

**Management of heart disease among Turkish immigrants: A
qualitative exploration of facilitators and barriers to
secondary prevention measures**

Sakine Satici
Internal Medicine, MD

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Abstract

Cardiovascular disease (CVD) is one of the leading causes of morbidity and mortality, impacting individual's quality of life and imposing a significant economic burden on the Australian healthcare system. The benefits of secondary prevention strategies on cardiovascular health outcomes are well recognised. However, they are underutilised, particularly by ethnic minorities.

Australia is a multicultural society; one in four Australians was born overseas. While previous studies have explored health outcomes in various immigrant communities in Australia, there is a lack of research specifically focusing on Australian Turkish immigrants' disparities in heart disease in an Australian context. This thesis aims to understand this significant gap by exploring the barriers and facilitator factors that impact cardiovascular secondary prevention interventions among Australian Turkish communities living in Victoria with existing heart disease. Understanding self-care behaviours is critical in tailoring health interventions to meet patient needs.

This explorative qualitative study recruited and conducted semi-structured interviews with fifteen Australian Turkish immigrants with CVD. All participants were born in Turkey and had resided in Australia for a Median of 39 years. Thematic analysis was guided by the socio-ecological model, a multilevel approach including five levels: 'intrapersonal', 'interpersonal', 'institutional', 'community' and 'policy levels.' Most participants experienced healthcare access issues across all these levels. Factors that put patients at risk for non-compliance with secondary prevention strategies for heart disease or prevent patients from experiencing further cardiac events were identified. The study was undertaken during the COVID-19 pandemic, and a theme specific to patients' experiences with healthcare during this time is presented.

At the intrapersonal level, four themes emerged as barriers: 'health knowledge deficit,' 'limited English proficiency (LEP),' 'implication of personal factors' and 'financial

strains.’ Participants consistently identified knowledge deficits about illness and available services as critical barriers. Language barriers to communication with providers negatively influenced patient access to available health information, understanding of the information received and involvement in the shared decision-making process to accept and adhere to secondary prevention and self-care. Inadequate knowledge and lack of understanding of the consequences of acute cardiac symptoms resulted in a delay in seeking urgent medical attention. LEP, limited health literacy and a lack of comprehensive communication with providers led to difficulties navigating the healthcare system to access necessary healthcare services. At the interpersonal level, two themes emerged. The first theme focuses on the positive influence of family and friends on health-seeking behaviours, compliance with secondary preventative measures, and medication adherence. The second theme highlights how family and friends can also be a source of stress.

Participants raised concerns about communication gaps with providers, which is crucial in gaining necessary information regarding heart disease. Poor communication with providers negatively impacted patient education regarding secondary prevention strategies. Language concordance between patients and providers improved health literacy and engendered trust. Barriers within the policy level were ‘long waiting times to access healthcare services’ and ‘limited coverage of Medicare.’

Tailored community-centred public health education conducted in collaboration with Turkish community centres may be a potential solution to optimising health literacy regarding secondary prevention of CVD.

Keywords: Cardiovascular disease, secondary prevention strategies, self-management, barriers, facilitators, ethnic minority, Turkish immigrants

Declaration of Authentication

I, Sakine Satici, declare that the Master of Research thesis entitled ‘Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures’ is no more than 50,000 words in length, including quotes and exclusive of tables, figures, appendices, bibliography, references, and footnotes. This thesis contains no material submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.

I have conducted my research in alignment with the Australian Code for Responsible Conduct and Victoria University’s Higher Degree by Research Policy and Procedures. All research procedures reported in the thesis were approved by the St Vincent’s Hospital Human Research Ethics Committee (HREC), and the approval number is LRR 095/22.

Dr Sakine Satici

17th January 2023



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Table of Contents

<i>Abstract</i>	<i>ii</i>
<i>Declaration of Authentication</i>	<i>iv</i>
<i>Acknowledgement</i>	<i>v</i>
<i>List of Tables</i>	<i>ix</i>
<i>List of Figures</i>	<i>x</i>
<i>Appendices</i>	<i>xi</i>
<i>Ethics Approval</i>	<i>xii</i>
<i>Abbreviations and Shortened Forms</i>	<i>xiii</i>
1 INTRODUCTION	1
1.1 Introduction	1
1.2 Background	2
1.2.1 Defining Study Terms	2
1.2.2 Health Disparities in CALD Populations	4
1.3 The Study Problem	8
1.4 The Study Aims	10
1.5 Significance of the Study	10
1.6 Research Approach	11
1.7 Thesis Structure	12
2 Literature Review	13
2.1 Cardiovascular Disease	13
2.2 Cardiovascular Risk Factors	13
2.2.1 Cardiovascular Risk Factors Among Immigrants	14
2.2.2 Acculturation Effects on Cardiovascular Risk Factors Among Immigrants	16
2.3 Cardiovascular Disease and Risk Management Among Immigrants	17

2.3.1 Primary Prevention	17
2.3.2 Secondary Prevention.....	19
2.4 <i>Cardiac Rehabilitation</i>	28
2.5 Heart Disease Self-care or Self-management.....	37
2.6 Conceptual Framework	40
2.6.1 The Social-ecological Model of Health.....	40
2.7 Self-management and the COVID-19 Pandemic	41
2.8 Summary of the Literature Review	42
2.9 Literature Gap	43
2.10 Research Question	44
3 <i>Research Design and Methodology</i>	45
3.1 Introduction	45
3.2 Research Paradigm.....	45
3.2.1 The Rationale for Choosing a Qualitative Research Method.....	47
3.3 The Study Aims and Research Question	48
3.4 Research Design.....	48
3.5 Conceptual Framework and Socio-ecological Model.....	49
3.6 Research Methods.....	52
3.6.1 Setting	52
3.6.2 Sample.....	53
3.6.3 Recruitment.....	54
3.6.4 Data Collection.....	56
3.7 Data Analysis.....	59
3.8 Ethical Considerations	62
3.8.1 Theoretical Positioning of the Researcher.....	63
3.9 The Rigor of the Research	63
3.10 Strengths and Limitations of the Study.....	65

4 Research Findings	67
4.1 Introduction	67
4.2 Study Participants	67
4.3 Themes and Subthemes	70
4.3.1 Intrapersonal Level	71
4.3.2 Interpersonal Level	92
4.3.3 Institutional Level	96
4.3.4 Community and Societal-cultural Level	99
4.3.5 Policy/Structural Level	100
4.3.6 Cardiac Rehabilitation Attendance	103
4.3.7 Implications of the COVID-19 Pandemic on Patients and Telehealth .	105
5 Discussion	110
5.1 Introduction	110
5.2 Intrapersonal Level	113
5.3 Interpersonal Level	123
5.4 Institutional Levels	125
5.5 Policy/Structural Level	128
5.6 Socio-ecological Model	129
5.7 The Implication of COVID-19 on Self-care and Telehealth	129
5.8 Conclusion	131
References	133
Appendices	153

List of Tables

Table 1. 1 The Most Common Forms of CVD in Australia	3
Table 3. 1: Inclusion and Exclusion Criteria for the Study	54
Table 3. 2: Example Coding Process for the Theme (Adapted from (Jin et al., 2020))	60
Table 4. 1: Participants' Demographic and Background Characteristics	68
Table 4. 2: Clinical Characteristics of Australian Turkish Participants with CVD	70
Table 5. 1: Individual Factors Influencing Self-care	113

List of Figures

Figure 2. 1: Effects of Secondary Prevention (Adapted from (The National Heart Foundation of Australia, 2019))	21
Figure 2. 2: Cardiac Rehabilitation Program and Its Goals (Adapted from (Chew et al., 2016)).....	29
Figure 2. 3: Comprehensive Cardiac Rehabilitation and Its Core Components (Adapted from (Woodruffe et al., 2015))	30
Figure 2. 4: Barriers to Cardiac Rehabilitation in Ethnic Minority (Adapted from (Vanzella et al., 2020))	36
Figure 2. 5: Factors Influencing the Heart disease Management (Adopted from (Jin et al., 2020)).....	37
Figure 2. 6: Self-care of Cardiovascular Disease (Adopted from (Riegel, 2017; Jaarsma, 2021)).....	38
Figure 2. 7: Steps for the Ecological Model (Adapted from (Sallis et al., 2000))	41
Figure 3. 1: Framework for the Research Study (Adapted from (Crewell, 2018))	46
Figure 3. 2: Philosophical Assumptions/Paradigms of the Study	47
Figure 3. 3: Research Approach, Methods and Analysis aligned with Research Question.....	49
Figure 3. 4: Socio-ecological Model to Understand the Factors Influencing Heart Disease Management.....	50
Figure 4. 1: Risk Factors for Cardiovascular Disease among 15 Participants (Self-reported).....	69
Figure 4. 2: Intrapersonal Barriers to Heart Disease Management	76
Figure 4. 3: Implications of Language Barriers for Healthcare.....	85
Figure 4. 4: Cardiac Rehabilitation Program Attendance Among the Participants.....	104
Figure 4. 5: Implication of COVID-19 Pandemic on Immigrant Patients	109

Appendices

Appendix 1: Information Leaflet for Participants (English Version).....	153
Appendix 2: Consent Form for Participants (English Version)	1
Appendix 3: Form for Withdrawal of Participation (English Version).....	1
Appendix 4: Information Leaflet for Participants (Turkish Version)	3
Appendix 5: Consent Form for the Participant (Turkish Version).....	1
Appendix 6: Form for Withdrawal for Participants (Turkish Version).....	1
Appendix 7: Interview Guide (English Version).....	3
Appendix 8: Participants Recruit Flyer	6
Appendix 9: Human Research Ethic Approval Letter.....	7

Ethics Approval

The St. Vincent Hospital in Human Research Ethics Committee approved all research procedures reported in the thesis, protocol numbers: 0.1, version: v1-4.4.13, LRR 095/22. Victoria University also added approval to do this research.

Abbreviations and Shortened Forms

ABS: Australian Bureau of Statistics

AGEs: Advanced glycation end products

ACC/AHA: American College of Cardiology/American Heart Association

ACRA: The Australian Cardiovascular Health and Rehabilitation Association

ACS: Acute coronary syndrome

AMI: Acute myocardial infarction

AIHW: The Australian Institute of Health and Welfare

BMI: Body mass index

CABG: Coronary artery bypass graft

CAD: Coronary artery disease

CALD: Culturally and Linguistically Diverse

CHD: Coronary heart disease

COVID-19: Coronavirus Disease-2019

CR: Cardiac rehabilitation

CSANZ: Cardiac Society of Australia and New Zealand

CVD: Cardiovascular disease

ED: Emergency Department

ESL: English second language

ESC: European Society of Cardiology

GP: General Practitioner

HBM: Health belief model

HCPs: Healthcare providers

HDL-C: High-density lipoprotein cholesterol

HF: Heart failure

IHD: Ischemic heart disease

IT: Information technology

JNC 8: The Joint National Committee

LEP: Limited English proficiency

LDL-C: Low-density lipid cholesterol

MBS: The Medicare Benefits Schedule

MI: Myocardial infarction
NCD: Non-communicable disease
NHFA: National Heart Foundation of Australia
NSTEMI: Non-ST Elevation Myocardial Infarction
Ox-LDL: Oxidized LDL
PAD: Peripheral arterial disease
PCC: Patient-centred care model
PCI: Percutaneous coronary intervention
PIS: Participant information statement
SEM: The socio-ecological model
SES: Socioeconomic status
STEMI: ST-segment Elevation Myocardial Infarction
SARS-CoV-2: Severe Acute Respiratory Syndrome Coronavirus 2
TIA: Transient ischemic attack
T1D: Type 1 diabetes
T2D: Type 2 diabetes
TG: Triglyceride
UA: Unstable angina
WHO: World Health Organisation

1 INTRODUCTION

This chapter aims to give you an overview of the problem, including background information, and investigate it thoroughly. We will also formulate the research question and clarify the study's purpose.

1.1 Introduction

Cardiovascular disease (CVD) is a leading cause of death globally and in Australia. The World Health Organization (2021) estimated that 17.9 million people died from CVD in 2019. From 1990-2019, the prevalence of CVD nearly doubled from 271 million to 523 million, and the number of CVD deaths steadily increased from 12.1 million to 18.6 million. Due to population growth and aging, this trend is likely to increase, resulting in the worldwide death of 23.3 million people annually by the year 2030 (Roth et al., 2020). In Australia, more than one in four deaths in 2018 were related to CVD, many premature and preventable (Australian Institute of Health and Welfare, 2021a).

Although significant technological advances have been made in managing CVD, it remains one of the most significant burdens on the Australian economy, with \$5.7 billion (12% of all healthcare expenditure) in 2015-2016 (AIHW, 2020). CVD is also a costly disease that places a heavy economic burden on the Australian healthcare system (AIHW, 2020).

CVD can severely impact the quality of an individual's life despite well-established and effective preventive options that reduce the incidence of CVD mortality and morbidity (Australian Institute of Health and Welfare, 2021b; World Health Organization, 2021). Thirty-eight per cent of the disease burden could have been avoided if modifiable risk factors such as smoking cessation and weight reduction were undertaken (Australian Institute of Health and Welfare, 2021a).

Australia has a growing ethnocultural diversity of society resulting from mass immigration in the decades following World War II. By 2066, the Australian population projection based on demographic trends (fertility, mortality, and overseas migration) is

estimated to reach 37.4-49.2 million people. The overseas migrant population is projected to reach 9.0-13.5 million (Australian Bureau of Statistics, 2020).

CVD is a significant health issue among immigrant populations in developed countries (Turk-Adawi et al., 2019; World Health Organization, 2021). Studies examining CVD and Australian immigrant groups have found that CVD's prevalence, incidence and mortality levels may vary significantly between migrants and host populations depending on ethnic background and duration of the residency (acculturation)(Agyemang, 2019; Hopgood et al., 2021).

No studies have investigated Australian Turkish immigrants' disparities in heart disease in an Australian context. The basis by which cultural and linguistic diversity may impact adversely on health outcomes, including secondary prevention and self-care, is undoubtedly multifactorial. Language barriers, inadequate comprehensive communication with providers, financial constraints, health knowledge deficit, low health literacy, limited coverage of health insurance, and poor adherence to medication and self-care may contribute to disparate outcomes in this immigrant group.

1.2 Background

1.2.1 Defining Study Terms

Cardiovascular Disease (CVD)

Cardiovascular disease is an umbrella term that involves the heart and circulatory system. CVD includes coronary heart disease (CHD), cerebrovascular disease and peripheral artery disease (World Health Organization, 2021). The leading underlying cause of these diseases and conditions is atherosclerosis, a chronic inflammatory disease, where progressive abnormal lipid deposition slowly builds up within the artery wall to form plaque, reducing or blocking the blood supply to the body organs (Zhu et al., 2018). The underlying pathology of atherosclerosis develops over many years and is usually advanced when symptoms occur; acute coronary or cerebrovascular events may occur suddenly and are often fatal before medical care can be given (Zhu et al., 2018).

This thesis primarily utilises the definitions and classification for CVD as described in the National Heart Foundation of Australia (NHFA)/ Cardiac Society of Australia and New Zealand (CSANZ) (Chew et al., 2016) and European Society of Cardiology (ESC) guidelines (Piepoli et al., 2016) (Table 1.1).

Table 1. 1 The Most Common Forms of CVD in Australia

<i>Coronary artery disease (CAD)</i>	<ul style="list-style-type: none"> • Coronary heart disease (CHD)/ischemic heart disease (IHD)
<i>Cerebrovascular disease (CVD)</i>	<ul style="list-style-type: none"> • Stroke and transient ischemic attack (TIA)
<i>Peripheral arterial disease (PAD)</i>	<ul style="list-style-type: none"> • Arterial disease of the limbs and arms which may result in claudication.

Cultural and Linguistic Diversity (CALD)

The term ‘cultural and linguistic diversity’ (CALD) is a broad concept drawing attention to individuals and communities who possess ethnic/racial, cultural, religious and language characteristics that are different to those of the majority living in Australia (Australian Bureau of Statistics, 1999). Although there is no standardised operational definition for CALD and numerous Australian databases were inconsistently defining CALD, a recent literature review by Pham et al. (2021) suggests CALD definition as individuals born in non-English speaking countries and their primary language is spoken in the home is not English.

Language Discordance

In the healthcare setting, *language discordance* can be defined as when a patient has limited proficiency in the language spoken by their healthcare providers. In the literature, there is no precise terminology to describe language discordance. In research taken place in English-spoken countries, to describe language discordance between patients and providers, different terms were used, such as *limited English proficiency* (Hsueh et al., 2019), *inability to speak English*, *language discordance*, *non-English speaking*, *limited English skill*. In this study, we preferred to use *limited English proficiency* as many

researchers have most commonly utilised this term. Limited English proficiency (LEP) is defined by the Australian Institute of Health and Welfare (AIHW (2022) as the inability to read, write, speak or understand English very well.

In language concordance, patients can communicate directly with providers in their preferred language. A systemic review by Hsueh et al. (2019) analysed the studies of patient-provider language concordance and health outcomes. The research found a positive correlation between language concordance and communication/information quality, listening skills, feeling understood and better risk factor control.

Healthcare Providers

Healthcare providers (HCPs) maintain health by applying evidence-based medicine and caring principles and procedures. HCPs study, diagnose, treat, and prevent human illness, injury, and other physical and mental impairments following the needs of the populations they serve. HCPs are involved in primary care, nursing care (licensed practical nurse, registered and advanced nurses), drug therapy (licenced pharmacist), dentists, and specialty care (health professionals in various specialties such as cardiologist) (World Health Organization, 2013b).

Immigrants

Although there is no formal legal definition of an international immigrant, an international immigrant is a person moving outside their usual country to settle for more than three months (Gimeno-Feliu et al., 2019). There are several underlying causes and purposes of immigration, including seeking better living conditions (economic, employment and educational opportunities and family reunion) and being forced to flee their home for their safety or survival (escape conflict, persecution, terrorism, natural disaster, or human right violations) (Willekens et al., 2016).

1.2.2 Health Disparities in CALD Populations

Newly arrived immigrants may have better health than those born in Australia, but this advantage seems to decline as time passes. The exact cause of this phenomenon is unclear,

but it could be linked to cultural assimilation or other socioeconomic factors. (Australian Institute of Health and Welfare, 2022; Henry Osokpo et al., 2021; Jin et al., 2017).

In the healthcare setting, CALD populations have been reported to experience health disparities such as language barriers, cultural differences, health knowledge deficits, and financial barriers (Ali & Watson, 2018; Khatri & Assefa, 2022; Mead et al., 2016; Weerasinghe et al., 2009). Limited English proficiency (LEP) is an established risk factor for health inequalities in cardiovascular health. It is associated with a negative impact on accessing healthcare, navigating the healthcare system and health outcomes. Inadequate comprehensive communication between providers and patients with LEP has been identified as a key contributor to adverse events in hospitals (Hsueh et al., 2019; Mackay et al., 2018). Limited English reading ability may make it challenging to find, comprehend, and interpret reliable health information (Australian Institute of Health and Welfare, 2022).

A large body of evidence indicates ethnic health disparities are largely due to social determinants related to the healthcare delivery system (Betancourt et al., 2003; James et al., 2017). For example, ethnic minority populations tend to be more socioeconomically disadvantaged, have lower education levels and have less access to healthcare. Those ethnic minorities who can access healthcare may experience disparities in the quality of care in using cardiac diagnostic and therapeutic procedures (Betancourt et al., 2003).

Specifically, we need to learn more about the factors influencing secondary prevention and self-care among Australian Turkish immigrants with heart disease because their data are aggregated in Australia under the category of Middle Eastern immigrants (Gholizadeh et al., 2011). This practice of categorising people based on the country where they come from while disregarding cultural background limits our ability to assess cultural beliefs, practices, and behaviours (Henry Osokpo et al., 2021). To effectively implement secondary prevention strategies and self-care among Australian-Turkish immigrants with heart disease, it is essential to consider the social, cultural, and contextual factors that could facilitate or hinder their success.

Recently, a qualitative study was conducted in Turkey by Field Sezgin (2017) involving 24 individuals diagnosed with heart failure who attended a cardiology clinic. The study

aimed to understand how they managed their self-care. Content analysis was used to analyse the data, revealing facilitators and obstacles. The facilitators included recognising symptoms, receiving support, believing in treatment, and feeling motivated. The obstacles included giving up habits, lacking knowledge, denial, low self-confidence, and having fatalistic attitudes. Even though the participants resided in Turkey and could access healthcare without language barriers, they still faced obstacles when it came to self-care. Currently, there are no studies that specifically examine the barriers that Australian Turkish immigrants encounter when it comes to managing heart disease. The impact of cultural and linguistic diversity on health outcomes, including secondary prevention and self-care, is undoubtedly influenced by multiple factors. Our research has identified several factors contributing to disparities in health outcomes among specific population groups. These include language barriers, inadequate communication with healthcare providers, financial constraints, limited health knowledge, low health literacy, insufficient health insurance coverage, and poor adherence to medication and self-care. Before examining the potential mechanisms underlying these disparities, it is crucial to establish their existence and extent.

The findings of this research contribute to our understanding of the key factors influencing the self-care of Australian Turkish immigrants with heart conditions and what kind of barriers or facilitators they face during self-management in Australia. This indicates a need to understand individual experiences and perceptions of self-management programs (monitoring signs and symptoms of the disease, adherence to appropriate treatment, and modifying long-term lifestyle) for CVD with a qualitative study. Furthermore, this study can contribute to essential data for researchers, healthcare providers, and policymakers, allowing these stakeholders to formulate better healthcare services and cost-effective interventions for short and long-term engagement in secondary prevention strategies and self-care among these ethnic minorities. Finally, implementing culturally and linguistically suitable educational programs for these patient groups could raise awareness of self-care and secondary prevention interventions.

Australia is a multicultural society with more than 200 ethnic groups. The 2020 census showed that one out of four Australians (30%) were born overseas, and more than half of these people came from non-English speaking countries. Most (82%) of the overseas-

born population live in three capital cities, Melbourne, Sydney, and Perth, where the proportion of overseas-born people account for one-third of these cities' population (Australian Bureau of Statistics, 2020). These statistics highlight the fact that a large number of Australians (over seven million people out of 25 million) may be defined as being from Culturally and Linguistically Diverse (CALD) backgrounds, including migrants (Australian Bureau of Statistics, 2020).

In the healthcare setting, CALD populations have been reported to experience health disparities such as language barriers, cultural differences, health knowledge deficits, and financial barriers (Ali & Watson, 2018; Khatri & Assefa, 2022; Mead et al., 2016; Weerasinghe et al., 2009). Limited English proficiency (LEP) is an established risk factor for health inequalities in cardiovascular health. It is associated with a negative impact on accessing healthcare, navigating the healthcare system and health outcomes. Inadequate comprehensive communication between providers and patients with LEP has been identified as a key contributor to adverse events in hospitals (Hsueh et al., 2019; Mackay et al., 2018). Furthermore, the limited ability to read English may cause difficulty sourcing, understanding, and interpreting trusted health information (AIHW, 2022).

A large body of evidence indicates racial/ethnic disparities in health largely due to social determinants of the healthcare delivery system (Betancourt et al., 2003; James et al., 2017). For example, ethnic minority populations tend to be more socioeconomically disadvantaged, have lower education levels and have less access to healthcare. Those ethnic minorities who can access healthcare may experience disparities in the quality of care in using cardiac diagnostic and therapeutic procedures (Betancourt et al., 2003).

An Australian study by Dassanayake et al. (2009) systemically reviewed published literature to determine the prevalence of CVD morbidity and mortality among immigrants. Research shows that females from the Middle East and South Asia had significantly higher hospitalisation rates from ischemic heart disease (IHD), and males had a higher mortality rate. Furthermore, immigrants from all regional subgroups had lower rates of circulatory system disease (CHD and stroke) than the Australian-born population. Unfortunately, all published studies analysed in this systemic review used different classification methods by grouping immigrants regionally. In this way, it is

difficult to analyse the reason behind it and limit the comparability between subgroups of immigrants. Overall, the prevalence of CVD morbidity, mortality, and risk factors, which varied according to region and gender, were higher among Middle Eastern and South Asian immigrants. It is necessary to note that data collection was self-reported except for biomedical risk measurements (Dassanayake et al., 2009). The researchers also emphasised that the morbidity and mortality rate from myocardial infarction (MI) and stroke tended to be higher among first-generation immigrants (Chinese and African) living in Western countries than among their non-immigrant counterparts (Dassanayake et al., 2011). A large population-based cohort indicated that acculturation was associated with a higher prevalence of CVD risk factors among Chinese immigrants in Australia (Jin et al., 2017). Myocardial infarction (MI) morbidity and mortality vary among immigrant groups from the same country of origin who have immigrated to different host countries, suggesting that individual (genetic) and environmental factors interaction may play a role in it (Dassanayake et al., 2011). Similar results have been reported in an Australian observational study (CONCORDANCE) (Juergens et al., 2016), which found that the mortality rate among immigrants with English as a second language (ESL) presenting with an acute coronary syndrome (ACS) was higher and they had increased CVD risk factors compared to patients who used English as their first language. Cardiac procedures such as percutaneous coronary intervention (PCI) rates and referral/attendance to cardiac rehabilitation (CR) were also lower for immigrants with ESL. It was suggested that language and cultural barriers may play a role in the adverse outcomes among patients from ethnic minorities (Juergens et al., 2016).

1.3 The Study Problem

The growing global migration to high-income countries such as Australia has highlighted the need for more information on cardiovascular disease, its risk factors and how it has been managed in migrant populations from different ethnic backgrounds. Little is known about CVD and Australian Turkish immigrants.

In 1967, the Australia-Turkey agreement on assisted migration was important in easing migration to Australia (Australian Government, 2012). Initially, most Turkish immigrants were unskilled and had limited English language proficiency, preventing them from

finding suitable jobs and causing a wide range of settlement problems (Cultural Atlas, 2019). According to the Ministry of Foreign Affairs of Turkey, there are 150,000 Turkish speakers in Australia. However, the Australian Census 2020 reported 32,178 Turkey-born people, excluding the second and third generations. The total number of Australian Turkish citizens is estimated to be around 90,000. The 2020 distribution by state and territory showed Victoria had the largest number of Australian Turkish immigrants, with 15,744 (48.9%), followed by New South Wales (12,808-39.8%) (State of Victoria, 2016). Compared to Asian and Western European countries, the Turkish community in Australia is much smaller. Australian Turkish immigrants are most likely to speak Turkish at home and have lesser English proficiency compared to all other immigrants (Australian Bureau of Statistics, 2020). They experience poverty at higher rates than immigrants overall (State of Victoria, 2016). The average weekly income for Turkish-born individuals in Australia aged 15 years and over was \$445 (\$688 for all Australian-born), and 4.4% had no qualifications (for total Australian 8.5%). The unemployment rate was 10% (total Australian population 6.9%) (Australian Bureau of Statistics, 2020).

Like other immigrants in Australia, Turkish immigrants face many challenges and stressors that may affect their self-care behaviours. These challenges may include cultural and linguistic adjustment, low socio-economic status, financial strain, lack of a support system, and lack of knowledge about the Australian healthcare system. These challenges may influence their self-care behaviours, resulting in migration-related health inequalities and may be associated with higher rates of recurrent CVD events and higher rates of CVD-related mortality than non-immigrants, as self-management is a key strategy in CVD secondary prevention. We also know little about how Australian Turkish immigrants manage their heart disease and what negative or positive factors impact their health or health behaviours.

Therefore, understanding and addressing the factors influencing heart disease management in Australian Turkish people is imperative to improve health outcomes. This may help us better understand issues and provide appropriate and accessible health services to this ethnic minority. Growing globalisation and migration create challenges for healthcare systems in providing quality care for immigrant populations. One of the significant challenges of these demographic changes is integrating immigrant populations

into existing healthcare services as they experience multiple factors contributing to health disparities. Immigrants are a heterogeneous population and face multiple barriers to accessing secondary prevention strategies and self-care to prevent and manage their chronic heart condition, including accessing the healthcare system, linguistic challenges and lack of culturally sensitive care (Davidson et al., 2007; Parajuli & Horey, 2020; Timmins, 2002), lack of information regarding the available health care provision (Parajuli & Horey, 2020), unawareness of risk factors for their heart condition (Ahmed, 2020; Langellier et al., 2012), poor access to secondary prevention strategies and self-management programs for CVD (Abdelmessih, 2019; Jin et al., 2020; Vanzella et al., 2021), limited health records, and acculturation (Jin et al., 2017).

In summary, immigrants have a higher incidence of CVD risk factors (including diabetes, hypertension, smoking, obesity, and physical inactivity) and poorer health outcomes, including increased hospitalisation, morbidity, and mortality (Briffa et al., 2011). The causes of these discrepancies are multifactorial, encompassing the characteristics of individuals, the healthcare system and communities, and are further impacted by local and national policies (Vanzella et al., 2021).

1.4 The Study Aims

This research investigated the factors affecting the self-care of Australian-Turkish immigrants with heart disease. The goal is to identify the obstacles that prevent healthcare providers from raising awareness and recommending appropriate healthcare solutions. The study intends to suggest practical solutions that can help patients overcome these barriers and effectively manage their medical conditions. In summary, the research seeks to answer the question: What are the positive and negative factors that influence the secondary prevention and self-management of Australian Turkish individuals who have CHD?

1.5 Significance of the Study

Many contributing variables could influence patient engagement in self-management in the long term. There is a scarcity of research that has examined Australian Turkish communities' heart management in-depth to understand better the factors that influence

health-related behaviours. Therefore, there is a need to evaluate how the Australian Turkish community with heart disease manage their illness to understand better and identify the active ingredients that facilitate self-management. If adherence to long-term secondary prevention strategies is a significant factor affecting outcomes of heart disease management, then transparency about the factors that influence self-care is vital.

Identifying the factors that influence individuals' ability and motivation for self-management and, thereby, informing the gap between the provision and utilisation of CR and secondary prevention strategies among Turkish immigrants living with heart disease may contribute significant information for HCPs, policymakers, and researchers to meet individuals' needs better and improve health outcomes among these ethnic minorities. Hence, identifying and addressing modifiable factors may assist in determining self-management support, enhance patient uptake of cardioprotective lifestyle choices and preventative medications, and improve quality of life.

1.6 Research Approach

This thesis approaches the topic with an explorative qualitative study. Semi-structured interviews with open-ended questions were conducted to explore the factors influencing secondary prevention and self-care of Australian Turkish immigrants living with CVD in Australia.

This project was conceived while working with Turkish immigrants with CVD at 'the HeartWest Clinic' in Melbourne. As a physician and cardiac technician, I witnessed that secondary preventative strategies have not been appropriately applied by ethnic minorities, particularly within the Australian Turkish community with heart disease. Therefore, an in-depth study is required to identify the factors that influence individuals' ability and motivation for self-management and to understand reasons for the lack of service utilisation for secondary risk prevention for CVD in this population to facilitate behaviour change in target groups, which is critical for self-management of CVD.

Based on the nature of the research topic, a constructivist paradigm with a qualitative approach was considered suitable for this study as it can uncover the experiences, beliefs,

and attitudes of people, as it offers a more neutral view of understanding human action in social context (Chauhan et al., 2010; Chun Tie et al., 2019; Creswell & Creswell, 2018). The constructivist ontology and interpretivist epistemological paradigm assume that individuals seek an understanding of the world by developing subjective meanings of their experiences. These meanings are a wide variety of interpretations that can be applied to the world (relativist ontology) (Creswell & Creswell, 2018). The researcher gathers data from the participants about their experience-related problems being studied with open-ended questions.

The individual semi-structured interviews with open-ended questions are original work, given the lack of studies about barriers and facilitating factors influencing secondary prevention and self-care of heart disease among Australian Turkish immigrants. The interviews contribute to the in-depth understanding of this ethnic minority's heart disease management, shedding light on overcoming these barriers.

1.7 Thesis Structure

This thesis consists of five chapters. The current chapter introduces the thesis. Chapter 2 presents a comprehensive literature review that examines and critiques the relevant literature on the thesis topic, then identifies the gaps in that literature and presents the aim of this Master of Research project. Here, it is shown how the thesis relates and further contributes to existing knowledge. Chapter 3 describes the methods and data analysis of the study conducted for this thesis. Details about the research sampling, recruitment method, study setting, data collection, and ethical considerations are given. This chapter also discusses data management, research rigour, and trustworthiness. Chapter 4 presents the findings, and Chapter 5 discusses the findings and also provides recommendations to overcome the barriers.

2 Literature Review

Chapter 2 focuses on cardiovascular disease (CVD), secondary prevention strategies, self-care, and cardiac rehabilitation (CR) program engagement among immigrants. Relevant literature and current research are discussed and critiqued. The chapter concludes by identifying the gaps in the literature and presenting the conceptual model used in the thesis.

2.1 Cardiovascular Disease

The most common types of CVD in Australia are coronary heart disease (CHD) and heart failure, the leading single cause of disease burden and death in Australia (Australian Institute of Health and Welfare, 2021b). Two major clinical manifestations of coronary heart disease are stable angina and Acute Coronary Syndrome (ACS). ACS incorporates unstable angina pectoris and Acute Myocardial Infarction (AMI), which is further classified depending on electrocardiogram results as Non-ST Elevation Myocardial Infarction (NSTEMI) and ST-segment Elevation Myocardial Infarction (STEMI) (Chew et al., 2016).

Managing CVD involves evidence-based, multidisciplinary, patient-centred therapies that aim to improve patients' symptoms and quality of life, reduce mortality, and prevent further cardiac events (Smith et al., 2011b). In this thesis, the treatment options for heart disease are discussed separately. However, there is some overlap between CVD and heart disease, particularly in long-term self-care management.

2.2 Cardiovascular Risk Factors

Factors that increase an individual's chances of developing or progressing CVD are known as cardiovascular risk factors (Australian Institute of Health and Welfare, 2021b). To date, no single risk factor has been identified to be solely responsible for causing CVD; instead, multiple interrelated factors seem responsible. Cardiovascular disease risk factors can be classified into two categories: modifiable (changeable) and non-modifiable (non-changeable) (Yusuf et al., 2004). Non-modifiable risk factors include those that cannot

be controlled by the individual, including age, gender, ethnicity, and family history (genetics) of CVD. Modifiable risk factors are related to lifestyle and its impact on health, such as smoking, physical inactivity, poor nutrition, excessive alcohol consumption, depression, stress, obesity, hypertension, diabetes, and hypercholesterolemia (AIHW, 2011). Modifiable risk factors and associated medical conditions are familiar warning signs that an individual is at risk for CVD (Hajar, 2017). Age, gender, and ethnicity may capture 63% to 80% of the prognostic performance of cardiovascular risk models, while individual modifiable risk factors contribute only modestly to the prognostic performance (Pencina et al., 2019). However, eliminating or controlling modifiable risk factors using preventative health interventions would substantially reduce cardiovascular events, their progression, or the impact of the CVD (Brown et al., 2022). Current clinical guidelines guide screening and identifying asymptomatic individuals at risk of developing CVD to eliminate or control its effects early and, therefore, to mitigate the resulting economic and disease-related burdens of CVD (AIHW, 2021a; Arnett et al., 2019)

A large global case-control study, 'INTERHEART', analysed the data of 27,098 participants from 52 countries (Yusuf et al., 2004). The study found that nine easily measured and potentially modifiable risk factors (smoking, abdominal obesity, hypercholesterolemia, diabetes, hypertension, consumption of alcohol and unhealthy diet, physical inactivity, and psychosocial factors) account for over 90 % of the risk of an initial AMI that is closely linked to our health behaviours. The findings were consistent with different genders, ages, ethnic groups, and geographic regions, suggesting that prevention strategies for CHD could be based on similar principles worldwide. Addressing behavioural risk factors such as a healthy diet, regular physical activity, and smoking cessation could reduce the relative risk for MI by about 80%. It should be the cornerstone of prevention strategies in all populations worldwide (Yusuf et al., 2004).

