and study approach

This PhD aimed to investigate the impact of culture on palliative care services for patients with heart failure from diverse backgrounds by focusing on individual understandings. In addition, the study aimed to identify cultural implications and challenges that need to be considered when developing and implementing interventions to support palliative care in advanced heart failure. In order to address these aims, the following research questions were constructed to guide this research project:

- What is the impact of culture on people's understanding of advanced heart failure?
- What cultural beliefs / attitudes may be involved in how patients construct their understanding of palliative care for heart failure?
- How do patients with heart failure from diverse cultural backgrounds perceive how palliative care is received and delivered?

The first question was addressed by reviewing culture and advanced heart failure literature. Three themes, or impacted domains, were constructed using a hybrid approach, integrative and thematic analysis, and synthesis. The results indicated that culture influences patients and their family members' understanding of heart failure and the related decisions and behaviours. Nevertheless, the implicit influences of the culture on the HF understanding, especially in self-care management, appeared to be more related to the broader view of culture, including age, ethnicity, religion, socio-economic and linguistic factors. Therefore, a cross-tabulation analysis was performed using the PEN-3 cultural model to capture the full range of influences. This process was employed to allocate barriers and enablers, positive and negative influences, to help-seeking behaviour.

In order to answer questions 2 and 3, a qualitative descriptive study was undertaken using focus groups. A total of seven focus groups with members of the public were conducted, four in community centres and three in religious or faith-based organisations. These focus groups explored the understanding of palliative care in heart failure from diverse backgrounds as situated in cultural contexts. Purposive and snowball sampling techniques were employed to enrol 55 participants from diverse backgrounds in Scotland. Data were analysed using Braun and Clarke's method for reflexive thematic analysis. The analysis was carried out within an experiential and contextualist approach to generate data-driven interpretations while acknowledging the 'researchers' active roles, subjective understanding, and the realist ontological position. Whilst considering these, the findings will be presented and discussed in relation to the literature.

7.3 Statement of principal findings

The findings have been discussed in Chapters 3 and 6, and each was organised under three themes addressing the research questions and aims.

7.3.1 A systematic review and mixed methods synthesis

7.3.1.1 What was already known?

Culture influences how people understand health, illness and their choice of treatment. However, healthcare systems do not recognise the intersection of culture with chronic disease and its impact on peoples' understanding. In the HF context, a better understanding of this impact would help overcome this failure and allow culturally appropriate care, particularly during the advanced stages.

7.3.1.2 What did we do, and what did we find?

A mixed-methods systematic review studied the existing empirical literature and critically synthesised data from seven databases and grey literature sources. Of the 194 full-text papers that were screened, only 13 articles were eligible; of which 6 were qualitative studies, five quantitative and 2 were mixed-method studies. Papers were thematically analysed and grouped into domains. Additional analysis using the PEN-3 theoretical framework was undertaken.

7.3.1.3 What did this review add?

The results showed that the influences of culture on the understanding of HF was seen as iterative and ongoing and evident by the three overlapping themes. The themes concerned the cultural impact on lay HF knowledge and beliefs and how central this theme was, culture as the key to understanding how symptoms were perceived and reported and the understanding HF self-care as a product of culture. Cultural norms and values were negatively or positively associated with HF understanding, knowledge and behaviours. In these studies, peoples' cultural beliefs about health and disease inform lay knowledge and understanding of all aspects of heart failure diagnosis and consequently their understanding of, and response to, symptoms and when to seek help. While culture drives HF self-care, inconsistencies between peoples' norms and beliefs and health recommendations restrict the understanding of HF and adherence to certain self-care practices.

People with heart failure and their family members could be helped better by health care practitioners if their cultural values and beliefs were integrated into health care practice and policy. This study provides robust insights into the varying needs of people with heart failure from different cultures and argues that this is essential for developing culturally tailored supportive interventions for all people with advanced heart failure.

7.3.1.4 What is next in research?

The lay understanding of heart failure has received very little attention in the existing literature, and this work highlight gaps in our understanding of the impact of culture that warranted further empirical investigation. Therefore, the findings from the review (Phase 1) were used as a baseline to inform the next steps in the data collection process to empirically assess for needs and analyse the current practice and context.

7.3.2 Qualitative focus groups with patients

7.3.2.1 What did we know at this stage?

Understanding the patients' situational and contextual circumstances is implicit to any application of effective palliative care, including for those with terminal heart failure (HF). However, literature on patients' and their families' experiences often neglects the roles played by socio-cultural structures in constructing this understanding.

7.3.2.2 What did we do?

An exploratory qualitative design underpinned by critical realism was used to explore the understanding of palliative care in heart failure from diverse backgrounds as situated in cultural contexts and practices. The purposively -selected participants were 55 adults (38 men and 17 women) living in diverse cultural communities in Scotland. Group discussions were audio-recorded, transcribed verbatim and analysed using a reflexive thematic analysis.

7.3.2.3 What did we find?

Here, cultural influences are thought of as three distinct but interdependent themes. The constructed themes were: (1) culturally embedded heart failure understanding – participants made sense of HF by fusing their worldviews and experiences; (2) understanding of palliative HF care – context is crucial to unravelling the interpretations and mechanisms of understanding the process of palliative care; (3) preferences for care – these broadly reflect values indicating which choices are influenced but not controlled by the interplay of illness and cultural understandings. In combination, these themes underline the complexities of 'peoples' choices and preferences at the end of life, as contextual responses inform decisions to changing health circumstances and care experiences.

7.3.2.4 Putting all together

The figure below visualises themes in the form of a DNA model. Analogous to the information storage function of DNA, culture has been found to store and transmit HF and palliative care meanings and experiences. Therefore, culture, directly and indirectly, determines how people understand, conceptualise, and behave within a given situation. DNA in a broader sense, as with culture, is dynamic and change on the evolutionary timescale dependent on the interplay of internal and external factors.

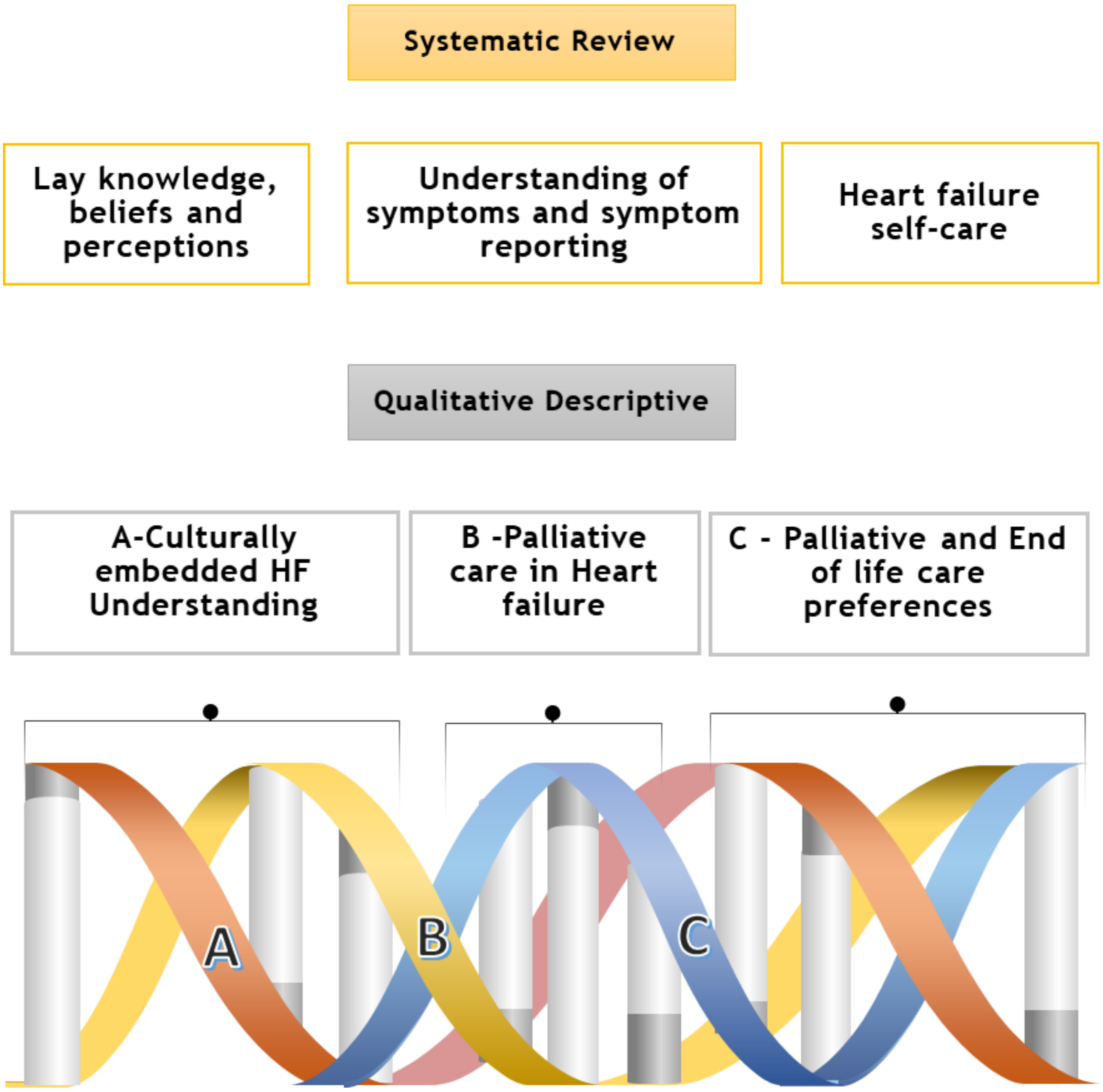

Figure 7.1: Thematic map as a triple-stranded DNA helix

In **conclusion,** people’s culture and experiences underpin their preferences and decisions during palliative HF care; cultural knowledge is critical to understanding behaviours. The uniformity of findings around the culturally embedded understanding of heart failure reveals the importance of creating a common language that transcends cultural interpretations and enhances optimal understanding for people from diverse backgrounds. Understanding cultural beliefs, values and preferences, and effective cross-cultural encounters must become embedded into developing and delivering culturally aware palliative care interventions.

7.4 Strengths and limitation of the study

This study makes an important contribution to the field of cardiology and palliative care. It points to the complex and ambiguous role of culture in shaping peoples' understanding of palliative care in advanced heart failure and as a driver for service utilisation. The novel insights provided into the cultural and contextual understanding of palliative care in heart failure is one of the strengths and originality of this study.

At the outset of this project, Sections Chapter 1&2 captured the complexity surrounding this topic that may explain the scarcity of empirical evidence concerning culture and palliative care in advanced HF. To my knowledge, this is the first empirical study to explore the perception and lay perspectives of hard-to-reach and ethnoculturally diverse samples. Another original factor in this study lies in the inclusion and involvement of the PPI advisors from diverse ethnocultural groups, to represent the patients' and family caregivers' voices and be involved in the research, planning, design and delivery. The participants and PPI advisors stated that they had never previously discussed culture, perception and experiences in such depth. So, the exploration and approach represented here may be regarded as a novel. This thesis also moved beyond the common understanding of culture in relation to religion, ethnic identity or shared racial heritage and demonstrated a broader view of culture as a complex phenomenon with various components. Another distinctive element is that while the findings demonstrate evidence of cultural impact on understanding HF and responding to palliative care referral, it also highlighted grey areas within the same culture, such as intergenerational differences and group heterogeneity that cultural studies usually overlook.

The strengths of the review study (Chapter 2): "Culture and the Understanding of Advanced Heart Failure: A Mixed-Method Systematic Review" included that the study was the first of its kind to address this gap in the literature using broad search terms without applying any limits. The study included published peer-reviewed and unpublished grey literature. In order to unite perspectives using various data extraction, analysis, and synthesis approaches, a mixed-methods synthesis was performed using a hybrid thematic analysis. Combining qualitative and quantitative evidence was also required during the preliminary intervention development phase, particularly in the absence of high-quality evidence to guide the process and better understand patients and families needs. Alongside the strengths, this study had a few limitations; see section 2.5.1 Limitations.

The strengths of the qualitative descriptive study (Chapter 5): “Palliative heart failure care: A focus group study of the cultural impact on understanding and construction of meanings” included the fact that the data were purposively collected from seven diverse backgrounds. This allowed a wide range of experiences, perceptions and perspectives to be presented and investigated by contextualised in their socio-cultural context. In addition, a key strength of this study was the high participation rate of members of the public (55 members) with patients, family caregivers and other members of the public participating.

Further, this study contributes to existing knowledge, particularly by using a vignette approach. The cultural approaches to the scenarios given were paramount in understanding how participants worldviews, past experiences, beliefs and values result in diverse interpretations of meanings and behaviours. In addition, it successfully provoked responses to sensitive topics that participants might otherwise be hesitant to discuss. A novel finding is that the hypothetical patient scenario and narratives about living with heart failure facilitated participants’ meaning-making. Our data thus illustrate how the multi-storylines scenario uncovers specific contexts of cultural practices, meanings and sense-making without being profoundly altered to give socially desirable responses.

An added strength of the study was the use of reflexive thematic analysis, a flexible method that allowed the conceptualisation of the data to evolve and develop constantly and enabled a more comprehensive explanation of this phenomenon. It allowed the researcher to actively engage and interpret the data, leading to an in-depth analysis of the diverse stakeholders’ perspectives. Furthermore, it allowed conceptualising themes as scenarios or stories about shared meaning patterns across the data. That is, themes are not necessarily related to a particular domain, but each shares a meaning pattern. This method has been widely used in similar nursing and healthcare research studies. Using complementary inductive and deductive approaches to reflexive thematic analysis is a novel approach that appears consistent with Braun and Clarke’s most recent reflections (Braun and Clarke, 2019, Braun and Clarke, 2021). However, this particular addition is the process of retroductive theorising. Insights from participants were incorporated with experiential, professional and content knowledge from the research group and relevant literature in a way that has not been previously described.

To maintain the thought flow and relevance of the constructed themes, transcription and translation tasks, when necessary, were assigned to the researcher, the facilitator, himself. All field notes taken by the facilitator and co-facilitators were analysed by the same person, given how informative field note analysis is to the researcher’s coding decisions, knowledge, and understanding (Braun and Clarke, 2006, Braun and Clarke, 2013). The author, is bilingual in Arabic and English with the ability to use Arabic, when necessary, which brought a unique perspective to the data collection and analysis processes. The author has translated the transcript into English and back-translated it to Arabic. Subsequently, a professional translator and a bilingual PPI advisor checked the material for accuracy purposes. Additionally, the author has been formally trained to conduct focus group interviews and was supported by my supervisor, Professor Johnston, who has expertise in focus group facilitation.

A few strengths were associated with the methodological and philosophical positioning, Chapters 4 and 5. This thesis has addressed the gap using the MRC framework as a conceptual guide underpinned by critical realism. The enriched model of the MRC framework development phase complemented well with my critical realist approach. Both emphasised understanding the current practice to know for whom the intervention would be effective and in which situation or circumstances. In addition, they encourage exploring participants' understanding, perspectives, and needs using qualitative methods. The critical realist lens allowed the study to explore what was happening behind each phase in the MRC development process. Apart from transcending methodological boundaries, the stratified ontology enabled an understanding of how an empirical reality can be perceived differently, consciously or otherwise, depending on one's position within the world system, which may have remained hidden using alternative philosophies.

In this respect, the use of the Lilypond metaphor to conceptualise, capture and portray what emerged from the focus group was a unique contribution. This conceptual framework underpinned by depth ontology provides an account of how people perceive, make sense of, and react to reality depending on their interaction and interpretation of experiences, perceptions and preconceptions.

However, our research also had several limitations. Firstly, the study sample consisted of predominantly men, and women were under-represented but not entirely absent from our study. Women, as well as men, were approached about participating in the study. I acknowledge that more female participation could have given more diverse perspectives, given the patriarchal culture still rooted in these societies which often discriminates against women. For example, the work of Daniel et al. (2022) vividly demonstrated how difficult it is for women to share experiences under the influence of these patriarchal cultures. Moreover, women should have been allowed to freely choose between focus groups and individual interviews and the ability to opt in or out at any point during the interview.

Secondly, the recruited participants were public members living or familiar with HF/disease or providing care for someone with heart failure or chronic heart disease with a keen interest and knowledge rather than an actual HF population. However, the non-clinical approach allowed us to recruit a large enough sample to address the research questions. Thirdly, the study reported that Twenty-two members of the public immediately declined to participate. However, it failed to report why they were unwilling to participate. Individuals who declined to participate may have been more interested in the topics, had significantly different understanding and views, or were more familiar with palliative care. Fourth, although this qualitative exploration comprises discussions with seven cultural groups, the findings cannot be generalised to a broader population but are transferable to other settings with similar characteristics as the work does not claim to represent all diverse groups nor is it clear that data saturation was achieved. Instead, discussions were rich in content, powered by meaning saturation and provided insights into the experiences of these groups and how culture drives palliative cardiology care in a contemporary milieu. The concept of “data saturation” is no longer a requirement for qualitative approaches due to being incompatible with reflexive thematic analysis, where coding is context-dependent, and the themes are constructed based on meaningful patterns derived from the interpretative process (Braun and Clarke, 2021, Malterud et al., 2016). Next, specifying the hypothetical patient’s age, as mentioned in Section 4.8.4, suggested comorbidity and frailty as essential factors in critical and treatment decisions. Hence, it would trigger more thoughts and extract additional information during the group discussions. Even though the study utilised a flexible specification of age that ranges between 50-80 years. It is also possible that this may have affected participants' responses or altered their perceptions. It may indicate that I fell into the trap of ageism due to insufficient awareness.

Finally, participants were recruited from the community and religious centres in a single but ethnoculturally diverse city in the UK. Therefore, the findings are difficult to generalise to broader contexts or those receiving institutionalised healthcare services.

Nevertheless, the purposively selected interviewees were stakeholders and key informants of different ethnocultural groups, and they tended to be better informed about the subject under study. It is possible that they possess more abilities and insights into the issues at hand than the hospitalised patients, many of whom might not be able to assist, have the ability, or even have any experience relating to palliative care. Using purposive and snowballing as sampling techniques are not without its limits. It does not allow for a gender-balanced sample to be recruited: the sample was predominantly males participating in this research. Due to the nature of the study, the claim that males were more likely to volunteer to participate than females, or it is related to culture and gender roles, cannot be made. Ideally, a more gender-balanced sample would have been preferred.

Palliative care in heart failure is ever-evolving, and our study did not capture the opinions of the other significant stakeholders. A critical limitation was the lack of inclusion of the perspectives of the service providers. Efforts were made to execute a third study directed at the clinician and service level. The study was designed to include a third Delphi consensus study seen in Appendix VI. However, due to the COVID-19 lockdown, the study was not carried out. Undoubtedly, the perspective of heart failure clinicians is critical to include for a complete understanding of the topic and for revisiting the intervention prototype. In addition, future implementation research in this area warrants the inclusion of the care recipient's perspective, an approach that would require great care, given the unstable, changing nature and new normal conditions of the Covid-19 pandemic

Nevertheless, most of the gaps and issues found in our study have not been adequately addressed. The project met its original objective, but some multifaceted and nuanced meanings draw attention to contextual understandings that reflect differences in values and priorities. At the next stage, the anticipated understanding would form the basis of further analysis and theorising. The result of that process would, in turn, lead to a clearer understanding of successful strategies that nurses can utilise when talking about the end of life in HF.

7.5 Meaning of the study and possible mechanisms

7.5.1 The Lilypond – a metaphor for the stratified understandings

As no respondents reported any palliative care information provided directly by healthcare providers, participants were encultured with their meanings of palliative care. Their knowledge was mainly second-hand experiential and was interpreted contextually. What emerged from the focus groups was a metaphor that accounts for the stratified understanding of palliative heart failure care among participants. These accounts were not fixed but dynamic and continually evolving, mirroring a stratified reality rather than independent and self-governing ones. By fusing the accounts into stratified ontology, this thesis contributes to the knowledge about how culture impacts the understanding and describes the mechanisms of this impact. This conceptual contribution is represented schematically in Figure 7.2 using a lily pond metaphor which also illustrates that each level of it is co-dependent on the other.

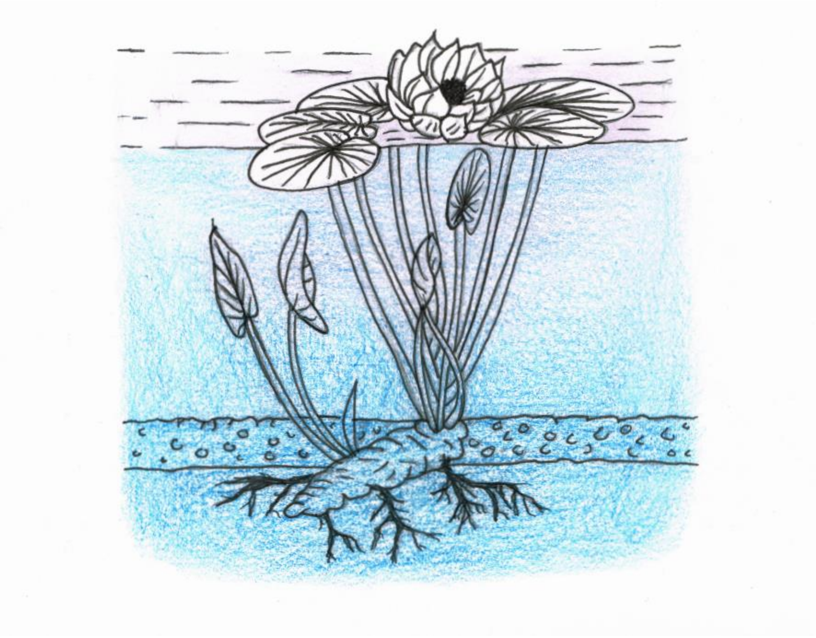

Figure 7.2: Lilypond metaphor for levels of understandings and meanings

The outer layer represents the cultural artefact of spoken words and understanding, or its lack, which equates to the flowers and leaves seen above the water. The pedicel holds the exposed flower in place and connects it to its inflorescence to get the aroma and colour. Nevertheless, how they perform depends on the structure of the inflorescence. However, our results proved that these words and understanding are more artefactual and explicit than the true meaning. The observable misunderstanding and confusion around palliation in heart failure and conflating palliative HF with end-of-life care were merely a lily above the surface. The claims seen in the quote below that changing the term palliative into supportive care might dispel the myths around palliative care confirmed that the current lack of understanding stemmed from and was nourished by the espoused, taken-for-granted, deep-rooted assumptions. The mechanism or the regulator for this process was the values that acted irrespective of participants perception and were often responsible for different outcomes.

> Consultant must be careful, saying the word palliative … it will be taken badly, supportive will be fine … Rather he could say no, we do not have a cure, but we can make his symptoms better.
>
> ***Indian, 70s, Male, Retired Gp***

The habits or the patterns of practice lie within the middle levels; the surface is seen through the water. This dimension represents the true meanings behind the labels, which are group-specific and are hard to communicate and share with outsiders. Certain cultural beliefs and values that influence participants understanding were not observable. However, the impact of these beliefs and values on understanding was visible and was even more visible on the related behavioural patterns. When such patterns are known, healthcare researchers and practitioners will understand the reasons underpinning the negative portrayal of palliative heart failure care. This layer represents the essence of what matters most to participants and their families within this context. This generative mechanism of the lack of understanding was controlled by norms in the form of cultural and familial rules and cultural traditions, preferences and expectations that reflect values. Using realist words, the underlying culture and the interactions within the actual level, drive the empirical or observable facet of reality and trigger the conflated understanding of palliative care and end of life care. For instance, in a particular culture, people tend to avoid analgesics and refuse any degree of mental compromise when death is imminent. They accept pain palliation but not near the end of life; the core tenet in palliative care went against the group's definition of a good death. It is noteworthy that the same participants previously declared having no idea about palliative care.

> *palliative care…hospitals are not properly organised for that. They keep people so much under the influence of drugs, people don't know what's happening.*
> *I've an experience, hospital palliative care was terrible for my mother, she's always drowsy, couldn't speak to her.*
>
> ***INDIAN, 50S, MALE, CAREGIVER***

Participants spoke a great deal about palliative care but did not understand the importance of receiving the correct information from legitimate sources. For example, sharing experiences led to the formulation of shared meanings intended for coping strategies. These experiences, if endorsed, would, therefore, become concrete and unquestionable "root-level" facts. However, this position was deemed liminal, mainly if the experience was negative. In another example, an active caregiver participant who showed a conflating understanding at the beginning of palliative care indicated that it is essential to inform society of the real nature of palliative care in heart failure.Otherwise, what matters most would often be abiding by the cultural traditions of keeping their loved ones alive, and stigmatising the non-medicalised death. The use of a death euphemism (live with it) that implies “to die from it“ here is important not just to characterise the death-denying culture or to communicate what matters most, their goal of care, but also to unearth the prevailing non-interventionist assumption on palliative care.

> *If there is no cure, we will have to [live with it].*
>
> ***Arab, 60s, Male, Patient***

Finally, the deepest level is the hidden roots, which feed the whole lily. This is the level of what is believed good or bad, what is ruled ethical or unethical, and what is assumed natural, normal or not related to palliative care in heart failure. It relates to the generative mechanism and contextual powers that change the actual. The taken-for-for-granted perceptions generate and explain the participants' understandings, decisions, and behaviours regarding palliative HF. For instance, participants who continuously situated palliative care as end-of-life care stated firm beliefs that choosing palliative care would result in a poorer quality of care. This was compounded by the perceived conflict with their cultural and ethical care responsibilities toward older people.

Nevertheless, at the end of the discussion, many participants acknowledged this holistic care as important to support patients with advanced HF and their families. Accessing or accepting care is challenging but more promising if carried out in a culturally considerate manner. In other words, if clinicians, as cited below, can unearth the matrix of relevant cultural milieus and lived experiences – the structures under the water surface – this knowledge and understanding could be used to develop palliative care interventions tailored to (collective or individual) needs.

> *This understanding is there because our experience tells the contrary … if there's a customised care that understand me then I'll let them know of the true facts and options available to care for the patient …*
>
> ***ARAB, 60S, MALE, CAREGIVER***

7.5.2 Philosophical and Methodological outcomes

Methodologically and following these assumptions, this qualitative study intended to understand the underlying mechanism of the cultural impact by primarily focusing on structure-related factors and the subsequent agency-related factors. Participants' narratives and experiences were the prime methods to understand these factors in an open system world. Gaining insight into the subject through focus group discussions provided a window into the cultural power driving their actions and practices. This characteristic of this study is reflected in the idea provided anout the generative mechanism and complex interplay between sociocultural factors, which is at the heart of critical realism.

Even though this thesis did not develop an intervention, it did, however, inform the development of future interventions and studied the subject matter through a unique analytical lens, guided by the MRC framework, the ‘gold standard’ reference for complex intervention development (Craig et al., 2008, Skivington et al., 2021). With the MRC guidance providing little detail on methodological and theoretical aspects, the related decisions were at the discretion of the research team. This thesis was primarily focused on the first stage of the framework to guide the intervention development informed by our findings.

This thesis drew upon a mixed-methods systematic review, an empirical qualitative study, and an expert supervisory team, which forms the main pillars of Evidence-Based Practice. A future intervention based on these pillars would lead to a better outcome, mainly if refined and prioritised by balancing between the ‘optimal’ and the ‘best fit’ and considering the nature of the syndrome, busy practice and context.

7.6 Relevance to clinical practice and future research

This thesis enhanced the understanding of culture and its impact on understanding heart failure and palliative care. It revealed issues related to the suboptimal provision of palliative care in heart failure, which were complex and stemmed from the interplay between peoples' understanding and the influence of context. This complexity, and interplay along with the uniformity of findings around the cultural understanding of heart failure, challenges the current approach to culture in clinical practice and necessitates patient-centred and culturally neutral intervention to enhance the patients' and their caregivers understanding of HF, transcends multiple cultural interpretations, help reduce symptoms and improve their quality of life.

Clinicians and healthcare researchers could take valuable lessons on how to (a) help patients and families from diverse backgrounds to navigate through HF by educating, advocating, and empowering them, (b) elicit and create a shared understanding, (c) get to know the patients and fulfil their best interests, particularly at the end of life, (d) account for cultural values and facilitate making-sense and negotiating meanings with patients and their caregivers, and (e) communicate effectively and strengthen connections and trust with culturally diverse patients with HF. In addition to several areas that warrant further explorations.

7.6.1 Relevance to clinical practice.

Notwithstanding the substantial steps that NHS Scotland has taken to provide high-quality, patient-centred and culturally responsive care to patients with HF and their families, there are areas with the potential for improvement that could deliver higher utilisation of palliative care and better patient outcomes.

The findings suggest that information concerning heart failure and palliative care are being explained on a need-to-know basis, which left key facts unknown and wide open to misinterpretation. For illustration, an apparent sign of relief was noticed upon explaining palliative care as care that does not affect the active management plan for HF and is not equal to comfort measures at the end-of-life. Clinicians, especially nurses, should deviate from this 'intuitive knowing' practice and use the formal terms 'heart failure' and 'palliative care' when informing patients about their diagnosis or care (Higginbotham et al., 2021). Even though using plain language helps patients understand their condition and interact with care providers, oversimplifying terms compromises the actual seriousness and severity of the situation (Chang et al., 2020, Ivynian et al., 2019).

The reported confusion and fear of these terms may persist because it is rooted partially in the curative (cultural) worldviews and the (incorrect) interpretation of most palliative care traditions (Agom et al., 2019, Ryan et al., 2020). Developing strategies and raising awareness about life-limiting illnesses, including heart failure, along with enhancing public education on palliative care, are critical steps toward successful palliative HF care. The shift in public awareness and perceptions is achievable but conditional on eliminating the providers' erroneous palliative care understanding. In untangling the long-standing complexities associated with palliative care as opposite to life-sustaining care, it is imperative to falsify the dichotomy of care and identify important domains for understanding values and responding to the needs of patients and families from diverse backgrounds contexts (Steiner and Kirkpatrick, 2020).

In addition to helping patients and families navigate through HF by educating and advocating for patients, empowering patients and families can be done through eliciting their understanding of the nature of HF and negotiating the benefits of palliative care. Once the patient, the family and the clinician reach a shared understanding of the benefit of palliative care in managing HF symptoms, maximising quality of life and facilitating care conversations, the referral statement is more likely to be accepted. Nurturing a shared HF and palliative care understanding requires the clinicians to know the context and culture in which these understandings are embedded, the experiences that led to them, and the cultural process underpinning them.

Therefore, professionals are urged to understand how they make sense of HF and evaluate palliative care options within their socio-cultural and family contexts (Russell et al., 2019, Steiner and Kirkpatrick, 2020). Sometimes, low uptake of palliative care could result from potential incongruity, mismatch, or even confusion over the cultural frames of reference. Clinicians can help patients minimise their confusion by identifying and negotiating cultural references that facilitate sense-making.

Participants' answers were endowed with many symbolic references underreported in the literature and unaddressed in clinical practice. For illustration, even the core references were, to a great extent, similar across groups; the true meanings, priorities, and outcomes were context-specific. The consciousness of those meanings and symbolism is central to establishing trust and rapport (Baik et al., 2020, Lobchuk and Stymeist, 1999), attending to patients' values and preferences (Callaghan and Fanning, 2018) and engaging in goals of care conversations. In addition, each individual has care experiences that sources exclusive preferences. These introduce implications for healthcare practices to avoid generalisations or unintentional bias, emphasise attentive listening and openness to other cultures, and invite providers' to self-reflect on cross-cultural encounters.

Our findings confirmed that culture provides a clear window into how these embedded understandings direct end-of-life decision-making, priority-setting and preferences. Getting to know the person through routine assessments, listening and spending time with the individual and their family is the path to reaching a shared understanding and fulfilling their best interests, particularly when it comes to the end of life, where the influence of culture becomes even more evident (Andersson et al., 2015). While this philosophy seemed embedded in hospice care settings, it was largely absent in general hospitals for many reasons. While it gives an incredible opportunity to provide holistic care, clinicians are left with less time, more duties and stress to cope with. Clearly, professionals require support in managing the challenges that can arise; it is no more acceptable to overlook the needs of staff working with patients with heart failure than depriving people the culturally appropriate palliative care. However, the data also highlighted explicit divergences and unveiled grey areas within the same culture that cultural studies usually overlook (Tucker Edmonds et al., 2020). For example, keeping/caring for loved ones at home or away from institutional settings during the later HF stages was disputed by participants, who identified themselves as having HF/disease. These discoveries may be explained by the differences in HF understandings or experience but could also be due to valid discordant care preferences and perspectives. This was evidenced when older patients tended to prefer comfort-based care, while family members were more focused on life-prolonging treatments. Notwithstanding the popularity of these discordances (George et al., 2019), palliative care clinicians must ask for any perceived disagreements as the presence of such discordances may leave the patients hesitant to participate in defining priorities or may leave family members unaware of what matters the most to the patient, which may prevent them from engaging in conversations about palliative care. Therefore, strategies need to be developed to enhance the skills and techniques of the discussion, including during nursing and medical training and mentoring. Also, families should be targeted with behavioural change communication counselling to develop a positive attitude towards end of life discussions.

Our findings provide insights into the impact of underlying values on the continuum of communication styles, care preferences and, therefore, on discussing the end-of-life care plans. Hence, clinicians also need to know their own communication preferences and be aware of the others' to provide health messages appropriately, avoid potential mismatches and nurture mutual understandings. In a diverse and multicultural setting, nurses and doctors can attend to different communication needs and preferences by gently inquiring about how the person would prefer to be approached and by who and to what extent they wished they and their families were informed about their condition to achieve practical but sensitive communication.

Nurturing mutual understanding depends on cross-cultural communication skills, which, If deployed effectively, can strengthen connections and trust enable clinicians to understand patients' needs and preferences. Therefore, helping patients to make decisions that align with personal and cultural values (Donlan et al., 2020, Dzau et al., 2017). Clinicians need to be aware of cultural context meanings and try to uncover them by applying humble cross-cultural communication. This can be best underpinned by adaptive, persistent and process-oriented care communication philosophies (Barnes et al., 2020). Of these approaches, cultural humility would help understand the cultural fluidity, elicit true meanings, address dynamic preferences and needs, identify perceived power gaps and promote the provision of shared authority and decisions.

Such interventions would boost access to palliative services, including engagement in complex conversations, for example, advance care planning and death discussions. Elaborative patient-centred forms of dialogue, such as motivational interviews or asking what patient's mean by a term, offer a context in which patients may feel understood, valued and able to share their thoughts. Hence, it facilitates an in-depth understanding of the symbolic meanings and cultural rules of behaviour relating to care delivery and utilisation of palliative care (Wittenberg et al., 2015).

Such a method could be helpful to minimise fears and reluctance of clinicians, cardiologists, in particular, to address the holistic needs of patients and initiate future care conversations. Failure to do so may result in more confusion, unmet needs and missed opportunities to receive appropriate palliative care treatments to tackle HF progression.

7.6.2 Relevance to future research

This PhD thesis invites several opportunities for future research. Firstly, regarding the mixed methods review presented in Chapter 3. It remains unclear to what degree cultural beliefs concerning HF symptoms determine the patient self-care engagement. In parallel, understanding HF symptoms, in particular how symptoms cluster cross-culturally, is not yet well understood.

Secondly, chapter 3 also highlighted that while culture and related concepts have been widely explored, little empirical work has been done on HF and the individuals' understanding of the quality of life and their experiences and its relationship with individuals' goal of care from different lay perspectives situated in cultural contexts. The need for further investigation has been partially highlighted stressed by Quinn et al. (2020).

Thirdly, as mentioned in chapters 2 and 6, participants used several explanatory models to construct heart failure knowledge. Again, the dissimilarity between the lay and the biomedical models is considered problematic and resulted in diverse symptoms understanding and treatment orientations. However, explanatory models were found potent mediators of patient understanding, decisions, and help-seeking behaviours, yet to date, they have received little attention in the heart failure literature than may have been warranted.

Fourthly, as discussed in chapters 2 and 6, the primary and secondary characteristics of culture determine how preference aligns or varies within the dominant culture. Similar cultural characteristics or defining attributes were more likely to produce similar meanings and priorities. Hence, they can be beneficial in many ways, for example, engagement in conversations at the end of life care.

Chapter 6 also emphasises accounting for patient culture to complement the patient-centred palliative care cardiology. Nevertheless, we remain convinced that healthcare systems, including the professionals, have their own cultures that direct their practice. A better understanding of the ‘other side of the coin’ is required to promote the feasibility of any future intervention. This is a crucial observation given that several interventions have been compromised due to their unfeasibility or incompatibility.

Finally, the findings provide insight that supports the development of theory-based, culturally neutral interventions aiming to improve palliative care in heart failure. The current thesis forms the basis for the intervention above, and the author is currently looking for a post-doctoral opportunity to explore and seek the clinicians’ views on the importance, acceptability and feasibility of the intervention.

7.6.3 Future work - Proposal

Overview

Culture has become an integral dimension of the effective development of complex interventions (Jirwe et al., 2009). Despite the growing palliative care movement in heart failure, the existing evidence and guidelines are still limited and lack a binding, cultural domain. (Ahluwalia et al., 2018). To date, there is a dearth of empirical evidence to address this domain, with no consensus made on its definition or component and the efficacy and feasibility of these models (Ahluwalia et al., 2018, Alizadeh and Chavan, 2016, Handtke et al., 2019).

A re-think of a new initiative to facilitate clinical encounters for clinicians and patients should be warranted. The challenge is big to establish effective communication when there is no shared language, particularly in the light of evidence to support the relatively ineffective use of interpreters (Gerrish et al., 2004, Hamilton and Essat, 2008, Kaihlanen et al., 2019) and stereotypical investable assumptions when studying specific cultures (Kai et al., 2007). Collectively, the above issues identify the need for a new language to provide a “quick fix” solution to assist the patients and clinicians in communicating about beliefs, values and preferences and subsequently enable person-centred care. Hence, it might have the potential to reduce cultural distress including alleviating symptoms of stress, promoting recovery, minimising health care utilisation, and restoring the power arising in clinical encounters (DeWilde and Burton, 2017).

This proposal will firstly propose a professional endorsement of the prototype of palliative care interventions. Secondly, upon agreement on content, philosophy and delivery, it will present how ‘‘The Heart Failure Common Language’’ can be used to enhance the patients’ understanding of heart failure and, therefore, improve communicating needs, beliefs, and preferences and subsequently enable person-centred care.

Aims

- To explore and seek the clinicians’ views on the importance, acceptability and feasibility of a theoretically based, culturally appropriate intervention to support the palliative care provision for people living with advanced heart failure in Scotland.
- Conduct a feasibility study to determine the feasibility and acceptability of intervention transcending multiple cultural interpretations to enhance the patients’ HF understanding and their caregivers, and help reduce symptoms and improve their quality of life.

A feasibility study of a new intervention will deploy a mixed-methods approach that utilises a nested process for data collection, an online Delphi, a cohort of a multi-centre prospective study, and an economic evaluation. The study will be conducted at various sites across the NHS Health Boards in Scotland. Those sites that agree to participate in the trial will be asked to become ambassadors for the programme if it is decided to roll out the programme across the whole of Scottish NHS boards following the assessment of the trial. I will use a bespoke hybrid model that combines purposive and convenience sampling, ensuring that all those who provide medical care to the participating patients are included. The principle behind this approach is to capture the perspectives of all those involved in providing HF care and support.

7.7 Conclusion

The cultural domain is central to patient-centred holistic care and is complementary to providing safe and high-quality care for diverse patient groups and their families. This PhD project studied the impact of culture on understanding heart failure and palliative care. The aim was to inform the development of an evidence-based, culturally appropriate, helpful intervention for clinical practice. A qualitative descriptive approach was utilised. A systematic review incorporating quantitative and qualitative data was conducted first. Then, a qualitative descriptive study where focus group discussions were utilised was carried out second. It was apparent that there is much complexity surrounding the impact of culture on the understanding of advanced heart failure and, therefore, heart failure-related decisions and behaviours. Particularly among non-Western patients, culture is crucial to understanding heart failure and its management. Our findings highlight that culture provides a clear window into what people understand by palliative care in heart failure and how these understandings direct decisions and behaviours. Culture and it's embedded understanding, shaped peoples' needs and responses to terminal heart failure at the end of life. Hence, it forms a part of their means of deciding on palliative care preference. The underlying culture sets the scene for how and where these needs are considered and met in a way that is consistent with their values and beliefs.

Participants needing palliation as well as palliative provisions were challenged by many uncertainties. The focus group approach allowed us to explore and compare cultural influences on understanding, using hypothetical scenarios, within and between groups, and to discuss various critical times in both HF and cultural trajectories until the point of death. Such uncertainties necessitate early discussion about end-of-life preferences and the completion of future care planning. The interplay between preserving the 'patients' right to express actual preferences and meeting them, tending to family needs, and assessing any discordances in preferences, considering the cultural approach to care decisions, priority setting and appropriate interventions and outcome evaluation in palliative care together with the recognition of other contextual factors, represent the complexity of identifying palliative care preferences for patients from diverse backgrounds, given the chronic lack of HF understanding.

To allow people from diverse backgrounds to access palliative care, we propose that a language to talk about HF needs to be developed that does not rely on multiple cultural interpretations. The cultural embeddedness of peoples' understanding of heart failure confirmed the importance of creating a common language that transcends cultural interpretations and enhances optimal understanding for people from diverse backgrounds.

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Appendices

Appendix I - Supporting definitions and terms

Kroeber's and Kluckholn's definition as cited by (Adler, 1997)

> '*Culture consists of patterns, explicit and implicit, of and for behaviour acquired and transmitted by symbols, constituting the distinctive achievements of human groups, including their embodiment in artefacts; the essential core of culture consists of traditional (i.e. historically derived and selected) ideas and especially their attached values; culture systems may, on the one hand, be considered as products of action, on the other, as conditional elements of future action.*' cited by (Adler, 1997)

The definition introduced by Edward Burnett Tylor and adopted UNESCO in 2001, cited by Avruch (1998)

> '*Culture ... is that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society.*' cited by Avruch (1998)

The definition by Napier et al., 2014 in Lancet Commission on Culture and Health.

> "The shared, overt and covert understandings that constitute conventions and practices, and the ideas, symbols, and concrete artefacts that sustain conventions and practices, and make them meaningful." (Napier et al., 2014)

The definition of culture by Helman, 2007 in Culture, health and illness.

> Culture is … a set of guidelines (both explicit and implicit) … that an individual inherits as a member of a particular society and that tell them how to view the world and learn how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces and gods and to the natural environment. It also provides them with a way of transmitting these guidelines to the next generation – by using symbols, language, art and ritual. To some extent, culture can be seen as an inherited 'lens' through which the individual perceives and understands the world that he inhabits and learns how to live within it. By Helman (2007)

Appendix II - Supplemental Information for the review

A. The published Mixed-method Systematic review.

Collegian 27 (2020) 459–470

Contents lists available at ScienceDirect

Collegian

journal homepage: www.elsevier.com/locate/coll

Culture and the understanding of advanced heart failure: A mixed-methods systematic review

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ARTICLE INFO

Article history:
Received 31 May 2019
Received in revised form 14 February 2020
Accepted 21 February 2020

Keywords:
Culture
Heart Failure
Comprehension
PEN-3 Cultural Model

ABSTRACT

Background: Cultural values and beliefs influence understanding of health and illness, but we do not know their impact on patients' understanding of advanced heart failure.
Aims: We explore how culture influences the understanding of advanced heart failure for patients and their family members, and how culture influences the adoption of healthy behaviours.
Method/Data Sources: In this mixed-methods systematic review, we systematically searched MEDLINE, EMBASE, CINAHL, Scopus, Web of Science, PsycINFO, and Cochrane CENTRAL with no time limits using relevant MESH terms and keywords. Papers were themed, synthesised, and grouped into domains. The theoretical framewok PEN-3 was used to underpin the findings.
Findings: We screened the full-text of 194 studies and found 13 articles eligible; of which six were qualitative studies, five quantitative and two were mixed-method studies. In these studies, patients' understanding of, and response to, symptoms were strongly linked to cultural beliefs. Patients from Eastern and Middle Eastern countries somatised symptoms more than those from Western cultures. Patients from Western cultures reported higher symptom distress scores. Peoples' cultural beliefs about health and disease inform lay knowledge of heart failure diagnosis, causes, treatment and self-management and influence their healthcare decisions and behaviours.
Conclusion: We found that health care practice and research in heart failure has not previously been influenced by culture. People with heart failure and their family members could be helped better by health care practitioners if their cultural values and beliefs were integrated into health care practice and policy. We argue that this is essential for the successful development of culturally competent care interventions for all people with advanced heart failure.

Summary of Relevance
Problem or Issue
The impact of culture on chronic disease and disease understanding is poorly understood, particularly for heart failure.
What is Already Known
Healthcare systems do not recognise the intersection of culture with chronic disease and its impact on peoples' understanding of chronic diseases. A better understanding of the impact of diverse cultural health beliefs would overcome this failure and allow provision of culturally competent care.
What this Paper Adds
This study provides robust insights to the varying needs of people with heart failure from different cultures and will help with development of culturally tailored supportive interventions.

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https://doi.org/10.1016/j.colegn.2020.02.008

1. Background

Heart failure affects 1–2% of the population (Piotr et al., 2014), with over 26 million patients affected, globally (Bui et al., 2011; Piotr et al., 2014). The prevalence increases steadily up to 10-13% with advancing age (Conrad et al., 2018). In the UK, 1-2% of National Health Service (NHS) expenditure is spent on heart failure management (Cowie, 2017); and 60–70% of this on patient hospitalisation costs.

Around 10% of people with heart failure will progress to advanced/end-stage heart failure (Deng et al., 2002; Fang et al., 2015; Xanthakis et al., 2016). Advanced heart failure is defined as 'a primary diagnosis of chronic heart failure under optimal therapy with persistent symptoms or NYHA Class III-IV symptoms with frequent hospitalisation during the previous 12 months (Abouezzeddine & Redfield, 2011). Patients reaching this stage often have burdensome refractory symptoms and poorer quality of life, which necessitates a collaboration between cardiology and palliative care (Sobanski et al., 2019). Palliative care (IAHPC, 2018) benefits patients with advanced heart failure (Conrad et al., 2018; Crespo-Leiro et al., 2018; Jaarsma et al., 2009) by relieving suffering and enhancing the quality of life for both patients and their families (McIlvennan & Allen, 2016). Increased mobility of global populations has created its own Western and Eastern cross-cultural challenges, particularly when attempting to provide culturally appropriate health and palliative care services for multi-ethnic minority groups within mainstream Western health systems.

Culture is known to affect people's health and health-related outcomes (Kagawa-Singer, 2011; Kwabi-Addo, 2017; Suurmond et al., 2015), but little is known about the influence of culture on chronic disease and disease understanding. Research is needed into how the understanding of advanced heart failure affects patients' and family members' heart failure beliefs, treatment preferences, expectations about disease and help-seeking behaviours at crucial points during the treatment process for heart failure. This research is vital for the development of culturally competent interventions to improve healthcare provision.

1.1. Aims

The purpose of this review is to explore how culture influences the understanding of advanced heart failure for patients and their family members, and how culture influences the adoption of healthy behaviours.

2. Methods

A mixed-methods systematic review design was used, incorporating a combination of approaches for data extraction, analysis, and synthesis. This approach was deemed a suitable method due to the heterogeneity of the primary research on culture and heart failure. The review was conducted in accordance with the PRISMA checklist (Liberati et al., 2009). The protocol was registered and published on PROSPERO (CRD42018084612).

2.1. Search strategy and study selection

The review question was developed using an adapted tool from the PICO (Cooke et al., 2012) and SPICE (Booth, 2006) frameworks. To ensure rigorous search strings, a combination of text words and medical subheadings were used, where applicable, for each search string. Following the recommendations of Brunton, Stansfield, Caird, and Thomas (2017), four search strings were iteratively tailored and refined in the aid of the adapted tool to address the review question (Appendix 1). Due to scarcity of evidence on the role of culture in shaping different understanding of disease, we piloted our search using broad search terms on MEDLINE though OVID. Thereafter, the established syntax was extended to EMBASE, CENTRAL, CINAHL, PsycINFO, WOS and Scopus in January 2018 with no date restrictions (Fig. 1).

2.2. Eligibility

All published and unpublished qualitative, quantitative and mixed-method studies that focused on at least one of the outcomes of interest were eligible for inclusion. Studies using primary or secondary data were eligible, as long as they provided more information or reported different results.

Studies published in English that identified participants to be adults (>18 years) with either advanced heart failure, or family members of someone with advanced heart failure, or health professionals who have provided care for someone with advanced heart failure were included.

2.3. Theoretical framework

Health or illness is culture-specific, and culture is a critical determinant of human health outcomes and shapes health behaviours. The PEN-3 model situates culture at the forefront of health determinants and healthcare interventions (Airhihenbuwa, 1990, 1995, 2007; Airhihenbuwa & Webster, 2004). Fig. 2 presents the three interconnected interrelated PEN-3 domains of inquiry. Each domain has three subcomponents assembled to form the three PEN acronyms and are assumed to represent the overall impact of culture on that domain.

We used two components of PEN-3 Model; the Relationships & Expectations and Cultural Empowerment domains of the model (Fig. 2) to guide our search strategy and data synthesis (Fig. 3).Themes were constructed solely based on the extracted data without reference to the PEN-3 model constructs. The two constructs were used as a guide to identify and assess all forms of cultural impacts in each study. The cultural impact themes were further evaluated using the concepts of perceptions (beliefs and values); enabler (factors barrier or hinder change) and nurturers (the role of social support) in the relationships and expectations domain. Then, we categorised the data under the constructs that reflect the form of impact (positive, existential or negative).

2.4. Data extraction

We developed our own data extraction form to best match the review aims in accordance with robust systematic review guidance (Higgins, 2011). The form was piloted for feasibility by the two authors, (BA) and (BJ). Data extraction was carried out by (BA) and confirmed subsequently by two reviewers (BJ) and (KH). The data extraction was conducted in two stages. First, we extracted data on study authors and year, methodology, methods of data collection, sampling method, sample characteristics, heart failure severity and the methodological quality score (Table 1). Second, population focus and data related to the cultural impact were subsequently summarised (Table 2). The use of assessment properties of PEN-3 model resulted in the cultural findings being framed and organised to centralise culture at the core of intervention development (Fig. 3). Table 3 set out the findings of additional analysis we have undertaken by cross-tabulate themes with component and subcomponent of the PEN-3 model.