2.2.1 Cardiovascular Risk Factors Among Immigrants

Cardiovascular disease risk is the probability that an individual will experience an acute coronary or stroke event within a specific period. Early identification of high-risk individuals and treatment of cardiac risk factors is crucial to assist in the prevention of CVD and its complications, improving the quality of health and minimising healthcare

costs associated with CVD (Arnett, Blumenthal, Albert, & Buroker, 2019; Australian Institute of Health and Welfare, 2021a). Overall, the evidence illustrates that prevention approaches for CVD risk factors in the future need to be best customised to individuals depending on their social, cultural, and religious backgrounds, as the prevalence, incidence, and mortality may vary based on ethnic background, country of residence, and duration of resident (acculturation) (Agyemang, 2019; Hopgood et al., 2021).

A retrospective population-based cohort of Canadian immigrants (CANHEART) by Tu et al. (2015) comprised 824,662 first-generation immigrants from 201 countries. It revealed that the prevalence of traditional cardiac risk factors (smoking, hypertension, diabetes, hypercholesterolemia) and the incidence of major cardiovascular events were lower among immigrants than in long-term residents. In this study, the lowest burden of cardiac risk factors and events existed among East Asian immigrants (Chinese). In contrast, South Asian and Middle Eastern immigrants had a high burden of traditional risk factors and frequent cardiovascular events. The data from this study revealed that the event rate increased with greater residence duration in Canada. The findings highlight that striking variations in CVD risk factors and events exist between immigrants from different ethnic backgrounds (Tu et al., 2015). It was estimated that the immigration selection criteria and medical screening requirements could play an important role in the lower cardiac risk factor score among immigrants, supporting the Healthy Immigrant Effect (Kennedy et al., 2015).

Similarly, cross-sectional data from 263,356 random samples were analysed to identify the CVD risk factor profile among migrants according to birthplace in Australia (Guo et al., 2015). The findings showed that the prevalence of CVD among overseas-born immigrants was significantly lower than in Australian-born individuals. However, the data from the participants were self-reported, which may have missed undiagnosed and untreated metabolic risk factors or disadvantaged migrants with limited English proficiency as the questionnaire used was only available in English. In this study, the findings revealed that a longer duration of residence in Australia was associated with an increased prevalence of current smoking and overweight/obesity. Importantly, striking differences in the cardiac risk factors profile exist across ethnic backgrounds (Guo et al., 2015). Acculturation with adaption to Australian culture was more likely to have more

cardiovascular risk factors (Jin et al., 2017). Migrating to a new country and adapting to a new host culture can negatively impact the immigrant health (Hopgood et al., 2021).

2.2.2 Acculturation Effects on Cardiovascular Risk Factors Among Immigrants

Acculturation is a multidimensional process of surrounding social, cultural, and psychosocial adjustment that occurs due to constant contact of one culture with another, typically between dominant and minority. Acculturation is experienced by migrants who live in multicultural societies and integrate with their new host culture and often anxiety-provoking environments (Berry, 2017; Rosenthal, 2014). As populations shift from low-income to affluent countries for work, more income, and a better life, lifestyle changes become major predisposing factors for cardiovascular disease. The immigrant population then changes in demography, income levels, education, eating habits, and physical activity. Healthcare providers must know the new communities for potential health outcomes and tailor culturally and linguistically sensitive prevention and treatment strategies. Studies on the association between acculturation and CVD health outcomes among immigrants within an Australian context could provide a deeper understanding of contributing factors to CVD among immigrants over time and help predict the future burden of CVD among these groups.

An Australian study by Jin et al. (2017) obtained analysed data from 3220 Chinese immigrants within the 45-and UP Study, a large population-based prospective cohort study, to investigate the association between indicators of acculturation (age at migration, length of residence and language spoken at home) and cardiac risk. Each participant had submitted an assessment of six CVD risk factors (hypertension, diabetes, hypercholesterolemia, current smoking, overweight/obesity, and physical activity) alongside demographic information (age, gender, educational status, marital status, location of residence, health insurance). The researchers identified a positive relationship between a higher level of acculturation and the increased prevalence of cardiac risk factors, particularly diabetes and weight status (overweight/obesity) (Australian Institute of Health and Welfare, 2021b; Jin et al., 2017). This may be partly linked to different exposure to the risk factors mainly driven by migration-related lifestyle risk behaviours, such as smoking, unhealthy diet, physical inactivity, poor adherence to medical therapy,

low socioeconomic status, poor access to healthcare systems responsible for prevention, effective management of risk factors and complications (Agyemang, 2019). The studies indicate how acculturation affects cardiovascular risk factors among immigrants, attest to the enormity of the problem of both cardiovascular disease management and financial cost, and highlight the glaring need for strategies to deal with it. The impact of post-migration lifestyle changes such as stress, smoking, physical inactivity, dietary patterns, unemployment, and poor socio-economic status were associated with increased cardiovascular disease risk factors among immigrants (Yusuf et al., 2004).

2.3 Cardiovascular Disease and Risk Management Among Immigrants

Individuals can prevent cardiovascular damage early and improve their health outcomes by identifying and focusing on risk factors and healthy lifestyle modifications (Smith et al., 2011b). The burden of CVD on both individuals and healthcare highlights the importance of early prevention as part of integrated disease management to improve clinical and economic outcomes (Arnett, Blumenthal, Albert, & Buroker, 2019; Chew et al., 2016; World Health Organization, 2021).

Preventative strategies can be divided into primary and secondary prevention. To reduce the risk of progression to or impact of CVD, targeted preventive health interventions are essential to improve modifiable CVD risk factors (The National Heart Foundation of Australia, 2019). The availability of new evidence has changed the treatment philosophy from treating only symptomatic patients to treating asymptomatic patients at risk for developing the disease.

2.3.1 Primary Prevention

Once an individual's risk factors for CVD have been assessed by a healthcare provider, proven risk-factor-reduction strategies such as lifestyle modification (smoking cessation, reducing weight, healthy diet, regular physical activity, reduced alcohol intake) and pharmacological treatment (statin therapy, blood pressure lowering medication, diabetes medication and antiplatelet medication) are established to minimise CVD risks (Arnett, Blumenthal, Albert, & Buroker, 2019). Furthermore, the underuse of these risk-factor-

reduction strategies, notably by ethnic minorities, has been established and may be the main reason for results indicating less motivation to seek treatment and modify their lifestyle to prevent negative health outcomes (Langellier et al., 2012).

Many factors influence an individual's perception regarding CVD risk factors and use that information to make decisions regarding health-related behaviour. A qualitative study by Kampf and Göksu (2014) explored Turkish migrants' perception of CVD risk factors and primary prevention strategies and the impact of culture in Germany. The study revealed that even though the participants were aware of the risk of cardiovascular disease, they were hesitant to seek professional help for primary prevention strategies to reduce modifiable risk factors unless the condition became acute. It is crucial to know how to develop a more cardioprotective lifestyle. This study shows that if risk factors for CVD were accurately understood, participants were more likely to utilise preventive health care management facilities. An Australian study by Gholizadeh et al. (2011) showed that the risks of CVD were understated by Middle Eastern women (including Turkish women), and surprisingly, participants raised concern about stress as a pervasive risk, in Australia (Gholizadeh et al., 2011). The study by Langellier et al. (2012) explored awareness of four diagnosable CVD risk factors (diabetes, hypertension, hypercholesterolemia, and overweight) among US immigrants. Immigrants were more likely than non-immigrants to be unaware of CVD risk factors and, therefore, may be less motivated to seek treatment and modify their behaviour to prevent adverse CVD outcomes.

One possible cause of this gap in awareness was that immigrants may be less likely to receive preventive health care services than other populations. This study importantly demonstrated that the awareness of risk factors (hypertension, diabetes, hypercholesterolemia, overweight) varies significantly based on immigration status. This view is supported by other Australian studies by Davidson et al. (2007) and Zhang et al. (2018), and they indicated that language barriers and ethnicity strongly influence knowledge, beliefs and attitudes regarding CVD and self-management. Language barriers and cultural differences can also affect access to and utilisation of healthcare, communication with health professional providers, and adherence to the treatment (Davidson et al., 2007; Zhang et al., 2018). A systemic review by Boateng et al. (2017)

synthesised existing evidence on knowledge, awareness and perception of CVDs and their risk factors. It was found that gaps in knowledge of CVDs, cardiac risk factors and clinical symptoms in general populations are important barriers to the effective prevention and treatment of CVD. A population-based study by Chinju et al. (2014) questioned 50 randomly selected participants to explore the level of knowledge and awareness of CVD risk factors. It concluded that 52 % of participants were unaware of CVD risk factors, which are early predictors of preventing cardiovascular disease. It was emphasised that community-based education programs are necessary to increase awareness among the population.

Similarly, the editorial review by Odone et al. (2018) argued the implication of migration on CVD risks by doing a conceptual framework for some of the key issues in the country of origin, the migration process itself (forced-voluntary), and legal status in the host country to understand patterns of CVD among migrants. It was highlighted that culturally competent health policy plans and implementation processes in the health care system were necessary to increase awareness of CVD risk factors for culturally and linguistically diverse populations (Odone et al., 2018). It is essential to understand individuals' perceptions regarding their heart disease and the risk factors behind it to evaluate their awareness. By doing this, we can determine the reasons (barriers and challenges) for the underutilisation of preventative interventions, which are the keystone to reducing the risk of CVD.

2.3.2 Secondary Prevention

Patients with coronary heart disease (CHD) are at an increased risk of further cardiovascular events and hospital admission with greater costs for society (Redfern et al., 2011). An Australian study by Briffa et al. (2011) described the trends in the prevalence of previous hospital admission, major cardiovascular events, and relative risk for cardiovascular events in those with existing CHD compared with CHD-free populations. It was found that more than 40% of major cardiac events, 50% of CHD deaths and 35% of nonfatal Myocardial Infarction (MI) occurred annually in patients with existing CHD, highlighting the imperative to implement systems of care that support effective secondary prevention (Briffa et al., 2011). Furthermore, according to a systemic

analysis of data from a World Health Organization (WHO) study, more than 75% of all cardiac deaths may be prevented with appropriate lifestyle modification (World Health Organization, 2021).

One of the most effective ways of reducing the burden of CVD is promoting secondary prevention, which refers to providing risk-reduction interventions to individuals with existing CVD aiming to reduce the risk of further cardiac events and death using long-term care management (Figure 2.1). Anderson and Oldridge (2016) systematically updated the existing meta-analysis of 63 randomised controlled trials that included 14,486 participants, in which researchers observed that the use of exercised-based Cardiac Rehabilitation (CR) in people with existing CHD was associated with a significant reduction in cardiovascular mortality and hospital admission, and improvements in quality of life during a median follow-up of 12 months compared with no-exercise controls (Anderson & Oldridge, 2016). Additionally, it is well proved by Shields et al. that CR is a cost-effective strategy to reduce cardiovascular mortality by 20% (Shields et al., 2018).

The WHO Global Action Plan 2013-2020 for the Prevention of Non-communicable Diseases (NCDs) emphasised the important role of CR implementation in addressing the burden of CVD and targeted a 25 % reduction in premature mortality from NCDs (World Health Organization, 2013a). CR program is a part of secondary prevention strategies that aim to educate patients about healthy living, including a healthy diet, regular physical activity, quitting smoking, reducing alcohol intake, weight management, coping stress and adherence to medication (Woodruffe et al., 2015). Additionally, the national (National Heart Foundation of Australia & Cardiac Society of Australia and New Zealand) (Chew et al., 2016) and international guidelines (Chew et al., 2016; Piepoli et al., 2016; Smith et al., 2011b) strongly recommend that all patients who experience a heart event are referred to and attend a cardiac rehabilitation service for long term maintenance and secondary prevention program. Long-term lifestyle changes, preventive pharmacological treatment, and self-management (self-care) are the key strategies to improve quality of life, reducing hospital readmissions and mortality rates (Figure 2.1) (The National Heart Foundation of Australia, 2019).



Figure 2. 1: Effects of Secondary Prevention (Adapted from (The National Heart Foundation of Australia, 2019))

Hypertension

Hypertension, or elevated blood pressure (BP), is an important determinant of cardiovascular disease risk for the development of atherosclerosis by inducing oxidative stress in the arterial wall and inactivating endothelium-derived nitric oxide and thus mitigates its vasodilator effect. Endothelial dysfunction and changes in morphology, which are cardinal features of hypertension, lead to the formation of atherosclerotic plaque (Alexander, 1995).

Blood pressure is a recommended component of the assessment when conducting an absolute CVD risk assessment. The classification of blood pressure is shown in Table 2.1. The entire diagnostic process aims to identify all cardiovascular risk factors, detect end-organ damage and related clinical conditions, investigate any causes of secondary hypertension, and establish if, what and when treatment should be initiated (James et al., 2014). The Eighth Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (JNC 8) and the American Heart Association (AHA) recommend treating hypertension (i.e., blood pressure greater than 140/90 mm Hg, or greater than 130/80 mm Hg for persons with diabetes mellitus or

chronic kidney disease) for the secondary prevention of CAD (Table 2.2) (James et al., 2014). For those patients with hypertension eligible for absolute CVD risk assessment, the goal is to reduce absolute CVD risk by managing multiple risk factors concurrently, not blood pressure in an isolation (Whelton et al., 2022). It is also recommended that all patients should be counselled regarding the need for lifestyle modification, including regular physical activity, weight management, dietary modification, salt restriction, smoking cessation, moderate alcohol consumption, and relaxation therapies should be managed with hypertension (Smith et al., 2011a).

Table 2. 1: Classification of Clinical Blood Pressure Levels in Adults

<i>Diagnostic criteria</i>	<i>Systolic (mmHg)</i>	<i>Diastolic (mmHg)</i>
Optimal	<120	<80
Normal	120-129	80-84
High normal	130-139	85-89
Grade 1 (mild) hypertension	140-159	90-99
Grade 2 (moderate) hypertension	160-179	100-109
Grade 3 (severe) hypertension	≥180	≥110
Isolated systolic hypertension	>140	<90

Diabetes Mellitus

Cardiovascular disease has been diagnosed as a micro-and macrovascular complication of diabetes. Diabetes is an important endocrine disease diagnosed by hyperglycaemia. Increased chronic glucose concentrations can promote macro- and microvascular complications by multiple mechanisms, with the formation of advanced glycation end products (AGEs) and increased oxidative stress (Orasanu & Plutzky, 2009). Cardiovascular disease is a common cause of morbidity and mortality among patients with Type 1 or Type 2 diabetes (Laing et al., 2003).

Recent clinical trials conclusively demonstrated the benefit of intensive treatment of hyperglycaemia in reducing the risk of microvascular disease, myocardial infarction, and

death in both Type 2 diabetes (T2D) (Holman et al., 2008) and Type 1 diabetes (T1D) (Table 2.2) (Control et al., 2005).

Lipid Management

The lipid goals are part of a comprehensive cardiovascular risk reduction strategy summarised in Table 2.2. It has been strongly recommended that a lipid profile in all patients with CAD should be performed, and if required, lipid-lowering medication should be initiated before discharge (Smith et al., 2011a). Intensive statin therapy reduces mortality in patients after ACS compared with standard therapy (Baigent et al., 2005). Lipid management primarily aims to reduce atherosclerotic risk by substantially lowering Low-density lipoprotein cholesterol (LDL-C). The targeted LDL-C level for high-risk patients is less than 1.8 mmol/L (70 mg/l) (Table 2.2). Individuals with CVD are considered at high risk and strongly recommended to be treated aggressively in addition to lifestyle modifications, including daily physical activity and weight management to achieve target lipid levels. Furthermore, low High-density lipoprotein cholesterol (HDL-C) is a recognised CHD risk factor, and a moderate rise in HDL-C is desirable (ESC/EAS, 2020).

Tobacco Cessation

A prospective Australian study conducted by Banks et al. (2019) estimated that smoking increased the risk of mortality from CVD for CVD subtypes. Exposure to second-hand cigarette smoke is also a cause of CHD in non-smokers. The critical underlying pathophysiology in most CVDs is atherosclerosis. Exposure to cigarette smoke activates several mechanisms predisposing to atherosclerosis (Lee & Cooke, 2011).

The Australian Institute of Health and Welfare (AIHW) reported that people born in Australia (English-speaking households) were more likely to be smokers than those born outside of Australia and speak a language other than English (Australian Institute of Health and Welfare, 2020b). However, the prevalence of smoking is not known among Australian Turkish immigrants.

Quitting smoking is linked to a significant decrease in the chances of dying from any cause among patients with CAD. This risk reduction remains consistent regardless of variations in cardiac events, age, gender, country, and period (Critchley & Capewell, 2003). Thus, secondary risk reduction therapy should include questioning patients about their tobacco use status, advising every patient who smokes to quit, assessing the tobacco user's willingness to quit, assisting by counselling and developing a plan for stopping or referring to a smoking cessation program at every office visit (Table 2.2). Finally, follow-up is recommended (Smith et al., 2011a).

Table 2. 2: Goals of Secondary Prevention for Individuals with CVD

Area of intervention	Recommendations
Smoking	Complete cessation, no exposure to environmental tobacco smoke in any form
Physical activity	At least 30 minutes, 7 days per week (minimum 5 days per week) moderate intensity aerobic activity, such as brisk walking
Weight management	BMI <18.5-24.5 kg/m ² Waist circumference women < 35 inches (<89 cm) men <40 inches (<102cm)
Diabetes mellitus	A target HbA1c of ≤ 7% (<53 mmol/mol)
Blood pressure control Normal BP: SBP<120, DBP<80	<140/90 mm Hg or <130/80 mm Hg with diabetes or chronic kidney disease
Lipid management	LDL-C Very-high risk <1.4 mmol/L (<55 mg/dl) High risk <1.8 mmol/L (<70 mg/dl) Moderate risk <2.6 mmol/L (<100 mg/dl) Low risk <3.0 mmol/L (116 mg/dl) HDL-C >1.0 mmol/L Triglycerides <2.0 mmol/L Apo B <65, 80, 100 mg/dl for very-high, high, and moderate-risk individuals, respectively
Depression	Screening for depression
Cardiac rehabilitation (CR)	All eligible patients with ACS or whose status is immediately post coronary artery bypass surgery or post-PCI should be referred to a comprehensive outpatient cardiovascular rehabilitation program either prior or during first follow-up office visit

Note: Summarized from the AHA/ACC 2019 guideline regarding secondary prevention strategies for individuals with CVD (Arnett, Blumenthal, Albert, Buroker, et al., 2019).

BMI: Body mass index, *BP:* Blood pressure, *SBP:* Systolic blood pressure, *DBP:* Diastolic blood pressure, *LDL-C:* Low-density lipoprotein, *HDL-C:* High-density lipoprotein, *Apo B:* Apoprotein B

Physical Activity

A meta-analysis of a prospective cohort study by Li and Siegrist (2012) found that a high level of leisure time physical activity and a moderate level of occupational, physical activity had a beneficial effect on cardiovascular health by reducing the overall risk of incident CHD and stroke. It has been estimated that physical activity lowers blood pressure, body weight and LDL-C levels, increases HDL-C and maintains standard glucose tolerance, contributing to risk reduction. In contrast, physical inactivity can potentially have pathogenic effects on atherosclerosis and plaque formation by promoting endothelial dysfunction and increasing endogenous inflammatory molecules and coagulation factors.

Therefore, all patients should be encouraged to undertake 30 to 60 mins of moderate-intensity aerobic activity, such as brisk walking, at least five days and preferably seven days per week to improve cardiorespiratory fitness (Table 2.2) (Smith et al., 2011a).

Weight Management

Overweight/obesity is a major preventable cardiac risk factor as measured by body mass index, dividing weight (in kilograms) by height (in metres squared). The WHO criteria for overweight as a body mass index (BMI) ≥ 25 and < 30 kg/m² and obesity as a BMI ≥ 30 kg/m² (World Health Organization, 2000), p.6). It is recommended that patients with CVD should be assessed for BMI and/or waist circumference at every visit and should be encouraged weight maintenance/reduction by doing regular physical activity and diet (Smith et al., 2011b).

Table 2. 3: Weight Classification by Body Mass Index (BMI)	
Classification	Body Mass Index (<i>kg per m²</i>)
Underweight	<18.5
Normal	18.5 to 24.9
Overweight	25.0 to 29.9
Obese	≥ 30.0

Adopted from WHO (2000)

The cornerstone of the management of overweight/obesity is a comprehensive or multicomponent lifestyle intervention, including lifestyle or behavioural training, dietary change to reduce energy intake, and an increase in physical activity.

Psychosocial Stress Management

Psychosocial distress, anxiety disorders and depression, low socioeconomic status, lack of social support and social isolation are independent risk factors for CVD. Stress, which may exist in many forms, is a pervasive component of the human experience that often leads to a maladaptive physiological response. Stressors can emerge abruptly or linger, manifesting in different ways, such as significant life changes (such as relationship issues or environmental catastrophes) and unfavourable socioeconomic conditions (including insufficient income or elevated crime rates). They may also be linked to mental health disorders (such as anxiety or depression) (Dar et al., 2019). Although acute emotional stress has long been linked to acute cardiovascular events, the long-term effects of chronic stress on physical well-being, specifically cardiovascular disease (CVD), have only recently been recognised. It has been shown that depression is commonly present in patients with CHD and is independently associated with increased cardiovascular morbidity and mortality (Lichtman et al., 2009). Therefore, it is reasonable to include depression screening, assessment, and treatment during secondary prevention of CAD (Table 2.2).

Alcohol Consumption

Over the last two decades, data from numerous epidemiologic studies have revealed complex associations between alcohol use and cardiovascular conditions such as hypertension, coronary heart disease, stroke, peripheral arterial disease, and cardiomyopathy. Low-to-moderate daily alcohol consumption (i.e., <15 to 20 g/day, 1 to 2 standard drinks) may be associated with a reduced risk of CV disease and mortality. In contrast, more significant amounts of alcohol consumption and a binge pattern of drinking have been linked to an increased risk. However, a recent analysis published in JAMA Network Open, which looked at over 100 studies with nearly 5 million participants, found not only no significant health benefit of moderate alcohol consumption but also that low-

volume alcohol drinking was not associated with protection against death from all causes (Zhao et al., 2023).

It is necessary to reassess the recommendations regarding the health benefits of moderate alcohol consumption.

A study conducted by Akvardar et al. (2003) investigated alcohol use in Istanbul and the severity of the issue in Turkey. The study found that 25.6% of the 1,550 residents surveyed reported using alcohol, with 15.9% of women and 34.5% of men reporting use. The highest rate of alcohol use was found in the 40- to 49-year-old age group. Despite being a Muslim country, alcohol use is prevalent in Turkey.

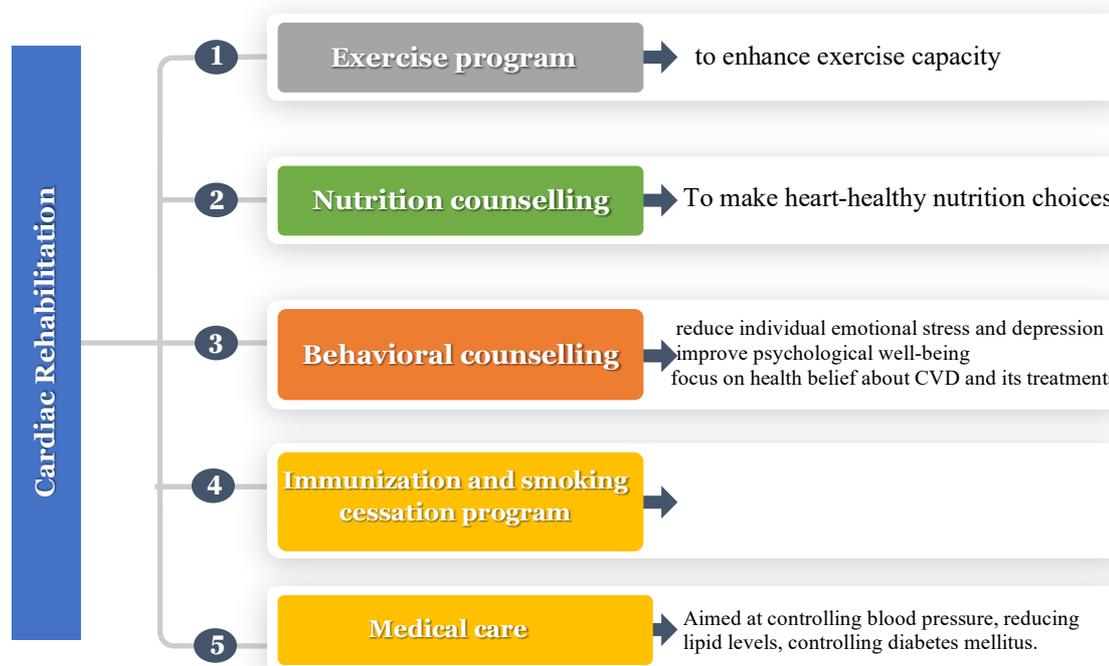
2.4 Cardiac Rehabilitation

Cardiac rehabilitation (CR) is a comprehensive, long-term and multidisciplinary outpatient program of secondary prevention and lifestyle changes that aim to assist patients with CVD in improving daily function and reducing cardiovascular risk factors to prevent the recurrence of cardiac events, control cardiac symptoms and reduce the risk for sudden death (Figure 2.2) (The National Heart Foundation of Australia, 2019).

Overall, secondary prevention strategies aim to focus on healthy and satisfying lives, not only to live longer but, most importantly, to live better by stabilising or reversing the atherosclerotic process. Therefore, after assessing individual risk factors, all the patients should be advised on lifestyle/ behavioural modification and medication adherence to reduce the risk of recurrence or progression of CHD events (Chew et al., 2016).

A CR program typically includes (Figure 2.2):

Figure 2. 2: Cardiac Rehabilitation Program and Its Goals (Adapted from (Chew et al., 2016)

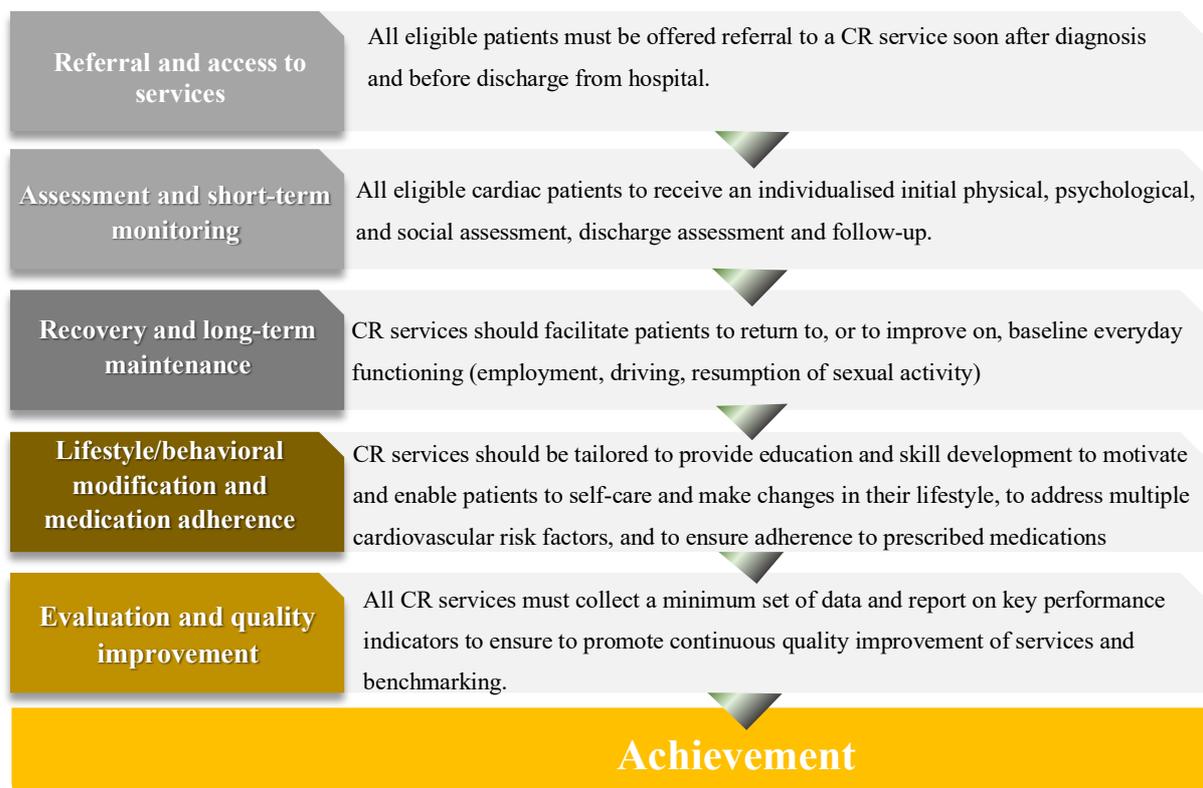


A recent paper by Driscoll et al. (2020) evaluated the lifetime cost-effectiveness of CR based on Australian data. It estimated that increasing CR uptake to 59.6% would save 536 lives and prevent 823 hospitalisations over ten years. This evaluation provides essential economic information regarding health benefits and costs associated with improving the uptake of CR. It justifies further research on investment in CR programs to identify areas for improvement to increase the uptake rate. Despite offering more accessible and flexible programs, the uptake rates remain low (Driscoll et al., 2020).

The Australian Cardiovascular Health and Rehabilitation Association (ACRA) convened in 2015 to provide guidelines on the latest Level 1 evidence to establish core components and delivery of effective CR for cardiovascular secondary prevention to patients after a cardiac event in Australia (Woodruffe et al., 2015). The core components of group CR are physical, psychological, and social assessment, education, self-care

strategies and exercise (Figure 2.3). Lifestyle modification has favourable outcomes for managing cardiac disease and its risk factors and aims to commence preventative care in an inpatient setting. CR educate the patients to be involved in many behaviours related to secondary prevention, including monitoring signs and symptoms, adhering to cardioprotective treatment, modifying their risk factors with long-term lifestyle, and copying the impact of the heart condition on personal well-being. Learning strategies are essential to make patients confident and motivated individuals to control risk factors and manage their condition. It is advised healthcare professionals use these core components to guide effective service delivery and promote high-quality, evidence-based care (Figure 2.3) (Woodruffe et al., 2015).

Figure 2. 3: Comprehensive Cardiac Rehabilitation and Its Core Components (Adapted from (Woodruffe et al., 2015))



Cardiac rehabilitation represents an efficient and safe secondary prevention model; however, it is not available in over half of countries worldwide, and where it exists, it is

insufficient to meet growing service demand. Most patients with CVD are missing the opportunity to benefit from CVD secondary prevention and CR programs. The first global survey on CR availability and capacity worldwide by Turk-Adawi et al. (2019) explored 203 countries' CR availability and utilisation. It has been established that CR is available in only 54.7% (111/203) of countries worldwide. Shockingly, 92 countries still do not have CR programs in place, which could potentially prevent 20% of deaths caused by cardiovascular disease (CVD). A major barrier to CR participation globally is the lack of referrals, insufficient personal and financial resources and lack of profitability (Sérvio et al., 2019; Turk-Adawi et al., 2019).

Despite the availability of well-established and effective evidence-based national and international guidelines support the clear benefits of secondary prevention in the management of ACS (Chew et al., 2016; Piepoli et al., 2016; Smith et al., 2011b), specifically in the long-term management phase, worryingly, provision of recommended medications at hospital discharge remains incomplete, and referral and attendance of CR programs remain alarming low in Australia.

The study by Redfern et al. (2014) evaluated the rate of preventive care (comprising medications, lifestyle advice, and referral to rehabilitation) received by patients who were admitted to an Australian and New Zealand hospital (including public, private, metropolitan, or rural) with ACS. They aimed to identify the important clinical factors influencing optimal preventative care during an ACS admission. Two thousand two hundred ninety-nine patients with suspected or confirmed ACS were identified from a potential pool of 525 hospitals across Australia and New Zealand. It was found that only 27% of patients received optimal secondary prevention with at least four cardioprotective medications, dietary or physical activity advice, and referral to CR. The majority of those patients were diagnosed with STEMI (51%), and it was more than NSTEMI (30%) and UA (15%) patients who received guideline-recommended preventive care. Despite universal guideline recommendations, around three-quarters of all patients admitted with ACS did not receive primary preventive care comprising proven pharmacotherapy, lifestyle advice, and referral to the rehabilitation (Redfern et al., 2014). This study found that 46% of ACS patients were referred to cardiac rehabilitation. Still, a 2010 report (n=1545) by the National Prescribing Service of Australia found that even when patients

were referred to cardiac rehabilitation, only half completed the programme (Wai et al., 2012). Significantly, attending CR was associated with less cardiovascular readmission and clinical events. Those eligible patients who did not undertake CR were more vulnerable populations (elderly, more likely female and more comorbidities). This evidence illustrates the need to implement an effective CR program to address non-participation in the 70% of patients who were not referred or referred/declined and identify areas for improvement, especially for socially vulnerable populations (Astley et al., 2020). The studies described below, referral/attendance to CR and self-care, attest to the enormity of the secondary prevention problem among immigrants and the resident population and highlight the glaring need for strategies to deal with it. Therefore, future trials powered on CR enrolment or adherence must clarify the understanding of barriers underlying ethnic minorities to attend CR.

A review by Okwuosa et al. (2016) highlighted phenotypes of disparities in cardiovascular management worldwide. It emphasised that the benefits of cardiovascular care have not been distributed equitably and caused disparities as a global problem. Disparities in heart disease management of individuals from different ethnic backgrounds, including immigrants, are a multifaced problem and, thus, should be addressed on many levels; however, there needs to be explored, well understood, and acknowledgment of what barriers and facilitator factors exist among Australian Turkish community before these barriers can be remedied.

2.4.1.1 Barriers to Accessing Cardiac Rehabilitation Services Among Immigrants

Cardiac rehabilitation (CR) with basic lifestyle advice and prescribed preventive pharmacotherapy should commence in all patients with acute coronary syndrome (ACS) according to the international guidelines' recommendations (Woodruffe et al., 2015). Although the importance of secondary prevention and attendance of CR is strongly emphasised, it is underutilised among immigrants in the practice. It is well known that immigrants face various barriers to their access to healthcare on an individual level in the form of language barriers, cultural differences, inadequate health literacy and difficulties in navigating the healthcare system (Vanzella, 2021; AL-Sharifi, 2019; Resurrection et al., 2019).

Resurreccion et al. (2019) systematically reviewed the existing literature that analyses factors that affect non-participation in and dropout from CR programs to understand why patients with CVD do not complete CR programs. Based on the data from 43 prospective cohort studies (to minimise the risk of effect bias), the findings showed low attendance rates were the result of both healthcare services-related factors (health professionals and healthcare services and system) and patient-related barriers to attendance or adherence after referral (Resurrección et al., 2019). Under the socio-ecological health model, the factors were classified into six categories (Table 2.5).

Table 2. 4: Barriers to Attendance and Completing the Cardiac Rehabilitation Program

Intrapersonal level	Age (older age) Gender (female) Socioeconomic level-low income Lack of insurance Comorbid conditions Emotional stress/depression
Clinical factors	Smoking Overweight Physical inactivity Hypercholesterolemia Diabetes Hypertension
Interpersonal level	Having low social support-being single Unemployed or retired
Logistical factors	Longer travel times Lack of transport Living in a remote-rural area
CR program factors	
Health system factors	

Adopted from (Resurrección et al., 2019)

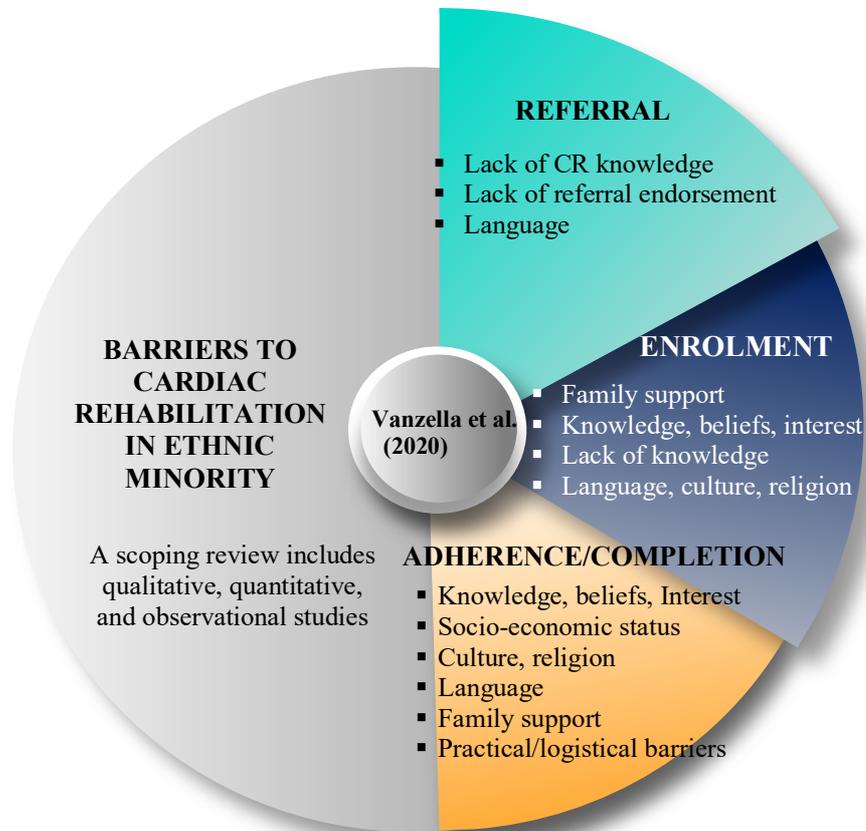
Similar findings were matched with a previous study by Ruano-Ravina et al. (2016) for participation and adherence to CR. Additionally, this systematic review revealed that there was scarce evidence for ethnic minority factors associated with non-participation in and dropout from CR (Resurrección et al., 2019). More worrisome is that this gap in referral, enrolment, and adherence seems to affect vulnerable patient groups more than others and persistent disparities in the quality of cardiovascular care among racial and ethnic minorities. Patients less likely to be referred were more likely to come from vulnerable populations, leading to suboptimal secondary prevention and clinical benefit. Integration of vulnerable populations in CR programs is essential not only for ethical considerations but also because CVD is more prevalent in these groups. Diverse racial and ethnic minorities, women, the elderly, patients with low socio-economic status and high-risk patients with heart disease and rural residents tend to have lower CR referral and participation rates when compared with the general population (Castellanos et al., 2019; Cortés & Arthur, 2006; Hamilton et al., 2018; Ilton et al., 2014; Valencia et al., 2011). A systemic review by Castellanos et al. (2019) analysed CR referral and participation rates based on race and ethnicity. Findings indicated that race, ethnicity, and language barriers contributed to the underutilisation of CR referral and participation. Therefore, it is necessary to understand the immigrant patients' experiences and opinions regarding how these factors are associated with the long-term self-management of heart conditions.

It is essential to be aware of the barriers to CR delivery among immigrants, not only enrolment and referral but also adherence and completion of the programs to achieve the benefits of the CR programs. Mead et al. (2016) have comprehensively explored the factors influencing CR utilisation among low-income minorities in three healthcare markets, including the healthcare system, the provider, and the individual, to reflect on the gaps and to understand the reasons for why and how disparities in CR utilisation for minorities. Despite the benefits of cardiac rehabilitation, the study has shown that CR referral and participation rates were significantly lower among patients from ethnic minorities. According to the healthcare professionals' perceptions, minorities were less willing and not motivated to use CR services because of certain cultural and socioeconomic factors. On the other hand, patients reported that they were not given sufficient information to make informed decisions or referrals to attend the programs,

thereby increasing disparities in the use of CR services. They estimated that minorities' interest in CR might be higher than providers' assumption as most minorities in the study expressed an interest in seeking out CR resources that would help them improve their heart condition. These results revealed poor patient-provider relationships (misunderstanding), lack of communication (miscommunication) and culturally inappropriate care. These findings are consistent with the recent scoping review conducted by Vanzella et al. (2021). The research summarised the peer-reviewed literature on barriers influencing ethnic minorities' CR referral, enrollment (attendance) and program adherence/ completion reported by patients, not by healthcare providers or families and developed strategies to overcome these barriers (Figure 2.4).

Three themes were categorised according to the CR participation phases (referral, enrolment, and program completion). Each theme was subdivided into three levels of barriers according to the socio-ecological model (individual, provider, and system level). It was found that the common barrier reported in all studies was a lack of knowledge regarding their underlying diagnosis, the CR program, and the importance of this intervention in managing their heart condition. Individuals who did not attend CR were unsure about referral due to communication or shared information problems with healthcare providers (provider-level barrier-language proficiency). The language barrier was the primary factor influencing individuals' access to and utilisation of the CR program (Al-Sharifi et al., 2019; Vanzella et al., 2021; Zhang et al., 2018). Ineffective communication between immigrants and health professionals is also associated with poor medication adherence. Other specific issues that can contribute to patient ambivalence include weather conditions, time constraints, CR location and transportation issues, and they were the practical/logistical barriers during CR adherence /completion (Figure 2.4) (Vanzella et al., 2021).

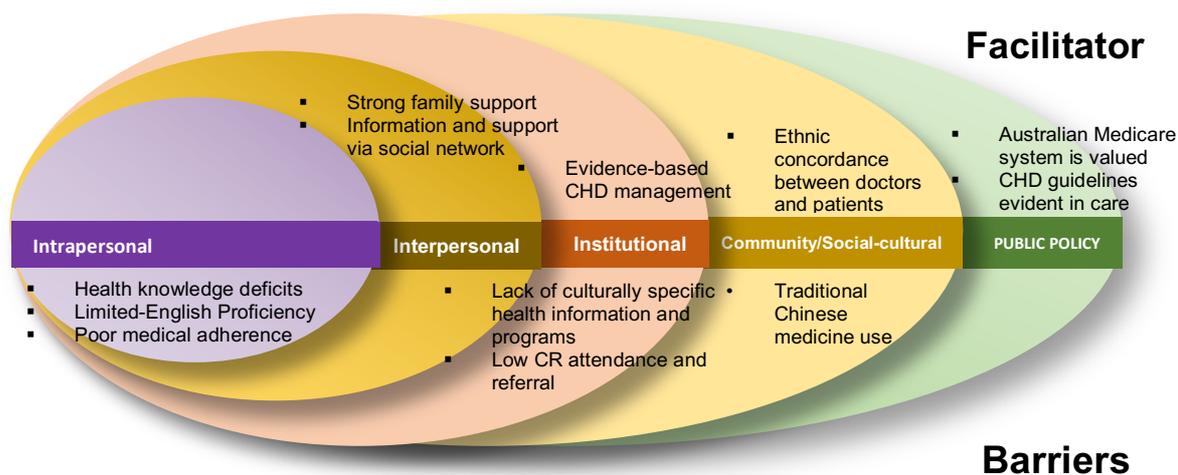
Figure 2. 4: Barriers to Cardiac Rehabilitation in Ethnic Minority
(Adapted from (Vanzella et al., 2020))



An Australian qualitative study by Jin et al. (2020) analysed in-depth interview data from Chinese immigrants and their family careers using a socio-ecological model (SEM) lens to investigate the factors influencing engagement with CHD primary and secondary prevention. The findings demonstrated that a lack of knowledge of CHD risk factors and ACS, limited English proficiency as negatively influencing communication with health professionals and poor adherence to cardioprotective medication were important barriers at the intrapersonal level (knowledge, language skill, and medication adherence) (Figure 2.5). Poor knowledge led to delays in seeking medical help for effective CHD management in Chinese immigrants (King et al., 2009; Zhang et al., 2018). Lack of culturally and linguistically appropriate health education is associated with poor

comprehension and compliance in Chinese immigrants. In contrast, strong family support was the positive interpersonal factor. These findings were consistent with recent findings of the scoping review by Vanzella et al.

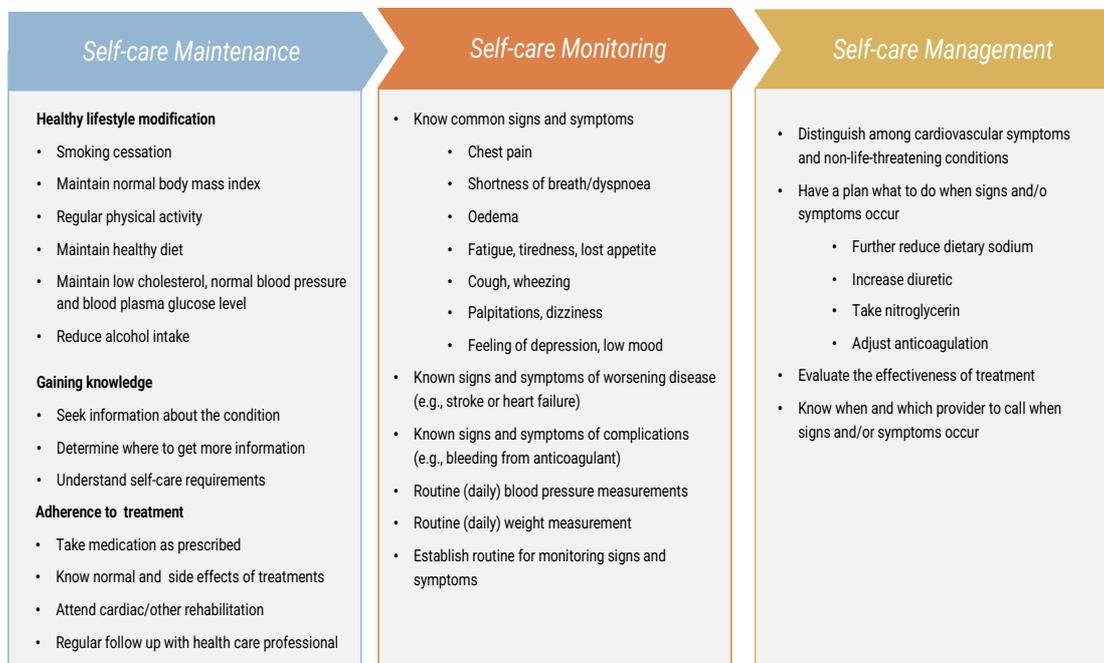
Figure 2. 5: Factors Influencing the Heart disease Management (Adopted from (Jin et al., 2020))



2.5 Heart Disease Self-care or Self-management

Self-care is essential in chronic disease management, such as cardiovascular disease. According to the middle-range theory of Chronic Illness (Riegel et al., 2017), self-care entails three core processes: maintenance, monitoring, and management. Self-care is an overarching concept that includes individual-level activities and processes and constructs the individual's behaviours to maintain stability (e.g., taking or adjusting medication as prescribed, engaging in physical activity, and adhering to a healthy diet), to monitor for changes (the process of observing oneself for changes in signs and symptoms) and self-care management behaviour to respond appropriately to signs and symptoms when they occur throughout the life course (Figure 2.6) (Jaarsma et al., 2021; Riegel et al., 2017).

Figure 2. 6: Self-care of Cardiovascular Disease (Adopted from (Riegel, 2017; Jaarsma, 2021))



In this naturalistic decision-making process, individuals with CVD can prevent and manage their chronic condition by being regularly instructed and educated to increase awareness and knowledge of the chronic condition and to engage in self-care behaviours to develop the skills and behaviour necessary to manage the situation before a symptom escalates. Self-management has been suggested as the most effective way to reduce the burden of CVD and substantially impact clinical and behavioural health outcomes (to maintain health and minimise complications) (Jaarsma et al., 2021). Self-management allows patients to play a significant role in their care while healthcare providers (HCPs) act as the mediators of such care. However, it does not mean ‘doing it all by yourself’. Patient education is vital to improve self-care behaviour and to reduce misconceptions, misunderstandings, and lack of knowledge contributing to insufficient self-care. Therefore, a multidisciplinary team with a patient-centred approach seems pivotal to increasing success by educating patients about their current health status and their risk

factors, teaching skills, supporting individual needs and abilities, and engaging with patients to make shared decisions. It is not only an individual-level behaviour, but also family members (supporting an individual to access healthcare services, adjust medication, monitor symptoms and signs, and modify lifestyle changes) and community (access to service, healthy food, open space, safe environments) exert a significant influence on self-care (Riegel et al., 2017). However, despite these benefits, immigrants may have barriers to self-manage their chronic diseases.

An individual's cultural background and ethnicity can affect their views and beliefs about illnesses, health, and healthcare. Providing self-management programs in different cultural settings can present challenges. Many culturally and linguistically diverse (CALD) communities struggle to access healthcare services. A study conducted in Australia showed that gender, age, English proficiency, and visa status can influence immigrants' use of healthcare services. Limited English proficiency and a lack of family support can make it difficult for individuals to access healthcare services (Kelaher et al., 1999).

Further high-quality research is needed, particularly in ethnic minorities, to identify the factors (barriers and facilitators) from the perspective of individuals living with CVD that may influence individuals' ability and motivation to self-manage and the quality of self-management. This research addresses the gap in factors influencing self-care among the Australian-Turkish population with CVD. It may assist individuals with cardiac disease and their healthcare providers to determine and address modifiable negative (barriers) factors and move them toward the positive (facilitators) side.

It requires a comprehensive understanding of the factors influencing CVD secondary prevention strategies and self-care among immigrants. Poor understanding of these immigrants' barriers to reaching secondary prevention strategies and self-care may contribute to poor disease management, as patients may not be sufficiently equipped to manage their health, which may increase their risk of recurrent CVD events or death (Briffa et al., 2011). Thus, it is necessary to explore the factors influencing self-management to improve cardiovascular care in this patient group in the socio-ecological model.

2.6 Conceptual Framework

Health promotion models aim to understand people's perspectives on health, including their personal experiences. By doing so, they can provide healthcare that meets the community's needs, enhancing patient satisfaction and improving health outcomes for those with chronic diseases (Balcázar et al., 2012). Such healthcare models include the Health Belief Model (HBM), the Patient-Centred Care (PCC) model and the Socio-ecological Model (SEM). Health behaviour theories explain why people do what they do related to their health and suggest ways this behaviour may be changed. The present study considers the health belief model and patient-centred care as a framework; however, our research examines the factors that influence self-care, not just individual dimensions but also interpersonal communities' effect on self-care. Therefore, we propose that the socio-ecological framework be used to organise and summarise the study findings concerning various factors influencing the behavioural intention of cardiovascular disease secondary prevention strategies and self-care among Australian Turkish immigrants and determinants of potentially promising recommendations to overcome the barriers.

Moreover, this framework considers the intricate interplay among individual, interpersonal, community, societal, and policy levels. It is essential to comprehend the factors that impede or facilitate access to secondary prevention strategies. Therefore, it is crucial to consider how interpersonal relationships, community, and public policy influence an individual's health behaviour.

2.6.1 The Social-ecological Model of Health

Bronfenbrenner (1977) first suggested the socio-ecological framework as an ecological systems theory and later redefined by McLeroy et al. (1988) as a framework to promote health-related behaviour change. The ecological model of health and well-being emphasises the importance of multiple factors (determinants) that might affect health and help us to understand health is affected by the interaction between the individual, the group/community, and the physical, social, and political environments (Sallis et al., 2000). The theoretical framework of the model has a multilevel approach that allows researchers to understand the range of influences on health behaviours (Golden & Earp,

2012; McLeroy et al., 1988) (Figure 2.5) as it has been used with studies of Chinese immigrant populations in Australia (Jin et al., 2020).

Simply educating and motivating individuals is not enough for effective health behaviour change. Environments and policies must also support self-management strategies. This is why it is crucial to identify the factors that influence health-related behaviours through the SEM framework. The data collected during this stage is vital for future behaviour change trials aiming to improve health outcomes (Figure 2.7).

Figure 2. 7: Steps for the Ecological Model (Adapted from (Sallis et al., 2000))



2.7 Self-management and the COVID-19 Pandemic

When writing this thesis, the world is still experiencing the consequences of the COVID-19 (SARS-CoV-2) outbreak and enforced social isolation and distancing recommendations that have disproportionately affected CVD patients. In such circumstances, self-care maintenance, monitoring and management are even more critical than usual to maintain CVD stability and avoid deterioration of CHD, which can lead to preventable contacts with the health care system, such as visits to the emergency room, visits to the general practitioner and recurrent hospital admissions.

The COVID-19 outbreak has significantly impacted people's well-being, including patients with heart disease. Radhakrishnan et al. (2021) conducted a qualitative study that interviewed seventeen older adults with HF to investigate how they practised during the

COVID-19 outbreak. The study revealed that the pandemic negatively impacted physical activity and self-care behaviour for HF patients. The effects of the COVID-19 pandemic on individuals varied depending on factors such as social isolation, financial stability, and access to necessary resources like medication and food. Those living in rural areas and relying on specific sources of income were found to be more vulnerable to the pandemic. However, implementing measures such as healthcare adaptations, engaging in health-promoting activities, utilising technology for socialising, and finding spiritual connections were all factors that increased resilience to the pandemic. While this study aims to shed light on the effects of the COVID-19 pandemic, it was not explicitly designed to address COVID-19-related experiences of immigrants. However, in future research, it is essential to investigate thoroughly the impact of COVID-19 pandemic-related changes on immigrant patients with heart conditions and determine how to overcome any resulting barriers.

2.8 Summary of the Literature Review

Effective management of cardiovascular disease (CVD) is essential for preventing recurring events and mortality, especially among immigrants with CVD. Failure to address secondary prevention measurements and self-care related to CVD can adversely affect disease management and health outcomes. These barriers and facilitators are complex and can only be fully comprehended through the perspective of the targeted patient group, in this case, Turkish-speaking immigrants.

Patients with existing heart disease benefit greatly from a multidisciplinary team that takes a patient-centred approach to cardiovascular disease management. This type of team can prevent recurrent cardiovascular events and CVD-related mortality, a significant issue among ethnic minorities with CVD. Understanding the factors that negatively affect secondary prevention and self-care, especially within the Australian Turkish community, is a significant contribution that can improve healthcare professionals' ability to provide better care.

2.9 Literature Gap

Evidence showed that CVD and recurrence of cardiovascular events are more prevalent among ethnic minorities compared to host countries' population (Briffa et al., 2011; Cortés & Arthur, 2006; Hamilton et al., 2018; Ilton et al., 2014; Valencia et al., 2011). Despite the well-described benefits of secondary prevention strategies on long-term health outcomes, it is underutilised by a significant proportion of immigrants with CVD, potentially due to poor self-care and experiences with the healthcare system in host countries (Dassanayake et al., 2011). What is not yet clear are the reasons behind it. A lack of studies has explored the socioecological factors that influence the ability and motivation to self-management of Australian Turkish individuals with heart disease, which significantly improves patients' health outcomes.

All the studies reviewed here support the importance of awareness for prevention strategies among immigrants. However, the implementation of secondary prevention strategies has remained a challenge. Although current studies have focused on the perception and knowledge of illness and primary prevention of CVD, this attention has not been extended to secondary prevention of CVD among immigrants and lay understanding of self-management, particularly for Turkish ethnic minorities in Australia.

This thesis aims to fill the above significant gap by exploring the barriers and facilitator factors that impact the individual's engagement with cardiovascular self-management strategies and secondary prevention interventions among Turkish Australian communities with existing heart disease. Importantly, there is a lack of studies exploring the experience of Turkish immigrants with heart disease in Australia. There is much to be learned about the patients' experience of heart disease diagnosis and events and self-management from the perspective of Australian Turkish communities living with heart disease to demonstrate the factors influencing self-management by conducting qualitative research. Qualitative research into heart disease among Australian Turkish immigrants is minimal, with only one study exploring Turkish with Arabic immigrants for cardiac risk factor awareness, which may not be generalisable to the broader Australian Turkish community (Gholizadeh et al., 2009)

2.10 Research Question

This project was conceptualised while I worked at HeartWest Clinic in Melbourne, assisting Turkish immigrants with cardiovascular disease. As previously mentioned, ethnic minorities, particularly the Australian Turkish community with heart disease, have not appropriately applied secondary preventative strategies. Therefore, an in-depth is required to identify the factors that influence individuals' ability and motivation for self-management and to understand the reasons for the lack of service utilisation for secondary risk prevention for CVD in this population to facilitate behaviour change in target groups, which is critical for self-management of CVD. This study is set up to fill this gap. In doing so, this study will answer the following research question: What factors influence facilitators (positive) and barriers (negative) to secondary prevention and self-management among the Australian Turkish community living with heart disease?

Three subsequent questions:

- To what extent would Turkish immigrants' knowledge, experience, perceptions, and beliefs influence their engagement with secondary prevention interventions and self-care?
- How can identifying facilitating factors among Turkish immigrants improve the implementation of self-management approaches?
- How can we improve secondary preventive strategies to provide quality healthcare for these patient groups? Are there any additional initiatives that can be implemented?

This small-scale qualitative research project explores the factors (barriers and facilitators) that impact heart disease self-management and secondary prevention strategies among the Australian Turkish community living with heart disease. Therefore, we will be able to adequately describe, analyse, and understand the implication of these factors for the effectiveness of the secondary prevention and self-management strategies and, finally, highlight the significance of self-management approaches regarding CVD to improve health outcomes.

3 Research Design and Methodology

3.1 Introduction

Chapter 2 reviewed the evidence providing that immigrants have a higher prevalence of recurrent CVD events and higher mortality compared to other groups in the Australia (Briffa et al., 2011) and underutilise self-management and cardiovascular secondary prevention strategies aimed at reducing the risk of further cardiac events and death (Anderson & Oldridge, 2016; Shields et al., 2018; World Health Organization, 2021). Little is known about why ethnic minorities underutilise CVD self-management and secondary prevention strategies. Moreover, there is a lack of studies exploring the barriers and facilitator factors influencing secondary prevention strategies and self-care among Australian Turkish immigrants with heart disease. This chapter outlines the research undertaken to determine the factors (barriers and facilitators) that impact heart disease secondary prevention and self-management among the Australian Turkish community living with heart disease using the exploratory qualitative research approach.

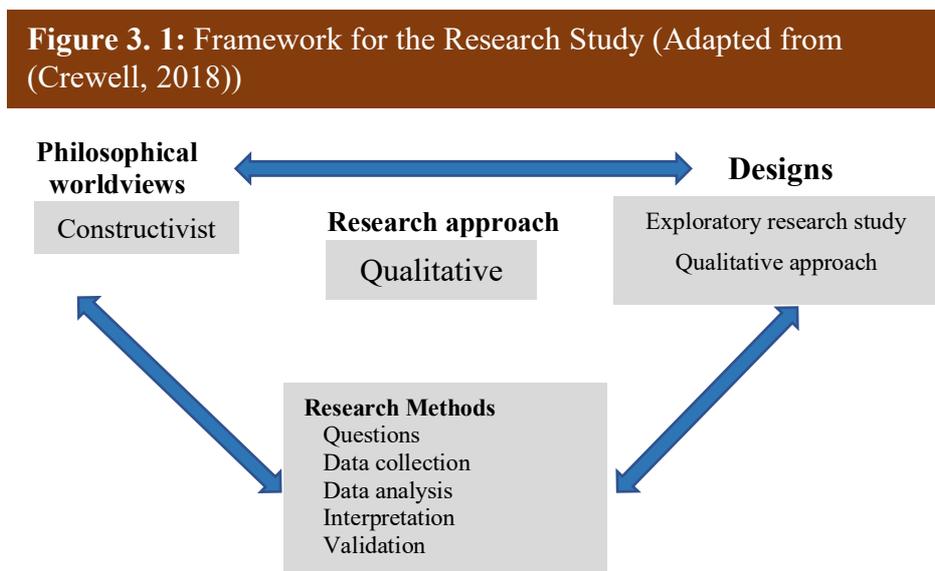
3.2 Research Paradigm

A research paradigm is a philosophical framework of any scientific research and is defined as a ‘world view’ or a cluster of beliefs associated with assumptions regarding the knowledge (Creswell & Creswell, 2018). Philosophical assumptions/paradigms guide researchers to collect, analyse and interpret the data. Paradigms encompass four elements: ontology (what is the nature of reality?), epistemology (how do we create knowledge?), research methodology (the standards controlling a scientific inquiry) and methods (the tools used to gather and analyse data) (Creswell & Creswell, 2018; Saunders et al., 2009). Paradigms include post-positivism, constructivism and transformative. The paradigm choice is based on the research question and impacts the research design, data collection and analysis. The constructivist paradigm, also described as interpretivism, takes a worldview wherein individuals seek an understanding of their known world in a manner that is based on their perceptions and experiences and cannot be explained without people’s points of view. (Creswell & Creswell, 2018; Denzin & Lincoln, 1995; Mertens, 2010; Schwandt, 2014) A person interprets their world through a subjective lens, which

influences and is influenced by epistemological, axiological, and ontological positions that define lived reality. Individuals live in the world of their reality and interpret it in their way. So, individuals may construct the meaning of the same phenomenon differently from others, as events are experienced differently by various individuals depending on their personal beliefs and past experiences.

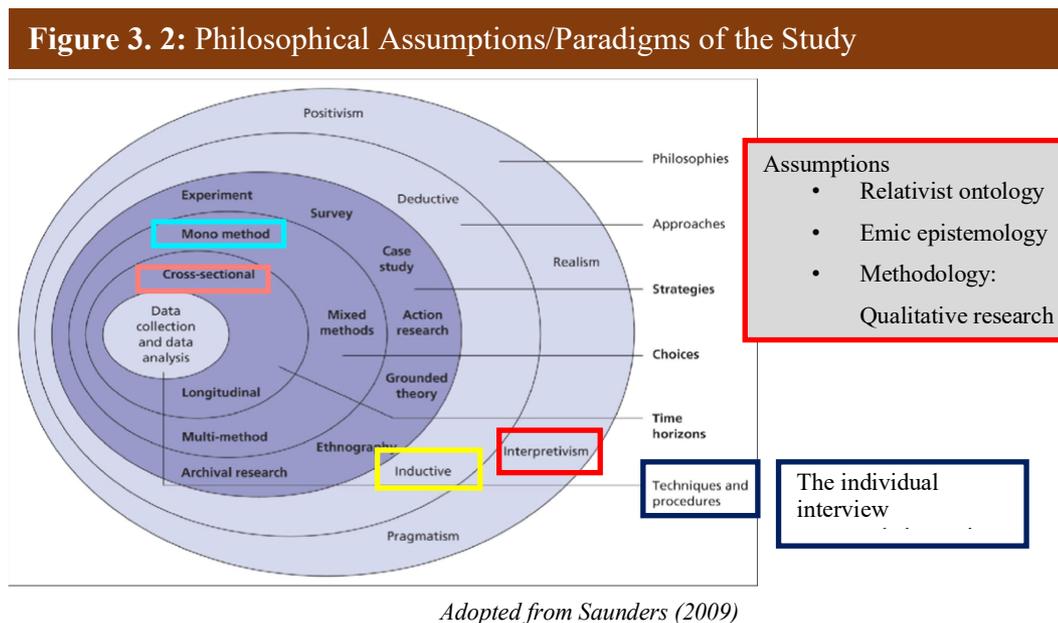
Relativism, the fundamental assumption, is the suitable ontological approach for qualitative researchers. According to relativism, there is more than one version of social reality/knowledge, leading the researcher to look for the diversity and complexity of views and focus on the specific contexts in which individual lives to understand the historical and cultural settings of the participants by gathering information personally without generalisation (inductive approach) (Creswell & Creswell, 2018). Constructivists believe that knowledge is based on the reality of the world where people experience and live, and knowledge can only be complete with understanding the subjective meaning of the experience as provided by the participants.

Epistemology is concerned with how knowledge can be generated and obtained. It allows the use of suitable research methods which apply to the research question (Figure 3.1).



The research questions, methods, perspectives of the researchers and the nature of the target audience are by constructivist/interpretivist philosophy. An exploratory qualitative research approach was chosen as the suitable method for this research topic, supported by the need for more studies regarding cardiovascular management among Turkish immigrants in Australia. The constructivist paradigm selected for this study aligns with relativist ontology and subjectivist epistemology (Figure 3.2).

The fundamental assumption of relativist ontology is that there is more than one version of reality/knowledge as various people may construct meaning of the same phenomenon; for example, barriers and facilitating factors influencing heart disease management may be multiple among the Australian Turkish population living with heart disease because events may be experienced differently by each person on their individual's beliefs (Creswell & Creswell, 2018).



3.2.1 The Rationale for Choosing a Qualitative Research Method

Qualitative research methods were used to identify socio-ecological factors influencing the self-management and secondary prevention interventions of heart management among the Australian Turkish population, as it provides detailed perspectives of

participants, thereby ensuring an in-depth understanding of the phenomenon of interest (Creswell & Creswell, 2018). While quantitative research focuses on a behaviour's frequency, intensity, or duration, qualitative research methods allow us to explore the beliefs, values, and motives that explain why the behaviours occur (Castleberry & Nolen, 2018).

One of the greatest strengths of qualitative methods is that they provide a richer, deeper understanding of the meanings that people place on actions, events, and relationships that quantitative analysis lacks. It is often utilised when exploring health-related issues among immigrant participants and was chosen as the method for this study. Therefore, qualitative research, and the use of qualitative research method, was considered most appropriate for this present research study to understand barriers and facilitating factors influencing self-management and secondary prevention interventions.

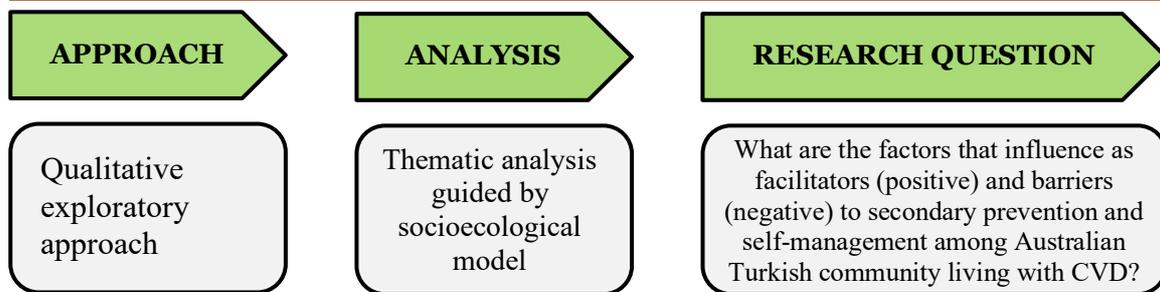
3.3 The Study Aims and Research Question

The study aimed to explore the factors (barriers-facilitators) influencing self-management and secondary prevention interventions of Australian Turkish immigrants living in Victoria, Australia, with heart conditions. The research question is “What are the factors that influence facilitators (positive) and barriers (negative) to secondary prevention and self-management among the Australian Turkish community living with CHD?”

3.4 Research Design

An exploratory research design was used for this study as it enabled an in-depth understanding of the factors (barriers-facilitators) influencing secondary prevention and self-care of Australian Turkish immigrants living in Victoria, Australia with heart disease is a topic that has not previously been studied, and there is no pre-existing knowledge regarding this issue which has not been clearly defined (Figure 3.3) (Saunders et al., 2007; Brown, 2006). The study sought to achieve new insights into the general nature of the issue, find out the character of this problem, become familiar with the subject area and be able to formulate suggestions for more conclusive investigation in the future (Singh, 2006). Exploratory research is often qualitative and provides insight but not definitive conclusions.

Figure 3. 3: Research Approach, Methods and Analysis aligned with Research Question



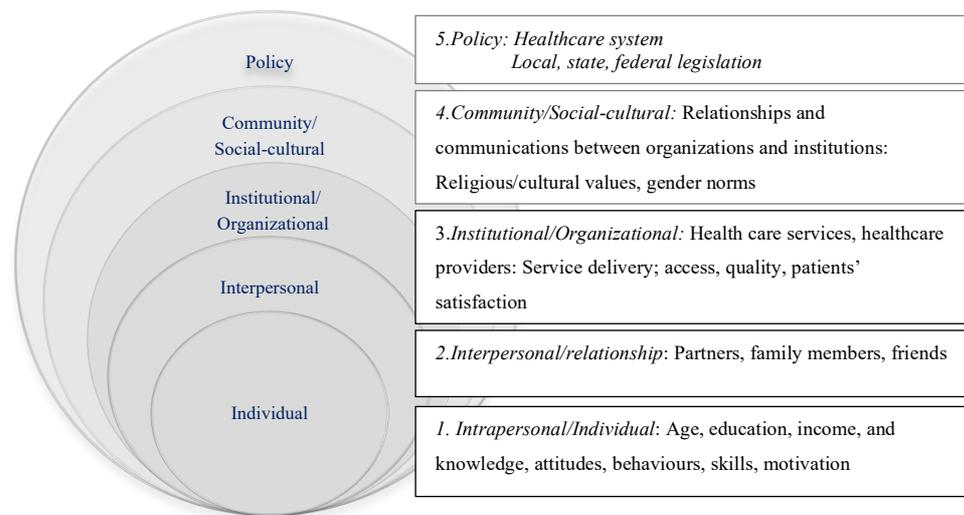
3.5 Conceptual Framework and Socio-ecological Model

The theoretical framework of this present study is guided by the socio-ecological model (SEM) and used as an overarching conceptual framework while exploring the factors influencing secondary prevention and self-management to understand heart management among the Australian Turkish community (Figure 3.4).

The term *ecology* refers to the interrelationships between individual and their environments. *Ecological models* focus on individuals' interactions with their physical and sociocultural environments. The *SEM* is a comprehensive theory-based framework and considers the environmental impact on individuals' health and health-related behaviours (Bronfenbrenner, 1977; McLeroy et al., 1988). The socio-ecological framework was first suggested by Bronfenbrenner (1977) as an ecological systems theory and later redefined by McLeroy et al. (1988) as a framework to promote health-related behaviour change as individuals' behaviour is influenced by many factors both at the individual level and beyond. The socio-ecological model was chosen for this study as it allows us to understand the factors that put patients at risk for non-compliance for secondary prevention and self-care for heart disease, thereby reducing their risk of further cardiac events or complications. The socio-ecological model was used for the CVD prevention (Jin et al., 2020; Vanzella et al., 2021). However, the SEM regarding

secondary prevention strategies among the Australian Turkish community with heart disease has not been evaluated. Therefore, a socio-ecological framework that focuses on barriers and facilitator factors influencing self-management and secondary prevention helps understand cardiovascular health for Australian Turkish immigrants. The overlapping rings in the model illustrate how factors at one level influence factors at another level (Figure 3.4). The model helps us understand the barriers and factors that facilitate cardiac events and emphasises the need to act at multiple levels of the model to prevent further cardiac events. This approach is more likely to have long-lasting effects and benefit the population. Educating people about healthy lifestyle choices is insufficient if environmental and policy support is lacking, as it only has short-term effects on health-related behaviour. (Sallis et al., 2000).

Figure 3. 4: Socio-ecological Model to Understand the Factors Influencing Heart Disease Management



The framework has five levels of analysis, including intrapersonal/individual, interpersonal, institutional, community and policy levels (McLeroy et al., 1988).

1) Intrapersonal/Individual:

The first level of the model includes individual biology/genetics and other personal characteristics such as age, education, income, knowledge, attitudes, behaviours, motivation, and skills that influence secondary prevention and self-care behaviour and medication adherence. Interventions at this level aim to change individuals' knowledge, beliefs, motivation, and skills to adhere to secondary prevention strategies and self-care. On the other hand, interpersonal and institutional-level interventions are designed to create change in social relationships and organisational environments (McLeroy et al., 1988).

Individuals' education regarding their illness, cardiac risk factors reduction, and its management motivates them to make wise choices to modify their risk factors with lifestyle changes and adhere to medications to prevent further heart events and complications. Intervention strategies at the intrapersonal level provide education and skill development to motivate and enable patients to self-care and change their lifestyle to address their cardiovascular risk factors and ensure adherence to prescribed medications as in core component 4 in a CR program (Woodruffe et al., 2015).

2) Interpersonal (Relationship):

The second level of the model includes a person's closest social circle, such as partners, family members, and friends, all of whom influence a person's behaviour and contribute to their experiences. Interventions at this stage include education and skill enhancement of the people interacting with individuals and modifications of home/family environments (McLeroy et al., 1988).

3) Institutional/Organisational:

The third level explores the settings in which people have social relationships, such as healthcare services, healthcare providers, and the workplace, and seeks to identify the characteristics of these settings that affect health. The critical role played by the community in promoting health is supporting the patients with lifestyle changes. However, accessing healthcare is problematic for vulnerable populations such as ethnic

minorities. Organisational/Institutional-based intervention aims to increase access to healthcare services for these disadvantaged groups.

4) *Community/Social-cultural:*

Formal or informal social norms among individuals, groups, or organisations can limit or enhance healthy behaviours.