2.5. Quality assessment

This literature synthesis included quantitative, qualitative, and mixed-methods research papers; we used one quality assessment tool to fit all study typologies. To ensure consistency we adopted

Table 1
Selected articles,

Article no,	Author (date); Country	Methodology	Data collection Methods	Sampling	Sample No, (Male/Female)	NHYA class	MMAT
1	Artinian et al, (2002); USA	Descriptive correlational	Investigator-designed questionnaire for sociodemographic data, a 4-points self-rated NYHA scale for severity and a 5-points self-perceived health scale, plus a 15-item heart failure knowledge test,	Non-probability (Quota)	123 Pts (89/32), gender was not reported in 2 cases,	The total means 2,57 ± 1,25 equal to class III,	Moderate
2	Barg et al, (2017); USA	Grounded theory	Open-ended, semi structured phone interviews with a sample from a previous study, Process not adequately described, Modified grounded theory analysis was employed,	Purposive	39 Pts (32/7) 42 CGs (9/33)	III & IV; 100%	Moderate
3	Dickson et al, (2013); USA	Mixed-Methods	Concurrent nested design employed using semi-structured guided interviews, standardised instrument and self-report surveys for sociodemographic data, Qualitative gives weight than quantitative data; both data collected simultaneously,	Purposive	30 Pts(18/12)	III; 67%	Moderate
4	Etemadifar, Bahrami, Shahriari, and Farsani (2015); Iran	descriptive, exploratory qualitative	Semi structure interviews were utilised and conducted according to patients' preferences, Field notes documented based on researchers' observations, Study adopted an inductive approach and data collection continued until full saturation, when no new threads emerged,	Purposive	21 CGs(5/16)	NS	Moderate
5	Jiang et al, (2013); Taiwan	Phenomenological	Semi-structured in-depth interviews conducted by the in a cardiac ward post-discharge, CGs interviewed when possible; however, in the case of disagreement patients' words preferred,	Purposive	12 Pts (8/4)	NS[a] (frequent rehospitalisation and Pts on fluid restrictions)	Low
6	Lip et al, (2004); UK	Cross-sectional	Questionnaire-based interviews conducted after initial pilot, Three researchers interviewed patients in English, Urdu, Punjabi and Hindi, Interviews conducted in standardised way, as far as possible,	Consecutive	103 Pts (66/37)	III &IV; 62,2%	Moderate
7	Mau et al, (2017); Hawaii	Randomised controlled trial	Three health behaviour questionnaires used at baseline and after 12-month follow-up; 23-item Kansas City Cardiomyopathy Questionnaire, 10-item Centre for Epidemiological Studies of Depression Scale; 12-item Health Survey,	Randomised	150 Pts (103/47)	III; 11%, IV; 48%	High
8	McCarthy et al, (2015); USA	Mixed-methods	Sequential transformative design study, Quantitative part collected first using Self Care Heart Failure Index, Duke Activity Status Index, Patient Health Questionnaire and standardised survey to estimate heart failure severity, Data collected qualitatively through open-ended, semi-structured interviews,	Convenience Secondary analysis of Dickson et al, (2013)	30 Pts(18/12)	III; 65%	Moderate
9	Moser et al, (2014); USA, China, Taiwan, Netherlands, and Sweden	Observational	Interviews for sociodemographic data, clinical data collected from medical records; symptoms identified using Minnesota Living with Heart Failure Questionnaire,	Purposive	720 Pts (455/265)	III &IV; 69,9%	Moderate
10	Namukwaya et al, (2017); Uganda	Constructivist grounded theory	Serial qualitative in-depth interviews, three times at 3 month intervals; interview consists of 9 open-ended questions with multiple prompts,[b]	Purposive	21 Pts (6/13)	III &IV; 100%	Moderate

Table 1 (*Continued*)

Article no.	Author (date); Country	Methodology	Data collection Methods	Sampling	Sample No. (Male/Female)	NHYA class	MMAT
11	Park and Johantgen (2017); USA vs. China and Taiwan	Cross-sectional, observational	All participants who have completed all symptom inventories in terms of symptom reporting and clusters were included in the study.[c]	Secondary analysis of Moser et al. (2014).	480 Pts (308/172)	III; 48.5% IV; 23.5%	Moderate
12	Pattenden et al. (2007); UK	Phenomenological Qualitative study	Semi-structured interviews were conducted in patients' homes by a qualified, bi-lingual researcher. 60% were interviewed with CGs. Patients and CGs had separate sets of questions. Interview notes were taken by the same researcher during and after each interview. An interpreter attended one interview.	Purposive	36 Pts (23/13) 20 CGs (2/18)	III; 36% IV; 22%	High
13	Rong et al. (2017); China	Descriptive qualitative	Semi structured interviews were conducted for 30–60 minutes until full saturation. All sessions took place in an accessible room in the cardiac ward.	Purposive	15 Pts (9/6)	III; 40% IV; 20%	Moderate

CG; Caregivers; MMAT; Mixed Methods Appraisal Tool; NS; Not Stated; NYHA; New York Heart Association; Pts; patients.

[a] Fluid restrictions are only recommended for patients with severe heart failure (European Society of Cardiology, 2012).

[b] These questions were used in a larger study which also aimed at understanding patients' beliefs about heart failure and its treatment.

[c] A ready data set was provided by the first and corresponding author Dr. Debra Moser. For more details, see Moser et al. (2014) above.

Table 2

Data extraction summary of the cultural impact outcomes.

Author (date)/ Country	Population Focus	The impact of culture on
Artinian et al. (2002)/ USA	African American communities	Culture and related sociodemographic factors inform patients' lay heart failure self-care knowledge of and adherence to.
Barg et al. (2017)/ USA	LVAD-DT community (European, Native and African American)	This cultural appreciation of the use of technology in healthcare affects patients' perceived control over treatment preferences and decisions
Dickson et al. (2013)/ USA	African American community	The culture endorses supernatural assumptions as a cause of heart failure, which limit the perceived control over health and motivation toward healthy self-care practices.
Etemadifar et al. (2015)/ Iran	Persian CGs community	Carers lack clear understanding of heart failure and rely on lay cultural beliefs. They believe in religion and culture as the main source of knowledge due to perceived role ambiguity.
Jiang et al. (2013)/ Taiwan	Older Chinese/ Taiwanese community	Patients were bound to cultural beliefs on food, medicinal products, exercise intolerance and the importance of family more than the health recommendations provided. Also, culture implies barriers to asking or interacting with clinicians.
Lip et al. (2004)/ UK	Multi-ethnic, multicultural communities including white European, Indo-Asian and Afro-Caribbean.	Ethnic, cultural and religious beliefs are guiding patient perception of heart failure and its treatments. This result in the majority of patients lack clear understanding of disease including symptoms, perceived control over patients' condition and adherence to treatment.
Mau et al. (2017)/ Hawaii	NHOPI communities	The health education programme has positive outcomes on the understanding of heart failure, morbidity and mortality when it is consistent with cultural beliefs and provided by trained staff in a sensitive fashion.
McCarthy et al. (2015)/ USA	African American community	Exercise was defined based on patients' cultural context, which led the majority of patient to refuse taking part in cardiac rehabilitation programmes, particularly among those living in low socioeconomic levels.
Moser et al. (2014)/ USA, China, Taiwan, Netherlands, and Sweden	Western (US & Europe) vs. Eastern communities	Understanding symptom, symptom experience, reporting and clustering were consistent across different cultures.
Namukwaya et al. (2017)/ Uganda	Kampala Communities	Cultural context is informing health beliefs, decisions and behaviours.
Park and Johantgen (2017)/ USA vs. China & Taiwan	Western vs. Eastern communities	Eastern patients have the same order of the distress code of the symptoms. However, they have delayed symptom reporting, less ability to recognise the change in psychological symptoms and underestimated severity of disease compared to patients from western backgrounds.
Pattenden et al. (2007)/ UK	South Asians living in western (Scottish & Irish) communities.	Culture is responsible for the formation of most of health beliefs and behaviours. This role also applies for people who have immigrate from eastern to western cultures.
Rong et al. (2016)/ China	Older Chinese communities	Chinese patients are unable to adhere to dietary and fluid restrictions due to their contradiction with innate cultural beliefs and religion. Culturally influenced beliefs should not be ignored particularly among older generations living in low economic levels.

Abbreviations- CG; Caregivers; LVAD-DT; Left Ventricular Assisted Device-Destination Therapy; NHOPI; Native Hawaiian and Other Pacific Islanders.

the Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2009), for use with the most common types of empirical studies. One of the reviewers (BA) evaluated the 13 included studies independently. Both other authors (BJ) and (KH) reviewed and assessed each paper for quality assurance. All studies were ranked according to the achieved score and number of criteria fulfilled. Studies were classified into low, moderate and high quality based on the MMAT criteria, along with the quality of reporting and reviewers' critiques

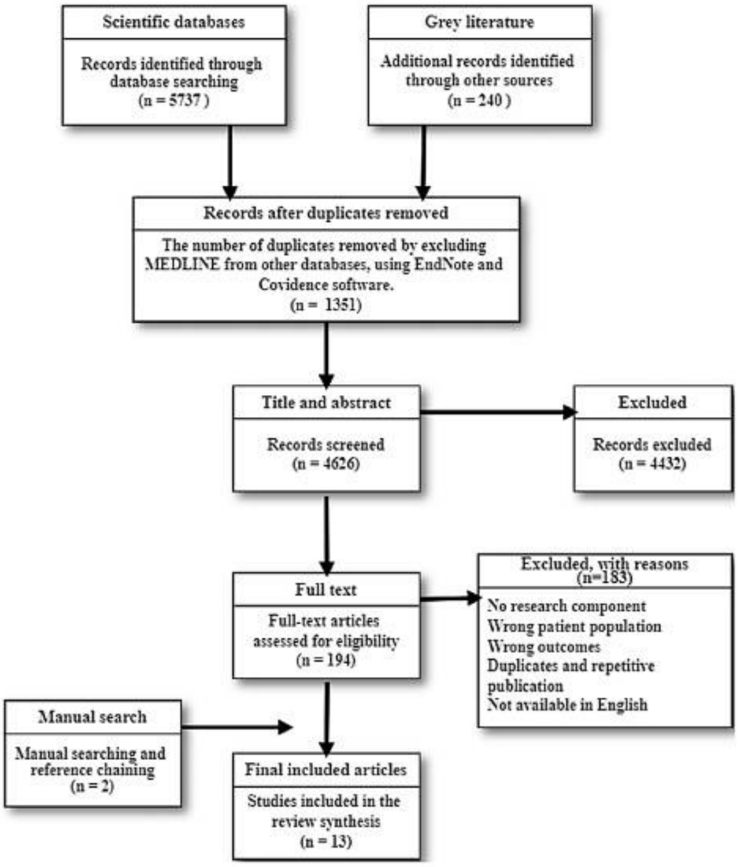

Fig. 1. XXX.

based on results. Quality level is presented in Table 1. These scores informed the data synthesis process.

2.6. Synthesis of results

The hybrid design to synthesise results (Sandelowski et al., 2006; Whittemore & Knafl, 2005) allowed the grouping of data into findings by domain rather than by different research methodologies (Sandelowski et al. 2006) as shown in (Fig. 3). Descriptive thematic analysis was utilised for qualitative and quantitative data. We analysed data then synthesised findings according to the five stages of the integrative synthesis proposed by Whittemore and Knafl (2005). Line-by-line data coding and grouping were conducted according to the domain. These codes were evaluated and compared within each domain. Qualitative and quantitative data were combined using the integrated design synthesis of mixed-methods synthesis (Sandelowski et al., 2006). The integrated design was appropriate as it allowed synthesising and assimilating quantitative and qualitative data together to explore the type, size, consistency of the cultural impact. Data comparison, by coding and summarising data related to aspects of influenced domain on understanding of advanced heart failure. Data was also compared within similar data sets. The conclusion and verification stage involved classifying themes according to their relationships with the understanding of heart failure. All authors have independently analysed data and then verified collectively. Three themes were constructed independently of the model constructs and solely by scrutinising the information from the primary resources constructed themes were then mapped onto the model.

Using the PEN-3 model we examined the cultural values and beliefs held by participants and that affected their their understanding of heart failure, ranging from positive to negative (Table 3). This acheived the first aim. The other two subconstructs were employed to achieve the second aim. Themes were cross checked with the included studies by the review team to ensure the coherence and consistency on the issues related to the cultural impact across the analysis phase to enhance credibility and reliability of the review findings.

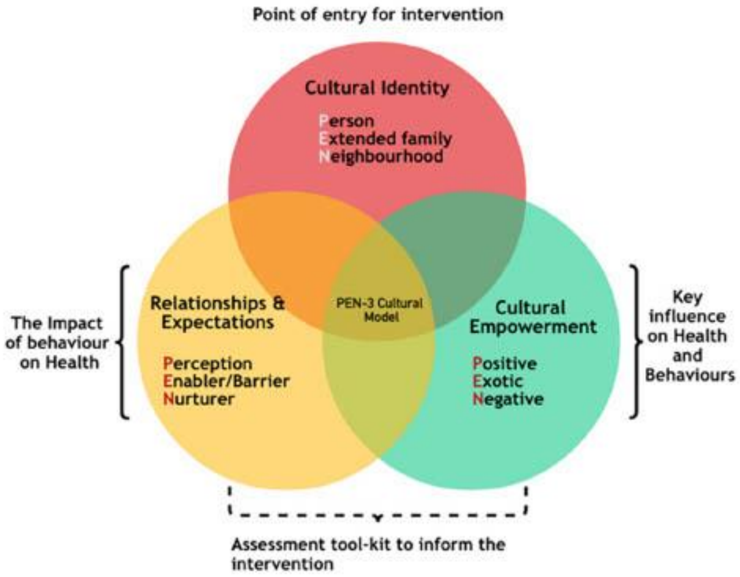

Fig. 2. XXX.

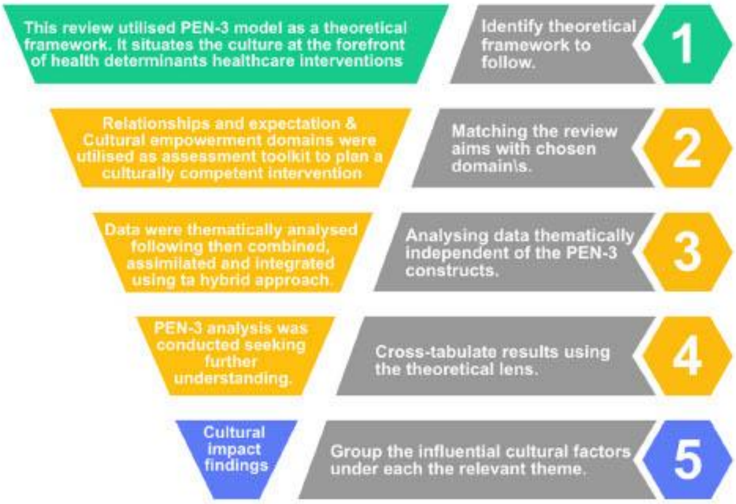

Fig. 3. XXX.

3. Results

3.1. Study selection

The scientific and grey database searches retrieved 5,977 citations; titles and abstracts were screened using Covidence systematic review software (www.covidence.org). To avoid selection bias, BA, BJ and KH independently reviewed these articles. While 11 articles fully met the inclusion criteria for our study, an additional two papers were identified through citation chaining and electronic hand searching of the European Journal of Cardiovascular Nursing and European Journal of Heart Failure from January 2015 to March 2018. The screening process is illustrated in Fig. 1.

3.2. Study characteristics

Thirteen articles published between 2002 and 2017 were reviewed. Table 1 reports these numbered articles. Six studies were

Table 3
Modified PEN-3 Model crosstabulation analysis,

2nd domain (Relationships &expectations)	Theme	3rd Domain		(cultural empowerment)
		Positive	Existential	Negative
Perceptions (Cultural values and beliefs held by people about their heart failure affecting the Knowledge and understanding of it),	The understanding of symptoms, reporting and clustering,	Physical symptoms are top priority, Symptoms when developed quickly and intensely should be reported as it reflects heart failure exacerbation,	The ranking orders of physical symptoms,	- Eastern patients had significantly lower perceived severity of disease and sensitivity to psychological symptoms, - Subjective understanding of symptoms and its severity, - The reported symptoms need to be confirmed and consistent with being severe as defined by the community,
	Lay heart failure knowledge and beliefs,	Common understanding was relatively uniformed within each culture	lack of knowledge	- Cultural non-biomedical understanding of heart failure definition, its causes and treatment, - Poor health literacy, - Experience-based knowledge including self-care, - Misconceptions about heart failure and new treatments, - The perception of supernatural power in developing diseases, low perceived control over their condition and the perceived superiority of traditional healers, food and medicine, - Role ambiguity and caregiver uncertainty when providing care, - Perceived family burden if they follow dietary advices,
	Understanding of heart failure Self-care,	Accepting illness and positive attitudes toward treatment if consistent with the cultural definition of disease, The family is responsible for the health, wellbeing and follow up of its members	The history of living healthy and active lifestyle,	- Patients do not comply with treatment regimen i,e, skipping medication if no symptoms - Misconceptions about self-care practices i,e, exercise was believed to be impossible with heart failure because it worsens symptoms, - Misunderstanding the benefit of cardiac diet and the preference of traditional unhealthy food,
		Positive	Existential	Negative
Enabler/Barriers, (The impact of systems-level factors, which could facilitate or impede any change i,e, help seeking behaviour)	Relationship between cultures and adopt healthy behaviour such as help-seeking,	The availability resources such as a wide range of healthy food and medicine, westernised as well as traditional, Social support and kinship, Healthcare system when responsive to patients' unique cultural needs		The low socioeconomic status, costly healthy food and health checks, Emphasising on the importance of family and social kinship and social gathering more than health, Lack of system combining western with traditional medicine, No regular health checks and follow ups unless if seriously ill Healthcare advice being culturally incompetent,
		Positive		Negative
Nurturer (The impact of social support and its role in changing health behaviour,		The embeddedness of caring role, Family and friends support patient's health and wellbeing, Family and friends understanding of heart failure and the importance of balanced food and healthy living during the course of illnesses, Friends; good resource for valuable advice,		Food etiquette and family members being burdened preparing different meals for patients, The suboptimal understanding of family and friends of heart failure and self-care, Inconsiderate healthcare system to family members and the lack of cultural competence in health system and information mainly about self-care,

qualitative (Articles 2; 4; 5; 10; 12; 13), five quantitative (Articles 1; 6; 7; 9; 11) and two mixed-methods studies (Articles 3 and 8). Most studies were conducted in Western countries (n = 7) (Articles 1; 2; 3; 6; 7; 8; 12). Most studies considered patients only (n = 10), two studies included caregivers with patients and one paper only studied caregivers (Article 4). Dyads of patients and their caregivers were in another four studies (Articles 2; 5; 10; 12). None of the studies considered the clinicians' perspectives. Eleven studies collected data fully or partially in hospital settings (Articles 1; 3; 4; 5; 6; 7; 8; 9; 10; 11; 13).

3.3. Review domains

The constructed themes can be integrated into a layered onion model (Fig. 4). The diagrammatic model depicts the multi-layered interrelationships between cultural beliefs and values and the understanding of advanced heart failure at different levels or layers. At the centre of the onion, the coloured tiles, are the main themes, which impact all other layers. Firstly, the influence of culture on lay knowledge and understanding of all aspects of heart failure. Secondly, emphasising culture as a major component of the way advanced heart failure symptoms are perceived and grouped. Thirdly, cultural norms and values that could negatively or positively be associated with self-management behaviours. The middle layer represents the way patients conceptualise the collectively agreed value and beliefs by the community. Therefore, a deeper understanding of this layer would guide and to a certain extent provide explanations on how multiple cultural milieus, along with other factors, interact to produce unique health decisions and behaviours. The outer layer shows the explicit influences of the culture on the HF understanding.The process of cultural influences on understanding was seen as iterative and ongoing. The three constructed themes all overlapped. Inconsistencies between patients own beliefs and health recommendations restrict, the understanding of disease and, the adoption of certain healthy behaviours.

3.4. Lay heart failure knowledge, beliefs and perceptions

Several studies showed that most patients lack a clear understanding of what heart failure is (Articles 1; 4; 6; 10; 12), why they developed heart failure (Articles 10; 12), and the implications of heart failure diagnosis (Articles 1; 6; 10; 12) (Table 1). For instance,

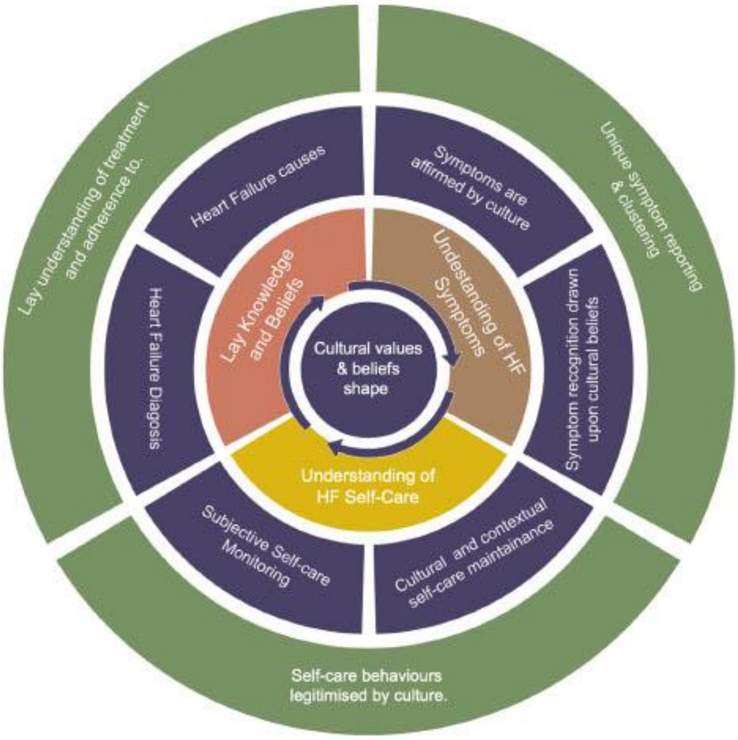

Fig. 4. XXX.

one-third of the enrolled subjects, and almost two-thirds of Asian patients were not aware of their heart failure diagnosis (Article 6). Patients and their families appear to define and correlate heart failure in different ways across cultures; none of these was close to biomedical explanations (Articles 3; 6; 8; 10; 12). The research evidence demonstrated that most non-Western patients consider families, friends and traditional healers as their main sources of heart failure knowledge. Interestingly, conversely to that, they also considered healthcare professionals to be the main sources of information during the advanced stages of disease (Article 1; 3; 4; 6; 7; 10; 12).

Patients with advanced heart failure and their families acknowledge that cultural beliefs shaped how they managed their chronic illness (Articles 4; 5; 8; 10; 12; 13). Markedly, this cultural appreciation also affects perceived control over the patients' condition (Article 6), self-care knowledge (Articles 3; 5; 8; 10; 12; 13); treatment preferences and decisions (Articles 2; 5; 8; 10; 12; 13) and family caregiving roles during the advanced, end of life stage (Articles 4) (Table 2). People frequently ascribed patient struggles with having a "bad heart" due to supernatural assumptions such as "God's will" (Article 12), stressors (Article 3), and devil spells or bewitching (Article 10). This cultural misconception led patients to continue worshipping, accepting distressing symptoms or practising stress reduction techniques, though these were not considered as self-care but their normal cultural practice (Articles 3; 4; 5; 6; 8; 10; 12; 13). This represents another distinct understanding of disease that is directly linked to cultural health beliefs.

Also, lay cultural knowledge was found to affect the acceptance of treatment. One of the studies (Article 2) proposed the influence of the cultural milieu on decisions, behaviours and, therefore, post-treatment experience with left ventricular assistive devices. These influenced beliefs on treatment decisions were particularly seen as important for those in low socioeconomic groups (Articles 1; 3; 8; 10; 12; 13).

Our synthesis demonstrates that lack of understanding led family caregivers to rely on cultural norms when providing care to their loved ones (Articles 2; 4; 5). It was clear that being ignored by the healthcare system, and sometimes other family members, further aggravated the role ambiguity and state of uncertainty (Articles 2; 4). Caregivers were found to be assisting other family members rather than carrying out "caregiving responsibilities" (Articles 4; 5). For example, in Article 4 the caregiver's role was attributed to cultural and religious beliefs (i.e. Allah-centred caring). This culturally-bounded understanding of caregiving confirms the results presented by Article 12, eight years previously in a similar culture.

3.5. Understanding symptoms, reporting and clustering

The studies suggested that patients' understanding of symptoms, and consequently the way they responded to them, were strongly linked to their own cultural and personal beliefs (Articles 3; 5; 6; 9; 10; 11). In people with heart failure, symptoms were subjectively understood and reported and derived from patients' cultural milieu (Articles 3; 6; 9; 10; 11). The more advanced the heart failure, the more likely it is for patients to have serious symptoms. However, patients were reluctant to report symptoms as they needed to be legitimised and consistent with the culture-specific definition of severe symptoms. For instance, some African cultures legitimise abdominal or leg swelling as serious symptoms that may, stop people from working, or require seeking help (Articles 3;10).

The understanding of symptoms and how symptom clusters across cultures were reported in two studies and were contradictory to each other (Articles 9; 11). It was clear that there was a tendency within each culture to report similar types, patterns and clusters of symptoms. However, contradictions were found comparing the variety of Eastern and Western cultures. With regards to physical symptoms, the ranking orders of physical symptoms were relatively similar across different cultures but not symptom severity scores. However, psychological symptoms were perceived differently and subjectively across cultures (Articles 9; 11). Patients from Eastern cultures may have delayed symptom reporting, a lower ability to recognise changes in psychological symptoms, and underestimated severity of disease compared with patients from Western backgrounds (Articles 6; 9; 11).

In Article 9, symptoms were identified and labelled according to type, and demonstrated that the Physical and Emotional clusters were mostly agreed upon across cultures. However, Article 11 describes some differences triggered by cultural beliefs and values, in which symptom labelling was based on symptom intensity. For instance, a higher symptom distress score was reported by patients from Western compared to Eastern cultures for 75% of symptoms. The symptom clusters in the Eastern cultures differed in terms of the number of classes and their composition. The influence culture has on the understanding of psychological symptoms, such as depression, was more evident in the Western cultures and less so in Eastern cultures. Eastern cultures were also more likely to ignore psychological symptoms and to perceive their physical symptoms as less severe. Unsurprisingly, the order of the distress code of the symptoms was similar across cultures (Articles 9; 11). These findings confirm that culture shapes the decisions of patients with advanced heart failure when monitoring, identifying, evaluating and linking symptoms to heart failure and how they respond to them.

3.6. *The understanding of heart failure self-care*

The culturally coined beliefs on heart failure self-care were salient features of determining the ability of non-Western cultures to adhere to self-care practices. Our results demonstrate the fundamental role of family's and friends' understanding, and therefore support, in enhancing heart failure self-care among traditional cultures (Articles 3; 5; 8; 10). Nevertheless, the understanding of self-care is defined by culture, and adherence to and performance of self-care are moulded by other co-impacting interdependent factors such as age, ethnicity, religion socioeconomic status and linguistic factors in traditional societies. Further, these factors have the potential to reform cultural influenced beliefs toward self-care. The problem with self-care is two-fold. Patients are not only not adhering to self-managing their disease, but also developing a blasé attitude toward change, even if this was followed by worsening symptoms or rehospitalisation (Articles 1; 3; 5). This was also found in patients with advanced heart failure (Article 13). For instance, cultural dietary habits, especially for people from low incomes were problematic; people found it difficult to reconcile changing to a cardiac diet or monitoring salt and fluid intake (Articles 3; 5).

In terms of self-care, cultural impacts were viewed to be explicit as enablers and implicit as barriers to self-care practices. Despite the positive responses about exercise, most participants were neither exercising nor aware of the use of exercise in heart failure rehabilitation (Article 8).

Similarly, a sense of contradiction was noted within certain cultures regarding adherence to prescribed medications, mainly when patients show admiration and gratitude that was not necessarily reflected in their behaviours (Articles 1; 3; 5; 6; 8; 10; 12; 13). For example, in African American culture, life-long adherence to medication was considered an essential step for living. However, more than two thirds of participants from the same culture had not correctly answered the heart failure knowledge questions about their medications (Article 1). Also, the longer heart failure symptoms persist, the less likely patients are to trust medications, particularly when biomedical treatment is no longer sufficient to relieve suffering during the advanced stages (Articles 5; 8; 13).

Most cultures appreciate the importance of family and extended kinship bonds in enhancing the understanding and performance of self-care (Articles 3; 8). When people have a good understanding of their disease with good health literacy, family played a positive role in enhancing positive self-care behaviours. These included adherence to medication, dietary and fluid restrictions, and help seeking behaviours (Articles 3; 8). Poor understanding of self-care practices by family members were influenced by culture (Articles 5; 13). In these cultures, self-management programmes are considered as stepping out of the norm and could lead to social isolation (Article 3); being a burden on family is perceived as an inevitable ending of such an adherence (Article 5).

Our results would further suggest that knowledge of heart failure symptoms and medications, were given the highest priority on patients' list of "unmet needs" (Articles 1; 3; 12). Primarily, for their direct and clear correlation with poor functionality and quality of life. Also, patients' self-management decisions and actions were consequently based on changes in symptom severity. However, patients' ability to recognise and evaluate change in symptoms were often low due to the subjective way they monitored symptoms (Article 3). For example, reporting dyspnoea as "too much pressure" or "losing breath". This subjective monitoring was affected by culture and led to poor and delayed actions such as delayed help-seeking behaviours.

Help seeking decisions are also based on patients' unique experience and knowledge and are easier to make and adhere to if they're consistent with cultural beliefs (Articles 3; 5; 8; 12; 13).

Most studies have recommended identifying more culturally appropriate interventions to increase knowledge (Article 1;2;6;10), reduce readmissions and cardiovascular deaths (Article 7), to facilitate self-care and enhance compliance (Article 1;3;5;8;11;13) and for better dyadic emotional, psychological, and coping support (Article 2;4;6;7;12). Our finding suggests that interventions were tailored based on the Western culture (Article 5;10;13) and implemented worldwide. These interventions need to be culturally customised before being implemented for the cultural groups residing in the western countries. Although, these groups do, to a certain extent, adapt to their host cultures, decisions regarding self-care are often driven by their original cultural beliefs (Article 1;2;3;6;7;8;12). There is reasonable evidence that interventions in which appropriate cultural modifications are applied, indicate better health outcomes. For instance, Article 7 provided evidence of effectiveness of programmes that fit with cultural beliefs and provided by trained registered nurses to patients and family members using interactive teaching techniques.

4. Discussion

This mixed-methods review identified three constructed themes on the influence of culture on the understanding of advanced heart failure. These themes were examined through a theoretical lens. The PEN-3 model was utilised and served as a tool to assess, analyse and synthesise the cultural impacts according to patients' and family members' understanding of heart failure across different cultures (Table 3). This study was challenging since our broad search strategy retrieved only 13 relevant articles, none of which directly addressed the cultural understanding of heart failure.

All studies, however, investigated the effects of cultural beliefs on patients' and/or family members' understanding of heart failure. However, none of them explicitly explored the understanding of health care professionals. These cultural insights could be critical to allow the development of complex interventions to overcome obstacles triggered by cultural misconceptions. Furthermore, a lack of consistency in methodological rigour was found across many studies, including in tool utilisation, data analysis methods and even the definition of culture, as a universal consensus on this definition is not available.

We found people from non-Western cultures, both living in a Western country or in their original country, are more likely to have a distorted understanding of heart failure because of the cultural ideas and beliefs that have been passed down through generations. People in modern, or Western cultures, who adopt biomedical ideologies, are also more likely to thrive on change (Ibeneme et al., 2017; Lip et al., 2004; Pattenden et al., 2007). Often, traditional cultures believe that faith, religion, and culture are integrated and intertwined, and culture and technology have always been interconnected. Patients were, therefore, accepting of their fate because of their cultural inherent faith in healthcare (Truitt & Verdial, 2017).

Our findings suggest that lay knowledge of heart failure diagnosis, causes, treatment and self-management is predominately influenced by cultural context. From a qualitative perspective, the impact of culture on lay knowledge was cumulative, starting early and occurring at every stage of heart failure trajectory until its advanced stages.

Each culture shares a specific set of interwoven values, beliefs and behaviours that influence patients and families' understanding of advanced heart failure. Patients from non-Western cultures were keen to control their condition and to seek health services when necessary, if this was compatible with their beliefs. However, due to the absence of culturally competent services they were compelled to seek help from their system of cultural health beliefs. Some of these beliefs limited their perceived control over their condition, which may lead to further ineptitude in managing healthy behaviours i.e. help-seeking. In summary, neither patients nor their families were readily prepared for the advanced stage of their illness and end of life care. This problem occurred across all studies irrespective of study designs, country, setting and date.

An understanding of heart failure is a pre-requisite for better management across the trajectory of the condition (Sobanski et al., 2019). Despite the recent universal focus on heart failure, people are still relying on culturally informed lay knowledge and understanding of heart failure. This review found little empirical evidence of this lay knowledge and no articles considered the correlation between lay knowledge and culture. Researchers have, however, investigated lay knowledge to understand non-compliant behaviours adopted by people when they are ill (Popay & Williams, 1996; Rosenstock, 1974), and more recently, there has been a growing recognition of the concept of lay knowledge within research (Rabeharisoa et al., 2014), especially in medical sociology.

This review contradicts in principle Namukwaya et al. (2017) who claimed that lay knowledge of heart failure definitions, symptoms and the use of folk medicine are not derived from patient cultural contexts. Our findings are broadly in line with the evidence from the heart failure 'initiative' campaign, where misconceptions and cultural misbeliefs led most people to ignore and perceive symptoms as age-related (Störk et al., 2016). A similar conclusion was reached by others who assert that cultural health beliefs, from caregivers' perspectives, do not only influence heart failure lay knowledge and understanding, but also create it. Nevertheless, family caregiving is seen as an embedded norm in life and culture in many non-Western cultures (Fang et al., 2016; Grant & Graven, 2018).

Our synthesis is consistent with a previous meta-analysis and reviews which explored the influences of cultural and familial beliefs on heart failure self-care (Attaallah et al., 2016; De Geest et al., 2004; Horne et al., 2013; Sebern & Riegel, 2009; Shahin et al., 2019). Culturally sensitive clinical management depends on the degree of understanding of clinicians of patients' cultural beliefs and values (McQuaid & Landier, 2018).

Cultural beliefs and norms may influence the understanding and the expression of symptoms. This interpretation is directly in line with previous findings by (Zhou et al., 2016). The contradictory conclusions from Moser et al. (2014) and Park and Johantgen (2017) on symptom clustering may, however, be due to the latter's use of a more advanced analysis technique and symptom intensity-based labelling. Both have utilised a customised set of subscales of the original Minnesota Living with Heart Failure Questionnaire (MLHFQ) tool. This may have compromised the validity of the tool and the reliability of findings as the reduced symptoms may be equally important to patients despite the enhanced readability of the utilised tool. In addition, the removal of items such as "difficulty walking or climbing" was neither discussed nor justified. It remains unclear to which degree symptom clustering are attributed to cultural, ethnical or societal factors. In parallel with DeVon et al. (2017), we believe that more attention should be paid to understand how symptoms cluster cross culturally

Another significant finding from our review relates to heart failure self-care. When discussing patients' understanding of heart failure self-care in different cultural contexts, it is imperative to understand their unique lifestyle and dietary patterns and traditions. The data implies that many cultures were neither motivated nor provided the necessary skills and knowledge for self-care. Although the majority believed that some of their cultural beliefs led them to poorly self-manage health, they did not agree the westernised way of living to be the solution. This gap would be best addressed by culturally competent heart failure interventions that could enhance understanding of self-care and related behaviours, increase service satisfaction and ultimately, improve their health-related outcomes. In addition, lay beliefs about heart failure were misleading in terms of symptom recognition, so it is not realistic to expect proper engagement in self-care.

The narratives of poor adherence to self-care, such as adherence to medication, may be due to communications pitfalls and can be attributed to cultural differences. Therefore, a disparity between the person's cultural understanding and clinician understanding may lead them to neglect medications or other healthcare recommendations. In addition to, the family members being neither empowered not kept in the loop of treatment or conversation. There is a global consensus on the vital role of specialist palliative care to deploy these critiques by proper addressing of the patient and their family members (Sobanski et al., 2019; WHO, 2016). Patients from non-Western cultures seek healthcare consultations for more serious or life-threatening illnesses when their traditional treatment fails or when their symptoms become worse (Jiang et al., 2013; Namukwaya et al., 2017; Rong, Peng, Yu, & Li, 2017). Cultural consideration when developing an intervention should, therefore, embrace patients' language, social context and role of family, and patient values and beliefs about disease to be viable and bridge the gap.

5. Limitations

There are a few limitations identified during this synthesis. The review was predominately qualitative, which reflects the recent but growing interest in this subject, globally. Qualitative inquiries are beneficial as a starting point to explore a new phenomenon, but the subjective nature of this type of enquiry also carries risk of bias and may compromise the transferability of findings. Moreover, the majority of data were collected in hospitals and so may not be representative of the general population. The low sample sizes of the primary studies may also reduce the generalisability of the results.

Additionally, the searches were limited to English-language articles which will exclude some of the literature from non-Western non-English-speaking cultures, especially from countries across Asia and South America.

Research in this field is difficult as the impact of culture is hard to measure; thus, drawing definitive conclusions and provide recommendations for better cultural care provision solely from the reports included here is problematic, This is still an area warranting further in-depth inquiry.

6. Conclusion

The purpose of this review is to explore how culture influences the understanding of advanced heart failure for patients and their family members, and how culture influences the adoption of healthy behaviours.

It is apparent that there is much complexity surrounding the effect of culture on the understanding of advanced heart failure and, therefore, heart failure related decisions and behaviours. Particularly among non-Western patients, the role of culture is crucial to the understanding of heart failure and its management. Patients' perception of the severity of their heart failure is primarily based on the severity of the symptoms. Patients act when their symptoms became severe, or worsen, based on the symptoms' perceived intensity and its cultural interpretations. Patients with heart failure who hold non-Western cultural beliefs were more likely to avoid or delay seeking healthcare services, and we found that this was because of their lay knowledge and understanding of heart failure diagnosis, causation, symptoms and treatment, coupled with other socio-economic barriers.

Cultural competency is central to patient-centred care and could be achieved by the development and the implementation of interventions to support healthcare providers to provide safe and high-quality care for diverse patient groups and their families in a culturally sensitive fashion. These interventions should be tailored according to the lay understanding of heart failure to maximise the benefit and cultural relevance of health messages and, therefore, their impact on peoples' knowledge and behaviours. The findings of the cultural impact on the understanding of advanced heart failure go some way to explain the delayed presentation of patients with heart failure and the under use of palliative care cardiology services.

7. Ethical statement

An ethical statement is not applicable as this publication is a secondary library-based review paper and did not involve human or animal subjects.

Author contribution

BA, BB and KH formulated the question and designed the protocol, BA searched the literature and acquired the data, BA, BB and KH analysed and interpreted the data, BA, BB and KH wrote the review paper.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Conflict of interest

The authors declare that there is no conflict of interest.

CRediT authorship contribution statement

The paper properly credits the meaningful contributions of co-authors and co-researchers.

Acknowledgments

This research has been part of a fully-funded PhD scholarship. The authors are gratefully acknowledge and extend our special thanks to the University of Glasgow and the British Council Palestine.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.colegn.2020.02.008.

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C. The Full search strategy as piloted on MEDLINE via Ovid

1. exp Heart Failure/

2. Heart Failure.tw.

3. Cardiomyopathy, Dilated/

4. Shock, Cardiogenic/

5. exp Ventricular Dysfunction/

6. Cardiac Output, Low/

7. ((heart or cardiac or myocard*) adj2 (fail* or insufficien* or decomp*)).tw.

8. ((dilated or congestive) adj2 cardiomyopath*).tw.

9. ((ventricular or ventricle*) adj2 (failure or insufficien* or dysfunction*)).tw.

10. cardiogenic shock.tw.

11. (DCM or heart failure or CHF or LVSD or HFrEF or HFpEF or HFmEF or RVD or RVDD).tw.

12. or/1-11

13. exp Patients/

14. exp Family/

15. exp Health Personnel/

16. (patient* or inpatient* or outpatient* or parent* or relative* or famil* or carer* or caregiver* or care-giver* or spous* or husband* or wife* or wive* or partner* or sibling* or daughter* or son* or clinician* or physician* or doctor* or nurs* or GP* or ((Health or healthcare or health care) adj2 (practitioner* or profession* or provider*))).tw.

17. or/13-16

18. exp Comprehension/

19. exp Knowledge/

20. exp Communication/

21. exp Health Literacy/

22. exp Attitude to Health/

23. (mean* or define* or comprehen* or experience* or belief* or thought* or view* or opinion* or perception* or perspective* or attitud* or know* or understand* or aware* or compl* implement* or operational* or philosoph* or appl* or conceptual* or interpret* translat* or value* or behavio*).tw

24. (health and (literate or literacy or numeracy)).tw.

25. or/18-24

26. exp Culture/

27. exp Anthropology, Cultural/

28. exp Continental Population Groups/

29. exp Ethnic Groups/

30. (cultur* or multicultural or multi-cultural* or intercultural* or inter-cultural* or transcultural or trans-cultural* or cross-cultural* or crosscultural* or multiethnic or bicultural* or bi-cultural* or ethnic*).tw.

31. or/26-30

32. 12 and 17 and 25 and 31

D. Grey literature search

The grey literature search, which wasn't systematic, was undertaken using platforms such as Google Scholar and ProQuest, since we believe that non peer-reviewed articles could also be relevant and contribute to better understanding of the subject matter.

The grey literature was approached through the following links:

1. CareSearch database (www.caresearch.com.au).

2. Websites of relevant organisations (PROSPERO and Joanna Briggs) for completed and published reviews.

3. Websites of relevant unpublished dissertations and thesis (ProQuest Dissertations).

4. Google website using (heart failure culture filetype:pdf).

5. The search also includes trials registered on www.ClinicalTrials.gov and www.who.int/trialsearch/.

E. *Grey literature search*

First author, (Year)	Qualitative studies					Comments
	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?	
Barg et al. (2017)	Yes	Yes	Yes, however, a few quotes did not appear to fit within themes	Yes	Yes, some quotes were linked to changed/ merged themes	The language and vocabulary utilised were complicated.
Etemadifar et al. (2015)	Yes	Yes, However, data were collected from 3 educational hospitals in the same region until achieving saturation	Yes	Yes, However, some codes were not substantiated by data or factual analysis	Yes	Extensive steps were taken to ensure rigour and trustworthiness. However, the small sample size and low site variation may compromise findings.
Jiang et al. (2013);	Yes	No, the small sample sizes and sampling from a narrow region. Sample recruitment criteria were not clear	No. On many occasions, codes were predetermined and not derived from the data	Yes	No, coherence between the dataset and interpretation was not clearly addressed	Ethnicity was used as a proxy for culture. Findings are limited and may not be transferable to other contexts. Small sample size, predominantly males with primary education NYHA HF class not clearly reported.

Namukwaya et al. (2017);	Yes	Yes, however, the single study covered a narrow geographical region.	Yes	Yes.	Yes, it utilised a theoretical framework to guide the whole study. However, relative coherence between data and how this fits within the framework.	Lay knowledge and beliefs were not addressed as cultural attributes, even though both are culturally framed within collective belief systems. A theoretical framework guided the study The sample was mostly females
Pattenden et al. (2007);	Yes	Yes. The study covered diverse cultural and religious urban and rural groups	Yes	Yes	Yes	External validity was enhanced by including carers with various caring relationships The use of a bilingual interpreter may enhance the explanation in the cultural context and credibility of findings Study design and carer details were not clearly stated
Rong et al. (2016);	Yes	Yes, however, the small sample size and the use of only one hospital limited findings.	Yes	Yes	No, the use of the Sunrise Model carries a risk of bias, arguing that all people within the same culture or ethnicity hold a similar understanding	Subjective and selective sample with gender imbalanced. Characteristics of culture were ignored.

Two-thirds of the sample had a no religion status

First author, (Year)	Quantitative studies					Comments
	Is the sampling strategy relevant to addressing the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of nonresponse bias low?	Is the statistical analysis appropriate to answer the research question?	
Artinian et al. (2002)	Yes	No, the sample was conveniently selected and not clearly described regarding age, gender, and essential HF characteristics.	No	No, the percentage of eligible subjects (response and attrition rate) was not adequately discussed	Yes	Selection and performance bias was not attended to
Lip et al. (2004)	Yes	Yes	Yes	Cannot tell	Yes	Due to the low sample size and the nature of recruitment, findings may not be generalisable beyond the patients included in the studies.
Moser et al. (2014)	Yes	Yes	Cannot tell	Yes	Cannot tell	No discussion of sample, setting, location, confounding variables. Using a modified version of the original tool with no rationale may compromise the reliability of the findings.

Park and Johantgen (2016)	Yes	Yes	Cannot tell	Yes	Yes	Secondary analysis of Moser et al. but more informative, better analysis technique & better reporting. Used a modified version of the original tool with no rationale, the reliability of the findings may be compromised.

First author, (Year)	Randomised controlled trials					Comments
	Is randomisation appropriately performed?	Are the groups comparable at baseline?	Are there complete outcome data?	Are outcome assessors blinded to the intervention provided?	Did the participants adhere to the assigned intervention?	
Mau et al. (2017)	No, unblinded randomisation	Yes	yes	Cannot tell	Yes	The inclusion of family members was encouraged Designed as a group-based intervention but delivered to individuals

First author, (Year)	**Mixed methods**					Comments
	Is there an adequate rationale for using a mixed methods design to address the research question?	Are the different components of the study effectively integrated to answer the research question?	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	
McCarthy et al. (2015)	Yes	Cannot tell	No, the analysing process was not clearly	Yes.	No	Small sample size limited to African American

			described. Consequently, the interpretation of quantitative data was limited.			participants, without other minority individuals. The qualitative data collection technique was insufficient to address the research question The mixed methodology and the research questions were neither justified nor clear
Dickson et al. (2013)	Yes	Yes	Yes	Cannot tell	Yes	Study used theoretical framework to guide their investigation. Study used a highly reliable tool. Study sample were male dominant.

Appendix III- Supplemental Information for recruitment phase

A. The cultural profile of Glasgow, Scotland

The cultural profile of Glasgow, Scotland

Scotland is a diverse, complex, multicultural country with a long history of domestic cultural interactions (Meer, 2015). Although Scotland has historically lower rates of diversity than elsewhere in the UK, recent reports on the socio-demographic profile of Scotland have highlighted an exponential growth of cultural diversity within its population (Smith and Simpson, 2015, Walsh et al., 2019). Diversity has grown for many reasons, notably the foreign and domestic immigration and movement within Scotland over the past three decades. Alongside Some UK policies that have contributed to the diversification of Scotland, including the dispersal of asylum seekers to Scotland, particularly in Glasgow areas. In 2011, the Scottish census, which proxy diversity using ethnicity and religion, showed a continuously rising diversity in Scotland, with just under a million out of the six million people identifying themselves as minority residents. The group has steadily increased by 29% between 2001 and 2011. Given these numbers, the diverse groups, including minorities, form an integral part of the healthy population and are important constituencies of the overall health and well-being in the present and future of Scotland (National Records for Scotland, 2019b; Walsh et al., 2018).

The National Records of Scotland has produced the Small Area Population Estimates (SAPE) for Scotland in august 2019. The NHS Greater Glasgow and Clyde (NHS GGC) has a population of 1,183,120. Figure **Error! No text of specified style in document.**.1 shows the six local authorities within this health board: Glasgow City, Renfrewshire, East Dunbartonshire, East Renfrewshire, West Dunbartonshire, and Inverclyde.

The study under consideration mainly covered the largest council area, Glasgow, out of all other thirty-two council areas in Scotland. It is a comparatively populous area with just over one-fifth of Scotland's population and recognised for its high levels of poor health. Long-term health problems have been rising steadily over the last decade and affected nearly 22% of the GGC population in 2011. The rate ranges from one-quarter in Northeast Glasgow city (25.6%) to 16.8% in East Renfrewshire population. On the other hand, the total Scottish population stood just under one fifth (19.6%). There were notably different patterns of diversity within Glasgow in the last three decades. Glasgow is becoming more ethnically and culturally diverse, and this diversity has become more widely spread across the country even faster than documented.

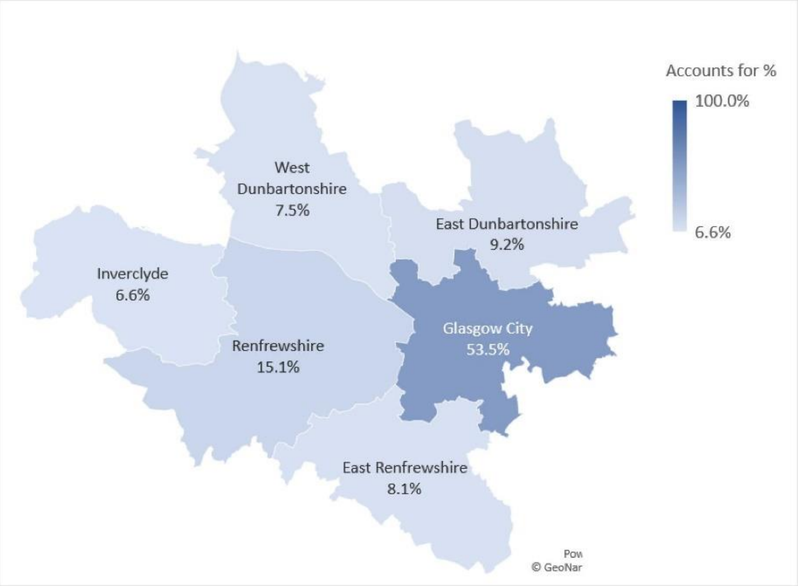


Figure Error! No text of specified style in document.**.1. The population of Greater Glasgow and Clyde, NRS, 2020.**

Meanwhile, the conurbation population increased by 6.7% and housed almost one-third of the ethnic minorities in Scotland (32%), or 44% if 'White Other British' is excluded (Kelly and Ashe, 2014, Walsh, 2017). The ethnic minority communities in Glasgow reached 11.6% of the total population, with a two-fold increase between 1991-2001 and four-fold growth of non-white ethnic groups between 1991 and 2011. In 2011, there was an increase from 13% to 21% of the total population. By 2031, it is anticipated that the non-white ethnic minority groups will constitute more than 20% of the total population in Glasgow. Therefore, there is a clear need to understand the impact and the possible implications of these changes.

Glasgow's ethnic diversity

In the 2011 census by the Scottish Government, the White Scottish group accounted for 79% of the population in Glasgow. The largest ethnic minority groups in Glasgow were Pakistani (4%), White Other British (4%), White Other (4%), Chinese (2%) and African (2%). Between 2001 and 2011, the ethnic groups' population increased disproportionately in Glasgow. The African community has increased the most with (890%), followed by Other Black (339%), Chinese (176%) and Other Asian groups (176%). The Pakistani and White Other British groups are the most geographically clustered, while most other ethnic groups are more evenly distributed across a wider geographical area. More African, Caribbean, White Other and Chinese ethnic groups lived in Glasgow's most deprived neighbourhoods in 2011 than in 2001. While the proportion of White Scottish and White Other British in the 10% most deprived areas in the city remained stable, the proportion of White Irish and Mixed ethnic groups living in these areas decreased during the last decade.

The religious affiliation of Glasgow residents is pretty similar to the overall affiliation of Scotland, with approximately one-half Christian, followed by more than one-third atheist or secular. Muslims in Scotland made up 45% of the non-Christian religious population in 2001, which increased to reach 56% in 2011. Glasgow has the highest Muslim population in Scotland, with 5% of residents identifying themselves as Muslims. However, these numbers are ten years out of date based on the last national large-scale consensus in 2011. More importantly, the data was questioned as it excluded the new asylum seeker and refugee communities, as many of whom have settled in Glasgow immigrated from Muslim countries.

References

Kelly, B. and S. Ashe (2014). Geographies of deprivation and diversity in Glasgow. *Local Dynamics of Diversity: Evidence from the 2011 Census*.
Meer, N. (2015). Looking up in Scotland? Multinationalism, multiculturalism and political elites. *Ethnic and Racial Studies* 38(9) 1477-1496.

Smith, A. and L. Simpson (2015). In what ways is Scotland's ethnic diversity distinctive. *Ethnic identity and inequalities in Britain: The dynamics of diversity* 93.

Walsh, D. (2017). The changing ethnic profiles of Glasgow and Scotland, and the implications for population health. *Glasgow: Glasgow Centre for Population Health*.

Walsh, D., D. Buchanan, A. Douglas, J. Erdman, C. Fischbacher, G. McCartney, et al. (2019). Increasingly Diverse: the Changing Ethnic Profiles of Scotland and Glasgow and the Implications for Population Health. *Applied Spatial Analysis and Policy* 12(4) 983-1009.