5) *Policy/Societal:*

The fifth level looks at the broad societal norms and the health, economic, educational, and social policies that help to create, maintain, or lessen socioeconomic inequalities between groups (McLeroy et al., 1988).

The ecological approach considers individuals' environmental determinants (social networks, organisations, communities, and public policies) by locating individuals in their ecosystem to determine the factors impacting the self-management of these disadvantaged populations. The model could frame the present research to identify and map out the factors that facilitate or hinder participation in CR and secondary prevention strategies at different levels (the individual, the interpersonal level, the institutional/community, policy/society) that might affect patients' health behaviours to manage their heart condition.

3.6 Research Methods

3.6.1 Setting

This study was conducted in the northern region of Melbourne, where most Turkish immigrants reside. Broadmeadows, Meadow Heights, Collingwood, and Brunswick suburbs were essentially the residence areas targeted (Australian Bureau of Statistics, 2021). The setting for this study was the HeartWest Clinic facility located in Coolaroo, a northern suburb of Victoria, Australia. This multi-cultural private outpatient clinic was established in 2011 by a cardiologist who resides and practices in the western region of Melbourne. Its goal is to provide medical assistance to underserved communities in the West and Northwest. The clinic only caters to patients with heart conditions referred by GPs or other physicians.

A room in the clinic was rented for conducting interviews. Consultant cardiologists at the clinic were informed about the study in detail. Patients visited their specialists during their routine follow-up appointments. If the specialist determined that the patient was eligible for the study, they provided information about the study (A participant information statement). Once participants agreed to join the study, they were directed to the clinic receptionist. They provided their contact details to the receptionist, so I called them to give additional information about the study.

3.6.2 Sample

The rationale for the sample selection in this study aligned with the study's aims and assumptions (the ontological and epistemological perspective). This qualitative research intends to contribute to understanding the heart disease management experiences of the Australian Turkish population living with heart conditions. Hence, the research procedures for selecting and recruiting participants who can best inform the research question were essential to identify information-rich cases to enhance understanding of the phenomenon under study (Sargeant, 2012).

This exploratory qualitative study used the SEM framework to analyse in-depth interviews with Turkish immigrants living in Australia. Non-probability, purposive sampling guided recruitment from a private clinic, the HeartWest clinic, in Melbourne. A snowball sampling strategy was also used by asking people interested in the study if they have acquaintances who may be interested in participating (Palinkas et al., 2015).

Decisions regarding including and excluding criteria to select the eligible participants were made based on the research question, theoretical perspectives, and evidence informing the study (Table 3.1). In this study, representative participants were considered Australian Turkish immigrants born in Turkey, aged over 18 years, diagnosed with cardiovascular disease and willing to participate in an individual face-to-face interview that would be audio recorded. Individuals who could not provide informed consent and participate in an interview due to insufficient cognitive abilities were not eligible to participate (Table 3.1).

Table 3. 1: Inclusion and Exclusion Criteria for the Study

<i>Inclusion criteria</i>	<i>Exclusion criteria</i>
<i>Turkish speaking migrants</i>	
<i>Age 18+</i> <i>Born in Turkey</i> <i>First language is Turkish</i> <i>Diagnosed with cardiovascular disease</i>	<i>Cognitive impairment</i>

3.6.3 Recruitment

The HeartWest clinic is located in northern Melbourne, Victoria, where most of the Australian Turkish population lives (Australian Bureau of Statistics, 2021). Telephone calls were made follow-up with HeartWest Clinic, and suitable times were arranged for recruitment through telephone conversations with HeartWest Clinic. After obtaining ethics approval and consent to allow recruitment, the clinic received participant information leaflets, flyers, and a copy of the ethics approval letter. The principal researcher, a medical doctor and native Turkish speaker provided healthcare providers and receptionists at the clinic with information about the research study, including its aim and the interview process.

Between September and October 2022, fifteen individuals were approached and given a research information package by healthcare professionals from HeartWest who were not involved in the research. The package contained a cover letter, participant information leaflet, and consent forms in Turkish and English, based on the preferred language. A professional translator has confirmed the accuracy of these translated documents. The contact information for the primary investigator (SS) was given to allow possible participants to ask any questions they may have regarding participation. All participants were unfamiliar with the researcher before the study. The researcher clearly explained her role to the participants.

During patient's routine follow-up visits, eligible participants were given an information leaflet (participant information sheet) and the informed consent form. A participant information statement (PIS) (Appendix 1-English and Appendix 4-Turkish) and the informed consent form (Appendix 2-English and Appendix 5-Turkish) were prepared to make sure that all participants received the core information about all aspects of the research and were adequately informed and understood the purpose of the project, their role in it, and any risk involved.

All potential participants who volunteered to participate were asked by the HeartWest receptionist to provide a contact detail to allow mailing of the invitation to participate. I contacted each participant by phone or in-person to schedule the interview. Informed consent was signed and collected before the interview. Participants were allowed to choose between Turkish and English for their recruitment paperwork and interviews.

Another consideration for this exploratory qualitative study was the sample size, which may or may not be predetermined. There are no definitive standards for mandatory sample size in qualitative research, and participants may be recruited continuously, simultaneous to data collection, until data saturation is achieved and no new concepts arise (Braun & Clarke, 2006; Clark et al., 2012; Ryan et al., 2007; Yin, 2015). The sample size can be considered sufficient when additional interviews do not identify new concepts and an endpoint called *data saturation* is achieved. Data saturation in this study was determined by analysing the data concurrently with data collection in an iterative cycle. Hence, it allowed us to document the emergence of new themes. The sample size was determined using a data saturation process, which involved continued sampling until the significant themes were thoroughly described and diverse case examples became evident. This study interviewed twelve participants and reached data saturation. Three more participants were interviewed to confirm this, resulting in a final sample of fifteen. The characteristics of the participants are discussed in the results chapter. For a complete description of their demographic characteristics, refer to Table 4.1.

3.6.4 Data Collection

Interviews

To gather comprehensive data, individual semi-structured interviews were conducted with all participants at the 'HeartWest Clinic' through face-to-face meetings, given the exploratory nature of the study (Sargeant, 2012).

Semi-structured interviews are a required qualitative method for data collection and offer a more flexible approach to the interview process to follow less structured questioning (Ryan et al., 2007). The wording of questions is flexible and facilitates different language levels to be used and clarifications to be made by the interviewer. The focus is on permitting the participants to tell their stories rather than answer a series of structured questions. Underpinning the discovery interview is the principle that participants understand the world in varying subjective ways. Therefore, issues are explored from an individualistic perspective.

We opted for face-to-face interviews instead of telephone interviews because they allow us to establish a connection and gain participants' trust, resulting in more honest and thorough responses and personal information. In addition, observing body language, facial expressions, and eye contact can help interpret non-verbal cues. This enhances understanding of the conversation and can reveal hidden information that may be useful in analysing different themes discussed (Ryan, 2007).

Individual interviews, rather than focus group interviews, were utilised as participants may not provide personal details and experiences when placed in a group (James et al., 2014). This way, the data collected will remain confidential, and participants will remain anonymous (unless they desire otherwise). To overcome language barriers, the interview was conducted in Turkish and English to suit participant preferences. However, all participants preferred to be interviewed in Turkish as the participants had limited English proficiency.

All participants were also reminded of the confidentiality of their responses to keep them relaxed and encourage participation. Participants' behaviour, such as facial expressions and body language, were noted during or immediately after the interviews.

The interviews were audio-recorded with the participant's permission, and it was made clear to them that the sole purpose of the recording process was to help the researcher analyse the collected data. Consequently, all participants were comfortable accepting the request and permission was granted. The reason for recording the interviews is to focus entirely on the interaction instead of feeling pressure to get the participants' words written in a notebook and enhance the quality of field observation (Patton, 2015). Although the interview protocol guided each interview process, several probing or follow-up questions were developed through the interviews. This encouraged the participants to be more open and flexible in sharing their knowledge, experiences, feelings, and stories related to the research questions. When new categories of theoretical interest emerged from the data, further questions were added to the analysis.

Interview Guide

To gain an in-depth understanding of factors influencing heart disease management among Australian Turkish immigrants living with a heart condition, a semi-structured interview guide (Appendix 7) consisting of open-ended questions was developed following an extensive literature review. The interview acts as a framework for the interview process and captures the participant's personal experiences relevant to the topic questions (Ryan et al., 2007). The interview consisted of two parts, each with probing questions that aimed to uncover deeper meaning and clarify the topic to answer the research questions. Several kinds of probes were used, including the silent probe (just waiting for a response), the echo probe (repeating what the participant said and asking for more), the uh-huh probe (nodding and making affirmative sounds to encourage the participant to go on), the tell-me-more probe (asked the participant to say more about what they just said). Probing questions were descriptive rather than closed questions to encourage the participants to talk and expand on their stories (Bernard et al., 2016). The first part of an interview is to collect demographic information from participants to establish rapport and trust. The essential interview questions in the second part mainly

focused on how they managed their heart condition and extracted their personal experiences regarding self-care for their heart condition.

The interview started by collecting sociodemographic information from each participant to describe the sample characteristics. Then, participants were asked open-ended questions regarding the knowledge/perception of their heart condition, the causes they identified for their disease, the perception and acceptance of self-management interventions and the secondary prevention measurements they undertake, and what kind of barriers and facilitators they have when they access to self-management interventions which include adherence to pharmacotherapy, lifestyle modification, health-seeking behaviour. In doing so, this study will answer the following research questions: What are the factors (facilitators (positive) and barriers (negative) influencing self-management among the Australian Turkish community living with cardiovascular disease?

The duration of each interview was between 30 and 75 minutes.

Audio-recorded interviews were transcribed verbatim (word by word). During the study, participants were allowed to interview in English or Turkish. However, those with limited English proficiency (LEP) chose to have their interview conducted in Turkish, which I later translated into English for analysis. To ensure the translation's accuracy, validity, and reliability, an independent translator randomly checked the translated transcript and then translated it. To reduce expenses, we decided to translate only selected transcripts with the help of an impartial interpreter, as translating all of them was costly.

The supervisors reviewed both audiotapes and transcripts. The transcripts were anonymous by assigning codes for data analysis, storage, and publishing so that no personal information was revealed. The transcripts of the semi-structured interviews were reinforced by field notes that were taken during or immediately after the interviews. After each interview, summary notes were taken to capture emerging insights. The impact of the COVID-19 epidemic on self-management was initially mentioned in the first two interviews and then further explored in subsequent interviews. We collected each participant's sociodemographic information and medical history to describe sample characteristics and enable maximum variation sampling.

Participants were explained before consenting the reason for wishing to tape record the interview, how the recordings will be used and stored, and the procedure for destroying the tapes when all the data have been transcribed. Explanation of the purpose and format of the research was carried out face-to-face with the participant in their preferred language.

Data collection was conducted between September and October 2022 after obtaining ethics approval.

3.7 Data Analysis

Thematic analysis for the semi-structured interview transcripts was the most suitable method for analysing the interview data and provides a systematic model for managing and mapping the data (Gale et al., 2013). Qualitative thematic analysis guided by SEM was used to analyse the qualitative interviews. Line-by-line and free coding were applied to organise the raw data into descriptive themes and further interpreted to generate analytical themes. Themes were guided by the socio-ecological model (SEM) and distributed into five levels by the SEM (Jin et al., 2020).

I carefully listened to the interview recordings multiple times to identify relevant answers to the research questions. Afterwards, I translated the conversations word-for-word from Turkish to English. As a Turkish speaker, I undertook this process myself. While transcribing the tapes, I immersed myself in the data and gained important insights. To strengthen our research findings, we randomly selected transcribes translated from Turkish to English by an independent translator. This also allowed for early analysis of transcripts, making it easier to compare and recognise when data saturation had been achieved (Jin et al., 2020).

The translated transcripts were initially browsed as a whole. Notes were made about first impressions, then read line by line and re-read with the supervisor's input until the text became intimately familiar. Immersion in the data can ensure accurate data analysis and a better understanding of phrasing or the meaning of a term within the whole context. At that stage, the raw data were formally appropriately arranged, which was considered a

database. Then, the compiled data was broken down into smaller fragments or pieces (Ryan, 2017).

Table 3. 2: Example Coding Process for the Theme (Adapted from (Jin et al., 2020))

Quotation/Data	Subthemes	Themes	Themes guided by SEM
<i>“... I thought this chest pain was caused by a cold. I had a discomfort on my chest. I stopped by my workplace with one of my friends and there I had a lemon tea to softening my chest...”</i>	Inadequate knowledge of causes, symptoms, and consequences of heart condition	Health knowledge deficits	Intrapersonal factors
<i>“... my wife is the biggest support for me. She cooks balanced diet with vegetable. When I go to walk, she accompanies with me, and we walk together or go some swimming...”</i>	Family/ friends’ role in supporting, motivating, and encouraging patients to maintain healthy behaviour.	Family/Friends as a facilitator	Interpersonal factors
<i>“Appointments are very difficult to get. I waited long time for the procedure.”</i>	Shortage of stuff/hospitals and hidden waiting list	Access to healthcare services	Institutional factors
<i>“... I prefer Turkish doctors... I explain my problem better, I understand better when the doctor explains the condition directly to me with my mother tongue. When I go to see a specialist, mostly, I have to take someone who speaks English for translation.”</i>	Effective communication between healthcare providers and patients	Language concordance between doctor and patients	Community and social-cultural factors
<i>“If your health condition needs urgent medical attention, then they (healthcare providers) act very fast and are genuinely interested. They (health care providers) give you all necessary information about what I should do. However, when it comes to follow-up, the system is collapsed, not working in clinics.”</i>	Health system is working better in hospital setting not in outpatient setting	Effectiveness of healthcare system	Public policy factors

After identifying significant patterns and drawing meaning from the data, ‘coding’ was applied, and data were grouped into clusters. The organised raw data were gradually converted into the initial coding by identifying similarities and differences in the raw data

(Yin, 2015). During my coding work, we established definitions for each code and grouped them, creating a code book that contained all the definitions. We frequently reviewed our previously coded material, re-coding it to ensure that all data was coded using the same criteria and definitions throughout the analysis. To enhance the coding process's consistency, validity, and quality, we regularly consulted with our supervisors and involved multiple coders (Castleberry & Nolen, 2018; Kuper et al., 2008; Yin, 2015).

Finally, the data were categorised to form themes that characterised the perspective and experience of participants regarding their heart disease management. These inductively derived codes were then put into context with each other to create themes (patterns in the codes), like building a wall (theme) from bricks (codes) about the research questions (Braun & Clarke, 2006). These themes were then considered under the framing of the SEM categories to provide a socioecological explanation for health understandings and behaviours. Further interpretation occurred through writing, rewriting, and consideration of data within participants' social and environmental context until a cohesive and conceptually clear description resulted (Yin, 2015; Creswell, 2007). Participant quotations were selected to evidence the creation of various themes and subthemes. Relationships between the coded data and participants' demographic information were explored. Following each interview, data were analysed, and new themes were developed. These were used to probe for information in subsequent interviews (Table 3.2).

I analysed the data first, after which two other supervisors and I reviewed the findings to identify themes. Any discrepancies were resolved through discussion.

Coding and coding information were used to develop the analytical framework in an inductive approach according to the epistemological stance and research question. Then, all the data is entered into the framework to create a new structure, which helps to summarise (reduce) the data to answer the research questions (Gale et al., 2013). These inductively derived codes were guided under the framing of the socioecological model (SEM), which considers the interaction of multiple levels of a social system between individuals and the environment to understand the experience of the Australian Turkish community in their sociocultural context (Figure 3.4) (McLeroy et al., 1988).

The analytic conclusion from data presented as codes and then themes lead to interpretations and drive the conclusions, which are the response to the research questions or purpose of the study and are not usually generalisable and cannot be replicated (Castleberry & Nolen, 2018)(Castleberry, 2018). However, it was new knowledge about the world from the perspective of the participants in the study. Data analysis required only pencil and paper.

3.8 Ethical Considerations

This study was approved by The St Vincent's Hospital Human Research Ethics Committee (protocol number:0.1, version: v1-4.4.13, LRR 095/22). All participants were informed of all study aspects with a participant information statement (PIS) before the interview. The participants were fully aware of what their involvement would entail, including the potential risks and benefits, and understood them completely. The PIS and consent forms were available in Turkish and English. According to the principles of freedom and autonomy, all the participants were reassured that the participant could withdraw from the research process at any time without any explanation. Then, potential participants were given adequate time to ask questions of the researcher, receive clear answers and reflect on this information before choosing to participate in the study. Before participating in the study, each participant willingly signed a written informed consent form after I provided them with a thorough explanation of the study. Each participant freely gave their consent without any influence or pressure.

The ethical considerations involved data privacy, maintaining confidentiality, and de-identification. Confidentiality and anonymity were maintained during the interview by removing all identifying information from the interview guide and responses. Access to individual participant data was limited to the research team only. The data was initially collected in a form that could identify participants by their personal information, such as names, birthdates, and places of residence. However, the personal information of participants was removed and coded using unique identifiers, or a fictional name was used instead of the participant's name for analysis and storage of information. This was done to reduce the risk of identification and ensure confidentiality when publishing the project results.

They were stored in Victoria University's R: drive for at least five years to ensure the safety of important research data, materials, and tape records. These folders are password-protected, automatically backed up, and can only be accessed by the user and their supervisors.

3.8.1 Theoretical Positioning of the Researcher

To establish a theoretical position, the researcher must acknowledge their disciplinary position, explain how they arrived at their research topic, outline their pre-existing assumptions, and demonstrate how their chosen method aligns with their research question (Caelli et al., 2003).

I am currently a Master of Research student. I am also an overseas-trained medical doctor who received my medical training in Turkey. However, I have yet to begin practising as a medical doctor in Australia. This qualitative study is a part of the Master of Research Study. When working as a cardiac technician at the HeartWest clinic, I noticed that Australian Turkish immigrants with heart conditions struggled to manage their heart conditions. This led me to establish a research question: what barriers do they face in accessing healthcare services, and how does this affect their understanding of cardiovascular risk and adherence to secondary prevention strategies? I left my position at HeartWest clinic to conduct the study, meaning I no longer hold any position there. Furthermore, I had no prior relationship or connection with the participants.

As a Turkish-born researcher in Australia, my perspective brought a unique view to data analysis. This required continuous reflection to manage challenges and seize opportunities.

3.9 The Rigor of the Research

The unique components of qualitative research about qualitative rigor are trustworthiness, which encompasses truth-value (credibility); applicability (transferability), consistency (dependability) and neutrality (confirmability) (Castleberry & Nolen, 2018; Graneheim & Lundman, 2004; Guba et al., 1994; Patton, 2015).

This report has been created to fulfil the requirements of the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007). To ensure the accuracy and reliability of the analysis, the researcher and supervisors were involved in every stage of the process. They developed their attitudes and beliefs through a reflective approach. In addition, several measures were taken to improve the accuracy of translation and interpretation. Firstly, the same person conducted, translated and interpreted interviews in non-English languages, minimising the risk of losing meaning during these steps. To further enhance the reliability, an independent translator randomly selected a transcript and translated it into English. Following that, the researcher conducted a comparison of both translated documents in order to verify their accuracy.

Guba et al. (1994) define *credibility* in qualitative content analysis as having confidence in the data's accuracy and emphasising that the analysis process should address research questions while considering the individual and their context.

The process of *investigator triangulation* was used to address the research question by researchers with varied backgrounds. This included a mix of Turkish (SS) and non-Turkish (SA, MD) individuals, as well as a combination of nursing (SA), public health expertise (MD) and a medical doctor (SS), including chronic care (SA) allowed for a thorough examination of the data from various angles. The *credibility* of the theses was improved through mentorship in qualitative interviewing and analysis, as well as researcher triangulation. This involved the research team coming together weekly during data collection to negotiate and confirm interpretations (Graneheim & Lundman, 2004).

Incorporating a single-site design with only one private clinic reduces the transferability of findings; however, in addition to the HeartWest clinic attendees, a snowball sampling strategy was implemented to reach other participants.

To improve trust and reduce bias, we developed a strong conceptual framework to support appropriate methods in addressing the research question. The data analysis was conducted systematically and conscientiously, carefully examining credibility issues since qualitative analysis relies on the analyst's insights, conceptual capabilities, and integrity (Patton, 2015). *Thick* and *rich* data descriptions were utilised during thematic analysis to

maintain the meaning of the text and accurately represent the researched situations. This method was employed to enhance credibility.

An essential element of rigour is ensuring the *dependability* of the thematic analysis process. This is achieved by promptly analysing the interview data and discussing similarities and differences in experiences with supervisors through an open dialogue. This can lead to new insights and further exploration in subsequent interviews (Graneheim & Lundman, 2004).

The *transferability* of findings is made by clearly describing the culture, context, selection and characteristics of the participants and their experiences to enhance understanding of their data and by clearly describing methods used. Transferability was also enhanced by presenting the findings with appropriate quotations, allowing the reader to seek alternative explanations (Graneheim & Lundman, 2004).

3.10 Strengths and Limitations of the Study

This study has a limitation in its small sample size, which can make it challenging to identify significant relationships from the data and may prevent the findings from being generalised without additional research. However, qualitative research aims to explain a phenomenon rather than examine statistical generalisation across a specific population, which is the strength of the study (Patton, 2015). Another limitation of this study is that the data collected is based on self-reports.

Although we asked participants about the facilitatory factors that helped them overcome barriers to self-care, it would have been beneficial to also ask for their suggestions on how to improve or make changes to their self-care practices. Nonetheless, we acknowledge this constraint as a potential area for future research.

The strength of this study is the recruitment method, which aimed at recruiting participants with maximum variation to obtain rich data and conducting interviews using open-ended questioning techniques with the participants' preferred language to elicit rich qualitative data. Conducting the research in participants' preferred language was another strength of this study as it offers the best opportunity to capture reliable and valid results

representative of their experiences. The interviews were conducted after reaching saturation to ensure complete data saturation. It is doubtful that using more participants would have impacted the data as no new themes emerged from the additional interviews. Although the heavily populated Australian states are Victoria and NSW (ABS, 2016), another limitation is that due to time and financial considerations, the study was undertaken only in one state. However, it is anticipated that the responses may not have varied significantly between the two states as the inclusion and exclusion criteria will be the same.

4 Research Findings

4.1 Introduction

This chapter presents thick and rich descriptions emerging from the interview transcripts' analysis. This chapter describes the study sample, including sociodemographic and clinical characteristics. Then, subthemes and themes representing the data were interpreted under the socio-ecological model (SEM) framework designed and set the stage for analysis.

4.2 Study Participants

Fifteen individuals who met the requirements were interviewed in person. Participants' sociodemographic characteristics are shown in Table 4.1, and participants' self-reported clinical characteristics are given in Table 4.2.

Participants Sociodemographic Characteristics

Out of the 15 participants, five were female (33.3%) and ten were male (66.6%). The majority were single men. All participants were born in Turkey, and Turkish was their primary language. English was identified as their second language, although two-thirds of participants (n=10) indicated their English proficiency was poor or unsatisfactory (66.6%). The age of participants ranged from 48 to 78 years, with two-thirds over the age of 60 (66.6%). Most participants were retired or not currently employed (13). Although the majority (80%) of the participants lived with family members (n=12), more than half were separated or divorced (n=8; 53.3%).

Participants have resided in Australia from 12 to 51 years (Median 39 years).

The reasons for Turkish immigrants to migrate to Australia were economic, educational, political, and family reunions.

Table 4. 1: Participants' Demographic and Background Characteristics

Characteristics	n	%
Gender		
Female	5	38.5
Male	10	61.5
Age		
40-49	1	6.7
50-59	4	26.7
60-69	5	33.3
70-79	5	33.3
Median years living in Australia		39 years
Education status		
No formal school education	1	
Primary school education	4	23.1
High school education	8	61.5
University degree or above	2	15.4
Employment status		
Employed	2	13.3
Retired	13	86.7
Living arrangement		
Living with family	12	80.0
Living alone	3	20.0
English proficiency(self-reported)		
Poor	8	53.3
Unsatisfactory	2	13.3
Satisfactory	4	26.6
Excellent	1	6.6
Marital status		
Married	7	46.7
Divorced/Separated	8	53.3

Figure 4.1 shows participant-reported (subjective) cardiovascular risk factors. Although participants were highly aware of the cardiac risk factors, all participants recognised and emphasised stress as a significant underlying cause of their cardiac health and major cardiac-related health events. The most frequently attributed risk factors for heart conditions among participants, alongside stress, were genetic/family history of CVD, unhealthy diet, and physical inactivity.

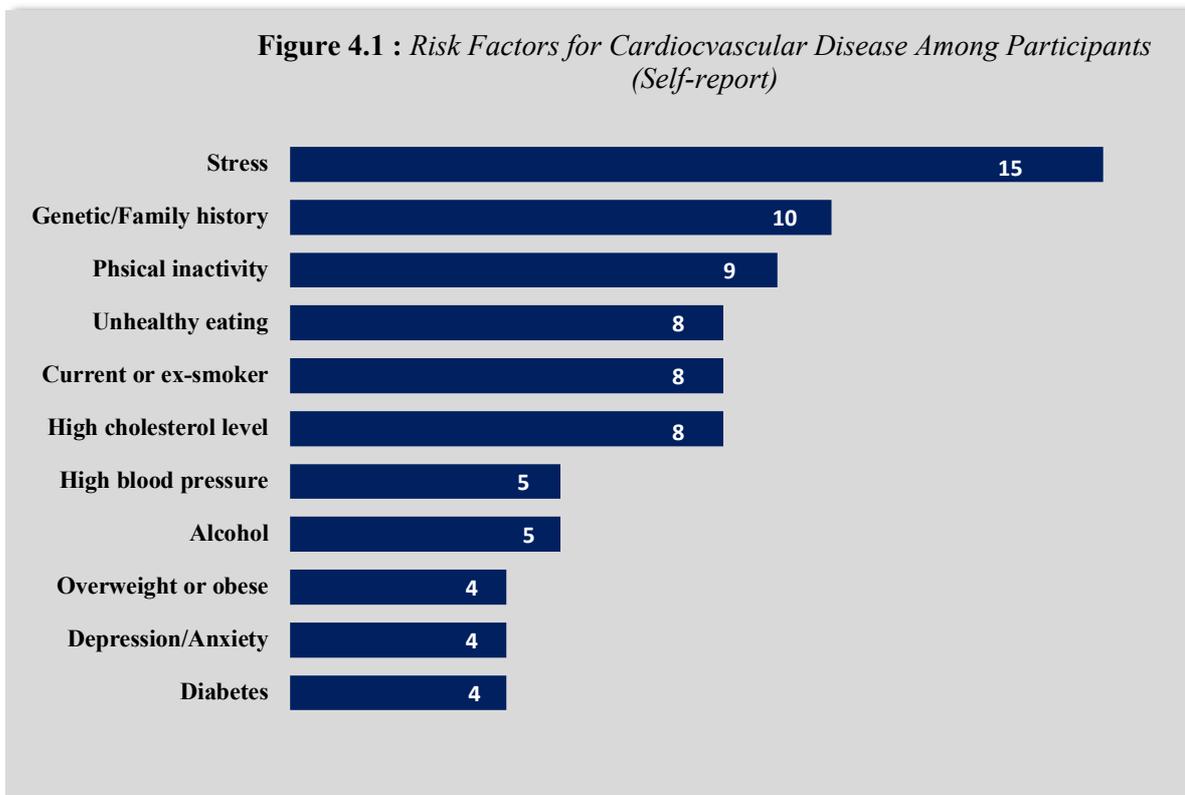


Figure 4. 1: Risk Factors for Cardiovascular Disease among 15 Participants (Self-reported)

The presence or absence of CVD risk factors was assessed through self-report and disease characteristics of the participants (as seen in Table 4.2). Participants disclosed any factors they considered a potential threat to their cardiovascular health as self-reported risk factors for CVD.

Nearly all participants (80%) reported more than two self-reported cardiovascular risk factors, with hyperlipidaemia being the most common. Seven of the total participants observed reported experiencing their initial cardiac episode. However, eight others reported additional cardiac events or complications, which included acute myocardial infarction or heart failure. All participants had cardiac interventions (invasive or surgery), while 10 required urgent revascularisation, either Percutaneous Coronary Intervention (PCI) or Coronary Artery Bypass Grafting (CABG).

Table 4. 2: Clinical Characteristics of Australian Turkish Participants with CVD

Participant-reported risk factors	
High blood pressure	5
High cholesterol level	8
Diabetes	4
More than 2 risk factors	12
More than 3 risk factors	7
Diagnosis	
First cardiac event	7
Further cardiac event	8
Signs and symptoms	
Asymptomatic	1
Chest pain/discomfort	14
Cardiac procedures	
PCI ^a +stent	9
CABG ^b	2
MVR+CABG	1
MVR ^c	1
Ruptured aorta dissection repairment	1
Aorta aneurysm repair	1
Elective surgery	5
Urgent surgery	10
a: PCI: Percutaneous Coronary Intervention	
b: CABG: Coronary Artery Bypass Grafting	
c: MVR: Mitral Valve Replacement	

4.3 Themes and Subthemes

For easier classification, SEM has organised the themes and subthemes into different levels, such as intrapersonal, interpersonal, institutional, community, societal-cultural, and policy/structural levels. Table 5.1 contains more information and can be referenced for further details.

To preserve the authenticity of the interviewee's statement, I purposely included any grammatical errors in their response. Furthermore, as outlined in the method section, all audio recordings were transcribed exactly as spoken.

4.3.1 Intrapersonal Level

At the intrapersonal level, health knowledge deficits, personal factors influencing self-care, financial strains and limited English proficiency were barriers to secondary prevention and self-management of heart disease (Figure 4.4).

Theme 1: Health Knowledge Deficits

Participants reported suboptimal knowledge regarding common cardiovascular risk factors, cardiac symptoms, and secondary prevention strategies. Although 80% (n=12) of participants had more than two known cardiovascular risk factors and were aware of them, they were still reluctant to modify their lifestyle to prevent further cardiac events, as evidenced by the following quotations.

Health knowledge and beliefs regarding cardiac symptoms and risk factors may directly affect how to manage risk factors. These themes had two subthemes: ‘Inadequate knowledge of causes, symptoms, and consequences of heart disease’ and ‘cardiac symptom misinterpretation and inability to address worsening acute symptoms.’ Language barriers to accessing health information sources, limited health literacy, and lack of comprehensive communication with providers were the main reasons preventing patients from accessing health information regarding their medical condition (Figure 4.4).

If patients believe they are at risk for heart conditions or related adverse health outcomes, their response to cardiac events could be timelier to prevent it.

Sub-theme: Inadequate Knowledge of Causes, Symptoms, and Consequences of Heart Disease:

Most participants indicated that they had an inadequate knowledge/understanding of cardiac risk factors, heart conditions and treatments and described how this led to a delayed response to acute cardiac events or poor self-management. For example, one participant said:

“I drink alcohol; maybe it's the effect of alcohol. Because alcohol, as far as I know, causes the hardening of the heart vessels. But I can't stay away from it... Because I believe that maybe alcohol socialises me” (P10, Male)

Limited English proficiency (LEP) prevents a participant from communicating efficiently with a provider to discuss health conditions and gain necessary information regarding their heart condition.

“It’s not important how much information you received; the important thing is understanding the spoken language” (Male, P1).

“It’s important to understand medical jargon well to comprehend the information doctors provide. So, you can focus on them or reply or ask questions regarding your heart condition or its treatment. If you don’t understand what they are saying, it’s not important how much information you receive; you do not understand them. The language barrier is the most important problem!” (Male, P7).

Lack of knowledge can be a substantial barrier to accessing healthcare services such as CR and smoking cessation programs. CR programs are essential to reduce the risk of further cardiac events. One of the participants referred to a CR program for the first time after having a 4th heart attack and reported that a lack of information about the availability of special healthcare services might prevent the patient from attending necessary heart disease management programs.

“I wasn’t sure whether I should have continued or not. Maybe it’s because I didn’t know enough about the program or couldn’t understand them very well with poor English. It finished with one day of walking. Maybe I will be given enough information in the future, or the hospital will give me the program again....” (Male, P1)

Similarly, another participant who had two heart attacks on separate occasions raised the same concern about obtaining adequate information regarding secondary prevention measurements.

“I think I’ve been smoking for 40 years. After having my first heart attack, I tried to reduce it myself, but without success. I have continued to smoke again. I am a heavy smoker now. No one told me about the smoking cessation program.” (Male, P9)

A lack of awareness of smoking cessation programs might prevent the patient from seeking help from providers to change the unhealthy habit.

Sub-theme: Inability to Recognise Worsening Cardiac Symptoms and Misinterpretation of Acute Cardiac Symptoms

According to the participants, a lack of knowledge and inadequate understanding of the consequences of cardiac symptoms resulted in misinterpretation and delayed acute cardiac response. The most common acute cardiac symptom reported before an acute cardiac event was ‘chest pain or discomfort.’ Participants mainly did not connect these symptoms with worsening their condition or impending acute cardiac events requiring urgent medical attention. Participants did recognise ‘something wrong with their health’, but very few participants understood that their symptoms might be related to acute cardiac events. They sought early medical help in an Emergency Department (ED). Many attributed their symptoms to a non-cardiac source, such as ‘muscle pain,’ a cold’, or ‘COVID-19 infection symptoms.’ They believed that the symptoms wouldn’t be a severe health issue and would disappear by themselves. Due to misinterpretation of cardiac symptoms, some participants delayed seeking medical health for several years. Despite having a strong family history of CHD, one participant reported experiencing intermittent chest pain for the past two years. However, he did not seek medical attention until experiencing sudden severe chest pain.

“It becomes worse in time. At first, I thought it was a muscle pain. I didn’t pay attention much. Because I had pain all over my body because of my work at that time, but this squeezing chest pain kept coming and stopped my breathing. I couldn’t get up from my bed and called an ambulance...” (Male, P9).

He was diagnosed with an acute heart attack requiring an urgent invasive cardiac procedure (PCI+stent).

Most participants believed they were not at risk for severe conditions and tried to alleviate the chest pain themselves before it worsened, delaying seeking medical care. As one mentioned,

“As it was winter, I initially attributed my chest discomfort to a cold. I stopped by my workplace with one of my friends, and there I had a lemon tea to soften my chest...” (Male, P10)

This lack of understanding of the potential consequences of cardiac symptoms led to delays in the decision-making process to seek the advice of others (family members, friends, their HCPs (family doctors/General Practitioner (GP)) or call 000/attending an emergency department (ED) or hospital). Participants described symptoms typical of a major cardiac event, such as chest pain/tightness/pressure, shortness of breath, pain in the arm, dizziness or numbness/weakness in the legs or arms.

Even after seeking medical advice, participants may choose to ignore that advice:

“I had a sudden chest pain and arms pain...I attributed the arm pain to my job (taxi driver) ...I was constantly steering the wheel the whole day.... went to my GP. After examining me, the doctor said there was a high probability that I might have heart disease and suggested I go to a hospital immediately.” (Male, P7)

“The doctor said to go to the hospital immediately, but I thought that wouldn't be a heart problem as I felt very healthy. I neglected it. I didn't go to the hospital. Instead, I went to a restaurant with my friends for dinner. My symptoms got worse during dinner; I got dizzy and passed out. In the meantime, my friends urgently took me to the hospital with their car.” (Male, P7) The patient received urgent invasive treatment at the hospital for a major cardiac event.

Participants who are familiar with cardiac-related symptoms may monitor cardiac symptoms. Once they recognise the symptoms' severity, they can apply the action plan to manage their cardiac symptoms or seek medical help urgently. Being able to access adequate information regarding secondary prevention strategies may be a key to managing heart disease:

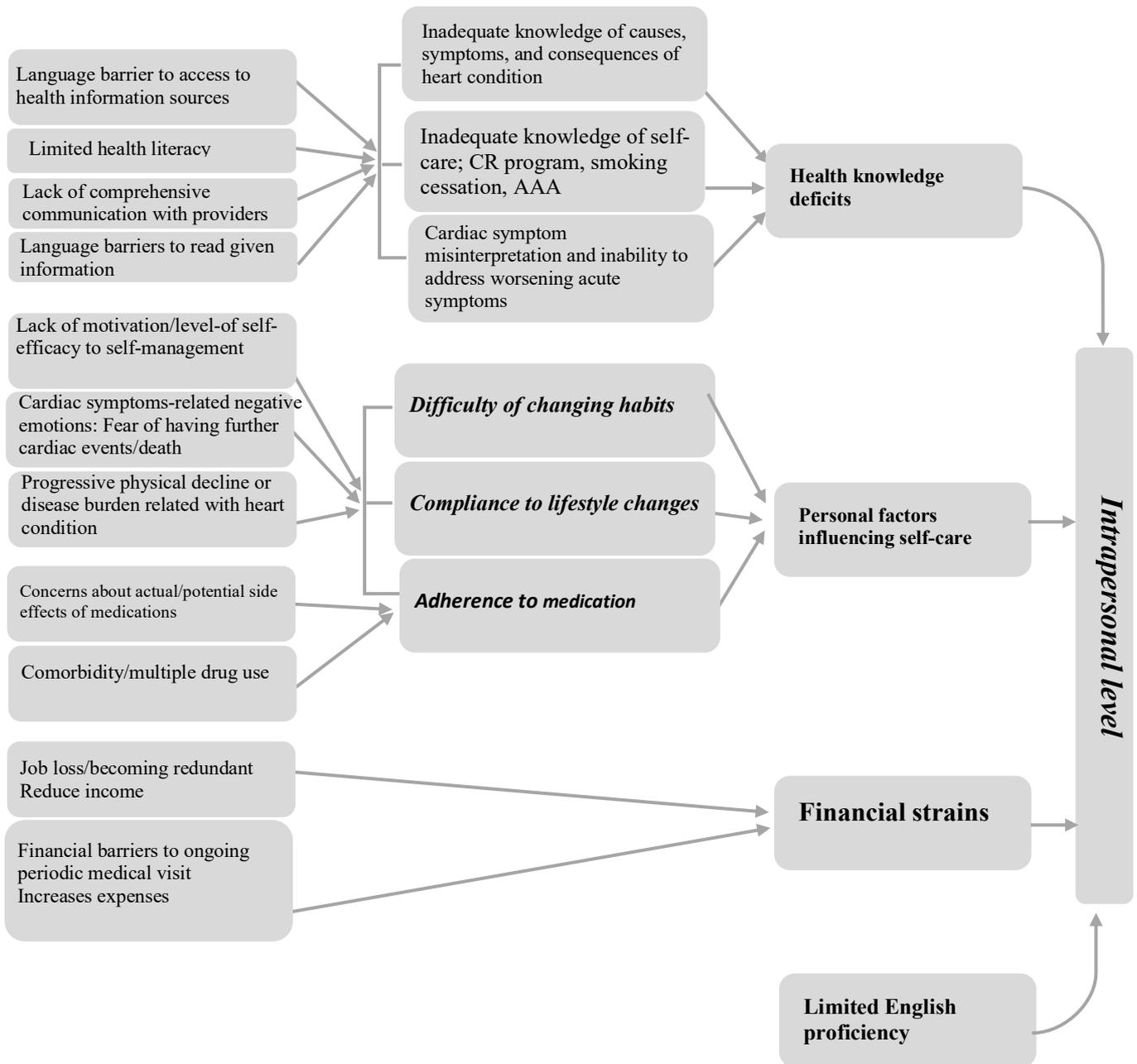
“I know this pain; it's familiar for me. Of course, I'm patiently waiting. I also have sublingual medicine with me. All the time, I carry this medicine with me. I was taught what to do with symptoms like these. If the chest pain does not go away or worsen, I call an ambulance or attend the hospital for further tests.” (Male, P7)

Having family members with heart disease may facilitate the patients to get familiar with cardiac symptoms and seek medical attention sooner. As one participant stated, adequate health knowledge led the patient to take precautions related to a healthy lifestyle for primary prevention.

“My mother had a second heart attack but did not make... heart disease is prevalent in our family. My two brothers, sister and my father also had a heart attack. So, I had some knowledge about the signs of a heart attack, I had learned. That's why I stopped smoking earlier, regularly exercise, and take long-distance walks... When I had chest pain, I immediately called my son to take me to hospital.” (Male, P15)

Based on the quotes above, individual knowledge and beliefs influence health-related actions or behaviours. (Figure 4.4).

Figure 4. 2: Intrapersonal Barriers to Heart Disease Management



Theme 2: Limited English Proficiency (LEP)

Irrespective of participants' self-assigned English proficiency, all reported that their English proficiency presented a barrier when navigating healthcare services, scheduling phone appointments with healthcare specialists, and effectively communicating with healthcare providers while seeking care and managing long-term self-care and follow-up. Four subthemes emerged under the LEP theme, including 'inability to identify and access healthcare services needed,' 'communication with healthcare providers,' 'engaging an interpreter', and 'factors shaping second language acquisition' (Figure 4.5).

Sub-theme: Inability to Identify, Access and Utilise Relevant Healthcare Services

Many participants reported difficulties accessing adequate healthcare information due to their limited English proficiency. Due to LEP, participants lacked knowledge about existing healthcare services that presented a barrier to accessing and utilising the healthcare system, delaying early diagnosis and immediate treatment of acute cardiac events or negatively impacting long-term self-management compliance.

One of the participants had an early sign of stroke, but he did not know what to do and waited for his condition to get better: "...when I could not take my regular pills, my blood pressure rose and caused terrible headaches...(The pain) was hitting my head in the back of my neck....I was alone at home." The participant waited for the symptoms to get better. However, his clinical condition became gradually worse. He had blurred vision, speech impairment and, finally, hemiparesis. "...I couldn't get up from the bed...He (my son) came home to check me and realise that I was having a stroke and called an ambulance." Instead of early hospital admission and receiving an early diagnosis, he attended the ED more than 12 hours after the first symptom started and stayed in the hospital for four months. As a result, late admission to the hospital led to an extended stay in the hospital to recover from the stroke.

Another participant summarised how language barriers influence their care for heart disease management.

"The first was the language barrier. I do not know where to apply, when, and what to do. The family doctor most often refers you to a specialist doctor. He can't do

anything else. I could not find anyone saying, "It would be better if you did these" and such and such. I've never seen anyone suggest these." (Female, P5)

Information leaflets/brochures/flyers given to participants about healthcare services were in English. This led to the underutilisation of healthcare services by missing appointments. Language barriers might impede the participant's ability to understand the information clearly about scheduled appointments with the CR program and lead to missing the CR program benefit for her heart condition.

"I do not know that it (cardiac rehabilitation program) exists. I wish someone had guided me on this program. However, the doctors and nurses gave me a bunch of flyers and information leaflets after surgery before being discharged from the hospital. It must have been written there. But they were in English. I could not read them. Maybe I could miss it; I didn't see it." (Female, P6)

Due to language barriers, some participants experienced difficulty scheduling/securing their follow-up appointment as they needed help understanding the phone instructions.

"I experience this language barrier when I try to arrange my appointments with clinics or hospitals. For example, everything is on the phone now. When you call the phone, you do not see a person directly but an answering machine. It says, if you want this, then press 1, press 2, press 3... We don't understand them either. Because it's not in a simple language that you can understand. If a person responds [to] your call, then you are lucky." (Female, P5)

Sub-theme: Communication with a Healthcare Provider

Limited English proficiency prevented participants from engaging in therapeutic conversations with their clinicians:

"They (doctors) also try to explain in plain language, but the problem is not in my ability to understand him. The main problem is having limited English." (Male, P7)

Participants could not be certain that they had adequately conveyed their health issue to the providers and that the issue had been understood:

“Because of limited English proficiency, I have difficulty telling my complaints to the doctor or understanding what they say. I have difficulty explaining my health problem like this to a heart specialist who cannot speak Turkish. Apart from this, I am unsure whether they understood my problem correctly.” (P5, female)

Communication difficulties with healthcare providers affected the participant’s relationship with their healthcare providers, leading to them questioning the quality of their healthcare, patient safety, and patient/HCPs’ satisfaction. Adverse effects of language barriers emerged in several ways. Participants could not adequately describe their cardiac symptoms to HCPs because of limited vocabulary and concern (doubt) that providers might misunderstand them and not receive an accurate diagnosis due to limited English proficiency.

“I would like to ask, ‘How do I differentiate chest pain from a heart attack?’ But I can’t ask it in English like in Turkish. I have a hard time describing these, for example. I have difficulty explaining the character of my chest pain to the doctor. Then I think, ‘I wonder if he understood what I wanted to say?’ Because of this language problem, I am not fully or 100% satisfied with my meeting with the doctor. Question marks remain in my mind.” (Female, P11)

All study participants raised concerns regarding poor communication with HCPs. Unable to effectively communicate with HCPs was the biggest challenge in managing their heart condition. When participants communicate with providers, they request an interpreter or someone who can speak English (family members, relatives, or friends) to attend appointments to undertake the translation.

“I cannot attend my appointment with my doctor without someone who can speak English so that they can translate for me. Sometimes, I arrange an interpreter before I attend the appointment.” (Female, P2)

They often used nonverbal communication like body language to express their subjective cardiac symptoms or to understand the information given.

“So, let’s say I have a squeezing type of chest pain; I explained it by pretending to squeeze the towel, and the doctors could understand what I was trying to say.

Now you would ask: 'Did you fully explain your problem 100%, as you do with your mother tongue? I would say, 'No, not in complete!'' (Male, P4)

"He talked, talked but I could not completely understand what he was explaining to me. Do you know what he did in the end? He used body language to explain the condition to me." (Female, P5)

While clinicians did their best to obtain an accurate or complete medical history and provided detailed information to patients to make final decisions, the study data reveals that participants with LEP were often concerned about not gaining adequate information from providers due to language problems. They had difficulties asking questions and were not encouraged to seek further clarification or discuss their health condition with providers. As a result of limited English proficiency (LEP), many participants were dissatisfied with the health information provided. This led to the concealment of problems and delayed diagnosis, affecting effective communication.

"They gave all related information. They even mailed some important information leaflets to my home. Also, a nutritionist came and gave detailed information about the diet. But the big problem starts in English and finishes there... to understand the information health professionals give, you need to understand their language very well. So, you can focus on them or reply or ask questions to them that you may have regarding your heart condition or its treatment." (Male, P4)

The situation becomes even more complicated when the HCP uses medical terminology during the conversation, which creates another barrier to effective communication with providers and hinders them from getting health-related information.

"In particular, doctors' language, medical jargon, they have their language, and it's tough to understand it." (Female, P6)

"But I also have a hard time understanding medical language as well. Even if you speak English well enough to express yourself, you may not understand medical language. Our spoken English is imperfect, but we do not know Doctor's English. It is almost impossible to understand medical language with this limited English." (P5, Female)

In the study, participants' satisfaction with their healthcare experiences depended on effective communication with their providers. Language barriers can make it difficult for patients to follow their providers' instructions and build a rapport with their providers, leading to mistrust and dissatisfaction with their care. Miscommunication and mistrust had negative impacts on shared decision-making between participants and providers. They were unaware of treatment instructions or surgery options to make a final decision or were confused by different treatment options because of LEP. Few participants kept seeking a second opinion from the language concordance provider.

“Because of the language problem, the doctors could not fully inform me. If I am going to undergo such an operation, the doctor who will perform the surgery must tell me what should happen from the beginning to the end of the operation. Whether there will be complications during the surgery, what will happen, and the risks. After all, this is my life and needs to be told to me. These were not told to me. I was confused and not satisfied with what I was told, and I sent all my test results to Turkey for a second opinion before I had surgery.” (Male, P13)

As mentioned before, low health literacy and language barriers negatively impacted the ability to obtain, understand, and use the information to manage heart conditions.

Sub-theme: Issues with Engaging Interpreters

Several participants reported requiring an interpreter when communicating with their healthcare providers. Some participants with limited English proficiency (LEP) often used professional interpreters to help bridge the communication gap between healthcare professionals and themselves. This helped facilitate engagement with the healthcare system despite the patients' self-reported English language skills.

“I only have language problems during conversations with my doctor. I'm trying to come over this language barrier by using a translator as well...” (Male, P7)

However, others have discussed the negative aspects of using a translator, such as privacy and confidentiality. Therefore, using interpreters did not equate with patient-centred and better care. The presence of an interpreter may create privacy and confidentiality issues. Patients may feel uncomfortable disclosing their privacy and prefer not to use an interpreter.

“I did not use an interpreter in my life. Especially in my conversations with my doctor as I may share my privacy...I didn't want to put an interpreter between me and my doctors and share my privacy with an interpreter. I did not want to use a second mouth (an interpreter) [not getting the information directly from the authorised person] to tell my symptoms and complaints to my doctor. I wanted to tell them myself even if it was difficult.” (Male, P4)

Participants may sometimes be concerned about the quality of the translation services:

“Because this is about my health. I am scared to have misinterpretations about my health, like I am scared to say something my interpreter translates incorrectly, cause misunderstanding, and end up with the wrong medication. This is a big fear for me.” (Female, P2)

An interpreter may have a different knowledge base or understanding of the context, which may lead to misunderstanding.

“So, I know my condition as much as the interpreter understood the doctor and translated it. You could guess how much I may understand and get information in a short visit period. (P6, female)

Limited availability or unavailability of interpreter services was a significant issue raised by study participants, especially in urgent hospital situations. In this scenario, seeking assistance from loved ones can be beneficial. Having an interpreter present may not be sufficient in addressing health concerns. Failing to conduct interviews with healthcare professionals due to lack of time can negatively affect the management of heart conditions.

“Furthermore, translators were not available most of the time, and the hospital which I was going did not have its translator.” (P6, female)

“The time is minimal with an interpreter. For example, when you call them for translation help, we can't get more than 10 minutes. It is not enough to talk about my heart problem with my doctor. That's a big problem.” (Male, P1)

In some cases, patients may not have access to an interpreter and may receive a lot of information in a short amount of time.

“I don't think I have reached enough information; it is not enough for me... because I had a language problem, and they couldn't find an interpreter. They tried to explain it to me again and again...because they could not find an interpreter... but frankly, I did not understand the details. I'm still unclear about the surgery” (P13, male who needed urgent CABG).

If the interpreter arrives late or doesn't show up for an appointment, it could have a negative impact on the participant's ability to follow through with their appointments.

“Sometimes there was a problem, and the translator did not come on time. I was waiting, waiting, waiting at the hospital... I mean, you're already sick; I can't sit properly. Wait... wait... wait.... The translator will come, wait! Sometimes they didn't. Then, they rescheduled the appointment for another time. Then I had to get another day off from my work to attend the appointment.” (Female, P6)

While there may be other options, utilising an interpreter remains the most efficient method for some participants to convey vital healthcare information to their providers.

“My English is not very good. That's why I always use an interpreter. At least you can say that my problem is explained to me in my native language, that I understand better. Then you relax. You relax, even psychologically. You understand your health problem, prepare yourself, and take precautions accordingly...” (Male, P14)

Some participants may prefer family members due to unavailability and lack of trust in interpreters.

“That's why mostly my daughter and my family help me more on the language barrier.” (Male, P1)

Finally, a commonly cited language barrier-related communication problem was gaining inadequate information from clinicians. Study participants reportedly relied on family members to communicate with their providers.

Sub-theme: Factors Shaping Second Language Acquisition

During the discussion, participants shared their strategies for overcoming language barriers, which led to the emergence of this particular subtheme.

Most participants were young when they arrived in Australia (median age: 25) and reported that they had never achieved the ability to speak English in Australia. The ability to speak English is a crucial driver for increased job opportunities, shopping, and social interaction for achieving social and economic integration. All participants experienced difficulties and stress in all aspects of their lives in Australia because of their limited English proficiency (LEP). Learning English as a second language (ESL) is crucial for immigrants' social and economic integration into the resident country and healthcare systems.

The study participants reported the factors associated with acquiring proficiency. Although the government offers free ESL courses for new arrivals as a part of the immigrants' integration program, many study participants said they felt ashamed not to learn after living in Australia for a long time. The lack of ability to speak English made them feel isolated, hopeless, and anti-social, which led to psychological stress. The inability to speak English fluently negatively affected participants' ability to build connections. One stated that they lacked the motivation and attitude to learn the language.

“I’ve been living here for 21 years... I was supposed to be fluent in English. I was ashamed...They give us (immigrants) enough rights here. You are entitled to 500 hours of free English course. After that, you can do any course you want for free. Many things are offered. Despite these opportunities, the fact that we do not have sufficient English...It is partly due to us; it is our own choice. We do not pay enough attention to the courses and are not motivated enough. Instead of English, we watch Turkish TV, Turkish series, and Turkish programs. Our friends we meet regularly are Turkish, and our dialogue with them is in Turkish.” (Female, P11)

All participants acknowledged the importance of learning English for immigrants to improve their lives. Many desired to enhance their second language acquisition skills. Still, the challenges of adjusting to a new country and working long hours to maintain financial stability prevented them from attending ESL courses and improving their language skills.

“When I first came to Australia, we were young. It was easier for us to learn English here... The government gave us opportunities to learn the language. They are giving you all the rights available to their citizens. But we started life from

scratch here. We had nothing, were renters, and had to pay rent...We needed money for these, too, and we had to work. Therefore, we did not have time to spend on education.” (Male, P7)

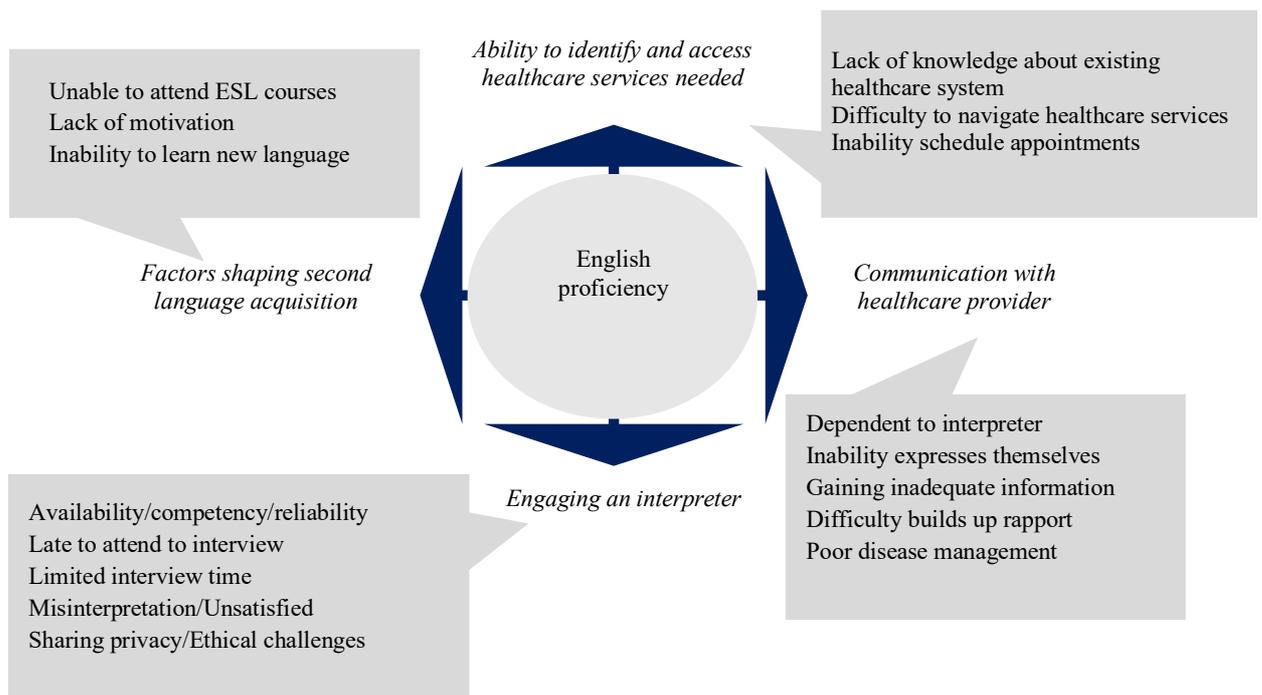
Many participants shared their enthusiasm for enrolling in night classes but reported a need for more convenient options for night-time ESL courses.

“I can't speak [English], but I understand a little. Unfortunately, evening schools are not enough, so I did not have the chance to go during the day in this country. Because I have to move on with my life. I have to live; I have to work.... Here's the solution: if they can do the night school anyway. Because in the daytime, everyone is after earning their bread.” (Male, P13)

Some participants mentioned having difficulty learning English.

“I have a little problem with learning the English language. So, no matter how hard I tried, I couldn't learn enough. Because I cannot memorise, I knew it.” (Male, P10)

Figure 4. 3: Implications of Language Barriers for Healthcare



Theme 3: Financial Strain

Financial barriers were commonly experienced among participants with heart disease and led to cost-related non-adherence to secondary prevention strategies (Figure 4.4). According to the study participants, the self-management of heart disease was an economic burden for participants. Diagnosed with a heart condition may result in losing jobs or early retirement, reducing income. A participant stated that they quit their job because they lacked physical activity and believed it could increase their risk of cardiovascular disease.

“Because of my health problem, I am retired.” (Male, P1)

“I had to quit my job after I had a heart attack. Because the job was not a physically active job, you need to sit a long time. So, I quit. I have retired since then.” (Male, P7)

Many participants required specialist follow-up after, and while acknowledging that they were satisfied with their specialist, and despite having Medicare health insurance, they experienced financial barriers as they still had to pay the high out-of-pocket cost in the form of additional payments for their periodic medical visits and sophisticated diagnostic test required for their ongoing healthcare. Reduced income and increased expenses may burden participants economically and negatively impact their self-care ability. Nearly all participants raised concerns regarding the affordability of their periodic medical visits with specialists, which resulted in cost-related follow-up:

“Specialist doctors' fees are costly. I don't know; they attached a Holter ECG monitor. They are very expensive, and I have to run these tests. I'm having difficulties affording them. I'm trying to pay back slowly. But still, I have difficulty paying it. For example, I had to pay \$400 with \$50 monthly in instalments with a credit card for the treadmill test. It's a tough situation. Everything is costly.” (Female, P5)

Similarly, another participant stated that: *“Every time I go to the doctor, for example, I pay the doctor a consultation fee, \$ 200” (P12, female)*

Theme 4: Personal Factors Influencing Self-care

Participants with cardiovascular-related chronic medical conditions experienced various barriers and facilitators that impacted their ability to optimally manage their heart condition and health outcomes (Figure 4.2). There were ‘difficulty of changing habits,’ ‘compliance to lifestyle changes’, and ‘medication adherence.’

Sub-theme: Difficulty of changing habits:

Participants emphasised the difficulty of changing unhealthy habits (smoking, alcohol consumption, unhealthy diet, sedentary lifestyle) and engaging in new healthy behaviours (smoking cessation, reducing alcohol consumption to a standard level, losing weight, and undertaking regular physical activity). One participant (Male, 67 years) was a long-term alcohol consumer, explained:

“So, I listened to my doctor, I tried not to take it (alcohol). After a while, when everything (cardiac-related symptoms) returned to normal, I started drinking alcohol again.” (Male, P14)

Participants attempted to change their lifestyles after experiencing an acute cardiac event. However, they were either unsuccessful or returned to previous unhealthy habits after their cardiac symptoms were alleviated. One participant who experienced a few further heart attacks explained the most important reasons for an inability to manage their lifestyle adjustment:

“We have some habits; we cannot give up on them. After all, we are human. For example, at the beginning [after the major cardiac event,] you adhere to the diet tightly, but this tight diet loosens after a while. It starts with a little taste, and you can miss the rope's end [Turkish idiom: Lose control, to let things get out of hand, let something get out of control]. So, it's a problem for us. This is not an obstacle, but I see it as a deficiency caused by us.... The doctors clearly explain all the risk factors (for heart disease) and the management of these risk factors in detail. It's up to you to control or eliminate the risks; you decide accordingly.” (Male, P7)

On the other hand, for some participants, cardiac symptoms-related negative emotions, the severity of illness/symptoms, and fear of having further cardiac events/death or complications were associated with greater adherence to lifestyle modification and self-

care. Fear was one of the most common emotions reported by participants. They noted they always fear death and disability due to further cardiac events, stroke, or other cardiac complications. This fear triggered their ability to change their habits positively.

After multiple heart attacks over several years, fear of another heart attack drove one participant to make and adhere to lifestyle changes:

“...I smoked for 56 years. I was smoking more than a pack a day. I got scared after getting dizzy for the second time after 4th heart attack. I quit smoking immediately because of my fear. ... I won't smoke anymore because the last heart attack emotionally negatively affected my mental well-being. Or rather, I am scared...” (Male, P1)

Another participant, who had a stroke, stated that during an extended stay in the hospital, seeing other patients who had more severe conditions motivated the participant to adhere to lifestyle modification and self-management:

“...I take regular walks. I am careful about what I eat and drink. For example, when I was in the hospital during my stroke, I thought I could be like this when I saw more serious patients in the bed beside me....” (Male, P14)

Participants who perceived their condition to have more severe consequences were more likely to adhere to a new lifestyle.

Sub-theme: Compliance with Lifestyle Changes

Motivation and self-efficacy of self-management was the most critical positive significant effect on maintaining lifestyle changes and long-term self-management for a heart condition. One participant explained:

“The treatment of this disease is something entirely in your hands if you believe. If you need to quit smoking or reduce drinking (alcohol), then you should....” (P7)

The participant emphasised that an individual may only adopt and comply with lifestyle behaviour changes if they believe they can do it. Self-efficacy/motivation was crucial in maintaining and adhering to a new lifestyle.

“For example, if the doctor said that you can drink 1 or 2 coffees and drink 5-6 coffees even if you know the consequence, it is not the doctor's fault; it should be

our responsibility. For example, they give you a list of what you should not eat in your diet; if you pay attention to it and provide it with importance, you will feel better. However, you may have health issues if you do not follow the diet list. Even if you don't have a heart problem, you have other health problems.

Most participants reported progressive physical decline or disease burden related to a heart condition negatively impacting maintaining a healthy lifestyle. According to them, having cardiac-related symptoms such as tiredness, physical weakness, and fatigue may progressively result in deterioration in the participant's health, and this impacts exercise-related lifestyle changes such as walking, swimming, and cycling:

"...I'd like to have a walk at the park sometimes; when I start to walk for a while, I get tired, and then I think about how I'm going to get home." (Female, P5)

Another participant noted that no longer being capable of cycling or walking (for exercise) because of tiredness:

"... I was riding a bicycle. When I was cycling, I started to feel more and more tired than before. I cannot do it recently" (Male, P14)

Sub-theme: Adherence to Medication

Participants were admitted to long-term cardioprotective medication after being diagnosed with heart disease; however, they were subsequently nonadherent. Although all participants reported being aware of the positive and negative consequences of (non) adherence/compliance in self-management and prescribed medication, some participants did not adhere to their long-term cardioprotective medications. Six participants reported their non-adherence behaviour to prescription and subsequently experienced severe consequences of non-adherence to their cardioprotective medication.

Two participants who were suffering from atrial fibrillation (AF) reported that they failed to adhere to treatment recommendations and had a stroke after immediately discontinuing their anticoagulant medications:

"I couldn't take my blood thinning medication. It was my fault because I was busy with this assembly... Otherwise, if I go to work, I forget to take my meds." (Female, P2)

“I missed taking my blood thinners while I was in Turkey. I couldn't take them regularly. After returning from Turkey, I had a 'stroke' here...This stroke was probably because I did not take my medication....” (P14)

The participant who failed to adhere to their medications described their poor behaviour in taking long-term cardioprotective treatment. They reported that they irregularly followed up on prescription (skipped) or discontinued use for intended or unintended reasons, leading to further cardiac events or stroke.

Most participants also explained the factors influencing their long-term cardioprotective treatment non-adherence.

One participant was prescribed lipid-lowering medication; however, mistrust of medications influenced his decision not to start. The participant did not trust his provider and was suspicious of their provider's motives for prescribing medication. In this case, the participant's trust in his providers was a crucial adherence component. The participant also emphasised that non-compliance with medication was a significant risk factor for him to have a heart attack. The participant expressed the desire to control cardiac risk factors with lifestyle instead of medication:

“Finally, my doctor told me we should start cholesterol medication. But I've heard on social media that some professors have speculated that drugs, especially cholesterol drugs, are only started because some doctors deal with companies to make money. The truth is that I believed them. That's why I didn't use the drug treatment method (for high cholesterol) as my doctor advised. Instead, I went toward self-treatment by dieting, doing sports, or exercising. But in the end, I couldn't control my cholesterol, and one day, I had a heart attack in the car.”
(Male, P10)

Concerns about actual/potential side effects negatively impacted adherence to medications. Some participants claimed that their providers informed them that taking medications could cause side effects; hence, they discontinued to avoid them. One participant was on anticoagulant medication for AF and CAD and mentioned that she stopped anticoagulant medication because of fear of the side effects of bleeding:

“...my doctor mentioned side effect of bleeding, he told me this pill may cause severe bleeding...Then I stopped. I didn’t take blood thinning medication for a while until I had this stroke.” (Female, P2)

Similarly, the other participants unpleasant experiences, such as dizziness and tiredness, as a reason for discontinuation:

“... when I took this 40-milligram tablet (diuretic for HF) the first time, I was dizzy/light-headedness on the road (driving), and my blood pressure fell...and I stopped to take it.” (Male, P14)

Forgetfulness to take medications as prescribed was another participant-related factor in adherence, as cited by another participant who expressed concerns that having multiple appointments with various providers reduced appropriate attention for all of them and

“Apart from this, I also have other health issues like high blood pressure and cholesterol, diabetes. I had a problem taking my medication regularly, sometimes I forget to take them.” (Female, P2)

Management of comorbid conditions was another disease burden-related barrier to compliance with secondary prevention measurements, especially medication adherence. The study participants were unsatisfied by taking multiple types of medication at different times, reducing their compliance with medication. One participant was 58 years-old male and had two times heart attack history:

“I take 9-10 pills a day. There is a corner in my house, [it’s] like a pharmacy.” (Male, P9)

The participant complained about managing these conditions by attending multiple medical visits with specialists, running various tests for each condition, and taking numerous medications.

Limited English proficiency may also be a factor in non-compliance for some participants as they may not completely understand the providers’ instructions due to language barriers and poor communication:

“But when they tell me how to use the medicine, I have difficulty in understanding.” (Male, P7)

4.3.2 Interpersonal Level

Theme: Family/Friends Influences on Self-care (Help or Hindrance?)

Two subthemes underpin this theme about how family/friends can be facilitators and/or barriers to participant healthcare self-management.

Sub-theme: Family/Friends as a Facilitator

Because CVD is a chronic lifelong health condition, patients with heart conditions may need strong support for self-care. Family members (spouses and children) were reported to be important in supporting, motivating, and encouraging participants to maintain healthy behaviours, attend regular healthcare follow-up appointments and investigations, and adhere to cardioprotective medications. Most participants emphasised the importance of exercise in coping with their heart condition, but they could not participate in regular exercise. In this case, family members may provide practical support by accompanying them on daily routine exercises or cooking healthy meals to help them adhere to a heart-healthy diet.

“My wife is taking good care of me. For example, I have to be careful what I am eating. My wife is the biggest support for me. She cooks healthy meals for me. She tries to cook a balanced diet with vegetables. When I go for a walk, she accompanies me... We go to exercise; we go to the pool, we go some swimming, she does them...” (Male, P3)

Family members also had a positive impact on medication management

“To not forget, my children adapted my medication time to my phone with an alarm. The alarm goes off at eight o'clock every morning. Sometimes, I turn off the alarm but am busy doing house chores and forget to take my medicine. This time, my husband reminds me and asks me whether I took my medicine.” (Female, P2)

All study participants acknowledged that family members assisted patients' communication with providers as a translator. Some preferred family members as translators.

“... I refuse to arrange an interpreter. Rather, I prefer my family or friends.” (Female, P2)

Participants were eager to gain more information from providers, and thereby, family members played a crucial role in strengthening participants’ self-management indirectly:

“For example, my daughter helps me translate with my doctor because my English is insufficient. She translates what the doctor says and what I am telling the doctor. This is a big necessity for me. It is tough for me to understand the doctors.” (Male, P1)

According to the participants, their family members played a crucial role in assessing and understanding their symptoms and prompting them to seek medical attention promptly for their acute cardiac event.

“When I had a headache, my son realised my condition was not good. When my son realised something was wrong with me, he returned to check on me... My son immediately called the ambulance, and they took me to the emergency room...” (Male, P14)

Many participants reported that a family member or friend influenced their decision to seek medical attention. Some participants chose not to inform their family members of their symptoms at night to avoid causing them fear, and unfortunately, waiting until the morning caused their symptoms to worsen. Family members recognised the severity of the participant’s symptoms and called an ambulance or transported the participant to the ED.

“... my son urgently took me to the emergency room of the hospital by car.” (Male, P10)

“I suddenly had a sweat, and my chest pain got worse. I got dizzy and passed out. In the meantime, my friends urgently took me to the hospital in their car. They couldn’t think of calling an ambulance because they wanted to take me to the hospital immediately, not to waste time.” (Male, P7)

Family members/friends provide the social and emotional support that helps patients manage the stress of illness:

“My sister took good care of me and accompanied me while exercising. When I started my first walk after surgery (CABG+ aorta aneurysm repair), having my sister by my side made me feel good and strong.” (Female, P11)

“So, friends are critical, loneliness is a terrible thing. You're always talking to your head. Loneliness is not a good thing.” (Female, P2)

“My friends have never stopped their support, they were always by my side, not just as a translator, they never leave me alone...God bless them.” (Male, P13)

Most study participants acknowledge that their family/friends were crucial across the entire illness trajectory from admission to discharge, assisting with access to health care services (transportation to doctors' visits) for continual follow-up consultation with providers and organising care after hospital discharge. Participants also expressed that family/friends accompanying them to doctors' visits may help them build up self-confidence and feel stronger (Supportive influence)

“Every time I go to the doctor or hospital for a check-up, my son comes with me. My son takes me by car.” (P15, Male)

“My family always drive me to hospital or clinics. I feel safer if someone is with me because I fear hurting others if something happens to me while driving. Anything can happen while driving because of this heart condition. I am not afraid myself; I am afraid to cause traffic accidents and hurt other drivers.” (P14)

Participants also emphasised that lack of emotional support and living alone is related to psychosocial distress, negatively impacting self-care. Without additional family/friend support, participants may struggle to set up follow-up appointments, refill prescriptions, and adhering to instructions. In the absence of support, self-care management might be poor.

“Maybe it's a problem because I live alone. So, it would have been better if I had someone with me when I had a heart attack. I had a friend with me, but again, I phoned the ambulance myself.” (Male, P9)

Sub-theme: Family as a Stressor or Barrier

Most participants mentioned the importance of family/friends' support on self-management and medication adherence and how they assist with managing stress. However, family involvement was not always experienced positively, and family are a significant stressor linked to a heart attack. Some participants reported experiencing a family-related stressful incident as an essential trigger before they had a heart attack or major health incident. This distress was mainly due to close family members being diagnosed with, or dying, from a significant health illness. The tremendous emotional stress led to physical symptoms. (Acute-external stress)

"...I felt nausea and vomited, later I had a terrible chest pain. I knew something wrong with me..." (Male, P1)

Some participants reported external stress related to health procedures and the experiences of physical symptoms:

"... My both arms were hurt badly after venesection. So, I came home. However, different pain started in my arms, and a stabbing pain started in my chest..."
(Acute external stress) (Male, P3)

One participant experienced long-term stress before a heart attack and reported that it was the main reason, he had a heart condition due to stress related to an adolescent child.

"... I have been living under big stress for about 15 years... Because we had a lot of problems during my son's adolescence..." (Male, P10) (Chronic-external stress)

Many participants experienced family-related stress (spouse relationship/divorce/unhappy marriage/problem with kids) and were reported as having cardiac risk factors (Chronic-external stress).

Some participants believed that having a family history of heart disease increases the risk of developing the condition. However, they also reported that learning about cardiac-related symptoms and prevention strategies from family members with heart conditions positively impacted their belief in primary prevention methods such as not smoking, regular exercise, and a heart-healthy diet. In addition, these participants could identify symptoms related to heart problems sooner and took prompt action during acute cardiac

incidents. Awareness of their genetic predisposition positively affected their ability to manage their health, make healthy lifestyle choices, and stick to their medication regimen. The participants also relied on their family members as a valuable source of health information.