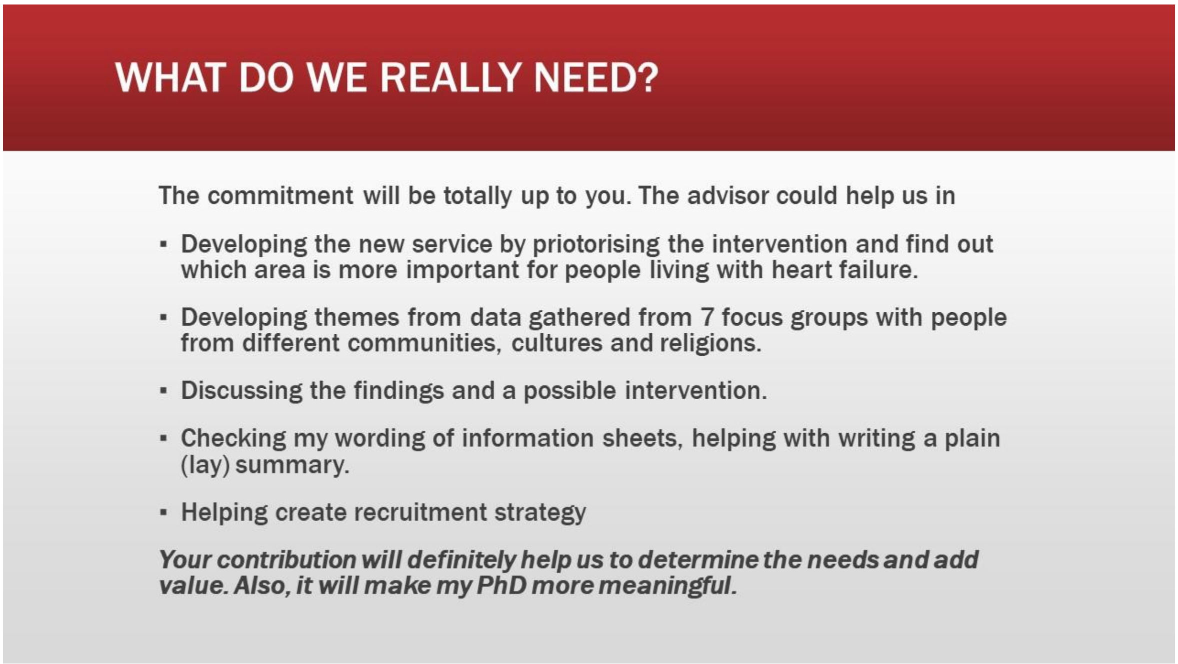
B. Patient and public involvement recruitming

Patient & Public Involvement (PPI)

Heart Failure and Palliative care : The influence of culture on the understanding of disease and Services

WHAT'S THIS FLYER ALL ABOUT?

The aim of this flyer is to introduce the principal researcher (Bahaa Alassoud) to all members of the public in Glasgow. Currently, I am looking for a patient or carer adviser to join our research team and to provide some regular advice for the duration of my PhD. We are looking for someone with heart failure or heart disease, or who has a good understanding of chronic heart disease, and/or the influence of culture on heart diseases."

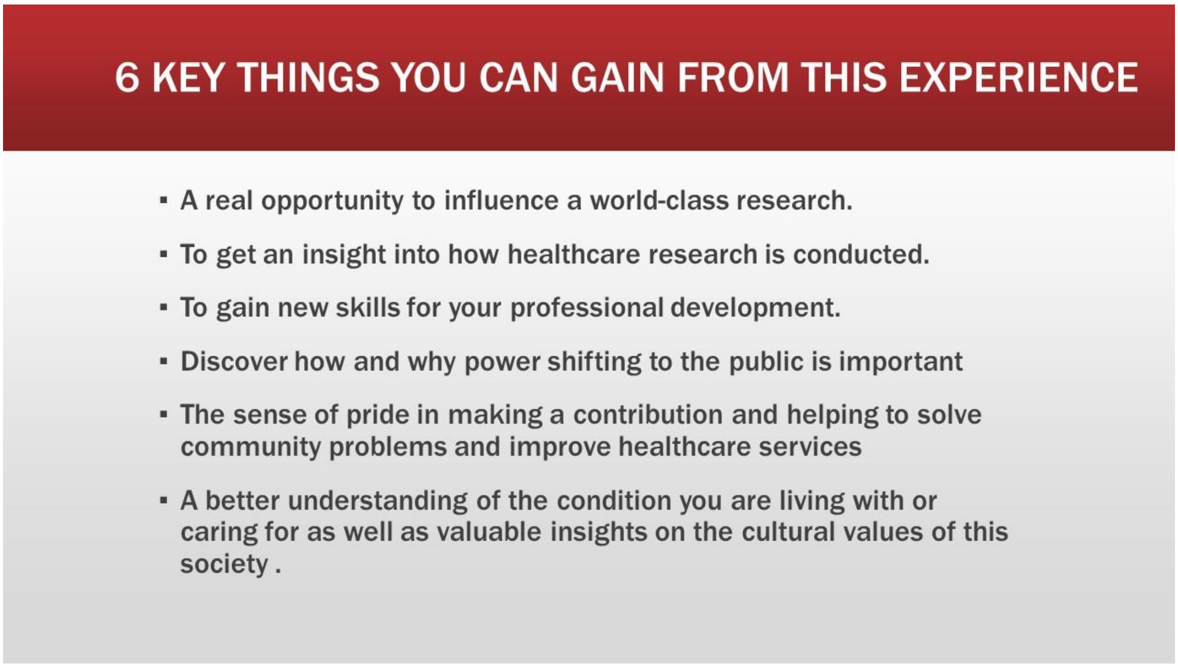


WHAT DO WE REALLY NEED?

The commitment will be totally up to you. The advisor could help us in

- Developing the new service by priotorising the intervention and find out which area is more important for people living with heart failure.
- Developing themes from data gathered from 7 focus groups with people from different communities, cultures and religions.
- Discussing the findings and a possible intervention.
- Checking my wording of information sheets, helping with writing a plain (lay) summary.
- Helping create recruitment strategy

Your contribution will definitely help us to determine the needs and add value. Also, it will make my PhD more meaningful.



6 KEY THINGS YOU CAN GAIN FROM THIS EXPERIENCE

- A real opportunity to influence a world-class research.
- To get an insight into how healthcare research is conducted.
- To gain new skills for your professional development.
- Discover how and why power shifting to the public is important
- The sense of pride in making a contribution and helping to solve community problems and improve healthcare services
- A better understanding of the condition you are living with or caring for as well as valuable insights on the cultural values of this society .

MY PROFILE

I am Bahaa Alassoud, a nurse educator and Cardiac Nurse from Palestine with more than 8 years of clinical and academic experience. Importantly, a husband and dad of three boys and a highly ambitious, enthusiastic, adaptive and professional second year PhD student at the University of Glasgow. I am conducting a 3 year PhD project on the impact of culture on the understanding of heart diseases, particularly heart failure. I particularly enjoy communicating and working with people from different cultural background. My specific research interest is around developing an intervention targeting patient with advanced heart failure and/or nurses who is caring of these diverse patient groups.

HOW TO GET INVOLVED?

Step 1

If you are willing and would like to be involved.

Step 2

Find out more about PPI

SCAN ME

Step 3

Please contact me on B.alassoud.1@research.gla.ac.uk

Mobile: +447511007111

C. Brief synopsis about the study's PPI advisors

Patient and public involvement, the first representative.

Cameron is a psychologist who was born in the UK. He is living with his wife and two daughters. He has a longstanding history of hypertension and tachyarrhythmia. He mentioned that he was frequently hospitalised due to breathlessness, leg oedema, and palpitations. Four years later, he had a heart attack and was diagnosed with heart failure at the age of 66. The devastating symptoms persisted and began to occur suddenly and sometimes during rest or sleep. These episodes usually stopped on their own and sometimes required a hospital visit. He had no idea about palliative care until his sister-in-law went to the palliative care unit. Nevertheless, Cameron had some difficulties linking palliation to his case or to cardiology.

Patient and public involvement, the second representative.

Muhammad Hussien is a father of six and a first-generation British Asian. He moved over to Glasgow from Pakistan and joined by his wife years later. Muhammad has a history of hypertensive heart disease with hypertension, hyperlipidaemia and three episodes of heart attack, one of them at an early stage. He was brought to A&E at a local hospital in Glasgow by his son after he falls unconscious. The moments before losing consciousness were not entirely clear. However, Muhammad said,' it came after a week of shortness of breath and night coughing when walking from the living room to the toilet were troublesome. A family member who attended the meeting said that he has a similar but less severe form of breathlessness, and syncope, all denied by Muhammad.

Patient and public involvement, the third representative.

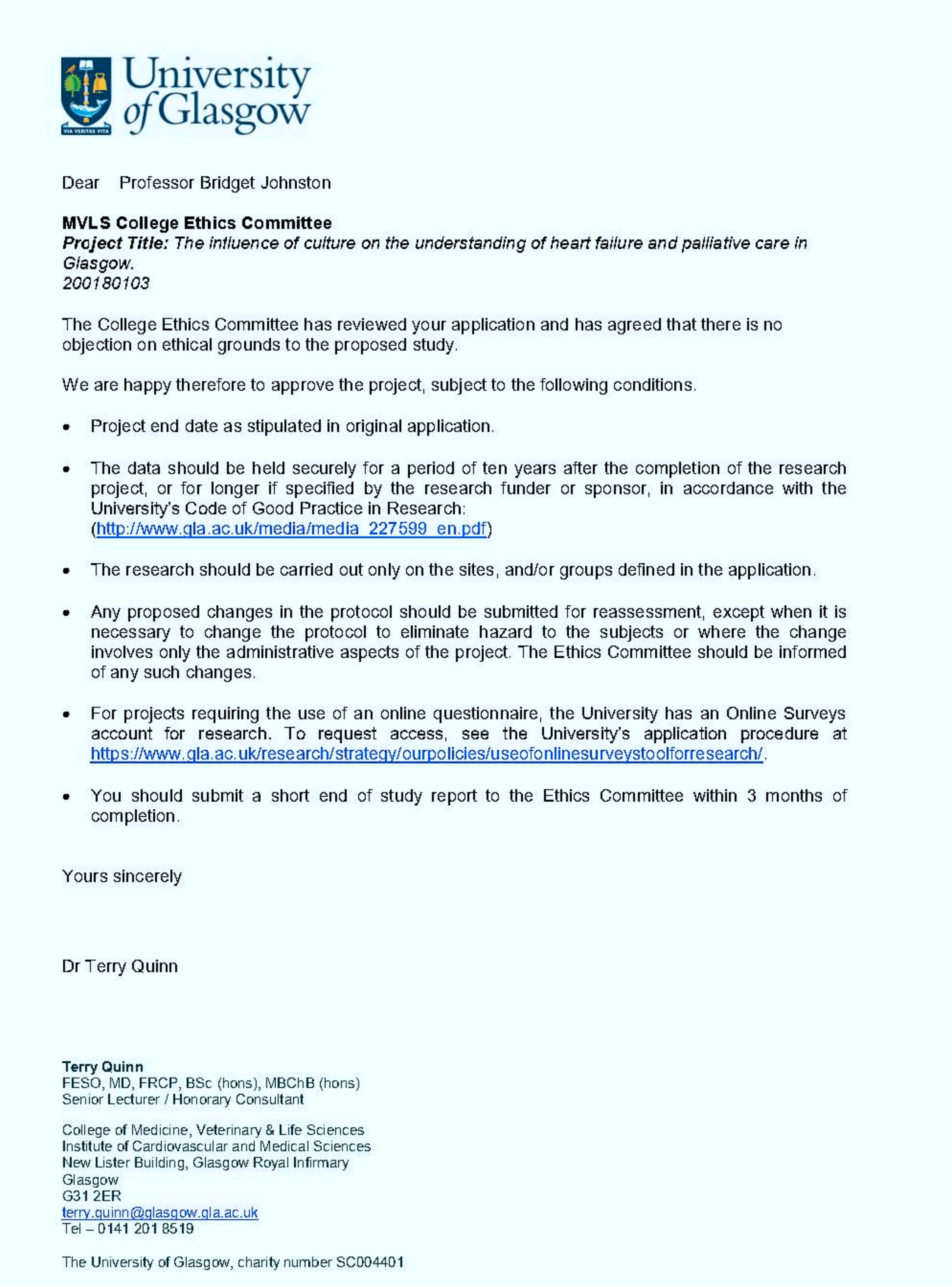
Allan was born in Glasgow and is a single 41-year-old man living on his own. He attended the College of Agriculture at the University of the West of Scotland, Paisley. He was diagnosed with heart failure at the age of 29, and within 3 years he required a heart transplant. His heart failure journey began shortly after he had started a new farming and agriculture job. His family felt that there was something wrong with him – he was a bit off colour, was not eating, and was tired. The GP told Allan that he was suffering from fatigue and weakness caused by a virus, but he was later diagnosed with heart failure. The scenario was shocking as the complaints were not alarming him. In 2015, Allan attended an evaluation session for his progressive fatigue after a year of repeated admissions to hospital. Later, he was diagnosed with cardiomyopathy, was considered to be a candidate for heart transplantation, and was referred to specialist care.

Patient and public involvement, the fourth representative.

Wael is an engineering manager and a father of two. Originally from the Middle East, he migrated to the UK in the 1980s. He has cared for his mother and mother-in-law as he believes a responsible person should do. He stated that his mother-in-law was diagnosed with heart failure after experiencing severe shortness of breath and swelling. Tests and scans showed an enlarged heart, which was not pumping effectively. She had a pacemaker fitted and may need further support. Wael mentioned that she felt much better on oral medication and with lifestyle modifications along with the device until she fractured her femur (thigh bone).

Appendix IV- Ethical approval Information

A. Ethical approval letter by MVLS College Ethics Committee



University of Glasgow

Dear Professor Bridget Johnston

MVLS College Ethics Committee
Project Title: *The influence of culture on the understanding of heart failure and palliative care in Glasgow.*
200180103

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study.

We are happy therefore to approve the project, subject to the following conditions.

- Project end date as stipulated in original application.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- For projects requiring the use of an online questionnaire, the University has an Online Surveys account for research. To request access, see the University's application procedure at https://www.gla.ac.uk/research/strategy/ourpolicies/useofonlinesurveystoolforresearch/.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

Dr Terry Quinn

Terry Quinn
FESO, MD, FRCP, BSc (hons), MBChB (hons)
Senior Lecturer / Honorary Consultant

College of Medicine, Veterinary & Life Sciences
Institute of Cardiovascular and Medical Sciences
New Lister Building, Glasgow Royal Infirmary
Glasgow
G31 2ER
terry.quinn@glasgow.gla.ac.uk
Tel – 0141 201 8519

The University of Glasgow, charity number SC004401

B. Recruitment flyer

THE INFLUENCE OF CULTURE ON THE UNDERSTANDING OF HEART FAILURE IN GLASGOW.

My name is Bahaa Alassoud. I am a Palestinian nurse and a PhD student at the University of Glasgow. I would like to invite you to take part in one group discussion that will form a part of my PhD research project at the University of Glasgow. The study is looking at the influence of culture on the understanding of heart failure.

We are looking for members of the public. We require participants who are familiar with heart failure, heart disease and/or other long-term conditions, who are willing to discuss their understanding of disease and culture in a single group discussion.

Thank you for taking the time to read this flyer.

If you would like to take part, please contact:
Bahaa Alassoud
Email : B.alassoud.1@research.gla.ac.uk
Mobile: +447511007111

We Need Your Help!

6 to 10 people from the same cultural Background.

Participants should live in Glasgow and be at least 18 years of age.

One-off meeting to address specific questions.

An opportunity for you to share your thoughts, feelings and ideas.

There are no right or wrong answers.

Your information will be kept private and confidential.

Your valuable insight will help develop a more culturally sensitive service.

Light refreshments will be provided.

School of Medicine,
Dentistry and Nursing.
(Nursing & Health Care)

C. Participant Information Sheet (PIS)

University of Glasgow | College of Medical, Veterinary & Life Sciences

Participant Information Sheet (PIS)

1. Study title

The influence of culture on the understanding of heart failure in Glasgow.

2. Invitation paragraph

My name is Bahaa Alassoud, a Palestinian nurse and a PhD student at the University of Glasgow. My specific research interest is around developing an intervention to help make the health care services in Glasgow more sensitive to cultural issues. The intervention that we create will consider the social, cultural and language related needs of people with heart failure. We hope the intervention will also help family members, nurses and/or other health care providers, who are caring for these patient groups.

I would like to invite you to take part in one group discussion that will form a part of my PhD research project. Taking part in the research is entirely voluntary. Before you decide, it is important for you to understand why the research is being done and what it will involve. This sheet should answer some questions that you may have before you consider taking part. Please do not hesitate to ask any questions that may have in relation to your participation. If you decide to take part, you will be given a copy of this Participant Information Sheet and the signed consent form to keep.

3. What is the purpose of the study?

The project aims to develop a new intervention that helps meet the needs of people with heart failure. More emphasis will be placed on their culture, religion and language. This project will contribute towards a PhD degree that is due to be completed by October 2021.

The group discussion is to enable me to collect information from members of the public, who are living in Glasgow. The topic is about the influence of culture on the understanding of heart failure and services provided. We require participants who are familiar with heart failure, heart disease and or other long term conditions and willing to discuss their understanding in a single group discussion.

4. Why have I been invited to participate?

I feel it is important that people from all backgrounds should be involved in as much as possible.This will ensure that the new intervention is one that they want and need. You have been chosen because you fit the profile of the population being studied that is:

- You are over the age of 18 years.

- You are living in Glasgow for more than a year.
- You have declared yourself as being from one of the cultural backgrounds being studied in this study.
- Your valuable insight will help me to plan and then develop the new intervention and ensure it is culturally sensitive

5. Do I have to take part?

Taking part is entirely voluntary. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. However, you are still free to withdraw at any time and without giving a reason.

6. What will happen to me if I take part?

- You will be required to attend one group meeting in Glasgow.
- The group meeting will have between 6 and 10 people from the same cultural background.
- The focus group will run for between 60-75 minutes on the date and location provided in the attached sheet.
- The group meeting will be led by a researcher. It is an opportunity for you to share your thoughts, feelings and ideas.
- There are no right or wrong answers.
- You will not have anything to prepare, you just need to be willing to talk during the group meeting.
- The discussions will be voice-recorded. However, your personal information will not be made public.
- There will be two researchers from the University at the group meeting. One will be Bahaa Alassoud and the second will be one of the student supervisors; Professor Bridget Johnston or Dr. Karen Hogg. They will help run the meeting and offer support if anyone requires this. Bahaa Alassoud's contact details are available later in this document.

7. What do I have to do?

If you decide to take part, you will be asked to contact Bahaa Alassoud via phone or email. Also you can express your interest to our contact person at your community venue. The contact name will be provided in the attached sheet.
You can change your mind at any time, however, if you decide to participate you will be required to attend on the agreed date, time and location.

8. What are the possible disadvantages and risks of taking part?

I understand that your time is very valuable, and I acknowledge that participating may reduce your free time. However, we do not expect you to experience any direct disadvantages or risks while taking part in this project.

I will be available to chat after the group meeting, if you would like to discuss or ask any questions privately. There is no personal risk to taking part as the discussions will be kept private and your input will not be identifiable.

9. What are the possible benefits of taking part?

Although there are no immediate personal benefits for people taking part in this study. It is hoped that this research will help understand how culture could shape a different understanding of disease. This is relevant to anyone in the Glasgow community as everyone, at some point in their lives, may be affected by, or know someone close to them who suffers heart failure.

10. Will my taking part in this study be kept confidential?

All information that we collect about you or the responses that you provide will be kept confidential. Only the researcher and the project's supervisors will have access to the original information. You will be identified by a number and information about you will have your name and contact details removed.

Your information will be kept anonymous. You will not be identified in any reports or publications. Your information will be stored on a computer that is password-protected.
Any information in paper form will be stored in a locked cabinet within a restricted access office at the University of Glasgow.

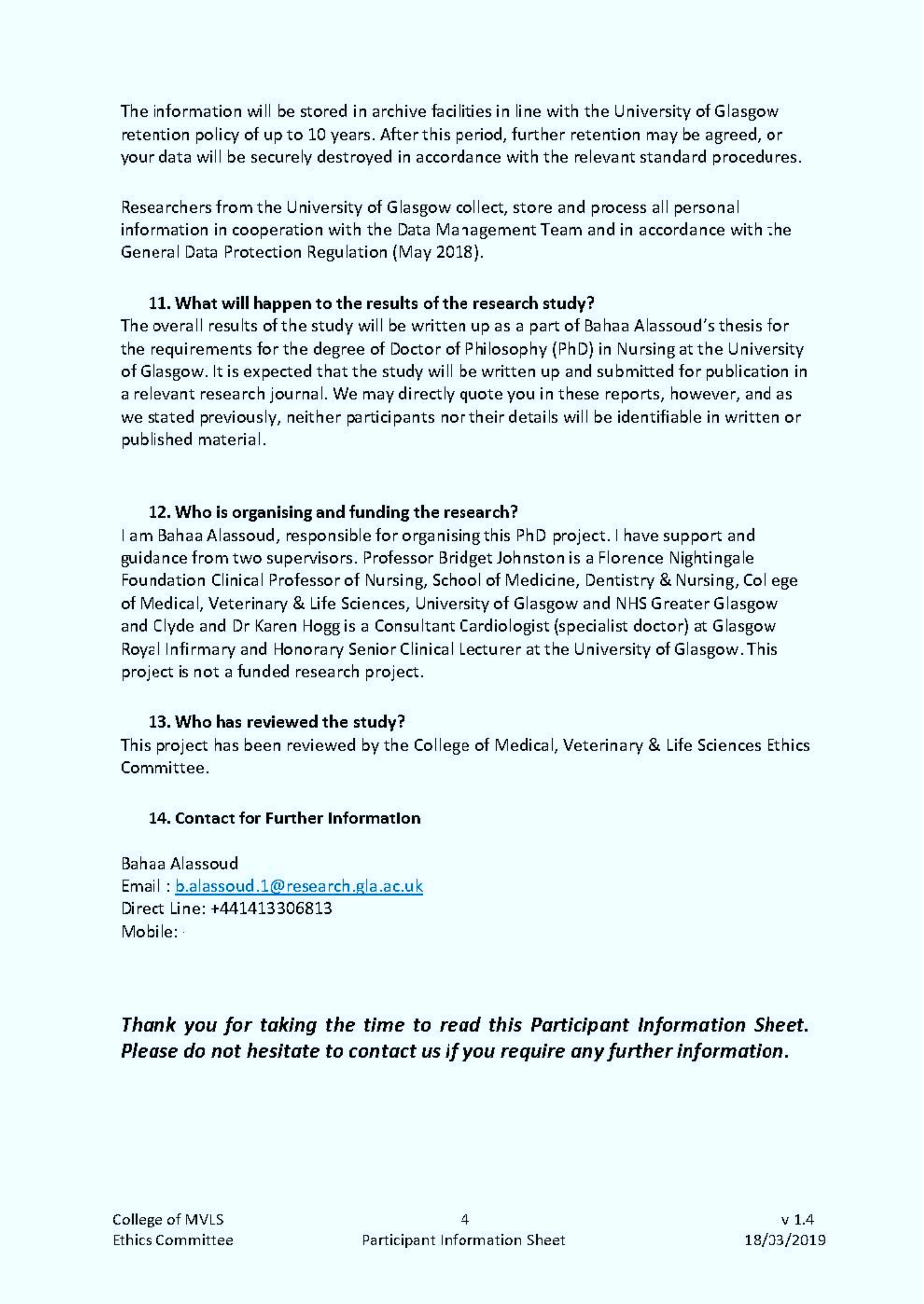
There will be ground rules for all participants to adhere. These rules will highlight the importance of maintaining confidentiality around the discussed topic. Please note that confidentiality will be strictly adhered to unless risk or evidence of serious harm is uncovered. In such cases, the University may be obliged to contact relevant legal bodies.

What will happen to my data?

The researcher will convert all voice-recordings from the group meetings to written scripts. This means they will be made into an exact document of what was said by everyone in the group meetings.

This document will be analysed by the research team, who will produce a report on the themes discussed in the group meeting. The results may be published in scientific journals, presentations, student thesis for other researchers to use.

There will be no identifiable information included in any of these publications.



The information will be stored in archive facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, further retention may be agreed, or your data will be securely destroyed in accordance with the relevant standard procedures.

Researchers from the University of Glasgow collect, store and process all personal information in cooperation with the Data Management Team and in accordance with the General Data Protection Regulation (May 2018).

11. What will happen to the results of the research study?

The overall results of the study will be written up as a part of Bahaa Alassoud's thesis for the requirements for the degree of Doctor of Philosophy (PhD) in Nursing at the University of Glasgow. It is expected that the study will be written up and submitted for publication in a relevant research journal. We may directly quote you in these reports, however, and as we stated previously, neither participants nor their details will be identifiable in written or published material.

12. Who is organising and funding the research?

I am Bahaa Alassoud, responsible for organising this PhD project. I have support and guidance from two supervisors. Professor Bridget Johnston is a Florence Nightingale Foundation Clinical Professor of Nursing, School of Medicine, Dentistry & Nursing, College of Medical, Veterinary & Life Sciences, University of Glasgow and NHS Greater Glasgow and Clyde and Dr Karen Hogg is a Consultant Cardiologist (specialist doctor) at Glasgow Royal Infirmary and Honorary Senior Clinical Lecturer at the University of Glasgow. This project is not a funded research project.