“Well, this heart condition is prevalent in our family. My two brothers, sister, mother, and father also had a heart attack. No matter how much we pay attention, this disease will occur one day. So, at my age, it is normal to have these types of diseases: heart condition, high blood pressure or cholesterol... You can't prevent them from happening, but you have to be careful and consider what you eat and drink. I learnt about heart attacks from my family. My brother, who had a heart attack, lives in Germany and walks a lot. He cares a lot about his health; he pays much attention to what he eats. I talk to him to share my experiences with him...”
(P15, Male)

4.3.3 Institutional Level

Theme 1: Access to Healthcare Services

The study participants raised concerns about factors that may prevent them from timely accessing quality healthcare services and, thereby, may impede self-care maintenance.

Sub-theme: Language Barriers to Accessible Care

Lack of information about the existing health system and language barriers had negative implications for navigating the system (whom to call, where and how to get help), accessing healthcare services and patient satisfaction.

“...especially the elderly, they don't know exactly where to apply for a health problem. The most important reason, of course, is English first. After that, they do not get enough information or know where to apply. Because they cannot search enough, they can't use technology to search, or their children have grown up and left them alone. They don't know what to do.” (Female, P12)

Participants prefer to use an interpreter to address the challenges related to language barriers. Although many healthcare institutions offer interpreter services to improve healthcare access, communication with providers and patient satisfaction, participants

reported poor access to interpreter services or unavailability of services, especially during urgent hospital admission or urgent surgery decisions.

“My biggest problem was the language problem. For example, when I first went to the hospital, they tried to explain it because they could not find an interpreter, but I did not understand the details. I'm still not clear about the urgent (bypass) surgery. I said, 'I need to discuss this with my GP (Turkish) and decide after that, and I was discharged.’” (Male, P13)

He postponed his urgent surgery because he was not clear and unsatisfied with the surgery option. He sought a second opinion from his Turkish GP to get more information before a final decision.

Sub-theme: Availability and Affordability of Healthcare Services

Despite having Medicare health insurance, most participants expressed that it was unaffordable to access specialist care and undergo cardiac tests such as MRI, CT, ECO, EST, and Holter. This extra health expenditure may burden patients economically and lead participants to skip necessary care for themselves, including specialist visits, which are important long-term self-care milestones. Some participants acknowledged that they had to skip to see a specialist because of financial issues. Having co-morbidities may increase these health expenditures.

“It's just that when I'm not at work, it's a bit of a financial problem. Every time I go to the doctor, for example, I pay the doctor consultation fee, \$ 200-\$300 when I go to a specialist.” (P12, Female)

The data from our study participants revealed that healthcare expenditures remain barriers to access to healthcare among immigrants. This can delay a patient receiving appropriate care and lead to poorer health outcomes.

Sub-theme 2: Healthcare Provider-related Barriers

The participants noted that they were not given enough interview time to discuss their health issues with healthcare providers, and restricted consultation times put pressure on them. In addition, participants had to share this limited time with an interpreter because of language barriers. Practical and comprehensive communication between medical providers and patients is crucial for delivering and receiving quality healthcare, especially

for patients with chronic heart conditions and needing self-care maintenance. However, the inability to speak English and limited interview time negatively affected managing heart conditions and patients' satisfaction. In a short visit interval, participants complained that providers did not perform a physical examination to find out their problem.

“They [providers] are trying to pass it off because they are busy, [have] no time to explain, and you cannot understand English. They give your medicine and look after the next customer's [patient]. Their job shouldn't be to give medicine. However, heart medicines are very important. They [patients] must know how to use it, when, and the side effects. Because doctors are very busy, they don't give enough time to explain these. They are very busy and don't want to spend more time with the language barrier. They want to finish quickly, send you off, and get another patient. I don't know why. Let's say that healthcare professionals do not give enough attention to the health issue. They don't have time to examine you.”
(P1, male)

While the healthcare providers-patient relationship is essential in improving access to healthcare services, immigrant patients often experience challenges in having good relationships with providers. Some participants expressed concerns that providers squeezed more patients into patient lists to boost revenue, resulting in a short time visit length, thereby less efficient with patients and more organisation-focused rather than patients-focused. As one mentioned,

“From my experience, I can tell you that for the doctors I have seen, their (providers') priority is more the money than the patient's wellbeing. Maybe it's a money thing. It's about the system we live in. The more money people make, the more they want to earn. Their (doctor's) priority shouldn't make more money but attend the patients more effectively.” (P9)

On the other hand, more extended visits allow more attention to several aspects of care, including a patient in the decision-making process, and provide patients with detailed information regarding their health condition and self-care education program.

Some participants identified that the unavailability of female healthcare providers led to delays in getting early medical attention. A female participant expressed that finding female healthcare providers was challenging due to her cultural or religious beliefs. She was not permitted to be examined by a male doctor according to her religious beliefs, which prevented her from receiving appropriate healthcare. She suffered long-time progressive tiredness and shortness of breath due to severe mitral valve regurgitation (MVR). It took a long time for her to access healthcare services,

“... we could not find a female specialist doctor. Then we found a Muslim doctor but not a woman. And he examined me over my singlet and advised me to have urgent heart surgery.” (P6, female)

4.3.4 Community and Societal-cultural Level

Theme 1: Language Concordance Between Providers and Patients

The ability of providers to speak the same language as the participants promote their compliance with medication adherence, self-care maintenance and regular specialist appointment. Most study participants with LEP acknowledged that speaking to providers in their language makes them feel listened to, facilitates the development of trust, and enables them to discuss their heart condition effectively, thereby enhancing their satisfaction with the health care services, as one participant mentioned:

“Generally, I prefer Turkish GP doctors about health. I explain my problem better; I understand better when the doctor explains the condition directly to me in my mother tongue. That's why I prefer Turkish doctors... When I go to see a specialist, mostly, I have to take someone who speaks English for translation.” (P1, Male).

Participants stated that providing language concordance care may facilitate providers' understanding of patients' health concerns, while immigrant patients may understand the treatment regimens outlined by providers. As one participant mentioned:

“I have a hard time explaining my health problem to a heart specialist who cannot speak Turkish. For example, our family doctors are Turkish. I communicate with him in my mother tongue, but a family doctor may have limited skills in managing heart disease, right?” (P5)

“I think [immigrant patients with LEP] are vulnerable in this regard because they do not have enough English. That's why maybe the Turkish and valuable doctors here can only give them confidence. If communication barriers between doctors and patients are solved by speaking the same language, you can help them. That's why I always prefer Turkish doctors to family doctors. At least we tried to get enough information about my heart condition from them.” (P10)

Although participants were willing to have the provision of concordant language care, they also mentioned the shortage of language concordance providers,

“The first barrier is language! The second is the shortage of Turkish-speaking doctors here! Very important! Speaking of the ‘shortage of Turkish speaking doctors’ I wish there were a Turkish doctor in the hospital where I had surgery; I wouldn't have communication problems with the doctors. At that time, my job would be easier if there had been enough doctors who spoke Turkish. There is still no Turkish heart specialist, or I haven't met yet.” (P6)

Using overseas-trained and/or language-concordant doctors could be a solution for immigrant patients who want to access providers familiar with their own culturally specific understandings of health. Patient-provider language concordance may improve communication quality, patient satisfaction with care, and the use of health services.

4.3.5 Policy/Structural Level

Theme 1: Providers/Hospital Shortage and a Hidden Long Waiting List

Many participants stated they could not benefit from healthcare services because they had difficulty arranging required appointments. They assumed that healthcare providers had a busy schedule with patients list, and this high demand has led to a long waiting list to attend a specialist clinic. As mentioned, LEP negatively impacted arranging appointments by phone, navigating the healthcare system, and gaining information about special self-care programs such as CR, smoking cessation, and AAA.

“Appointments are tough to get. You need to wait in a long line to get your appointment date. Even if we can get it, it is given to a distant date. So, you have to wait for a long time. I don't have only a heart condition; I am also suffering from diabetes and have hypertension and cholesterol problems as well. I've been

waiting for a very long time to get a follow-up appointment with the specialist for the heart conditions after a heart attack. I am trying to say that there are not enough doctors and hospitals.” (P9, Male)

Participants reported that by the time they were added to the elective surgery waiting list, they had already waited the period between their general practitioner (GP) referral to the date of consultation with an outpatient specialist to assess their surgery's urgency or need. Participants raised concerns regarding the deterioration of their heart condition and that delays in the early diagnosis/treatment opportunities were exacerbated by this waiting time. Every delayed diagnosis or treatment may negatively impact self-care, leading to fear of further cardiac events/complications and loss of quality of life. From the participants' viewpoint, the most important underlying cause was the shortage of staff/hospitals.

“I waited a long time for the procedure... They say, ‘OK. We'll take care of you; we're putting your appointment in order,’ they say. But this sequence can take months or years. During this time, our existing diseases are also progressing. Then, we may encounter other problems. There are a lot of people around me who are experiencing the same problem.... This may also be related to the shortage of hospitals.” (Male, P10)

“Recently, I had irregular rhythm and irritating sounds on the left side of the chest. I was scared and concerned about my heart condition. My routine appointment with my specialist was long-distance, and waiting for my normal appointment date would have made me more anxious and nervous about these symptoms. So, I went to my Turkish GP. He examined my chest and heart and told me what would cause this. Then, he helped me to reschedule my appointment with the specialist earlier. Now I felt better being seen by a Turkish family doctor.” (Male, P14)

To reduce their anxiety, they consulted with their own Turkish-speaking GP to get more information, but GPs were not qualified for heart conditions and ended up referring them to another specialist and thereby again waiting for their specialist's appointment.

“I told him (GP) about my heart problem and that I hadn't seen my doctor for two years. I asked him to send me to another heart doctor if possible. But now, I feel that I am not well. Sometimes, my heart beats so fast when I climb the stairs. I feel palpitations. I also get tired very quickly when I climb the stairs. I know that I am not well now and getting worse. I don't know what will happen after that. I had a hard time getting an appointment... I don't know how my heart problem will be solved or how it will end. I've got many questions in my mind but cannot ask....”
(Female, P5).

Theme 2: The Health System is Working Better in a Hospital/ED Setting

Most participants reported that they were given sufficient written and verbal information about their heart condition, long-term treatment options (including medications, lifestyle changes, and self-care), and the need for regular follow-ups with a specialist. They also felt they received practical advice and guidance on changing their behaviour to improve their heart health and were motivated to eliminate any modifiable cardiac risk factors before discharge. The relationship between healthcare providers and patients was positive overall. However, one participant (Participant 9) expressed dissatisfaction with the healthcare system and its functioning in outpatient settings.

“If your health condition needs urgent medical attention, then healthcare providers act quickly and are genuinely interested. The [healthcare providers] give you all the necessary information about what to do. However, regarding follow-up, the system is collapsed, not working.” (Male, P9)

“I was not informed well, except only what the doctors told me when I was in the hospital.” (Male, P9)

“Because it has become impossible to get an appointment to see a doctor again. I guess it has to do with Australia's health policy. Well, I believe that the system limits social rights. I think health has become more expensive for the government. That's why they started cutting health expenditures down, which I don't think is right.” (Male, P9)

“I believe that these health policies should be based on humans, and they should act more quickly in health so that people cannot suffer for a long time from health

issues and live longer or live healthier. For example, I would like to wait one week instead of 2 years to get an appointment with a specialist for the examination or follow-up.” (Male, P9)

4.3.6 Cardiac Rehabilitation Attendance

Over half (53.3%) of participants were not referred to a cardiac rehabilitation (CR) program. Of the seven (46.6%) participants referred to CR, five completed the program, one did not, and one did not enrol (Figure 4.3). The participants who reported that they did not receive any referral or information from providers regarding the CR program (Figure 4.3) also indicated they lacked knowledge about the existence of CR programs.

“I don’t know this program. I did not attend this program. Maybe I missed. I haven’t received diet or exercise program.” (P2, Female)

“I didn’t attend any program. No one mentioned this kind of program to me.” (P3, Male)

The participant, who was referred but still needs to complete CR, indicated a lack of understanding of the program's details, including its length and importance in managing their heart condition (Intrapersonal level).

“After having a fourth heart attack, the hospital sent me an appointment to attend the cardiac rehabilitation program. It was just one day of walking; I wasn’t sure whether I should have continued. Maybe it’s because I didn’t know enough about the program or couldn’t understand them very well with poor English. It finished with one day of walking.” (P1, Male)

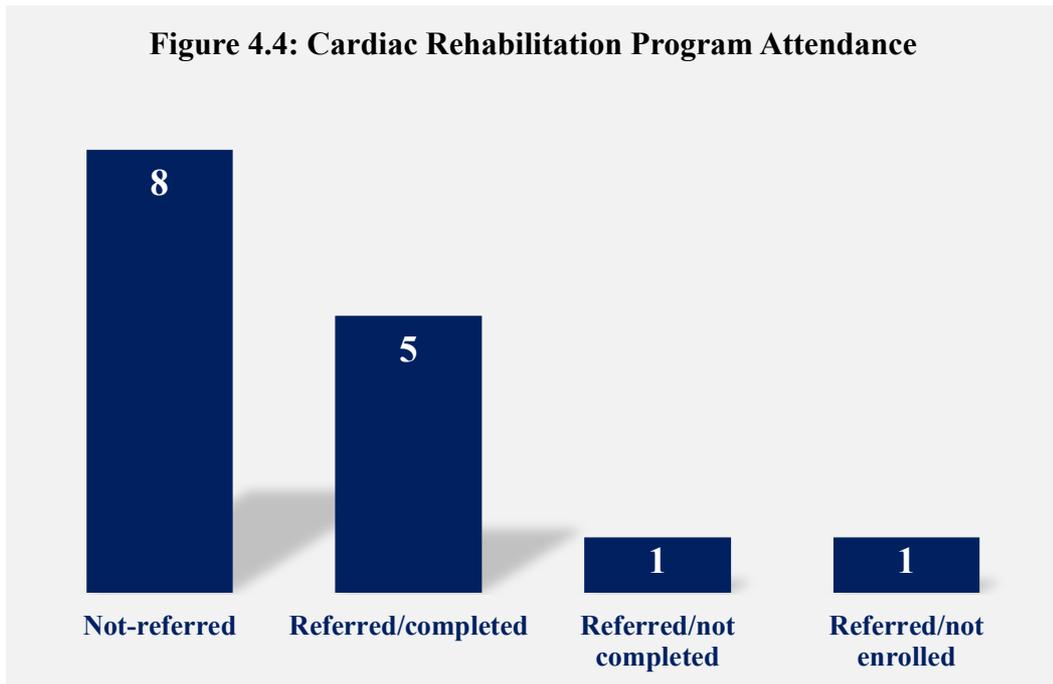


Figure 4. 4: Cardiac Rehabilitation Program Attendance Among the Participants

Some participants who reported not attending CR were unsure if they were referred, which can also be considered a communication or shared information problem (Interpersonal level). This may be associated with a general lack of discussion about CR with healthcare providers during hospital stays (interpersonal and system-level barriers). Another barrier to attending CR was the language barrier and the lack of understanding of verbal or written instructions. English-written information leaflets/brochures/flyers were given to participants in the hospital without discussion with healthcare providers.

Knowledge, beliefs, and interests (individual perception) were identified as individual-level barriers to enrolment in CR programs by 8 participants who had a limited or incorrect understanding of their underlying diagnosis and were more likely to hold cardiac misconceptions. The inability to speak English was described as a CR barrier and related to significant communication difficulties when participants were using healthcare services (individual- and provider-level barrier), including the CR program.

“I have not attended to such a place, and I do not know it exists. I wish someone had guided me on this program. However, the doctors and nurses gave me a bunch of flyers and information leaflets after surgery before discharge from the hospital. It must have been written there. But they were in English. Maybe I could miss it; I didn't see it.” (P6, Female)

Barriers to the CR program mentioned by participants were characterised as multi-level, involving individual-, institutional/organisational-, and system levels, with more barriers identified within the individual level (lack of knowledge about CR and their heart condition, lack of motivation, feeling the program was not helpful).

“They suggested the cardiac rehabilitation program, but I did not go. I didn't think it would be beneficial. I did not have time. Frankly, I didn't care much.” (P12, Female)

4.3.7 Implications of the COVID-19 Pandemic on Patients and Telehealth

Some participants had a negative healthcare experience during the COVID-19 pandemic. A small number of participants mentioned that they were unable to access healthcare services, which made them feel unsatisfied with the care they received. Many participants were reluctant to seek medical attention during the pandemic due to limited access to healthcare services and concerns about getting infected with COVID-19. The following quotes support this:

“I scheduled an appointment with a heart specialist 2 or 2.5 years after my second heart attack. It was postponed a few times and rescheduled. I could not get any opportunity to meet in person with any heart specialist due to the COVID-19 pandemic. They also cancelled my appointment themselves during the COVID-19 pandemic.” (Male, P9)

“I have not been able to see my heart doctor for the last two years due to the last pandemic (COVID-19). I had a hard time getting an appointment...” (Female, P5)

Consequently, participants felt vulnerable to delays in investigation, diagnosis and healthcare treatments, resulting in the deterioration of their cardiac symptoms, causing increased psychological distress (anxiety) and further cardiac events (Figure 4.6).

“Everything was normal until this COVID-19 pandemic started. However, these regular checks and follow-ups were stopped after this COVID-19 outbreak. Because no one takes you seriously, hospitals say they are constantly busy, and doctors cannot care for patients from their practice for a long time anyway. So, I haven't seen my doctor for a long time.” (Male, P10)

“In the period when the curfew of the COVID-19 pandemic was very strict, I had been experiencing terrible shortness of breath. At first, I was afraid of getting COVID-19. I was wondering if my lungs got COVID-19. I was breathing very briefly and very quickly. I could not see my heart specialists during the lockdown. When my condition worsened, I was taken to the emergency room by ambulance. My chest x-ray was taken, and they said, 'Your lungs are collecting water,' so the heart is having difficulty working.’ (Male, P14)

During the pandemic, the Medicare Benefits Schedule (MBS) introduced alternative strategies to ensure that patients with heart conditions receive continuous care. In-person outpatient visits shifted from face-to-face appointments to the virtual care (Australian Institute of Health and Welfare, 2020a). While virtual consultation (telehealth) was imperative to allow providers to continue routine appointments, participants raised concerns about creating new barriers to access to healthcare for immigrant patients. Participants’ LEP led to poor communication with providers on the phone and cancellation of outpatient visits.

“The doctor suggested to my interview on the phone... He said let's meet in such a thing. I refused to communicate with the doctor on the phone or online. I said that now my English is not good enough... I find it difficult to talk to you face-to-face; how can I explain myself on the Internet or by phone without seeing a doctor and interpreter... I did not accept that either.” (Female, P5)

Participants explained that virtual consultations reduced the opportunity to be examined in person by clinicians. According to the participants, they only used telehealth to refill prescriptions and did not have the chance to receive a physical examination to diagnose any health issues.

“Well, it took me a long time to see a doctor by phone! I think the last time a doctor called me was a month ago, for the first time in 2 years because of the COVID-19 pandemic! During this meeting, he only asked me to stop my medications. They didn't even do any physical examination on me to check how my heart was doing after a second heart attack. How come they examine you on a phone call?” (Male, P9)

“I was only able to go to prescribe my meds. Before I go to my doctor's clinic, I call the receptionist, ask them for my medication to be written, and then get my prescription. I do this without seeing a doctor because of the COVID-19 pandemic. In the last six months, the permission of the doctors to perform the examination was given, so I was able to see my family doctor.” (Male, P10)

Some participants raised concerns about the shortage of healthcare staff and hospitals to meet the increased demand during the pandemic.

“... I think the hospitals and doctors have been insufficient to meet the demand in recent years, especially after the COVID-19 pandemic. The time they (health care professionals) allocate to a patient could be very short, or the appointment with a doctor could be postponed too far. This does not mean that doctors are not interested in their patients; on the contrary, doctors are interested in their patients but cannot spare enough time because they are very busy. This may also be related to the shortage of hospitals.” (Male, P10)

“I've been waiting a very long time to get a follow-up appointment with the specialist for the heart conditions...This problem in the health system was revealed with the COVID-19 pandemic. The government itself needs to understand this. It was so obvious that the health care system was not enough. After the COVID-19 pandemic, the government should have more doctors and hospitals to solve citizens' health issues; they need to understand that the health system needs more investment. This is a necessity. More investments must be made in the health system to close this gap. This makes patients' lives easier.” (Male, P9)

As reported by the participants, the COVID-19 pandemic and associated challenges in healthcare have shed light on pre-existing barriers in self-care practices among immigrant patients. Participants 9 and 10 suggested above that a rapid restructuring and strengthening of healthcare services with increased healthcare staff and hospital numbers were needed to improve heart disease self-management and be resilient to future COVID-19 waves and pandemics.

Several participants stated they isolated themselves to minimise their chances of contracting COVID-19. Nevertheless, they encountered challenges in maintaining healthy habits such as exercising regularly, following a nutritious diet, and managing stress during the pandemic. Long-term lockdown and ‘stay-at-home orders promoted less physical activity, more unhealthy food consumption and compliance with self-management. Participants had difficulty strengthening relationships because of the COVID-19 isolation and social distancing requirements.

“Well, the COVID-19 pandemic was so bad. We had to be isolated at home for a long time. We used to go to the park occasionally for a walk. It finished our social life.” (Female, P5)

“I don't go to exercise or anything else like exercise. I used to go to the pool to exercise, but I haven't been since COVID-19 because I am scared of having a COVID-19 infection again. I had a COVID-19 infection. I had a tough time. I have never had an infection like this before. That's why I am scared of having this infection again and trying to stay away from crowded areas like swimming pools.” (Male, P3)

According to the participants, the COVID-19 pandemic adversely affected their mental health, leading to anxiety, uncertainty, loneliness, and isolation. Prolonged lockdowns imposed a significant psychological burden, causing distress.

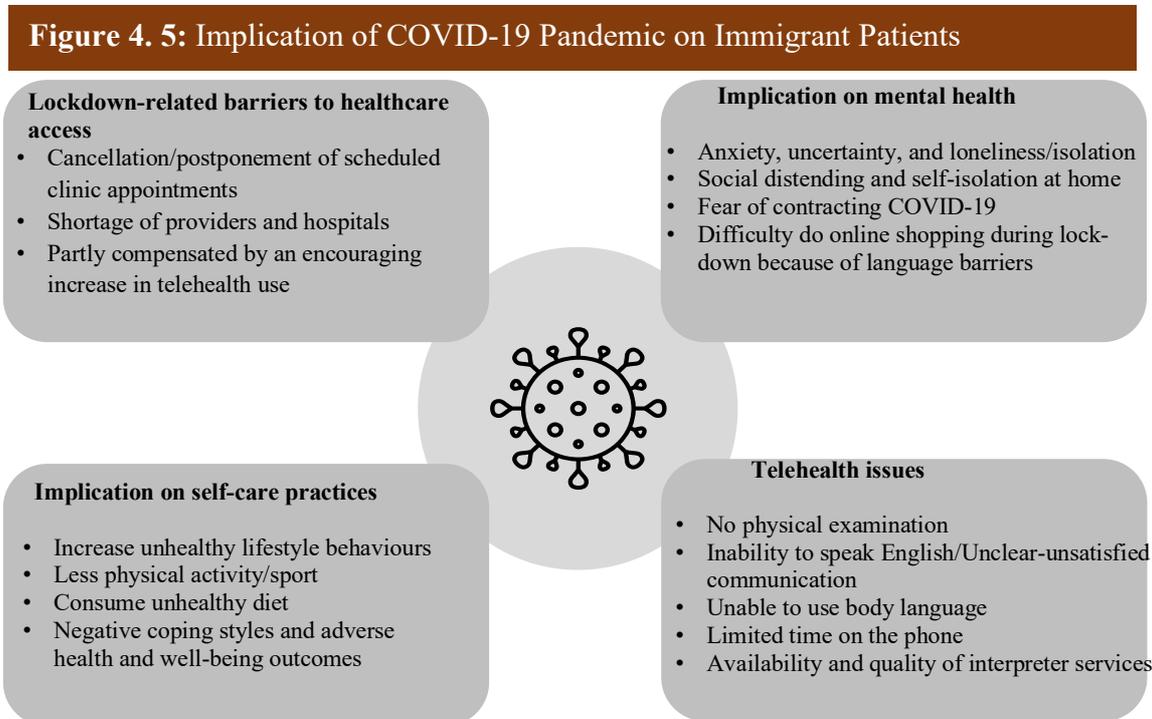
“I am a person who prefers to socialise with my friends instead of spending time at home. So, I love going out. Since I stayed home during the COVID-19 pandemic, my anxiety attacks and palpitations became frequent. I had a tough time during this period, very hard. I was bored and couldn't leave the house. I was terrible then. After the COVID-19 pandemic, I started to go out with my

friends. I felt better now. When I socialise with friends, my anxiety attacks reduce, and I feel more comfortable.” (Female, P11)

Some participants experienced more distress from COVID-19 and the lockdown. Fear of being infected by COVID-19 significantly impacted participants’ regular routines and socialisation.

I want to be a social person. I mean family... For example, I’d like to visit my friends often or have them visit me. These were hugely effective during the COVID-19 pandemic. I was scared to get a COVID-19 infection because of my heart condition. So, I most of the time isolated myself during the COVID-19 pandemic. It affected my psychological well-being. If I go out, I want to come home right away. You know that I am sick [meaning heart disease].” (Female, P5)

Most participants reported difficulties carrying out secondary preventive measures and self-care due to the COVID-19 pandemic (Figure 4.5).



5 Discussion

5.1 Introduction

This chapter will summarise the key findings under the SEM levels, discuss health implications and explore the link between the literature presented in Chapter 2 and the research findings.

This research aimed to explore how Australian Turkish immigrants manage heart disease and identify factors that affect their ability to self-manage and engage in secondary prevention. We have identified significant factors that can hinder or facilitate effective cardiovascular disease (CVD) treatment at different levels of society and the environment. Furthermore, the research highlighted the impact of the COVID-19 pandemic on the prevention and care of cardiac events among the study participants. The study's participants encountered various social and environmental barriers that impacted their capacity to handle their heart disease.

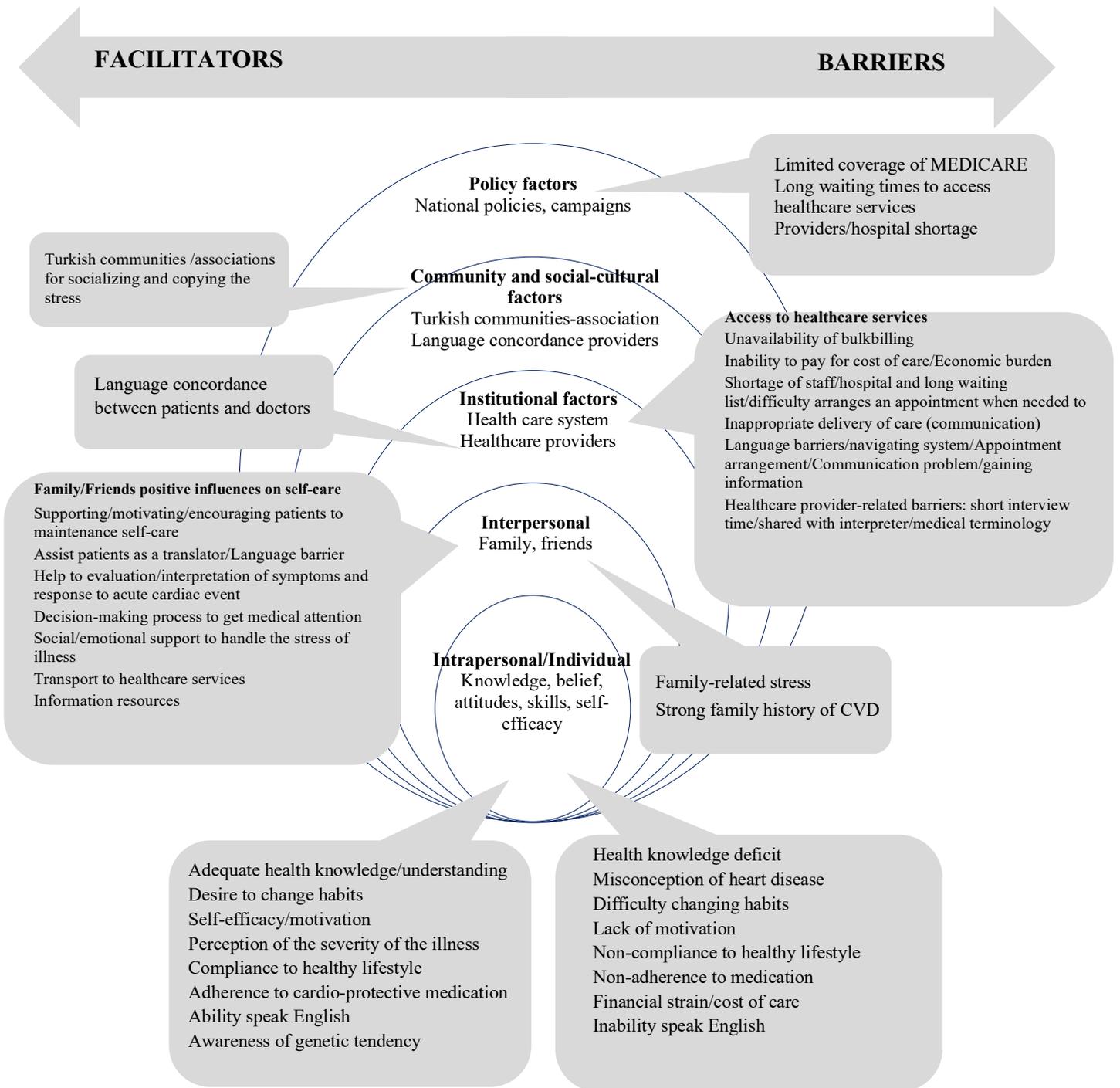
This is the first explorative qualitative study to focus on the factors influencing secondary prevention measures and self-care in Australian Turkish immigrants living with heart disease. It is essential to comprehend the factors that affect secondary prevention and self-care behaviours in heart disease to customise interventions according to patients' requirements. Using an exploratory qualitative research design based on the constructivist paradigm, we gained comprehensive insight into self-care factors that Australian Turkish immigrants experience.

Figure 5.1 summarises the factors that hinder or help with secondary prevention measures and self-care based on the socio-ecological model.

Previous studies have shown that immigrants face various barriers to managing their CHD and accessing healthcare. These barriers include insufficient information, provider support, and psychosocial issues. The results of this research align with these findings (Mead et al., 2010; Scheppers et al., 2006). This study analysed the findings using the SEM framework, which consists of multiple layers beyond intrapersonal levels.

In this study, Turkish-born Australians with heart disease may not receive the secondary prevention strategies that might benefit them. These vulnerable patients' access to secondary prevention strategies may be hindered by a myriad of barriers occurring at the intrapersonal level (health knowledge deficit, limited English proficiency, financial strains, and personal factors influencing self-care), interpersonal level (family/friends as facilitators or barriers), institutional level (access to healthcare services and HCPs related barriers), community/socio-cultural level (language concordance between providers and patients) and policy level (providers/hospital shortage and hidden long waiting list, health system problems in clinic setting) (Figure 5.1). As this study was undertaken during the COVID-19 pandemic, findings regarding the pandemic's influence on the participant's experience in diagnosis, treatment, and continued care are presented.

Figure 5. 1: The Factors Influencing Secondary Prevention and Self-care of Heart Disease Management



The study findings are consistent with several studies that examined the barriers to the care (Gholizadeh et al., 2009; Jin et al., 2020) in other immigrant populations in Australia.

5.2 Intrapersonal Level

Intrapersonal-level barriers, including health knowledge deficit, language barriers, financial strains, and personal factors influencing self-care, may increase cardiovascular risk and result in delayed hospital presentation and diagnosis at a more advanced stage of disease (Table 5.1).

Table 5. 1: Individual Factors Influencing Self-care

Factors	Barrier	Facilitator
Knowledge	Lack of knowledge /understanding	Adequate knowledge/understanding
Beliefs	Perceived negative consequence of SM	Perceived positive consequence of SM
Motivation	Lack of motivation Lack of confidence	Motivated/Desired Self-care efficiency
Maintenance behaviours	Difficulty of changing unhealthy habits	Engaging in new healthy behaviours
Management behaviours	Inability symptoms recognition/evaluation response	Ability symptoms recognition/evaluation response
Language skill	Inability to speak English	English proficiency
Financial situation	Financial instability	Financial stability

SEM: Socio-ecological model
SM: Self-management

Health Knowledge Deficit

Understanding a patient's heart condition and risk factors is crucial for healthcare professionals and patients. It helps determine health-related behaviour. A lack of awareness or poor understanding of cardioprotective strategies minimises the patient's chance to take appropriate actions to reduce their risks.

Our research showed that participants had limited knowledge about cardiovascular disease (CVD) and its risk factors. This aligns with a systematic review conducted by Clark et al. (2012), which found that inadequate information about cardiac rehabilitation (CR) programs and their benefits from healthcare professionals were significant personal barriers to attending CR. Nonetheless, the review also indicated that motivation from a physician was a strong factor in attendance.

Wai et al. (2012) analysed data from 1545 inpatient medical records regarding prescribing guideline-recommended cardiovascular medications to patients at discharge and providing education on lifestyle modifications (referral of patients to and attendance at CR programmes). It was demonstrated that although most patients had some component(s) of the management plan documented, only a minority of plans were comprehensive. The study participants appeared to have poor knowledge regarding cardiovascular secondary prevention strategies and self-care. In our sample, this knowledge deficit led to misinterpretation of cardiac symptoms, leading to a delayed response to acute cardiac events or inability to address worsening acute cardiac symptoms, leading to further cardiac events such as heart failure, acute myocardial infarction, or stroke.

One of the biggest influences on health-seeking behaviours in Australian Turkish immigrants is their lack of knowledge about heart disease and its associated risk factors. Many participants had difficulty accessing health information resources due to limited English proficiency, low health literacy, and the need for clear communication with healthcare providers. This finding is consistent with recent Australian findings among Australian Chinese immigrants living with heart disease (Jin et al., 2020). Improving health literacy can assist patients in understanding and utilising information related to secondary prevention.

Our study found that the Australian-Turkish participants had insufficient knowledge and understanding of acute cardiac symptoms, including chest pain. The pain was attributed to the pain to non-cardiac causes, and many waited for spontaneous improvement before seeking urgent treatment for an acute cardiac event. It is well known that early treatment of patients with AMI is critical to maximising beneficial health outcomes (Steg et al., 2012). A delay in receiving timely treatment for acute myocardial infarction (AMI) is associated with increased myocardial damage and mortality (De Luca et al., 2004; Steg et al., 2012). Based on the study participants' high rate of urgent cardiac intervention and bypass surgery, it is possible that delayed diagnosis and medical treatment resulted in significant myocardial damage.

Study participants who have previously experienced heart problems or have a familial history of heart conditions tend to recognise cardiac symptoms sooner, reducing prehospital delay.

The study findings suggest that healthcare providers must consider immigrants' health knowledge deficits regarding cardiac symptoms and seek urgent medical attention. Such patients merit special attention with more culturally and linguistically sensitive secondary prevention and self-care education and require targeted approaches by healthcare providers to improve treatment compliance and health outcomes. Moreover, effective policy measures should aim at mitigating heart disease by enhancing awareness about heart disease and related risk behaviours such as smoking, unhealthy diet, physical inactivity, sedentary lifestyle, overweight and alcohol consumption among this ethnic minority.

According to a study by Vanzella et al. (2021), many people with heart conditions are not attending cardiac rehabilitation (CR) programs because they lack knowledge about their diagnosis, the CR program, and the benefits of this intervention. Some people who don't attend CR are also unsure how to get referred to the program because of communication issues with their healthcare providers. It's essential to increase referrals to self-care programs to improve attendance rates. Lack of awareness of the availability and participation in heart disease self-care programs such as CR program (Vanzella et al., 2021) or those to mitigate risk factors such as smoking cessation program and AAA may correlate with limited use of healthcare and LEP. It is essential to highlight that health

knowledge deficits can also be considered at the institutional level as they can result from poor communication with providers. Likewise, in one study, participants who could communicate effectively with HCPs were more likely to have access to health information that could impact their ability to navigate within the healthcare system and the possibility of being involved in their healthcare (Dhaliwal et al., 2017; Wiltshire et al., 2006). For instance, patients should be able to share concerns regarding smoking with HCPs, as then the provider can offer and access information regarding smoking cessation programs. Our study findings align with the results of this research.