13. Who has reviewed the study?

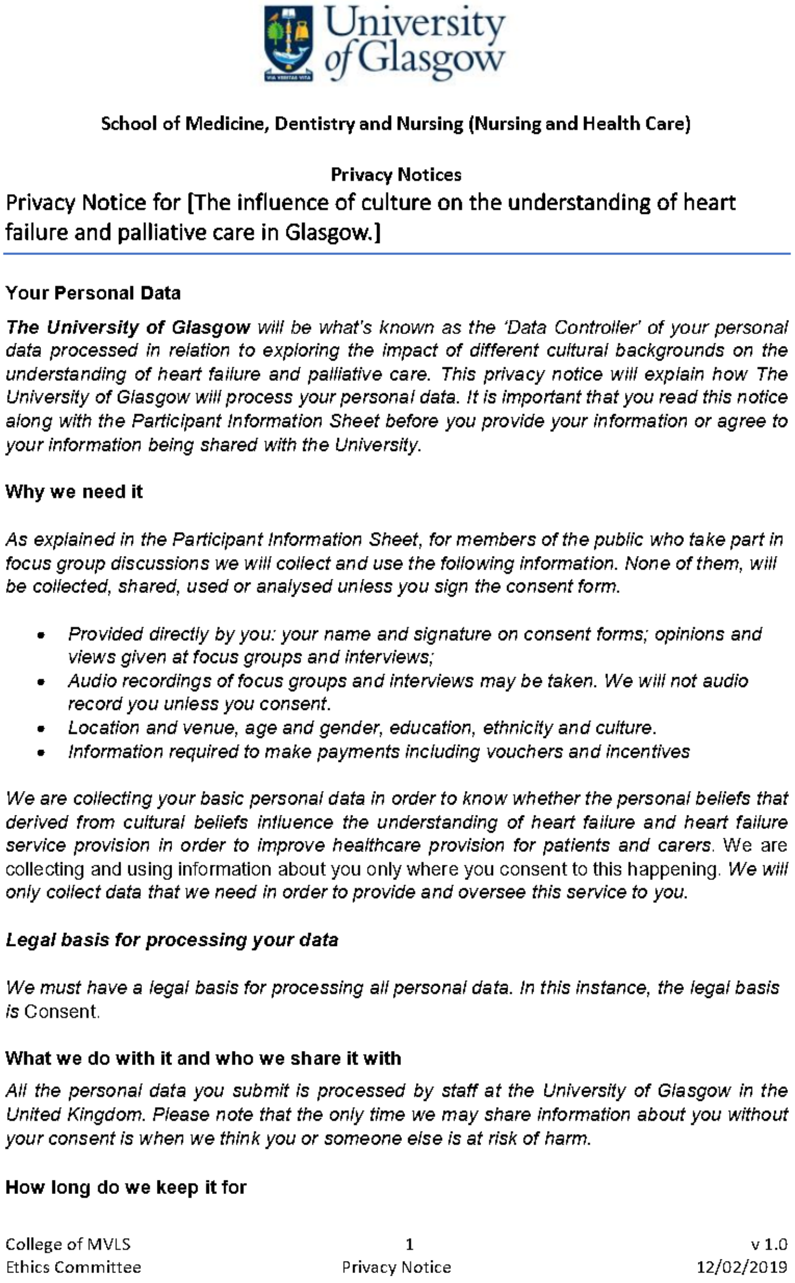
This project has been reviewed by the College of Medical, Veterinary & Life Sciences Ethics Committee.

14. Contact for Further Information

Bahaa Alassoud
Email : b.alassoud.1@research.gla.ac.uk
Direct Line: +441413306813
Mobile:

Thank you for taking the time to read this Participant Information Sheet. Please do not hesitate to contact us if you require any further information.

D. Data protection- privacy notices form



School of Medicine, Dentistry and Nursing (Nursing and Health Care)

Privacy Notices

Privacy Notice for [The influence of culture on the understanding of heart failure and palliative care in Glasgow.]

Your Personal Data

The University of Glasgow *will be what's known as the 'Data Controller' of your personal data processed in relation to exploring the impact of different cultural backgrounds on the understanding of heart failure and palliative care. This privacy notice will explain how The University of Glasgow will process your personal data. It is important that you read this notice along with the Participant Information Sheet before you provide your information or agree to your information being shared with the University.*

Why we need it

As explained in the Participant Information Sheet, for members of the public who take part in focus group discussions we will collect and use the following information. None of them, will be collected, shared, used or analysed unless you sign the consent form.

- *Provided directly by you: your name and signature on consent forms; opinions and views given at focus groups and interviews;*
- *Audio recordings of focus groups and interviews may be taken. We will not audio record you unless you consent.*
- *Location and venue, age and gender, education, ethnicity and culture.*
- *Information required to make payments including vouchers and incentives*

We are collecting your basic personal data in order to know whether the personal beliefs that derived from cultural beliefs influence the understanding of heart failure and heart failure service provision in order to improve healthcare provision for patients and carers. We are collecting and using information about you only where you consent to this happening. *We will only collect data that we need in order to provide and oversee this service to you.*

Legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis is Consent.

What we do with it and who we share it with

All the personal data you submit is processed by staff at the University of Glasgow in the United Kingdom. Please note that the only time we may share information about you without your consent is when we think you or someone else is at risk of harm.

How long do we keep it for

College of MVLS 1 v 1.0
Ethics Committee Privacy Notice 12/02/2019

Your data will be retained by the University, either on paper or recorded electronically, will be stored in secure locked cabinet in the university's Nursing and Health Care Department or on University systems for 2 years. *After this time, data will be securely deleted.*

What are your rights?*

You have the right to access the personal information that is held about you by the University. this is called a Subject Access Request (SAR), further details are set out on the University's data protection and freedom of information webpages.

https://www.gla.ac.uk/myglasgow/dpfoioffice/a-ztopics/subjectaccessrequestsar/

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or, erased. You may also have the right to object to the processing of data and the right to data portability.

Where we have relied upon your consent to process your data, you also have the right to withdraw your consent at any time.

If you wish to exercise any of these rights, please contact dp@gla.ac.uk.

Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer who will investigate the matter.

Our Data Protection Officer can be contacted at dataprotectionofficer@glasgow.ac.uk

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/

☐ I consent to the University processing my personal data for the purposes detailed above.

I have read and understand how my personal data will be used.

Signed: ……………………………………………………………………………………

Date: ………………………………………………………………………………………

E. The informed consent form

University of Glasgow | College of Medical, Veterinary & Life Sciences

Centre Number:

Project Number:

Participant Identification Number for this trial:

Title of Project: The influence of culture on the understanding of heart failure and palliative care in Glasgow.

Name of Researcher(s):

Bahaa Alassoud
Professor Bridget Johnston
Dr Karen Hogg

CONSENT FORM

	Please initial box
I confirm that I have read and understood the Participant Information Sheet version v1.4 dated 18/03/2019.	☐
I confirm that I have read and understood the Privacy Notice version v.1.0 dated 12/02/2019.	☐
I have had the opportunity to think about the information and ask questions, and understand the answers I have been given.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.	☐
I confirm that I agree to the way my data will be collected and processed and that data will be stored for up to 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations.	☐
I understand that all data and information I provide will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of researchers.	☐
I agree that my name, contact details and data described in the information sheet will be kept for the purposes of this research project.	☐
I understand that if I withdraw from the study, my data collected up to that point will be retained and used for the remainder of the study.	☐
I agree to take part in the study.	☐

I agree to my interview/focus group being audio-recorded. ☐

I understand that the recorded interview/focus group will be transcribed word by word and the transcription stored for up to 10 years in University archiving facilities in accordance with Data Protection policies and regulations. ☐

I understand that my information and things that I say in an interview or focus group may be quoted in reports and articles that are published about the study, but my name or anything else that could tell people who I am will not be revealed. ☐

Name of participant	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

(1 copy for participant; 1 copy for researcher)

F. Focus group topic guide

School of Medicine, Dentistry and Nursing (Nursing and Health Care)

Focus Group Topic Guide – Members of the Public

Project Title: The influence of culture on the understanding of heart failure and palliative care in Glasgow.

Preparation

- Prior to the group's arrival, set out chairs so that everyone can see each other, and have consent forms ready for distribution. Test the recording equipment to ensure that everyone will be able to be heard.
- As the group arrive, introduce yourself and thank them for coming. Get each participant to sign two copies of the consent form (v1.3 18/03/2019), retain one copy and return the other to the participant.
- Once everyone is settled, go around the group and get everyone to introduce himself or herself. Use this opportunity to map out where everyone is sitting, to assist with note-taking.

Begin by reading out the following confidentiality statement:

All information which is collected about you, or responses that you provide, during the course of this project will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name removed so that you cannot be recognised from it. Please note that confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases, the University may be obliged to contact relevant statutory bodies/agencies.

Ensure that everybody is happy with this statement and answer any questions they may have regarding it.

Finally, ensure that nobody objects to the use of electronic recording equipment. If everybody is happy, switch on the recorder and begin the focus group.

Introduction

Begin by stating the purpose of the focus group. A statement such as this may be read:

Thank you very much for taking the time to participate in this focus group. The aim of this group is to explore the influence of culture on the understanding of heart failure and palliative care in Glasgow. There are no right or wrong answers or opinions, and I hope that everyone will be comfortable sharing what they think and feel about this subject.

Key Questions

The remainder of the focus group should be structured around the following key questions/domains. The focus group is intended to be largely unstructured, however, these key questions should be asked at some point, unless they arise naturally during the discussion. The questions were identified using the three domains and the nine constructs of PEN-3

Cultural identity (person, extended family, neighbourhood)

- What are your thoughts on how people in this community understand Heart Failure?
- Do you personally know someone who has Heart Failure?
- What do you believe is the cause of Heart Failure?
- What do you believe will help people get through such disease?
- What factors do you think influence treatment decisions and behaviours?
- What do you see as the most effective way to help people who have Heart Failure?
- What specific cultural beliefs about individuals with Heart Failure are characteristic of your culture?
- Have you heard of palliative care? What is people's understanding of palliative care? *(spontaneous and prompted)*
    - What do you think palliative care aims to achieve in Heart Failure?
    - What services exist for heart failure palliative care?
    - Do you know the difference between the provision of palliative care for patients with heart failure and cancer?
    - How are palliative care services accessed?
    - What does the community want to know about palliative care?
- Who do you go to when you have any questions?

Relationships and expectations (perceptions, enablers, nurturers)

- What are your thoughts on the relationship between people's knowledge and people's understanding of heart failure?
- What are your thoughts on the relationship between incomplete understanding heart failure signs and symptoms and health behaviours?
- "Comprehensive understanding of Heart Failure is a facilitator for self-care": What does this mean to you?
- How well do you feel healthcare providers understand the special needs of your culture?
- Have you attended any educational session provided by healthcare professionals? If yes, was it too generic?
- What do you think is the most culturally competent way of information giving and communication about goals of care?

Cultural empowerment (positive, existential, negative)

- How does being ( ) influence your understanding of heart failure?
- To what extent do you think people with heart failure have a problem in accessing healthcare services due to cultural barriers? *(spontaneous and prompted)*
    - Explain how it is a problem
    - How do you deal with the challenges?
    - Do you think there could be some improvements that would make it more accessible to you?
    - What other suggestions do you have to overcome these barriers?
- Who influences your understanding of heart failure and palliative care and your subsequent decisions?
- How could local healthcare facilities encourage your community to seek care?
- How you identify appropriate ways to improve access to Heart Failure palliative care clinics in Glasgow.
- What do you see as the strengths and the weaknesses of palliative care? What are the 'pros and cons'?

Debriefing and Reflection

Reflecting on the focus group conversation that you participated in, what is your view/thinking/feeling about the state of multiculturalism in Glasgow and its healthcare system?

Concluding the Session

Once the session reaches a natural conclusion, or if the time limit of approximately one hour is being exceeded, recap the main points discussed. This may or may not elicit further responses, and these should be welcomed. Thank everyone for coming, switch off the recorder, and ensure that all consent forms are accounted for. Make sure participants have contact details for the research team (on Participant Information Sheet v1.4, 18/03/2019) should they need any more information.

Appendix V- Supplemental Information for data analysis

A. Steps to ensure the methodological quality

In this qualitative inquiry, the researcher is the data collection instrument, analysis, and construction of findings. The study followed criteria and an accompanying strategy to ensure its methodological strength and foster confidence in its findings. This qualitative investigation focuses on credibility, transferability, dependability, confirmability, authenticity, and reflexivity.

Credibility

Credibility has been defined as the extent to which the findings truly reflect the participants' realities described in the focus group (Denzin and Lincoln, 1994, Denzin and Lincoln, 2011). However, it is acknowledged that the study addresses nature from a critical realist perspective of one reality that exists independently of human knowledge. Credibility was ensured using member checking and triangulation in analysis. Member checking was the primary method of ensuring that the analysis was grounded in participants' experiences. Triangulation was achieved by peer checking and validating coding, theme construction, and interpretations to confirm that the findings were consistent and the analysis was not biased. In addition, the multiple professionals, patients, and caregivers, and public perspectives within the research team, including PPI advisers, who also checked initial interpretations, have further enhanced the credibility. Credibility was also maintained by peer checking, prolonged engagement and observation, and authenticity. The research team engaged with the topic throughout the 1-year duration of the study, including the 4-month data collection period; prolonged engagement was applied. However, persistent observation was not possible due to practical constraints. Credibility was attained by using an audit trail and being thorough in every step of the text analysis, including debating and questioning for and against interpretation. The qualitative research training concerning interview and focus group techniques and the analysis of the data collected enhances the credibility of the researchers. In addition, the author has previously conducted qualitative research using semi-structured interviews.

Transferability

Polit and Beck (2017) described transferability as a quality measure that establishes to what extent the research findings have applications outside of the study and can be transferred to other contexts or settings. While recognising the inevitably limited generalisability in this qualitative research, the investigator has been explicit about all aspects of the study, including its strengths and limitations. Furthermore, transferability was enhanced by providing sufficient and thick details of the underpinning philosophy, methodology, and method decision making, as well as the detailed description of the research context and participants (Hallberg, 2013). These accounts allow researchers to judge whether or not the research is applicable, and the extent of its application. Furthermore, to enhance the transferability, participants were recruited through non-probability purposive sampling, which includes members of the public from seven different cultural groups. As a result, the broad participation of people from various cultures and the brief demographic details were obtained during data collection, enhancing the generalisability of the study. Finally, transferability has been ensured by reflexive practice, adequate and purposive sampling documenting the steps taken in the research process, and allowed for replication.

Dependability

As stated by Lincoln et al. (2011), dependability is broadly associated with transparency, which is a prerequisite for credibility and parallel to reliability (Denzin and Lincoln, 2011). It reports how well different researchers may audit the research decisions and rationale (Polit and Beck, 2017). To demonstrate dependability to any external reviewers means that the construct also indicates the stability of data over time and conditions, and the replicability of the study processes. Dependability was ensured by applying the correct methodology and methods for the research question and ensuring its appropriateness, to avoid method slurring. In this study, dependability was associated with a clear audit trail, evidenced by prolonged and persistent engagement, member and peer checking, triangulation, and reflexive practice. The researcher facilitated this by providing a detailed description of the documented paradigm and trackable process throughout the study life cycle, including study assumptions, reflexivity, and methodological decisions (i.e. recruitment, data collection, and analysis). Finally, the use of similar measures, such as the hypothetical scenario and questions across focus groups. However, the departure from the traditional method of data collection to the use of vignettes may affect or limit the dependability of the findings.

Confirmability

Confirmability denotes how objective the researcher was when analysing the accuracy, relevance, or meaning of the data. Lincoln et al. clarified in 2011 that this measure involves the extent to which the analytical process was centred on participant accounts which demonstrate the integrity of findings and is devoid of any potential biases (Denzin and Lincoln, 2011, Polit and Beck, 2017). The current research therefore included reflexive statements in the discussion chapters covering the whole research process. In addition, the researcher sought consultation (member checking and peer checking) for the research findings as part of the analysis in the service of confirmability. The main strategies for demonstrating confirmability in this study were audit trail and triangulation, member checking, bracketing the researcher, and establishing reflexivity during the research process. Finally, authenticity relates to how emotionally candid the researcher is, which is again a function of self-reflexivity, demonstrated in the current research through reflexive statements.

B. Sample part of an anonymised transcript

So what do you think the community understands by the term heart failure or palliative care?

R2: Heart failure, almost everybody knows that the heart is not working fully. That's what their understanding is. That the heart is not working fully. Palliative care, there are misgivings about it. Quite a lot. And a lot of people think that it is terminal care when you are given palliative care. That means there is no cure for anything and you're just passing the time. That is the understanding at the moment.

I: Do you think it's there, this understanding, that the heart is not working, do you think it's there for all people?

R2: No. It can be any…younger as well. But that's what they will understand, that yes, the heart is not working. But they understand probably better if you tell them what is it that your heart is working, 40 per cent is working, 30 per cent is working, 60 per cent. But they do understand that.

I: But like is it in general community perspectives or it's personal perspectives?

R2: General community, that's my view anyway.

I: Any other thoughts? When you hear the word…

R9: When you're that age, I don't think they have that understanding.

R2: No, not that person, no.

R9: No, not that person. But generally, in the community I think the younger people understand more than the older generation.

R3: Maybe palliative care is the one that the doctor was saying is…in the Indian community they relate it to cancer more than the heart. I mean that's the… If somebody said palliative care, I would just think of terminal cancer. I wouldn't associate it with heart. But I didn't know that you got palliative care with heart conditions as well.

I: The issue with palliative care, it's kind of care focusing on relieving suffering by…whenever, in any condition. There is symptom burden, it's like the symptoms burden the person and affecting his quality of life. The palliative care for example in heart failure, working on just to control the symptoms, which is part of our study. So I'm with you that the trend is palliative care for cancer, and that's why this service is solely under used. People don't seek the service.

Maybe because they thought it's for cancer. Anyone who has…and it doesn't necessarily mean or reflect that people at the end stage should go for palliative care. Even when you have any troubles that are affecting your quality of life or symptoms that are affecting your life, you can see palliative care.

R2: Well I think it is that the consultant who is speaking to the family has to be careful, saying the word palliative care. Rather he could say no, we don't have a cure but we can make his symptoms better by doing this and this. Rather than using the word palliative, which will be taken badly.

I: Yes.

R2: That's what I meant.

I: Yeah, I totally agree with you. What do you think of supportive care?

R2: Yes, that will be fine. That will be taken fine. But palliative still may not be taken kindly.

R4: Also, palliative care, although we saw for the cancer, hospitals are not properly organised for that. They keep people so much under the influence of drugs, people don't know what's happening. And if the same patient is transferred to some other organisation like a hospice, life is much better there for them because the drug which is given to them is much lower and much controlled. And the patient is not feeling very painful and also, they can feel who's there. So I think the trend in the hospital is becoming so bad that if somebody is over 80, even the consultant says this person had a good life, I think now is the time for them to rest and go. I don't think palliative care is given very much to older people these days.

I: So more focus on the real meaning of palliative care you mean?

R2: Another thing is I think at that age if you are telling them all in English and you don't have an interpreter, in Punjabi, then it's a waste of time. Because that person will not understand anything.

R9: No.

R2: So they need to have translators there.

R4: Interpreters.

R2: Punjabi interpreters.

I: Are you happy with the current interpreting services?

R2: Well…

R4: It's pretty poor at the moment.

R9: I don't think they ask for it really to be honest. My mother never asks. She's in hospital just now, she's in her 70s going into her 80s. I've just visited her. She'll just wait until the family comes and then she'll get the family to… She will not ask for… She doesn't like to trouble anybody.

R4: Interpretation will be done by the family rather than…

R9: It'll be just done with the family.

I: And the patient won't ask anything because he or she won't make any burden over the family?

R4: No, to the hospital.

R9: No, they don't like to burden the hospital. So wait for the family to come.

R4: Our people don't demand things…

R9: Don't demand things at all.

R4: …what the locals do. So if I was a Scottish person, I'd say I need an interpreter now. Whereas our people say oh, my son will come and he will interpret. My daughter will come and interpret. So they don't even give…even if they're in pain they won't say.

R9: They won't.

R4: It's much easier…

R9: My mother would never trouble…

I: So what about when anyone goes to the hospital, what about the instructions like the [inaudible 9:12] discharge instructions, if there is no one who can speak English like very well.

R2: No, the youngsters can speak, most of them. It's the older generation.

R9: It's the older…

I: Yeah, I mean the older.

R4: Yeah. People like me. A health problem…

R2: Youngsters can speak, most of them.

R4: Most people at my age…

R2: Very few… But most of them can speak. It's the older generation that…

R9: Yeah. The first generation that came, they're the ones that obviously…

R4: They're the most suffering.

R9: Yeah. They're not illiterate but they just didn't need to speak, so they didn't learn. Some of them learnt, some of them didn't. I'm not saying…the majority…they don't like to trouble anybody.

R4: I have experience of two members of my family going to hospital and the palliative care was terrible for my mother, and she was always drowsy. You couldn't speak to her.

I: So this is why we are here. So what do you prefer, the palliative or the supportive care to look like? It's like what I understand, you need to relieve her pain but at the same time for her to stay awake and communicate with her.

R4: Awake, yeah, that's what it should be. That's what it should be and I also work, as I said, with the body which is not a hospital but does the same job as the NHS. People over there have a much better life. They have more sense in what they're doing and they can feel, they can talk, and their pain is controlled. That's what it should be. If a body like a hospice can do it why can't the hospital do it?

I: So you feel that the hospice is doing this job more…

R4: Much better, yes. People are much happier there when they go there. Unfortunately, there are not many hospices around. But they are overworked. People don't get a place. If somebody is seriously sick… My friend's wife was seriously bad and we asked for a hospice for them, they said there's no place. She suffered in hospital.

I: They are introducing a new hospice for Glasgow, a big one…

R2: That has been open…that is opened with the… in the sense that it has changed from one place to another. So they have slightly increased that.

R4: No, the same beds more or less.

R2: Oh, the same beds. One or two increase.

R4: Yeah, two extra.

R2: So it's new in the sense that they have changed building.

R4: It's a new building.

R2: New building. But it was there already.

R2: No, it was already there…

R4: There was a hospital in Greenock. My friend lives in Greenock, when his wife was sick. So they couldn't give her a place anywhere in a hospice.

R9: She was in hospital.

R4: She was terrible there, always paining.

I: So in this regard do you think in general people in this community and culture would prefer such a case? Mr Gudgid to be treated at hospital, home or hospice if you like?

R2: I think probably it will be better to be treated at a hospice.

C. Sample focus group summary- first level coding

[redacted]

During this focus group, the biggest uncertainty and need were demonstrated in relation to the participants' lack of understanding about this condition. The overwhelming majority of participants expressed their need to know more about heart failure and palliative care thereof. The interviewee enjoyed the opportunity for reflection on health, culture and religion. It provided a clear window into what they understood and how these understanding. This was evident by most of their input coming in the form of questions.

Four principal codes discussed concerning the cultural influences on the understanding of heart failure and palliative care, as follow :

- The understanding of heart failure.
- The understanding of palliative care.
- Care preferences, procedure and outcomes.
- Advanced care planning.
- Death and Dying discussions.
- The intersection between culture and religion

First: The understanding of heart failure.

1. Participants seen unfamiliar with the term Heart Failure lack the understanding of the disease and the management thereof. The majority of participants expressed their need to know more about the condition itself and would like to understand where it comes from and what is palliative care can do for them. They stated that they were merely heard that a friend or a relative had this condition. However, when they have been told that heart failure is an incurable but treatable condition and would benefit from palliative care, some of them presume that nothing can be done for the patient.

2. Heart Failure was referred to as an another more updated name for heart attack. This was later justified by the participant (R2), who is in the late 60s, as a decade ago heart attack was heard a lot among this age group. With reference to a friend's story who was diagnosed with a heart attack years ago and end up having heart failure recently. It was seen then as being a consequence of age and other co-morbid conditions.

3. Perhaps some of our questions triggered off thoughts about heart failure. The brief explanation and several prompts from the facilitators gave participants the opportunity to start thinking about these issues and elaborate on their responses.

4. Every now and then, each participant was finishing each other's sentence, or confirm that with a reference to the case scenario. Most participants were nodding their heads in agreement while these comments were brought forward. Another participant commented "would that be standard to say you've got heart failure" he exclaimed, meaning that the term "heart failure" hadn't been used as a clue that this might be a bit scary or not standard.

5. The first paired conversation was made from two participants, there was a rich and full interaction as both participants had enough time to share their experience and views in details. Both participants are from the same age group, retired and have been living with their families. Both participants belong to the same culture and attending the same church.

Table 1: The understanding of heart failure

Respondent	Summary of comments	categories
R2:	I suppose it's somebody that had what used to be called a heart attack decades ago.	Lack of disease-specific knowledge, Critical health literacy, quality of health communications, meaning making or making sense of Hf
R7	I don't know if people are necessarily when they've had a difficulty with the heart …but I don't know if they're told at that moment whether that is actually heart failure or if they're just being treated for a heart which isn't working in the way it should.	
R8	can you have minor heart failure?	
R7	There would also be cases… you don't know about them, with undiagnosed minor heart failure	
R5	Can having other illnesses bring on heart failure?	
R3	When you think of these other illnesses would that include things like, say, arthritis or joint trouble or anything like that?	

R2	One of the concerns that many people would have, especially if they're under stress through serious illness	
R2	once people are starting to think of where they're going to go, what it's going to cost, what it maybe isn't going to cost, that would generate a level of stress. Stress I would reckon doesn't go well with advanced heart failure.	
R2	I know somebody, she has never used the word heart failure, who is in that kind of position… she was talking about being there to get particular treatment to do with the heart. I don't think it was treatment to bring about a cure but treatment to help. And she could spot some people being more agitated, more panicky, more on edge, more worried than others.	
R2	Maybe that term hadn't been used. I'm not sure, would that be standard to say you've got heart failure?	

Second: the understanding of palliative care

1. Participants had a distorted understanding of palliative care and the services they could offer. Palliative care is understood as a stage rather than a healthcare service. The initial reference to palliative care as (Nothing can be done), seems like participants were cure-oriented rather than care or treatment-oriented.

2. Mostly, participants had a strong focus on their experiences associated with people living in a terminal stage. Their understanding of terminal stages is the stage leading straight and directly to death, so people succumb to death's grip and families start to countdown to this grip as soon as they have heard the word palliative.

3. At least half of the participants demonstrated a lack of understanding of how palliative care could be helpful to manage heart failure. They believe that palliative care is only for dying people. None of them understands that palliative care is not associated with prompt death. This was clear when participants often refer to palliative care as end of life care terminal stages. This is maybe one reason why palliative care for heart failure has not been utilised by people optimally

4. The interviewee reflected on what they know about heart failure and palliative care and how they were making sense of the two terms by building on their experience and prior knowledge and understanding. This could potentially indicate that they were still in the process of assimilating new understandings with previously held information and experiences. Participants end up having a brief but clear understanding that people could have heart failure and receive palliative care for several years.

5. In terms of heart failure and palliative care, low (critical) health literacy was noticed among participants to influence participants' understanding. The current state of low health literacy could lead to additional misunderstandings by increasing the likelihood of complex terminology interpreting. Culture and religion played an important role in how people communicate, understand, and respond to health information, thus culture and religion impact health literacy or may create it.

Table 2: the understanding of palliative care

Respondent	Summary of comments		codes
R4:	A.	there can be nothing done for it	Misconceptions and lack of understanding of palliative care. Critical health literacy, meaning making or making sense of PC
R2	B.	can you have palliative care for several years?	
R4	C.	You'd have great empathy with him, with anyone who was in terminal state or palliative care.	
R8:	D.	We're talking about end of life care?	
R6:	E.	I know somebody at the moment that's in palliative, reached the palliative care situation in a hospital,	
R2	F.	she was talking about being there to get particular treatment to do with the heart. I	

		don’t think it was treatment to bring about a cure but treatment to help.	

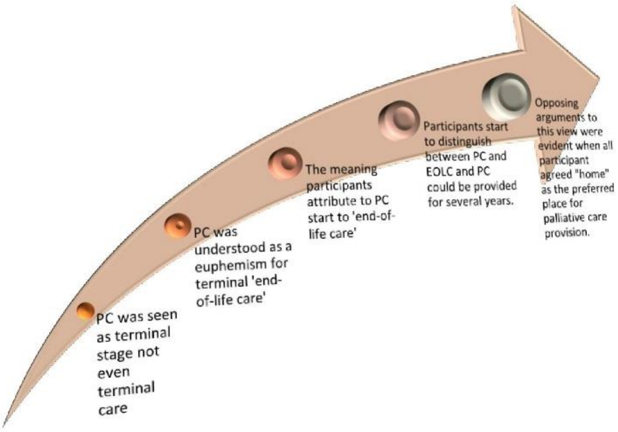


Figure 1: The meaning-making process of palliative care

Third: Care preferences, procedure and outcomes.

1. Participants personally think patients still want to be cared for at home if possible. If they cannot get enough day-care coming in at home, then the only alternative is to be in a hospice. They all have agreed that It is very much dependent on what is needed to alleviate symptoms and stabilise the case. However, the familiar and routine support after stabilisation is always preferred to be at home.

2. The hospital was preferred if it is close or specialist equipment is required but hopefully not for a long time due to several reasons i.e. hospital-acquired infections. The hospital policies regarding patient discharge *and it is practicalities were seen below optimal. The hospital* would discharge the patient either if they see that there was sufficient support at home or if there was not sufficient support at home. Mentioning that hospitals require beds to be cleared so will not assess the readiness of the patient's home before getting them discharged. Unlike the hospices, hospitals nowadays would not guarantee to consider the patients' Christian beliefs and would treat them the same as anyone else.

3. Participants expressed their preferred place of care to be outside the hospital setting and preferably at home, which may echo their wishes not to die at the hospital. Hospital settings were seen suitable on the short term, however, avoided and deemed unsuitable on the long run as in the case of palliative care service. Mostly participants felt the single -room structure in hospitals would intensify the feelings of loneliness and isolation if the patient is older or dependent in some cases. These disadvantages were perceived reasons, from participants' perspectives, for avoiding hospitals in such a case.

4. It was noted that all participants in this group discussion agreed that the preferred place of care is home. However, one participant changed his mind regarding their preferred place of care and add this comment (R7). Even though respondents were asked about the preferred place of care, their answers which would reflect that participants were unconsciously referring to the preferred place of death, rather than the place of care. The results illustrate that the place of care and death was seen as an integral part of the end of life process.

5. The preferred place of care was found dependent on the ability of family caregivers' readiness to cope with caring responsibilities. Almost all participants agreed on ”readiness” to be defined by two elements, the ability and willingness. In relation to this case, participants agreed that this old gentleman is less likely to die at home potentially due to his wife's abilities or age. Neither culture nor the lack of family support, access to home care, or amplified care needs, seems to influence participants decisions regarding the care or death preferences.

6. The conflict and stress arise when patients' preferred place of care and/or death wishes are not met or possible either due to the family being unaware of the

proximity of death or since securing a place in a hospice, for example, is not always guaranteed extends into the moment of death.

7. Three participants suggested that palliative care and end of life decisions should be first communicated with the wife or family before the disclosure of information to the patients. They were surprised that family are no longer in the position or allowed to decide on behalf of the patient.

8. In two cases, respondents have represented and made decisions on behalf of a member of the family who was entirely incapacitated.

9. Even though participants were mostly lacking sufficient understanding of palliative care provision at hospitals and hospices, their decisions regarding the place of care seem not to be negatively influenced by this knowledge deficit.

10. The last-minute nature of these complex discussions should be flexible and is not preferred to take place near the end of life to avoid creating more stress for the person and the family members.

Table 3: care preferences

Respondent	Summary of comments	codes
R2 [Agreement]	most people want to be at home.	Home is the preferred place for care, Family involvement and ability to cope, poor quality palliative care provided in hospital settings, The need for heart failure specific support groups, a need for understanding of care process and the financial side of it.
R4:	Do you think he still wants to be at home? Yes	
R7:	that necessitates getting specialist equipment in a big … I think the feeling would be get to hospital, get what's required for it to alleviate his symptoms, hopefully for not too long, but to get to the familiar circumstances of home.	
R7:	when you're in the hospital you have to take the food that you get, and then there's all this talk about the different bugs you can get while you're in hospital.	
R4 [Agreement]	Do you think the hospital would ask him and would respect his beliefs and would know what to do? Probably not.	
R6 R8 [Agreement]	Hospitals are quite isolating.	
[Agreement]	No day rooms anymore	
R4:	Can we not have more input into home care?	
R4:	people coming in in the morning, they're in for ten minutes and they're out the door again. I feel at times if more money was put into the medical and ordinary	

	care at home that would be a good thing, because people mostly when they come to this stage in life their partners, who will be their carers, are elderly too.	
R9:	It depends how his wife is and how supportive. Some people are so much better at coping with this sort of thing than others. Some people can turn their hand to nursing care in a way that perhaps others can't in the same way. I think a lot depends on her really and the rest of the family.	
R7 R5	If the care is possible at home then you'll want to have it there. And if care is not possible at home and if you can't get enough day care coming in at home then the only alternative is to be in… A hospice.	
R2:	One of the concerns that many people would have, especially if they're under stress through serious illness, would be what is going to happen here financially. There are certain establishments that I could possibly go to and there might be a huge financial implication, such as a care home. What about the hospice, is there going to be a financial implication; but the person might not have thought about the hospice, not knowing whether it's going to be free or there's going to be some kind of charge or whatever; what's going to happen to my pension; what's going to happen to this, that and the next thing financially.	
R9:	How long can you stay in a hospice? Because I remember trying to arrange my mother-in-law to go into a hospice and I was told no, because they're only really for people who have got about ten days to live. And at this point she had six months to live as it turns out.	
R6:	I was just wondering if there are any groups, like support groups, within the community specifically for people with heart disease … that might help them that also this sort of information could	

	be fed into the group in an informal way. I think there are.	
R4:	That's right. But someone there to look after them, someone who would come in for a couple of hours to sit with them.	
	They wouldn't be discharged if there wasn't sufficient support at home. No. [Agreement] R4: Because the hospital needs the beds. R1: Yeah. R4: There's a care plan.	

Four: Advanced care planning.

1. Advance care planning (ACP) was defined for the group as conversations with the patient and family to adjust aims of treatment and preference of care. But they have not certainly been accepted by some participants who have understood it incorrectly and confuses advanced care planning with organ donation. Some participants felt wary and/or chary of organ donation, one participant felt that donating organs to others through the government was detrimental and financially oriented.

2. beyond the cultural beliefs in the respective countries, the availability of services is likely to have a considerable influence on people's preferences. Participants saw themselves at a liminal state between encouraging people to commit ACP conversation and the "no-guarantee state" to get what you do prefer or at least a bed in a hospice when required.

3. Most of participants plans and decisions about how they want to live, to be treated and where to receive the treatment and die were essentially influenced by their religious and spiritual beliefs. Moreover, the majority of participants acknowledged that quality and strategy of communications when discussing the end of life plan should be congruent with the cultural and familial backgrounds of people to ensure the viability of these communications.

4. Death, dying and ACP conversations if tailored upon the lay understanding, as well as the plain communication, may reinforce the normalisation of these topics and the willingness of people to be engaged with such talks. Respondents in agreement see that people are becoming more open to speak about death and dying, at both the personal and public levels, and to bring their ideas to the forefront. Such discussions, including this focused discussion, perhaps are important to enhance and encourage the ACP dialogue and process. Further, to identify what people understand by these terms and what are the key factors that shape this understanding.

5. It was evident, many times, throughout the discussion the impact of some socio-cultural and religious norms in meaning-making of the end of life process or when a patient is terminally ill. The assigned meaning to care facilities, care provision, spouse's coping ability, family and friends' systems, the acceptance of death and afterlife, the acceptance of the caregiving responsibilities and fear and uncertainty about the financial implication of care were all influenced by the groups' cultural and religious identities.

6. Complex conversations were seen challenging due to the different perceptions of what constitutes the "peaceful moment". This understanding was driven by contextual and practical factors. From the socio-cultural context, the long-standing reluctance to engage in discussion about living with or dying from a chronic illness; peoples' reluctance to publicly, and to a certain extent personally initiate or even participate in death and dying discussion, and how they would prefer to be cared for at the end of their lives.

D. Sample cross-group final pattern coding

Preliminary transcript analysis

Name	Description
1. Culturally coined understanding of Heart Failure	Culture is a dynamic, ever-changing and constantly evolving system that incorporates concepts like race, ethnicity, ancestry, language, religion, and commonplace of origin. Culture creates a pre-understanding and shaped the personal worldview about HF as a life-limiting illness. Heart failure and palliative care are seen, defined and interpreted through personal and cultural lenses. These lenses determine and filter how people create meaning and make sense of the two terms by building on their experience and prior lay knowledge and understandings.
Findings: Across all focus groups, the most significant uncertainty and need were demonstrated concerning the participants' confusion or lack of understanding and familiarity with heart failure and palliative care. The overwhelming majority of participants expressed their need to know more about heart failure and palliative care thereof. The interviewee enjoyed the opportunity for reflection on health, culture and religion. It provided a clear window into what they understood and how these understanding. This was evident by most of their input coming in the form of questions. As a result of their confusion, they have been making sense and trying to understand HF through their illness experience or similar diseases or at least their experience of providing care for someone who has heart failure. All participants tried to define, interpret, or comprehend HF based on their culture's principles and belief systems. Confused or lack of understanding of heart failure resulted in all heart failure narratives emerging from their cultural understandings but was reproduced and reinforced through personal experiences. This could potentially indicate that they were still in the process of assimilating new understandings with previously held information and experiences.	
Sub-theme	Description
a. Confused or lack of understanding	There was limited awareness and understanding of HF among people interviewed from diverse cultural groups. Respondents seemed to lack the understanding of this disease or confuse heart Failure with other acute heart problems or diseases. While people exposed to the disease understood HF concerning their experience, they did not understand the causal pathway and confused HF with heart attack and other heart diseases. Confused understanding of disease owing to unavailability of other formal information resources and/or poor communication led them to understand HF through the cultural lens thoroughly
b. Create our pre-understanding or worldview about	The majority of participants have constructed the meaning of heart failure in line with the personalistic disease theory system by attributing the cause of this disease to supernatural powers. This was problematic as using the late explanatory

causality, prognosis, treatment	model to construct knowledge about the cause of heart failure will guide their attitude and decisions. Overall, these models avoid prognosis and vary in terms of symptoms, treatment and care, mainly when death is imminent
i. Cure culture	Some cultures have adopted curative cultural beliefs or a cure culture that contradicts culturally and religiously with the biomedical understanding of this disease. Culture has a massive impact on all related processes. The pre-understanding of life-limiting illnesses created by cultural worldviews impacts people's understanding of palliative care services, the need for palliative care, and when to seek palliative care services.
ii. Clinicians' beliefs in curative medicine	Cardiologists are reluctant to address patients with heart failure more holistically. It could be because they believe more in curative rather than palliative medicine, or maybe due to being unable to meet these holistic needs or the fear of introducing something that contradicts patients' cultural and religious needs. Noteworthy, this attitude is perhaps stemmed from a lack of trust, expertise or understanding of the use of PC in HF.
c. Understanding HF through experience	Participants understandings of heart failure and palliative care were not based on biomedical knowledge and understanding of the disease. Instead, people use the experience-based lay knowledge to make sense of them in terms of their illness experience and its burden or impact and the consequences of living with such incurable disease. Experiences of suffering were given meaning through preconceptions, worldviews and cultural understandings.
d. The understanding of palliative care.	Having a life-limiting illness such as heart failure is challenging the pre-understanding and worldviews of people. Their understanding of terminal stages is the stage leading straight and directly to death, so people succumb to death's grip and families start to countdown to this grip as soon as they have heard the word palliative. Cultural beliefs and values are commonly used as resources to redefine and renegotiate the meaning ascribed to these diseases and a coping mechanism during these critical stages. The culture was found to play a vital role in shaping the understanding of palliative care, how important it is and who can seek the service at the end of life. Despite the participants' distorted understanding of palliative care and what the service can offer to people living with heart failure, people reject it and prefer to pursue a curative

	option. The persistent reference to palliative care as Nothing can be done confirms the cure-orientation of some cultures. For those who already accessed palliative care, this cure culture led them to remark the service as futile or not working. In some cultures, people denied the inevitability of living with HF without cure and preferred to seek help from other non-biomedical identities. People may exhaust all other alternatives before moving from denial to acceptance of palliative care.

E. Summary of data analysis and the contibution of authors.

Familiarisation	The seven focus groups were transcribed and translated when necessary. Transcripts were consistently read and checked against the recording for accuracy purposes by BA and BJ. The investigators became immersed in the data by repeatedly reading and listening to transcripts, recordings, and notes. The thorough reading and the iterative process allow the generation of initial codes and the identification of meanings and patterns of the participants' accounts relevant to the research question.
Generating initial codes	This comprises an in-depth individual transcript analysis followed by a cross-cutting analysis. The individual group analysis helped to follow discussion threads and then condensed them into key influenced domains. The cross-cutting analysis was used to understand patterns across cultures and communities and to reflect past and current understandings. The analysis began as data driven (semantic), and as the coding progressed it became increasingly researcher developed (latent).
Constructing themes	Following the creation of codes in NVivo, these were reviewed with the journaled notes for connections, categorised, and allocated to parent codes. The grouping allowed the combining of related concepts, considering how combined codes could best capture the patterns across the datasets and then create preliminary themes. An early review and refinement of the steps for codes was necessary and resulted in a more in-depth understanding of the data and a significant shift to the hierarchical relationships of codes.
	Codes with a high degree of similarity were merged, and codes with similar meanings were grouped as parent, child, and grandchild nodes, while codes that did not capture the required pattern were discarded in NVivo.

	The search for themes was done inductively and situated in the contextualistic critical realist position. Once the initial codes had been exhausted, they were collated into a list. The codes were then sorted into themes by searching for ways to answer the main research question and capture the research aims.
Reviewing themes	This stage involved reviewing the preliminary themes by revisiting the dataset, codes, notes, and reflections to represent accurately. The revisiting of the data allowed the capturing of any relevant data that might have been missed initially before refining themes. An initial thematic map was created for visualising codes, themes, connections, and the relationships between them. The review processes were discussed and cross-checked to assess whether the codes within the themes were appropriate, and to increase the reliability of the findings. While coding was underpinned by an 'experiential' framework that prioritised respondents' meanings, perceptions, experiences, and interpretations, themes were refined and reviewed by BA, BJ and KH based on the interpretative approach.(1).
Revising	BA defined and labelled themes by producing names that captured the essence of the dataset contained within each theme. Supervisors approved the candidate themes and labels and the relationships identified.
Report production	Answers to the case scenario were condensed into text summaries that focused on key influenced domains, which have many benefits and can potentially generate rich and meaningful codes and allow a deeper interpretation of the data. The final themes incorporated a description of each theme with direct quotes from the data to demonstrate its representation.
(1) The individual case and cross-cutting analysis of transcripts along with the researchers' realist position have facilitated the development of reflexive interpretations not only present in the accounts of the participants but also the hidden contextual meanings.	

F. Reflection after the first focus group session

The best start in the series of cultural impact
(中国文化)

For the past 16 months, I have been studying a new exciting topic: the impact of culture on understanding heart failure. This PhD project aims to develop an intervention to help make healthcare services in Glasgow more culturally sensitive. At the current stage, we are interested in exploring the influence of culture on the understating of heart failure and palliative care in Glasgow. We plan to conduct 6-8 focus groups with members of the public from the main cultural backgrounds in Glasgow. We are recruiting for these focus groups at the public community centres. Recruiting participants from different cultural identities is challenging, difficult, problematic, and extremely rewarding.

That is why we have started with the Chinese community

Last Wednesday, I had my first focus group discussion with a lovely bunch of people from Chinese culture. It was a lovely, exciting opportunity for me to listen to the participants share thoughts and discuss the disease and culture in nearly an hour. I have not chosen to conduct the first one with the Chinese community. However, people and the liaison lady were the most interested, cooperative, and enthusiastic among other groups during recruitment. The liaison lady responded to my announcement that my study got approved by the University of Glasgow relevant ethics committee “we do not waste any opportunity to socialise, interact or benefit people living in Glasgow”. She also added, “we are undoubtedly happy to participate in this focus group” those were words I will never forget.

Now, I am reflecting on the first conversation of my focus group sessions. This experience was not easy for me as it was the first one in this series. Having nine participants interacting with one another in a facilitating discussion was just too scary for me. Also, being with my professor in my first focus group will add extra pressure on me, and I won’t be able or free enough to focus on what I am here for. However, soon after, we start the discussion by introducing the topic. I felt extensive support.

On that day

I have arrived 30 minutes before the beginning of the focus group. I prepared the room environment to be appropriate and convenient for the participants. Chairs were arranged around the table so that everyone could see each other. Several booklets and leaflets were available to view on the side table. The Chinese pastry tea and coffee were also available on the round table so that all participants could reach/access them

On arrival

I have repeatedly introduced myself and thanked everyone for coming. Then, get each participant one information sheet to read again if they did not have the chance to read it thoroughly and two copies of the consent form to sign plus the privacy notice. As I was supposed to facilitate this focus group, I have started by greeting people and introducing the research team. I also gave a short introduction about the purpose of the focus group, Confidentiality and ground rules.

In our discussion together, we discussed the influence of Chinese culture on the understanding of the disease. All participants were willing and happy to discuss that openly and honestly and that cultural influence is authentic for each of the participants. We have started the conversation but introducing each other, which created a level of familiarity with the people and focus group environment. Then, I have asked the first question, which was if anyone knows someone who has heart failure. Some hands were up saying yes. Then, another lady replied, questioning has or HAD? She refers to her mum, dad and older brother, who died of heart disease.

The focus groups were positive and went extraordinarily well. All participants were friendly, talkative and willing to participate in the discussion. When my professor took over, I breathed a big sigh of relief. I was conscious that it was my first time ever leading a focus group with people I did not know. So I felt that I hoped if I have the time to establish the rapport. However, there was no time as it was a one-off focus group discussion, and more luckily, there were no issues here.

Also, they were a very diverse group, and each one came from a different field, i.e. social workers, housewives and one retired nurse who served in the NHS for more than 35 years. This retired gentleman has added a different flavour to the discussion. Having a colleague who has extensive experience always makes the discussion even more interesting when the issue of comparison between healthcare services before nearly three decades and what we can see now in the healthcare settings gets thrown on the table.

After the first focus group

I start to release the benefits of holding six focus groups. The first session will contribute to a better second session. It is a tremendously personal and professional learning experience. The first meeting has highlighted some areas for improvement, gaps to be maintained, and some strong arguments to rely on in the second group. I was cautious not to waste their time and hold them for more than an hour or drag them away from the discussion. They were doing me a favour by taking part. Hence, I stuck to the rules and asked the questions I had decided to do initially because of the fear that I did not want to poke my nose into their personal lives and make sure that we stayed on topic.

Nevertheless, upon reflection, I realised that this was the wrong approach and the road not taken. When my professor started to take over, some of the best information came when it was least expected. Also, participants bounced a couple of exciting ideas and encouraged conversation, which made me think that her approach is always the best. On the other hand, I misunderstood the idea of being sticky to formality in the focus group discussions. I realised that building your questions on participants' responses with less formality would eventually build trust and create a friendly atmosphere. Luckily, all participants became more comfortable, and the responses became more focused, creating a spirit of optimism, harmony and cooperation.

Of the things I was aware of and found difficult was the liminal state between my desire to engage everybody in the discussion and respecting participants desire to remain quiet. Luckily, my professor has helped me with that and relieved me by motivating most of them to participate. She encouraged a participant who remained quiet in the first 10 minutes by pointing a question directly to him, and he was happy to answer. My understanding of the focus group etiquette is that if any participant didn't want to be involved in this bit of the focus group for a reason, I should not be directing any question to him as he will feel uncomfortable and leave the discussion. However, my professor has perfectly done that, and this went smoothly and happily.

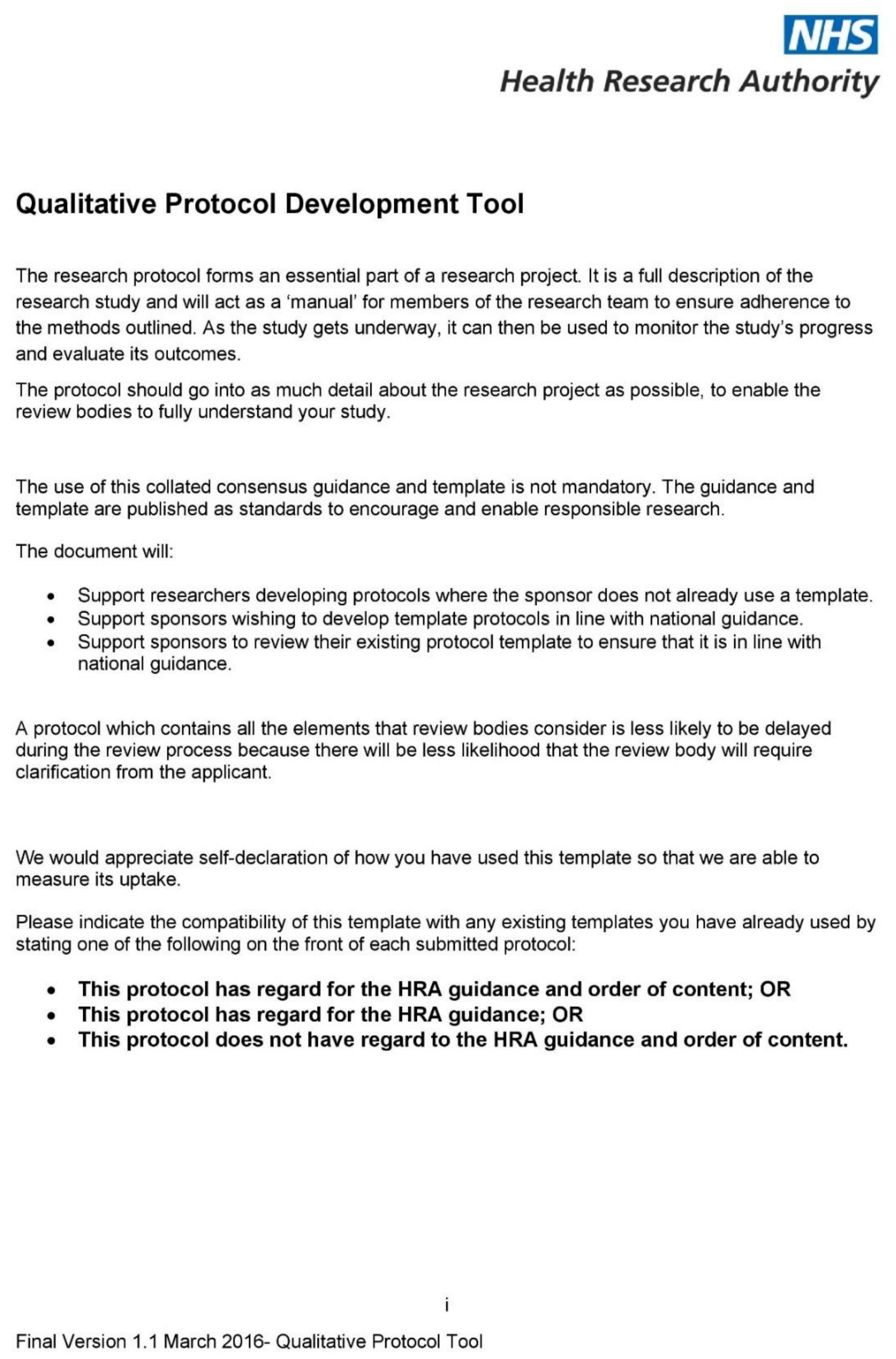
Overall, I think the first focus group went successfully, and I am genuinely pleased with how it went. I got some insightful, quality information out of it. However, I would recommend spending some time at the beginning of each focus group to break the ice and get a sense of their personality. This would allow you better to understand the participant’s preferred way of communicating.

中国糕点和小圆面包(deeply rooted in the Chinese culture)

Food is fundamental in the Chinese culture and providing food is a sign of hospitality. The participants did not expect the Chinese food to be provided. Even though they are familiar with western meals, they still prefer their cultural food. I provided them with some Chinese buns, tea and coffee. They felt more welcomed and enjoyed the authentic Chinese buns. I was surprised when I saw the participants were curious to try the food before the commencement of our discussion. I felt that being interested in the food has contributed to better engagement with the discussion. I planned to invite them to try them after we finished the discussion. Impressively they all went, which I considered a significant achievement. I brought more food than they may eat or want, which is a sign of hospitality in our culture. However, I was aware that food has high importance in Chinese culture, and wasting food is discouraged. Therefore, I think it was an excellent idea to let people treat and introduce themselves, and then the moderator can take over and start the discussion.