Interestingly, the study participants' knowledge of stress as a risk factor for heart disease was relatively high. This strong relationship between perceived stress and heart disease is consistent with the literature (Rosengren et al., 2004). The belief and perception of the influence of stress on heart disease in our study could, however, be related to experiences of psychosocial stressors associated with the transition to a new country combined with additional stress arising from a period of unemployment affecting mental health (Kennedy & McDonald, 2006). Based on the study findings, heart disease approaches should aim at modifying these psychosocial stresses arising from stress at work and home, financial strains, and previous experiences of significant life events.

Limited English Proficiency and Effective Communication with Providers

Patient-centred care (PCC) is the holistic treatment of patients based on their assessed clinical condition, considering their individual preferences, priorities, and sociocultural contexts (Epstein & Street, 2011). PCC is a quality of personal, professional, and organisational relationships. In this approach, comprehensive communication is essential for the patient's role as an active, informed participant in shared decision-making. To receive PCC, the patient must comprehend their medical condition fully, the significance of clinical services, the importance of prevention, and the need for timely treatment (Martinez & Leland, 2015).

Language barriers can create significant challenges in accessing high-quality healthcare, effectively communicating with healthcare providers (poor comprehensive communication) and achieving high satisfaction levels among Australian Turkish immigrants with heart disease.

Many participants acknowledged that one main problem with language barriers was navigating the healthcare system and the inability to identify healthcare services and access them when needed. The most common access barriers cited by our study participants were a lack of knowledge about existing healthcare services (CR program, smoking cessation programs) and an inability to schedule periodic appointments with HCPs on the phone due to LEP. On the other hand, communicating with HCPs may improve access to the information appropriate to their needs and may enhance adherence to self-management and treatments.

In this study, participants raised concerns about communication gaps with healthcare providers. Practical, comprehensive communication between patients and HCPs is crucial in gaining necessary information, receiving an accurate diagnosis, allowing patients to understand their medical condition, underlying risk factors and treatment and making a final decision regarding their disease treatment (Okunrintemi, 2017).

Limited English proficiency may negatively impact Australian Turkish patients' ability to express health concerns, discuss cardiac symptoms with providers and understand providers' explanations and instructions. We learnt from our study participants that inadequate description of cardiac symptoms due to limited vocabulary might result in misunderstanding, leading to concern about negative health-related consequences, including not receiving an accurate diagnosis or may cause delayed help-seeking behaviour. Although previous research has detected positive implications of self-management education on the health outcomes of patients with heart disease (Clark et al., 1992), unfortunately, poor communication with HCPs may negatively impact patient education regarding secondary prevention strategies, including the use of evidence-based cardioprotective medications, self-management, and treatment adherence. A comprehensive self-management plan may enhance patients' self-confidence in heart disease management and increase adherence to treatment, which is critical to preventing further cardiac events (Bitton et al., 2013; DiMatteo et al., 2002). However, our study participants reported difficulty asking questions and a poor understanding of medical conditions. They were also not encouraged to seek further clarification or discuss the heart disease with providers, leading to patients' dissatisfaction. They also stated that limited communication due to their inability to speak English might conceal problems

and prevent early diagnosis. Therefore, the study participants often expressed poor satisfaction with their healthcare.

Due to language barriers, patients with LEP may feel uncomfortable about treatment instructions, surgery, or different treatment options. Thereby, miscommunication and mistrust led individuals to seek a second opinion from a language-concordant family doctor. Accessing language-concordant providers was viewed as an effective way to mitigate language-related communication barriers and improve medical comprehension. This finding is consistent with previous studies focusing on the impact of language-concordance providers (Wilson et al., 2005). The limited availability of language-concordant providers, particularly specialists, necessitated using interpreter services to facilitate communication between providers and patients. Using an interpreter may help bridge the communication gap between immigrants and HCPs, promote engagement with the healthcare system, increase patient satisfaction, and enhance the quality of care (Jacobs et al., 2001). Access to an interpreter is necessary for patients to attend their scheduled health appointments, which can lead to non-adherence to follow-up care. Like others, in this study, access to professionals and qualified interpreter services, such as limited availability or unavailability of interpreter services, or delays or non-attendance, resulted in misinterpretations by patients (Flores et al., 2003). Privacy and confidentiality concerns can arise when an interpreter is used in the provider-client therapeutic relationship. This can make patients hesitant to disclose their private health concerns. Some individuals rely on their family members as interpreters to maintain their privacy. However, English-speaking family members may not always be available when needed the most. Despite the aforementioned negative issues, using an interpreter during provider conversations is still recommended as it remains the best option.

During the study, participants pointed out that healthcare providers' medical terminology hindered effective communication with patients. This language can make it difficult for patients to comprehend health-related information.

Financial Strains

Cardiovascular-related chronic conditions require ongoing monitoring by healthcare professionals and long-term self-management to prevent further cardiac events (Chew et al., 2016). Self-reported financial barriers to secondary prevention strategies may also be

experienced among Australian Turkish immigrants with heart disease. While some study participants experienced self-management barriers (payments for regular follow-up with health care professionals and cardiac tests), others experienced indirect financial barriers (e.g., lost job/becoming redundant, employment difficulties and early retirement). Participants who experienced an economic burden because of a reduced income and increased expenses related to their health may find themselves unable to adhere to secondary prevention strategies. In this study, all participants reported having health insurance but encountered substantial out-of-pocket costs. Many participants reported avoiding attendance at periodic healthcare provider appointments and performing cardiac tests due to their financial expenses. Obviously, having Medicare is not enough to cover health expenditures and, thus, may not eliminate financial barriers to care and may prevent patients from accessing essential health care services such as monitoring and screening with regular follow-up by providers and potentially contribute to poor health outcomes. Our study finding is consistent with prior studies that insurance coverage may not eliminate financial barriers and result in substantial co-payment (Dhaliwal, 2017). It is well known that patients' health outcomes impacted by financial barriers result in impaired quality of life and increased hospitalisation rates (Campbell et al., 2014; Rahimi et al., 2007). Our finding may highlight that any plan for health care reform regarding Medicare coverage may benefit patients with financial barriers to secondary prevention strategies and self-care.

The Implication of Personal Factors on Secondary Prevention Measures

Secondary prevention is a strategy to reduce further cardiac events and stroke in patients with known cardiovascular disease, including CHD, cerebrovascular disease, and peripheral artery disease (Redfern et al., 2011; Smith et al., 2011b). According to a systematic analysis of data from the World Health Organization (WHO) study, more than 75% of all cardiac deaths may be prevented with appropriate lifestyle modification (World Health Organization, 2021). Effective secondary prevention and self-management following a diagnosis of heart disease are essential but challenging due to the implications of personal factors on secondary prevention measures. Contemporary evidence suggests that preventative interventions and standard medical care should be

flexible and tailored to the individual's preferences, needs, and values to achieve optimal and sustainable benefits (Redfern et al., 2011).

The study findings indicate that lifestyle change is personal; however, the support provided by providers and others (family/friends) is essential to enhance self-efficacy and motivation to maintain lifestyle changes and self-care. Personal factors negatively impacting secondary prevention measures and self-care were difficulty changing unhealthy habits, poor compliance to new healthy behaviours and medication adherence (Figure 4.5). These factors appear to influence long-term self-care maintenance behaviours, which were crucial given the multiple cardiac risk factors and cardiac events patients had experienced.

Difficulties in keeping up with changes may be due to personal obstacles such as a lack of motivation, past unsuccessful attempts to reduce alcohol consumption or quit smoking, and established habits. It has been proven that adopting a healthy lifestyle helps prevent future cardiac events and manage chronic heart conditions (Anderson, 2006; Shields, 2018). Changing unhealthy behaviours (smoking cessation, reducing alcohol consumption, weight management, regular physical activity, and coping stress) requires institutional and individual commitment with social support. Lack of motivation or difficulty staying motivated were individual factors complicating lifestyle changes. According to the study participants, enhanced knowledge, self-efficacy, self-confidence, and desire to change their lifestyle habits were crucial in maintaining and adhering to a new lifestyle. Motivational interviewing by providers in a clinical setting and social support through the involvement of others in lifestyle changes may enhance an individual's ability to cope with heart conditions and adhere to recommended lifestyle changes and cardioprotective medications.

Motivated participants may be more conscious of what they eat and may increase their adherence to a healthy diet. A randomised controlled trial by Rouleau et al. (2018) examined the impact of motivational interviewing on the intention to attend CR among patients with existing CHD. The results suggested that motivational interviewing with a patient-centred counselling style for addressing the individual barriers of ambivalence would encourage patients to attend CR and increase their adherence to exercise programs. This should be done before patients start the program. Patient education about CR

programs and the benefits of adopting a healthier lifestyle by health professionals is crucial to enhancing CR enrolment and adherence to secondary prevention. The factors that motivate patients to participate in and follow the CR program were categorised into three themes: "belief," "group cohesion," and "supporters." Patients' belief in the benefits of CR for their heart condition is crucial for their motivation (Shahsavari et al., 2012). Health professionals must possess effective communication skills to educate patients and boost their confidence and motivation in managing their heart disease. Additionally, health professionals must understand the barriers and motivational factors that affect patients' participation in CR (Chauhan et al., 2010; Vanzella et al., 2021).

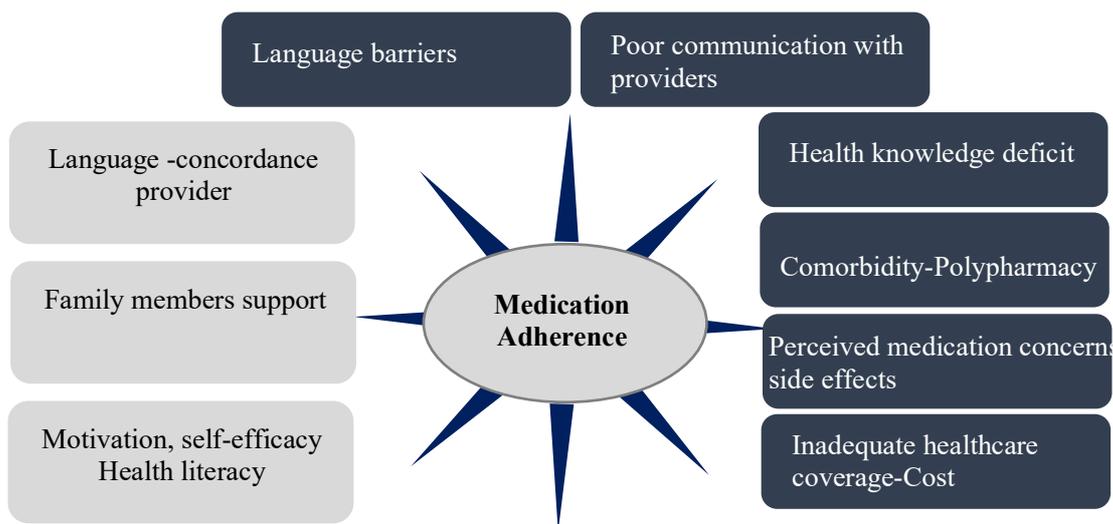
A qualitative study by Ruano-Ravina et al. (2016) explored factors that influence enrolment in outpatient CR and provided insight into the individual decision-making process about enrolment in CR. Participants were interviewed regarding their experience with decision-making for enrolment after referral but before CR participation. Efforts to educate and motivate patients with individualised motivational interviews can counter negative factors affecting intention in CR.

While heart disease-related progressive physical decline (tiredness, fatigue) and disease burden may prevent patients from attending regular physical activity, cardiac symptom-related negative emotions (fear of further heart attack/death) may motivate the patients to adhere to secondary prevention strategies and self-care.

International guidelines recommend long-term use of evidence-based cardioprotective medication to manage heart conditions; however, adherence is a significant challenge to achieving optimal benefit from medications (Knuuti et al., 2020). Interestingly, many individuals desired to control cardiac risk factors such as hypercholesterolemia with lifestyle instead of medication. This could be a unique barrier to medication adherence among Australian Turkish immigrants. According to the guideline recommendations, lifestyle changes are the cornerstone in managing cardiac risk factors, and if cardiac risk factors are not achieved with these lifestyle modifications, medication should be augmented, not replaced with lifestyle changes (Chew et al., 2016; Smith et al., 2011b). This is to the findings of others who found that patient concerns regarding the side effects of medication and scepticism about the necessity of medication may prevent patients' adherence to medication (Mann et al., 2009). Moreover, our findings confirmed that poor

medication adherence was related to a significant risk of adverse clinical outcomes such as further cardiac events, heart failure and stroke (Du et al., 2017).

Figure 5. 2: Factors Influencing Cardioprotective Medication Adherence



Multiple factors at different levels may explain the underlying causes of poor medication adherence, including individual attitudes and beliefs about medication, knowledge deficits caused by language barriers and poor communication with providers, concerns about medication's actual/potential side effects, having comorbidity and using multiple drugs (Figure 5.2). These barriers can be addressed through continuing education by language concordance providers in outpatient settings. Specific educational messages on medication efficacy and the importance of consistent medication adherence for heart-health outcomes by language concordance providers could improve compliance with evidence-based cardioprotective medication. Similarly, public health intervention at Turkish community centres on heart disease self-management and secondary prevention strategies may be beneficial to address and discuss patients' beliefs and perceptions with them in Turkish.

Other barriers to adherence to medication cited by the study participants were language barriers, poor communication with providers and poor access to health information, leading to a health knowledge deficit regarding medication. This aligns with the research on effective communication challenges with providers (Aseltine et al., 2016). Language barriers and poor communication with providers may also enhance poor adherence by compromising understanding of the medication regimen. The study suggests that language concordance between patients and healthcare providers improves medication adherence. Patients feel more comfortable discussing their challenges and concerns with their providers in a collaborative environment when they speak Turkish. Language and cultural concordance between patients and providers may help to build trust between them (Wilson et al., 2005).

In our study, family support from spouses and children emerged as an essential facilitator factor to improve adherence to medication and lifestyle modifications such as regular exercise, healthy diet and coping the psychological stress caused by their medical condition. We learnt from the study participants that family members were a valuable resource and could be incorporated into heart disease self-management interpretations.

5.3 Interpersonal Level

Family/Friends' Influences on Secondary Prevention (*Help or Hindrance?*)

Several studies have provided evidence that a family-based approach effectively reduces cardiac risk factors by enhancing the adoption of lifestyle changes and maintaining self-management (Jeemon et al., 2021; Shahriari et al., 2013). Because CVD is a chronic lifelong health condition, patients with heart disease may need strong support for secondary prevention and self-care, particularly for vulnerable groups (Grey et al., 2006). In the study, we learned that family members (spouses and children) can be an essential source of support and may positively impact an individual's self-management and self-monitor cardiac symptoms. Family members and friends may play a critical role in supporting, motivating, and encouraging patients to maintain health-related behaviour, attend regular follow-ups, and adhere to cardioprotective medications. Educating patients and their families about the medical aspects of heart disease, advising on healthy food choices, and attending provider visits together may encourage family members to take responsibility for secondary prevention.

Families can also be a source of stress (divorce, spouse/children relationship problems, lost loved ones). Many in the study recognised stress as a main risk factor for heart disease or an acute cardiac event. A positive, stable family relationship and a conducive home environment are related to better health behaviours, such as regular exercise and a healthy diet. This finding is consistent with previous research on family influence on self-care (Dunbar et al., 2008).

Family/friends were crucial in recognising a major cardiac event by recognising cardiac symptoms, interpreting their severity, and accelerating help-seeking behaviour for immediate medical attention. When participants needed help, their family/friends were the ones who determined the best course of action. They would decide whether to take the person to a nearby hospital and whether to transport them by car rather than calling an ambulance. In addition, participants expressed a positive view about family/friends' support on hospital admission, discharge, and access to healthcare services as a transporter and interpreter.

Dealing with the uncertainty of heart disease can be stressful for family members and patients. Social and emotional support provided by family and friends can be beneficial for patients managing the stress caused by heart disease, especially during recovery after surgery. Conversely, people who live alone and feel socially isolated are more likely to experience greater depression and lack of emotional support. Some evidence suggests that social isolation and loneliness contribute to increased risk of incidence of cardiovascular disease (National Institute on Aging, 2019). It is essential to conduct further research to understand the difficulties people living alone may encounter.

While the study participants acknowledged that family support can positively impact self-management and medication adherence, they also highlighted the negative effects of family dynamics on heart disease. The participants believed that family-related stress could trigger acute cardiac events, such as strained spousal relationships, divorce or unhappy marriages, and conflicts with children.

Another family-related factor was having a strong family history of cardiovascular disease. A positive family history is associated with a higher risk of future cardiac events and is described as a non-modifiable cardiac risk factor (Prabhakaran & Jeemon, 2012; Yusuf et al., 2004). In contrast, as mentioned before, becoming familiar with the cardiac-

related symptoms may encourage the patients to practice primary prevention or enhance their compliance to secondary prevention as they may know the consequences of heart disease from family experiences.

In conclusion, the key points were that family/ friends positively influenced health-seeking behaviours and increased compliance to secondary prevention and self-care. The study findings highlight the importance of family/friend engagement in heart disease management and raise awareness of the role and potential benefits of family/friend engagement in self-care. Therefore, healthcare providers must consider empowering family/friends to participate in self-care and decision-making.

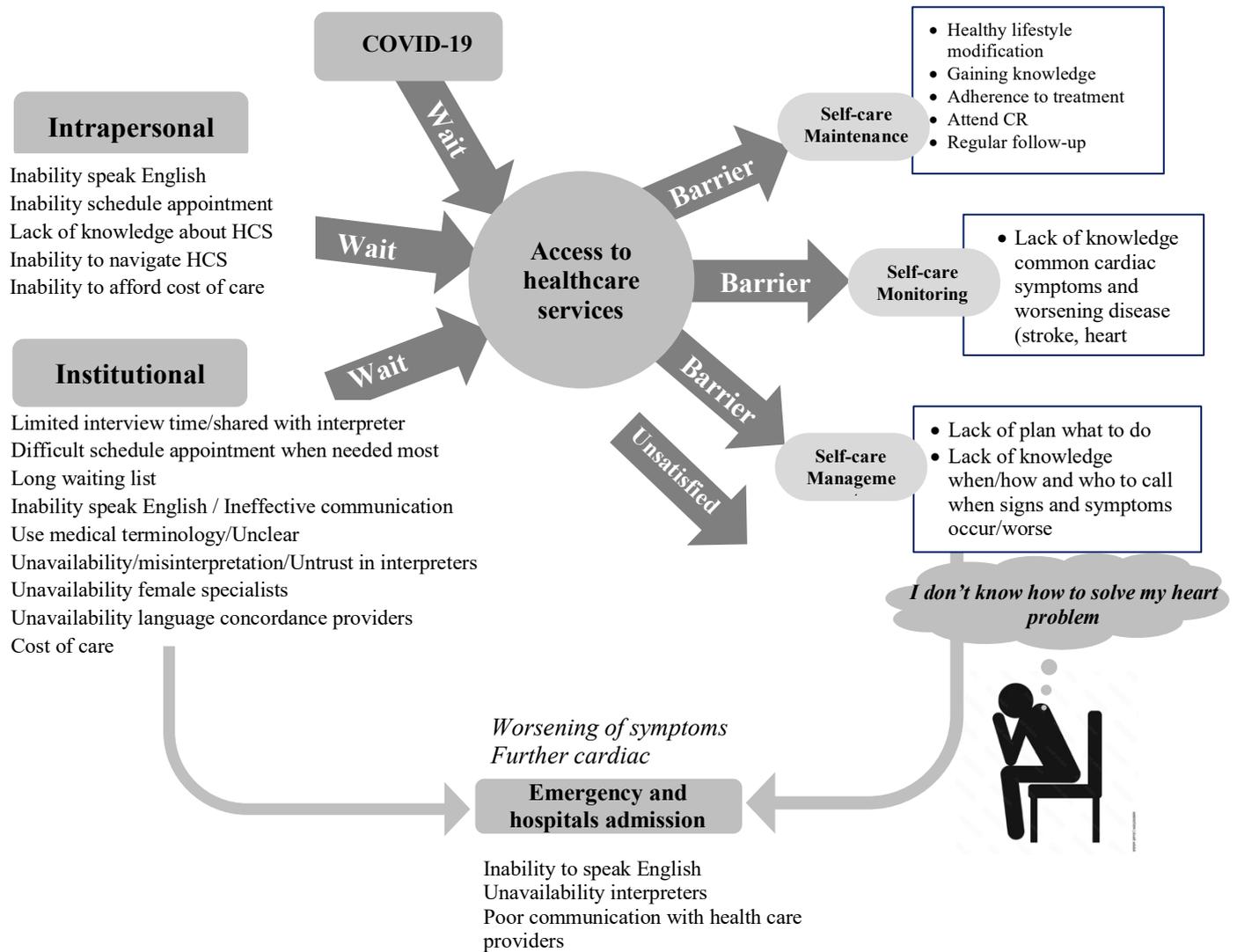
5.4 Institutional Levels

Access to Healthcare Services

In the research literature, ‘access to healthcare services’ is defined in a wide range from the narrow approach of service entry to a multidimensional approach, including availability (physically available), accessibility, affordability (economically accessible), acceptability, and accommodation (Wilson et al., 2012). Healthcare providers are central to patient care and have a role in the organisational system. Thus, comprehensive communication with providers is crucial to access healthcare. Barriers to accessing providers may impede patients receiving medical care, rapport relationship with providers, and achieving heart disease management. Identifying factors that impede patients from accessing available healthcare services may be the solution to improve the delivery of healthcare services and optimise self-management for ethnic minority populations living with heart disease.

The study participants expressed various views about self-care, social support, and access to and interaction with the healthcare system. Our analysis of the interviews revealed critical insights into the barriers and facilitators for access to secondary prevention and self-management care among the Australian Turkish community living with heart disease (Figure 5.3). Nearly all the study participants experienced access issues caused by intrapersonal level, interpersonal level, organisational/institutional, societal/cultural, policy/structural levels, or the COVID-19 pandemic.

Figure 5. 3: Participants’ Experiences with the Healthcare Delivery System and Barriers Faced When Accessing Healthcare



Within *the individual level*, participants consistently identified a *lack of knowledge/awareness* about the illness and available services as critical barriers. As mentioned before, language barriers to communication can negatively influence patient access to available health information, understanding of the information received and shared decision-making process to accept and adhere to secondary prevention and self-care.

The other access barriers cited by the participants were *difficulty navigating the system* and scheduling *a phone appointment* for periodic specialist visits. This ‘health knowledge deficit’ theme emerged repeatedly on several different levels. Thus, a potential solution to overcome this barrier may be tailored to community-centred public health education efforts to optimise their health literacy regarding secondary prevention at Turkish community centres in Turkish. However, community-hosted health events may need reliable funding support to provide effective services.

Within the *institutional/organisational level*: Some participants reported not receiving sufficient information from the healthcare provider about their medical condition. They stated that providers may not take enough time to explain the condition to patients with limited English proficiency. The contributing factor that perpetuated ineffective patient-provider communication was the providers’ failure to devote adequate time and attention to the patients with LEP to explain their medical condition and treatment. However, HCPs should have good communication skills, including reflective listening, empathy and acknowledging patients’ personal values (Patak et al., 2009). Patients with LEP may need a more extended interview time to build effective communication and trust between patients and providers. Patients have the right to be informed about the care they receive, make educated decisions about their care, and have the right to be listened to by their providers. However, according to our findings, poor doctor-patient communication was an important barrier to self-care in patients with LEP. In the case of patients with LEP, language access services such as interpreters or translated documents are either unavailable or infrequently used (Ramirez et al., 2008).

The availability of interpreting services was not always guaranteed, especially in urgent care situations. While healthcare facilities recognised the importance of having interpreting services, using interpreters was somewhat time-consuming (Farley et al., 2014). The study participants emphasised this point of view, reporting that sharing the time with the interpreter resulted in a short consultation time with their providers and reduced patient satisfaction. Individuals with Limited English Proficiency (LEP) may require additional time to communicate their concerns effectively or receive adequate information about their medical treatment. Therefore, the study participants had poor satisfaction with their healthcare.

Within the organisational level, the study participants frequently mentioned logistical barriers to accessing services, such as cost of care or work conflict, leading to skipping necessary care, including periodic specialist visits and performing cardiac tests.

5.5 Policy/Structural Level

Within the *policy/structural level*, limited coverage of Medicare was frequently identified as a barrier. The study participants noted that healthcare cost was prohibitively high without complete health insurance coverage. Thus, extra health expenditure for appointments was a common barrier to attendance at regular specialist visits, a necessity for self-management maintenance care. The participants highlighted that providing health coverage policies that cover the complete cost of an appointment would eliminate barriers to receiving healthcare.

Many study participants experienced *long waiting times* to access healthcare services. Although waiting lists allow for planning and structuring for patients and institutions (Sæther et al., 2020), increasing the list size may exceed the ideal waiting situation. Difficulty scheduling an appointment when needed due to long waiting lists was frequently reported as policy/structural barriers to accessing secondary preventative care. Participants waiting a long time for healthcare reported deterioration symptoms of the existing heart disease, leading to patients ending up in acute care, reduced ability to exercise/work and negative implications on mental well-being while waiting. These findings are consistent with previous research (Derrett et al., 1999; Reichert & Jacobs, 2018).

Furthermore, long waiting times for elective hospital/clinical care may delay early intervention treatment, leading to patients suffering from worsening cardiac symptoms. Resources (providers/hospitals) were insufficient to meet the demand and break the vicious circle (growing demand waiting list). According to Sæther et al. (2020), simply changing policy while waiting lists are excessively long may not shorten the waiting times.

The COVID-19 pandemic has exposed the limited institutional capacity regarding time and resources. Healthcare services were unprepared to handle the overwhelming demand caused by the outbreak. Although the COVID-19 lockdown prevented further spread and

saved lives, study participants had to postpone their regular visits and care routines. Policies should aim to recover from the lasting impact of the COVID-19 outbreak, translate the long waiting times to shorter and increase the capacity above the demand. Policies can be tailored to prepare a future of action to guide resilience for future COVID-19 waves or another pandemic.

5.6 Socio-ecological Model

We used the socio-ecological model to explore the factors affecting secondary prevention and self-care at various levels. Through this framework, we found that many social and environmental factors can influence people's behaviours. This helped us identify barriers and supportive factors that can hinder or promote these measures and self-management. This multi-layered approach provides a framework for developing comprehensive prevention strategies at different levels - individual, interpersonal, organisational, community, and policy - to increase public awareness of cardiovascular risk factors and improve health outcomes. Using the model's principles, we can overcome language, cultural, and political barriers, ensuring everyone can access the care and resources needed for optimal health outcomes in future research.

5.7 The Implication of COVID-19 on Self-care and Telehealth

The COVID-19 pandemic, caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has created significant healthcare crises and an unprecedented challenge across the globe (Huang et al., 2020). Therefore, international healthcare responses focused on infection control and prioritising acute and urgent services for people with COVID-19. To prepare for this challenge, several initiatives were implemented. Access to healthcare services, outpatient clinics and day services was limited for outpatients, and ward access was granted only for urgent procedures. All scheduled outpatient non-urgent visits were suspended. Services to address cardiovascular care were negatively impacted (World Health Organization, 2020).

The implication of COVID-19 emerged in various ways and profoundly reshaped existing care pathways. The study found that participants faced difficulties accessing regular healthcare services due to the limited availability of services catering to their self-care

needs due to the COVID-19 pandemic. Their healthcare was negatively affected. This is consistent with the results of a recent systematic review that showed healthcare service utilisation decreased by about one-third during the pandemic (Ray et al., 2021).

Cancellation/postponement of elective procedures and periodic specialist visits during the height of the COVID-19 pandemic led to difficulties accessing healthcare and caused emotional and psychological distress (Byrnes et al., 2021).

Alternative strategies for continued self-care, such as telehealth, were introduced under the Medicare Benefits Schedule (MBS), thereby reducing the need for in-person consultations (Australian Institute of Health and Welfare, 2020a). Although the OPTIMIZE heart failure program's result reported advantages of remote consultations and significant patient satisfaction (Cowie et al., 2022), in our study, the experiences of Australian Turkish participants with telehealth differed from the published literature (Hanlon et al., 2017). In our study, participants were reluctant to use telehealth due to their LEP and the limited options for a physical examination. Face-to-face consultations and in-person physical examinations were expected for the worsening of cardiac symptoms. For those with LEP, nonverbal behaviours, such as body language, can be the principal means of communication. The telehealth method may, therefore, be ineffective in conducting a consultation in such cases.

Furthermore, inadequate information technology (IT) experiences and poor internet coverage and access exacerbated virtual consultations' negative aspects and discouraged patients' usage. A lack of effective patient-provider communication has been cited as a significant factor contributing to adverse outcomes (Bartlett et al., 2008). During the COVID-19 pandemic, a cross-sectional study was conducted to compare the use of video and telephone among patients with limited English proficiency (LEP) (Hsueh et al., 2019). The study found that one-third of LEP patients opted for video visits instead of telephone visits. This suggests that using video may help overcome barriers to telehealth for LEP patients.

The COVID-19 lockdown posed particular challenges for acute care management of heart disease, such as urgent admission for decompensated HF, stroke, and further cardiac events. One of the participants in the study, who experienced shortness of breath with a persistent cough, assumed he had a COVID-19 infection and isolated himself at home

until proven otherwise. Misdiagnosis of COVID-19 in a patient with HF caused the patient a delayed early diagnosis and treatment for HF, and the consequences were severe. The recent case report has highlighted the risk of misdiagnosing COVID-19 patients with heart conditions (Yousefzai & Bhimaraj, 2020). It is essential to remain vigilant in diagnosing COVID-19, but HCPs must also remember to consider other common diagnoses.

According to the study participants, the effects of the pandemic on secondary prevention have been experienced not only in accessing healthcare but also in the supply of evidence-based cardioprotective medication and adherence to healthy lifestyles such as physical inactivity, unhealthy diet, and weight gain. The study participants reported that self-isolation due to fear of contracting the COVID-19 infection and the pandemic-related lockdown reduced outdoor exercise time and may lead to weight gain (Li et al., 2021). Despite the online food supply and distribution model allowing people to access food during the COVID-19 pandemic, the study participants experienced difficulties with online food purchases due to language barriers. Furthermore, self-isolation/loneliness and lack of social support during the pandemic were sources of stress. The psychological implications of COVID-19 cited by the study participants were anxiety, panic, uncertainty, depression, loneliness/isolation, and fear of having a severe form of COVID-19 infection or death. Virtual communication and social media are commonly used as the primary ways for participants to overcome social isolation and psychological stress.

5.8 Conclusion

The study findings demonstrate that heart disease management among Australian Turkish immigrants is not experienced as recommended in the guidelines to prevent further cardiac events and improve health outcomes. This highlights the importance of communicating with healthcare providers to overcome the barriers.

Australian Turkish immigrants with heart disease have a range of barriers to healthcare and secondary prevention due to poor health knowledge, language barriers and financial strains. Using an interpreter during conversations with providers is still the optimal situation to overcome language barriers. However, there are issues with engaging interpreters, including unavailability, privacy, and confidentiality issues. Language concordance between providers and patients may improve their heart disease

management by increasing their understanding of medical conditions, the treatment plan, adherence to the treatment plan, and patient satisfaction. Through culturally humble and linguistically appropriate communication, providers may discuss immediate and long-term treatment options and ask about barriers that impede patients from adhering to secondary prevention strategies and facilitate connecting their patients to needed resources. This is critical to ensure understanding and ability to complete secondary prevention strategies and optimise health outcomes.

Furthermore, personal factors negatively impact successful secondary prevention measures and self-care, including difficulty changing unhealthy habits, poor compliance with new healthy behaviours, and medication adherence, and increased risk for further cardiac events.

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Appendices

Appendix 1: Information Leaflet for Participants (English Version)

Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures

Participant Information Sheet/Consent Form

Non-Interventional Study - *Adult providing own consent*

Site: HeartWest Community Cardiology Services

Title	‘Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures’
Short Title	Heart disease management among Turkish immigrants
Protocol Number	1.0
Project Sponsor	Mitchell Institute, Victoria University
Coordinating Principal Investigator/ Principal Investigator	Prof Maximilian de Courten
Associate Investigator(s)	Sakine Satıcı, Adj. Prof Sharon Andrew
Location	The ‘HeartWest Clinic’, Coolaroo, Melbourne

(*This is for you to keep)

Part 1 What does my participation involve?

1 Introduction

You are invited to participate in this research project, *‘Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers of secondary prevention measures’*. This is because you are of Turkish background and have valuable experience living with and managing your heart condition. The research project aims to explore your experience, understanding and beliefs regarding treating and managing your heart condition.

Sakine Satici, a Master of Research candidate at Victoria University, is undertaking this project.

The Principal Investigator, Professor de Courten, will oversee the project.

This Participant Information Sheet/Consent tells you about the research project. It explains the research involved. Before you decide whether to participate in this study, you need to understand why the research is being done and what it will affect. Please take the time to read the following information carefully and discuss the information with others if you wish. Ask questions about anything you don’t understand or want to know more about.

Participation in this research is voluntary. If you don’t wish to participate, you don’t have to. You will receive the best possible care whether or not you take part.

If you decide to participate in the research project, you will be asked to sign the consent section. By signing it, you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to the research that is described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

The purpose of this study is to explore your self-management of your heart disease through the eyes of the participants, to gain a greater insight into your understanding of self-management, and to hear your story of how your heart condition has changed your life. We also wish to understand the factors that influence your self-management of your heart disease. It appears that some immigrant patients may miss out on some health care. This may be partly because of language and cultural barriers that impact access to and utilisation of the available healthcare services to manage their heart condition. As a Turkish-speaking patient with heart disease, you probably have experience with it and its challenges and a valuable opinion regarding how to deal with it. Sharing your experiences might shed light on this issue and help to improve the health care of the Australian Turkish community living with heart disease. Your view will be of great importance in this research. You are invited to participate in this research project because you are of Turkish background and have valuable experience living with and managing your heart condition. The research project aims to explore your experience, understanding and beliefs regarding treating and managing your heart condition.

Based on your experience with heart disease, the findings of this study can provide valuable information to support healthcare professionals to make them aware of the factors that influence your ability and motivation for self-management. The findings of this research may also contribute significant information to healthcare professionals, policymakers, and researchers to be tailored to meet your needs and improve adjustment to managing your heart condition and make you successfully manage your heart condition.

3 What does participation in this research involve?

- Your participation will involve face-to-face conversational-style interviews at the 'HeartWest Clinic' facility in Coolaroo, a northern suburb of Melbourne.

- We are interested in your experience with self-management of your heart condition and to understand what kind of barriers and facilitators you experienced in your self-management of your heart disease.
- The interview may take up to approximately 60 minutes and will be audio recorded using a digital voice recorder to translate into English and analyse the information later.
- Any details identifying you, such as your name or where you live, will be removed or changed to maintain confidentiality.
- You can be interviewed in English or Turkish to ensure you understand and express yourself best. Sakine Satici, fluent in Turkish, will conduct the interviews.
- If you become upset or emotionally distressed during the interview, you will be able to take breaks or discontinue the interview. You will be given information on online counselling services Beyond Blue and Lifeline Services provide ongoing support if required.
- Before the interview, you will be informed about the research and given adequate time to ask questions of the researcher and receive clear answers. This Participant Information Sheet/Consent Form tells you about the research project. It explains the research involved. Knowing what is involved will help you decide whether to participate in the research.

This research project has been designed to ensure the researchers interpret the results fairly and appropriately and prevent researchers or participants from jumping to conclusions.

There are no costs associated with participating in this research project. You will be given a \$20 voucher as a thank-you for attending and participating in the interview.

4 What do I have to do?

Once you have agreed to be interviewed, please give your recent contact number to the HeartWest clinic receptionist. So, you will be contacted by phone to organise a date and time convenient to you and the researcher to interview at the 'HeartWest' clinic at Coolaroo, located in North Melbourne. Please arrive 30 minutes earlier to be given verbal information about the research and to get consent signed for the interview.