Another point is to keep audio recording until all participants leave the room. In my opinion, this is something I would not have thought of before, but I found that once the focus group had officially finished and we had turned off the recorder, people were debriefing with each other across the table and asking the liaison lady for her opinion. In doing so, some insightful comments were discussed, and feedback was given, which were not captured on record. So, finally, my first focus group, by all accounts, was successful. Honestly and personally, I did not know that much about Chinese culture other than what I found in my first study and what I ended up with from my scoping and reading, so it was a case of ensuring that I was comfortable just as much as they were.

Appendix VI- Phase 2 e-Delphi meeting with healthcare professionals



NHS
Health Research Authority

Qualitative Protocol Development Tool

The research protocol forms an essential part of a research project. It is a full description of the research study and will act as a 'manual' for members of the research team to ensure adherence to the methods outlined. As the study gets underway, it can then be used to monitor the study's progress and evaluate its outcomes.

The protocol should go into as much detail about the research project as possible, to enable the review bodies to fully understand your study.

The use of this collated consensus guidance and template is not mandatory. The guidance and template are published as standards to encourage and enable responsible research.

The document will:

- Support researchers developing protocols where the sponsor does not already use a template.
- Support sponsors wishing to develop template protocols in line with national guidance.
- Support sponsors to review their existing protocol template to ensure that it is in line with national guidance.

A protocol which contains all the elements that review bodies consider is less likely to be delayed during the review process because there will be less likelihood that the review body will require clarification from the applicant.

We would appreciate self-declaration of how you have used this template so that we are able to measure its uptake.

Please indicate the compatibility of this template with any existing templates you have already used by stating one of the following on the front of each submitted protocol:

- **This protocol has regard for the HRA guidance and order of content; OR**
- **This protocol has regard for the HRA guidance; OR**
- **This protocol does not have regard to the HRA guidance and order of content.**

FULL/LONG TITLE OF THE STUDY

Agreement on the key components, desirability and feasibility of culturally informed patient-centred palliative care heart failure intervention in Scotland: An online Delphi Study of clinicians.

SHORT STUDY TITLE / ACRONYM

Experts' opinion on the feasibility of complex intervention.

PROTOCOL VERSION NUMBER AND DATE

V2.0 1st April 2020

RESEARCH REFERENCE NUMBERS

IRAS Number:	NA
SPONSORS Number:	NA
FUNDERS Number:	NA

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor.

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest, accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: B Alassoud Date:23/03/2020

Name (please print):

Bahaa Alassoud

Position: PhD Nursing Student

Chief Investigator:

Signature: .... Date: ....../....../......

Name: (please print):

....

LIST OF CONTENTS

GENERAL INFORMATION	Page No.

KEY STUDY CONTACTS

Insert full details of the key study contacts including the following:

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Study Co-ordinator	**Professor Bridget Johnston** **Florence Nightingale Foundation Clinical Professor of Nursing,** School of Medicine, Dentistry & Nursing, College of Medical, Veterinary & Life Sciences, University of Glasgow and NHS Greater Glasgow and Clyde (joint appointment) 57-61 Oakfield Avenue Glasgow G12 8LL Direct Line +44 (0) 141 330 3691 Mobile : +44(0)7976 819133 Email : Bridget.Johnston@glasgow.ac.uk Website: http://www.gla.ac.uk/schools/medicine/nursing **Dr Karen Hogg** **Consultant Cardiologist and Honorary Clinical Senior Lecturer** Glasgow Royal Infirmary University of Glasgow & NHS Greater Glasgow and Clyde Direct Line +4 (0) 141-211-4833 Karen.Hogg@glasgow.ac.uk
Sponsor	NA
Joint sponsor(s)/co-sponsor(s)	NA
Funder(s)	NA
Key Protocol Contributors	NA
Committees	NA

STUDY SUMMARY

It may be useful to include a brief synopsis of the study for quick reference. Complete information and, if required, add additional rows.

Study Title	Agreement on the key components, desirability and feasibility of culturally informed patient-centred palliative care heart failure intervention in Scotland: An online Delphi Study of clinicians.
Internal ref. no. (or short title)	Experts' opinion of the feasibility of complex intervention.
Study Design	Online Delphi Survey.
Study Participants	Cardiology consultants and heart failure nurses.
Planned Size of Sample (if applicable)	There is no agreed method to calculate a sample size for Delphi studies statistically. Thus, we will send email invitations to approximately 200 potential panellists to ensure a response rate of 30 from each cohort. Yielding a final sample size of 60 panellists. Snowball sampling approach will increase our sample by encouraging potential participants to share the invitation email with other potentially relevant participants.
Follow up duration (if applicable)	NA
Planned Study Period	June 2020 – September 2020
Research Question/Aim(s)	

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON-FINANCIAL SUPPORT GIVEN**
NA	**NA**

ROLE OF STUDY SPONSOR AND FUNDER

NA

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

The Consultation Team (CT)

Make up

A consultation team of four will be involved primarily in the development of the Delphi survey. The members will be chosen to represent both nurses and cardiologist views and to act as advocates. Professor Simon Stewart, who is a cardiovascular nurse scientist; Yvonne Millerick, a senior Lecturer and Specialist Heart Failure Nurse; Dr. Inderjit; Mr Allan Gilmour, the PPI advisor for the current PhD I am undertaking.

Frequency of meetings

The CT will meet approximately twice or three times via video conference over the course of the study.

Responsibilities

The group will be involved in reviewing the wording of the survey, refining the questions in terms of the required completion time (fewer than 10 minutes), the clarity and readability of questions, and their relevance to the current study. In addition, the consultation group will have a crucial role in establishing the face and content validity of the survey. Besides, the group will be invited, all or individuals, to support the research team in the distribution of the survey; revising the positioning of the panellists; modelling the final intervention with outcomes, and to ensure the trustworthiness of findings they will be invited to take part in member checking. Lastly, the survey will be pilot tested with the consultation group, and the necessary revisions and updates will be made accordingly before the deployment.

The Patient and Public Involvement Group

This study is a part of a larger mixed-methods PhD project currently undertaken by the Chief Investigator (BA) and supported by patient and public involvement advisors at every stage to ensure that the patient/public voice is heard. The PPI advisory group was formed to provide input into the design, analysis and resultant intervention of this project and will continue to play an important role until the end of the project. The CT comprises a patient representative who was mainly involved in developing this protocol. This study was formed from two previous studies, guided by the patient and public involvement group.

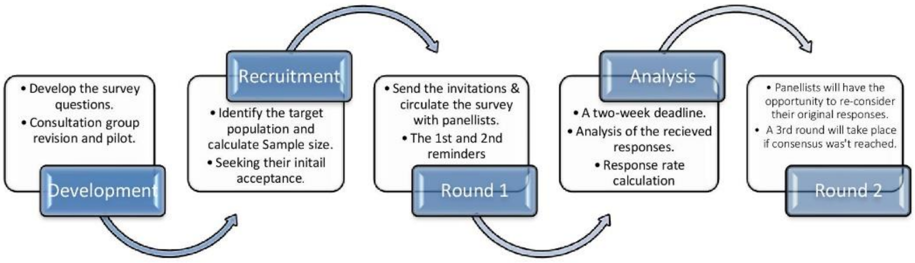
One advisory group member will be invited to attend two meetings with the Delphi consultation group. The first meeting will be introduced to the topic and the team. The second meeting the PPI person will attend is the last consensus meeting, which aims to interpret the Delphi results. None of the PPI persons will receive the survey as it aims at the level of healthcare professionals.

PROTOCOL CONTRIBUTORS

The study plan and protocol design were developed by the research team Bahaa Alassoud (CI), Professor Bridget Johnston (Principal investigator and supervisor for the whole PhD project) and Consultant Cardiologist Dr Karen Hogg (PhD co-supervisor and co-author). Bahaa Alassoud is the Chief Investigator and has overall responsibility for the operation of this study. He is responsible for writing the study protocol and the ethics application, developing the tool and materials, recruitment, analysis and preparing the final report. He will be supported and supervised in this by both supervisors, Professor Bridget Johnston and Dr Karen Hogg, particularly the study recruitment, data analysis, and writing up of results to be disseminated as an article and report.

KEYWORDS: Heart Failure, Complex intervention, Cultural appropriateness, Delphi technique, survey,

STUDY FLOW CHART



STUDY TIMETABLE

STUDY PROTOCOL

Insert title, consistent with the title on the front page

1 BACKGROUND

Heart failure (HF) is a global epidemic, affecting 1–2% of the population worldwide [1, 2]. This complex syndrome is a foremost cause of morbidity and mortality and therefore is a global health care problem. Over 26 million patients are affected by this clinical syndrome [1, 3]. The prevalence increases up to 10-13% with age advancement of over 80 years [4]. In the UK, 1-2% of the total NHS expenditure is being spent on heart failure and its management [5]. Of them, 60–70% is related to the costs of hospitalisation with nearly 1 million admissions annually.

Although heart failure is a life-limiting condition, palliative care along with therapeutic and technological advances can help patients and their family members to control symptoms, to regain quality of life and to cope with the disease [2, 6-8]. Also, it can assist clinicians to manage their patients with as infrequent as possible readmissions and, therefore, save the National Health Services and minimise the risk of death [2]. However, to the provision of palliative care heart failure is still underused by patients and caregivers. The utilisation rates have continued to be unsatisfactory in the last decade. In 2014, patients with heart failure made up only 7% of the palliative care registry [9]. Moreover, Riley and Beattie [10] have revealed in 2017 that 4% of eligible heart failure cases were actually receiving palliative care services [10]. Even though the literature is very rich in terms of barriers and enablers to access palliative care, the role played by culture in accessing the service is still scarce [11-14].

Recently, culture has proven to influence multiple dimensions of patient understanding of heart failure and palliative care. We have found that cultural beliefs and values can affect peoples' understanding of heart failure and, therefore, the patients and family members' perceived needs and care preferences in many ways. Hence, it can determine peoples' health decisions and access to and utilisation of palliative care. Lack of attention to cultural differences has led to further aggravate the problems. Cross-cultural communication has the potential to facilitate access to healthcare service for people from diverse ethnic and cultural backgrounds. Furthermore, clinicians might unintentionally trigger or contribute to the palliative care disparities through clinical uncertainty and stereotyping. Nevertheless, we must acknowledge though that clinicians should be aware of cultural, religious and ethical principles of people they are providing the care to. Adequate and culturally appropriate communication with patients regarding treatments, decisions, palliative and end of life care preferences, would expel the culturally induced misconceptions and modify, when necessary, the culturally coined understandings. These communications should be initiated as early as possible, documented and regularly reviewed.

2 RATIONALE

The recent trends of globalisation and the continuous growing cultural diversity have necessitated the healthcare services to be culturally appropriate for better health outcomes. In the UK, healthcare professionals are increasingly working with patients from culturally diverse origins with approximately more than 9% of the UK population are decended from non-British cultures [15]. The recent influx of immigrants from asylum seekers and refugees has additionally reflected the diversity of British society[15]. The changing composition of British society poses challenges to provide healthcare services responsive to the needs of the multicultural population.

To date, no consensus is made on either the concept or the component of these cultural competency models [16]. Moreover, there is a dearth of empirical evidence regarding the efficacy and feasibility of these models in the palliative care and heart failure contexts [17]. There is general agreement on the need for further research on this matter to include systematic reviews of the literature combined with the empirical evidence on the perspectives of experts, members of the public and patients [16]. It is further recommended to utilise mixed methods to develop culturally appropriate services to achieve more reliable results and more feasible interventions. It is noteworthy that culture has become an integral dimension of effective development of complex interventions [18]. Thus, these interventions could address the problems experienced by people with heart failure from diverse backgrounds and enhance the access to and utilisation of appropriate palliative care services in the UK and worldwide.

The evidence from around the world highlights the mainstream healthcare services are not optimally responding to the needs of people from different cultural backgrounds [18]. Nurses and physicians are seen lacking the necessary knowledge and skills, which impede the provision of culturally appropriate care [16, 19, 20]. However, the clinical interactions and communications involve clinicians, patients and families. The focus on clinicians' deficits only serves to entrench one side of reality. Ineffective clinical encounters can be profoundly linked to patient, or family. The evidence on how cultural diversity of different communities may affect people's health decisions and behaviours is the other side of reality, which is still scarce [18]. This scarcity has resulted in clinicians possibly treating all patients according to the norms of the mainstream culture. Our current findings from both the systematic review and the focus group studies add to the growing body of literature showing that the required skills and knowledge are more than merely understanding the local cultures and subcultures and mastering every patient's cultural norms and beliefs is deemed to be impossible [21, 22].

A re-think of a new initiative to facilitate the clinical encounters for both clinicians and patients should be warranted. The challenge is big to establish effective communication when there is no shared language which has been highlighted by both patients and professionals, particularly in the light of evidence to support the relatively ineffective use of informal or professional interpreters [23-25] and investable stereotypical assumptions when studying specific cultures [26]. Collectively, the above issues identify the need for a new language that could overcome and provide a "quick fix" solution or communication tool to facilitate the patients to communicate needs in a precise and standardised pattern within a multicultural society [18, 23].

3 THEORETICAL FRAMEWORK

Aim: To describe the theoretical framework for the study.

- A clear explanation of the proposed approach and why it is suitable to address the gaps outlined in the BACKGROUND section.
- Briefly outline a system of concepts, from published literature, that frames your study.
- Can be presented either visually or textually.

4 RESEARCH QUESTION/AIM(S)

To explore and seek the clinicians' views on the importance, acceptability and feasibility of a theoretically based, culturally informed intervention to support the palliative care provision for people living with advanced heart failure in Scotland.

4.1 Objectives

- The objective is to contact healthcare experts who are heart failure specialists and can circulate the survey to the relevant staff within and outside their organisations.
- To define through consensus the positions of experts' panellists, the heart failure nurses and medical doctors, on the proposed intervention and to gain agreement on the underpinning philosophy to the prevailing approach.

- To investigate how important the idea of the intervention is to help patients from different cultural, ethnic and religious backgrounds communicate their needs and receive the best care from the NHS.
- To seek agreement on the key components of culturally appropriate interventions and And what the expected feasibility of this idea may be for clinical practice

4.2 Outcome

Aim: To outline potential broad outcomes for the study, reflecting the research question aim(s).

5 DELPHI SURVEY DESIGN AND METHODS OF DATA COLLECTION AND DATA ANALYIS

5.1 Delphi Survey Design

Evidence in healthcare interventions is simply information demonstrating the effectiveness and acceptability of interventions in achieving specific outcomes and conclusions. Choosing the right evidence is an important step to achieve the warranted outcome. This aim is difficult to fulfil due to the ample evidence as well as the multiple potential sources. Le May and Holmes [27] have classified the Delphi method as a technique to access a reliable and rigorous source of evidence in nursing practice. The Delphi method or technique is the most abundant and formal consensus-reaching technique in nursing research and practice [28, 29]. This method combines evidence passed by experts and reflects the professional experience that facilitates discussion and observation and accurately reflects the clinical practice [27].

The technique provides a platform where consensus by subject matter experts can be achieved on a topic despite the limited evidence, lack of precise information and prior research [30, 31]. Moreover, the Delphi technique is suitable for application whenever policies, plans, or ideas must be based on informed judgment. A modified Delphi technique, which is defined as an iterative and structured process of group negotiation has been used widely in healthcare (Hasson et al., 2000) and nursing research. However, this approach has some disadvantages that diminished its usage. Over the past few decades, the application of Delphi has been growing and drawn more attention to this method. The emergence and rapid spread of the internet-based online tools and its utilisation in research support/ brought Delphi to the front again. Among other techniques, the Technology-based, online or e-Delphi survey allows researchers and experts to communicate opinions and experiences in a more time-efficient and resource-effective way. The e-Delphi method maximises the advantages and limits the disadvantages of the traditional version of the method [32, 33].

The online Delphi survey was chosen for its flexibility, anonymity, confidentiality, active feedback process and appropriateness of numerous analytical approaches [30, 34] and also, to overcome the disadvantages associated with face-to-face meetings, which are known to be time-consuming and lengthy, and the potential impact of group dynamics and direct confrontations between experts [34]. By using e-Delphi survey, these obstacles can be avoided [30, 35] and influential results and inaccurate analysis can be eluded or averted. All these factors along with the scarcity and disparity of evidence on the subject matter, necessitate the use of a structured method to reach consensus on the proposed intervention: e-Delphi was deemed the best method of choice.

5.2 Methods of Data Collection - Delphi Survey

The study involves completing two or three online surveys, two weeks apart. The first survey will elicit a brief demographic profile and the panellist's answers to six questions provided with a succinct description of the study. The survey results from the first round will form the basis for the subsequent survey/s.

The survey will be developed from the literature review and previous focus group interviews concerning the cultural influences on the understanding of heart failure and palliative care. An online modified Delphi method will be the data collection tool to gain consensus of experts in the field of heart failure. This consensus would be established through the presentation of the results of our two studies concerning people living with heart failure from different cultural backgrounds.

Upon the approval of the study by the MVLS ethics committee, the data collection process will begin through two rounds.

- *Round one:* a link to the online questionnaire will be emailed to panellists. Nurses and physicians will be asked to consider what approach of cross-cultural communication might be appropriate and practical for implementation in healthcare settings. Importantly, to rate the importance, acceptability and feasibility of our intervention, a two-week deadline for survey return will be given and two reminders will be sent. The importance and feasibility will be rated using Likert-type scales ranging 0-5, from zero (0) not at all important/ not feasible to (5) very important/ very feasible. Open-ended questions after each topic could apply to seek additional comments and feedback. The consensus is to be set a priori at 75% agreement. Responses will be aggregated and fed back to the panellists through email. Panellists then review the results and can compare their individual responses to the group ones. They can further amend or justify their responses until a consensus is formed.
- *Round two:* in a further survey round panellists will be asked if they want to reconsider their responses from round one considering the summarised group responses to each item. One week will be given this time and one reminder only to be circulated. As responses remained stable across the two rounds, the consultation will be closed after round two.
- At this point, if we reach a consensus on the most important elements of the intervention, the administration mode and philosophy the study will be complete. Otherwise, a third round will be initiated to reach consensus.

5.3 Methods of Data Analysis - Delphi Survey

Given the mixed nature of Likert scale and open-ended questions, Thematic Analysis (TA) and descriptive statistics will be utilised to analyse the qualitative responses and the quantitative data. The panellist's responses will be exported from Online Surveys via Jisc to SPSS and NVIVO software. The agreement score for each item will be indicated by the median and mean absolute deviation from the median (MADM). The level of consensus for each survey question will be set at 75%; three quarters of the panellist's responses fall within the highest (4 or 5) or lowest categories (0 or 1) on the 5-point Likert scale. The number of items for which to achieve a consensus and the association between each topic will be calculated according to profession.

In order to enhance the robustness of such results, the qualitative data will be assessed and analysed using reflexive thematic analysis and the analysis process will be facilitated by NVivo software. BA will assess the data through reading and re-reading and set the initial codes in order to identify and construct the potential themes. These codes will be then reviewed and refined by the study supervisors, BJ and KH. The constructed themes from data will be categorised as statements below each question to allow the consensus assessment. All comments from the panellists in response to each question will also be transferred to NVIVO and themed along with the qualitative responses. Qualitative findings will then be discussed and agreed with the authors and the consultation team. Any irrelevant response that is not addressing one of the survey questions will be neither analysed nor carried forward but could be considered in relation to the whole thesis.

The quantitative data from the 1st and 2nd rounds will be analysed according to the strength and extent of agreement using descriptive statistics, the Median and Interquartile Ranges are the best statistical measures to calculate the central tendency and dispersion in Delphi studies [36]. The 5-point Likert scale will be thereafter collapsed into three categories. The strength of consensus for each item will be calculated using the percentage, mean, median and interquartile range. For items which the participants left unanswered, expert advice will be requested. Appropriate statistical tests will be used to analyse the data. Expert statistical consultation will be sought before undertaking the study. George Vazanellis, the Statistical Adviser for the college of MVLS will be contacted for a one-to-one consultation.

6 STUDY SETTING

Virtually, experienced heart failure professionals will be asked questions derived from previous studies using a web-based survey for the iteration of their anonymous opinions. The panel members will be asked to rate the importance, acceptability, desirability and feasibility of the intervention and to give opinions and feedback on the appropriateness and methods of delivery. This study will be conducted in English and administered electronically only through a web-based platform hosted by a third-party software provider "Online Surveys" [37]. This platform allows panellists to log on as much as needed. However, a time limit for completion of the survey will be set for two weeks.

Surveys is an online, flexible and easy-to-use platform that is used by over 300 different organisations in the UK and internationally. The University of Glasgow has accredited this service and has an institutional licence for this web tool. Online Surveys allow researchers to design, organise, circulate and then analyse surveys using the Web promptly. The service is compliant with the General Data Protection Act and meets UK accessibility requirements.

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

7.1. Inclusion & Exclusion criteria

The identification and selection of participants will be driven by a simple eligibility criteria. To be considered eligible, clinical expertise in heart failure is required with a multicultural population. To draw on the focused perspectives of clinicians on culturally appropriate health failure care, participation will be sought from heart failure nurses working in clinical practice and cardiologists with knowledge and experience of multi-ethnic and multicultural contexts. Clinicians with less than 2 years of experience or who have not been residing in Scotland or working during the last year will not be eligible for the study.

7.2 Sampling

7.2.1 Sample Size

There is no agreed method to statistically calculate a sample size for Delphi studies. Thus, we will send email invitations to approximately 200 potential panellists to ensure a response rate of 30 from each cohort, yielding a final sample size of 60 panellists. Snowball sampling approach will be followed to increase our sample through encouraging potential participants to share the invitation email with other potentially relevant participants.

7.2.2 Sampling Technique

Since the nature of the Delphi method research is exploratory, only those who are relevant, or experts in the field will be included. A nonprobability purposive and snowball sampling of nurses and medical doctors who are caring for patients with advanced heart failure will be taken..

7.3 Recruitment

Since proper recruitment planning can contribute to the success of Delphi studies, we will adopt a multifaceted recruitment plan to boost the response rates and enhance the internal and external validity of the results [36]. The multifaceted strategy would enable accessing the opinions of a diverse range of busy heart failure expert health professionals is complex matter. The members of the research team will use several strategies for recruitment including their professional networks. We will try to recruit members from the Heart Failure Hub Scotland, the Scottish Heart Failure Nurse Forum (SHFNF) and/or Scottish National Advanced Heart Failure Service. Heart failure nurses and medical doctors will be purposively selected using purposive and snowball sampling. Equal numbers of participants will be recruited to both subgroups (Nurses and Medical doctors) to ensure that no subgroup unduly influenced the consensus or over/underrepresented. We will limit the geographic scope to Scotland with a proportional distribution of experts across the country. An initial list of heart failure nursing and medical societies in Scotland was drawn up by research team members. These organisations will be contacted via email and a meeting to discuss the study in detail will be set. The recruitment entails an introductory meeting with the representative organisations to get their initial acceptance and share our findings from the focus group study as well as the systematic review investigating the impact of culture on the understanding of advanced heart failure and palliative care. If they initially accept to take part, they will be asked to nominate a representative from their organisations to help with sending the mass emails with invitation letters, the participant information and the online Delphi survey link. All members of each society/forum will be invited to complete each Delphi round unless they decide not take part or to withdraw thereafter from the study. Participants who refuse, apologise or are unable to take part will be kindly asked to share the survey link with colleagues. The data collection process will not commence, until a written approval from the MVLS ethics committee is granted.

7.3.1 Sample Identification

Healthcare professionals will be identified by the collaborating organisation using a range of strategies. Purposively, we will ask the collaborating organisations to share the invitation email with their members. A quick review will be performed to scope the recently published Scottish evidence on heart failure. Names and emails will be extracted from their publication and a brief invitation email will be sent to them. Additionally, the consultation group will be requested to send the invitation email to colleagues working in Scotland if any. Panelists will also be recruited via snowballing and clinicians will be appealed to forward the invitation to eligible nursing and medical colleagues.

7.3.2 Consent

The selection process will be designed to include panelists with the knowledge, background and experience in heart failure in multicultural settings to maximise the validity and reliability of findings. Nurses and medical doctors who will meet the eligibility criteria will receive an email with a brief explanation about the study and a flyer attached. In the online survey studies, it is very common that participants' consent is to be assumed by clicking on the survey link and/or the consent box. However, we understand that gaining the consent form signed by panelists after being fully informed about the subject is of the most significant milestones in the Delphi process. We decided to add a page at the beginning of the survey to provide the full consent form as provided by the MVLS ethics committee. This form will include additional information to reassure the total confidentiality and anonymity of participants data as well as clearly informed that taking part is voluntary. This extra step would further boost the reliability and the validity of the study as well as reduce the attrition rate, which all help to reach the most reliable consensus among experts.

8 ETHICAL AND REGULATORY CONSIDERATIONS

Upon the approval of the supervisory team, an ethics application and the study protocol along with the necessary documents will be submitted for the MVLS ethics committee at the University of Glasgow. An introductory email will be circulated and will include information about the study. Given the nature of the study, the panellists will be conducted anonymously or confidentially. Accessing the survey, by clicking the personalised link and agreeing on the informed consent form designated page will be taken as evidence of consent to participate. Notably, the "online Surveys", the platform for this survey, is compliant with the new General Data Protection Act and will automatically create a page at the beginning of the survey to act as the Informed Consent Form.

Even though the study involves clinicians who are currently working for the NHS, completion of the Health Research Authority online checklist from the NHS confirmed that this pilot did not require ethical approval and that there is no requirement for NHS ethical review unless the study involves randomisation of participants; any modification to the current care procedure or standards for the investigational purposes or the study is meant to provide generalisable findings. Evidence to prove that the NHS ethical review was deemed unnecessary for this Delphi survey is available in the Appendices.

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