5 Other relevant information about the research project

If you feel unwell or experience fever or flu-like symptoms such as coughing, sore throat, or fatigue, please get in touch with the principal investigator, Sakine Satici. If you have tested positive for COVID-19 or have been in close contact with someone who tested positive for COVID-19, you must stay in isolation. You will be contacted to reschedule another time convenient for you.

6 Do I have to take part in this research project?

You are under no obligation to participate in this research. Participation in any research project is voluntary. If you do not wish to participate, you do not have to. If you decide to take part and change your mind, you can withdraw from the project at any stage without effect or consequences.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign, and you will be given a copy to keep. Please read and sign the consent form before interviewing.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with HeartWest Clinic.

7 What are the alternatives to participation?

You do not have to participate in this research project to continue receiving treatment at the HeartWest clinic.

8 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from your participation in this research study directly. However, your experiences, opinions and thoughts will provide significant benefit to understand better the experience of the Australian Turkish community living with heart disease and identify the factors (facilitators and barriers) influencing their self-management of a heart condition. This may help develop strategies to improve the health care of Turkish-speaking migrants with heart disease.

9 What are the possible risks and disadvantages of taking part?

We do not anticipate any severe risks related to participation in this study. This study has 'low risk'; the only foreseeable risk is potential discomfort.

While very unlikely, some people may experience emotional discomfort as you tell your story about your health condition. If you become upset or emotionally distressed as a result of your participation in the research, you will be offered information on online counselling services provided by Beyond Blue and Lifeline Services. This counselling will be provided free of charge.

The researchers have taken steps to minimise any risk to participants to protect their privacy. Data de-identification, so you will not be identified in the data collected.

10 What if new information arises during this research project?

If new information becomes apparent during the research project and makes this research absolute, we would have finished the study. You will continue your regular health care as previously.

11 Can I have other treatments during this research project?

Participating in this research project does not change in any way your current treatment.

12 What if I withdraw from this research project?

If you wish to withdraw from this research project once it has started, you can do so at any time up until data analysis without giving a reason. Please notify a member of the research team before you withdraw. A research team member will inform you if there are any special requirements linked to withdrawing.

13 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly if the research question is answered by another researcher.

14 What happens when the research project ends?

The findings will be written up and published at the end of the research project.

Part 2: How is the research project being conducted?

15 What will happen to information about me?

Data collected will be transferred onto the password-protected electronic database and coded for analysis, once transferred, the raw data will be securely stored for five years by the university policy. Only those researchers who are immediately involved with this study will have access to the data.

By relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to the information collected and stored by the research team about you. You also have the right to request that any information with which you disagree be corrected. Please contact the research team member named at the end of this document if you would like to access your information.

By signing the consent form, you consent to the relevant research staff collecting and using personal information about you for the research project. Any information obtained in connection with this study will remain strictly confidential. Your information will only be used for this research project and will be disclosed only with your permission or as required by law. Information will not be published or communicated in a way that makes you identifiable. Your personal information will be coded using a fake name (pseudonym) or initials and numbers so you cannot be identified.

It is anticipated that the results of this research project will be published and/or presented in various forums. In any publication and/or presentation, information will be provided so that you cannot be identified.

16 Complaints and compensation

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact the numbers below. If you become emotionally distressed during the interview and need to be discontinued, you will be given the information on online counselling services provided by Beyond Blue and Lifeline Services for ongoing support if required.

17 Who is organising and funding the research?

This research project is being conducted by Master of Research candidate Sakine Satici Victoria University under the supervision of the Principal Investigator, Professor Maximilian de Courten.

18 Who has reviewed the research project?

The study has been reviewed by the Human Research Ethics Committee (HREC) of St Vincent's Hospital and Victoria University HREC.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

19 Further information and who to contact

The person you may need to contact will depend on the nature of your query.

If you want any further information concerning this project, you can contact the principal researcher on **99192208** or any of the following people:

Name	Prof Maximilian de Courten
Position	Chief supervisor/ Principal Investigator
Telephone	
Email	maximilian.decourten@vu.edu.au

Name	Sakine Satici
Position	Principal Investigator/Master of Research candidate
Telephone	
Email	sakine.satici@live.vu.edu.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Complaints Contact Person

Position	Patient Liaison Officer at St Vincent's Hospital Melbourne
Telephone	(03) 9231 1954
Email	PLO@svhm.org.au

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	St. Vincent's Hospital Melbourne HREC
Position	HREC Executive Officer
Telephone	(03) 9231 6970
Email	Research.ethics@svhm.org.au

Local HREC Office contact (Single Site - Research Governance Officer)

Name	Elizabeth Hill
Position	Manager, Research Ethics and Integrity, Victoria University
Telephone	+61 3 9919 4781
Email	researchethics@vu.edu.au

Appendix 2: Consent Form for Participants (English Version)

Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures

Consent Form - *Adult providing own consent*

Title	Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures
Short Title	Heart disease management among Turkish immigrants
Protocol Number	01
Project Sponsor	Victoria University
Coordinating Principal Investigator/ Principal Investigator	Prof. Maximilian de Courten
Associate Investigators	Sakine Satici, Adj. Prof. Sharon Andrew
Location	HeartWest clinic, Coolaroo, Melbourne

Consent Agreement

I have read the Participant Information Leaflet on the above-named research study.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I have been made aware of any known or expected inconvenience, risk, or discomfort and of their implications as far as they are currently known by the researchers.

I am aware that interviews will be audio-recorded. I understand that while interview findings will be used in published research reports, I will not be identifiable in these reports.

I understand my participation in this study will allow the researcher to have my personal information and to collect basic demographic information and information about my condition and hospital treatment. This information will remain confidential and will not be identifiable in any published



reports. The Principal Researcher for this research project is to confirm I meet the eligibility criteria or exclusion criteria of the study, and I agree to this.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time until data analysis has been completed during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

Declaration by Participant – for participants who have read the information

Name of Participant	
Signature	Date

Declaration by Senior Researcher[†]

I have given a verbal explanation of the research project, its procedures and risks, and I believe that the participant has understood that explanation.

Name of Senior Researcher [†]	
(please print)	
Signature	Date

[†] A senior member of the research team must explain and information concerning the research project.

Note: All parties signing the consent section must date their signature.

Appendix 3: Form for Withdrawal of Participation (English Version)

Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures

Form for withdrawal of participation - *Adult providing own consent*

Title	Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures
Short Title	Heart disease management among Turkish immigrants
Protocol Number	01
Project Sponsor	Victoria University
Coordinating Principal Investigator/ Principal Investigator	Prof. Maximilian de Courten
Associate Investigator(s)	Sakine Satici, Adj Prof Sharon Andrew
Location	The 'HeartWest Clinic', Coolaroo, Melbourne

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment, my relationship with those treating me or my relationship with the HeartWest Clinic.

Name of Participant (please _____ Signature _____ Date _____

Declaration by Study Doctor/Senior Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project, and I believe that the participant has understood that explanation.

Name of Study Doctor/ Senior Researcher [†] (please print)	
Signature _____	Date _____

[†] A senior member of the research team must provide the explanation of and information concerning withdrawal from the research project.

Appendix 4: Information Leaflet for Participants (Turkish Version)

Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures

Katılımcı Bilgilendirme / Gönüllü Onam Formu

Girişimsel Olmayan Çalışma – Gönüllü onamini kendisi verebilen yetişkin

Çalışma sahası: HeartWest Kardiyoloji Kliniği

Araştırmanın adı

'Türk göçmenleri arasında kalp hastalığının bakımı ve tedavisi: Rehabilitasyona ulaşılmasında zorlukların ve kolaylaştırıcı faktörlerin araştırılmasına yönelik niteliksel bir araştırma'

Kisaltılmış Başlık

'Türk göçmenleri arasında kalp hastalığının bakımı ve tedavisi'

Protocol Number

0.1

Project Sponsor

Mitchell Institüsü, Victoria Üniversitesi

Koordinatör Baş Araştırmacı

Prof Maximilian de Courten

Yardımcı Araştırmacı(lar)

Sakine Satıcı, Adj. Prof Sharon Andrew

Çalışma Sahası

The 'HeartWest Kliniği', Coolaroo, Melbourne

(*Bu sende kalacak)

Bölüm 1 Araştırmaya katılımim neleri kapsıyor?

1 Giriş

Türkçe konuşan kalp hastası bir göçmen olmanızdan oturu, sizi HeartWest Kliniğinde yürütülen 'Türk göçmenleri arasında kalp hastalığının bakımı ve tedavisi: İkincin önlemeye yönelik tedaviye ulaşılmasındaki zorlukların ve kolaylaştırıcıları faktörlerin

arastirilmasina yonelik niteliksel bir arastirma' baslikli bilimsel arastirmaya katilmaya davet ediyoruz. Avustraliya'da yasayan kalp hastaligina sahip Turk gocmeni olmaniz ve kalp hastaliginin bakimi ve tedavisi konusunda degerli deneyime sahip olmanizdan oturu arastirmaya katkida bulunmaniz degerli olacaktir. Bu arastirma projesi, kalp rahatsızlığı ile ilgili tecrubelerinizi anlamayi ve tedavisi ile ilgili yasadiginiz sikintilari, zorluklari ya da kolaylastirici faktorleri arastirmayi amaclamaktadır.

Bu proje, Victoria Üniversitesi'nde Araştırma Yüksek Lisans adayı olan Sakine Satıcı tarafından yürütülmektedir. Baş araştırmacı Prof de Courten projeyi denetleyecek.

Bu katılımcı bilgilendirme /Gonullu onam formu size araştırma projesi hakkında bilgi verir. İlgili araştırmayı açıklar. Bu araştırmaya katılıp katılmama kararını vermeden önce, araştırmmanın ne amaçla ve nasıl yapılacağını, bu araştırmmanın gönüllü katılımcılara getireceği olası faydaları, riskleri ve rahatsızlıklarını bilmeniz ve kararınızı bu bilgilendirme çerçevesinde özgürce vermeniz gerekmektedir. Bilgilendirilmiş onam formu araştırmaya katılmak isteyip istemediğinize karar vermenize yardımcı olacaktır. Bu nedenle bu formun okunup anlaşılması büyük önem taşımaktadır. Anlamadığınızı veya hakkında daha fazla bilgi edinmek istediğiniz bölüm hakkında lütfen sorunuz. Araştırmaya katılmak tamamen gönüllülük esasına dayanmaktadır. Çalışmaya katılmama veya katıldıktan sonra herhangi bir anda çalışmadan çıkma hakkına sahipsiniz. İstemediğiniz sorulara cevap vermeme hakkına sahipsiniz. Her üç durumda da hiçbir yaptırıma ve hak kaybına maruz kalmayacağınızı bildirmek isteriz. Katilip katilmamaniz HeartWest Kliniginde olan takip ve tedavinizi hicbir sekilde etkilemeyecektir

Araştırma projesine katılmaya karar verirseniz, onam bölümünü imzalamanız istenecektir. Bu formu imzalayarak bize şunları söylüyorsunuz:

- Okuduğunuz bilgilendirme formunu anladığınızı
- Araştırma projesinde yer almak için onay verdığınızı
- Tanımlanan araştırma için onay verdığınızı

- Kişisel ve sağlık bilgilerinizin açıklandığı şekilde kullanılmasına izin verdiğinizi.

Katılımcı Bilgilendirme ve Gönüllü Onam Formunun bir kopyası da size saklamanız için verilecektir.

2 Arastirmanın Amacı Nedir?

Bu bilimsel araştırma projesi, kalp rahatsızlığınızın hayatınızı nasıl etkilediğine dair deneyimlerinizi birincil ağızdan dinlemek ve kalp rahatsızlığının tedavisi ile ilgili deneyimlerinizi araştırmayı amaçlamaktadır. Bu yolla kalp rahatsızlığının tedavisinde etkileyici unsurları incelemeyi amaçlamaktadır.

Gecmişte yapılmış diğer bilimsel çalışmalar, göçmen hastalarının, dil engelleri ve kültürel farklılıklar gibi engelleyici faktörler nedeniyle kalp rahatsızlıklarının bakımı ve tedavisi konusunda buldukları ülkede sağlık hizmetlerine erişim ve bu hizmetlerden faydalanma konusunda zorluklar yaşadığını göstermiştir. Türkçe konuşan ve kalp hastalığı olan bir göçmen olarak, muhtemelen hastalık ve zorluklarıyla ilgili deneyiminiz ve zorluklarla başa çıkmanın yolları hakkında değerli tecrübeleriniz ve fikirleriniz vardır.

Deneyiminize dayanarak elde edilecek veriler, kalp rahatsızlığının bakım ve tedavisinin daha etkili yapılmasında sağlık bakım uzmanlarına yaşadığınız zorlukları ya da kolaylaştırıcı faktörleri göstermesi bakımından aydınlatıcı bilgiler sunacaktır. Bu, size daha etkili ve verimli sağlık hizmeti sunulmasında temel olacaktır. Bu araştırmada görüşleriniz büyük önem arzedecektir.

Bu araştırma projesine katılmaya davet edilmeniz nedeniyle Türk kökenli olmanız ve kalp hastalığı ile yaşama ve kalp rahatsızlığınızın tedavisi konusunda değerli deneyimlere ve bilgiye sahip olmanızdan oluşmaktadır. Bu araştırma projesi, kalp rahatsızlığınızın tedavisine ilişkin kişisel deneyiminizi, anlayışınızı ve inançlarınızı keşfetmeyi amaçlamaktadır.

Kalp hastalığı tedavisi ile ilgili deneyiminize dayanarak elde edilen veriler, sağlık çalışanlarına, karşılaştığınız tedavi ile ilgili sorunlar ve tedavi konusundaki motivasyonunuzu etkileyen faktörler hakkında farkındalığı arttırmak için değerli bilgiler sağlayabilir. Ayrıca; bu araştırmanın verileri sağlık uzmanlarına, politikacılara ve

arařtırmacılara, kalp hastası olan bir gocmen olarak, kalp hastalığı tedavisi konusunda karasılařtıđınız sorunları giderecek ve tedavinin bařarılı bir řekilde sürdürülmesine yardımcı olacak yeni sađlık projeleri oluşturmalarında önemli bir kaynak olabilir.

3 Arařtırmaya katılım neleri icerir?

- Bu çalışma projesine katılımınız, Melbourne'nun kuzeyinde bulunan Coolaroo'da HeartWest kliniginde yüz yüze görüşme şeklinde gerçekleşecektir.
- Kalp rahatsızlığınızın tedavisi konusunda yaşadığınız sorunları, zorlukları ya da kolaylaştırıcı faktörleri anlamayı amaçlıyoruz.
- Yüz yüze görüşme tahminen yaklaşık 60 dakika olması planlanıyor. Sizden elde edilen veriler daha sonra İngilizceye çevrilerek analiz edileceği için dijital bir ses kayıt cihazı ile ses kaydı yapılacaktır.
- Kimlik bilgileri ya da adres gibi sizi tanımlayan tüm ayrıntılar, gizliliđi korumak için kaldırılacak veya deđiřtirilecektir.
- Kendinizi en iyi ifade edeceğiniz dili, İngilizce veya Türkçe olarak secebilirsiniz. Görüşmeler, akıcı Türkçe konuşabilen Sakine Satıcı tarafından gerçekleştirilecektir.
- Mülakat sırasında duygusal olarak sıkıntılı anlar yaşarsanız, görüşmeye ara verebilir veya görüşmeyi bırakabilirsiniz. Gerekli görülmesi halinde Beyond Blue ve Lifeline Servisleri tarafından sađlanan online danışmanlık hizmetleri hakkında, sürekli destek için bilgilendirileceksiniz.
- Görüşme öncesi arařtırma hakkında bilgilendirileceksiniz ve arařtırmacıya soru sormanız, net cevaplar almanız için yeterli zaman verilecektir. Katılımcı Bilgi Formu/Onay Formu size arařtırma projesi hakkında bilgi vermek amacıyla hazırlandı ve sozkonusu arařtırmayı anlatır ve arařtırmaya katılıp katılmamanıza karar vermenize yardımcı olacaktır.

Bu arařtırma projesi, arařtırmacıların sonuçları adil ve uygun bir şekilde yorumladığından emin olmak ve arařtırmacıların veya katılımcıların onyargıyla sonuca ulaşmasını önleyecek şekilde dizayn edilmiştir. Bu arařtırma projesine katılmanın hiçbir maliyeti yoktur. Arařtırmaya katıldığınız için teşekkür olarak size 20 dolarlık bir kupon verilecektir.

4 Ne yapmam gerek?

Arastirmaya katılmak isterseniz lutfen telefon numaranizi HeartWest kliniginin resepsionistine birakiniz. Boylece arastirmaci tarafından telefonla iletisime gecileceksiniz. Görüşmeyi Kuzey Melbourne'da bulunan Coolaroo'daki 'HeartWest' kliniğinde yapmak üzere size ve arařtırmacıya uygun bir tarih ve saat bu telefon gorusmesiyle saptanacak. Lütfen arařtırma hakkında sözlü bilgi almak ve görüşme için imzalı onam almak için 30 dakika önce gelin.

5 Arařtırma projesiyle ilgili diđer bilgiler

Kendinizi iyi hissetmiyorsanız veya ateř, öksürük, bođaz ağrısı, yorgunluk gibi grip benzeri belirtiler yaşıyorsanız, lütfen baş arařtırmacı Sakine Satici ile iletiřime geçin. COVID-19 testiniz pozitifse veya COVID-19 testi pozitif olan biriyle yakın temasta bulunduysanız, karantinada kalmanız gerekmektedir. Sizin için uygun olan başka bir zamanı yeniden planlamak için sizinle iletiřime geçilecektir.

6 Bu arařtırma projesinde yer almak zorunda mıyım?

Bu arařtırmada yer almak tamamen sizin isteđinize bađlıdır ve gönüllülük esasına dayanır. Arařtırmada yer almayı reddedebilirsiniz ya da herhangi bir aşamada arařtırmadan ayrılabilirsiniz; bu durum herhangi bir negative sonuca ya da sizin yararlarınıza engel duruma yol açmayacaktır

Katılmaya karar vererseniz, 'Katılımcı Bilgilendirme ve Onay Formu' imzalamanız için size verilecek ve saklamanız için bir kopyası size iade edilecektir. Lütfen görüşmeden önce onay formunu okuyun ve imzalayın.

Katılıp katılmama veya katılım sonrası herhangi bir asamada geri çekilme konusundaki kararınız, rutin tedavinizi, sizi tedavi edenlerle veya HeartWest Kliniđi ile olan iliřkinizi etkilemeyecektir.

7 Katılımın alternatifleri nelerdir?

HeartWest kliniğinde tedaviye devam etmek için bu araştırma projesinde yer almak zorunda değilsiniz.

8 Araştırmaya katılmanın olası faydaları nelerdir?

Bu bilimsel çalışmaya katılımınızın size doğrudan herhangi bir fayda sağlayacağını garanti veya taahhüt edemeyiz. Ancak deneyimleriniz, görüşleriniz ve düşünceleriniz, Avustralya'daki Türk göçmenlerinin kalp rahatsızlığının bakımı ve tedavisi konusunda karşılaşılabilecekleri sorunları ve kolaylaştırıcı faktörleri daha iyi anlamamıza yardımcı olacaktır. Bu, kalp hastalığı olan Türkçe konuşan göçmenlere sunulan sağlık hizmetlerinin iyileştirilmesine yardımcı olacak stratejilerin geliştirilmesine temel kaynak olabilir.

9 Araştırmaya katılımın olası riskleri ve dezavantajlar nelerdir?

Bu çalışmaya katılımdan kaynaklanabilecek ciddi bir risk beklemiyoruz. Sizin için öngörülebilir tek riskin rahatsızlık olduğu “düşük riskli” bir çalışma olacak. Sağlık durumunuz hakkında sıkıntı, öfke, hayal kırıklığı gibi duygularınızı dile getirirken duygusal anlar yaşabilirsiniz. Böyle bir durumda, gerek görürse, online danışmanlık hattı olan “Beyond Blue” ve “Lifeline” sitelerinden yardım alacağınız konusunda bilgi verebilirsiniz. Bu online danışmanlık hizmetleri ücretsiz verilmektedir.

Araştırmacılar, özelinizi korumaya yönelik her türlü özveriye gösterecekler. Size ait olan her türlü özel bilgileriniz ses kayıtlarınızdan çıkarılacak ve sahte isimler kullanılacak. Böylece kimliğini gizli tutulacak.

10 Bu araştırma projesi sırasında yeni bilgiler ortaya çıkarsa ne olacak?

Araştırma projesi sırasında araştırmanın sorusuna yanıt verebilecek yeni bilgiler ortaya çıkarsa ve yayınlanırsa, araştırma projesine son verilebilir. Bu durumda, düzenli sağlık bakımınıza eskisi gibi kaldığınız yerden devam edeceksiniz.

11 Bu araştırma projesi sırasında başka tedaviler alabilir miyim?

Bu araştırma projesine katılmak, mevcut tedavinizde hiçbir şekilde degisiklige neden olmayacaktır.

12 Bu araştırma projesinden çekilirsem ne olur?

Bu araştırma projesi başladıktan sonra geri çekilmek isterseniz, bunu herhangi bir neden belirtmeden veri analizine kadar istediğiniz zaman yapabilirsiniz. Bu araştırma projesinden çekilmeye karar verirsiniz, lütfen geri çekilmeden önce araştırma ekibini bilgilendirin. Araştırma ekibinin bir üyesi, geri çekilmeyle ilgili herhangi bir özel gereksinim olup olmadığını size bildirecektir.

13 Bu araştırma projesi beklenmedik bir şekilde durdurulabilir mi?

Araştırma sorusu başka bir araştırmacı tarafından yanıtlanırsa bu araştırma projesi beklenmedik bir şekilde durdurulabilir.

14 Araştırma projesi sona erdiğinde ne olur?

Araştırma projesinin sonunda arastırmanın bulguları yazılacak ve yayınlanacaktır.

Bölüm 2 Araştırma projesi nasıl yürütülecek?

15 Hakkımda toplanan bilgilere ne olacak?

Toplanan veriler şifre korumalı elektronik veri tabanına aktarılacak ve analiz amacıyla kodlanacak. Ham veriler, üniversite politikasına uygun olarak beş yıl boyunca güvenli bir şekilde burada saklanacaktır. Arastirmaya ait depolanmış verilere yalnızca çalışma ekibi erişebilecektir.

İlgili Avustralya ve/veya Victoria mahremiyeti koruma ile ilgili yasalara uygun olarak, araştırma ekibi tarafından sizin hakkınızda toplanan ve saklanan bilgilere erişim talep etme hakkına sahiptir. Ayrıca verdiğiniz bilgilerin sonradan düzeltilmesini talep etme hakkınız da vardır. Bilgilerinize erişmek istiyorsanız lütfen bu belgenin sonunda adı geçen araştırma ekibi üyesiyle iletişime geçin.

Onay formunu imzalayarak, ilgili araştırma personelinin araştırma projesi için sizinle ilgili kişisel bilgileri toplamasına ve kullanmasına izin vermiş olursunuz. Bu çalışma ile bağlantılı olarak elde edilen her türlü bilgi kesinlikle gizli kalacaktır. Bilgileriniz yalnızca bu araştırma projesinin amacı için kullanılacak ve yalnızca sizin izninizle veya yasaların gerektirdiği şekilde açıklanacaktır. Bilgiler, sizi tanımlanabilir kılacak şekilde yayınlanmayacak veya ileilmeyecektir. Kişisel bilgileriniz, kimliğinizin tespit edilememesi için sahte isim veya isminizin baş harfleri veya sayılar kullanılarak kodlanacaktır.

Bu araştırma projesinin sonuçlarının çeşitli forumlarda yayınlanması ve/veya sunulması planlanmaktadır. Her hangi bir yayın ve/veya konferansta çalışma sonuçlarının sunumunda, hiçbir şekilde kişisel bilgiler kullanılmayacaktır. Hiçbir kişisel bilginin tanımlanabilir bir biçimde yayınlanmayacağını bilmeniz önemlidir.

Bu araştırma projesinin sonuçlarının çeşitli forumlarda yayınlanması ve/veya sunulması planlanmaktadır. Herhangi bir yayın ve/veya sunumda, kimliğinizin desifre edilmemesine özen gösterilecektir.

16 Şikayetler ve Onerileriniz

Projenin herhangi bir yönü, yürütülme şekli veya genel olarak araştırma katılımcısı olmakla ilgili herhangi bir şikayetiniz varsa, aşağıda verilen numaralarla iletişime geçebilirsiniz. Mülakat sırasında duygusal olarak sıkıntıya düşerseniz ve görüşmeye ara vermeniz ya da sonlandırmanız gerekebilir. Gerekli olması halinde sürekli destek için Beyond Blue ve Lifeline hizmetleri tarafından sağlanan online danışmanlık hizmetleri hakkında size bilgi verilecektir.

17 Araştırmayı kim organize ediyor ve maliyeti kim tarafından karşılanıyor?

Bu araştırma projesi, Prof Maximilian de Courten gözetiminde Yüksek Lisans Çalışmasının bir parçası olarak Araştırma Yüksek Lisans Öğrencisi Sakine Satici tarafından yürütülmektedir.

18 Arařtırma projesini kim gözden geçirdi?

Bu arařtırma projesinin etik yönleri, St Vincent Hastanesi İnsan Arařtırmaları Etik Komitesi (HREC) ve Victoria Üniversitesi HREC tarafından gözden geçirilmiştir.

Bu proje, İnsan Arařtırmalarında Etik Davranıř Ulusal Bildirgesi'ne (2007) göre yürütülecektir. Bu beyan, insan arařtırma çalıřmalarına katılmayı kabul eden kiřilerin çıkarlarını korumak için geliştirilmiştir.

19 Daha fazla bilgi ve kiminle iletiřime geçilecegi

İletiřim kurabileceğiniz kiřiler talebinizin içeriğine göre aşağıda belirtilmiştir

Bu projeye ilgili daha fazla bilgi almak isterseniz, 99192208 numaralı telefondan baş arařtırmacıya veya aşağıdaki kiřilerden herhangi biriyle iletiřime geçebilirsiniz:

Klinik İletişim Geçilecek Kiři

Ad	Prof Maximilian de Courten
Pozisyon	Supervisor/Bas arařtırmacı
Telefon	
Email	maximilian.decourten@vu.edu.au

Şikayetlerin İletilecegi Kiři

Ad	Sakine Satici
Pozisyon	Bas arařtırmacı/Arařtırma Yüksek Lisans öđrencisi
Telefon	
Email	sakine.satici@live.vu.edu.au

Projenin herhangi bir yönü, yürütölme řekli veya genel olarak bir arařtırma katılımcısı olmakla ilgili herhangi bir řikayetiniz varsa, o zaman aşağıdakilerle iletiřime geçebilirsiniz

Bu arařtirmayı onaylayan HREC'in gözden geçirilmesi ve HREC İcra Kurulu

Reviewing HREC name	St Vincent's Hospital Melbourne HREC
Position	HREC Executive Officer
Telefone	(03) 9231 6970
Email	Research.ethics@svhm.org.au

Başkanı

Yerel HREC Ofisi irtibat kişisi (Tek Tesis - Arařtırma Yönetim Görevlisi)

Name	Elizabeth Hill
Position	Manager, Research Ethics and Integrity, Victoria University
Telephone	+61 3 9919 4781
Email	reserahethics@vu.edu.au

Appendix 5: Consent Form for the Participant (Turkish Version)

Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures

Gönüllü Onam Formu

- Gönüllü onamini kendisi verebilen yetişkin

Araştırmanın adı

'Türk göçmenleri arasında kalp hastalığının bakimi ve tedavisi: Rehabilitasyona ulasilmasinda zorluklarin ve kolaylastirici faktorlerin arastirilmasina yonelik niteliksel bir arastirma'

Kisaltilmis Baslik

'Türk göçmenleri arasında kalp hastalığının bakimi ve tedavisi'

Protocol Number

01

Project Sponsor

Victoria Universitesi

Koordinatör Baş Araştırmacı

Prof. Maximilian de Courten

Yardımcı Araştırmacı(lar)

Sakine Satıcı, Prof. Sharon Andrew

Calisma Sahasi

The 'HeartWest Clinic', Coolaroo, Melbourne

Gönüllü Onam Sözleşmesi

Yukarıda konusu ve amacı belirtilen araştırmaya ilişkin bilgilendirme bölümünü okudum ve aşağıda imzası olan ilgili tarafından önce sözlü sonra yazılı olarak bilgilendirildim.

Projenin kapsamını ve amacını, riskleri ve gönüllü olarak üzerime düşen sorumlulukları anladım.

Çalışma hakkında soru sorma ve tartışma imkanı buldum ve tatmin edici yanıtlar aldım.

Bana, çalışmanın muhtemel riskleri ve faydaları sözlü olarak da anlatıldı.

Araştırmaya gönüllü olarak katıldığımı, istediğim zaman gerekçeli veya gerekçesiz olarak araştırmadan ayrılabilceğimi biliyorum.

Görüşmelerin ses kaydının yapılacağını farkındayım. Görüşmeden elde edilen veriler yayınlanmış araştırma raporlarında kullanılacak olsa da, bu raporlarda kimliğimin gizli tutulacağını biliyorum.

Bu çalışmaya katılmamın, araştırmacının kişisel bilgilerime erişmesine, sağlık sorunlarım ile ilgili bilgilerime ulaşmasına ve hastanedeki tedavim hakkında temel bilgileri toplamasına olanak



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sağlayacaktır. Bu kişisel bilgiler gizli kalacak ve yayınlanan hiçbir raporda kimliğimin desifre edilmeyeceğini biliyorum. Bu araştırma projesinin amacına yönelik, çalışmanın uygunluk kriterlerine veya hariç tutma kriterlerine uygun olup olmadığımı Bas Araştırmacının onaylayacağını bunu kabul ediyorum.

Bu koşullarda;

- 1) Söz konusu araştırmaya hiçbir baskı ve zorlama olmaksızın kendi rızamla katılmayı kabul ediyorum.
- 2) Çalışmada elde edilen bilgilerin (*kimlik bilgilerim gizli kalmak koşulu ile*) yayın için kullanılma, arşivlenmesine izin veriyorum.
- 3) Saklamam için bu belgenin imzalı bir kopyasının bana verileceğini anlıyorum.

Katılımcı Beyannamesi – bilgileri okuyan katılımcılar için

Tönüllünün (Kendi el

Imza

Tarih

Çalışma Doktoru/Kıdemli Araştırmacının Beyannamesi

Araştırma projesi, prosedürleri ve riskleri hakkında sözlü olarak açıklama yaptım ve katılımcının bu açıklamayı anladığına inanıyorum.

*Araştırmacı Öğrencinin
Adi/Soyadı (Kendi el yazisi
ile)*

Imza

Tarih

Appendix 6: Form for Withdrawal for Participants (Turkish Version)

Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures

Katılmadan Çekilme Formu
- Gönüllü onamini kendisi verebilen yetişkin

Araştırmanın adı	'Türk göçmenleri arasında kalp hastalığının bakimi ve tedavisi: Rehabilitasyona ulaşılmasında zorlukların ve kolaylaştırıcı faktorlerin araştırılmasına yönelik niteliksel bir araştırma'
Kisaltılmış Başlık	'Türk göçmenleri arasında kalp hastalığının bakimi ve tedavisi'
Protocol Number	01
Project Sponsor	Victoria Üniversitesi
Koordinatör /Baş Araştırmacı	Prof Maximilian P. de Courten
Yardımcı Araştırmacı(lar)	Sakine Satıcı, Yrd Prof Sharon Andrew
Çalışma Sahası	The 'HeartWest Clinic', Coolaroo, Melbourne

Katılımcı Beyannamesi

Yukarıdaki belirtilen araştırma projesine katılımimi geri çekmek istiyorum ve böyle bir geri çekilmenin rutin tedavimi, beni tedavi edenlerle olan ilişkiyi veya HeartWest Kliniği ile olan ilişkiyi etkilemeyeceğini biliyorum.

*Tönüllünün (Kendi el yazısı
ile)* _____

İmza _____

Tarih _____

Arastirmacinin Beyannamesi

Arastırma projesinden çekilmenin sonuçları hakkında sözlü bir açıklama yaptım ve katılımcının bu açıklamayı anladığına inanıyorum.

*Arastirmaci Ogrencinin
Adi/Soyadi (Kendi el yazisi
ile)* _____

İmza _____

Tarih _____

Appendix 7: Interview Guide (English Version)

Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures

Interview guide

INTRODUCTION:

The interview is divided into two parts. First, I want to learn about you. I, then, want to hear about your experiences of living with your heart problem.

The interview can be conducted in English or Turkish.

Part A: Background-Demographic Information about participants

1) Could you tell me about yourself?

Prompts:

- a) Age
- b) Gender
- c) Marital status
- d) Living arrangements (alone or with family (or others)
- e) Work (type of work)-retired
- f) Education level (Primary School; High School; Bachelor or above)
- g) Other health conditions

- h) Length of time living in Australia

Part B: Heart condition and its management

In this second part, I would like to understand your perceptions of your heart condition, and how you manage your heart condition. I also want to find out about practices you have experienced that support or present challenges or barriers when you are engaging with your heart condition management.

2) Could you tell me about your heart condition?

Prompts:

- a) Perceptions of a heart condition and what may have caused it
 - i) Diagnosis; procedures (elective or urgent)
- b) Cardiac rehabilitation program
- c) Education about lifestyle changes (smoking, weight, diet, stress management, alcohol etc.) from healthcare professionals

3) Can you please tell me how you manage your heart condition?

Prompts

- a) Managing your care
 - i) Self-care (monitor and manage your heart symptoms, adjust medications, follow a heart-healthy lifestyle, regular review by your doctor, other traditional medicine or treatments)
- b) Care involvement from others: family, friends
- c) Reducing the risk of having further heart conditions

4) I want to know about the main barriers and facilitators that you have experienced when managing your heart condition.

- a) Can you tell me what are the main things that make managing your heart condition challenging or difficult?

Prompts

Language barriers, cultural differences, access to health care services or others

b) What are the main things that help (facilitators) with the management of your heart condition?

Prompts

Family, friends, community centres

5) What do you think the greatest challenges are for members of the Australian Turkish community that live with heart problems?

Appendix 8: Participants Recruit Flyer



Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures

If any of your patients are eligible, please contact:
Sakine Satici

sakine.satici@live.vu.edu.au

Inclusion Criteria

- Age :18+
- Turkish speaking immigrants
- Born in Turkey
- First language is Turkish
- Diagnosed with cardiovascular disease

Exclusion Criteria

- Cognitive impairment

Appendix 9: Human Research Ethic Approval Letter



ST VINCENT'S
HOSPITAL

MELBOURNE

A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA

St Vincent's Hospital
(Melbourne) Limited
ABN 22 052 110 755

41 Victoria Parade Fitzroy VIC 3065
PO Box 2900 Fitzroy VIC 3065

Telephone 03 9288 2211
Facsimile 03 9288 3399
www.svhm.org.au

01 August 2022

Professor Maximilian de Courten
Mitchell Institute for Education and Health Policy
Victoria University

Dear Prof de Courten,

Project ID: 81363
St Vincent's local reference number: LRR 095/22

'Management of heart disease among Turkish immigrants: A qualitative exploration of facilitators and barriers to secondary prevention measures'

Approval is given in accordance with the research conforming to the *National Health and Medical Research Council Act 1992* and the *National Statement on Ethical Conduct in Human Research 2007 (updated July 2018)*

This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Research Involving Humans 2007 (updated July 2018), and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

Approval Date: 01 August 2022

Ethical approval is given for this research project to be conducted at the following sites:

- HeartWest, Coolaroo VIC

This approval will be ratified by St Vincent's Hospital (Melbourne) HREC at the next meeting.

Approved documents

The following documents have been reviewed and approved:

Document	Version	Date
VSM	-	10 May 2022
Protocol	1.0	01 Aug 2022
Appendix 7: Interview Guide	1.0	01 Aug 2022

UNDER THE STEWARDSHIP OF MARY AIKENHEAD MINISTRIES

Facilities
St Vincent's Hospital Melbourne
Caritas Christi Hospice
St George's Health Service
Prague House